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“We could do better”: the nature and meaning of information-giving in end-stage COPD

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# **Abstracts of the 9th World Research Congress of the European Association for Palliative Care (EAPC)**

Dublin, Ireland  
9-11 June 2016

## **Abstracts of the 9th World Research Congress of the European Association for Palliative Care (EAPC)**

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# EAPC2016: Invited Speakers

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**Abstract number:** INV1

**Abstract type:** Invited Speaker

## Palliative Care Services in the US Health Care System – What is the Evidence?

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Empirical evaluation of specialist palliative care is a very complex endeavor in any country. It requires explicit definition of the service delivery model, a clear research question, and a study methodology that addresses an array of complicated issues. Methodological problems that may be encountered in all contexts include the selection of an appropriate comparator and the best methodology for comparative trials, the lack of consensus about the most meaningful primary and secondary outcomes, uncertainty about the appropriateness and sensitivity of the methods used for measuring outcomes, the problem of measuring fidelity to the intervention, and the best approach to incorporating economic endpoints. In the U.S., all of these difficulties are further complicated by the complexity of the health care system. Although U.S. specialists in palliative care appear to agree that specialist palliative care requires a medical provider with specialist competencies, access to an interdisciplinary team with highly skilled members, and service delivery that addresses concerns categorized in eight broad domains, the actual systems of care may or may not comport with this understanding. Hospice is by far the largest system providing specialist palliative care and its government-mandated structure and processes of care vary greatly from other models. Hospital-based consultative services are also widespread but demonstrate wide variation in the professionals involved and the tasks performed. Community-based palliative care “upstream” from hospice is just now emerging and exists in a matrix of community-based models that are not labeled “palliative care” but have commonalities in the services provided. A discussion of these challenges is foundational to a meaningful review of the extant data related to the benefits of hospice, hospital-based palliative care and community-based palliative care in the U.S. Studies that have been done in all these contexts detect a signal suggesting benefit in specific domains, such as improved symptom distress, but overall

provide a relatively constrained view. Together, the existing data suggest that the growth of specialist palliative care is positive for the U.S. healthcare system while concurrently highlighting the need for more research.

**Abstract number:** INV2

**Abstract type:** Invited Speaker

## Cancer-related Fatigue: Evaluation by Mobile Electrophysiology

*O'Connor B.*<sup>1,2</sup>, *Markicevic M.*<sup>3</sup>, *O'Higgins C.*<sup>1,3</sup>, *Newman L.*<sup>3</sup>, *Kallidir R.*<sup>3</sup>, *Ui Dhuibhir P.*<sup>1</sup>, *Sukor S.*<sup>4</sup>, *Hanrahan E.*<sup>4</sup>, *Armstrong J.A.*<sup>5</sup>, *Cuffe S.*<sup>6</sup>, *Reilly R.B.*<sup>3,7,8</sup>, *Walsh D.*<sup>1,2,7</sup>

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**Background:** Cancer related fatigue (CRF) is common (25-99%). The biology is poorly understood. The aetiology may be central or peripheral and originate anywhere from the brain to the muscle fibre. Objective measurement is complex and usually in specialised laboratories. Mobile electroencephalography (EEG) and electromyography (EMG) may enhance objective measurement.

### Aims:

1. Determine feasibility of mobile EEG-EMG to evaluate CRF
2. Assess device acceptability

### Population:

Study A: Pilot with 10 healthy volunteers (VT)

Study B: 10 participants (PT) with newly diagnosed inoperable pre-treatment non-small cell lung cancer and fatigue

**Methods:** Prospective observational study in oncology outpatients. Sustained isometric hand-grip contraction at 30% maximal level (S30) until self-perceived exhaustion. High-density 128 channel EEG and 2-channel EMG signals of forearm muscles recorded during S30. EEG and EMG signal coherence determined throughout. Cancer participants were compared to healthy volunteers. Device acceptability evaluated by questionnaire. Analysed by SPSS® Version 22.

**Results:** Fatigue task was in 2 stages; first and last 20 secs. PT perceived exhaustion much earlier (mean/SD: 137.4 +/- 76.2 secs v 208.3 +/- 51.2 secs in VT). As fatigue progressed, EMG amplitude increased significantly (VT:  $p=0.04$ ; PT:  $p=0.02$ ) in both groups as did EMG  $\beta$ -power (VT:  $p=0.006$ ; PT:  $p=0.008$ ). Increase was less in PT (amplitude:  $p=0.032$ ;  $\beta$ -power:  $p=0.014$ ). EEG  $\beta$ -band power in contralateral somatosensory cortex increased significantly (VT:  $p=0.019$ ; PT:  $p=0.03$ ) in both but was greater ( $p=0.024$ ) in cancer. EEG-EMG coherence showed no significant difference between cohorts. PT reported 100% device acceptability.

**Conclusions:**

1. Mobile EEG-EMG effectively evaluated CRF
2. High patient-evaluated acceptability supports clinical utility of methodology
3. There was more central fatigue in cancer than healthy volunteers
4. There was also evidence of peripheral abnormalities

**Abstract number:** INV3

**Abstract type:** Invited Speaker

**Remote Patient Monitoring in the Delivery of Supportive Care**

*Maguire R.*

School of Health Sciences, University of Surrey, Surrey, United Kingdom

Remote patient monitoring in the home care setting allows symptoms experienced by people with cancer to be identified in a timely manner, facilitating early intervention. The Advanced Symptom Management System (ASyMS) is the most evolved remote monitoring system to assess and manage the symptoms of cancer and its associated treatments. Based on clinical algorithms, ASyMS facilitates immediate tailored management of symptoms the home care setting and automatic and immediate triaging of care where patient symptoms exceed clinical norms and require intervention. In this presentation Professor Roma Maguire will discuss the development and evolution of the ASyMS programme of work and its current and future application in supportive care delivery.

**Abstract number:** INV4

**Abstract type:** Invited Speaker

**Effectiveness of Early Palliative and Simultaneous Care in Oncological Settings. A Systematic Review**

*Apolone G.<sup>1</sup>, Costantini M.<sup>2</sup>, Alquati S.<sup>2</sup>, Bassi M.C.<sup>2</sup>*

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Several teams have explored the effectiveness of early palliative and simultaneous care programs in several cancer diseases and settings, with variable results. Recent evidence suggests that early palliative intervention integrated with anti-cancer and supportive care can improve the quality of life of lung cancer patients, decrease anxiety and depression, reduce aggressiveness of care and extent survival. As pointed out by ASCO, because no trial to date have demonstrated that early palliative care may harm patients and caregivers or induce excessive costs, combined standard oncology and concurrent palliative care should be considered early in the course of the disease in all patients with advanced/metastatic cancer. In order to understand better the value of these complex interventions in cancer patients and try to identify potential factors that could mediate the effect across different diseases and settings, we carried out a literature review by retrieving and assessing eligible papers (in English, reporting results from controlled studies in advanced, adult cancer patients) published from 2000 to 2015. Starting from a preliminary list of 2405 candidate papers, a subset of 168 Abstracts have been selected and 86 full papers are under evaluation with a standardized approach. The lecture will present the preliminary results and discuss potential implications for health care programs and future research.

**Abstract number:** INV5

**Abstract type:** Invited Speaker

**Integrated Care Pathways in Palliative Care - What Is the Evidence and Does It Work?**

*Kaasa S.<sup>1,2,3</sup>*

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A major concern in oncology and palliative care is the rapid cost increase and the complexity of treatment. The patients' transition between home and community care, and between local and university hospitals, require

effective and adequate planning of care (pathways) and adequate exchange of information. Appropriate planning and communication across health care levels will strengthen patients' empowerment, enable self care and facilitate the possibility for living at home.

Despite continuous developments and updated evidence-based guidelines, the implementation into clinical practice remain a universal challenge in medicine. Several barriers seem to obstruct the use of best practice, and these barriers clearly operate on different levels. They include the lack of leadership commitment, lack of support by electronic patient-recorded systems and lack of universal understanding of the need for clinical care pathways to cover the transition between different levels of care.

A method which might be used to address barriers is the development of integrated care pathways, which is a systematic approach to patient care that takes into account every step from referral to the hospital, through the diagnostic and treatment processes. It also includes rehabilitation and community home care. For each clinical pathway, the method specifies the content of each stage of the patient's movement through the health care system. Then it specifies a systematic and unique plan for each specific clinical pathway.

Patients' perspectives have been recognised as valid outcomes in clinical medicine, and are endorsed by the National Institute of Health Consensus Conference. There are similar recognitions in cancer care, and the term patient-reported outcome measures (PROMs) encompasses all outcomes related to patients' health, level of function and well-being. PROMs may be regarded as a supplement to clinical observations and objective findings with unique individual patient information.

**Abstract number:** INV6

**Abstract type:** Invited Speaker

### **Palliative Care in Community Care - How Much Integration is Needed and Possible?**

Albreht T.

Centre for Health Care, National Institute of Public Health, Ljubljana, Slovenia

Health care has gone and is continuously going through various transformations. One of the important changes is the move from hospital in-patient to community- and home-based care in different stages of a chronic and also acute disease, whenever possible. There are different drivers for this process ranging from the intensification and specialisation of hospital care to patient preferences to be cared for closer to home and to their loved ones. In those cases when palliative care is needed and indicated, patients, their families and/or their carers will often opt for community-based care. Obviously, there are three important conditions for such expectations to be met - organisation of care in the community and/

or at the primary care level that supports such delivery of palliative care, adequate professional competence of palliative care professionals in such settings and patient trust and confidence in such an organisation of palliative care (compared to hospital- or specialist-based settings).

In order for a health care system to achieve such delivery of care it should invest into its development. In the first place, this means education and training of multi-disciplinary teams. These should work closely with the carers, families and the social services. Integration of health and social care with strong base in the community is not only possible but should be provided in all cases where this arises from patient's needs and preferences and can facilitate the delivery of such care - e.g. proximity to home, patient having tight networks in the community or none at all. Social care, which should have a special role in the comprehensive care of all chronic patients, has a focused role in palliative care in all periods of life in terms of coordination, integration and financial support (depending on the specifics of the particular health system).

**Abstract number:** INV7

**Abstract type:** Invited Speaker

### **Starting from Scratch: Building a Palliative Care Research Environment in the Czech Republic**

Loucka M.<sup>1,2</sup>

<sup>1</sup>Center for Palliative Care, Prague, Czech Republic,

<sup>2</sup>Third Faculty of Medicine, Charles University in Prague, Prague, Czech Republic

The aim of this presentation is to review the learning and research experience of the speaker, this year Early Researcher Award winner. After his graduation at Lancaster University in the UK as one of the EURO IMPACT (EU FP7 training network project) PhD students, he returned to his country of origin, the Czech Republic, to establish the first palliative care research centre in the country. To be the only research group in the field brings several advantages and also risks, which will be discussed and explained using examples of specific activities and projects of the Center for Palliative Care.

**Abstract number:** INV8

**Abstract type:** Invited Speaker

### **What I Learned from my Research in Physiology and Neurosciences for my Career in Palliative Care**

Wentlandt K.

University of Toronto, Toronto, ON, Canada

Most colleagues believe I wasted a lot of time- having spent years working on a PhD in neurosciences and then

having to cross the divide between basic and clinical sciences; both in research and practice. For those of us who have had the opportunity to do both, it is clear that working at the bench side teaches us many things about working at the bedside. In this talk, I will review how gap junctions, western blots, crazy scientists, mice, and microscopes taught me how to navigate the healthcare system, clinical research, relationships with colleagues and peers, medications and how to develop innovative solutions for patients.

**Abstract number:** INV9

**Abstract type:** Invited Speaker

### **Developing a Research Agenda for Palliative Care: From Nursing to Cochrane**

*Candy B.*

Marie Curie Palliative Care Research Department,  
Division of Psychiatry, UCL, London, United Kingdom

I started my career as a nurse. I moved into research because I began to ask questions about aspects of healthcare that seemed to me to be odd, such as why feeding of neonates occurred at strict 4-hour intervals or why there was a wide-variability in other practices such as wound care. A degree in anthropology, and in demography provided me with research skills. I came to palliative care research in 2007 having undertaken systematic reviews in mental health. I am based at the Marie Curie Palliative Care Research Department at University College London; where I am a dedicated systematic reviewer. The focus of my research is on providing evidence, as published in the Cochrane Library and elsewhere, on the effectiveness of interventions in palliative care. Such systematic reviews in palliative care can sometimes seem of limited value. Randomised controlled trials, the gold standard method for assessing treatment effect, are often scarce. In some other areas of palliative care where trials have been conducted there may be so much heterogeneity between trials that drawing overall conclusions is impossible. However, systematic reviews that demonstrate a lack of evidence or clarity still have value. By identifying gaps in our knowledge they inform clinical guidelines, and can help set research agendas through e.g. priority setting exercises.

To provide more complete answers, methods of systematic reviewing are evolving. Trials with negative findings are less likely to be published and so are less likely to be included in a review. Initiatives are being developed to tackle this and I am starting to test these. Qualitative research can capture peoples' experiences. A review of qualitative studies can reveal more powerful understandings than are available from a single study. In my PhD I explored and developed novel techniques for combining qualitative and quantitative review data. Such analysis may inform better development of interventions in palliative care.

**Abstract number:** INV10

**Abstract type:** Invited Speaker

### **Which Outcomes Best Reflect Patients' Experience of Cancer Pain Management in Clinical Practice and Research?**

*Bennett M.*

University of Leeds, Leeds, United Kingdom

This session will examine which outcomes matter to patients with cancer pain and how best to measure these. Recording pain intensity alone fails to provide a complete picture of patient experiences. Research suggests that patients make constant trade-offs between pain intensity and side effects from analgesia in order to reduce interference in daily living, which is a highly individualised judgement. Developing a patient reported outcome measure that captures these domains would enable more accurate assessment of good and poor outcomes for patients.

**Abstract number:** INV11

**Abstract type:** Invited Speaker

### **From Questions to Methods: Challenges and Opportunities for Palliative Care**

*Portenoy R.<sup>1,2,3</sup>*

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Research may be defined as a process of steps used to collect and analyze information that contributes to an interpretable, verifiable and generalizable understanding of a topic or issue. The information obtained through clinical research is the raw material for evidence-based medicine. Although randomized controlled studies are properly considered to yield the highest level of evidence, the clinically-relevant evidence base for any medical issue, such as cancer pain, includes data from a broad array of methodologies. Research always starts with a question and one of the key processes needed to make a contribution to the evidence base is the rigorous crafting of a meaningful and "researchable" question, which targets a gap in knowledge and both addresses a broad research goal while allowing highly focused specific aims. Questions may be intended to generate data that allow the more focused inquiry (hypothesis-generating studies), to advance understanding of mechanisms (explanatory studies), to improve clinical knowledge of disease or illness in individuals (descriptive or relational studies), to expand information about populations (epidemiologic studies), or to advance clinical therapeutics (pragmatic studies). This goal framework, in turn,

emphasizes that the best methodology may be qualitative, quantitative or mixed methods. Each of these methodological categories includes multiple designs, and each design requires multiple processes to increase the likelihood of meaningful data and reduce the likelihood of bias and error. Studies of cancer pain can illustrate the complexity and value of a systematic approach to the crafting of a research question and the decision making that culminates in a proposed set of research procedures.

**Abstract number:** INV12

**Abstract type:** Invited Speaker

### **Clinical Challenges in Cancer Pain Management which Inform our Research Question**

*Mercadante S.*

Pain Relief & Supportive Care, La Maddalena Cancer Center, Palermo, Italy

Most of pain due to cancer can be relieved with relative simple methods using analgesics, adjuvants, and symptomatic drugs. Recent recommendations on the use of opioids for cancer pain management, based on a limited available evidence, have been produced suggesting the need for specific studies.

However, many patients presenting difficult pain conditions still require more complex strategies to achieve an adequate pain control. An effort to find evidence in certain challenging conditions have been reported. However, the many questions remain opened as most of these studies do not reflect the real world and are inapplicable in the clinical settings, thus minimizing the value of these conclusions. The complex interrelation among pain, disease, patient, and analgesics have a tremendous impact on the final outcome. These aspects are unlikely to be resolved with protocols dictated by the rigid design of a controlled randomized study. Rather, difficult problems in pain management need elegant interpretation of the physiopathology and pharmacology, as well as the use of clinical instruments for understanding the clinical problem and find the right solution. The careful examination of the different factors implicated in the opioid response in that specific clinical context may help resolving most cases which apparently seem to be intractable.

**Abstract number:** INV13

**Abstract type:** Invited Speaker

### **The Value of Mortality Follow-back Surveys in End-of-life Care Research**

*Cohen J.*

End-of-Life Care Research Group, Vrije Universiteit (VUB) and Ghent University, Brussels, Belgium

**Background:** Retrospective approaches to studying end-of-life care have been criticized as not providing accurate portraits of care for patients who ‘are dying’. However, mortality follow-back surveys provide several advantages that are difficult to achieve with prospective studies. This presentation will discuss these advantages.

**Method:** Examples of mortality follow-back approaches in end-of-life care research are reviewed for their advantages, including surveys using death cases (eg death certificates) as sampling framework and registration methods evaluating all deaths within representative groups of family physicians.

**Results:** Some advantages of mortality follow-back designs include:

- They can allow a population-based approach that is not limited to certain care settings or patient populations. All people having died are studied instead of only those defined a priori by health care staff as dying, which removes important biases in terms of eg socio-economic position. Populations are included that would otherwise remain hidden.
- Bias due to non-equivalence in physicians’ judgment about who is dying is removed. This increases the validity of multicenter or international comparisons.
- While there are issues in meaningfully reconstructing the full care trajectory and experiences, they have good validity for evaluating circumstances closely before and around death.
- When evaluating these circumstances, they are feasible and cost-effective compared to prospective cohort studies where problems of follow-up, respondent burden and attrition would lead to serious bias of the results.

**Conclusion:** While retrospective studies on end-of-life care such as mortality follow-back designs have intrinsic limitations, they provide an indispensable source of public health information on the manner in which populations are dying. Main strengths include their population-based approach, which prevents an exclusive focus on those who may be dying in an ‘advantaged’ manner.

**Abstract number:** INV14

**Abstract type:** Invited Speaker

### **How to Plan a Mortality Followback Survey: Study Design Issues and Assessment Tools**

*Gomes B.*

King’s College of London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

**Aims:** The retrospective evaluation of end of life care via patient proxies (usually bereaved relatives but also health

care professionals) is increasingly common. This presentation aims to help researchers: 1) decide the best study design approach, and 2) prepare a robust assessment of the outcomes of interest for their studies.

**Methods:** Drawing on the rising number of mortality followback surveys and the example of the QUALYCARE study, we discuss 10 key aspects to consider when planning a survey of this kind.

**Results:** To choose the study design that best fit their research aim within the resources available, researchers will need to consider a range of options that are often interlinked: 1) service vs. population-based method, 2) inclusion of the whole target population vs. a sample, 3) face-to-face vs. telephone vs. postal approach, 4) ways to increase response, 5) ethical issues (e.g. timeframe for contact after the patient died, opt-in vs. opt-out, procedures to reduce and handle distress, reminders use). Outcome measurement must take into account the potential for recall and proxy biases. We recommend: 6) using a well-established survey tool as a basis (e.g. Ann Cartwright's in the UK, Joan Teno's in the US); 7) integration of validated measures of the outcomes of interest; 8) assessment of health services use; 9) having a clear assessment timeframe (ideally common to outcomes and health services use); 10) incorporating a pilot phase using cognitive interviewing with a small sample of the target population, with a view to test and improve measurement prior to rolling out the main survey.

**Conclusions:** The growing body of evidence generated by mortality followback surveys helped identify 10 key aspects and best practice solutions related to study design and measurement. This examination provides a first step in setting quality standards for mortality followback surveys in the future.

**Abstract number:** INV15

**Abstract type:** Invited Speaker

### An Overview of Results from the EPCCS Study

*Hjermstad M.J.<sup>1,2</sup>*

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**Background:** Palliative care (PC) organisation and case mix differ.

**Objectives:** The EPCCS study aimed to describe PC organisation paired with medical and patient reported data (PROs) in participating centres.

**Methods:** This international prospective study consisted of a one-time web-survey on PC organisation, services and academics, and clinical data and PROs every 3-5 weeks, by health-care providers and PC cancer patients respectively.

**Results:** 30 centres in 12 countries participated; 24 hospitals, 4 hospices, 1 nursing home, 1 home-care service. 22 centres (73%) had PC in-house teams and in- and outpatient services. Twenty centres (67%) had integral chemo/radiotherapy services and 28 of 30 had access to general medical or oncology inpatient units. Physicians or nurses were present 24h/7d in 50% and 60% of centres, respectively. 14 centres (47%) had professorships, 12 (40%) had full/part-time research staff. Of 1698 patients at baseline, 50% were males; age 66 (range 21-97); median Karnofsky score (KPS) 70 (10-100); 83% had metastatic disease; tiredness and pain past 24 hours were most prominent. 62% died during follow-up, 43% < 3 months from inclusion, 68% within 6 months. Hospice/nursing home patients were older, had poorer KPS, and shorter survival compared with hospital patients ( $p < 0.03$ ). 65% reported breathlessness at some point during follow-up, with low KPS ( $p=0.039$ ) and moderate/severe pain ( $p=0.012$ ) as risk factors for more breathlessness over time. 11% developed cognitive impairment, associated with low KPS (OR=1.6, 95% CI: 1.0-2.5). Those who improved cognitively had less pain and better appetite. Survival days decreased with increasing stages of cachexia; stage 1; 370 days, stage 4:102, ( $p < 0.001$ ).

**Conclusion:** The variation in PC services and patients has implications for the development of services, research and funding. Prospective studies, with consecutive sampling and systematic characterisations with PROs and objective ratings are necessary.

**Abstract number:** INV16

**Abstract type:** Invited Speaker

### PhD and Master Education - An Update

*Knudsen A.K.<sup>1,2</sup>, Balstad T.R.<sup>1</sup>, Haugen D.F.<sup>1,3</sup>, Caraceni A.<sup>1,4</sup>, Gjeilo K.H.<sup>5,6</sup>, Borchgrevink P.C.<sup>6,7</sup>, Kaasa S.<sup>1,8</sup>*

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To achieve high quality palliative care both in specialist and community care, and to implement research results into clinical practice, formal education in palliative care research and clinical practice is needed.

To increase the scientific competence among palliative care clinicians, a biomedically focused international PhD programme in palliative care was established by the PRC in 2010. The three-year PhD programme is formally established at NTNU, Trondheim, Norway, and is based upon contribution from many of the at present 16 PRC core collaborating centres. Enrolment to the programme is continuous. All candidates must be enrolled at NTNU, but can reside at any institution. Since the establishment 23 candidates have been enrolled, and seven have completed their PhDs in palliative care.

A PhD introductory course in palliative care research is held every autumn, this is open for applicants regardless of being part of the programme or not: "Palliative Care Research - Theoretical, Practical, Ethical and Methodological Aspects". Since 2011 in total 48 researchers from 17 countries have completed the course, which is arranged in close collaboration between Trondheim and Edinburgh, UK.

In 2014, a specialisation in pain and palliative care as part of the master programme in clinical health science was established at the NTNU. Symptom assessment, treatment, multi-disciplinarity, collaboration and coordination of services are in focus. It is a two-year programme including a series of courses and a thesis. Ten students can be enrolled each year.

The programmes will contribute to improved palliative care services mainly through increasing the knowledge base and through improved clinical practice, respectively. Furthermore, they will contribute to strengthen international and national collaboration, and may support students to establish a professional network for their future career in palliative care research and clinical practice.

**Abstract number:** INV17

**Abstract type:** Invited Speaker

### **Integration of Palliative Care into Oncology Care: An Overview of the Evidence**

*Zimmermann C.*

Supportive Care, Princess Margaret Cancer Centre, Toronto, ON, Canada

Early palliative care is increasingly recommended, but seldom practised. This presentation will examine the

evidence that supports integration of palliative care into oncology care. We will review the quantitative evidence from recent randomized controlled trials of early palliative care interventions, which has demonstrated benefits for quality of life and satisfaction with care of patients and their caregivers. In addition, we will consider qualitative evidence that supplements these trials and provides insight into models of care. Lastly we will discuss pragmatic considerations in putting these research findings into practice and future directions for research in this area.

**Abstract number:** INV18

**Abstract type:** Invited Speaker

### **Advance Care Planning in Frail Older People and Nursing Homes: Results of the International PACE Study ([www.eupace.eu](http://www.eupace.eu))**

*Van den Block L.<sup>1</sup>, Smets T.<sup>1</sup>, van Dop N.<sup>1</sup>, Finne-Soveri H.<sup>2</sup>, Onwuteaka-Philipsen B.<sup>3</sup>, Payne S.<sup>4</sup>, Szczerbińska K.<sup>5</sup>, Deliens L.<sup>6</sup>*

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**Aims:** The EU project PACE aims to investigate country differences in prevalence and characteristics of advance care planning among deceased nursing home residents

**Method:** To obtain a representative nationwide sample, we conducted a study of deceased residents in care/nursing homes in Belgium, Finland, Italy, the Netherlands, Poland and the UK in 2015 using proportional stratified random sampling. In each country, all participating homes retrospectively report all deceased residents over the previous three-month period. For each case, structured questionnaires are sent to the staff member most involved in care. We report results for five countries.

**Results:** In a total of 286 care/nursing homes participating in BE, FI, NL, PL and UK, 1480 deceased residents were identified of which 1190 questionnaires (80%) were returned. Staff members reported to know that residents *ever expressed a specific preference* about a medical treatment they did/did not want in the last phase of life in 34%(BE), 23%(FI), 39%(NL), 6%(PL) and 26%(UK) of cases.

Staff members reported they *never spoke to the resident* themselves about medical treatment or preferred course of

care in 64%(BE), 82%(FI), 59%(NL), 84%(PL) and 55%(UK) of cases, while they *did speak to a relative* in 75%(BE), 61%(FI), 75%(NL), 28%(PL) and 64%(UK) of cases prior to a decision about medical treatment or course of care.

*Living wills* stipulating end-of-life treatment preferences were documented in 49%(BE), 41%(FI), 51%(NL), 4%(PL) and 58%(UK) of cases. Assigning a *proxy decision-maker in writing* was reported in 34%(BE), 34%(FI), 38%(PL) and 65%(UK) of cases.

**Conclusion:** With the exception of Poland, advance directives are present for a large group of care home residents, although there are still important differences between countries. The strong focus on advance care planning within policy and clinical practice over the past decades in several EU countries seems to have influenced practice considerably.

PACE GA n° 603111

**Abstract number:** INV19

**Abstract type:** Invited Speaker

### **Advance Care Planning in Australia - Evidence on Effectiveness and Implementation**

Detering K.

Advance Care Planning Department, Austin Health, Heidelberg, Australia

Advance care planning (ACP) implementation has been occurring in Australia since approximately 2002. This has included specific implementation strategies for hospitals, aged care facilities and the community, and has targeted specific populations such as the elderly, those with cancer, and others with chronic disease.

This presentation will present and discuss:

Australian research supporting the benefits of ACP. This includes formal research studies, and other evaluation of implementation strategies. Outcomes in some specific populations will also be presented.

Specific healthcare professional education approaches utilized, and evaluation of some of these programs, including those aimed at more specifically doctors, and those aimed more generally.

Factors believed to be important to the successful implementation of ACP. This will include discussion of the Victorian implementation strategy, a large-scale implementation aiming to embed ACP into the 84 public health services, which service more than 5 million people, within the state of Victoria.

**Abstract number:** INV20

**Abstract type:** Invited Speaker

### **Knowledge Transfer, Adoption and Implementation**

Higginson I.J.

Department of Palliative Care, Policy & Rehabilitation, King's College London, Cicely Saunders Institute, London, United Kingdom

A guideline outlines best practice. The next challenge is to convey this knowledge and ensure the guideline is cost-effectively and faithfully introduced into practice and policy.

But in this process what works, what doesn't, and how do we know?

There are many examples when knowledge transfer and implementation goes wrong, not only for guidelines but also for research findings more widely. This 'gap' is often called the second or third translational gap.

Best practice guidelines are suggested to be more likely to lead to knowledge transfer, and subsequent adoption and implementation when:

- a) A systematic well-developed, evidence-based process is used to produce guidelines
- b) Appropriate stakeholders are identified and engaged
- c) Implementation of the guideline is considered while it is developed to ensure appropriate workforce, infrastructure and other "environmental readiness" for implementation
- d) Evidence-based implementation strategies are used based on above
- e) Resources are available for knowledge transfer and implementation, something which is difficult to achieve
- f) The knowledge transfer and implementation is evaluated, in particular with regard to uptake and fidelity of actions.

However, knowledge transfer and implementation are not linear processes. This session will review some examples of knowledge transfer and implementation of guidelines in palliative and end of life care, whether and how they were successful, what does success mean, and how do we know? It will draw on the MORECARE guidance[1] for the development and evaluation of therapies and interventions in palliative and end of life care, and recent work in the South London National Institutes of Health Research (NIHR) Collaboration for Leadership in Applied Research and Care (CLAHRC).[2]

### **References**

- 1 BMC Med. 2013 Apr 24;11:111. doi: 10.1186/1741-7015-11-111.
- 2 <http://www.clahrc-southlondon.nihr.ac.uk/>

**Abstract number:** INV21

**Abstract type:** Invited Speaker

**Cancer Pain Guidelines - An Institutional Approach:  
A Cluster Randomised Controlled Trial***Fallon M.*

Palliative Medicine, University of Edinburgh, Edinburgh, United Kingdom

Evidence points to less than 50% of patients achieving acceptable cancer pain relief. The majority of this could be controlled by non-palliative care specialists. Research demonstrates healthcare professionals develop short cuts for assessment which can lead to poor pain control outcomes. Management is often hampered by broad guidelines rather than specific guidance for individuals. Reassessment of opioids can be inadequate leading to significant side effects and poor QoL. The Edinburgh Pain Assessment and management Tool (EPAT) was developed for use at the patient's bedside to direct pain assessment as part of vital signs and link with management algorithms, in a busy clinical setting. A preliminary non-randomised evaluation of EPAT was conducted to clarify feasibility and methodology. A 2 arm parallel group

multicentre cluster RCT in regional UK cancer centres (UKCC) was conducted. UKCCs were enrolled if they met inclusion/exclusion criteria and had a Caldicott Guardian willing to give consent for participation at institutional level. Patients who met inclusion/exclusion criteria on admission were consented and enrolled at individual level. 50 patients were recruited from each participating UKCC prior to randomisation, each UKCC was randomised to either EPAT or continuation of usual care after recruitment of these patients. Primary trial outcome was clinically significant improvement in pain defined as  $\geq 2$  points in worst pain in last 24 hours, measured 3 days post admission. Some secondary outcomes and prescribing practice were also compared between baseline and day 3. 20 UKCCs and 1921 patients participated. The proportion of patients with a clinically significant improvement in pain by day 3 fell from 51% (before randomisation) to 46% post randomisation in the centres allocated to continue usual care and increased from 47% to 54% in those allocated to EPAT ( $p = 0.04$ ). A 4 point drop in worst pain was highly clinically significant between groups ( $p = 0.004$ ).

## EAPC2016: Plenary Sessions

### Plenary I

**Abstract number:** PL1

**Abstract type:** Plenary

#### **Fentanyl Sublingual Tablets versus Subcutaneous Morphine for the Management of Severe Cancer Pain Episodes in Patients on Opioid Treatment: A Double-blind Randomized Non-inferiority Trial (eudraCT 2013-003319-23)**

*Zecca, Ernesto<sup>1</sup>, Brunelli, Cinzia<sup>1</sup>, Centurioni, Fabio<sup>1</sup>, Manzoni, Andrea<sup>1</sup>, Pigni, Alessandra<sup>1</sup>, Caraceni, Augusto<sup>1,2</sup>*

<sup>1</sup>Palliative Care, Pain Therapy & Rehabilitation Unit, Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy, <sup>2</sup>European Palliative Care Research Center, Norwegian University of Science and Technology, Trondheim, Norway

**Background:** Sublingual transmucosal fentanyl (SLF) is potentially an easy to use alternative to parenteral opioids like subcutaneous morphine (SCM), to treat severe cancer pain episodes. No direct comparison between SLF and SCM is available. The aim of this study is to show if SLF is non inferior to SCM during the first 30 min. after administration.

**Methods:** Patients with a severe pain episode, on stable opioid therapy and controlled pain, were randomized to receive either 100µg SLF or 5mg SCM in a double blind, double dummy design. Patients could receive a second dose of drug after 30min, for insufficient pain relief. Average pain intensity (PI 0-10 NRS) in the first 30 min. after drug administration (average of 10, 20 and 30 min. PIs) was the main outcome measure (API30). ANCOVA of AVP30, adjusted by pretest PI was the main analysis; the non-inferiority margin (NI<sub>m</sub>) for the between group difference was set at 0.6, i.e.=1/3 of the minimum clinically important pain intensity difference established at 2 points.

**Results:** 114 patients were randomized either to SLF (58) or SCM (56). One patient (SLF group) withdraw consent before drug assumption and was excluded from analysis. Baseline mean PIs were 7.5 in both groups; mean API30s were 4.9 and 4.5 respectively for SLF and SCM, with a between group difference of -0.51, 95%CI -1.10 to 0.07 which includes the NI<sub>m</sub>; results from ITT and PP analysis were equal. SLF patients more frequently received a second analgesic drug dose after 30 min. (51% vs 37%, risk difference -13%, 95%CI -30% to 3%). Only 1 patient (SLF group) reported nausea. 93% of patients preferred the SL route of administration.

**Conclusions:** Although both drugs showed to be effective and patients preference confirmed higher acceptability of FSL, the trial cannot conclude for non inferiority of 100µg SLF vs 5mg SCM within the chosen non-inferiority margin. Further analyses are needed to explore whether SLF can be non inferior to SCM in specific patient subgroups.

**Abstract number:** PL2

**Abstract type:** Plenary

#### **Early Palliative Care for Patients with Advanced Cancer: Caregiver Results from a Cluster-randomised Controlled Trial**

*McDonald, Julie<sup>1,2</sup>, Swami, Nadia<sup>1</sup>, Hannon, Breffni<sup>1,2</sup>, Pope, Ashley<sup>1</sup>, Oza, Amit<sup>3</sup>, Leighl, Natasha<sup>2,3</sup>, Krzyzanowska, Monika<sup>2,3</sup>, Rodin, Gary<sup>1,4,5</sup>, Le, Lisa<sup>6</sup>, Zimmermann, Camilla<sup>1,2,4</sup>*

<sup>1</sup>Department of Supportive Care, Princess Margaret Cancer Centre, Toronto, Canada, <sup>2</sup>Department of Medicine, University of Toronto, Toronto, Canada, <sup>3</sup>Department of Medical Oncology, Princess Margaret Cancer Centre, Toronto, Canada, <sup>4</sup>Campbell Family Research Institute, University Health Network, Toronto, Canada, <sup>5</sup>Department of Psychiatry, University of Toronto, Toronto, Canada, <sup>6</sup>Department of Biostatistics, University of Toronto, Toronto, Canada

**Background:** Early palliative care improves the quality of life (QOL) and satisfaction with care of patients with advanced cancer, but little is known about its impact on caregivers. Here we report secondary outcomes of caregiver QOL and satisfaction with care from a cluster-randomised controlled trial of early palliative care.

**Methods:** 461 patients with advanced cancer were recruited from 24 medical oncology clinics to participate in a cluster-randomised controlled trial of early palliative care versus standard care<sup>1</sup>. Primary caregivers were approached for consent to complete validated measures at baseline and monthly for 4 months, assessing QOL (Caregiver QOL-Cancer [CQOL-C] and SF-36v2 Health Survey), and satisfaction with care (FAMCARE-19). We used a linear random-intercept mixed effect model, which took clustering into account, to test whether there was improvement for the intervention group relative to the control group over 3 months (primary endpoint) and 4 months (end of study).

**Results:** 182 caregivers completed baseline measures (94 intervention, 88 control); 151 completed at least one follow-up assessment. Satisfaction with care improved in the

intervention group compared to control over the 3-month period ( $p=0.007$ ) and the 4-month period ( $p=0.02$ ). There was no significant improvement in the intervention group compared to the control group for the other outcomes: CQOL-C (3 months:  $p=0.92$ ; 4 months:  $p=0.51$ ), SF-36 PCS (3 months  $p=0.83$ ; 4 months  $p=0.20$ ); SF-36 MCS (3 months:  $p=0.87$ ; 4 months:  $p=0.60$ ).

**Conclusions:** In this study, early palliative care improved caregiver satisfaction with care, complementing similar findings in patients. The lack of improvement in QOL may result from inadequate caregiver sample size, insufficient sensitivity to change of QOL measures, or requiring a tailored caregiver intervention.

1. Zimmermann, C et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet* 2014;383:1721-30.

## Plenary II

**Abstract number:** PL3

**Abstract type:** Plenary

### A Brief, Patient- and Proxy-reported Outcome Measure for the Adult Palliative Care Population: Validity and Reliability of the Integrated Palliative Outcome Scale (IPOS)

*Murtagh, Felicity<sup>1</sup>, Ramsenthaler, Christina<sup>1</sup>, Firth, Alice<sup>1</sup>, Groeneveld, Esther I.<sup>1</sup>, Lovell, Natasha<sup>1</sup>, Simon, Steffen<sup>2</sup>, Denzel, Johannes<sup>3</sup>, Bernhardt, Florian<sup>3</sup>, Schildmann, Eva<sup>3</sup>, Bausewein, Claudia<sup>3</sup>, Higginson, Irene J.<sup>1</sup>*

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**Background:** Outcomes are recognised the most valid way to understand people's needs, monitor change and determine the results of treatment and care. We aimed to refine and validate the Integrated Palliative Outcome Scale (IPOS), a measure underpinned by extensive development work over the last 15 years, in terms of its construct validity, reliability and longitudinal responsiveness to change.

**Methods:** Concurrent, cross-cultural validation study of two versions of IPOS - i) patient self-report and ii) staff proxy-report - in a multicentre longitudinal survey in hospice in-patient units, hospitals, and community (home-based) settings in the UK and in Germany. Validation comprised: cognitive testing & item adaptation, internal consistency, agreement, structural validity, known-group comparisons, correlational analysis, and longitudinal evaluation in form of test-retest reliability and responsiveness to change.

**Results:** 373 patients and 161 staff members were recruited. The final 19 item version showed very good internal consistency ( $\alpha = 0.77$ ) and good test-retest reliability as well as patient-staff and staff-staff agreement on most items. A three-factor structure (physical symptoms, gastrointestinal symptoms, emotional concerns) was confirmed. The IPOS and its subscales showed a strong ability to distinguish between clinically relevant groups (total IPOS and IPOS subscale scores being higher in those patients with unstable or deteriorating disease vs. stable disease,  $F=11.1$ ,  $p<0.001$ ). Excellent convergent and discriminant validity to hypothesised items and subscales of the ESAS and the FACT-G was demonstrated. Longitudinal validity in form of responsiveness to change was good.

**Conclusions:** The IPOS is a valid and reliable outcome measures, both in its patient and staff version. It is suitable for assessing and monitoring palliative care outcomes in clinical practice and research.

Funded by the NIHR (RP-PG-1210-12015).

## Plenary III

**Abstract number:** PL4

**Abstract type:** Plenary

### Randomised Double Blind Placebo Controlled Phase II Trial of Prolonged Release Melatonin for Prevention of Delirium in Inpatients with Advanced Cancer

*Agar, Meera<sup>1,2,3</sup>, Lawlor, Peter<sup>4</sup>, Ely, E. Wesley<sup>5</sup>, Lam, Lawrence<sup>1</sup>, Nikles, Jane<sup>6</sup>, McCaffrey, Nicola<sup>7</sup>, Bush, Shirley<sup>4</sup>, Draper, Brian<sup>8</sup>, Luckett, Tim<sup>1</sup>, Chye, Richard<sup>9</sup>, Le, Brian<sup>10</sup>, Martin, Peter<sup>11</sup>, Clark, Katherine<sup>12</sup>, Currow, David<sup>3</sup>, Palliative Care Clinical Studies Collaborative*

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**Background:** Many non-pharmacological preventative strategies for delirium are not feasible or sustainable in advanced cancer due to fatigue or poor functional status, often at the time delirium risk increases as cancer progresses. Emerging evidence suggests circadian system desynchrony and/or low melatonin levels contribute to delirium. Three randomised controlled trials (RCT)

support melatonin as a potential safe preventative agent in hospitalised elders. This study aimed to test feasibility of a phase III RCT to evaluate effect of oral prolonged release melatonin in preventing delirium in people with advanced cancer in hospital. Secondary aims were to obtain preliminary data on the effect (number of delirium events and time to first incident delirium event) and tolerability of melatonin in advanced cancer. (ACTRN12612000931875).

**Methods:** Advanced cancer inpatients were randomised to 2mg prolonged-release melatonin or placebo nocte for the inpatient stay. Outcomes included: percentage patients randomised completing and eligible patients randomised; safety; and preliminary data on delirium incidence.

**Results:** The target sample size of 30 was attained within 8 months (14 melatonin, 16 placebo), with 97% of screened participants randomised. There were no differences in clinical and demographic characteristics between groups. 67% completed to discharge or delirium occurrence. Adverse events (2 in melatonin arm) were not related to the intervention. Delirium incidence was 7% (1/14) in the intervention arm and 25% (4/16) in placebo, with time to delirium in each case being 2 (2 cases), 9 and 18 days for controls, and 7 days for the treatment arm.

**Conclusions:** This pilot provided evidence for feasibility and has informed fine-tuning of eligibility and methods. The study intervention was well tolerated and showed sufficient potential to move to a Phase III RCT. Results suggest a lower incidence of 4.5/1,000 population-days in the melatonin arm.

**Abstract number:** PL5

**Abstract type:** Plenary

### Longitudinal Changes and Predicators of Severe Depressive Symptoms in Bereaved Family Caregivers over the First 2 Years after the Death of Terminally Ill Cancer Patients

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**Background:** Bereaved family caregivers endure tremendous stresses. However, few studies have longitudinally investigated their bereavement reactions more than one year postloss and none from family-oriented Asian countries.

**Aim:** We explored longitudinal changes in and predictive factors of severe depressive symptoms for Taiwanese terminally ill cancer patient's bereaved family caregivers over the first 2 years postloss.

**Design:** Descriptive, longitudinal. Severe depressive symptoms were measured with the Center for Epidemiological Studies Depression Scale (CESD>15) at 1, 3, 6, 13, 18, and 24 months postloss. Multiple logistic regression model with the generalized estimating equation (GEE) was used to identify factors (preloss depressive symptom levels, subjective caregiving burden, objective caregiving loads, preparedness for the patient's death, and postloss social support) associated with severe depressive symptoms.

**Setting/participants:** A convenience sample of 285 bereaved caregivers was recruited from a medical center in Taiwan.

**Results:** The prevalence of severe depressive symptoms for bereaved family caregivers peaked at 1 month (73.3%) and significantly decreased to 15.2% at 24 months after the patient's death. After adjusting for confounders, bereaved caregivers' likelihood of severe depressive symptoms was significantly higher if they had heavy objective caregiving loads and had higher depressive symptom levels. Great preparedness for the patients' death and good social support decreased bereaved caregivers' likelihood of postloss severe depressive symptoms.

**Conclusion:** Severe depressive symptoms among bereaved caregivers decrease significantly over time. Healthcare professionals should conduct assessments for at-risk bereaved caregivers starting when patients are still alive and provide appropriate interventions to facilitate them return to their normal lives postloss.

## EAPC2016: Oral Sessions

### Symptoms other than pain

**Abstract number:** FC1

**Abstract type:** Oral

#### Patients with Advanced Cancer and a Depressive Disorder Report a Substantially Higher Symptom Burden than Non-depressed Patients

*Grotmol, Kjersti<sup>1</sup>, Loge, Jon Håvard<sup>1,2</sup>, Aass, Nina<sup>1</sup>, Lundeby, Tonje<sup>1,2</sup>, Finset, Arnstein<sup>2</sup>, Kaasa, Stein<sup>3</sup>, Hjerstad, Marianne<sup>1,4</sup>, Lie, Hanne<sup>2,5</sup>*

<sup>1</sup>Regional Centre for Excellence in Palliative Care, Oslo University Hospital, Oslo, Norway, <sup>2</sup>Department of Behavioural Sciences in Medicine, University of Oslo, Oslo, Norway, <sup>3</sup>Department of Oncology, Oslo University Hospital, Oslo, Norway, <sup>4</sup>Dept. of Cancer Research and Molecular Medicine, NTNU, Trondheim, Norway, <sup>5</sup>Radiumhospitalet, National Resource Center for Late Effects after Cancer Treatment, Oslo University Hospital, Oslo, Norway

**Background:** We have observed that patients with advanced cancer that are diagnosed with a depression disorder (DD) report higher symptom levels than patients without DD, but this is rarely tested empirically.

**Aims:** To investigate the association between DD and self-reported symptoms in patients with advanced cancer controlled for disease related factors.

**Methods:** 969 patients (M:50%, mean age 63) from an international multicenter study (EPCRC) were included. DD was defined according to the DSM criteria, assessed by the PHQ-9. Symptom burden was assessed by ESAS sum score; excluding the depression item. Item-by-item scores and overall symptom burden were compared using t-tests. Multiple regression analysis was used to test the association between DD and symptom scores while controlling for survival, CRP and Karnofsky score.

**Results:** The 133 patients (14%) with DD reported significantly higher symptom intensity on all ESAS-items and higher ESAS sum score ( $p < .001$ ) than the non-depressed. The following variables were independently associated with a higher ESAS sum score; DD ( $\beta = .26$ ,  $t = 7.3$ ,  $p < .001$ ), survival ( $\beta = -.10$ ,  $t = -2.1$ ,  $p < .06$ ), CRP ( $\beta = .11$ ,  $t = 2.9$ ,  $p < .01$ ), and Karnofsky ( $\beta = -.15$ ,  $t = -4.6$ ,  $p < .001$ ).

**Conclusion:** DD in patients with advanced cancer is associated with higher symptom burden, irrespective of other factors known to increase symptom burden. The cross-sectional design does not permit conclusions on causation. Results point to the need for prospective intervention studies and systematic clinical routines to better identify and treat those suffering from DD.

	Pain	Tiredness	Nausea	Anxiety	Drowsiness	Appetite	Feeling of well-being	Shortness of breath	Sum score (excl depression item)
Not DD	2.0	3.5	1.0	1.8	3.2	3.0	3.1	1.8	19.3
DD	3.1	5.2	1.8	3.6	4.8	5.2	5.5	2.9	32.1
t-value	-4.9	-7.6	-3.6	-6.6	-7.5	-8.0	-11.4	-4.0	-11.4

[Mean symptom scores in patients with and without DD]

All differences were highly statistically significant ( $p < .001$ )

The EPCRC was funded by the European Commission's Sixth Framework Program (Contract no. LSHC-CT-2006-037777)

**Abstract number:** FC2

**Abstract type:** Oral

#### General Symptom Level, Pain and Anxiety Predict Declining Health-Related Quality of Life in Multiple Myeloma: A Prospective, Multi-centre Longitudinal Study

*Ramsenthaler, Christina<sup>1</sup>, Gao, Wei<sup>1</sup>, Siegert, Richard J.<sup>2</sup>, Edmonds, Polly M.<sup>1</sup>, Schey, Stephen A.<sup>3</sup>, Higginson, Irene J.<sup>1</sup>*

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**Background:** Haematological cancers show rising incidence due to the ageing of the population. There is little longitudinal data to understand changing levels of need. We aimed to determine distinct classes of quality of life and symptom trajectories over time, and to determine which demographic and clinical characteristics predict declining health-related quality of life (QOL).

**Methods:** We recruited patients with multiple myeloma at various stages in their disease trajectory into a 14-site multicentre, longitudinal study. QOL data (Myeloma Patient Outcome Scale, EORTC QLQ-C30 and EuroQol) and clinical parameters (symptom level, disease, treatment details, Hospital Anxiety and Depression Scale) were assessed at baseline, 2, 4, 6 and 8 months. Trajectories of QOL were analysed using latent growth mixture models, and using multivariable general and generalised mixed regression models to determine predictors for deteriorating QOL.

**Results:** 238 patients, on average 3.5 years (SD: 3.4) post-diagnosis, were recruited. 18.2% had newly diagnosed disease, 47.9% were in the stable and 32.7% were in the advanced, palliative phase of illness. Patients reported a mean of 7.2 (SD: 2.7) symptoms. Over 70% had pain, 88.7% fatigue and 61.1% breathlessness. The most burdensome symptoms in the advanced stages were fatigue, poor mobility, pain, and tingling in the hand/feet. Four distinct classes of trajectories were found: improving QOL, medium to poor stable QOL, good stable QOL and deteriorating QOL. None of the biomedical factors was predictive of poor and deteriorating QOL at the end of follow-up, but general symptom level, presence of clinically relevant anxiety and pain or fatigue.

**Conclusions:** Burden of symptoms in multiple myeloma is high and symptoms are not resolved even during the treatment-free intervals. Symptom burden and psychological distress should be monitored regularly to identify those patients that can benefit from early referral to palliative care services.

**Abstract number:** FC3

**Abstract type:** Oral

### Outpatient Paracentesis in Management of Malignant Ascites

*McCann, Mary-Ann, O'Neill, Conor, Graham, Erica, Corcoran, Bernie, Wilkinson, Pauline*

NI Cancer Centre, Belfast Health and Social Care Trust, Belfast, United Kingdom

**Background:** Therapeutic paracentesis is a simple procedure commonly used in the symptomatic management of malignant ascites. Practice within the UK however varies considerably.

**Aims:** To review outpatient paracentesis in a regional cancer centre which will then guide development of local guidelines.

**Methods:** Retrospective review of all outpatient paracentesis procedures performed in Regional Cancer Centre between March 2012- March 2015. Information obtained from the Clinical Oncology Information System and the Northern Ireland Electronic Care Record.

**Results:** 509 procedures were performed in 3 years with mean of 4.4 per patient (range 1-33). Diagnosis included ovarian carcinoma (64%), carcinoma of gastrointestinal tract (22%), breast carcinoma (7%), endometrial carcinoma (4%) and other (3%). All were carried out under direct ultrasound guidance. Mean and median volume of fluid obtained were 3000mls and 3281mls respectively. 11/509 patients (0.02%) were recorded as being on anticoagulants -7 on warfarin and 4 on therapeutic enoxaparin. Only 1 patient required intravenous fluids following procedure and no one received intravenous albumin. Complication rate was 7% (37/509 procedures) with 1.2% (6/509) requiring admission post-procedure. Complications included fluid leakage (17/509), failure to obtain fluid (10/509), multiple insertions (5/509), abdominal pain (3/509), cellulitis (2/509) and bleeding (1/509). Mean survival from initial paracentesis to death was 197 days. 24.8% of patients proceeded to have a PleurX drain inserted.

**Conclusions:** Paracentesis is a simple, low-risk procedure that provides rapid symptomatic relief from malignant ascites. It can be carried out within the outpatient day case setting safely with low complication and admission rates. Information collected will help develop procedural guidance for paracentesis and subsequently the development of indications for PleurX drains to assist in improving patient experience.

**Abstract number:** FC4

**Abstract type:** Oral

### Assessing the Presence and Severity of Constipation with Plain Radiographs in Constipated Palliative Care Patients

*Clark, Katherine<sup>1,2</sup>, Can Less be Better Study Group*

<sup>1</sup>Palliative Care, Calvary Mater Newcastle, Waratah, Australia, <sup>2</sup>Medicine and Public Health, University of Newcastle, Newcastle, Australia

**Background/aims:** Palliative care guidelines recommend plain radiographs to assess the severity of constipation. This is based on the presumption that visible faecal shadowing represents stool retention. In contrast, gastroenterology guidelines recommend against plain films as unreliable and not reflective of people's symptom experiences. This work's aim was to compare clinician's reports of faecal loading on plain radiography versus radio-opaque marker transit studies and patient's self-reported constipation symptoms.

**Methods:** This study was conducted in constipated palliative care patients requiring laxatives. All had colon transit

studies using radiopaque markers and plain radiographs; and contemporaneous assessment of constipation symptoms with the Patient Assessment of Constipation Symptom (PAC-SYM) questionnaire. Four clinicians independently reported faecal loading with a faecal loading scale. Descriptive statistics summarised participant's characteristics. The pair-wise inter-rater agreement among all four raters were examined using the Bland-Altman approach. For the comparisons of the clinicians' assigned faecal loading score between the radiographic assessment of the normal and slow colon transit time, a non-parametric approach of Mann-Whitney U tests were used. Spearman's correlation analyses were employed to investigate the association between the clinicians' assigned faecal loading score and patients' self-reported PAC-SYM scores.

**Results:** The results of this study were very similar to other studies conducted in functional constipation. Systematic disagreement between observers was observed with poor correlation between faecal loading scores and colon transit times and patient's self-reported symptoms.

**Conclusions:** These results are very similar to other studies conducted in chronic constipation. This work questions the ongoing use of radiographs in the diagnosis and management of constipation.

**Abstract number:** FC5

**Abstract type:** Oral

#### **The Impact of Delirium on Cognitive Status Across Time: Short Term Observations**

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**Background:** Delirium is considerably prevalent in palliative care settings and can adversely impact patient management, decision making capacity and outcomes.

**Aims:**

- 1) To evaluate overall cognitive status (using the Montreal Cognitive Assessment; MoCA) among a palliative care inpatient unit on 2 separate time-points within a 7 day time period.
- 2) To determine if there a discernable difference in overall cognitive capacity within a short time-frame for the following population subgroups:
  - Patients with resolved delirium on the second occasion

- Patients with no delirium on both occasions
- Patients with delirium on both occasions
- Patients who developed delirium on the second occasion

**Methods:** The MoCA was used to investigate cognitive status and the Short CAM (Confusion Assessment Method) was used to examine the incidence of delirium in 101 patients admitted to a specialist palliative care unit.

**Results:** 41 participants were excluded from the aggregate analysis due to incomplete MoCA measures. Of the 60 participants (Female=33, male=27; Mean age 69.20±9.95), 95% (n=57) had a diagnosis of cancer. The overall mean MoCA score for time 1 was 20.01±5.14 (cognitive impairment >85% of sample); a similar trend was noted for time 2, MoCA mean score = 20.26±4.23 (cognitive impairment >90% of sample). When mean MoCA scores for each subgroup were compared longitudinally, the results were as follows: patients with resolved delirium (n=8; 13.33%), score time 1=14.46±5.93 and time 2=17.18±4.63; patients with no delirium (n=48; 80%), score time 1= 21.09±4.2 and time 2= 21.17±3.85; patients with delirium on both occasions (n=1; 1.66%), score time 1 = 23 and time 2 =14; patients who developed delirium (n=3; 5%), score time 1= 16.44±8.14 and time 2 = 16±1.0.

**Conclusions:** These findings demonstrate that a slight improvement in cognitive capacity may be evident across short term time periods, further emphasising the importance of accurate identification and resolution of delirium.

**Abstract number:** FC6

**Abstract type:** Oral

#### **Randomised Controlled Trial on the Effectiveness of Home-based Walking Exercise on Anxiety, Depression and Cancer-related Symptoms in Patients with Lung Cancer**

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**Background/aims:** Although exercise has been addressed as an adjuvant treatment for anxiety, depression and

cancer-related symptoms, limited studies have evaluated the effectiveness of exercise in patients with lung cancer. We hypothesised the walking-exercise group to be superior to the usual-care group regarding patient-rated anxiety, depression and the severity of cancer-related symptoms.

**Methods:** We recruited 116 patients from a medical centre in northern Taiwan, and randomly assigned them to either a walking-exercise group (n=58) or a usual-care group (n=58). We conducted a 12-week exercise programme that comprised home-based, moderate-intensity walking for 40 min per day, 3 days per week, and weekly exercise counselling. The outcome measures included the Hospital Anxiety and Depression Scale and the Taiwanese version of the MD Anderson Symptom Inventory.

**Results:** We analysed the effects of the exercise programme on anxiety, depression and cancer-related symptoms by using a generalised estimating equation method. The exercise group patients exhibited significant improvements in their anxiety levels over time (P=0.009 and 0.006 in the third and sixth months, respectively) and depression (P=0.00006 and 0.004 in the third and sixth months, respectively) than did the usual-care group patients.

**Conclusions:** The home-based walking exercise programme is a feasible and effective intervention method for managing anxiety and depression in lung cancer survivors and can be considered as an essential component of lung cancer rehabilitation.

## Palliative care organisation and health care services I

**Abstract number:** FC7

**Abstract type:** Oral

### Effects on End-of-Life Care by Palliative Consultation Services in Sweden

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**Background/aims:** The extent of palliative care consultation services availability vary widely between different geographical locations in Sweden. The Swedish Register of Palliative Care (SRPC) collects data from 60 000 (66% of all) deaths annually focusing on quality of provided palliative end-of-life care during the last week in life. One included question concerns whether any external palliative competence was consulted. The research question in this study was whether support from an external palliative care consult implied any significant improvements in the provided end-of-life care compared to those without such support?

**Methods:** Data from persons deceased outside specialized palliative care during one year who had received support

from a palliative care consultation service where matched with controls for gender, age, diagnosis, and place of care. Chi2-analysis with a significance level of  $p < 0.05$  was used for statistical analysis.

**Results:** The study identified 2304 cases and the same number of matched controls of which 52% were men, mean age was 75 (range 3-106), 84% died from cancer, and 62% died outside hospital (at home, nursing homes, and community respite care). The group that had got external palliative care support received significantly more appropriate end-of-life care activities compared to matched controls, such as prescriptions of injectable prn-drugs (against pain 98% < ->95%, anxiety 96% < ->89%, nausea 87% < ->78% and pulmonary secretions 94% < ->88%), information to patients (79% < ->64%) and next-of-kin (85% < ->76%) about the transition to end-of-life care, assessment of pain (43% < ->35%) and other symptoms (20% < ->16%), and died more frequently in their preferred place (58% < ->50%).

**Conclusion:** The involvement of external palliative care consultation services seems to be significantly associated with more appropriate palliative care activities at the end-of-life.

**Abstract number:** FC8

**Abstract type:** Oral

### Improving National Palliative Care Symptom Outcomes Systematically through Point-of-Care Data Collection, Structured Feedback and Benchmarking

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**Background:** Every aspect of health care needs to systematically improve the services that it offers and continually strive to improve care. An Australian strategy to achieve this in palliative care is through measuring patient-defined outcomes.

The Australian Palliative Care Outcomes Collaboration (PCOC) was established in 2005 to provide a framework for routine clinical assessments and point-of-care data collection with the intent of capturing clinically meaningful information at significant periods in a patient's disease trajectory. The program aims to drive improvement through providing a feedback loop to individual services, identifying improvement opportunities and providing service-to-service benchmarking.

**Aim:** To confirm that it feasible to measure patient-centred palliative care outcomes routinely at point of care as an integral part of the clinical encounter and to demonstrate it is possible to systematically improve the care that it is provided.

**Method:** Data were collected through point-of care assessments and reported by the Palliative Care Outcome Collaboration for 45 specialist palliative care services consistently engaged in the report and feedback cycle over a four-year period, between January 2011 and December 2014.

**Results:** Results from routine assessment data were analysed for 60,816 patients and 196,152 phases of illness. Mean patient age was 72.7 years (SD 14.3), 47% were female and 79% had cancer as their primary life-limiting illness. For both patient and clinician reported outcomes, there were statistically significant improvements in all eight assessed symptom domains including pain and family-carer problems. Further results indicate more consistent patient outcomes were being achieved as evidenced by reduced variation in service level outcomes and greater equity of patient outcomes.

**Conclusion:** A national point-of-care data collection and outcome measurement program improves both quality of the care and patient outcomes.

**Abstract number:** FC9

**Abstract type:** Oral

### Cancer Patients who Die in the Emergency

#### Department: A Descriptive Study

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**Background:** In the UK, approximately 2% of all deaths from cancer occur in NHS emergency departments (ED). Such deaths are viewed as undesirable, however little is known about the circumstances of these deaths or the characteristics of this group of patients.

**Aim:** To describe deaths from cancer occurring in NHS EDs.

**Methods:** We used linked patient-level data from two routinely collected databases (the Office for National Statistics Mortality Database and Hospital Episode Statistics Accident & Emergency Database) to describe all deaths from cancer that occurred in NHS EDs in England, UK, during a one year period (01/04/2011 to 31/03/2012).

**Results:** Among 124,030 patients who died from cancer in England during the study period, 1.5% (n=1,909) occurred in an NHS ED. The mean age at death was 71 years (SD: 13.2), 57% (n=1,084) of patients were male, and 46% (n=872) were from the two most deprived socio-economic quintiles. The two most common underlying causes of death were lung cancer (n=561, 29.4%) and upper gastrointestinal (GI) cancer (n=235, 12.3%). Cardiac conditions were the most common reason for ED attendance (n=433,

22.7%). 64% (n=1,214) of deaths occurred out of hours (Monday to Friday 18:01 - 08:29, Saturdays, Sundays and Bank holidays).

**Conclusion:** A greater proportion of ED deaths occurred in men, persons of lower socio-economic status, and those with a diagnosis of lung or upper GI cancer. The majority of ED deaths also occurred out of hours. Further research exploring the symptoms that resulted in these ED visits may help future planning and development of community healthcare services.

**Abstract number:** FC10

**Abstract type:** Oral

### The Economic Potential of Interventions to Support Carers in Home Palliative Care

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**Aim:** To investigate the potential economic impact of a reinforced carer support intervention, designed to build carers' problem-solving skills, COPE (Creativity, Optimism, Planning, and Expert information) in a home palliative care system in England.

**Methods:** A system modelling approach was used with palliative care stakeholders including lay people, to model the home care system. A review of economic and effectiveness evidence for reinforced home palliative care was undertaken. Elicitation of expert judgement supplemented evidence from published and routine data sources. The marginal impact on resource use and costs were modelled. The economic analysis used a National Health Service and Personal Social Services perspective.

**Results:** No existing economic evaluations of reinforced home palliative care were found and only a limited number examining (non-reinforced) home care. The COPE intervention, delivered by specialist palliative care nurses, was estimated to cost £250 - £300 per patient, the projected impact on subsequent nurse time meant that the marginal cost would be approximately £90 per patient (-£230, £240). However, throughout the wider health and social care system cost savings were estimated at -£560 (-£1440, £170).

**Conclusion:** Reinforced carer support interventions in home palliative care have the potential to be cost saving. The largest component of projected savings is from reduced avoidable emergency hospital admissions arising from the formal carer training. Estimates are reliant on expert elicitation and are subject to uncertainty. Barriers to

realising cost savings include poor co-ordination and communication between services. Interventions to support carers need to be considered within wider initiatives to provide co-ordinated palliative care. As a complex intervention in a complex setting these interventions need to incorporate mechanisms for evaluation and adaptation.

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**Abstract number:** FC11

**Abstract type:** Oral

### Early Palliative Care: Attitudes and Opinions of Canadian Palliative Care Physicians

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**Background:** Early palliative care (EPC) is increasingly recommended; however, referrals are typically late. The aim of this study was to describe Canadian palliative care physicians' attitudes and opinions about EPC and to determine factors associated with receiving early referrals.

**Methods:** Palliative care physicians identified by the Canadian Society of Palliative Care Physicians were invited to complete a survey evaluating their attitudes and opinions about EPC by mail and email. Logistic regression was performed on a subsample of 256 specialized palliative care (SPC) physicians, (i.e. who received referrals from other physicians) to determine factors associated with receiving early referrals. Backwards likelihood ratio was used to enter covariates into the model (entry  $p \leq 0.25$ ).

**Results:** The overall response rate was 71% (530/747); 48% were SPC physicians. The majority reported that for cancer (93.8%) and non-cancer (90.2%) patients, referral to palliative care should ideally be early (at prognosis >6 months, or upon diagnosis of cancer/life-limiting illness regardless of prognosis, or upon diagnosis of incurable cancer). However, only 20.9% reported that the average

survival time for patients referred to them was >6 months. Multivariate analysis showed that those with a postgraduate degree (OR 2.5, 95% CI 1.1-5.4); who provided care mainly (>50%) for non-cancer patients (3.3, 1.2-8.7); or who practised palliative care in a private office (2.7, 1.2-6.2) were more likely to receive early referrals. Male physicians (0.46, 0.21-0.99) and those who agreed that patients should have stopped all chemo before referral to palliative care (0.34, 0.17-0.69) were less likely to receive early referrals.

**Conclusions:** Although SPC physicians prefer EPC, the majority do not receive referrals early. Potential barriers to receiving early referrals include demographic and attitudinal factors as well as those related to the nature of palliative care practice.

**Abstract number:** FC12

**Abstract type:** Oral

### Who Accesses Befriending Services Near the End of Life? Baseline Results from a Wait-list Controlled Trial (ELSA) of a Volunteer Befriending Service in the Last Year of Life

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**Background:** Volunteers are central to the provision of much end of life care, but their impact is little understood. Volunteer befriending services could work to reduce isolation, meet emotional needs and maintain a sense of community connectedness.

The **primary aim** of this study is to evaluate the effectiveness of receiving care from a volunteer service plus usual care at improving quality of life than usual care alone for adults in the last year of life. Here we provide descriptive baseline data on trial participants.

**Study participants:** Patients (estimated to be in their last year of life) referred to volunteer befriending services across 11 end of life care providers in England.

**Study design and methods:** A wait-list controlled trial, with participants randomly allocated to intervention (immediate receipt of volunteering intervention) or wait list arm (four week wait for intervention). Data collection at baseline, 4, 8 (12) weeks: WHO QOL BREF, Loneliness scale, mMOS-SS, social networks. Intention to treat analysis includes fitting a linear mixed effect model to each outcome variable at 4, 8 and 12 weeks. ISRCTN 12929812

**Results:** Participants (n= 138 to 10/2015) baseline data return currently 87% (n=120). Participants mean age 72 years, *SD* = 12, 57% female, 82% retired, 56% living alone, 96% white ethnicity. No significant differences on main outcome measure (WHO QOL Bref) at baseline were observed between genders, but as age increases, scores on social, psychological and environmental sub scales worsen (*ps*.< .01). Age and living alone were significant predictors of lower environment scores (*ps*.< .01).

**Conclusion:** This study is the first to examine volunteer befriending in a trial context, and to robustly describe the characteristics of those who receive such services. Early indications are that for maximum effect services might target older people living alone, and full results will indicate the effect of such interventions on quality of life.

## Palliative care in specific groups I

**Abstract number:** FC13

**Abstract type:** Oral

### Palliative Care Intervention in Patients with Haematological Neoplasms: A Systematic Literature Review

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**Objective:** To assess the role of Palliative Care (PC) in the management of patients with haematological tumours treated by Onco-haematological Services (OHMT).

**Material and method:** A systematic literature review was performed using both text words and Mesh/EMTREE terms on PubMed, Cochrane, CINAHL, Scopus and Web of Science, from their set up date to 1st May 2015.

**Results:** After data base search 393 articles were retrieved, finally 139 were included; 83% of them published in the last five years. Revealing five broad categories:

- 1) Referral characteristics from OHMT to PC: usually patients are referred to PC teams very late with a survival rate of few days, except for Multiple Myeloma where pain was the main cause of consultation.
- 2) Patients' clinical characteristics: the three more common symptoms were fatigue (83%), drowsiness (54%) and insomnia (54%); delirium was more frequent than in solid tumours

- 3) End-of-Life (EOL) care issues, due to the difficulty of identifying EOL phase which leads to late PC interventions
- 4) Patients and families advanced disease experience: reporting a belated PC intervention as common, and EOL care involving high-tech and aggressive treatments, and
- 5) Home care: scarcely used since patients need frequent IV treatments or blood transfusions, few authors consider home care to be feasible.

**Conclusions:** Based on the systematic review, patients with haematological tumours are seldom referred to PC teams either in the hospital or home, and when referrals are made, patients are usually in their last weeks or days of life, enduring harsh treatments. The symptom burden is similar to those experienced by solid tumours patients, apart from delirium. EOL care is mainly seen as feasible in an in-patient setting. Despite recent rising interest in PC in Haematology, there is an urgent requirement for more studies to improve knowledge on all areas of care of onco-haematological patients facing advanced disease stages and their families.

**Abstract number:** FC14

**Abstract type:** Oral

### Integrating Palliative Care into Neurology Services: What Do the Professionals Say?

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**Background/aims:** Evaluations of service development initiatives for palliative care in non-cancer conditions are few. OPTCARE Neuro is a multicentre trial evaluating the effectiveness of short-term integrated palliative care (SIPC) for progressive long-term neurological conditions. Here we present survey results comparing the collaboration between neurology and palliative care services and explore the views towards the new SIPC service.

**Methods:** Neurology and palliative care teams from four trial sites (London, Nottingham, Liverpool and Cardiff) were approached via email to complete an online survey. The surveys consisted of 13 (for neurology) or 10 (for palliative care), multiple choice or open comment questions. The survey was launched in July 2015 and responses collected using Google forms.

**Results:** 27 neurology and 21 palliative care professionals responded. Current levels of collaboration between the two specialties was reported as "Good/Excellent" by 37% of neurology and 67% of palliative care professionals ( $\chi^2=4.1$ ,

$p < 0.05$ ). Neurology professionals listed psychological care and care for family caregivers as most difficult aspects of care. Both neurology (70%) and palliative care (67%) professionals believed the new SIPC service would improve the collaboration between the specialties. The most commonly identified barriers for the new SIPC by both specialties were resources, time pressures and funding.

**Conclusions:** Our results demonstrate that collaborations can be improved and both specialties are positive about the impact the new SIPC service will make. However, the barriers identified must be considered in order to shape future service delivery.

**Funding:** National Institute for Health Research (NIHR), Health Services & Delivery Research (HS&DR) programme and the NIHR Collaboration for Leadership in Applied Health Research & Care (CLAHRC). The views expressed are those of the authors and not necessarily those of the NHS, NIHR or Department of Health.

**Abstract number:** FC15

**Abstract type:** Oral

### The Use of the 'Surprise' Question in Paediatric Palliative Care

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Question Timing	Sensitivity	Specificity	Positive Predictive Value (PPV)	Negative Predictive Value (NPV)
3 month	82.6% (75% - 87.5%)	89.3% (81% - 93.7%)	30.7% (17.2% - 42.4%)	99% (98.5% - 99.3%)
12 month	87.1% (80.7% - 91.7%)	67.6% (55.2% - 84.4%)	21.1% (14% - 30.3%)	98.2% (97.2% - 99.2%)

[Data presented are means, with ranges in brackets]

**Discussion:** The SQ used by members of the MDT was highly sensitive at capturing patients nearing the end of life at both 3 and 12 month intervals. The specificity of the SQ was also high at 3 months although this was less marked at 12 months. The PPV indicated a tendency to over estimate death but the NPV indicates that professionals were very accurate at predicting patient stability over a 3 and 12 month period.

**Conclusion:** The SQ is a sensitive measure in identifying life-limited children at risk of dying within 3 and 12 months; as well as identifying stable patients over the same time period. It offers a useful screening tool for advanced care and service planning when looking at tailoring and enhancing services for children in the last 3 and 12 months of life.

**Funding:** Caroline Menez Trust.

**Abstract number:** FC16

**Abstract type:** Oral

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**Background:** The question 'would you be surprised if this patient dies in the next 12 months' is a validated tool for identifying adult patients in the last year of life enabling timely access to palliative care services. However, to the authors' knowledge no studies have explored the accuracy of using this tool in a paediatric population. The aim of this study was to assess the sensitivity and prognostic value of the surprise question (SQ) in a paediatric palliative care population by measuring multi-disciplinary team (MDT) members' predictions of patient's death at 3 and 12 months.

**Method:** Members of the MDT from a children's hospice in England independently answered both a 3 and 12 month SQ for patients who were reviewed or referred between 2011 and 2013.

**Results:** A total of 320 children with a range of life-limiting conditions were included, of which 28 died within 12 months of the SQ being asked. Results are displayed in the table below. Only small variability was found between individual MDT members.

### Cancer Symptoms and Functional Status in Patients with Advanced Cancer - Does Age Matter?

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**Background:** Although most patients with cancer are older, the relationship between age, functional status, and symptom burden in patients with advanced cancer is unclear.

**Aims:** To investigate if cancer symptoms and functional status vary according to age in two large cohorts of patients with advanced cancer.

**Methods:** Combined, 2775 patients (mean age 65.8, 50% males) with advanced cancer were recruited in two international studies; the EPCRC-CSA (CSA) and the EPCCS. Symptoms were assessed by self-report using ESAS (CSA) and ESAS-revised (EPCCS). Physical function was measured using 3 items from the EORTC QLQ-C15-PAL, while physicians rated Karnofsky performance status (KPS). Patient age was categorized into 3 groups: < 60; 60-74; 75+ years. One-way ANOVAs were used to compare ESAS sum-scores and physical function scores between the 3 groups.

**Results:** The number of patients in the 3 groups were 366/517/154 (CSA) and 499/849/390 (EPCCS). The majority had cancer of the digestive organs (CSA: 26%; EPCCS: 30%). There were no differences in ESAS sum-scores across the age groups in either cohort. In the CSA cohort, older patients experienced less nausea (mean 1.0 in 75+ versus mean 1.4 in < 60,  $p=0.02$ ). In the EPCCS cohort, older patients experienced less pain (1.8 vs 2.3,  $p<0.01$ ) and less anxiety (2.0 vs 2.5,  $p=0.027$ ), but had worse appetite (3.3 vs 2.7,  $p=0.03$ ). KPS scores and self-reported physical function were significantly lower in the oldest age groups in both cohorts.

**Conclusion:** Older patients with advanced cancer report similar symptom burden as younger patients, despite a poorer functional status. Nausea, pain, and anxiety seem to be less intensive in older patients, while appetite is worse. More research is needed to investigate the relationship between age, functional status, and tumor burden for patient reported outcomes, with the hypothesis that tumor burden and age-independent host factors are more important than chronological age.

**Abstract number:** FC17

**Abstract type:** Oral

**Feasibility of Delivering a Model of Short-term Integrated Palliative and Supportive Care for the Frail Elderly with Non-cancer Conditions in Community Settings: A Phase II Randomised Trial (OPTCare Elderly Study)**

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**Background:** Palliative care (PC) is recommended for frail older people with non-cancer conditions. Short-term integrated palliative and supportive care (SIPS) is a proposed model to support frail older people in the community at periods of deterioration but its feasibility is unknown.

**Aim:** To examine the feasibility of delivering SIPS to frail older people with advanced illness and non-cancer conditions at home or in a care home.

**Methods:** A randomised controlled feasibility trial of SIPS in 2 areas of South England. Patients were identified as eligible by GPs if aged 75+, CSHA Clinical Frailty Scale score >4 (range 4-9), non-cancer diagnoses with 2+ unresolved symptoms or concerns. Recruited patients were randomised to receive either SIPS with usual care or usual care only. SIPS was delivered by specialist PC teams integrated with GPs and community nurses and involved 1-3 contacts with patients including a holistic comprehensive PC assessment. Main outcome: 5 key symptoms (breathlessness, pain, anxiety, constipation, and fatigue) measured by Palliative care Outcome Scale at baseline, 6 weeks and 12 weeks (primary end point).

**Results:** 125 patients were approached by GPs. 50 patients and 26 carers were recruited, (40% recruitment rate) and randomised to SIPS ( $n=24$ ) or usual care ( $n=26$ ). Mean age 85.6 years, 52% were men and 48% lived at home alone. Most were moderately frail (mean score 5.64, range 4-7). Main diagnoses were cardiovascular (38%) and respiratory disease (18%), and 8 lacked capacity with advanced dementia. Preliminary evidence of benefit pertained to anxiety.

**Conclusions:** The SIPS model is deliverable by PC teams working with generalist community and primary care services. GPs can identify frail older people with advance conditions and study design enabled participation. It is feasible to undertake an RCT on PC involving frail older people in community settings, including adults lacking capacity often excluded from research.

**Funder:** NIHR RfPB.

**Abstract number:** FC18

**Abstract type:** Oral

**Effectiveness of an Interdisciplinary Palliative Care Intervention for Family Caregivers in Lung Cancer**

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**Background:** Family caregivers (FCGs) experience significant deteriorations in physical, emotional, social, and spiritual well-being while caring for lung cancer patients. This study tested the effectiveness of an interdisciplinary palliative care intervention for FCGs of patients diagnosed with stage I-IV non-small cell lung cancer (NSCLC).

**Methods:** FCGs who were identified by lung cancer patients as the primary caregiver were enrolled in a prospective, quasi-experimental study whereby the usual care group was accrued first followed by the intervention group. FCG and patient dyads in the intervention group were presented at interdisciplinary care meetings. FCGs also received four educational sessions organized in the physical, psychological, social, and spiritual domains of QOL. Sessions included creating self-care plans to support the FCG's own needs. Caregiver burden, caregiving skills preparedness, psychological distress, and FCG QOL were assessed at baseline and 12 weeks using validated measures.

**Results:** A total of 366 FCGs were included in the primary analysis. FCGs were primarily female (>60%) and mean age was 57.2. FCGs who received the interdisciplinary palliative care intervention had significantly better scores for social well-being (5.84 vs. 6.86;  $p < .001$ ) and lower psychological distress (4.61 vs. 4.20;  $p = .010$ ) at 12 weeks compared to FCGs in the usual care group. FCGs in the intervention group had significantly less caregiver burden compared to FCGs in the usual care group ( $p = .008$ ).

**Conclusions:** An interdisciplinary approach to palliative care in lung cancer resulted in statistically significant improvements in the FCG's social well-being, psychological distress, and less caregiver burden.

**Funding:** NCI Program Project Grant #1P01CA136396-01 .

## Assessment and measurements

**Abstract number:** FC19

**Abstract type:** Oral

### Missing Data in Palliative Care Randomised Controlled Trials Reduce the Power and Validity of Trial Results: A Systematic Review and Meta-analyses

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**Background:** Missing data (MD) due to death and disease are expected in palliative care randomised controlled trials (RCTs). Such MD reduce the power and precision of trial results, and may introduce bias. This study of palliative care RCTs aimed to:

- (i) quantify the extent of MD,
- (ii) assess factors associated with MD,
- (iii) determine the risk MD pose to internal validity.

**Methods:** A systematic review of MD in RCTs of palliative interventions in participants with advanced life-limiting disease was conducted, and random-effects meta-analyses and meta-regression were performed. CENTRAL, Medline and EMBASE (2009-2014) were searched with no language restrictions. Double screening, selection and data extraction was conducted.

**Findings:** 108 RCTs including 15,560 patients were included (mean age: 64 years, ECOG performance status: 2). The estimate for MD at the primary end-point was 23.1% (95%CI 19.3, 27.4). Once MD was accounted for, 61.6% (45/73) of RCTs were inadequately powered. Larger MD proportions were associated with increasing numbers of questions/tests (odds ratio (OR) 1.31, 95%CI 1.07, 1.54) and longer study duration (OR 1.13, 95%CI 1.02, 1.26). Meta-analysis found evidence of differential rates of MD between trial arms, which varied in direction (OR 1.04 (95%CI 0.90, 1.20),  $I^2$  35.0,  $p = 0.001$ ). Despite randomisation MD in the intervention arms (vs. control) were more likely to be attributed to disease-progression unrelated to the intervention (OR 1.31 (95%CI 1.02, 1.69)).

**Conclusion:** The overall proportion of MD is at a level that poses a significant risk to the validity of trial results that inform palliative care clinical practice. Trial burden and duration need consideration when adjusting sample size calculations for MD. Differential rates and reasons for MD present a significant risk of bias. In RCTs the finding of more MD being attributed to disease progression in the intervention arm indicates there is systematic misclassification of the reasons for MD.

**Abstract number:** FC20

**Abstract type:** Oral

### The Outcome Assessment and Complexity Collaborative (OACC): Patterns of Phase of Illness in a Hospital Palliative Care Advisory Service

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**Background:** The Outcome Assessment and Complexity Collaborative (OACC) is a London initiative working with six Specialist Palliative Care (SPC) services to support routine use of patient centred outcome measures. OACC measures include phase of illness, defined as; stable, unstable, deteriorating, dying, and deceased. OACC is seeking to develop training, implementation, and feedback strategies to help inform future national data collections.

**Aim:** Compare duration of episode of care, and distribution/duration of phase of illness for episodes ending in death with episodes ending in discharge, in a hospital palliative care advisory service.

**Methods:** Data from one hospital SPC advisory service was collected at point of care. Differences, between patients who died receiving SPC and those discharged, in median length of episode and length of phase, were tested using Mann-Whitney *U*. The proportional distribution of phase of illness was described for the two groups, differences were tested using Pearson's  $\chi^2$ .

**Results:** Between Apr-Sep 2015, 806 hospital inpatients received SPC; 912 episodes of care, and 3,270 phases were recorded. 274 episodes ended in death, 573 ended in discharge from SPC. Deaths had more non-malignant disease and were older (69.0% non-malignant; mean 72.4 years), than those discharged (55.0% non-malignant; mean 62.1 years).

A significantly larger proportion of episodes ending in death were in the terminal phase at first contact with SPC, 44.5%, compared to 3.8% of those discharged ( $p < .001$ ). Those who died spent a significantly shorter median period in the dying phase, 1 day, compared to those discharged, 3 days ( $p < .03$ ), which suggests patients have been correctly classified according to phase of illness.

**Conclusions:** Point of care data collection is a new initiative for SPC services in the UK. Early results suggest phase of illness is a useful discriminator between patient groups in the hospital setting.

**Funder:** Guy's and St Thomas Charity/CLAHRC South London.

**Abstract number:** FC21

**Abstract type:** Oral

### Hospital Mortality Reviews: What Do they Tell us about the Palliative Care Management in the Last Days of Life?

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**Introduction:** The Risk Adjusted Mortality Index has traditionally been used to compare hospital death rates within the UK. However, in recent times government agencies & National Health Service hospitals are increasingly using mortality reviews to monitor the quality of inpatient care. While the plan in England is to undertake a total of 2000 hospital death reviews annually, all hospital deaths in Wales are reviewed. Mortality reviews in Wales are usually undertaken by senior clinicians from various specialties.

**Aim:** To determine what information mortality reviews provide regarding the palliative care management in hospital deaths in two acute hospitals.

**Method:** A retrospective review of mortality review data on deaths in two acute hospitals in South Wales, from 1/4/14 to 31/3/15. Both qualitative and quantitative data was reviewed.

**Results:** A total of 553 deaths were reviewed across the two hospital sites. Most common days of death was Thursday. 65% had a non-malignant diagnosis. 81% had a do not resuscitate (DNACPR) order in place. In 443 cases (80%), the death was anticipated - 92% of these had a DNACPR order in place & 16% were managed using the Integrated Care Priorities for the Last Days of Life (ICP). Just over one third of anticipated deaths had been reviewed by the specialist palliative care (SPC) team. Further analysis of data from one hospital showed that 69% of patients reviewed by SPC had adequate EOLC. Of these almost half were managed using the ICP. Only 14% of patients where death was anticipated and not reviewed by SPC were deemed to have adequate EOLC. Interestingly, one reviewer with little experience in palliative care, did not consider adequacy of EOLC in any review.

**Conclusion:** Mortality reviews can provide useful information regarding EOLC management. Despite 80% of deaths being anticipated, less than half were reviewed by palliative care team. Utility value of the reviews is dependant on the training and specialty of the reviewers.

**Abstract number:** FC22

**Abstract type:** Oral

### Assessing Depressive Symptoms in Palliative Care Inpatients with the Cornell Scale for Depression in Dementia (CSDD)

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**Background:** The assessment of depression in the palliative care setting is often complicated by the overlap of symptoms between depression and the primary illness, for example fatigue and weight loss.

**Aims:**

1. To assess rates of depression in palliative care inpatients using the Cornell Scale for Depression in Dementia (CSDD), comparing with formal clinical diagnosis based on Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria.
2. To identify items of the CSDD that most distinguish depressive illness in a palliative care setting.

**Methods:** We measured rates of depression in patients admitted into a palliative care inpatient unit with the CSDD. DSM-IV clinical diagnosis of major depressive disorder (MDD) was achieved using all available clinical information by an independent rater. We calculated Cohen's Kappa to measure concordance between the CSDD and DSM-IV diagnosis. Non-normal data (e.g. individual CSDD items) were compared with Mann-Whitney U tests for group comparisons.

**Results:** We assessed 101 patients [54.5% male (n=55); mean age 69.8 ± 10.4 years], the majority of which had a cancer diagnosis (n=95; 94.1%). Over a fifth (22.2%) met DSM-IV criteria for MDD, while 16.2% scored ≥6 on the CSDD with 15 cases of depression common to these two methods (K =0.74).

A comparison of CSDD item scores for patients with and without MDD indicated significantly higher frequency in depressed patients for 10 of the 19 items, with sadness, lack of reactivity, loss of interest, pessimism and low self-esteem especially distinguishing (p < 0.001). A five-item abbreviated version of the CSDD achieved high accuracy in identifying DSM-IV MDD (AUC=0.90).

**Conclusions:** There was a high level of concordance between the CSDD and DSM-IV diagnosis of MDD. Certain depressive symptoms are more distinguishing of depression in palliative care inpatients and may facilitate more accurate assessment of depression in this setting.

**Funding:** HRB/AIIPC-SRN/2012/1.

**Abstract number:** FC23

**Abstract type:** Oral

**The Association between Phase of Illness and Patient and Carer Outcomes. Is 'Time Spent in the Stable Phase' a Potential High Level Key Performance Indicator? The Results of a Prospective Observational Cohort Study of Consecutive Admissions to a Specialist Palliative Care Unit in Ireland**

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**Background:** Five phases of patient illness have been identified: stable, unstable, deteriorating, terminal and bereaved. Patient 'time in the unstable phase' is implemented as a national benchmark for quality of care in Australia. Research evaluating the use of phase as a potential Key Performance Indicator (KPI) of quality of care is needed.

**Aims:** The aim of this study was to evaluate the association between phase of illness and patient and carer outcomes.

**Methods:** This was a prospective, observational cohort study of consecutive admissions (n=400) to a SPCU. Using the Australian case mix tool (Eager 2003), Phase of illness and the palliative 'problem severity score' (a numerical score for Pain, Other symptoms, Psychological and Carer distress) were recorded along with performance status (Palliative Performance Scale) on admission and then daily by medical staff. Data was entered into SPSS and descriptive statistics generated.

**Results:** 342 patients had full data recorded on admission. 28.6% of patients were recorded as stable, 43% as unstable, 22.2% as deteriorating and 8.7% as being in the terminal phase. Over the first 72 hours patients in the unstable, deteriorating or terminal phase of illness were associated with higher PSSs (p < 0.001). Stable phase was associated with significantly higher performance scores than other phases (Cramer's V=0.526, p < 0.001). Patients in the unstable, deteriorating and terminal phases were significantly more likely to have higher pain scores (V= 0.180, p < 0.001), higher 'other symptom' scores (V= 0.180, p < 0.001), higher psychological distress scores (V=0.153, p < 0.001) and higher family and carer distress scores (V=0.140, p < 0.001).

**Conclusion:** In this study there is a clear association between phases other than the stable phase and higher levels of patient and carer distress. With further research and development, 'time spent in the stable phase' could be used as a high level KPI for quality of care in a palliative setting.

**Abstract number:** FC24

**Abstract type:** Oral

**The Needs Assessment Tool for Interstitial Lung Disease Patients (NAT:PD-ILD): Construct Validity Process**

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**Background:** People with non-cancer conditions have unmet palliative care needs. All clinicians need to be able to identify, manage and refer to specialist palliative care

services (SPC) as needed. People with Interstitial Lung Disease (ILD), currently have less access to SPC and there is no needs assessment tool (NAT) designed for clinical use. We adapted the NAT:PD-cancer for use in ILD and conducted psychometric testing.

**Aim:** To test construct validity of NAT:PD-ILD.

**Methods:** ILD clinicians were trained to use the NAT:PD-ILD. After a consultation, the clinician completed the NAT:PD-ILD, patients completed the St. George Respiratory Questionnaire (SGRQ-I) and carers completed the Carer Strain Index (CSI) and Carer Support Needs Assessment Tool (CSNAT).

Patient and carer concern items were compared using Kendall's Tau b correlation. We present the preliminary patient domains analysis.

**Results:** We recruited 68 people with ILD (male 42 [62%] mean age 66.5; SD: 10.2; range 34-87). Average duration of ILD was 40.3 months (SD: 53.7; range 1-216). Oxygen was used by 37% and the average MRC dyspnoea score was 3.3 (range 1 to 5). 69.2% patients had a carer; 54% were spouses. Preliminary analysis showed statistically significant agreement between NAT:PD-ILD item rating and patient self-report for physical function, psycho-social concerns/function, but not for physical symptoms (Table I).

**Table I.** NAT:PD-ILD Construct: Preliminary analysis.

Construct	NAT:PD-ILD (Sec.2) items	Comparator SGRQ-I	Kendall's Tau b / p-value*
1. Physical symptoms	Unresolved physical symptoms	Symptoms domain	0.01 (p=0.95)
2. Physical functioning	Problems with daily living activities?	Activities domain	0.33 (p<0.01)
3. Psycho-social concerns	Unresolved psychological symptoms/loss quality of life? Work, financial or legal concerns?	Impact domain	0.33 (p<0.001)
4. Psycho-social functioning	Spiritual or existential concerns (issues about the meaning of life and suffering)	Impact domain	0.30 (p<0.01)
	Health beliefs, cultural or social factors making care delivery complex?	Impact domain	0.26 (p=0.01)

\*p<0.05 = statistically significant association between the two variables.

**Conclusion:** The NAT:PD-ILD has acceptable validity for several constructs. Analysis is ongoing.

This study was funded by a Marie Curie Cancer Care Research Grant.

## Bereavement and family care givers

**Abstract number:** FC25

**Abstract type:** Oral

### The Influence of Organisational Context on Staff Attitudes to the Implementation of a Carer Support Needs Intervention

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**Background:** The Carer Support Needs Assessment Tool (CSNAT) is an evidence based intervention which facilitates family carer support towards the end of life, and requires a change from a practitioner-led to carer-led assessment process. Enabling factors to implementing evidence-based practice (EBP) include positive staff attitudes

and organisational context e.g. strong leadership and a culture facilitative to change. A paucity of studies have explored how organisational context impacts on staff attitudes towards the new EBP.

**Aim:** To examine the relationship between organisational context and staff attitudes to the CSNAT and explore how attitudes change over time.

**Methods:** Implementation of the CSNAT was investigated in 36 UK palliative care services. Survey packs administered to staff included: (i) The Alberta Context Tool to assess context e.g. supportiveness of the culture, satisfaction with staffing, and (ii) a survey to assess staff attitudes to the CSNAT (administered prior to and six months after the implementation began). Correlations between ACT concepts and staff attitudes, and changes in attitudes over time, were analysed.

**Results:** 163 surveys from a range of professionals across 31 services were returned. A positive organisational 'culture' supportive of staff development and balancing best practice and productivity, was associated with higher ratings of appropriateness and perceived benefits of using the CSNAT. Positive 'social connections' e.g. opinions being valued, were associated with higher ratings of acceptability, perceived benefits of, and motivation to use the CSNAT. Attitudes to the implementation of the CSNAT decreased in positivity over time.

**Conclusion:** We know that aspects of organisational context are amenable to change. Modifications to such elements prior to, and during the implementation process, have the potential to enhance practitioner readiness and motivation for practice changes.

**Abstract number:** FC26

**Abstract type:** Oral

### Predictors of Complicated Grief in Bereaved Family Caregivers: A Nation-wide Prospective Cohort Study

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**Objective:** Complicated grief in bereaved caregivers has been associated with factors such as female sex, spousal relation and previous depression. Population-based, prospective studies are scarce. The aim of this prospective study was to investigate predictors for complicated grief in bereaved caregivers.

**Methods:** All 9,512 eligible adult patients receiving drug reimbursement for terminal illness in Denmark in 2012 were

mailed a questionnaire and requested to pass it on to their closest relative. Responding caregivers bereaved within six months also received a follow-up questionnaire six months after the loss. Complicated grief was assessed with the PG-13 scale. Based on previous research, the following predictors were considered: age, gender, relation, educational level, pre-loss grief (pre-loss version of PG-13), pre-loss depression (BDI-II), caregiver burden (BSFC), preparedness for death (single-item question) and communication about illness and death (CCID). Predictors of complicated grief were analysed in an adjusted logistic regression model.

**Results:** Participants comprised 3,635 caregivers at baseline (response 38%). Of bereaved caregivers (n=2,420), 2,125 (88%) participated and 1,989 caregivers had complete data on complicated grief (PG-13). Spousal relation (OR=2.04 (95%CI: 1.2-3.6)), low education (OR=2.19 (95%CI: 1.1-4.2)), pre-loss grief (OR=3.76 (95%CI: 2.3-6.0)) and pre-loss depression (OR=5.91 (95%CI: 3.7-9.6)) were predictors of complicated grief.

**Conclusions:** In this large-scale, population-based, prospective study, sex and age were, unexpectedly, not predictors of complicated grief. Health professionals should be aware that spousal relation, low socio-economic position, pre-loss grief and depression during caregiving may predict complicated grief. Support for caregivers with psychological distress during caregiving is crucial and may aid adjustment to bereavement.

**Funding:** The Danish Cancer Society and Trykfonden.

**Abstract number:** FC27

**Abstract type:** Oral

### Losing a Parent to Cancer as a Teenager: Associations between Health-care Interactions and Family Cohesion

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**Background/aims:** Family function, including good cohesion and communication, is a key factor for the wellbeing of bereaved children and teenagers. Despite that, little is known about a potential impact of health-care interactions

on family cohesion among bereaved families, especially from the perspective of the youths. Our aim was to investigate whether emotional support from health care and end-of-life information from a doctor were associated with self-reported level of family cohesion the first year after the loss of a parent to cancer.

**Methods:** In this nationwide population-based study, 622 (73%) youths (aged 19-26) responded to a questionnaire 6-9 years after having lost a parent to cancer during teenage (ages 13-16). Associations were assessed with univariate analysis and multivariate logistic regression. Adjustments were made for a number of possible confounding variables.

**Results:** The majority (79.5%) of the youth reported that their family received poor (no/little) emotional support from the health care professionals caring for their ill parent. This group was more likely to experience report poor family cohesion the first year after the death of a parent compared to those reporting good (moderate/much) emotional support (adj. OR:2.8, 95%CI:1.4-5.7). Likewise, those who were not given information about their parent's disease, treatment and forthcoming death by a doctor were more likely to report poor family cohesion the first year after the loss compared to those who were informed before the death (adj. OR:2.2, 95%CI: 1.1-4.6).

**Conclusion:** Poor emotional support and lack of end-of-life information from health care professionals to the family was associated with poor family cohesion the first year post-loss, as self-reported by parentally cancer-bereaved youths. This does not reveal a causal relationship, but warrant further studies to see if improving these health care interactions could strengthen cohesion among bereaved families with teenage offspring.

**Abstract number:** FC28

**Abstract type:** Oral

#### **“Living on a Precipice” - The Experience of Caring for People Living Longer with High Grade Glioma**

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**Aim:** Caregivers of longer-term survivors of high grade glioma (HGG) face the challenging task of caring for a person with cognitive changes as well as cancer-related issues over a prolonged period. This study aims to explore the experiences of this population.

**Method:** Caregivers of eligible patients with HGG surviving greater than two years were recruited from two Australian metropolitan tertiary hospitals. Caregivers were purposively sampled until data saturation was reached. In-depth interviews were conducted exploring their experiences, perspectives and needs. Transcripts were subjected to thematic analysis by three researchers, using methods informed by grounded theory.

**Result:** Twelve caregivers were interviewed. Most were spouses and had been caring for a mean of 10.0 years (range 2.7-18.4) since the patient's diagnosis. Caregivers described a liminal state - that is, grieving the loss of their former 'normal' life, yet unable to either embrace survivorship status or move into bereavement. They experienced a changed existence shaped by pervasive thoughts of tumour recurrence and, ultimately, the death of the patient. Preoccupation with future grief lead to a sense of life being on hold, with caregivers unable to plan ahead and yet resisting living as though the patient is dying. Caregivers simplified their daily life and some also began to memorialise their loved one whilst they remained alive.

**Conclusion:** This study provides rich insights into the experiences of caregivers of longer-term survivors of HGG. These caregivers reported unique and isolating experiences of liminality which had a profound effect on their decision-making and wellbeing.

This study was funded by the Victorian state government via the Victorian Palliative Medicine Training Program.

**Abstract number:** FC29

**Abstract type:** Oral

#### **Can we Have a Single Guidance for Bereavement Care in European Palliative Care Services? Exploring Common Priorities for Bereavement Care and Perceptions of Cultural Determinants of Grief**

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**Aims:** Describe priorities for development of bereavement care in palliative care Explore perceived cultural uniqueness influencing the experience of grief Conclude on feasibility of common guidance for European palliative care bereavement services.

**Study population:** Palliative care services in Europe.

**Study design and methods:** A cross-sectional descriptive study using online survey methods allowed quantitative and qualitative analyses. A survey was distributed to 56 national associations in EAPC in 32 countries in December 2013 and January 2014. Responses (n=370) were received from 25 (78%) countries. Descriptive statistics were applied & common themes were generated through coding of open-ended responses.

**Results and interpretation:**

Responses on priorities for future development of bereavement care were received from n=187 (50%) services in 21 countries.

Three main themes were indicated. Need to

- Improve structures for assessment of need evaluation of service provision
- Expand range of clinical services in response to bereavement need
- Build or enhance links to community services

Respondents n=179 (48%) described what was unique about their country with regard to bereavement.

Six common themes were identified by almost all countries

- Grief as belonging to the private sphere of individual/family or community
- Importance of rituals & church based supports
- Bereavement care mainly provided by hospice volunteers/palliative care
- Lack of societal openness to speak about death & dying
- Bereavement care lacks guidance and methodology
- Cultural diversity within the countries as challenge

**Conclusion:** The main themes in the responses suggest that the systematic development of bereavement care is a shared goal. Characteristic commonalities in the bereavement experience across countries were expressed and cultural uniqueness in grief might be less than believed. These findings indicate a need for further development of, and shared recommendations for bereavement care.

**Abstract number:** FC30

**Abstract type:** Oral

**Characteristics of the Family Caregivers who Did Not Benefit from a Successful Psycho-educational Group Intervention during Palliative Cancer Care: A Prospective Correlational Study**

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**Background:** A randomised psycho-educational intervention trial, aiming to promote preparedness for caregiving in family caregivers was delivered at 10 palliative settings in Sweden by health professionals (physician, registered nurse and social worker/priest). Although the overall results of the intervention showed a significant improvement in family caregivers' feeling of preparedness for caregiving, the effect size was quite small, indicating a need to focus on family caregivers who did not benefit from the intervention.

**Aim:** To explore the characteristics of the family caregivers who did not benefit from a successful psycho-educational group intervention in palliative cancer care compared to those who did.

**Methods:** Questionnaires were used to collect data at baseline and following the intervention. The preparedness for caregiving scale (PCS) was the main outcome for the study and was used to decide whether or not the family caregiver had benefited from the intervention (PCS difference score  $\leq 0$  vs  $\geq 1$ ).

**Results:** 82 family caregivers completed the intervention and follow up. Caregivers who did not benefit from the intervention had significantly higher ratings of their preparedness and competence for caregiving and their health at baseline compared to the group who benefited. They also experienced lower levels of environmental burden and a trend towards fewer symptoms of depression.

**Conclusions:** Family caregivers who did not benefit from the intervention tended to be less vulnerable at baseline and might not have been in the same need of the intervention. There is a possible need to target family caregivers in palliative care who are more likely to benefit from an intervention. However this needs to be explored further in research.

**Mixed session I: Ethics and psychosocial care**

**Abstract number:** FC31

**Abstract type:** Oral

**Feeling to Be a Burden to Others and Wishes to Die in Palliative Care**

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**Aims:** Feelings to be a burden to others are frequently expressed by palliative care patients and are sometimes associated with a wish to die. Little is known about what patients experience when expressing this feeling and how it relates to wishes to die.

**Methods:** Two semi-structured interview studies on wishes to die with palliative cancer patients' (N=30; 116 interviews) and non-cancer patients' (N= ca. 30; ca. 150 interviews). Data analysis: Grounded Theory and Interpretive Phenomenological Analysis.

**Results:** In our study, patients gave different explanations why they experienced feeling to be a burden. Only some related it also to wish to die statements.

*Patients' explanations:* Patients were concerned to impose physical hardship, deprivation of sleep, limited private time or emotional burden on others. Associated emotions (guilt, shame, self-hate etc.) were related to moral values that patients felt violated. Patients adopted strategies to avoid being a burden, such as choosing for institutionalized care, avoiding burdensome communication, not calling for help or deciding for or against certain treatments.

*Burden-feelings and wishes to die:* For some, the feeling to be a burden was the predominant reason for their wish to die. Others with a wish to die, instead, worried that expressing this wish would burden others. Frequently, patients refrained from executing a wish to hasten death arguing that they did not want to create suffering for others by hastening death. Feelings to be a burden were deeply connected to personal moral understandings and self-concepts, but were as well generated in social interactions, through tacit assumptions or verbal and non-verbal communication.

**Conclusions:** While feelings to be a burden can lead patients to state a wish to die, these feelings can also counterbalance a wish to hasten death. In caring for these patients, it is important to understand which of their or others' moral values patients perceive to be violated.

**Abstract number:** FC32

**Abstract type:** Oral

**Procedures for Gaining Ethical Approval for Multi-Centre Research Across Europe: Results of a Survey of Practices Across Three European Studies (ACTION, INSUP-C and PACE)**

*Preston, Nancy J<sup>1</sup>, Hughes, Sean<sup>1</sup>, Dunleavy, Lesley<sup>1</sup>, Hasselaar, Jeroen<sup>2</sup>, van der Heide, Agnes<sup>3</sup>, Van den Block, Lieve<sup>4</sup>, Groot, Marieke<sup>2</sup>, Csikos, Agnes<sup>5</sup>, Payne, Sheila A<sup>1</sup>*

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**Background:** Procedures exist to regulate the ethical conduct of trials of medicinal products (CTIMPs) to safeguard participants. Guidance outside of this sphere of research is less clear. Whilst conducting three European multi centre studies it was apparent that a range of ethical procedures existed.

**Design and methods:**

**Aim:** To identify ethical and research governance procedures across Europe in relation to non-CTIMP trials.

An online survey was conducted across 11 countries involving 19 study investigators. We surveyed ethical and research governance procedures for participants including patients, family caregivers and health care professionals. The survey explored the practice of three research projects; ACTION, Insup-C and PACE. The study designs were: two cluster trials and one case study.

**Results and interpretation:** 13/19 investigators from 9 countries responded. There was variation in the level of ethical approval required. The UK had stringent and lengthy ethical procedures. In two countries (NL, DK) ethical approval was not always required for interview studies with patients. Most used national research ethics committees but some only required university level approval. Time to gain full approval ranged from < 1 month to >12 (median 6 months).

Only two countries required data monitoring committees. Written consent was required for participants in over half of sites but two did not need any type of consent. Medical records were accessible for screening in two sites by researchers without additional approval. GCP training was required in 50% of cases.

**Conclusion:** Current variation in ethical and research governance procedures make planning and obtaining ethics approval for international research collaborations problematic. Whilst developments have been made in ethical guidance in trials of medicinal products, similar guidance is required for other types of research to prevent unnecessary delays when preparing protocols and data collection materials.

**Abstract number:** FC33

**Abstract type:** Oral

**Physicians, Caregivers and Families' Perceptions towards Artificial Nutrition and Hydration (ANH) for People in Permanent Vegetative State (PVS). A Photo-elicitation Study**

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**Introduction:** The survival of people in PVS is often only correlated with the ANH. In these situations, both health professionals and families may have to confront questions regarding the meaning of a life that is prolonged in such conditions. Some consider that indefinite survival in a PVS is of no benefit to the patient and that there is no moral or legal obligation to continue life-sustaining treatment, including ANH. This question sparks fierce ethical and legal debates in many countries. Therefore, understanding the representations that influence decision of maintaining or withdrawing the ANH is crucial.

**Aim:** The NUTRIVEGE national study aims to describe perceptions and attitudes of physicians, caregivers and families towards ANH for people in PVS.

**Method:** Situations of 32 people in PVS were explored in 23 dedicated centers across France and 138 photo-elicitation interviews were conducted with professionals and families. During one-to-one interviews, participants were asked to choose photos among a original set of photos built for this study and to talk about them. Verbatim were then organized with the support of NVIVO software and analyzed by an interdisciplinary research group according to qualitative research methodologies.

**Results:** Our presentation will discuss 4 key results: 1/ Tube-feeding is described as a very *disturbing* act but isn't perceived as *unreasonable obstinacy*; 2/Over time, ANH is paradoxically perceived as a *natural* way to eat, 3/Withdrawing the ANH *can't be thought* since feeding is perceived as an ethical duty and since 4/feeding crystallizes the engagement in the relationship when the consciousness and the communication are lost.

**Conclusion:** Qualitative research is needed to understand the reality of concerns of those close to persons in PVS. This is necessary to help them engage in ethical reflection without being in search of a normative solution.

**Funding:** National Clinical Research Public Grant (PHRC) from the French Ministry of Health.

**Abstract number:** FC34

**Abstract type:** Oral

### Multi-dimensional Illness Trajectories in People with Cancer, Organ Failure or Frailty: A Synthesis of 8 Qualitative Longitudinal Studies

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Edinburgh, Edinburgh, United Kingdom, <sup>2</sup>Allergy and Respiratory Research Group, Centre for Population Health Sciences, The University of Edinburgh, Edinburgh, United Kingdom

**Background:** Three typical illness trajectories of physical decline have been described for patients with progressive chronic illness: cancer, organ failure, and frail older persons. However palliative care is concerned with more than the physical.

**Aims:** To explore if there are typical trajectories of social, psychological and existential distress in people dying from cancer, organ failure and frailty, and to gain insights into how best to provide effective palliative care for people dying with different conditions.

**Methods:** We synthesised data from eight longitudinal interview studies we had conducted to identify patients' and carers' holistic needs in the last year of life: three studies in cancer - lung, glioma and colorectal; three in organ failure - heart failure, chronic obstructive pulmonary disease (COPD) and liver failure; one in frailty; and a combination illness study with participants from South Asia . Each study had used interviews with patients up to four times over 12 to 18 months. Participants' narratives were synthesised by illness trajectory and the findings were discussed through dedicated analysis workshops.

**Results:** The dataset comprised 828 in-depth interviews with 156 patients, 114 family caregivers and 170 health professionals. Cancer patients had physical and social decline in parallel, with psychological and existential distress occurring around diagnosis, returning home, at recurrence and terminally. In organ failure marked psychological and social distress occurred at acute exacerbations. Frail older people had a very gradual physical and social decline with psychological and existential well-being often eventually decreasing.

**Conclusions:** Being aware of these trajectories may help clinicians plan care to meet their patient's multidimensional needs better, and help patients and carers understand and cope with their situation. New models of palliative care are necessary for patients with organ failure and frailty.

**Abstract number:** FC35

**Abstract type:** Oral

### Meaning in Life: Comparison between Palliative Patients and a Representative Sample of the Swiss Population

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**Background:** The concept of meaning in life (MIL) became a central one in recent years in the palliative care domain. The aim of this study was to compare meaning in life between palliative patients (PP) and a representative sample of the Swiss population (SP).

**Methods:** MIL was evaluated in PP with face to face interviews and in the SP with a telephonic survey, using the *Schedule for Meaning in Life Evaluation* (SMILE). This instrument allows individuals to choose the life areas which are relevant for their own MIL. They are asked to indicate the importance and satisfaction for each domain, which allows for the calculation of an importance score (IoW, range 20-100), a satisfaction score (IoS, 0-100) and overall meaning in life score (IoWS, 0-100).

**Results:** 1015 individuals of the SP and 206 PP were evaluated. In both groups, the most mentioned relevant areas were “family” (80.1% in SP vs 75.7% in PP,  $p=.157$ ) and social relations (43.3% in SP vs 48.1% in PP,  $p=.219$ ). The SP listed significantly more frequently “work” (50.9% vs 24.8%,  $p=.000$ ), “finances” (9.7% vs 1.9%,  $p=.000$ ), and “health” (30.6% vs 14.6%,  $p=.000$ ) as meaningful areas. PP favoured “spirituality” (32.5% vs 12.6%,  $p=.000$ ) and “personal growth” (16.5% vs 7.2%,  $p=.000$ ). The SP scored significantly higher in IoWS ( $87.0 \pm 13.5$  vs  $81.9 \pm 17.2$ ,  $p=.000$ ) and in the IoS ( $86.1 \pm 10.3$  vs  $79.9 \pm 17.6$ ,  $p=.000$ ) and higher in the IoW ( $82.9 \pm 11.4$  vs  $80.9 \pm 14.3$ ,  $p=.038$ ). P-values were Bonferroni corrected.

**Conclusion:** Although PP scored lower in the IoWS and IoS, the means scores remained high. Compared to the SP, “spirituality” and “personal growth” were particularly of importance in PP. These results could be understood as a form of “hedonic adaptation to positive and negative experiences” or as a manifestation of the “response shift phenomenon”. In clinical practice, the SMILE may represent a valuable tool to identify critical areas and potential resources for palliative patients.

**Abstract number:** FC36

**Abstract type:** Oral

### The Impact of the Social Support Network on Parental Distress in Pediatric Palliative Care

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**Background:** Care of children with life-limiting illnesses at home can be very distressing for parents. However, practice and literature show that there are differences in stress levels and coping, which can even lead to mental illness.

**Aim:** The aim of our study was to identify relevant network parameters by which parent risk groups can be identified in order to allow for early psychosocial interventions.

**Method:** Study participants were parents who cared for a child that received Specialized Home Pediatric Palliative Care for at least two weeks. Parental burden and coping strategies were measured by the *Impact-on-Family Scale (IOFS)* and the *Coping Health Inventory for Parents (CHIP)*. Quantitative network data were collected using network maps. Data analysis relied on hierarchical cluster analyses. Clustering on the basis of the degree of stress and the ways of coping was correlated with parameters of the parents’ support networks.

**Results:** 43 family caregivers were enrolled in the study from 10/12 to 02/14. Based on the variables *total stress* (IOFS) and *family integration* (CHIP), two distinct clusters were identified with regard to the total amount of stress and the families’ coping strategies. Parents in cluster 1 ( $n = 24$ ) are significantly more stressed than parents in cluster 2 ( $n = 19$ ;  $p=.01$ ). A comparison of the network parameters shows that cluster 1 parents feel significantly less supported by their families ( $p=.01$ ) in relation to the overall support they receive and that they name a significantly higher number of supporting actors ( $p=.05$ ).

**Conclusion:** With the help of cluster analysis particularly stressed parents can be identified. The network parameters *extent of family support* and *number of supporting actors* might provide indications for specific psychosocial interventions. Follow-up studies to verify the risk factors and to develop and test specific interventions are needed.

## End of life care and quality of dying I

**Abstract number:** FC37

**Abstract type:** Oral

### Cross-setting Anticipatory Prescribing Guidance for Common Symptoms at the End of Life with Short Tailored Teaching: Does it Make a Difference?

*Scott, Kirsty<sup>1</sup>, Thomas, Micheal<sup>1</sup>, Sarah, Gear<sup>1</sup>, Palmer, Joanne<sup>2</sup>, Smith, Jo<sup>3</sup>, Ridley, Saul<sup>3</sup>, Deborah, Stevens<sup>1</sup>, Carey, Angela<sup>3</sup>, Thomas, Elizabeth<sup>2</sup>, Campbell, Carolyn<sup>1</sup>, Newman, Rachel<sup>2</sup>, Hart, Angela<sup>2</sup>, Gibbins, Jane<sup>4</sup>*

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**Background:** A UK survey of bereaved relatives revealed nearly a quarter of them felt symptom control (SC) in the last 2 days of life (in home/hospital) had been poor or fair.<sup>1</sup> Following phasing out of the Liverpool Care Pathway (LCP), there was no clear guidance to facilitate SC. Our aim was to explore whether the roll out of unified Anticipatory Prescribing Guidance (APG) with access to 24/7 hospice telephone advice to healthcare professionals (HCP) with tailored teaching across one region in the UK would lead to improved SC for the dying.

**Methods:** APG developed & agreed by each sector; acute & community hospitals, hospices, nursing homes, General Practice, dementia units & ambulance services. Pilot of APG in acute hospital wards & GP practices. APG rolled out with teaching interventions by specialist palliative care teams throughout the region, facilitated by an EOL Facilitator & incorporating attendees' experience to inform the project, using quality improvement methodology. Participants asked to complete an initial questionnaire at time of teaching, & an electronic questionnaire 12 weeks after teaching to capture impact of such teaching on care of the dying.

**Results:** 700 HCP have received teaching to date (ongoing). Of these, 344 initial evaluations have been analysed; a significant improvement in mean knowledge scores; 2.75 to 4.23 on a 5-point scale ( $p < 0.05$ ). After 12 weeks, 57 participants have responded (on-going); 61% (35) had cared for a patient at EOL since APG teaching. Of those, 86% (30) used APG to support decision making at EOL, & 90% perceived APG led to improved SC for the patient who they cared for.

**Conclusion:** Roll out of unified APG across care settings with short tailored teaching interventions, backed up with 24/7 hospice advice has led to improved knowledge and confidence in EOL SC & prescribing for HCP, resulting in perceived improvement in SC for the dying.

## References

1. Department of Health. National survey of bereaved (VOICES). 2013

**Abstract number:** FC38

**Abstract type:** Oral

### Admissions to Hospital, Nursing Home and Hospice in the Last Year of Life of Community-dwelling Older People in 16 European Countries

*Overbeek, Anouk<sup>1</sup>, Van den Block, Lieve<sup>2</sup>, Korfage, Ida<sup>1</sup>, Penders, Yolanda<sup>2</sup>, Van der Heide, Agnes<sup>1</sup>, Rietjens, Judith<sup>1</sup>*

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**Background:** Many older people prefer receiving care at home while avoiding admissions to hospitals and other

healthcare institutions. From a policy perspective such admissions tend to be discouraged because of their high costs. We aim to describe admissions to healthcare institutions in the last year of life of community-dwelling older people in 16 countries in Europe.

**Methods:** Proxy respondents of 5092 deceased people participated in a computer-assisted structured interview within the context of the Study of Health, Aging and Retirement in Europe (SHARE). In this study, admissions to institutions refer to either hospital, nursing home or hospice admissions.

**Results:** The proportion of people with any admission in the last year of life ranged from 54% (France) to 76% (Austria, Israel, Slovenia). Most of these admissions concerned hospital admissions. For people with hospital admissions only (47% of those with admissions to an institution in France - 97% in Greece), the duration of the total time spent in hospital varied considerably, with more than half of older people from Austria, Belgium, Switzerland, Czech republic and Germany spending more than one month of their last year of life in hospital. Multivariable analyses showed that hospital admissions were more likely for persons aged 50-65 (compared to 80+), males, lower educated people, those who were ill for more than 6 months and those who needed help with activities of daily living.

**Conclusion:** In the studied countries, admissions to healthcare institutions of older people in their last year of life are rather common, especially to a hospital. Differences between the countries in the proportion of people who are admitted in their last year of life and the length of their admission may be explained by different policies and rationales for admission.

SHARE is funded by the European Commission, the US National Institute on Aging and national sources.

**Abstract number:** FC39

**Abstract type:** Oral

### Level of Comfort Improves after the Administration of Continuous Palliative Sedation: A Prospective Multicenter Study

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**Introduction:** There is currently no clear standard for the monitoring of (dis)comfort during the administration of continuous palliative sedation (CPS). Therefore, little is known about the course of discomfort in patients receiving CPS, and accordingly the efficacy of CPS. This prospective study aims provide more insight into patient (dis)comfort during CPS.

**Methods:** A prospective observational multicenter study was performed in six Dutch hospices and three nursing home-based palliative care units, from March 2011 until December 2012. The Discomfort Scale-Dementia of Alzheimer Type (DS-DAT) was used for the monitoring of the level of discomfort during CPS by a trained independent nurse, twice a day (0=no discomfort; 27=max. discomfort). The measurements of the DS-DAT were grouped into four time frames based on clinical relevance: before sedation; first 8 hours (titration); in between group; last 8 hours (final phase). Mean group scores with 95% CI were calculated for each group using a mixed model controlled for age, gender, the diagnosis malignant neoplasms, chronic lower respiratory diseases, and the symptoms pain, dyspnea, delirium, anxiety, exhaustion and existential distress. Between group differences were tested with t-testing. Ethical approval was received.

**Results:** 130 sedated patients were included in the study. In 106 patients the DS-DAT was completed at least one time. Group mean scores were: before sedation phase (12.2; 9.8-14.5); titration phase (8.1; 5.5-10.6), in-between phase (7.8; 5.5-10.2), final phase (7.4; 4.9-9.9). A significant reduction of discomfort compared to the phase before sedation was found for all three following phases of CPS ( $p < .001$ ).

**Conclusion:** The level of discomfort decreased after the administration of CPS. Although the DS-DAT appeared to be of added value for monitoring discomfort, further research on the implementation and the use of this scale in CPS patients is recommended.

**Abstract number:** FC40

**Abstract type:** Oral

### Visual Techniques to Engage Patients, Family and Staff in Discussions about Improving the Care Environment at the End-of-Life

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and Design, Stockholm, Sweden, <sup>11</sup>Innovation Centre, Karolinska University Hospital, Stockholm, Sweden

Care facilities are generally designed for medical/technical functionality rather than the experiences of those who spend time in the facilities. In this transdisciplinary project, part of the DöBra research program, we aim to engage patients, family and staff in joint discussions about their experiences of EoL care environments, as part of a change process. In this presentation, we focus on the feasibility of different visual techniques (VTs) to stimulate discussion. We used a combination of two separate VTs, photo-elicitation and film. Participants were recruited from acute care hospitals, specialized palliative care (PC) inpatient and home care, and residential elderly care homes in Sweden. Patients/residents (n=23), family (n=33), and staff (n=11) took photographs they felt depicted meaningful aspects of their EoL care/work environment and reflected on them in an interview. Inductive thematic analysis of the database of 138 photographs with interviews was used to create three 6-7 minute "trigger films" on topics salient in the data. The films focused on Space/Place, Relationships and Movement, respectively, and were used to stimulate reflection in a modified Experience-based Co-design process. The photo-elicitation process was said to be engaging and positive by most participants, although there were some difficulties recruiting family members. The trigger films were shown in two workshops. These were facilitated by design and PC researchers, with patients, family and staff from at a specialized PC unit with inpatient and homecare participating together to share experiences and suggest improvements to the EOL environment. The films successfully stimulated sharing of experiences and provided a clear agenda for discussions. In this presentation we show an excerpt of a film to illustrate pros and cons of these VTs. We found that they enabled interactive discussions on complex phenomena within EOL care, and have helped to facilitate ongoing improvement processes.

**Abstract number:** FC41

**Abstract type:** Oral

### Effectiveness of Home-based Palliative Care

*Burns, Jacob<sup>1</sup>, Polus, Stephanie<sup>1</sup>, Brereton, Louise<sup>2</sup>, Pfadenhauer, Lisa<sup>1</sup>, Chilcott, James<sup>2</sup>, Ward, Susan<sup>2</sup>, Rehfuess, Eva<sup>1</sup>*

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**Research aims:** As part of the INTEGRATE-HTA project, we updated the Cochrane systematic review by Gomes et al. (2013). This review assessed the effectiveness of

home-based palliative care services in adults and their caregivers across a range of outcomes.

**Study design and methods:** Using the strategy employed by Gomes et al (2013), we updated their searches for six databases through November 2014. We included randomized and clinical controlled trials, as well as high quality controlled before-after and interrupted time series studies. Screening, data extraction and quality appraisal were performed in duplicate. We created harvest plots, which allow for the visual assessment of effectiveness where statistical pooling of results may not be appropriate. We then performed a gap-analysis to review major findings and identify gaps in the evidence. These were discussed with palliative care professionals (n=4), to explore the evidence further, and to potentially gain new information based on their experiences.

**Results and interpretation:** In addition to 19 studies included originally, we identified 10 studies. Patient outcomes (pain, symptom control, quality of life, psychological health, death at home, hospitalization, response, satisfaction with care) and lay caregiver outcomes (quality of life, psychological health, satisfaction with care, and coping/mastery) showed largely a mix of no effect and positive effects for the intervention. Gap analysis and expert consultations complemented evidence from the primary studies. These suggested that in considering our results and interpretations, several issues should be considered, e.g. the heterogeneous nature of usual care, which is individually tailored for patients and informal caregivers based on illness trajectory and diagnosis, the outcomes chosen in the primary studies, and the difficulties in conducting experimental research for such interventions.

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**Abstract number:** FC42

**Abstract type:** Oral

### Valuing Friends' and Family Support for End of Life Cancer Care: A National Study of the Economic Costs of Informal Care-giving

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**Background:** Family carers provide vital support for cancer patients at the end-of-life (EoL) often enabling them to

die at home. The economic value of this care is probably substantial but is poorly understood as carers' time and out-of-pocket costs are rarely included in evaluations. Without knowledge of the economic impact of family care it may not be recognised by service providers and policy makers. This study aims to provide population-level information on the scale of cancer related care-giving and its economic contribution to EoL care.

**Method:** A cross-sectional survey was conducted. The UK Office for National Statistics (ONS) sent 5,217 surveys to those who registered a cancer death in early May 2015 (~4.5 months bereaved). Non-responders received reminders at 4 and 8 weeks. Questions focused on 3 months before death and included: demographics, details of illness, time spent on care tasks, out-of-pocket expenses, and carer well-being (EQ-5D-5L (retrospective recall and present day) and GHQ12 (retrospective)). ONS supplied: ICD cancer classification, date of death/registration, index of multiple deprivation and date of birth and sex of deceased.

**Results:** To date we have received >1,000 completed surveys and aim for n=2,000 completed surveys by December 2015. We will present data which

- i) describe the carer population and care tasks undertaken,
- ii) estimate the costs of care-giving for society including: cost to replace carers, opportunity costs for carers' time, and loss of tax revenue/productivity, and
- iii) identify factors influencing hours of care, costs and carer well-being, to distinguish carers who need most support.

**Conclusion:** To our knowledge this is the first UK population-level study of the costs of EoL care-giving. As delivery of EoL services move further into the community these data are needed to facilitate planning and investment, ensuring economic evaluations include family care contributions.

### Pain

**Abstract number:** FC43

**Abstract type:** Oral

### Are Strong Opioids Equally Effective and Safe in the Treatment of Chronic Cancer Pain? Results from CERP Study

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**Research aims:** This study was designed to compare the analgesic efficacy, changes of therapy and safety profile of

four strong opioids, morphine (active comparator), buprenorphine, fentanyl and oxycodone, used for the treatment of cancer pain.

**Study population:** Oncological patients with moderate to severe pain requiring WHO step III opioids.

**Study design and methods:** In this four-arm multicenter, randomized, longitudinal (28 days follow-up), comparative, of superiority, phase IV trial, patients were randomly assigned to receive one of the opioids. The primary efficacy endpoint was the proportion of patients with a worsened or unchanged average pain intensity (Non-Responders). The secondary main endpoints included the opioids daily dose escalation over time, (measured by Opioid Escalation Index (OEI%) >5%) and the proportion of

patients requiring a switches to other opioids during the follow-up.

**Method of statistical analysis:** The analyses of efficacy were done on patients included in the intention-to-treat (ITT) population with at least one pain evaluation after baseline. Patients who started opioid were included in the safety analysis. The chi-squared test was used to assess differences between oxycodone, buprenorphine or fentanyl compared to morphine.

**Results:** 520 patients were randomized and 515 were evaluable for analysis. Primary and the main secondary endpoints results are reported in the table. Adverse drug reactions were similar except for effects on the nervous system, which significantly prevailed with morphine.

	Morphine	Oxycodone	p*	Buprenorphine	p*	Fentanyl	p*
Number of patients	122	125		127		124	
Non-responders (%)	11.5	14.4	0.494	11.0	0.910	8.9	0.499
OEI>5% (%)	10.7	19.2	0.060	14.2	0.401	36.3	<0.0001
Switches (%)	22.1	12.0	0.034	16.5	0.0263	12.9	0.057

\*Chi-square p-value for comparison morphine vs. other opioids.  
[Primary and main secondary endpoints results]

**Conclusion:** Strong opioids seem to achieve similar analgesic effects, notable differences in therapy schedule over time and different profiles of safety. The proportion of poor responder patients is considerably high. NCT01809106

**Abstract number:** FC44

**Abstract type:** Oral

### From “Breakthrough” to “Episodic” Cancer Pain? An EAPC RN Expert Delphi Survey towards a Common Terminology and Classification of Transient Cancer Pain Exacerbations

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**Background:** Cancer pain can appear with intermittent spikes of higher intensity regardless of background pain. Breakthrough cancer pain (BTcP) is the most common term for the transient exacerbations of pain, but the ability of the current nomenclature to capture pain variations and give guidance on treatment is questionable.

**Aims:** To reach international consensus on definitions, terminology, and sub classification of transient cancer pain exacerbations.

**Methods:** The most frequent authors on BTcP literature were identified by a PubMed search using the same strategy as in a recent systematic BTcP review. The authors were invited to participate in a two-round Delphi survey. Topics with a low degree of consensus on BTcP classification identified in the systematic literature review were refined into twenty statements. The study participants rated their degree of agreement with the statements on a numeric rating scale (NRS 0-10). Consensus was defined as a median NRS score of seven or more and an inter-quartile range of three or less.

**Results:** Fifty-two authors had published three or more papers on BTcP over the past ten years. After two reminders, 27 respondents provided complete answers in the first round and 24 in the second round. Consensus was reached for 13 of 20 statements. Transient cancer pain exacerbations can occur both without background pain, when background pain

is controlled or uncontrolled, and regardless of opioid treatment. There exist transient cancer pain exacerbations other than BTcP, and the phenomenon could be named “episodic pain”. A sub classification according to pathophysiology is important with respect to guidance on treatment. Finally, patient reported pain treatment satisfaction is an important outcome measure when assessing both background pain and episodic pain.

**Conclusions:** This expert Delphi process resulted in agreement on several hitherto unclear issues related to definitions, terminology, and sub classification of episodic pain.

**Abstract number:** FC45

**Abstract type:** Oral

### Effectiveness and Tolerability of Buprenorphine for Cancer Pain - A Cochrane Review

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**Objectives:** To assess how effective and tolerable Buprenorphine is in the treatment of cancer pain

**Methods:** We searched CENTRAL, MEDLINE, ISI Web of Science, EMBASE, ClinicalTrials.gov, ISI BIOSIS, metaRegister of controlled Trials, WHO International Clinical Trials Registry Platform and the Proceedings of the Congress of the European Federation of International Assc. for the Study of Pain to early 2015

**Results:** 19 randomised controlled trials comparing buprenorphine with placebo, buprenorphine or another active drug for cancer pain were included. The trials included 1421 patients and looked at 16 different intervention comparisons. 11 studies compared buprenorphine to another drug. Of these, five, three and three studies, respectively, found Buprenorphine to be superior, no different or inferior to the alternative treatment in side effect profile or patient acceptability. One study identified faster onset of pain relief after sublingual administration when compared to the subdermal route, with similar analgesic duration and adverse event rate. Two studies found transdermal buprenorphine superior to placebo, whereas a third study found no difference between placebo and different doses of transdermal buprenorphine. No clear dose-response relationship was found for transdermal buprenorphine. Quality of evidence was limited by small sample sizes, under-reporting and attrition.

**Conclusions:** Buprenorphine can be considered as a fourth-line option compared to more conventional cancer pain therapies like morphine, oxycodone and fentanyl. Even then, it is only suitable and effective for some patients.

**Abstract number:** FC46

**Abstract type:** Oral

### Evidence of the Analgesic Role of Bisphosphonates and Denosumab in the Treatment of Pain due to Bone Metastases: A Systematic Review within the EAPC Guidelines Project

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**Background:** Bisphosphonates (BP) and denosumab are well-established therapies for reducing skeletal related events in patients with bone metastasis; in contrast, evidence for the analgesic use of these medications to alleviate bone pain is scant.

**Aim:** To identify, critically appraise, and synthesise the existing evidence regarding the effectiveness and safety of BP and denosumab to alleviate pain associated with bone metastases in adult cancer patients and to determine the most appropriate treatment schedule.

**Design:** Standard systematic review and narrative synthesis.

**Data sources:** MEDLINE, EMBASE, and the Cochrane Central Register of Controlled Trials databases. These databases were searched for relevant articles published from the database set up until January 31, 2014. Inclusion criteria were as follows: 1) study conducted in adult patients; randomized controlled trial design or meta-analysis of reported data with information on pain efficacy and/or side-effects of BP/denosumab versus placebo/other BP; written in English.

**Results:** Search strategy identified 1,585 papers of which 43 met the inclusion criteria. These 43 studies enrolled a total of 8,595 patients in BP trials and 7,590 for denosumab. Twenty two (79%) of the 28 placebo-controlled trials, carried out on 7,168 patients, failed to find any analgesic benefit for BP. In the remaining six studies pain reduction was statistically significant after  $\geq 2$  weeks. In denosumab trials time-to-bone event was used as an indirect pain assessment outcome.

**Conclusions:** Evidence to support an analgesic role for BP and denosumab is weak. Most of the trials in this review

show that although these medications can delay pain onset, they do not produce an analgesic effect *per se*. The optimal treatment dose and duration of these drugs remain unclear.

**Abstract number:** FC47

**Abstract type:** Oral

**“A Tool Doesn’t Add Anything” Physicians’ Perceptions and Use of Pain Assessment Tools with People with Advanced Dementia Approaching the End of Life**

*De Witt Jansen, Bannin<sup>1</sup>, Brazil, Kevin<sup>2</sup>, Passmore, Peter<sup>3</sup>, Buchanan, Hilary<sup>4</sup>, Maxwell, Doreen<sup>5</sup>, McIlftrick, Sonja<sup>6</sup>, Morgan, Sharon<sup>7</sup>, Watson, Max<sup>8</sup>, Parsons, Carole<sup>1</sup>*

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**Background:** People dying with advanced dementia are often unable to effectively self-report pain and are at risk of under-assessment which may hinder pain diagnosis and management. Pain assessment tools for use in advanced dementia are available but their use by physicians with dying patients has not been explored.

**Aims:** To explore hospice, secondary and primary care physicians’ use of pain assessment tools with patients dying with advanced dementia.

**Methods:** Twenty-three, semi-structured, face-to-face physician interviews were conducted and transcribed verbatim. Thematic analysis was applied to identify core themes across healthcare settings. Three researchers verified final themes.

**Results:** Four key themes emerged: non-use of pain assessment tools; perceived limitations of tools; clinical outcomes of use and improving pain assessment. Physicians did not routinely use pain assessment tools with patients dying with advanced dementia. Information from physical examination, physiological parameters and patient observation in addition to collateral patient history from families and nursing staff were perceived to provide a more reliable and holistic approach to assessment and management. Scoring subjectivity, proxy-reporting and overreliance on nonverbal and behavioural cues were limitations associated with pain tools. Physicians perceived the

clinical outcome of pain tool use to be quicker identification and reporting of pain by nurses. Most physicians believed pain assessment could be improved via better integration of secondary, hospice and primary care services in addition to ongoing medical education and mentoring.

**Conclusion:** Physicians preferred clinical investigation and collateral patient history from family and other health professionals to assess pain and guide management. These findings have important implications for medical education, practice and health policy.

**Funding:** HSC Research and Development Division, Public Health Agency, Northern Ireland.

**Abstract number:** FC48

**Abstract type:** Oral

**Factors Related to Non-adherence to Strong Opioids Analgesics in a Population of Advanced Cancer Patients with Pain**

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**Background/aims:** Medication adherence to strong opioids in an advanced cancer population is poorly understood. The use of the 4-item Morisky Medication Adherence Scale (4-MMAD) can help clinicians to identify those patients that are non-adherents to analgesic regimes.

The aim of this study is to determine the prevalence and the factors associated with the non-adherence to strong opioids in a population of advanced cancer patients with pain and to know the associated factors.

**Methods:** A pilot study on 89 patients showed a prevalence of 47%. A further study with a sample of 219 consecutive advanced cancer patients (level of confidence 90%; accuracy 5% and 15% expected loss ratio) was designed. Univariate and multivariate statistical analysis was applied. Statistical significance was accepted for  $p < 0.05$ . SPSS v20 was used.

**Results:** Median age was 70 years (27-98) and 67% were men. Global rate of medication non-adherence was 51%; of them 75% was intentional and 25% unintentional. In the univariate analysis factors such as living alone ( $p=0.008$ ), self-administration of medication ( $p=0.038$ ), higher cognitive impairment (assessed with the Pfeiffer test) score ( $p=0.035$ ) were correlated with analgesic regime non-adherence. The use of Fast Onset Opioids (FOOs) ( $p=0.029$ ) was related to fail question A (forgetting to take

medication); age ( $p=0.038$ ) was associated with failing question B (taking medication at the time indicated); age ( $p=0.014$ ) and higher doses of ROOs ( $p=0.003$ ) were related to mistake question C (they stop taking medication if they feel well); patients attended at the OPC ( $p=0.015$ ) failed to question D (if they don't feel well, don't take medication). In the multivariate analysis only cognitive impairment ( $p=0.034$ ) and living alone ( $p=0.038$ ) were associated with non-adherence.

**Conclusion:** A great level of non-adherence was found. Factors related to cognitive impairment and social issues are associated with non-adherence.

## Mixed session II: Epidemiology and palliative care organisation

**Abstract number:** FC49

**Abstract type:** Oral

### Ranking of Palliative Care Development in the Countries of the European Union

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**Background:** There is growing interest in monitoring palliative care development internationally. One aspect of this is the ranking of such development for comparative purposes.

**Aims:** To generate a ranking classification and to compare scores for palliative care development in the countries of the European Union, 2007 and 2013. Palliative care 'development' in this study is understood as a combination of the existence of relevant services in a country ('resources') plus the capacity to develop further resources in the future (vitality).

**Methods:** 'Resources' comprise indicators of three types of palliative care services per population (inpatient palliative care units and inpatient hospices (IPCU), hospital support teams (HST) and home care teams (HCT)). 'Vitality' of palliative care is estimated by numerical scores for the existence of a national association, a directory of services, physician accreditation, attendances at a key European conference and volume of publications on palliative care development. The leading country (by raw score) is then considered as the reference point against which all other countries are measured. Different weightings are applied to 'resources' (75%) and 'vitality' (25%). From this an overall ranking is constructed.

**Results:** The UK achieved the highest level of development (86% of the maximum possible score), followed by Belgium and The Netherlands (81%), and Sweden (80%). In the domain 'resources', Luxembourg, the UK and Belgium were leading. The top countries in 'vitality' were Germany and the UK. In comparison to 2007, The Netherlands, Malta and Portugal showed the biggest improvements, whereas the positions of Spain, France and Greece deteriorated.

**Conclusion:** The ranking method permitted a comparison of palliative care development between countries and shows changes over time. Recommendations for improving the ranking include improvements to the methodology and greater explanation of the levels and changes it reveals.

**Abstract number:** FC50

**Abstract type:** Oral

### Place of Death of Children with Complex Chronic Conditions. A Cross-national Population-level Study in Eleven Countries

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**Study objectives:** The objectives of this cross-national population-level study were to examine where children

with Complex Chronic Conditions (CCC) die, and to investigate associations between place of death and sex, cause of death and country.

**Methods:** The study used death certificate data from 2008 of all deceased children 1-17 years (n=40,624) in 11 European and non-European countries. Data were explored and multivariable logistic regression performed to determine associations between place of death and other factors.

**Results:** Between 24.4% (USA) and 75.3% (Spain, Andalusia) of children 1-17 years died of CCC. Of these between 6.7% (South Korea) and 42.4% (New Zealand) died at home. Among the children who died from neuromuscular diseases, 12.7% (South Korea) to 48.3% (Mexico) died at home. In deaths caused by malignancies, home deaths ranged from 1.8% (South Korea) to 60.8% (Belgium). Deaths from cardiovascular diseases and other CCC occurred less often at home. Multivariable logistic regression showed variations in associations between place of death and cause of death, and between place of death and country. Compared to Belgium children, those in Mexico and New Zealand (OR= 2.18, 95% CI= 1.41-3.59) were more likely to die at home, whereas children in South Korea (OR= 0.27, 95% CI: 0.18-0.40), Spain (OR=0.45, 95% CI:0.26-0.78) and France (OR=0.52, 95% CI: 0.37-0.73) were significantly less likely to die at home.

**Conclusion:** This study shows large cross-national variations in place of death. These variations may relate to paediatric palliative care accessibility, financial and health infrastructural inequities, healthcare policies, and differences in cultural values related to place of death in the study countries. These factors however, need to be investigated in future research. Regardless, the patterns in place of death for children with CCC can inform the development of paediatric palliative care programs internationally.

**Funding:** Research Foundation Flanders.

**Abstract number:** FC51

**Abstract type:** Oral

### How to Better Visualise the Distribution of Expected Annual Deaths in a “Standard” French GP Surgery? Rebuilding the Three Main Illness Trajectories through a Modified Delphi Study

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**Introduction:** There is currently no « proactive » public health policy relying on primary care, in France, aiming to improve access to specialist palliative care — and no formal identification of patients towards the end of life by health professionals. Yet, scientific recommendations encourage the early integration of palliative care for patients with advanced chronic conditions. Such an integration, in parallel with disease-modifying treatments, would be facilitated by a better understanding of illness trajectories (ITs) at the end of life by primary care professionals, entailing a timely identification of palliative needs (PN) in patients.

**Objectives:** 1/ To promote a better visualisation of the distribution of expected annual deaths in a French GP surgery (around 1500 patients per GP), according to the three main ITs

(« Cancer », « Organ failure », « Frailty, dementia ») by the means of a pie chart based on recent French mortality data in adult patients. 2/ To highlight the likely distribution of palliative needs (PN) in patients, between the three main ITs.

**Method:** Analysis of data on causes of mortality in adults (19+), in France (Death certificates, CépiDC [1], 2011). Allocation of the underlying causes of death (expressed in ICD-10 codes) between the three main ITs, by an expert panel (modified Delphi study).

**Results:** Pie chart #1: « Distribution of deaths in a year, according to the three main ITs, within a list of 1500 patients, for a French GP ». Diagram #2 (pie chart or histogram): « Distribution of likely PN among patients dead in a year, and according to the three main ITs, within a list of 1500 patients, for a French GP »

**Discussion:** The concept and definition of ITs (and their endpoint, using ICD-10 codes); the definition and significance of PN in patients with advanced chronic conditions; the challenge of involving primary care professionals in identifying palliative needs.

[1] Center of epidemiology on medical causes of death

**Abstract number:** FC52

**Abstract type:** Oral

### A Survey of Attitudes towards Palliative Medicine amongst Nurses Working in the ED

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**Background/aims:** A quality improvement initiative integrating Palliative Care in the Emergency Department is underway in an Irish teaching hospital. The objectives of the project are to improve the recognition of palliative care needs of patients presenting to the ED, to improve the response of staff to these needs and to embed reflective practice. To assess the understanding and attitudes of ED nurses about palliative care needs in the ED, the working environment, behaviour in practice, their previous education/training and educational preferences.

**Methods:** A survey tool was designed with closed and open-ended questions and 44 questionnaires were distributed to ED nurses anonymously. Quantitative data was analysed using SPHINX software package and qualitative data through thematic analysis.

**Results:** A response rate of 34% was achieved. 62% of respondents considered the ED a place to provide resuscitation and aggressive medical care, not palliative care. 95%

had >5 years experience working in ED but 87% of these had no previous training in palliative care. Nurses felt they would benefit from additional education in symptom control, training in syringe drivers and communication with families. Overall there was a clear understanding of the role of palliative care and they cited pertinent triggers in initiating palliative referrals. Most nurses (64%) did not have difficulty in recognising when a patient is dying. They identified significant environmental barriers to the provision of palliative care in the ED, overcrowding (100%), lack of privacy (100%), lack of space (93%) and noise levels (80%). The majority of nurses (79%) experienced a delay in obtaining an End of Life suite/single room for an actively dying patient on transfer out of ED.

**Conclusion:** ED nurses had a positive attitude to caring for palliative care patients in the department and were willing to embrace interventions, protocols and guidelines to enhance patient care.

**Abstract number:** FC53

**Abstract type:** Oral

### Palliative Care Declarations: Mapping a New Form of Intervention

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**Background/aims:** In recent decades we observe palliative care associations, organisations and groups issuing 'declarations' of various kinds as a form of advocacy, to influence policy, raise awareness and call others to action. Despite the importance given to palliative care declarations however and their increasing occurrence and prominence, they have attracted little attention from researchers. The aim of this study is to map the rise, spread, content and purpose of palliative care declarations in the international context.

**Methods:** Systematic internet search and review of literature; documentary and content analysis.

**Results:** We identified 27 palliative care declarations (1994 to 2015), 15 since 2010. In their geographical scope 12 are global, 9 international, 5 national and 1 regional. Seventeen declarations were issued at international conferences. Formats include: list of recommendations, affirmations of convictions, statements of 'commitments', charters, manifestos, proclamations, challenges and resolutions. Key topics include: palliative care education, policy change, access to palliative care, essential drugs and opioid availability, pain relief, research, public awareness and human rights.

**Conclusions:** Issuing declarations has grown in importance as an advocacy intervention in palliative care and

can take several forms. The documents demonstrate those issues of most prominence in the palliative care field over time. They are therefore one way to understand the global development of palliative care. In most cases however there is little evidence of follow up or impact assessment of palliative care ‘declarations’.

**Abstract number:** FC54

**Abstract type:** Oral

### Comparison of Care Use in the Last Three Months of Life among the Elderly in Three Countries

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**Background:** There is a lack of international comparisons concerning care utilisation, and formal (paid) and unpaid care costs, including at the end of life

**Aim:** To determine and compare the formal and informal care used in the last three months of life by elderly patients who had accessed specialist palliative care in three countries.

**Design:** A mortality follow-back survey.

**Setting:** 3 countries: UK (London), Ireland (Dublin) and USA (New York City and San Francisco).

**Data collection:** Postal survey using self-completion questionnaires including the Client Services Receipt Inventory, sent to bereaved caregivers of patients aged  $\geq 65$  who accessed specialist palliative, plus extraction of patient record data.

**Methods:** Care costs (formal and unpaid) were calculated, combining service use and unit costs in each country. Lost productivity was measured by the proportion of carers who had stopped/reduced work and by the days off work for 3 months before and after patient’s death.

**Results:** 721 questionnaires were returned. Patients were: 53% women; mean age 79.9; 46% with cancer; 68% living with someone else; and mean number of carer 2.7. 70% of patients had been inpatients; 34% in ICU, 64% visited ER or A&E, 65% used ambulance services. In the community, 74% saw a doctor; fewer nurse contacts in the USA than UK and Ireland, although more social service use. Weekly total hours of informal care varied by city (e.g. 176 in SF versus 212 in NYC), but composition was similar. 30% of

carers stopped/reduced work with 3 weeks off before and/or after death. Substantial formal and unpaid care costs per patient for 3 months were identified: for example, in London £10,623 and £8,087 respectively.

**Conclusions:** Formal and unpaid care varied across the cities, although similar unpaid care was volunteered. Unpaid care was not negligible, and unpaid carers often reduced or stopped working and this also adds to societal costs.

### Palliative care organisation and health care services II

**Abstract number:** FC55

**Abstract type:** Oral

#### Palliative Care at the Front Door - Improving the Recognition of Palliative Care Needs of Patients Attending an Irish Emergency Department

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**Background/aims:** Many patients with life limiting illnesses attend the Emergency Department (ED) because of worsening symptoms that cannot be controlled in an outpatient setting and are admitted to hospital without assessment by a Palliative Medicine (PM) service.

Early engagement with PM services in an acute hospital setting leads to better outcomes.

“The Three Rs of integrating Palliative Care and Emergency Department Care” is an initiative supported by the Emergency Medicine and Palliative Care Programmes. This project was designed and undertaken in a large Dublin teaching Hospital.

Our aim was to improve the recognition of palliative care needs of patients attending an Irish Emergency Department.

**Methods:** New guidelines and systems for the early identification of patients with palliative care needs were introduced in the ED. A new tool - P.A.U.S.E. was developed to identify patients not known to PM. The patient administration system in the ED was modified to “flag” patients known to the Hospital’s PM Service. PM Education for doctors and nurses in the ED was augmented by the daily presence of the PM team in the ED. Referrals to PM were

audited for two months before and after these interventions. Data was analysed using SPHINX software package.

**Results:** During the baseline period, 61% of all referrals to the PM Service were admitted to the hospital via the ED, but only 6 patients (10%) were referred and seen while in the ED. Following the introduction of the new guidelines and systems, 54% of all referrals (91) patients were admitted via the ED, 46 of whom (51%) were referred and seen while in ED, a 5 fold increase.

**Conclusion:** The introduction in the ED of specifically designed referral guidelines to PM services leads to a significant increase in early referrals and enhanced delivery of service.

**Abstract number:** FC56

**Abstract type:** Oral

### Responding to Urgency of Need In Palliative Care: Initial Stages in the Development of a Decision Aid for Palliative Care Triage

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**Background:** Demand for inpatient and community-based palliative care (PC) services is increasing and transparency of decision-making around priority of service response is required, yet no valid or reliable PC triage tools currently exist.

The aim of this study was to identify factors health professionals considered salient when triaging PC needs and determine the relative importance of these, in order to inform the development of an evidence-based clinical decision-making tool.

**Methods:** This study used a mixed-method sequential design.

Stage 1 involved exploration of prioritization factors using semi-structured focus groups with purposively sampled PC and generalist clinicians from metropolitan and regional Victoria, Australia. Transcripts were subjected to deductive thematic analysis.

Stage 2 consisted of an online discrete choice experiment involving PC health professionals across Australia

and the United Kingdom, whereby participants compared the urgency of multiple pairs of randomly generated clinical cases to establish the relative importance of the triage factors derived from Stage 1.

**Results:** Focus groups (n=20 health professionals) revealed the factors considered important to determine urgency, such as problem severity, caregiver distress and mismatch between the level or complexity of care needs and the capacity of the care environment. Performance status was reported to be less important when considered in isolation. Challenges associated with the triage process and the implementation of a decision aid were highlighted. The discrete choice experiment established the relative weightings for the triage factors.

**Conclusions:** Indicators of urgent PC needs are complex, dynamic and contextual. The results of this study have important implications for the development of a decision aid to enable a standardised approach to ensuring equitable, efficient and transparent PC service allocation.

Funded by the Victorian state government Department of Health.

**Abstract number:** FC57

**Abstract type:** Oral

### Part 1: Mapping Complexity of Needs in Palliative Care: A Qualitative Study of Stakeholder Perspectives

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**Background:** Until now complexity in palliative care has largely been described in terms of four care domains (physical, psychological, social and spiritual). A more comprehensive, yet standardised way to report complexity has not been established.

**Aim:** To describe the full range of complexity of needs in palliative care and the interrelationships between components.

**Study design/methods:** Face-to-face semi-structured interviews with UK stakeholders across palliative care settings, purposively sampled by geographical location, background and experiences of models care. Vignettes were used to elicit discussion of complexity. Techniques to enhance trustworthiness were informed by COREQ guidelines. Framework analysis was conducted, with data handled in NVivo. Complexity components were mapped

using Bronfenbrenner's framework and depicted in a visual graphic.

**Results:** 65 stakeholder interviews; 10 patient/carer representatives, 38 clinicians (i.e. medical/nursing/allied/spiritual care/social care), 8 EoLC national leads and 9 managers. A map of complexity was identified comprising: micro (individual level), meso (personal/family circumstances) and macro (interaction with services) levels. Micro level factors include the four care domains as well as dynamic (e.g. coping) and fixed (e.g. comorbidities) individual factors. Meso level factors include family/carer needs and socioeconomic status. Macro level factors include access to services, coordination of care, and service capacity. The map highlights the interrelationships between different components of complexity, with some elements dominating overall complexity. Mediating factors (e.g. uncertainty and control) and temporal aspects (e.g. changing needs) were also identified.

**Conclusion:** Complexity extends far beyond holistic assessment. From this map, a conceptual model of complexity is developed to capture the multi-level, dynamic and interacting components that affect complexity.

**Funder:** NIHR PGfAR(RP-PG-1210-12015).

**Abstract number:** FC58

**Abstract type:** Oral

### Challenges in Living Alone Near the End of Life: An International Comparison from the InSup-C Project

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**Background:** Policy in end of life care assumes that family caregivers will be available and willing to support those living with terminal illness in the last year of life. But what are the challenges for those who live alone with varying degrees of support from family or other non-professional caregivers?

**Design and methods:** Patients with advanced cancer, COPD and chronic heart failure (CHF), with a prognosis of less than 12 months, were recruited at clinical services sites in five European nations: Belgium, Germany, Hungary, the Netherlands and the UK. Data were collected using semi-structured interviews at baseline and at three months follow-up. Interviews focused on how integrated palliative care services responded to patients' needs and

problems. A transnational comparative analysis was conducted using a qualitative thematic approach.

**Results and interpretation:** Of 157 patient participants, 48 (30%) lived alone (range by country: 13%-41%). Of this sub-sample, the mean age was 74, 65% were women and diagnoses were: cancer 58%; COPD 27%; CHF 15%. Loneliness and/or reduced social contact were apparent in the data from all countries. In Germany, patients were concerned with meaning making and existential questions: 'Why am I still alive?' In the UK, positive experiences included maintaining independence and control over daily life but for some, a reliance on variable home care services was evident and replicated data from the Netherlands. In Hungary and Belgium, dealing with symptoms like pain and fatigue were main concerns of this group.

**Conclusion:** Commonalities across the participating nations in the concerns of patients living alone in the last year of life were apparent. Whilst loneliness might be a self-evident challenge, increasing social isolation had a detrimental effect for some. Further analysis comparing these experiences with those cohabiting with others is anticipated.

On behalf of InSupC: EU FP7 funded project on integrated palliative care in Europe

**Abstract number:** FC59

**Abstract type:** Oral

### Integrated Palliative Care Practices: Group Interviews in Five European Countries

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**Introduction:** Many palliative care patients experience unnecessary transfers in the last months of life. The integrated care approach, involving timely palliative care at the right place, by the right caregivers, can be of interest. This study investigated European local care initiatives to reveal which factors underlie optimal integration of palliative care.

**Methods:** 23 integrated palliative care (PC) initiatives in five countries (UK, NL, HU, DE, BE) were selected based on having multidisciplinary treatment, an established service providing PC, and more than one organization involved. From March until September 2015, semi-structured group interviews with multiprofessional representatives from the initiatives have been performed, completed with structured inventory lists. Preliminary analyses of the

inventory lists and the first series of verbatim transcribed group interviews are reported.

**Results:** Most collaborations consisted of hospital-home care collaborations, often complemented with local hospices. Agreements were mostly based on policy documents or pilot projects, whereas contacts were often absent. Integration rested mostly on informal relations between professionals. Systematic use of guideline varied widely. The main goals of collaboration were building expertise for recognizing the need for palliative care and providing continuous, transmural care, often stimulated by 'key figures'. Identified communication genres were:

- 1) the care plan,
- 2) (digital) information transfer,
- 3) multidisciplinary team meetings (MDT),
- 4) the advisory function
- 5) the role of the hospital, and
- 6) patient involvement. Sharing values, trust, and mutual appreciation were important subthemes.

**Conclusion:** Across Europe, the integration of palliative care is implemented in various ways. Joint MDTs, informal relations, and 'key figures' seem to be the most important constituting factors, rather than organizational arrangements or the shared use of guidelines.

**Funded:** InsupC (EU-FP7).

**Abstract number:** FC60

**Abstract type:** Oral

### Compassion Fatigue in Nursing Staff Caring for Palliative Patients in Tertiary Care Settings in Ireland

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**Background:** There is a growing interest internationally in the clinical phenomenon of compassion fatigue and how it impacts on healthcare workers. With increasing numbers of patients being cared for by specialist palliative care services and the fact that people are living for longer, more nursing staff will increasingly be involved in the delivery of care to palliative patients. It was therefore imperative that compassion fatigue among nursing staff caring for palliative patients was explored.

**Methods:** A cross sectional descriptive design was undertaken across three palliative care sites in the Mid-western region of Ireland using the professional quality of life scale ProQOL, a validated measure of compassion satisfaction and fatigue. A convenience sample of 139 nursing staff were surveyed. Data was analysed using IBM SPA Statistics 20.

**Results:** A response rate of 75% (n=100) was achieved. The findings revealed that the majority of nursing staff experienced compassion fatigue across all sites, however one site had higher scores in compassion fatigue & burn-out. There were also high levels of compassion satisfaction across all three sites indicating that nursing staff were happy to be working in palliative care. The most important factors reported as influencing risk for compassion fatigue in nursing staff according to analysis of the ProQOL were the traumatic experiences of patients (47%), difficulty with professional boundaries (36%) and being preoccupied with more than one of those they care for (72%).

**Conclusion:** This study demonstrated the extent of compassion fatigue among palliative care nursing staff and clearly indicated that this is a significant problem that required attention. Furthermore the identification of the factors that led to compassion fatigue prompted a follow on study which examines whether educational and psychological interventions can reduce levels of compassion fatigue and burnout in nursing staff caring for patients with delirium.

### Mixed session III: Symptoms and end of life care

**Abstract number:** FC61

**Abstract type:** Oral

#### Feasibility of Monitoring Patients' Cancer-related Pain via the Internet

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**Background:** In the outpatient setting, pain management is often inadequate in patients with cancer-related pain, because of patient-and professional-related barriers in communication and infrequent contacts at the outpatient department. The internet provides new opportunities for monitoring these patients.

*The aim* of this study is to investigate whether internet monitoring is feasible in outpatients treated for cancer-related pain.

**Methods:** We developed an internet application (and app) that contained a pain diary, eConsult and a link to patient information about cancer-related pain. In the pain diary, patients scored their pain intensity, side effects and their analgesic use daily. These data were monitored by a nurse specialist. Outpatients with a difficult pain problem were eligible.

**Results:** We included 100 patients. Seventeen (17%) of them were not evaluable due to language/ cognitive problems (2); not having been started because they were too ill (11); withdrawal of participation (2), and internet problems (2). Of the 83 evaluable patients, 47% was male,

median age was 60 years (range:25-76). In total, these patients filled in a median of 28 diaries (range:1-396), and asked for a median of 5 eConsults (range:0-58). Analgesics were changed thrice (range:1-11). Patients most frequently used an eConsult for questions about pain or side-effects, how to use their analgesics and to improve their self-management. During the first 6 weeks, current pain intensity decreased from 3.4 (sd=2) to 2.5 (sd=1.6, P=0.021), and worst pain intensity decreased from 5.7 (sd=2) to 3.8 (sd=2.0, P< 0.001).

**Conclusions:** Internet monitoring of pain is feasible in patients with cancer-related pain. The frequent use of the pain diary in the majority of patients indicates that those patients do not perceive barriers for the frequent assessment of pain and side effects. Especially eConsults were frequently asked, probably enhancing patients' self-management.

**Abstract number:** FC62

**Abstract type:** Oral

### Phase III Randomized Double-blind Controlled Trial of Oral Risperidone, Haloperidol or Placebo with Rescue Subcutaneous Midazolam for Delirium Management in Palliative Care

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**Background:** Delirium is one of the most significant medical complications in advanced illness. Guidelines recommend targeted use of antipsychotics for specific delirium symptoms however this approach has not been evaluated in randomized trials. The aim was to compare the efficacy of risperidone relative to placebo in the control of specific delirium symptoms in palliative care patients (communication, behaviour and/or perceptual disturbances on Nursing Delirium Screening Scale) at 72 hours. Secondary aims were to compare haloperidol and placebo; and risperidone and haloperidol. (ACTRN12607000562471).

**Methods:** Dose titration occurred twice daily to effect by predefined increments to maximum 4mg (2mg if >65). All participants had delirium precipitants managed and non-pharmacological measures. Subcutaneous midazolam rescue was available. Improvement of delirium symptoms between baseline and follow-up was assessed using linear regression adjusted for baseline score and group.

**Results:** The trial recruited to its full sample (n=247) - 82 risperidone; 81 haloperidol; and 84 placebo.

For the primary intention-to-treat analyses (with 95 resamples drawn) between risperidone and placebo (n = 166), those in the risperidone group had significantly greater delirium symptoms on average at study end than control group 0.48 (95% CI 0.09 to 0.86) p=0.016; similarly, those in the haloperidol group also experienced significantly greater delirium symptoms at study end 0.24 (95% CI 0.06 to 0.42) p=0.009; when compared to the placebo group.

**Conclusions:** This adequately powered study has shown individualized management of delirium precipitants and non-pharmacological strategies results in better control of delirium symptoms in palliative patients than seen with the addition of risperidone or haloperidol, without the need for midazolam rescue. These results fundamentally challenge the pharmacological approach to manage delirium.

**Abstract number:** FC63

**Abstract type:** Oral

### "I Don't Need a Piece of Paper with Scores to Tell Me that Somebody's in Pain and I Need to Do Something about it". Nurses' and Healthcare Assistants' Perspectives on and Use of Pain Assessment Tools with People Dying with Advanced Dementia

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**Background:** The use of pain assessment tools in patients with advanced dementia is widely recommended in health-care policy but their impact on clinical outcomes for dying

patients is unclear. Healthcare assistants have a significant role in caring for the dying but their contribution to pain recognition is unexplored.

**Aims:** Explore nurses' use of pain assessment tools in patients dying with advanced dementia in hospice, secondary and nursing home care settings and investigate the role of healthcare assistants in pain assessment.

**Methods:** Semi-structured, face-to-face interviews were conducted with 24 nurses and 14 healthcare assistants. Thematic analysis of verbatim transcripts was used to identify emergent themes. Three researchers confirmed final themes.

**Results:** The Abbey Pain Scale formed part of the pain assessment protocol for nurses across care settings but most reported challenges in using it with dying patients. Scores based on brief observation were perceived as a poor substitute for knowledge of the patient, observation over time and collateral history from healthcare assistants and family. Most nurses reported pain tools resulted in no measurable clinical outcomes for patients nearing death. Healthcare assistants described methods of recognising and reporting pain and their role in observing for treatment response and side effects. Nurses and healthcare assistants described mixed experiences discussing pain with physicians.

**Conclusion:** Nursing staff described challenges with integrating pain assessment tools in practice and preferred patient knowledge, observation and collateral history from family and healthcare assistants to assess pain. The contribution of healthcare assistants in recognizing and reporting pain and assessing treatment response is described. These findings have important implications for health policy, nurse education and healthcare provision.

**Funding:** HSC Research and Development Division, Public Health Agency, Northern Ireland.

**Abstract number:** FC64

### A Qualitative Study about Comfort Perceptions in Palliative Care Patients

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**Background:** Comfort is a core concept in palliative care (PC), difficult to define and evaluate. Little is known about what is comfort in patients' perspectives which is really important regarding effective interventions. The study is based on the authors' ongoing PhD research about the development and evaluation of comfort as a complex intervention.

**Aim:** To analyse perceptions about comfort in PC patients admitted to acute settings.

**Methods:** Qualitative study using in-depth, semi-structured and face-to-face interviews, from January to March 2015, according to the *Consolidated Criteria for Reporting Qualitative Research*. Interviews were tape-recorded, transcribed verbatim and analysed using interpretative content analysis. Thirteen PC patients, aged over 18 years, with uncomfortable experiences in last 15 days were recruited at 5 in-patient medical-surgical settings.

**Results/discussion:** The majority of participants were male, married and have a cancer (n=7). Five themes and 10 categories emerged: *Me and what I feel* (symptom management); *Me and I how I react* (self-control, vulnerability/disability, information management); *Me a human being in society* (significant relationships); *Me and the meaning of my life* (faith/hope, reconciliation, meaning of life, spiritual distress); *Me and the world around me* (place of care provision). Pain and difficulty in resting were very uncomfortable symptoms. Insecurity, physical dependence and transmission of unclear information were considered negative factors for achieving comfort. To love/to be loved, to express gratitude, to feel in peace and to have the control of decisions were considered positive factors. Home is the preferred place to be but hospital is a place of security and relief. The results should be explored in other samples, using other research methodologies.

**Conclusions:** The study focuses the perspective of PC patients adding a contribution to the meaning of comfort and to the design of more effective interventions.

**Abstract number:** FC65

**Abstract type:** Oral

### Moral Distress Related to Palliative Sedation as Described by Nurses

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**Background:** Palliative sedation (PS) is used to alleviate unbearable and refractory suffering in the last phase of life, which usually occurs in complicated cases. Previous studies have shown that nurses experience emotional burden related to PS. When emotional burden becomes too much, moral distress can ensue. Moral distress is defined as "a type of moral conflict that occurs when one knows the right thing to do, but can't pursue the right action." Moral distress has not previously been studied in relation to PS.

**Aim:** The aim of this study was to explore nurses' reports on PS focusing on moral distress and conflicts.

**Methods:** In-depth interviews were held with 36 nurses working in a hospital, nursing home or primary care. They were asked about their experiences with the practice of PS.

**Results:** Several nurses described situations in which they felt that initiation of PS was justified but at the same time felt restrained because the physician did not agree, leading to difficult situations while dealing with the patient and his family. These situations are in line with the traditional description of moral distress. More often however nurses reported on situations where they 'experienced pressure' towards a certain action, while feeling that the action was not in the patient's best interest. These situations were related to

- (1) an untimely request for PS by family members or the physician when the nurse felt that not all options had already been explored;
- (2) a request by family to increase the level of sedation when the nurse felt that may involve unjustified hastening of death;
- (3) a request for PS that was not in line with the patient's wish because the patient had e.g expressed an explicit wish for euthanasia.

**Conclusions:** Trying to act in the patient's best interest can result in moral distress in several ways. To deal with this, nurses need to be able to be aware of their own motives and to adequately communicate with distressed family members and physicians.

**Abstract number:** FC66

**Abstract type:** Oral

### Factors Associated with Multiple Emergency Department Visits by Patients with Cancer in the Last 30 Days of Life: A Population-based Cohort Study

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**Aim:** To identify factors associated with multiple (2+) emergency department (ED) visits by patients with cancer in the last 30 days of life.

**Design:** Population-based retrospective cohort study using linked patient-level data from two routinely collected databases: the Office for National Statistics Mortality Database and Hospital Episode Statistics Accident & Emergency Database.

**Methods:** We used multivariable logistic regression to identify factors associated with multiple ED visits in the last 30 days of life for all adult patients who died from cancer in England during a one year period (01/04/11 to 31/03/12).

**Results:** Of 124,030 cancer decedents, 30.7% visited the ED once in the last 30 days of life, and 5.1% made

multiple visits. Patients were more likely to visit the ED multiple times if they were younger (adjusted odds ratio for each increasing year 0.99, 95% confidence interval 0.98-0.99), male (1.26, 1.19-1.34), Asian or Black (1.49, 1.27-1.74 and 1.21, 1.01-1.46 respectively, reference White), of lower socio-economic status (most deprived quintile 1.19, 1.09-1.30, reference least deprived quintile), had a higher level of co-morbidity (Charlson co-morbidity score of two or more 1.34, 1.26-1.42, reference zero or one), and a diagnosis of lung or head and neck cancer (1.74, 1.56-1.95 and 1.67, 1.40-2.00 respectively, reference colorectal cancer). Patients with four or more ED visits prior to the last month of life were also more likely to make multiple visits in the last 30 days of life (4 to 7 or more prior ED visits 1.13 to 1.81, reference no prior ED visits, test for trend  $p < 0.001$ ).

**Conclusions:** Socio-demographic factors, clinical characteristics and patients' prior use of the ED all influence cancer patients' ED attendance at the end of life. Knowledge of patients' prior ED attendance may help healthcare professionals identify individuals at greater risk of multiple visits towards the end of life, therefore allowing additional care services to be provided.

## Communication and information

**Abstract number:** FC67

**Abstract type:** Oral

### Low Prevalence of Advance Directives in European Countries: Results from the SHELTER Study

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**Background:** Advance directives (ADs) in nursing homes in the United States have been extensively researched. However, research on ADs across European nursing homes is currently lacking. This study aimed to describe the prevalence of ADs in place across European nursing homes.

**Methods:** Data from the Services and Health for Elderly in Long TERM care (SHELTER) project were used. With

use of the interRAI instrument for long-term care facilities, data was collected on residents in 57 nursing homes across 7 EU countries (Czech Republic, United Kingdom, Finland, France, Germany, Italy, the Netherlands) and Israel. Cross-sectional analyses were performed on 3681 residents. In this study, ADs were defined as documented treatment restrictions. Five types of ADs were distinguished: do not resuscitate; do not intubate; do not hospitalize; no tube feeding; medication restrictions.

**Results:** ADs were most frequently in place in the Netherlands (50%). In the UK, Finland and Germany

20% - 30% of residents had at least one AD. In France, Israel, Czech Republic and Italy the prevalence of ADs ranged between 0% and 6%. The five types of ADs showed the following ranges of prevalences across countries: do not resuscitate 0% - 45%; do not intubate 0% - 19%; do not hospitalize 0% - 21%; no tube feeding 0% - 19%; medication restrictions 0% - 18%.

**Conclusions:** There was a large difference in the prevalence of ADs between countries. These results are in line with studies on end-of-life communication, which also show large variation between countries. The differences might be related to cultural differences. Above that organizational factors might also differ and influence for instance the way discussion of potential treatment restrictions structurally take place.

**Funding:** The SHELTER study was funded by the Seventh Framework Programme of the European Union.

**Abstract number:** FC68

**Abstract type:** Oral

### Understanding Advance Care Planning within the South Asian Community: A Qualitative Patient Engagement Research Study

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**Background and aims:** Advance care planning (ACP) is a process of reflection on and communication of a person's future healthcare preferences. Participation in ACP by visible minorities is especially poor, and the literature suggests that minority perspectives toward ACP and end-of-life care varies. The South Asian ethnic group is the largest visible minority group in Canada, and more information is urgently needed on how best to approach ACP within this community.

**Methods:** A peer-to-peer inquiry was conducted by members of the South Asian community in Calgary, Alberta,

Canada who graduated from the Patient and Community Engagement Research program (PaCER) at the University of Calgary. The PaCER method (SET, COLLECT, REFLECT) engaged members of the South Asian community in a focus group (SET phase) to set the direction and goals for the study, family interviews (COLLECT phase) to collect data on South Asian families' perspectives toward ACP, and a community forum (REFLECT phase) to reflect on findings together with the researchers. Interview data were analyzed using narrative techniques.

**Results:** For the most part, the concept of ACP was foreign to this community and was often misassociated with other end-of-life issues like organ donation and estate planning. Cultural aspects (e.g. trust in shared family decision-making, superstitions related to talking about death), religious beliefs (e.g. fatalism), and immigration challenges emerged as barriers to participation in ACP. However, participants were eager to learn more about ACP and recommended several engagement strategies (e.g. disseminate information through religious institutions and community centres, respect cultural norms/include families in ACP discussions, encourage family physicians to initiate discussions, translate materials).

**Conclusions:** Use of a patient engagement research model proved highly successful in understanding ACP participation within one South Asian community.

**Abstract number:** FC69

**Abstract type:** Oral

### Discussing End-of-Life Care Issues in Nursing Homes: A Nationwide Multicenter Study in France

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**Objectives:** Discussing end-of-life issues with nursing home residents and their relatives is needed to ensure patient-centered care near the end of life. This study aimed to estimate the frequency of nursing home physicians discussing end-of-life issues with residents and their relatives, and to investigate how discussing end-of-life issues was associated with care outcomes in the last month of life.

**Methods:** Retrospective cohort study in a nationwide, representative sample of 78 nursing home facilities in France. Residents who died from non-sudden causes between 1 October 2013 and 31 May 2014 in these facilities were included (n= 674).

**Results:** End-of-life issues were discussed with at most 21.7% of the residents who died during the study period. In one third of the situations (32.8%) no discussion about end-of-life related topics ever occurred, either with the resident or with the relatives. Older people with severe dementia were less likely to have discussed more than 3 of the 6 end-of-life topics we investigated, compared with residents without cognitive impairment (OR= 0.17, 95% CI= 0.08-0.22). In the last month of life, discussing more than 3 end-of-life issues with the residents or their relatives was significantly associated with reduced odds of dying in a hospital facility (adjusted OR= 0.51, 95% CI= 0.33-0.79) and with a higher likelihood of withdrawing potentially futile life-prolonging treatments (adjusted OR= 2.37, 95% CI= 1.72-3.29).

**Conclusion:** During the last months of life, discussions about end-of-life issues occurred with only a minority of nursing home decedents, although these discussions are likely to improve end-of-life care outcomes.

**Abstract number:** FC70

**Abstract type:** Oral

### Preferences and Practices of Patients with Lung Diseases and their Healthcare Providers Regarding Advance Care Planning

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**Purpose:** Advance care planning (ACP) supports people in identifying personal values and goals of care, discussing these with relatives and healthcare providers (HCP) and recording these if desired. Little is known about the practice of ACP in pulmonology.

**Methods:** A variety of databases like Embase.com and Medline Ovid were systematically searched for empirical studies on the preferences and practices of patients with lung diseases and their HCPs regarding ACP.

**Results:** The search yielded 2892 articles, 21 were relevant for this review. The studies (12 quantitative, 9 qualitative) were predominantly from the US (47%), most of the articles concerned patients with COPD (52%), lung diseases in general (19%) and lung cancer (14%). 15-32% of patients had engaged in ACP (n=2 quantitative studies) and 69-99% of patients would like to engage in ACP (n=4 quantitative studies). Reported barriers of patients to engage in ACP were: uncertainty about ones' preferences for medical care and treatment, not being ready to engage in ACP, and uncertainty about who will be the future main care provider; facilitators for engaging in ACP with a healthcare provider were: the HCP being truly interested in

the patient and the HCP being knowledgeable about the patients' condition.

Of the healthcare providers, 13-38% engaged in ACP with most of their patients (n=2 quantitative studies). 69-71% of HCPs found engaging in ACP difficult (n=2 quantitative studies), but 54-77% considered it to be important (n=2 quantitative studies). Reported barriers of HCPs to engage in ACP were the fear of taking away hope in patients and the unwillingness of patients to engage in ACP. Patients accepting their illness was identified as a facilitator.

**Conclusion:** ACP appears to be rather uncommon in pulmonology. Some patients seem to be ambivalent about engaging in ACP. While many healthcare providers underline the importance of ACP, they often find it difficult to engage in these discussions.

**Funding:** FP7.

**Abstract number:** FC71

**Abstract type:** Oral

### Who Decides when to Stop Palliative Oncologic Treatment?

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**Background:** It is well-known that metastatic breast cancer patients tend to receive overtreatment at the end-of-life, beyond evidence base. Still, the patients' motives for and thoughts about the palliative chemotherapy treatment are not well studied.

**Aim:** To explore breast cancer patients' motives, perceptions and experiences of palliative oncologic treatment.

**Method:** A qualitative study design with tape-recorded semi-structured interviews that were transcribed verbatim and analysed with a qualitative content analysis.

**Results:** The median age of the 20 women was 65 years, (range 40-80) and they varied in socioeconomic status. The women had lived with incurable disease for 4 years in median (range 1-15) and received 3 lines of palliative treatment (range 2-8). The majority had visceral metastases (90%).

Two main categories emerged:

- 1) The treatment (with 4 subcategories) and
- 2) The doctor's role (with 2 subcategories).

In short, all the participants saw continuing treatment as the only acceptable choice, despite disturbing side-effects. Emotionally, discontinuation was no option. They trusted their doctor who was considered an expert and most of them wanted their doctor to decide about treatment. They

all knew that the cancer was disseminated but despite this, they tended to have hopes for cure. Any cancer *symptom* triggered death anxiety, whereas they patiently accepted similar *side-effects* from the treatment.

**Conclusion:** The majority of the women hope for cure and have not perceived there is an option not to continue with next line of palliative chemo/antibody therapy. They also feel that both their doctors and relatives expect them to continue treatment.

**Abstract number:** FC72

**Abstract type:** Oral

### Rare Diseases Website: Developing the Parent-to-Parent Content of a Rare Disease Website in Ireland

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**Research aim:** The aim of this follow-up study is to further examine parents' requirements for a live parent-to-parent support platform on an innovative Irish website for parents of children with rare conditions (RD-WIFI 2014).

**Study population:** Parents of children with rare conditions.

**Design and methods:** A qualitative design descriptive exploratory study to capture parents' views on a live parent-to-parent support platform. A purposive non-probability sample (n=10) was recruited via the study's gatekeeper, (n=3) in a focus group and (n=7) in individual telephone interviews. Ethical approval was obtained.

**Methods of analysis:** Biographical data were analysed using simple descriptive statistics (MS Excel) and all participant views were combined for simple thematic data analysis.

**Results:** The findings support those of RD-WIFI study and found participants viewed that, they as parents living in Ireland, need the support of an Irish online community to share similar experiences, with a UNIQUE type database and a system to contact parent 'expert groups'. While online support was viewed as important, it is not sufficient, as face-to-face encounters are also required as is information specific to the Irish context.

**Limitations:** The sample was limited to that recruited by the gatekeeper. Initially the study sought to hold four nationwide focus groups. However, following difficulties in obtaining sufficient numbers, one focus group was held and further data were collected via telephone interviews.

**Discussion:** The importance of this project is based on 70% of people with a rare condition are children (DOH, 2014) and it is estimated that 30% of these children will not survive past their fifth birthday. The majority of these

children are cared at home by their parents, making the need for parental information about their child's condition a critical component to their care.

**Funding:** The Irish Research Council New Foundation Award (2014).

## Palliative care in specific groups II

**Abstract number:** FC73

**Abstract type:** Oral

### How Often Do General Practitioners Communicate about End-of-Life Topics with Community-dwelling Older People and their Family in Three European Countries?

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**Background:** The involvement of family in shared decision making and communication about medical issues at the end of life may be particularly relevant to older people, but it is unknown how often this happens in different countries.

**Method:** Nationwide representative mortality follow-back study among general practitioners (GPs), who filled in a weekly questionnaire regarding all their patients who died. The study included people who died non-suddenly over the age of 75 and whose longest place of residence in the last year of life was home (n=1556) in Belgium, the Netherlands and Italy in 2013, 2014 or 2015. GPs indicated if they had communicated with the patient and/or family about diagnosis, prognosis, approaching end of life, pros and cons of treatments, options for end-of-life care, spiritual issues and psychological or social issues.

**Results:** GPs communicated more often with older patients about all topics in Belgium (65%-81%) and the Netherlands (51%-87%) than in Italy (3-33%). On average, GPs in Belgium communicated with older patients about 3 out of 7 end-of-life topics, compared with 5 topics in the Netherlands and 1 topic in Italy. In all countries GPs communicated with family about an average of 4 topics, particularly diagnosis (75%-89%), prognosis (74%-90%) and the approaching end of life (71%-89%). In Belgium and Italy, all topics were more frequently discussed with family than with the patient; in the Netherlands, only options for end-of-life care were more frequently discussed with the family.

**Conclusion:** That communication between GP and family was similar in all countries suggest that family are seen as an appropriate avenue for communicating about end-of-life issues in different cultural settings, but whether this should be in conjunction with communication with the patient differs as shown by the substantial variance across countries in communication with older patients themselves.

**Funding:** None.

**Abstract number:** FC74

**Abstract type:** Oral

### Providing Palliative Care in Hostels: A Case Series

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**Objective:** The homeless are a vulnerable patient group, particularly the visible homeless. Delivery of palliative care to hostel dwellers is affected by barriers such as sporadic transitions between temporary accommodations, risk of sudden death from injury or accident and lack of knowledge about healthcare entitlements. This study reviews the deaths of hostel dwellers receiving specialist palliative care (SPC) from a Dublin service.

**Methods:** Information was retrieved from the SPC database from 1997 to 2015. Charts of all hostel dwelling patients were reviewed. Data included diagnosis, symptom burden and service use. The patients' notes were analysed using content analysis, to identify care issues.

**Results:** The charts of 14 homeless patients were reviewed. The median age at death was 62, 6 years earlier than the general SPC population. All patients had cancer; 44% (n=6) had ENT malignancy. 79% of patients were referred to SPC from the primary care setting. 57% of patients received SPC in the hostel environment. Patients were referred to SPC social work (50%) and chaplaincy (35%). 50% of patients died in the hospital, 35% in hospice and 15% in their hostel. Patients had an average of 8 symptoms, with pain, constipation and

anxiety being the most common. 75% suffered substance misuse. 70% had poor compliance. 50% were estranged from their family. Hostel staff were concerned about symptom management and drug safety. SPC staff were concerned about symptoms, compliance and family estrangement an implications for the patients completing life-work.

**Conclusions:** The number of hostel dwellers referred to SPC is low. The needs are complex. Development of resources to support hostel staff, primary care teams and SPC providing care for this patient group has the potential to improve care. This work has commenced.

**Abstract number:** FC75

**Abstract type:** Oral

### Hyperglycemia and Hypoglycemia in End of Life Diabetic Patients on Insulin: Application to Daily Care

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**Background/aims:** Prevalence of diabetes in hospice patients is 10-15%. The objective of treatment is to avoid symptoms of hypo- or hyperglycemia. However no practical guidance is available due to the absence of data. This study aims to provide initial data on glucose control with insulin.

**Methods:** Data for the last 3 weeks of life of all patients on basal insulin therapy and hospitalised more than 6 days before death were extracted from a database of 7793 patients (2007-2013) in a single hospice.

**Results:** 150 patients (71 ± 13 years; 94 % with terminal cancer) were analysed with 1336 days of treatment and 2839 capillary blood glucose (BG) readings. 97% of patients were on intermediate-acting (IA) insulin, 52% in the morning, 17% in the evening and 28% on both.

Mean BG was subnormal at 8 am and increased further during the day. BG was increased on corticosteroids (CS; daily dose > 20 mg prednisolone equivalent, 57% of patients). BG was more stable throughout the day on morning versus evening IA, irrespective of CS dosage.

	8 am	12 am	6 pm
All	174 ± 74	217 ± 88	225 ± 88
Corticoid (CS) ≤ 20 mg daily	166 ± 63	200 ± 79	191 ± 72
Corticoid (CS) > 20 mg daily	180 ± 81	230 ± 93,***vs CS ≤ 20 mg	252 ± 90,***vs CS ≤ 20 mg
Intermediate-acting (IA) insulin in the morning	172 ± 71	210 ± 88	209 ± 86
Intermediate-acting (IA) insulin in the evening	152 ± 68,***vs IA in the morning	204 ± 73	238 ± 80,***vs IA in the morning
CS > 20 mg daily plus IA insulin in the morning	173 ± 80	215 ± 98	238 ± 92
CS > 20 mg daily plus IA insulin in the evening	158 ± 64,***vs CS > 20 mg and IA in the evening	219 ± 74	260 ± 72,***vs CS > 20 mg and IA in the evening

[Blood glucose (mg/dL) mean ± SD ; \*\*\* : p < 10<sup>-3</sup> (M)]

Hypoglycemic episodes (38/2839 BG readings < 60 mg/dL in 31/150 patients) were asymptomatic for all but two and 68 % were predictable with BG < 120 mg/dL in the preceding 24 hours. Hyperglycemia was frequent (190/2839 BG readings > 350 mg/dL in 45/150 patients; 15% of readings at 6 pm on CS).

**Conclusion:** IA insulin should be administered in the morning, especially in CS treated patients. BG < 120 mg/dL should trigger immediate measures to prevent hypoglycemia.

**Abstract number:** FC76

**Abstract type:** Oral

### Developing Systems to Review End-of-Life Care

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**Introduction:** A suite of resources have been introduced as part of a pilot programme to support Older Persons' Residential Care Centres to enhance their end-of-life care. Two initiatives outlined here are the Review after Death (CEOL Review) and the Bereaved Relatives Questionnaire.

**Aim:** To develop systems for staff to comprehensively reflect upon and review their end of life care (EOLC), after a death of a resident.

**Methodology:** Development of the CEOL Review process included a staff workshop, tools to use when carrying out a review, and post review procedures. Part 1 of the day-long workshop provided information and support in three key areas: Facilitation skills, Elements of good End of Life Care (I.H.F., 2014), and Planning and Executing a Review meeting. A supervised review of a recent death was then performed by participants in part 2.

Engaging bereaved relatives/friends after the death of a resident is a 3 step process that follows a CEOL Review. The questionnaire is based on an established tool, modified for use in Residential Care. Staff are given comprehensive information and direction regarding obtaining consent, dissemination of questionnaire, bereavement support information, follow up and analysis.

**Results:** Since March 2015, 105 participants have attended 15 workshops, and 20 CEOL Reviews have taken place. All feedback post workshops and post reviews has been very positive. The Bereaved Relatives and Friends Feedback Questionnaire development phase is completed and the supporting documentation and processes are in final editing at present. The questionnaires will be ready for distribution in November 2015.

**Conclusion:** The CEOL after Death Review and Bereaved Relatives and Friends Feedback Questionnaire are two processes aiming to support staff to improve End of Life Care through structured reflection and review of care. The tools and processes are presently available to Residential Care Centres engaged in the pilot programme.

**Abstract number:** FC77

**Abstract type:** Oral

### Initial Results from an All-Ireland Study to Identify the Pathways into and through Palliative Care for Individuals who Have a Pre-existing Mental Illness

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**Background:** This study is part of a larger project focusing on palliative care needs of a vulnerable group of people in Irish society with Serious Mental Illness (SMI). This group are more likely to develop an additional chronic health condition and die sooner than 30 years ago.

**Aim:** To determine the prevalence and profile of patients with SMI requiring palliative care in Ireland attending their General Practitioners (GP).

**Method:** A Survey Design was implemented. A specific study Questionnaire entitled "Palliative care needs of patients with a diagnosed mental illness" was developed and sent to 3,900 GPs in Ireland.

**Results:** A total of 567 (14.5%) GPs throughout Ireland returned the questionnaire. Data were entered into SPSS and descriptive analyses indicate 44.8% (n=254) of GPs had in excess of 100 SMI patients with palliative care needs attending their practice in the past 3 years. One third of GPs (n=201) reported identifying patients with a SMI diagnosis and having additional palliative care needs in the previous year. Thirty one percent of GPs (n=171) and 16.8% (n=95) of the practice nurses had completed a palliative care course. Depression 30.5% (n=173), Mood Disorders 46.4% (n=263) and General Anxiety 20.6% (n=117) were each ranked 1<sup>st</sup> as the most common mental illness GPs encountered in their practice in the year previous. Cardiovascular conditions (79.2%, n=449) were the most frequently reported physical health conditions, followed by Respiratory Related Disorders (71.3%, n=404), Diabetes (70.0%, n=397), Breast (19.9%, n=113) and Lung Cancer (18.5%, n=105) in patients with an SMI.

**Conclusion:** Initial findings indicate that a significant proportion of GP's are identifying and providing care for those with SMI and a Co-morbid physical condition. Given

the low response rate it is reasonable to conclude that the need for palliative care among those with a diagnosed SMI is high. Supported by the ICGP & funded by the All Ireland Institute of Hospice and Palliative Care (AIIHPC).

**Abstract number:** FC78

**Abstract type:** Oral

### **Interdisciplinary Palliative Care for Patients with Lung Cancer**

*Ferrell, Betty<sup>1</sup>, Borneman, Tami<sup>2</sup>, Koczywas, Marianna<sup>3</sup>, Reckamp, Karen<sup>3</sup>, Hurria, Arti<sup>3</sup>, Williams, Anna Cathy<sup>2</sup>*

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**Objective:** Palliative care, including symptom management and attention to quality of life (QOL) concerns, should be addressed throughout the trajectory of a serious illness such as lung cancer. This study tested the efficacy of an interdisciplinary palliative care intervention for patients with stage I-IV non-small cell lung cancer (NSCLC).

**Methods:** Patients undergoing treatments for NSCLC were enrolled in a prospective, quasi-experimental study whereby the usual care group was accrued first followed by the intervention group. Patients in the intervention group were presented at interdisciplinary care meetings and appropriate supportive care referrals were made. Patients also received four educational sessions. In both groups, QOL, symptoms, and psychological distress were assessed at baseline and 12 weeks using surveys which included the FACT-L, FACIT-Sp-12, LCS, and the Distress Thermometer.

**Results:** A total of 491 patients were included in the primary analysis. Patients who received the intervention had significantly better scores for QOL (109.1 vs. 101.4;  $p < .001$ ), symptoms (25.8 vs. 23.9;  $p < .001$ ), spiritual well-being (38.1 vs. 36.2;  $p < .001$ ), and lower psychological distress (2.2 vs. 3.3;  $p < .001$ ) at 12 weeks, after controlling for baseline scores, compared to patients in the usual care group. Patients in the intervention group also had significantly higher numbers of completed advance care directives (44% vs. 9%;  $p < .001$ ), and overall supportive care referrals (61% vs. 28%;  $p < .001$ ).

**Conclusions:** Interdisciplinary palliative care in the ambulatory care setting resulted in significant improvements in QOL, symptoms, and distress for NSCLC patients.

**Funding:** NCI Program Project Grant #1P01CA136396-01.

### **Mixed session IV: Education and communication at end of life**

**Abstract number:** FC79

**Abstract type:** Oral

### **How Effective Is End of Life Care Communication Skills Training for Non-specialist Palliative Care Providers? Findings from a Systematic Review and Meta-analysis**

*Selman, Lucy<sup>1</sup>, Brighton, Lisa<sup>2</sup>, Hawkins, Amy<sup>3</sup>, McDonald, Christine<sup>2</sup>, Koffman, Jonathan<sup>2</sup>, Robinson, Vicky<sup>2,4</sup>, George, Rob<sup>2,5</sup>, Khan, Shaheen A.<sup>4</sup>, Transforming End of Life Care*

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**Background:** As most end of life care (EoLC) occurs in generalist rather than specialist palliative care settings, effective training of non-specialist palliative care providers (NSPs) is crucial. In particular, NSPs need training in EoLC communication skills. Despite the widespread availability of such courses, there has been no comprehensive review of their effectiveness to inform evidence-based training and clinical practice.

**Aim:** To identify and appraise the effectiveness of EoLC communication skills training interventions for NSPs.

**Methods:** Systematic review of literature up to Nov. 2014 using 10 electronic databases. Reports of EoLC communication skills training interventions evaluated in NSPs were included. Study quality was assessed independently by 2 authors using published criteria. Data from randomised controlled trials (RCTs) were converted to effect sizes to synthesise results. Comparable outcomes were combined in meta-analyses.

**Results:** 10,296 records were identified. 153 papers representing 144 studies were eligible for inclusion. Of these, 19 were RCTs; these were from USA (n=10), Japan (n=2), Belgium (n=2), and Canada, Germany, Netherlands, Spain, and UK (each n=1). Training was consistently associated with positive effects on staff confidence. The effects of training on staff behaviours were greater in simulated interactions than real patient encounters. The few studies examining outcomes among patients and families found trends towards positive effects. Meta-analyses showed small, non-significant improvements in patient depression, anxiety and satisfaction.

**Conclusion:** This first synthesis of research studies examining the effectiveness of EoLC communication skills

training programs for NSPs found training can increase confidence and positively change behaviours. However, simulated interactions can overestimate the effects of training, and future work must assess the impact of training on patients and families.

**Funder:** Health Education South London.

**Abstract number:** FC80

**Abstract type:** Oral

### Training General Practitioners in Timely Identification of their Palliative Patients and in Anticipatory Care Planning: Results of an RCT

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**Background:** Palliative care still is mainly restricted to reactive terminal care. General practitioners (GPs) asked for guidance in how to timely identify palliative patients and to structure anticipatory care. For that reason, we developed a training for GPs in these aspects and studied its effect on out-of-hours contacts, contacts with their own GP, hospitalizations and place of death.

**Methods:** We performed a cluster RCT. GPs in the intervention group were trained in identifying their palliative patients and in anticipatory care planning. They were also offered a communication training, and for each identified patient, a coaching session with a specialist in palliative care. The GPs in the control group did not receive training or coaching, and were asked to provide care as usual.

After one year, characteristics of patients deceased of cancer, COPD or CHF in both study groups were compared with mixed effects models for out-of-hours contacts, contacts with their own GP, place of death and hospitalizations in the last months of their life. As a post-hoc analysis, of identified patients (of the intervention GPs) these figures were compared to all other deceased patients, who had not been identified as in need of palliative care.

**Results:** We did not find differences between both groups. However, only half of the trained GPs (28) identified patients (52), which was only 24% of the deceased patients. The identified patients had more contacts with their own GP (B 4.5218;  $p < 0.0006$ ), were less often hospitalized (OR 0.485;  $p 0.0437$ ) more often died at home (OR 2.126;

$p 0.0572$ ) and less often died in the hospital (OR 0.380;  $p 0.0449$ ).

**Conclusions:** Although we did not find differences between the intervention and control group, we found in a post-hoc analysis that identified palliative patients had more contacts with their GP, less hospitalizations, and more often died at home. We recommend to explore ways to timely identify more palliative patients.

**Abstract number:** FC81

**Abstract type:** Oral

### Medical Students Writing on Death, Dying and Palliative Care: A Qualitative Analysis of Reflective Essays

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**Background:** Medical students and doctors are becoming better prepared to care for palliative care patients. This needs to start at medical school and develop during the students' career. Reflection forms an important part of this. **Aims:** To assess how students learn about death, dying and palliative care using reflective essays.

**Methods:** Qualitative study in which reflective essays, written by third year medical students in one year from one UK medical school were analysed. All reflective essays from this year group were anonymously screened for those that discussed their experience of death, dying and palliative care during a clinical placement. These were analysed using QSR NVivo 10 software by three researchers with different professional backgrounds and research expertise. The analysis used a grounded theory approach and included three phases:

- (1) open coding;
- (2) axial coding and
- (3) selective coding.

**Results:** 54 essays met the inclusion criteria, 22 students gave consent for participation in the study and their 24 essays were included. Saturation of themes was reached with these essays. Three overarching themes were identified: emotions, empathy, and experiential and reflective learning. The students emphasised trying to develop a balance between showing empathy and their emotional state "biting my tongue to stop myself crying". The essays showed that students learnt a lot from the clinical encounter and watching doctors in the difficult situations "text-book cases are no longer the method of learning", as well as from their reflection during and after the experience "for

future scenarios I think it would be helpful to learn about how to approach talking to patients”.

**Conclusion:** Reflective essays give insights into the way students learn about death, dying and palliative care and how it affects them personally. The essays also helped develop the basis of strategies to make them more effective learning tools.

**Abstract number:** FC82

**Abstract type:** Oral

**Advance Care Planning: When and by whom? Perspectives of Patients, Relatives, Physicians and Nurses**

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**Background/aims:** Although the importance of ACP is not contested, little is known about the preferred timing and preferred initiator of ACP discussion. The aim of this study is to get insight in preferred timing and preferred initiator of ACP discussion from different perspectives.

**Population:** Dutch patients (n=91), relatives (n=594), physicians (n=349) and nurses (n=389) with experience with end-of-life care. Participants were recruited through patient, elderly and medical organizations.

**Design:** Online structured questionnaire, open access.

**Analysis:** Descriptive study, groups were compared using Pearson Chi square test (two-sided).

**Results:** Respondents differed in their ideas when ACP should be initiated: While the answer most often given by relatives was that ACP can best be initiated before illness (42%), patients (41%) and physicians (47%) mostly thought that the best timing is after diagnosis of a serious illness/frailty, and most nurses (44%) preferred to wait until the disease was incurable. Most respondents described that a conversation about ACP could be initiated by patient, physician, relative as well as nurse, but the majority preferred the patient and/or the physician (76% and 67%) to initiate this conversation. Respondents who preferred the patient to initiate the discussion, more often described that ACP should start before illness (34%) than respondents who had no preference for the patient (12%). Respondents who preferred ACP to be initiated by the physician, more often had a preference for a conversation on ACP later in the disease trajectory (80% compared to 54%).

**Conclusions:** There is no consensus about preferred timing among patients, relatives, physicians and nurses. Respondents who prefer early ACP, see a bigger role for the patient as initiator. However, because not all patients

are able to start a conversation on ACP, initiating this conversation is a task for all involved.

**Funding:** KNMG Royal Dutch Medical Assoc.

**Abstract number:** FC83

**Abstract type:** Oral

**The Quality of End of Life Care of Patients with Metastatic Small Cell Lung Cancer: Does it Differ from Other Lung Cancer Patients?**

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**Aims:** To date, discussions around integration of palliative care into lung cancer care has centred on those with non-small cell histology. Small cell lung cancer has received little attention, and its responsiveness to chemotherapy suggests there may be different patterns of care for this group of patients. This study seeks to determine those patterns of care for patients with metastatic small cell lung cancer (mSCLC) including the current quality of end of life care.

**Methods:** This was a retrospective population cohort study of mSCLC cases that died between 2003 and 2010 (n = 1873). Linked hospital inpatient, emergency, and death registration data were used to track health service use and survival from first multi-day hospital admission to death. Descriptive statistics on health service use, procedures, survival, and place of death are presented.

**Results:** Following a multiday admission with metastatic disease, the cohort (n = 1873) survived a median of 2 months (IQR 1, 7). Fifty percent (945) had inpatient chemotherapy (including day cases) in the interval between metastatic disease admission and death. In the last 30 days of life: 1026 (55%) had more than 1 acute hospital admission, 177 (9%) more than 1 Emergency Department presentation, 986 (53%) spent more than 14 days in hospital,

286 (15%) received chemotherapy and 68 (4%) spent time in intensive care. While 1220 (65%) had a palliative care approach in place by the time of death, this first occurred in the final admission for 870 (71%).

**Conclusions:** These data reveal that patients with mSCLC have care patterns similar to published data around those with non-small cell histology. In particular, palliative care is considered proximal to death for those with mSCLC. Strategies to foster integration of palliative care in lung cancer must be expanded to incorporate small cell lung cancer patients.

**Abstract number:** FC84

**Abstract type:** Oral

### Predictors of the Stability of End-of-Life Treatment Preferences over Time

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**Context:** End-of-life (EOL) treatment preferences may change over time, yet findings related to the direction of change have been inconsistent.

**Aims:** To identify the clinical, demographic and psychosocial predictors of the stability of the EOL treatment preferences of older Latinos with advanced cancer.

**Methods:** One-hundred and three older Latinos with advanced cancer (metastatic, recurrent or locally advanced) enrolled in a longitudinal study were interviewed once a month up until 12 months or death to assess preference stability over time. Measures in the interview included: patient EOL preferences, demographics, ESAS, EQ-5D, ECOG, FACT-G, Powe Fatalism Index, Lubben Social Network Scale-6 and Medical Mistrust Index. Data were analyzed using a generalized linear model with repeated measures over time.

**Results:** Fifty percent preferred palliative care (PC) and 50% preferred life extension (LE) at baseline. The percentage of patient preferences shifting from LE to PC was 5X greater than that shifting from PC to EL ( $P=0.005$ ). Thirty-eight percent changed their treatment preferences (32% changed from LE to PC and 6% from PC to LE) and 62% remained stable. Those with no problems in mobility or usual activities (EQ-5D) showed a greater preference for LE ( $P < 0.04$ ). Male gender, older age, low overall well-being (ESAS) and low fatalism predicted greater increases for PC preferences over time ( $P < 0.04$ ).

**Conclusion:** This is the first longitudinal study to investigate how clinical, psychosocial and demographic/cultural factors influence the stability of EOL treatment preferences

in older Latinos with advanced cancer. Findings suggest that a combination of all of these factors influence the stability of preferences over time. Findings will inform culturally appropriate PC strategies, including fluid advance care planning and the types and frequency of discussions physicians should have with patients.

**Funding Source:** NCI (K01CA151785-06).

### Mixed session V: Non-cancer

**Abstract number:** FC85

**Abstract type:** Oral

### Hand Grip Strength as a Surrogate for Disease Severity and Prognosis in Advanced Chronic Obstructive Pulmonary Disease

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**Background:** Chronic Obstructive Pulmonary Disease (COPD) causes significant mortality and morbidity. Early identification of end stage COPD patients is important for timely initiation of Palliative Care. Exercise capacity predicts mortality and is part of prognostic scores such as the BODE index. Unfortunately, exercise testing is time consuming and seldom performed in the clinic setting. Hand grip strength, however, can be easily done and has been shown to be a reliable indicator of body strength. We aim to investigate the relationship between Hand grip strength and markers of disease severity and prognosis in advanced COPD patients.

**Methods:** Stage III/IV COPD patients were prospectively recruited from the Respiratory Clinic of a Singapore tertiary hospital. Components of the BODE Index namely Body Mass Index (BMI), 6-minute walk test (6MWT) distance, Forced Expiratory Volume in 1s (FEV1) and Dyspnea scale were assessed. Dominant hand hand grip strength was measured for all patients. Statistical analysis was performed using Independent T test and Chi-Square analysis.

**Results:** 80 subjects with a mean age of 71.3 +/- 8.2 years were studied. Patients with hand grip strength in the lowest quartile ( $\leq 17$ kg) had significantly lower mean FEV1 and higher mean BODE score compared to the rest (Table1). At a median followup duration of 749 days, there were 7 (30.4%) deaths in the lowest quartile group compared to 6 (10.5%) deaths in the rest of the cohort (hazard ratio 2.9; 95% CI 1.1 to 7.7;  $P < 0.05$ ).

**Conclusion:** Reduced hand grip strength was associated with worse FEV1, BODE scores and higher mortality in advanced COPD. Hand grip strength can be a surrogate for disease severity and prognosis especially in settings where formal exercise testing cannot be done, allowing early identification of sicker patients in need of palliative care.

Table 1.

	Hand Grip Strength Lowest Quartile	Hand Grip Strength First to third quartiles	p value
FEV1 (% predicted)	30.4 +/- 13.8	37.7 +/- 10.5	0.01
BODE Score	6.8 +/- 2.3	5.7 +/- 2.2	0.05

**Abstract number:** FC86

**Abstract type:** Oral

### Future Care Planning in Advanced Heart Disease; A Stepped Wedge Randomised, Controlled Trial

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**Background:** Holistic palliative care is recommended for patients with advanced heart disease but often poorly delivered. Barriers include: few clinical trials, a culture of disease-focused care in cardiology, and challenges of time and expertise in discussing future care planning with patients and families.

**Aims:** To pilot a randomised, controlled trial of a future care planning intervention at hospital discharge in patients with advanced heart disease.

**Methods:** 50 patients hospitalised with acute on chronic heart failure or acute coronary syndrome and a predicted twelve month mortality risk of 20% or more were randomised to receive a twelve week 'Future Care Planning' intervention at discharge or twelve weeks after discharge home. A cardiologist and a cardiac nurse specialist met the patient and family to discuss the person's condition, goals, priorities and future treatment/ care planning. Care plans were shared with the GP and hospital teams. The nurse provided two follow-up meetings (six and twelve weeks) and telephone support, updating the plans. Quality of life, symptoms and anxiety/distress were assessed by questionnaire. Case note review documented hospitalization and deaths for 24 weeks after discharge. Qualitative interviews evaluated participants' experiences.

**Results:** The intervention increased power of attorney nomination, CPR decisions and anticipatory care plans. There was no increase in anxiety or distress (Kessler score - E 16.7 (7.0) v D 16.8 (7.3),  $p=0.94$ ). Quality of life remained stable twelve weeks after discharge (EQ5D - E 0.54 (0.29) v D 0.56 (0.24),  $p=0.86$ ). The intervention was valued greatly by patients, carers and GPs.

**Conclusions:** A randomised, clinical trial of future care planning is feasible, deliverable and acceptable following an acute hospital admission for patients with heart disease at high risk of deteriorating and dying. A larger Phase 3 trial of integrated palliative care assessment and care planning is indicated.

**Abstract number:** FC87

**Abstract type:** Oral

### Do Lung Transplant Patients and Carers Have Unmet Palliative Care Needs?

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**Background:** Increasing numbers of patients with life-threatening respiratory illnesses are referred for lung transplantation (LTX). These patients have a poor prognosis and (along with their carers) often endure substantial morbidity and significant hardship, both before and after LTX. They may therefore benefit from palliative care (PC).

**Aim:** To determine if patients and carers at a major LTX service have PC needs.

**Methods:** In this prospective cross-sectional study, consecutive patients (n=556) and their carers attending LTX clinics between April and October 2015 were invited to complete surveys examining their quality of life (Medical Outcomes Study SF-36), symptoms (Edmonton Symptom Assessment System) and supportive care needs (Carer Support Needs Assessment Tool). Results were analysed using descriptive statistics and independent samples *t* tests were performed to compare differences between groups.

**Results:** The sample consisted of 113 patients (mean age 60 years, 52% female) and 87 carers (84% spouse). Most respondents were post-LTX (75%). Regardless of LTX status, a significant proportion of patients and carers indicated a need for more support, for example with prognostication (patients 42%, carers 51%) and coping (patients 28%, carers 37%). Pre-LTX patients experienced significantly worse quality of life across several domains, including physical functioning (pre-LTX  $m$  18.9  $sd$  15.1 versus

post-LTX  $m$  71.8  $sd$  24.6,  $p < .001$ ) and social functioning ( $m$  41.1  $sd$  25.2 versus  $m$  77.1  $sd$  26.2,  $p < .001$ ). They were also more likely to report moderate to severe symptoms, such as dyspnoea (96% versus 14%,  $p < .001$ ) and tiredness (82% versus 38%,  $p < .001$ ). Correspondingly, pre-LTX carers were more likely to describe a higher burden of care (67% versus 35%,  $p = .01$ ).

**Discussion:** LTX patients and carers in this study *do* have substantial PC needs. Incorporating PC into both pre- and post-LTX care may enhance symptom management and bolster psychosocial support for patients and carers.

**Abstract number:** FC88

**Abstract type:** Oral

### Earlier Integration of Palliative Care: Examining the Palliative Care Needs and Quality of Life of Carers for People Living with Advanced Heart Failure

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**Background:** Evidence suggests that end-of-life care in heart failure is poor, characterized by high levels of symptoms, inadequate support and poor quality of life. Family carers play a crucial role in supporting advanced HF patients yet there is a lack of knowledge on the needs and experiences of carers for this group of patients.

**Aim:** To examine the palliative care needs, quality of life, perceived burden and level of preparedness of carers of people living with advanced heart failure.

**Methods:** A sequential confirmatory mixed methods approach comprising two phases.

Phase 1: Postal survey with carers identified via a database of patients living with advanced heart failure (NYHA Classification III-IV, ejection fraction  $< 40\%$  and  $\geq 1$  unscheduled hospital admission in the previous 12 months) across Ireland. Data included measures of depression, anxiety, QoL, perceived social support and illness beliefs, caregiver burden, needs assessment and preparedness for caregiving. Inclusion criteria: carers identified by the patient as the main person who provides care.

Phase 2: semi structured face to face interviews with carers ( $n=20$ ). Thematic analysis of verbatim transcripts was used to identify emergent themes. Descriptive and inferential data analysis using SPSS was undertaken.

**Results:** 82 carer responses was obtained (response rate 47%). Nearly one third of the carers experienced moderate to severe levels of depression and anxiety and their quality of life was impacted by their caregiving role. They spent a considerable time on caregiving tasks with over 60% spending over 50 hours per week. Themes from the

qualitative interviews indicated that the carers considered that their life is on hold; expressing feelings of isolation and frustration at a perceived lack of support.

**Conclusions:** Carer's needs are variable depending on the patients' medical stability. A holistic approach is needed to support these carers.

**Funding:** Health Research Board & AIIHPC.

**Abstract number:** FC89

**Abstract type:** Oral

### Living and Dying with Heart Failure in Kenya: Exploring Patients' Understanding of their Illness

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**Background:** Exploring patients' understanding of illness is important for knowing how patients make sense of their illness so as to tailor services to meet their needs. There is limited evidence on how people living with heart failure in Sub Saharan Africa perceive their illness.

**Aim:** To explore the ongoing lived experience of heart failure in Kenya focusing on patients' understanding of their illness from diagnosis to death.

**Methods:** We recruited 20 patients admitted with a diagnosis of advanced heart failure at a district hospital in Kenya. We conducted three serial in depth interviews with patients at 0, 3 and 6 months after recruitment, initially in hospital and then at home. Bereavement interviews were conducted with nominated carers. Interviews were recorded, transcribed into English and analysed using the Framework approach, assisted by Nvivo software package.

**Results:** Patients expressed multiple understandings of the cause and likely course of their illness. In the beginning, they described their illness as 'ordinary', similar to common infections, and often sought care when their illness began to limit their capacity to work. Some felt confused by their diagnosis, believing their illness to be a disease for the rich or affecting the aged. Many were unaware of the chronic nature of their illness, choosing to stop treatment once they felt well. Others described illness as fate, believing 'once you get this illness in your body you can't tell it to go'. Patients were more fearful about the costs of the illness than the physical decline, and self-selected their prescribed drugs, purchasing only the cheaper ones which provided immediate relief such as furosemide.

**Conclusion:** Acknowledging patients' diverse illness beliefs is vital for informing acceptable patient-centred approaches to promote earlier presentation and diagnosis,

better treatment compliance and better quality of life for people living and dying from heart failure in Kenya.

**Abstract number:** FC90

**Abstract type:** Oral

### **ICD and LVAD Deactivation at the End of Life: Patient and Caregiver Experiences**

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**Introduction:** The use of cardiac implantable devices such as implantable cardioverter-defibrillators (ICDs) and ventricular assist devices (VADs), continues to increase in patients with advanced heart disease. These technologies are implanted to extend life; nevertheless, patients will ultimately die with these devices in place thus end-of-life (EOL) planning should include plans for deactivation. Devices that are not deactivated may contribute to a decreased quality of death for patients and distress for family members.

**Purpose:** The purpose of this study was to determine whether device deactivation and use of EOL services occurred prior to death.

**Methods:** Patient-caregiver dyads, who were part of a longitudinal study on the palliative care needs of patients with less than a 2-year predicted survival, participated. The parent study (n=100) included 48 patients with ICDs and 16 of those also had VAD implantation during the study. In the qualitative interview process, dyads were asked about their knowledge of device deactivation as part of advance care planning. After patients died, caregivers (n=27) were interviewed about device deactivation and EOL services (palliative care or hospice) prior to death.

**Results:** The majority of patients and caregivers did not have discussions with health care providers concerning deactivation of devices at the time of implantation or as patients were actively dying. Of the 27 patients who died with an ICD in place, only 6 were deactivated prior to death. Of the 2 patients who died with a VAD in place, one was deactivated prior to death. Twenty-one patients received EOL services.

**Conclusions:** The majority of patients had EOL services but few device deactivations occurred prior to death. Discussions concerning device deactivation should ideally occur at the time of implantation and continue through the EOL. Several consensus statements are available to guide healthcare providers in discussions of device deactivation at the EOL.

### **End of life care and quality of dying II**

**Abstract number:** FC91

**Abstract type:** Oral

### **The Final Illness: Decision-making in the Family Unit**

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**Background and aim:** Although family members have a significant role in the care of terminal patients, if a patient is mentally competent, they have no legally or morally place in making medical decisions. The study aims to explore the actual place and function of family members in medical decision-making.

**Study method:** Semi-structured in-depth interviews were conducted with 13 families. Patients and family caregivers were interviewed separately (n=27). The patients suffered from metastasized cancer and were treated by oncological services and simultaneously by home hospice unit. The findings were analyzed using Grounded Theory method.

**Findings:** The study yielded a comprehensive picture of the patterns of family action. The main axis emerging was the **family unit** acting together, although in four styles:

1. **Mutual decision-making** in which patient and family exercise "equal weight" in making medical decisions and there is constant negotiation.
2. **Delegating decision-making:** The patient "deposits" decisions in the hands of the family, which in turn deposits it in the hands of the physician.
3. **"The Lost":** The patient and family react to changes in the illness but do not manage to lead decision-making.
4. **Relative autonomy:** The patient leads decision-making about treatment, while at home the family leads.

**Conclusion and recommendation:** The findings attest the gap between the legal approach to the family - having no part in decision-making, and the actual approach - playing a part; There is a need to furnish professionals with more tools to cope with the family's presence, such as 'family conference'. There is a need to raise the awareness of professionals as to different family textures. No "one rule" is relevant to all. There is room to develop ethical principles to help regulate the place of the family in medical decision-making.

The study was funded with a scholarship from Bil Berman, MYERS-JDC-Brookdale and the Israel National Institute for health Policy Research.

**Abstract number:** FC92

**Abstract type:** Oral

### **How to React to a Desire to Hasten Death: Development of a Training Programme**

*Frerich, Gerrit<sup>1</sup>, Romotzky, Vanessa<sup>1</sup>, Galushko, Maren<sup>1</sup>, Wolf, Jürgen<sup>2</sup>, Voltz, Raymond<sup>1</sup>*

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**Aims:** Although health professionals (HP) in palliative care (PC) are regularly confronted with desires to hasten death (DHD), there is considerable uncertainty concerning how to deal with them. This study wants to identify the needs regarding the content and structure of a possible training programme.

**Methods:** Focus groups comprising HPs in specialised and general palliative care (physicians, general practitioners, nurses, psychologists, pastoral workers, social workers) were carried out at four locations by two facilitators. These sessions were transcribed and analysed using content analysis.

**Results:** Four focus groups consisting of HPs from specialised palliative care as well as three with representatives from general palliative care were held. The participants requested information on the type, detection of and reasons for DHD as well as on possible interventions. Moreover, they requested information on the assessment, the legal situation regarding euthanasia and on obtaining external expertise. Reflecting one's own attitude towards death and DHD, and the accompanying emotions and ways of coping with stress was seen as essential. The training programme should take into account that HPs are often under time pressure and that there is sometimes no culture for dealing with DHD in a sensitive manner in the workplace. Multidisciplinary exchange of experience, possibilities for personal experience and practicing methods were requested as teaching methods in addition to lectures.

**Conclusion:** HPs express a clear need for an improvement of competences for coping with DHD. In order to learn how to effectively and confidently cope with DHD, developing, carrying out and evaluating a training programme would be helpful. Of particular importance for improving competences, in addition to current knowledge concerning DHD and the legal situation, is the reflection of one's own behaviour and emotions as well as practicing specific ways of dealing with DHD.

**Abstract number:** FC93

**Abstract type:** Oral

### **Does Implementation of a Care Pathway for Dying Patients in Nursing Homes Improve Communication with the Relatives?**

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**Background/aims:** Almost 50% of all deaths in Norway take place in nursing homes. To improve the care for dying patients and their relatives, a project was launched to implement the Liverpool Care Pathway (LCP) in 40 nursing homes in Bergen. The study aim was to examine whether implementation of the LCP (hereafter implementation) in nursing homes led to changes in communication, symptom relief and nursing care, as evaluated by bereaved relatives.

**Methods:** Postal survey to a close relative of patients who died an expected death in six nursing homes in Bergen, before and after implementation. The survey asked about communication, nursing care, and symptom relief the last three days of life, as well as demographic questions about the deceased and the responder. The study had ethics approval and written informed consent.

**Results:** 625 residents died in the six nursing homes 2012-2014. 217 cases were considered for inclusion, but no close relative or other reasons excluded 61. 130 relatives consented to the study, and 102 returned a completed questionnaire, 46 before and 56 after implementation. 52% were women, 63% >60 years, 76% had lost a parent. 92% of the deceased were >80 years, 72% were women, 70% had been living in the nursing home >1 year. The respondents were generally satisfied with the care. After implementation, the nursing home physician was more often involved (with the nurse) in informing the relatives about impending death (39 vs 17%,  $p=.02$ , chi sq). Furthermore, the responders were kept better informed about the patient's condition, and fewer had wanted to be more involved in decision-making (18 vs 28%). The satisfaction with nursing care and the degree of symptom relief were the same before and after implementation.

**Conclusions:** Our results indicate that implementation of a care pathway for dying patients in nursing homes improves communication with and involvement of the relatives.

**Funding:** Norwegian Medical Association Fund for Quality and Patient Safety.

**Abstract number:** FC94

**Abstract type:** Oral

### **Silence: A Dimension of Spiritual Care Beyond Words (PhD thesis)**

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**Background:** In end of life care, silence seems to play an increasing role in communication between healthcare professionals and patients and their families. Yet times of silence may be under-used and under-valued as a dimension of spiritual care. This may be exacerbated when healthcare professionals are not comfortable with silence themselves. Greater understanding of the phenomenon may help to inform palliative care practice.

**Aim:** To explore the nature, meaning and value of silence in spiritual care giving at the end of life.

**Methods:** A two phase phenomenological study utilising heuristic inquiry and hermeneutic phenomenology was undertaken in the UK. Data were gathered through reflective journaling and conversation-style interviews. A reflexive and hermeneutic approach to analysis was adopted to explicate the lived experience in order to produce an interpretation of the essence of silence as a dimension of spiritual care at the end of life.

**Results:** 15 palliative care chaplains participated in the study. Silence was identified as a powerful medium for communication at times when words fail and when there is no longer any need for words. Silence is also an enabler of speech, creating an 'accompanied processing space' where deep truths can be articulated and shared. In the presence of a caregiver who is willing to transcend their own vulnerability and stay with another in a non-verbal space, silence can offer an environment where acceptance, healing and peace may be found.

**Conclusion:** Care giving silence complements the spoken word as a person-centred dimension of spiritual care. It has particular relevance when verbal interventions seem inadequate, unnecessary, or intrusive. In a culture which privileges speech and activity, this understanding supports a claim for the recognition of the value of silence, which may find wider resonance with chaplains and other palliative caregivers.

The study is self-funded.

**Abstract number:** FC95

**Abstract type:** Oral

### Palliative Care Physicians' Involvement in the Swiss Civil Model of Assisted Suicide

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International Observatory on End of Life Care, Lancaster University, Lancaster, United Kingdom

**Background:** Assisted suicide (AS) in Switzerland is mainly performed by right to die associations (RTDAs). Medical input outside RTDAs is generally limited to certification of the patient's medical condition. Palliative care (PC) has previously been perceived in Switzerland as generally opposed to AS, but PC professionals are increasingly involved.

**Aim/methods:** To explore PC physicians' attitudes and experiences of AS, qualitative interviews were conducted with a purposive sample of 23 Swiss PC physicians. Interviews covered topics including the physicians' general views of AS, their level of training, experience and involvement in AS, their views of the current system for AS in Switzerland, and on the place of AS in PC. Thematic analysis was performed.

**Results:** Participants regularly received AS requests and engaged in AS decision-making, but the majority did not prescribe the lethal drug nor actively support the patients AS requests; only three had attended an AS. The majority responded to AS requests by extensively (usually over a period of days or weeks) exploring the patients' reasons and offering alternatives, tending to emphasise the possible negative aspects of AS.

Some interviews evidenced that, by slowing down the decision-making process, PC involvement can delay or frustrate the patient's AS wish. Most participants had little or no direct contact with the RTDAs, but a few had and found the collaboration valuable for the patient. While some were satisfied with the current Swiss AS systems, others saw a greater potential for AS as part of PC, or alongside it. The majority supported a better collaboration with RTDAs in order to improve AS services in the best interests of the patients, and a clearer regulatory framework.

**Conclusion:** Changes in AS participation by PC physicians, developments in cantonal legislation and the active role of the RTDAs are shaping a unique and evolving Swiss model of civil assistance to AS.

**Abstract number:** FC96

**Abstract type:** Oral

### The Experiences and Responses of Patients with a Limited Life Expectation to Advance Care Planning: A Systematic Review

*Zwakman, M.<sup>1</sup>, Jabbarian, L.J.<sup>2</sup>, Pollock, K.<sup>3</sup>, Seymour, J.<sup>3</sup>, van der Heide, A.<sup>2</sup>, van Delden, J.J.M.<sup>1</sup>, Kars, M.C.<sup>1</sup>*

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**Introduction:** Advance care planning (ACP) is a process of communication between patients, relatives and health care professionals (HCP) about patients' values and care preferences. It raises awareness of the need to anticipate possible future decisions. Previous work demonstrates that ACP has the potential to improve the quality and patient experience of end-of-life care. Moreover, ACP may be more effective in meeting patients' preferences than written documents alone. However, evidence about the role and value of ACP from the patient perspective is limited. Therefore, a systematic review was conducted.

**Methods:** A systematic review resulting in a thematic synthesis. A three-step approach was performed to formulate and refine the search string. PUBMED, CINAHL, PsychINFO and EMBASE from 2000 till 2015 were searched. Studies in children and patients with dementia were excluded.

**Results:** 3079 papers were identified. By screening title and abstract 204 articles were identified as eligible for the review. After full text screening 19 articles were included. All articles were qualitative studies and included non-cancer as well as cancer patients. Three principal themes were identified. The first theme concerns the conditions of the ACP conversation. Patients emphasized a need for information and a comfortable setting. Patients varied in preferring a face to face conversation or a group session approach. Ambivalence about ACP, the second theme, reflects that participating in ACP raised feelings of relief and happiness and a sense of control, but also feelings of confrontation and disturbance. The third theme concerns the positive and negative influences of ACP on patients' relationships with family and HCPs.

**Conclusion:** This review revealed that ACP involves a process which can result in positive outcomes as well as challenges for patients. More research is needed to understand the contradictory feelings patients experience in response to ACP and how HCPs can guide them.

#### Mixed session VI: Organisation and specific groups

**Abstract number:** FC97

**Abstract type:** Oral

#### Palliative Care in Prison: Findings from a Survey of Older Prisoners

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**Background and aims:** Since 2002, the number of older prisoners in the UK has increased by over 164%, and there are now around 12,000 prisoners over the age of 50. Many older prisoners have complex healthcare needs, and deaths in custody from natural causes are becoming increasingly common (141 in 2014, the highest figure on record). This paper reports findings from a survey of older prisoners in one prison in England, which investigated the healthcare needs of older prisoners, as part of a wider study called 'Both sides of the fence: using action research to improve end of life care for prisoners'.

**Methods:** The research team in partnership with prison staff devised a questionnaire consisting of 20 items covering six areas: demographic information; health status; daily life and mobility; healthcare in the prison; social and psychological needs; and future developments. Staff distributed the survey to 202 prisoners aged 55 and over; 127 were returned (62.9% response rate). Numeric data were analysed using SPSS Statistics 21; free text data were fully transcribed and a thematic analysis was undertaken.

**Results:** Respondents' ages ranged from 55 to 91; the mean age was 64.9 (median 64), and 26% were aged 70 or over. A high level of ill-health was reported; 55.9% of respondents had three or more medical conditions, and 49.2% were prescribed five or more medications. Almost a fifth (18.9%) were unable to manage a flight of stairs unaided; 43.3% used at least one mobility/health aid, and 30.7% had experienced a fall within the last 2 years. Analysis of free text data revealed a wide range of factors related to imprisonment in older age, including prisoners' anxieties about dying in custody.

**Conclusions:** The results of this survey revealed a high degree of frailty as well as poor health in the older prisoner population. The prison service needs to adapt rapidly in order to meet the healthcare, social care and palliative care needs of this group of prisoners.

**Abstract number:** FC98

**Abstract type:** Oral

#### Strengthening a Palliative Approach in Long-term Care (SPA-LTC): A Stakeholder Analysis of a Canadian, Evidence Informed, Multi-Component Program

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**Study aims:** The purpose of this study was to conduct a stakeholder assessment of a palliative intervention, called Strengthening a Palliative Approach in Long Term Care (SPA-LTC). The SPA-LTC program was developed to include core components: (a) the formation of onsite interdisciplinary palliative champion teams; (b) Comfort Care Rounds; (c) implementing the Palliative Performance Scale to help trigger end-of-life Family Care Conference; and, (d) providing bereavement follow-up for family members.

**Methods:** Using a qualitative descriptive design, we held 20 focus groups at four LTC homes in Ontario, Canada. In total, 24 residents, 14 family members, 33 personal support workers, 25 nurses, 21 support staff, and 7 others participated. Data was analyzed using thematic content analysis.

**Results:** Participants provided positive feedback about the SPA-LTC program, stating that it would help formalize education, involve interdisciplinary staff, and improve communication between staff and families. However, some family felt it was too soon to talk about palliative care at the time of admission into LTC. Other barriers to implementation were identified, including time and workload constraints of staff and managing competing priorities with the LTC home.

**Conclusions:** The findings of this study have the potential to improve the quality of life of older adults living and dying in LTC and provide better support to their families. Given the growing aging population living and dying in this complex health environment, the proposed study promises to offer valuable information on implementation processes, clinical and administrative tools, and educational materials that will inform how qualified health professionals and decision-makers can improve the delivery of palliative care in LTC globally. This research is funded by TVN (Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) program.

**Abstract number:** FC99

**Abstract type:** Oral

### **No Sugarcoating - What Members of the German Association for Palliative Medicine Think about Assisted Suicide**

*Jaspers, Birgit<sup>1,2</sup>, Jansky, Maximiliane<sup>1</sup>, Bahr, Patrick<sup>2</sup>, Radbruch, Lukas<sup>2</sup>, Nauck, Friedemann<sup>1</sup>*

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**Background and aim:** Legal matters concerning physician-assisted suicide (PAS) and right-to-die organisations in assisting suicide (AS) have been controversially debated

in Germany for some time. The German Bundestag is expected to vote on various draft bills on the matter at the end of 2015. The DGP board commissioned a taskforce to explore the views of its members.

**Methods:** Items for the survey were derived from the literature using a focus group. Literature searches: 2005-2015 - PubMed: PAS [Title/Abstract] AND survey (all countries); grey literature: surveys in Germany, statements of relevant bodies, e.g. National Ethics Council, Churches, draft bills, DGP, etc. Answer options, among others, were a five-point-Likert scale (fully agree - totally disagree), free-text entries and don't want to answer this question. Database: Members of DGP (n=5.152). Online/paper survey (07-08/15), pilot, 3 reminders, database anonymised by a trustee, quantitative and qualitative analysis using SPSS and MaxQDA.

**Results:** Response rate 36.9% (cleared dataset); gender ♂ 32.2, ♀ 42.8, other 0.4%; physicians 47.7, nurses 17.4, other 14.0, ca. 20% missing sociodemographic data. More than 90% agreed to statements that a wish for PAS may be ambivalent or rather a wish to end an unbearable situation; 56% of physicians declared they would -on principle- never perform PAS, 3% had done so. A change of existing legal regulations in order to penalise AS by right-to-die organisations was supported by 56%. More than 50% agreed to the statement that PAS should not be part of palliative care. Detailed results will be presented.

**Conclusion:** Even though a majority of members agreed with statements of the board of directors of DGP, there was a broad variety of views. This requires careful discussion among the members of the association and the board. The DGP has initiated this discussion at the members' conference in September 2015.

**Abstract number:** FC100

**Abstract type:** Oral

### **Eliciting Older Patients' Preferences for Complex Packages of Palliative Care in the Acute Hospital Setting**

*Johnston, Bridget M<sup>1</sup>, Tobin, Katy<sup>1</sup>, Normand, Charles<sup>1</sup>, Ryan, Karen<sup>2,3</sup>, McQuillan, Regina<sup>3,4</sup>, Daveson, Barbara A<sup>5</sup>, Smith, Melinda<sup>5</sup>, Selman, Lucy<sup>5</sup>, Meier, Diane E<sup>6</sup>, Morrison, R Sean<sup>6</sup>, Higginson, Irene J<sup>5</sup>, on behalf of BuildCARE*

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**Background:** The application of economic evaluation methods to palliative care interventions is limited and the evidence base remains small. Interventions are complex and personalised, making it difficult to capture relevant costs and outcomes. Discrete choice experiments (DCEs) offer a promising alternative to standard evaluation techniques, but there have been few applications among service users. DCEs require that individuals be forced to make a trade-off between two or more hypothetical options, making it possible to quantify their preferences for attributes of services. Evidence of the attributes of care packages most valued by patients is needed to inform service delivery and support efficient resource use.

**Aims:** To evaluate preferences for services among patients  $\geq 65$  receiving specialist palliative care.

**Methods:** The study was carried out in three cities: Dublin, London and New York. Preferences were elicited using a DCE administered during face-to-face interviews with patients. A random effects probit model was used to analyse data.

**Results:** 88 patients were interviewed, with 66 participating in the DCE (response rate=75%). Patients preferred easy access to palliative care services, including input at any point during their illness ( $P < 0.001$ ), out-of-hours access ( $P < 0.001$ ) and free care at home ( $P < 0.001$ ). They demonstrated preferences for supports that minimised unpaid caregiver burden ( $P < 0.001$ ). While males had a significant preference for family to provide care in their free time ( $P < 0.001$ ), this was not influential for females. Patients in Dublin prioritised having ongoing input from palliative care ( $P = 0.001$ ), but this was less influential at other sites.

**Conclusion:** Patients derive significant benefit from attributes of care not accounted for using standard valuation methods. This work provides insights into the feasibility of data collection in palliative care.

**Funders:** Cicely Saunders International & The Atlantic Philanthropies.

**Abstract number:** FC101

**Abstract type:** Oral

**Palliative Care Nursing Education: From 2005 to 2015, a Rising Trend? Results from a Nationwide Survey and Qualitative Analysis of Nursing Undergraduate Curricula**

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**Background:** Making palliative care accessible to all citizens who are in need of this type of care requires effective

policies and education. Moreover, healthcare professionals have an ethical and legal responsibility to ensure quality palliative care. Nevertheless, palliative care has traditionally had a limited emphasis in healthcare professionals' undergraduate education.

**Aims:** To study the current status of palliative care education in nursing undergraduate curricula and investigate its evolution over the last decade.

**Design:** An online survey was sent to all public schools providing nursing undergraduate education in Portugal ( $n = 21$ ). The survey assessed if and how palliative care was included in the curricula, and whether or not national and international recommendations for palliative care nursing education were followed. Further analysis included the content of available curricula/syllabi.

**Setting/participants:** A total of 19 schools completed the survey. These institutions are geographically dispersed and representative of public nursing education in Portugal.

**Results:** All 19 participant schools integrated palliative care in their curricula. Nevertheless, only 9 schools had palliative care as an independent curricular unit. The inclusion of palliative care clearly increased from 2005 to 2015. While in 2005 only 14 schools included palliative care explicitly in their curricula, in 2015 all 19 schools do so. National and international recommendations (e.g., the ones of the EAPC) were followed. The most frequent contents referred to symptom control, terminal phase, death and bereavement, ethical issues and organisation (7 schools per content; not always the same school).

**Conclusions:** A clear investment was made in Portugal in the last decade to include palliative care in nursing undergraduate curricula. Further research is needed to understand the contribution of education in the access, care provision, quality and development of palliative care in this country.

**Abstract number:** FC102

**Abstract type:** Oral

**Unresolved Grief and its Consequences 6-9 Years after Teenage Loss of a Parent to Cancer**

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**Research aims:** The early loss of a parent is a serious life event that might involve health consequences. Emotional processing of the loss, i.e. grief work, is acknowledged as part of a coping and adjustment process. However, in interviews with youths that had been bereaved during teenage, descriptions of delayed grief were not uncommon. This study investigated the level of self-assessed grief resolution and morbidity six to nine years after teenage loss of a parent to cancer.

**Study population, design and methods:** In a nationwide population-based study of 622 of 851 (73%) youths who as teenagers six to nine years earlier had lost a parent to cancer, we explored the magnitude of unresolved grief and its association with psychological and physiological morbidity. Participants answered a study-specific anonymous questionnaire including questions about the degree to which they had worked through their grief and about their current health.

**Method of statistical analysis:** Univariable and multivariable logistic regression.

**Results and interpretation:** Six to nine years post-loss 49% reported unresolved grief (8% no and 41% a little grief resolution). They had, in comparison with youths reporting resolved grief, statistically significantly elevated risks e.g. for insomnia (sons' relative risk [RR] 2.3, 95% CI 1.3-4.0; daughters' RR 1.7, 95%CI 1.1-2.7), fatigue (sons' RR 1.8, 95% CI 1.3-2.5; daughters' RR 1.4, 95% CI 1.1-1.7), and moderate to severe depression, i.e. score >9, PHQ-9 (sons' RR 3.6, 95% CI 1.4-8.8; daughters' RR 1.8, 95% CI 1.1-3.1).

It remains to be tested if early interventions, e.g. grief education, can facilitate grief reactions and thus reduce unresolved grief as well as depression and insomnia in cancer-bereaved teenagers.

## EAPC2016: Meet-the-Expert Sessions

### Meet-the-expert session I

**Abstract number:** MTE1

**Abstract type:** Meet-the-expert

**ELSA: A Randomised Wait-list Controlled Trial and Embedded Qualitative Case Study Evaluation Assessing the Causal Impact of Social Action Services on End of Life Experience**

*Walshe, Catherine<sup>1</sup>, Dodd, Steven<sup>1</sup>, Hill, Matt<sup>2</sup>, Ockenden, Nick<sup>2</sup>, Perez Algorta, Guillermo<sup>3</sup>, Payne, Sheila<sup>1</sup>, Payne, Nancy<sup>1</sup>*

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<http://www.abstractserver.com/EAPC2016/uploads/0524-1446229133.pdf>

**Abstract number:** MTE2

**Abstract type:** Meet-the-expert

**Effectiveness of the ‘Cancer Home-life Intervention’ for People with advanced Cancer: A Randomised, Controlled Trial Protocol**

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<http://www.abstractserver.com/EAPC2016/uploads/0996-1446294779.pdf>

**Abstract number:** MTE3

**Abstract type:** Meet-the-expert

**Protocol: Advance Care Planning with Older Patients who Have End-stage Kidney Disease - Feasibility of a Deferred Entry Randomised Controlled Trial Incorporating a Mixed Methods Process Evaluation**

*O'Halloran, Peter<sup>1</sup>, Noble, Helen<sup>1</sup>, Brazil, Kevin<sup>1</sup>, Fogarty, Damian<sup>2</sup>, Shields, Joanne<sup>2</sup>, Brown, Joan<sup>2</sup>, Murtagh, Fliss<sup>3</sup>, Morton, Rachael<sup>4</sup>, Cardwell, Chris<sup>5</sup>, Clarke, Mike<sup>5</sup>*

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<http://www.abstractserver.com/EAPC2016/uploads/0812-1446218035.pdf>

**Abstract number:** MTE4

**Abstract type:** Meet-the-expert

**A Single Centre, Prospective, Randomised Controlled Trial of Using Subjective Quality of Life and Symptom Outcome Measures as a Clinical Tool, Reporting to the Multidisciplinary Team to Determine its Impact on the Subsequent Quality of Life and Symptoms Outcomes of Individual Patients with Cancer**

*McInerney, Veronica<sup>1</sup>, Waldron, Dymphna<sup>2</sup>, Mannion, Eileen<sup>3</sup>*

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<http://www.abstractserver.com/EAPC2016/uploads/0856-1446227370.pdf>

### Meet-the-expert session II

**Abstract number:** MTE5

**Abstract type:** Meet-the-expert

**Views and Policies of Directors of Health Care and Volunteer Organizations on the Roles of Volunteerism in Palliative Care: A Cross-Sectional Study. A Study Protocol**

*Vanderstichelen, Steven<sup>1</sup>, Cohen, Joachim<sup>1</sup>, Van Wesemael, Yanna<sup>2</sup>, Deliens, Luc<sup>1,3</sup>, Houttekier, Dirk<sup>1</sup>*

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<http://www.abstractserver.com/EAPC2016/uploads/0657-1446138437.pdf>

**Abstract number:** MTE6

**Abstract type:** Meet-the-expert

**Quality of Life, Decision Making, Costs and Impact on Carers in People Managed without Dialysis - The PACKS Study**

*Noble, Helen*

Queens University Belfast, Belfast, Ireland

<http://www.abstractserver.com/EAPC2016/uploads/0061-1442226187.pdf>

**Abstract number:** MTE7

**Abstract type:** Meet-the-expert

**UK Consensus Project on Quality in Palliative Care Day Services**

*Dempster, Martin<sup>1</sup>, McCorry, Noleen<sup>2</sup>, O'Connor, Sean<sup>1</sup>, Armour, Kathy<sup>3</sup>, Coast, Joanne<sup>4</sup>, Cohen, Joachim<sup>5</sup>, Donnelly, Michael<sup>1</sup>, Finucane, Anne<sup>6</sup>, Fyvie, Joan<sup>2</sup>, Jones, Louise<sup>7</sup>, Kernohan, George<sup>8</sup>, Leemans, Kathleen<sup>5</sup>, Oxenham, David<sup>9</sup>, Perkins, Paul<sup>10</sup>*

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<http://www.abstractserver.com/EAPC2016/uploads/0927-1446262714.pdf>

**Abstract number:** MTE8

**Abstract type:** Meet-the-expert

**Integration of Advanced Care Planning and End of Life Care into the Management of Patients with Advanced Chronic Liver Disease**

*Hudson, Benjamin<sup>1</sup>, McCune, Anne<sup>2</sup>, Verne, Julia<sup>3</sup>, Forbes, Karen<sup>2</sup>*

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<http://www.abstractserver.com/EAPC2016/uploads/0798-1446215717.pdf>

## EAPC2016: Poster Discussion Sessions

### Poster discussion session I

**Abstract number:** P170

**Abstract type:** Poster Discussion

#### How Are Decisions Made about Bereavement Support in Palliative Care? - Investigating Theoretical Models & Decision-making Processes

*Keegan, Orla<sup>1</sup>, Guldin, Mai-Britt<sup>2</sup>, Murphy, Irene<sup>3</sup>, Benkel, Inger<sup>4</sup>, Lacasta Reverte, Maria Antonia<sup>5</sup>, Monroe, Barbara<sup>6</sup>*

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**Background:** Scientific models to explain bereavement and plan interventions have developed over 25 years. The extent to which these developments are implemented by services is unknown.

**Aims:** To describe bereavement care planning in palliative care. Specifically to determine: How is need for bereavement care identified

Who makes decisions about support offered

Which care models and policies underpin decision-making

Are bereavement care services audited/ evaluated

**Study population:** Responses from 370 palliative care services in 25 countries in Europe, where 302 (82%) provided bereavement care.

**Study design & methods:** A cross-sectional descriptive study using online survey methods allowed quantitative & qualitative analyses. The survey was distributed to 56 national associations in 32 countries in December 2013 & January 2014. Descriptive statistics were applied and common themes generated through coding of qualitative responses.

**Results:** Tool-based assessment was provided by n=75(25%), with most decisions based on team opinion, n=243(80%). Responsibility for deciding which support to offer rested with a wide variety of professions and in over one third of services was decided by the team n= 110 (36 %). Only half named bereavement models as informing their care provision n=157 (52%), some of which were not contemporary. Some respondents relied on a single model while for others a range of models informed bereavement care. One third of services had a local bereavement care

policy n=98(33%), and n=132(37%) identified a national policy. While n=142 (49%) of services engaged in audit/evaluation 'sometimes or occasionally', n=89 (31%) had continuous audit, and n=59 (20%) never reviewed their bereavement care service.

**Interpretation:** Provision of equitable and responsive bereavement care requires consistent evidence-based decision-making & evaluation. Results illustrate a wide variation in decision-making processes and a dearth of guidance at national and clinical levels.

**Abstract number:** P190

**Abstract type:** Poster Discussion

#### RADPAC Indicators Contribute to Early Identification of and Multidimensional Care for Palliative Patients by the General Practitioner, One Year after Being Trained: Long-term Effects of an RCT

*Thoonsen, Bregje<sup>1</sup>, Groot, Marieke<sup>1</sup>, van Weel, Chris<sup>2,3</sup>, Verhagen, Stans<sup>1</sup>, Vissers, Kris<sup>1</sup>, Engels, Yvonne<sup>1</sup>*

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**Background:** To support general practitioners (GPs) in providing early palliative care to patients with cancer, COPD or heart failure, the RADboud indicators for Palliative Care needs tool (RADPAC) and a training were developed to identify such patients and to facilitate anticipatory care planning. We studied whether GPs, one year after being training, identified more palliative patients and had provided more often multidimensional palliative care than untrained GPs.

**Methods:** We performed a survey one year after GPs in the intervention condition of an RCT were trained. With the help of a questionnaire, all 134 GPs were asked how many palliative patients they had identified, and whether anticipatory care was provided.

We studied number of identified palliative patients, expected lifetime, contact frequency, whether multidimensional care was provided and which other disciplines were involved. Three weeks after the first questionnaire, responding untrained GPs received RADPAC and completed an equal questionnaire in which they documented additionally identified palliative patients.

**Results:** Trained GPs identified more palliative patients than untrained GPs (3.8 versus 2.6;  $p = 0.046$ ) and more often provided multidimensional palliative care ( $p = 0.008$ ). In both conditions, most identified patients had cancer. After having received RADPAC, the untrained GPs additionally identified a mean of 3 patients, of whom 28% had organ failure.

**Conclusions:** RADPAC sensitizes GPs in the identification of palliative patients. Trained GPs more often provided multidimensional palliative care. Further adaptation and evaluation of the tools and training is necessary to improve early palliative care for patients with organ failure.

**Abstract number:** P246

**Abstract type:** Poster Discussion

**The Effectiveness of the Care Programme for the Last Days of Life to Improve the Quality of Dying and End-of-Life Care for Patients at Acute Geriatric Hospital Wards: A Cluster Randomized Controlled Trial**

*Beernaert, Kim<sup>1</sup>, Smets, Tinne<sup>1</sup>, Cohen, Joachim<sup>1</sup>, Verhofstede, Rebecca<sup>1</sup>, Costantini, Massimo<sup>2</sup>, Van Den Noortgate, Nele<sup>3</sup>, Deliëns, Luc<sup>1</sup>*

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**Background:** The quality of dying in older people in acute hospital settings is often suboptimal. We assessed the effectiveness of the Care Programme for the Last Days of Life on improving quality of dying and end-of-life care for older patients in acute geriatric wards in hospitals.

**Methods:** A cluster randomized controlled trial (ClinicalTrials.gov nr NCT01890239) was conducted between October 2012 and March 2015 in 10 hospitals having one or more acute geriatric wards. The clusters (hospitals) were randomly assigned to intervention group (implementing the Care Programme) and control group (standard care). A one-year baseline measurement and a one-year post-intervention measurement were conducted for all eligible patients that died in the selected hospitals. The primary outcome was the quality of dying measured with the CAD-EOLD by nurses. Secondary outcomes included POS and satisfaction with care (SWC-EOLD).

**Results:** During post-intervention assessment nurses completed assessment for 132 (81%) of 164 of patients in the intervention group and 109 (92%) in the control group. Implementation of the Care Programme significantly improved comfort around dying (CAD-EOLD) compared to the control (score 34.6 vs 31.3; cluster-adjusted mean

difference 4.3 [95%CI 2.07 to 6.53];  $p < .001$ , Cohen's  $d = .78$ ). Compared to the control group intervention improved the total mean score on symptoms and care needs (POS) (-2.62[-4.96 to -.71];  $p = .009$ ,  $d = -.51$ ), but decreased satisfaction with care (SWC-EOLD) as assessed by family carers (-4.00[-7.87 to -.12];  $p = .04$ ,  $d = -.74$ ).

**Conclusion:** The Care Programme for the Last Days of Life significantly improved quality of dying for older patients at acute geriatric wards in terms of comfort around dying, symptoms and care needs, but at the same time worsened families' satisfaction with care. While the results are encouraging for wider-scale implementation, the negative impact on families' satisfaction with care warrants further exploration first.

**Abstract number:** P268

**Abstract type:** Poster Discussion

**Palliative Care for Patients Dying by Voluntary Stopping of Eating and Drinking: An Ethical Analysis**

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**Aims:** Patients who suffer from a terminal, advanced illness sometimes express the wish to hasten death. In many European countries, legal and professional codes prohibit euthanasia and assisted suicide. Dying by voluntary stopping of eating and drinking (VSED) is increasingly advocated as an alternative for these patients. If patients resort to this possibility, however, they often need symptom management by health care professionals. This presentation aims to analyze whether this practice is ethically legitimate.

**Method:** Ethical analysis based on conceptual, legal, and empirical literature.

**Analysis:** VSED shares salient features of suicide:

- (i) the intention to bring about one's own death and
- (ii) the deliberate action to impede a necessary condition of life (food and fluids).

It is also sufficiently distinct from refusing artificial nutrition and hydration, which are medical life-prolonging measures. It has three unique characteristics: First, VSED does not require an active (and often aggressive)

intervention to end life. Second, a comparably slow and reversible process has an appearance similar to natural dying. Third, VSED may entail the practical problem to distinguish it from a situation of end-of-life anorexia, where patients lose the drive to drink and eat due to the disease itself. Whether palliation during VSED is considered an assistance in suicide depends on the question whether the assistance (or the promise to assist) is a necessary precondition for the patient to use VSED and whether death would not occur without the assistance. There are at least some situations where this is the case, as will be demonstrated by highlighting four paradigmatic examples.

**Conclusion:** The largely embraced position by palliative care organizations and legal scholars that VSED is ethically legitimate while assisted suicide is not has been shown to be inconsistent. Ethico-legal guidance should be developed to give clinicians orientation in this regard.

**Abstract number:** P304

**Abstract type:** Poster Discussion

### Seven Songs for a Long Life: The Experience and Impact of Public Screening of a Documentary Film on Attitudes to Open Discussion about Death and Dying

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**Background:** Discussion about death and dying is being encouraged within UK Society but is not always easy to achieve. Seven Songs for a long life is a new documentary feature, filmed over three years in a Hospice. It was selected by Hospice UK to screen in a range of cinemas and hospices throughout the UK as a way to achieve widespread discussion among the general public.

**Aims:** To use the art medium of film to help change perceptions of hospices in the UK and to help people talk more openly about death and dying.

**Methods:** The film has screened in 70 locations across the UK to date. Where possible, audiences were invited to participate in Question and Answer (Q&A) sessions with the cast and film director. The audience were invited to complete a questionnaire on their views about talking about end of life issues, and whether they had changed as a result of the film. Topics covered in the Q & A sessions were analysed thematically and survey responses collated.

**Results:** Topics covered in the Q&A sessions included:

- surprise at the individual journeys patients made towards confronting death;
- the medical emphasis on disease rather than person;

- the importance of being able to contribute to society as a patient with a life-limiting disease.

Further discussion centred around advances in life expectancy and medical care that have resulted in people living longer with life limiting disease - but not every time. This uncertainty was a powerful focus of community discussion, with its implications for the need of protracted family and hospice support.

Questionnaire data showed that having seen the film, respondents were more confident about thinking, talking about and sharing their end of life plans and felt more informed about what hospice care was and that it was about both living and dying.

**Conclusions:** Using an immersive documentary film experience and engaging in public forums can help people to increase their confidence in talking about issues relating to death and dying.

**Abstract number:** P340

**Abstract type:** Poster Discussion

### Integrative Review on the Impact of Family Caregiving for Patients with Cancer: A Comparison between Asian and Western Studies

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**Aim:** To explore differences and similarities in the impact of the family caregiving of palliative patient with cancer in Asian and Western countries.

**Method:** An integrative literature review was performed in which articles published between 2004 and 2014 in the electronic sources PUBMED, CINAHL, Web of Science, PsycINFO and Cochrane were included. Search terms included “caregivers AND neoplasm” and “palliative care OR terminal illness”.

**Results:** Of a total of 3117 articles, 39 articles were included in the current review. Three impact categories were found: burden, anxiety and depression and quality of life. Because papers described different populations (type of cancer and stage of disease) and used different instruments, comparisons were made on a global level. In the Asian studies, most data were collected in hospitalized patients, in contrast to Western studies, where most studies concerned outpatients. Only a few studies conducted a longitudinal design. Burden in Asian studies was never

reached a higher level than moderate while in Western studies ranged between low to high level of burden. QoL of family caregivers in Asian was always lower than norm population where as Western studies pointed out a lower level in mental well-being as compared to physical well-being. In both regions patients suffered from anxiety, depression and distress, although some studies in Western region did not reach a pathological level of psychological distress.

**Conclusion:** Overall, despite differences in family role and health care systems, more similarities than differences were found in the impact of family caregiving on burden, QoL and anxiety and depression in both regions.

## Poster discussion session II

**Abstract number:** P7

**Abstract type:** Poster Discussion

### Evaluation of Adjuvant Psychological Therapy with Clinical Hypnosis and Self-hypnosis for Pain, Anxiety and Psychosomatic Symptoms Relief, in Patients with Severe Chronic Diseases in Palliative Care

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Adjuvant psychological therapy with clinical hypnosis is a newly developed behavioural treatment which has been designed specifically to alleviate pain, suffering, and emotional distress improving the quality of life of patients in Palliative Care.

**Study design:** Is a Prospective controlled trial comparing the quality of life of patients receiving psychological therapy with hypnosis and self-hypnosis, with patients receiving no hypnosis' therapy, measured before therapy, and at 1 year of follow up. We measured pain with the VAS scale and anxiety with Hamilton Anxiety Scale.

**Setting:** Dep. Pain Therapy University of Verona, Italy.

**Intervention:** 50 patients with a confirmed diagnosis of severe chronic disease were divided in 2 groups: group 1 received hypnosis as adjuvant for pain and suffering relief; group 2 did not received hypnosis.

**Statistical analysis:** VAS pain score was at baseline =81 (68;85) for the hypnosis group; 82(72;90) for the control group with a p-value 0.553. After 1 year follow-up VAS pain score was at baseline = 45 (38;56), hypnosis group; =63 (54;68)control group with a p-value=< 0.001. The Hamilton's anxiety score was at baseline=32(24;38)for the

hypnosis group; =27 (21;36) for the control group with a p-value =0.351. After 1 year follow-up The Hamilton's anxiety score was at baseline= 21 (14;23), for the hypnosis group; =27 (18;33), for the control group with a p-value =0.281. The Data was expressed in median (1<sup>st</sup>;3<sup>rd</sup> quartile); p-values from Mann-Whitney test. The group of patients that received an adjuvant treatment with hypnosis, had a significant statistical decrease of pain, anxiety and psychosomatic related symptoms.

**Conclusions:** clinical hypnosis in Palliative Care, produces significant decrease of physical pain and psychological distress among patients. The effect of therapy observed after 1 year follow-up, showed patients receiving therapy had significantly lower scores than controls on pain, anxiety and psychological symptoms.

**Abstract number:** P35

**Abstract type:** Poster Discussion

### Evaluation of Physical Function Outcomes Related to Change in Muscle Mass in Patients with Cancer Cachexia

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**Background:** Cancer cachexia is a common condition in advanced cancer associated with increased mortality and morbidity. Loss of muscle mass is both a key feature of cachexia and a primary outcome of clinical trials. Whether loss or gain in muscle mass translate into changes in physical function (PF) is not well studied. This study examine whether change in muscle mass during 6 weeks is related to a change in PF in patients with advanced cancer.

**Methods:** Patients participating in a RCT investigating the effect of a multimodal intervention(exercise, NSAIDs and nutrition) were included. All reported outcomes were measured at baseline and after 6 weeks and presented as change over time.

Cross sectional area of muscle mass( $\text{cm}^2$ ) at the L3 level was measured using CT scans and converted to kilograms(Lean Body Mass, LBM). Muscle mass loss is defined as  $>2\%$  loss. PF outcomes were six minute walk test, handgrip strength and self-reported PF(QoL). Descriptive statistics, correlation analysis and independent t-tests were used in the analysis.

**Results:** Data from 40 patients are presented (pancreatic=17, lung=23, age 35-76, M23/W17). Twenty two (55%) patients lost muscle mass, with a mean loss of LBM of -2.9 kg (range -1.1 - 5.9). No significant difference in change in PF was observed between patients that lost muscle and those who maintained or gained muscle ( $p < 0.05$  for all outcomes). There was a trend that loss of muscle mass correlated with loss of self-reported PF ( $r=0.43$ ,  $p=0.054$ ).

**Conclusion:** In this study using various objective and self-reported PF outcomes, we found no significant differences between patients that lost muscle and those who maintained or gained muscle. Few patients were included in this study. Muscle loss has consequences for survival, hospitalization and chemotherapy toxicity but it is necessary to further evaluate the consequences of changes in muscle mass on PF and identify outcome measures that fully enclose the cachectic patient's perceived changes in PF.

**Abstract number:** P71

**Abstract type:** Poster Discussion

### Is Inpatient Hospice Care Clinically Effective? A Prospective Observational Cohort Study of Consecutive Patients Admitted to a Specialist Palliative Care Unit in Ireland

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**Background:** Clinical effectiveness is defined as the application of the best knowledge, derived from research, clinical experience and patient preferences to achieve optimum processes and outcomes of care for patients. (DOH, UK). In Palliative Care, clinical effectiveness involves evaluating how effective interventions are at achieving beneficial patient and family outcomes.

**Aims:** The aim of this study was to evaluate the clinical effectiveness of inpatient care in a Specialist Palliative

Care Unit (SPCU) in Ireland. The objectives were to document the temporal relationship between admission to the unit, the patients Phase of illness and different aspects of patient and family distress.

**Methods:** This was a prospective, observational cohort study of consecutive admissions ( $n=400$ ) to a SPCU. Using the Australian case mix tool (Eager 2003), Phase of illness, Pain, Other symptoms, Psychological and Family distress and performance status were documented on admission and then daily by medical staff. Data was entered into SPSS and descriptive statistics generated.

**Results:** 342 (85%) of patients had full data recorded on day 1. 43% were in an unstable phase on admission. One third (32.3%) of these were stabilized to a stable phase within 48 hours of admission. Over the first 72 hours of admission, 70.7% of unstable patients were stabilized to a stable phase. There was also a significant correlation between phase stabilization and pain and symptom control ( $P=0.007$ ). There were linear correlations demonstrated between time of admission and progressive improvements in pain (Cramer's  $V=0.131$ ,  $p < 0.001$ ), other symptoms ( $V=0.206$ ,  $p < 0.001$ ), Psychological distress ( $V=0.101$ ,  $p < 0.001$ ) and Family distress ( $V=0.124$ ,  $p < 0.001$ ). Stable phase over the first 4 days and first 14 days was associated with significantly better performance status.

**Conclusion:** This study demonstrates the clinical effectiveness of admission to a SPCU across the different aspects of Patient and Family care.

**Abstract number:** P93

**Abstract type:** Poster Discussion

### Cluster Randomised Controlled Trial of Facilitated Case Conferencing for Aged Care Residents with Advanced Dementia

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**Background:** Quality of palliative care for people with advanced dementia (AD) in residential aged care facilities (RACF) is often compromised by lack of staff expertise

and poor communication between health professionals and families. Case conferencing (CC) enables planning person-centred, best practice management. This study compares the efficacy of a facilitated CC approach with usual care in improving end of life for aged care residents with AD.

**Methods:** 20 large (>100 bed) Australian RACF were recruited, randomised as clusters (n=10 RACF facilitated CC, 10 usual care). Registered nurses at intervention RACF were trained as Palliative Care Planning Coordinators, using evidence-based triggers to identify residents with advanced dementia likely to benefit from CC; organising CC with optimal family, multi-disciplinary staff and external health professionals' involvement; developing/implementing care plans; training other staff in person-centred palliative care. The primary endpoint was quality of end of life care (End of Life Dementia scales, satisfaction with care, symptom related comfort and management; EOLD). Primary analyses were intention to treat, secondary analyses accounted for intervention dose. Mixed models adjusted for individual (resident, family, staff) and cluster-level covariates, and inherent intra cluster correlation.

**Results:** 131 of 272 (48%) enrolled residents died. Analyses indicate minimal intervention effect on EOLD. Various patient and RACF-related factors were associated with EOLD (e.g. dementia severity, staff knowledge), differing between scales and family or staff-derived measures. Qualitative data highlighted the importance of funded support, structured approach to CC and involvement of diverse perspectives.

**Discussion:** This trial informs understanding of the factors associated with quality end of life care in advanced dementia. Success of PCPC roles requires managerial and staff support, PCPC motivation and aptitude for change management.

**Abstract number:** P150

**Abstract type:** Poster Discussion

### Place of Death Trends in Stockholm Elderly, 2004-2011: From 'Aging in Place' to 'Dying in Place'?

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**Background/aims:** Most individuals prefer to die at their place of residence, yet timely and appropriate end-of-life care may not always be available there. This potential lack of access to palliative care is of particular concern in the context of Swedish eldercare, where the supply of publicly financed services has been reorganized or even cut in

recent years. This study aims to investigate changes in the place of death distribution in Stockholm over the last decade, and discuss how this might have been affected by changes in the public eldercare system.

**Methods:** The data come from a longitudinal quantitative study covering all recipients of public eldercare in one Stockholm municipality. Preliminary analysis included all deaths from March 2004 through December 2011 for which the date and place of death were recorded (n=2208). Statistical methods included frequency descriptives and logistic regressions.

**Results:** Preliminary results indicate that between 2004 and 2011, hospital deaths decreased from 20% to 11%, care-home deaths decreased from 70% to 57%, and ordinary-home deaths increased from 10% to 32%. Multivariate logistic regression showed that individuals dying in the years 2008-2011 were significantly and increasingly more likely to die in a residential setting than those dying in 2004. Stratified analysis by Type of residence (care home v. ordinary home) revealed that this effect emerged primarily from the individuals residing in ordinary homes prior to death. Care-home residents showed no significant changes over time in their high probability of residential death (97%).

**Conclusions:** Among recipients of public eldercare services in Stockholm, an individual's place of residence increasingly predicts their place of death: where they reside is most likely where they will die, especially those residing in care homes. This trend warrants careful planning and regulating to ensure that timely, high quality end-of-life care is accessible in all types of residences.

**Abstract number:** P356

**Abstract type:** Poster Discussion

### Assessment, Reporting and Discussion of Patient-Reported-Outcomes (PROs) in Randomized-Controlled-trials in Advanced COPD. A Systematic Review According to CONSORT-criteria

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**Background:** In advanced COPD (aCOPD) quality of life (QoL) is one of the main treatment goals. In clinical trials, this can only be assessed via patient-reported-outcomes (PROs).

**Objectives:**

*Primary:* To investigate how often PROs are reported in publications of randomized controlled trials (pRCTs) in aCOPD.

*Secondary:* To assess the reporting quality for PROs according to *Consolidated Standards of Reporting Trials* (CONSORT) criteria extension for PROs (CONSORT-PROs).

**Methods:** A systematic review was performed for pRCTs assessing the effect of pharmacologic, surgical, ventilatory or medical device interventions on adult patients with aCOPD (GOLD III-IV). We aimed to obtain a random sample of RCTs published between 2003-2014 in MEDLINE and EMBASE (via DIMDI (German Institute of Medical Documentation and Information)). The hits were numbered in chronological order and screening started in order of a web-based (random.org/sequences) random list until a total of 122 publications could be included.

**Results:** Of 3834 hits, 2923 remained after removal of duplicates and 122 pRCTs could be included (60921

patients, male: 71.5%, age: 65.5±3.2 years, FEV<sub>1</sub>: mean 44.2% (standard deviation (SD) 9.7). In 88 (72%) pRCTs PROs were reported as results, ten trials (8%) chose a PRO as the primary endpoint. In the 88 studies reporting PRO results, an average of 6.5 (SD 2.7) of the 14 CONSORT-PRO items were covered. PROs were mentioned in the abstract in 57 (47%) pRCTs and 73 (60%) pRCTs considered PROs when interpreting the effect of the intervention.

**Conclusion:** Roughly half of the pRCTs considered PROs in key sections such as abstract and discussion, but PROs were much more often assessed, reported and discussed than in pRCTs in other diseases (e.g. cancer). If this research culture could be further improved, this may facilitate a more patient-centered assessment of the available treatment options. The CONSORT-PRO extension should be consulted by all researchers in this field.

## EAPC2016: Posters

### Pain

**Abstract number:** P1

**Abstract type:** Poster

#### How Much Pain Is Acceptable?

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**Background:** For patients with cancer-related pain, the numerical rating scale is the most frequently used instrument to measure pain intensity. In the literature, it has been suggested to interpret these ratings in relation to the score which is acceptable to the individual patient. We aimed to examine the feasibility and stability of acceptable pain intensity (API).

**Methods:** Patients with cancer included in this study originated from a randomized controlled trial in which we tested the effectiveness of standard pain treatment versus pain consult and patient pain education. Patients were asked to identify the intensity of pain that would be acceptable with 0-10 numeric rating scales at baseline and after 2, 4 and 8 weeks. Data were analysed using nonparametric tests.

**Results:** 72 patients were included, 35% male, mean age 59 years. Almost all patients (97%) were able to give a score for API. At baseline, 51% patients rated their API as mild, 36% rated their API in the range which is considered as moderate and 13% as severe pain. Patients' ratings of API were stable; after eight weeks, 69% of patients had a variation of up to 1 compared to baseline. However, the mean API remained equal in the standard care group (from 4.6 (range:0-8) to 5.0 (range:2-8)), and decreased in the intervention group (from 4.6 (range:2-8) to 3.8 (range:0-7,  $P < 0.01$ ), difference between groups  $P < 0.05$ ).

**Conclusions:** Acceptable pain intensity is a feasible and simple measurement to indicate patients' own thresholds. The majority of patients was capable to answer this question. However, patients seemed to accept more pain than professionals consider acceptable. Acceptable pain intensity especially decreased in the patients who were educated about pain and pain management, indicating that patients' barriers influence patients' level of acceptable pain. More research is needed before we can use acceptable pain intensity as a reference for the interpretation of pain ratings.

**Abstract number:** P2

**Abstract type:** Poster

#### Opioid Consumption Systematic Review to Prove Palliative Care Development: Have they Always Parallel Ways?

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**Background/aim:** Pain is a very common symptom in cancer patients. Palliative Care (PC) from its approach may be critical to get the suitable treatment.

The review aims to ensure that the PC development in different countries take a parallel way to the increased opioids consumption for better cancer pain control in patients at end of life

**Methods:** A systematic review of the literature search was conducted in PubMed, Embase, CINAHL, PsycINFO, Proquest and The Cochrane Library using the MeSH terms and free text. The quality of the studies was assessed according to the relevant design used. Specifically, PRISMA for systematic reviews and meta-analyses, and the checklist of the JAMA series of other designs (Oxman, 1994).

637 articles were identified by searching the database with the criteria inclusion, which 48 were duplicates. 589 references were analyzed for the first screening, 505 of them were discarded for various reasons and finally included 84 items for the systematic review.

**Results:** The treatment of cancer pain is a health issue worldwide. In Europe there are studies that show different patterns between countries and consumer show progress in countries with emerging development of CP. It also shows the individual consumption of each opioid, as DDD. In the US we have more comprehensive bibliography prevalence data and population characteristics using prescribed opioids and national and regional consumer in a given time, in a similar way to other countries. In Latin America and Africa, are helpful for the development and implementation of health policies in the field. In many countries, excessive bureaucratic burden for prescription, limits its use.

**Conclusions:** The development of PC programs can clearly increase the consumption of opioids. This type of study allows us to see the international consumption reality; establishing the differences, international health realities, cultural conditioning,...

**Abstract number:** P3

**Abstract type:** Poster

#### A Retrospective Study of Japanese Patients who Switched from Opioid to Methadone for Cancer Pain Control

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**Background:** In Japan, oral administration of methadone was approved for patients with cancer pain in March 2013. However, as methadone has complex pharmacokinetics with individual differences and rare but serious adverse effects, methadone is only prescribed as a fourth-line drug by cancer pain specialists.

**Aims:** To assess the analgesic and adverse effects of switching from other opioids to methadone.

**Methods:** The clinical characteristics of 54 patients who were prescribed oral methadone between April 2013 and September 2015 were analyzed.

**Results:** The switch from other opioids to methadone was initiated due to refractory pain in the stop-and-go switching. As determined in Japan, the starting dose of methadone ranged from 15–45mg/day, depending on the previous opioid dose. Forty-five cases (11 outpatients, 34 inpatients) were successfully switched to methadone, although 9 cases subsequently exhibited rapid progression of illness and failed due to oral difficulty during the course of dose titration. At the outset, the average of the oral morphine equivalent daily doses before methadone administration was 159mg (range, 60–660mg) and the average numerical rating score (NRS) for pain was 7.5 (range, 3–10). Upon completion of the dose titration, the mean methadone dose was 26mg (range, 10–90mg) and the average NRS was 2.4 (range, 0–6). The starting methadone dose was decreased in 5 patients due to somnolence. No serious effects, such as QT prolongation or respiratory depression, were recognized. However, paroxysmal atrial fibrillation occurred coincidentally in one inpatient who had been prescribed methadone in our palliative care unit, but defibrillation was achieved with oral administration of aprindine (1b antiarrhythmic agent) and the methadone administration could be continued.

**Conclusion:** Switching from other opioids to methadone is one of the useful methods for control of refractory cancer pain, and the side effects are few and easily controlled.

**Abstract number:** P4

**Abstract type:** Poster

**Half Dose Administration Using Once-a-Day Fentanyl Patch 12.5 µg/h with Film Dressings**

*Teraoka, Reiko<sup>1</sup>, Miyake, Mai<sup>1</sup>, Okamoto, Yoshiaki<sup>2</sup>, Nakayama, Mizue<sup>2</sup>, Numata, Chikako<sup>3</sup>, Hirai, Midori<sup>4</sup>, Yutani, Reiko<sup>1</sup>, Kitagawa, Shuji<sup>1</sup>*

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**Objective:** Although the minimum effective dose of once-a-day fentanyl patch (tape) as a cancer pain drug is 300 µg/d, this may be excessive, depending on patients' conditions. When an overdose is anticipated, it is administered at a half dose using film dressing because the tape cannot be cut and patched; however, the feasibility of dose adjustment using this method has not yet been confirmed. To examine variations of released drug due to differences among the types of film dressing, drug dissolution and skin permeability tests were conducted.

**Methods:** The tape was covered with OPSITE\* FLEXIFIX (OP), PERME-ROLL (PE), or Tegaderm™ Roll (TE) as film dressings, adopting 2 different methods: (1) bonding the application surfaces of the tape and film dressing; and (2) pasting the tape on the surface of the film dressing. A drug dissolution test was conducted, adopting the paddle over disk method. A skin permeability test was also conducted using Yucatan Micro Pig Skin. HPLC analysis was performed to measure residual drug.

**Results:** The average dissolution rate of fentanyl after 24-h attachment without film dressings was 95.8%. When covering the entire pasting surface of the tape with OP, PE, and TE, the dissolution rate was 10.6, 73.4, and 98.2%, respectively, when adopting method (1), and 65.4, 81.5, and 99.6%, respectively, when adopting method (2). OP was shown to prevent dissolution more markedly when adopting method (1) compared with (2).

Without film dressings, the fentanyl average permeation rate was 80.4%. When attaching half the tape covered with OP that had been shown to reduce fentanyl dissolution markedly, adopting method (1), the permeation rate decreased to 38.4%; approximately half of the value obtained without film dressings.

**Conclusion:** These results support the feasibility of dose adjustment by covering the surface of drug release of the tape with OP, adopting method (1).

There is no conflict of interest.

**Abstract number:** P5

**Abstract type:** Poster

**Pain in People with Intellectual Disabilities Receiving Palliative Care: Differences in Pain Recognition and Treatment Are a Big Issue**

*Tonino, Marijke, Braam, Rob, Echteld, Michael Anthony*

Stichting Prisma, Biezenmortel, Netherlands

The increasing longevity of people with intellectual disabilities (ID) stresses the importance of excellent palliative care. In the Netherlands a high care hospice specifically for people with ID was started. In this study pain is reviewed. Since communication often is impaired, diagnosis or recognition of pain and monitoring (the effects of) treatment is a serious challenge. The aim of this study is to report the prevalence of pain in patients admitted to the ID hospice and its medical treatment.

Data are collected within hospice and home care facilities of a Dutch care organisation using a retrospective cohort of 52 people. Data were extracted from the patient records between November 2012 and October 2015. Pain was assessed using observation scales and behaviour observation.

All levels of ID were represented in the sample. Pain was recognised in 2/3 of the patients. Of these only 1/3 were able to report pain themselves. In the other 2/3 trial medication was given because of the likelihood of the presence of pain due to the underlying illness. If medication made a difference, the diagnosis pain was established and treatment continued. Limited self-report also hampered the assessment of treatment effectiveness.

All patients with pain needed opioid treatment and 1/2 needed additional neuropathic pain treatment. All patients were treated for obstipation. Delirium was observed and treated in all patients, but not all delirium could reliably be associated with opioid treatment. In about half the patients other serious side-effects were seen such as itch, hyperalgesia and nausea.

Treatment is mostly dependent on observation and interpretation of behaviour and changes in behaviour. It's a fallacy that people with ID do not feel pain because they cannot tell. Accurate pain (observation) scales are very important and developing appropriate assessment scales suitable for this population is highly needed.

**Abstract number:** P6

**Abstract type:** Poster

### **Review of Alfentanil Switching in a Specialist Palliative Care Service**

*Ma, Siobhan, Cranfield, Faith, McQuillan, Regina*

St Francis Hospice, Dublin, Ireland

**Background:** The use of alfentanil in palliative care is supported by research about its use in renal failure. There are case reports about withdrawal when there is a switch from other opioids to alfentanil. Conflicting animal studies regarding tolerance have been reported.

The aim of our study was to review switches from alfentanil to other opioids

**Methods:** A retrospective chart review was conducted in a specialist palliative care service 9-month period. Cases were identified when an alfentanil infusion was switched to an alternate opioid. Data collected included diagnosis, reason to start alfentanil, alfentanil dose, alternative opioid dose, reason for switch and any adverse effects.

**Results:** 56 patients were identified on an alfentanil infusion over the 9 months. 6 patients had a total of 9 switches from alfentanil to other opioids. All 6 patients were on alfentanil due to toxicity on other opioids. All were switched from alfentanil because of drug availability, especially in relation to discharge home. Prior to the switch, pain and alfentanil dose was stable and the patients were not toxic. Out of the 9 switches, initial doses of alfentanil ranged from 6-110mg; on 4 occasions, patients were on more than 1gm oral morphine equivalent (OME). Dose reduction during the switch ranged from 0-98%. Toxicity developed in 2 cases and in both cases patients OME of more than 1gm/day and had reductions of 6 and 25%. The other two patients on OME greater 1 gm/day had reductions of 37% and 88%. One patient self-discharged, and effectively had a 98% dose reduction in opioids with no evidence of withdrawal.

**Conclusion:** Further research is needed to determine if tolerance occurs with alfentanil, especially at high doses and if a dose reduction is recommended, especially at doses equivalent to greater than 1g/24hr of PO morphine, even in the setting of well controlled pain and no toxicity.

### **Symptoms other than pain**

**Abstract number:** P8

**Abstract type:** Poster

### **Association of Cancer Related Fatigue with Other Symptoms and Impact on Quality of Life of Palliative Care Patients in a Tertiary Cancer Institute: A Prospective Observational Study**

*Ghoshal, Arunangshu, Deodhar, Jayita, Muckaden, MaryAnn*

Tata Memorial Centre, Mumbai, India

**Background:** Fatigue with other symptoms affects quality of life (QOL) in advanced cancer patients. This study looks into the factors associated with fatigue, its impact on QOL at baseline and predictors of improvement of same at first follow-up visit.

**Methods:** A prospective, observational study was conducted in the outpatient clinic from January to June 2014. Registered adult advanced cancer patients with PC clinic meeting the inclusion criteria (ECOG  $\leq$  3, ESAS fatigue score  $\geq$  1) were assessed after taking informed consent for symptom burden (ESAS) and QOL (EORTC-QOL PAL15) along with demographic details. They were given standard treatment for those symptoms. They met the PC

team or were telephonically contacted for the same domains after an interval of 15-30 days. Descriptive statistics, comparison of baseline and follow up data, correlation and multiple linear regressions between fatigue and symptoms at baseline, logistic regression model to determine factors associated with improvement in fatigue were performed. (CTRI no. : REF/2014/02/006537)

**Results:** A total of 402 subjects were assessed at baseline and follow-up (median age, 52 years; 51.6% male). Significant change in fatigue score was observed ( $p < 0.001$ ) at follow-up. Hemoglobin, albumin levels, type of cancer, sites of metastasis, ECOG score, body weight, ESAS items except drowsiness, overall QOL, emotional functioning and constipation were found to be significantly associated with fatigue at baseline ( $p < 0.05$ ). The logistic regression model showed that changes in hemoglobin and albumin levels, pain, dyspnea, physical functioning, insomnia on QOL scale significantly contributes to the improvement in fatigue.

**Conclusions:** Fatigue is strongly associated with certain physical, emotional and biochemical parameters; some of which are predictive of improvement of fatigue. As it is a single centered referral based study, its generalizability needs to be ascertained in a larger study.

**Abstract number:** P9

**Abstract type:** Poster

### Prevalence and Intensity of Dyspnea in Advanced Cancer and Factors Affecting it

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**Background:** Dyspnea is a subjective, multidimensional experience of breathing discomfort, commonly seen in patients with advanced cancer that influences all aspects of patient's life. To find the impact of dyspnea on the quality of life in this population, it is important to understand the prevalence and factors influencing dyspnea.

**Aim:** The aim of this study was to determine the prevalence, intensity and factors influencing dyspnea in advanced cancer and determine its impact on overall quality of life.

**Methods:** The study was a prospective cross sectional study. Prevalence of dyspnea and its impact on quality of life was determined on 500 patients registered with Palliative Medicine OPD. The patients were asked to fill a set of questionnaires which included the Cancer Dyspnea Scale (translated and validated Hindi and Marathi versions), Visual Analogue Scale for dyspnea and EORTC QLQ C 15 PAL. Other details of symptoms, disease, treatment and the demographics were collected from the departmental

assessment form of the patient. Descriptive statistics, univariate and multiple regression analysis were used to calculate results.

**Results:** 44.37 % of the patients experienced dyspnea. The factors of dyspnea increased with increase in anxiety, depression, fatigue, loss of appetite, loss of wellbeing, pain, lung involvement by primary or metastatic disease, performance status and deteriorating overall quality of life and emotional well being on EORTC QLQ C15 PAL.

**Conclusions:** Prevalence of dyspnea in advanced cancer population is as high as 44.37% and it causes a negative impact on overall quality of life of patients.

**Abstract number:** P10

**Abstract type:** Poster

### A Longitudinal Assessment of Cognitive Function in Patients with Cancer in Palliative Care

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**Aim:** To assess development of cognitive function and predictors for cognitive impairment during a period of 6-10 weeks in patients with cancer in palliative care.

**Methods:** Prospective longitudinal investigation derived from the European Palliative Care Cancer Symptom study (Europe, Canada, and Australia 2011-2013). Inclusion criteria: advanced cancer, in palliative care,  $\geq 18$  years, at least 1 assessment post-inclusion. A 4-item version of Mini Mental State Examination was applied as the primary variable; total score = 5, scores  $\leq 4$  = cognitive impairment. Baseline variables included in the multiple imputation based on logistic regression model were age, sex, education, time of diagnosis, cancer diagnosis, CNS metastasis, oncologic treatment, chemotherapy, opioids, corticosteroids, and sedatives/anxiolytics. Only patients with complete baseline data and with survival of  $> 6$  weeks were included in the model.

**Results:** 1568 patients (50% male, mean age 65.5, 42% had 10-12 years schooling, mean Karnofsky 68%).

Prevalence of cognitive impairment at baseline (n=1477) was 28.5% and at follow-up (n=825) 24%. Longitudinal analysis of the patients with complete MMSE at both assessments (n=801) suggested that 11.4% became impaired, 12.5% remained impaired, and 11.6% improved. The predictive model (n=1351) showed that those with low Karnofsky (OR=1.6, 95% CI: 1.0-2.5, P=0.0386) were more likely to develop cognitive impairment, while patients with breast cancer (OR=0.4, 95% CI: 0.2-0.7, P=0.0039) were less likely to develop impairment.

**Conclusion:** A substantial number of patients under palliative care seemed to develop or remain with cognitive impairment; however, improvement was also observed in some patients. Physical performance was the significant predictor of cognitive impairment, while breast cancer presented lowers odds for impairment.

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**Abstract number:** P11

**Abstract type:** Poster

### **A Scratch for Every Itch? Drugs with Large Effects and with No Effects for Pruritus Patients with Chronic Kidney Disease - Preliminary Results from a Cochrane Review**

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**Background:** Pruritus (itch) is a distressing and puzzling symptom that occurs in patients with different advanced diseases. The prevalence in patients with chronic kidney disease (CKD) under hemodialysis exceeds 70%.

**Aim:** To highlight drugs against CKD-related pruritus with *large* and with *no effects*.

**Methods:** This work is part of a Cochrane Review that is being updated. Randomized controlled trials (RCTs) with adult pruritus patients suffering under an incurable progressive disease were included. We searched the databases MEDLINE, EMBASE and CENTRAL in May 2015. Two reviewers screened and extracted information of relevant RCTs.

We performed continuous meta-analyses with RevMan 5.3 (inverse variance method; fixed effect model). A mean improvement of  $\geq 2$  on the visual analog scale (VAS) was considered as large effect. Here, only data of patients with CKD-related pruritus are presented.

**Results:** Concerning the CKD population, we included 30 studies (n=1269) with 21 different treatments and conducted meta-analyses for six drugs (versus placebo).

We found large effects for gabapentin (-5.91, 95% confidence interval [CI] -6.87 to -4.96; n=118, 2 studies) and for cromolyn sodium (-2.94, 95% CI -4.04 to -1.83; n=100, 2 studies). A subgroup analysis indicated that oral cromolyn sodium was more effective than topical cromolyn sodium (-4.70, 95% CI -6.57 to -2.83; n=40, 1 study versus -2.00, 95% CI -3.37 to -0.63; n=60, 1 study). Ondansetron showed no statistically significant effect (0.80, 95% CI -0.51 to 2.11; n=34, 1 study).

The risk of bias was unclear or low for most items of the three presented drugs.

**Conclusion:** Gabapentin and cromolyn sodium showed large effects. In contrast, ondansetron was not effective. However, the sample size in ondansetron was small and the quality of evidence was low.

Further RCTs are needed to reproduce these effects for CKD patients and to research other pruritus patients, e.g. with cholestasis or cancer.

**Abstract number:** P12

**Abstract type:** Poster

### **Patients in Palliative Care - Predictors for Feeling Depressed - An Analysis of the Hospice and Palliative Care Evaluation 2007 - 2011**

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**Aim:** In patients with advanced or terminal diseases to feel depressed is one of the common psychological symptoms. This study aims to detect possible predictors of feeling depressed in patients receiving palliative care.

**Methods:** To develop a predictive model for feeling depressed we revert to a training set with two-thirds of a randomly divided data set collected in the Hospice and Palliative Care Evaluation (HOPE) from 2007 till 2011. HOPE is used as a quality management benchmarking system in Germany and includes a validated symptom and problem checklist. Dichotomized staff ratings for feeling depressed (none or mild vs. moderate and severe) served as target variable, whereas other information from HOPE were used as predictor variables. By backward stepwise selection we determined a multivariable logistic regression

model whose predictive accuracy was evaluated using a test set containing the remaining one-third of the records by the area under the receiver operating characteristic curve (AUC).

**Results:** An analysis of 9798 data sets results in a fair predictive value for feeling depressed (AUC=0.72). The predictive model for feeling depressed includes gender, age, ECOG, living situation, brain tumors, pain, nausea, constipation, loss of appetite, tiredness, wound care, need for assistance with activities of daily living, problems with organization of care, medication with sedatives/anxiolytics, and medication with antidepressants.

**Conclusions:** Wide-ranging aspects of disease and care appeared as useful for the prediction of feeling depressed in patients receiving palliative care. These findings could be helpful to enhance the assessment of psychological symptoms, the psychological support of patients in palliative care and to sensitize staff members for possible predictors of psychological burden in patients with terminal diseases. Further analysis and research are recommended.

**Abstract number:** P13

**Abstract type:** Poster

### The Role of Physical Therapy in Cancer-related Fatigue and Breathlessness

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**Aims:** Assessment the role of physical therapy in cancer-related fatigue and breathlessness.

**Methods:** 30 patients with moderate or severe fatigue induced by cancer and its treatment participated to a program which lasted 10 days and involved physical therapy. An assessment of fatigue using "Edmonton Symptom Assessment Scale - ESAS" was made to all hospitalized patients; breathlessness was assessed too. Patient's blood pressure and heart rate were monitored daily before and after physical therapy.

**Results:** Regarding their education 40,00% patients had elementary studies and 60,00% patients had high school. According to ECOG, 33,34% patients had ECOG 1, while 40,00% patients had ECOG 2 and 26,66% patients had ECOG 3. The study showed that in the day 1, the fatigue level was severe for 73,34% patients and moderate for 26,66% patients, compared to day 10 when the fatigue level was severe for 26,66% patients and moderate for 73,34% patients. Breathlessness level was, in the day 1,

severe for 20,00% patients, moderate for 40% patients and mild for 13,33% patients, compared to day 10, when the breathlessness level was severe for 0,00% patients, moderate for 33,33% patients and mild for 26,67% patients.

**Conclusions:** Exercises are known to improve neuromuscular tone and physical therapy has an important role in cancer-related symptoms, improving symptoms like fatigue and breathlessness.

The study concluded that in the management of cancer-related fatigue and breathlessness, physical therapy is recommended, playing an important role and maintaining dignity, confidence and self-esteem in patients with an advanced illness.

**Abstract number:** P14

**Abstract type:** Poster

### Clinical Study on the Distinction between Refractory Cachexia and Starvation in Terminal Cancer Patients

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**Aim:** Cachexia appears in many terminal cancer patients. The aim of this study was to identify terminal cancer patients under the condition of starvation considered to have refractory cachexia.

**Methods:** This was a prospective study. Study subjects were terminal cancer patients who were admitted to the PCU with severe malnutrition and poor general condition. Based on prognostic predictions using the Palliative Performance Index (PPI) and nutritional indices, we distinguished starvation from refractory cachexia. Statistical analysis was performed using Mann-Whitney U test.

**Results:** Out of 180 patients who were considered to have refractory cachexia on admission, we administered nutrition therapy to 18 patients who we determined to be in a 'state of starvation' because of improvement in Palliative Performance Scale (PPS) and oral intake after alleviation of the symptoms and administration of infusion. The initial evaluation on admission showed albumin < 2.5g/dL, trans-thyretin < 10mg/dL, PPS < 30, and an estimated prognosis of 3 weeks or shorter for all patients. Ten of these patients achieved significant improvement in nutritional indices and PPS (p < 0.01), and improved general status was maintained with continuation of nutrition therapy, resulting in improved prognosis (median survival: 52 days (33 to 82 days), p < 0.05). We had no choice but to discontinue the nutrition therapy for the other 8 patients because their improvement in nutritional indices and PPS were only temporary and overhydration symptoms also occurred. After discontinuation, they developed refractory cachexia, their general condition worsened, and their prognosis did not improve (median survival: 23 days (18 to 33 days)).

**Conclusion:** It is important that we accurately assess the difference between refractory cachexia and starvation, and perform adequate nutrition therapy which may lead to better general condition and prognostic improvement. The author received no financial support.

**Abstract number:** P15

**Abstract type:** Poster

### Functional Iron Deficiency Anaemia in the Palliative Care Population

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**Background:** Anaemia is a common cause of fatigue in patients with advanced disease. Although other causes are commonly described, functional iron deficiency (FID or anaemia of chronic disease) is increasingly recognised as an important aetiology and is caused by systemic inflammation. FID is characterised by normocytic normochromic anaemia and iron restricted erythropoiesis.

**Aims:**

- to establish the prevalence of FID anaemia in a palliative care population.
- to examine the relationship between anaemia and systemic inflammation.

**Methods:** Blood tests were identified for all patients referred to two specialist palliative care services between April 2013 and March 2014. Blood results closest to the referral date were used to assess degree and cause of anaemia. The relationship was analysed between anaemia, %hypochromic red cells (%HCr, indicating iron restricted erythropoiesis if >5%) and C-Reactive Protein (CRP, marker of systemic inflammation if >10).

**Results:** Data on 2139/2416 patients were available. 79% had a cancer diagnosis. Prevalence of anaemia was 63% using WHO criteria: 25% mild, 35% moderate and 3% severe. 44% had raised %HCr which was significantly related to degree of anaemia, indicating probable FID. CRP was recorded in 68% of patients, mean value of 82. A significant relationship was found between severity of anaemia, %HCr and CRP.

Severity of anaemia (n/%)	Mean % hypochromic red cells	Mean CRP
Normal Hb (785/37%)	6.5	54
Mild (536/25%)	10	75
Moderate (748/35%)	24	109
Severe (70/3%)	33	128

[Relationship between anaemia, %HCr and CRP]

**Conclusion:** Anaemia was common in this population; 38% had moderate to severe anaemia. FID is estimated to have a prevalence of 44% in this population; it is a significant but under recognised cause of anaemia. Limitations of this research include the lack of clinical information on patient symptoms. Further research is needed to shape clinical practice with regards treatments for FID anaemia.

**Abstract number:** P16

**Abstract type:** Poster

### A Systematic Review of the Use of Anti-Secretory Medicines for the Control of Gastrointestinal Symptoms in Patients with Malignant Bowel Obstruction

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**Background:** Malignant bowel obstruction is a common condition in patients with gastrointestinal and gynaecological cancers. Anti-secretory agents are used to reduce gastrointestinal symptoms such as nausea, vomiting, abdominal pain, cachexia, and constipation in patients who are deemed unsuitable or unfit for surgery.

**Aim:** The aim of this systematic review is to analyse, evaluate and the evidence for the use of anti-secretory medications in treating gastrointestinal symptoms in patients with malignant bowel obstruction who are unfit or unsuitable for surgical intervention.

**Method:** Medline and Embase were searched from inception to November 2014. All clinical trials which used anti-secretory medications as the intervention for patients with malignant bowel obstruction to reduce gastrointestinal symptoms were included. These included randomised controlled clinical trials, controlled clinical trials and open label intervention studies.

**Results:** Of 236 screened references, 8 studies were included. These included, 4 randomised controlled trials, 1 phase 1/11 study and 3 prospective interventional studies. A total of 284 patients were included. 3 studies compared Octreotide (300-600mcg/24 hrs) with Hyoscine Butylbromide (60-80mg/24 hrs). 4 studies assessed Octreotide only and 1 study assessed long and short acting Octreotide against matched placebo. Octreotide improved nausea and vomiting scores when compared with Hyoscine Butylbromide but other symptoms such as pain showed no difference. When assessing Octreotide only, both nausea and vomiting were improved compared to baseline and in one study quality of life was improved.

**Conclusion:** There is limited evidence of moderate quality in showing the effectiveness of Octreotide over Hyoscine Butylbromide for symptoms of nausea and vomiting for patients with malignant bowel obstruction. There was no

difference in abdominal pain or distension. Further comparative RCTs are required to corroborate these results.

**Abstract number:** P17

**Abstract type:** Poster

### A Long-term Follow-up the Health-related Quality of Life on Taiwanese Patients with Head and Neck Cancer

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**Background/aims:** The quality of life can be seen as an indicator of cancer survivorships. Little is known about the long-term effect on the quality of life in Taiwanese patients with head and neck cancer. Therefore, this study aimed to investigate the changes in quality of life and related factors in head and neck cancer patients over 2 years after diagnosis.

**Methods:** Prospective and longitudinal design was used in the study. 122 participants were recruited from four hospitals in Taiwan. Data was collected at six time points: one week after diagnosis (baseline, T<sub>0</sub>), the start of treatment (T<sub>1</sub>), and 3 months (T<sub>3</sub>), 6 months (T<sub>4</sub>), 12 months (T<sub>5</sub>) and 24 months (T<sub>6</sub>) after diagnosis. Subjects were assessed by the following questionnaires: EQ-5D, EORTC QLQ-C30, EORTC QLQ-HN35, KPS, and background information.

**Results:** The results indicated patients persisted in having moderate levels of cancer-related quality of life (EORTC QLQ-C30), and disease and treatment-related quality of life at T<sub>0</sub>-T<sub>5</sub> (EORTC QLQ-NH35). The levels of general quality of life (EQ-5D), and disease and treatment-related quality of life were significantly lower at starting treatments (T<sub>1</sub>) than the other of time points. During the six time points, pain/discomfort affected their general quality of life most severely, followed by anxiety/low moods. Amongst all of the symptoms related disease and treatment, problems with swallowing and thickness of saliva affected the quality of life of patients most severely. The time since diagnosis, the levels of KPS, and the levels of physical status and pain in cancer-related quality of life scores (QLO-C30) could predict the general quality of life.

**Conclusions:** Symptoms related disease and treatment long-term affected the quality of life of patients. Therefore, the healthcare staffs need to develop and implement intervention to prevent or minimize adverse outcomes related to cancer diagnosis and treatments, so as to improve their quality of life.

**Abstract number:** P18

**Abstract type:** Poster

### Cancer Cachexia Assessment in a Specialist Palliative Care Inpatient Unit

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**Introduction:** Cancer cachexia is associated with poor quality of life, increased cancer treatment morbidity and reduced survival. Accurate assessment enables appropriate intervention. Multiple barriers to cachexia assessment exist in the palliative setting.

**Aims:** To examine current practice in a specialist palliative care unit (SPCU) and whether cachexia is accurately assessed, based on the 2011 international consensus definition of cancer cachexia.

**Methods:** Unified healthcare records of consecutive cancer admissions to the SPCU from September 2014 to February 2015 were retrospectively reviewed. Documentation of anorexia, catabolic drivers (C-Reactive Protein; CRP), functional status (Palliative Performance Scale; PPS), nutrition impact symptoms, weight and weight change was sought. Outcome of admission (death/discharge) was recorded. Statistics were generated with Microsoft Excel.

**Results:** 214 admissions were reviewed. Anorexia was documented in 68% (n=135). Median CRP was 47.8mg/L (range:0.6-456 mg/L). Median PPS was 40% (range:10-80%). Median number of symptoms was 3 (range:0-7 of 12 potential). Weight was documented in 19% (n=41). 13% (n=27) were asked about weight change of whom 95% (n=25) reported weight loss. Weight loss was quantified in 8 cases. The word "cachexia" was noted in 47 admissions. 23% (n=49) were discharged home.

**Conclusions:** Nutritional assessment was neither comprehensive nor routine despite a high prevalence of abnormalities consistent with cachexia. Anorexia was common. Weight evaluation was infrequent. Symptom burden was high and inflammatory markers elevated. Almost one quarter of patients were discharged and might have benefited from intervention. Screening tools and education are

needed to prompt recognition and appropriate management of cancer cachexia in the palliative care setting.

No funding was received for this study.

**Abstract number:** P19

**Abstract type:** Poster

### **The Effectiveness of Complex Decongestive Physiotherapy for Lymphoedema in Advanced Cancer Patients**

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**Background:** Complex Decongestive Physiotherapy (CDP) is a regime of physical treatments for lymphoedema. Its effectiveness for advanced cancer patients has not been proven.

**Aim:** To evaluate the effectiveness of CDP in advanced cancer patients.

**Methods:** Prospective observational cohort study over 18 months of advanced cancer patients with lymphoedema, who received 3 or more CDP treatments.

**Method:** Limb measurements were taken before the first treatment (T1,) and then before treatments 3 (T3) and 6 (T6) as follows: Limb volume using circumferential measurements, quality of life (QOL) using 2 adapted questions, and skin quality using a locally developed 4-point scale (1 score=1/4 surface area of limb). This measured abnormalities in each domain of colour, thickness and texture. Data was collected by the treating physiotherapists and analysed using Microsoft Excel.

**Results:** 12 patients (2 male and 10 female), with an age range of 42-73 (median 69.5) were included. One patient had arm oedema, the remainder had leg oedema. Survival (days from last treatment to death) ranged from 3-262 days (median 40).

At T3 (n=12, 20 limbs), average reduction in limb volume was 6.3% (range -9.4 to +15.3%). There was reduction in abnormal skin thickness (average 1.2 points) and texture (average 0.85 point). At T12

(n=7, 12 limbs) average reduction in volume was 9.3% (range -9.2 to +18.9%). There was reduction in abnormal skin thickness (average 2.1 points) and texture (average 1.6 points). QOL changes included improvements in function, limb appearance and patient comfort. Improvements in QOL and skin quality occurred regardless of changes in volume.

**Conclusion:** For the first time, this study shows that CDP treatments can be effective for a cohort of palliative care patients. Improvement in limb volume, skin quality and QOL were recorded. Larger studies using valid skin and QOL measures are required for this patient population.

**Abstract number:** P20

**Abstract type:** Poster

### **The Process of Developing an Operational Definition of the Wish to Hasten Death**

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**Background:** One of the feelings occasionally experienced by some patients with advanced illness is the desire to die. The lack of common terminology regarding this wish to hasten death (WTHD) hampers our understanding of this phenomenon and advances in clinical research.

**Aim:** To reach a common conceptualization and develop an internationally agreed operational definition of the WTHD.

**Methods:** The process involved three phases:

- 1 literature review and discussion within the Steering Group who coordinated the whole process,
- 2 a modified nominal group process with 17 European experts and
- 3 a modified Delphi process involving 24 experts from 19 institutions from Europe, Canada and the USA.

**Results:** All 24 experts completed the three rounds of the Delphi. The statements finally included in the definition had a consensus that ranged between 79% and 96%. The final definition of the WTHD and its Related Factors was:

*The WTHD is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon.*

*The WTHD may arise in response to one or more factors, including physical symptoms (either present or foreseen), psychological distress (e.g. depression, hopelessness, fears, etc.), existential suffering (e.g. loss of meaning in life), or social aspects (e.g. feeling that one is a burden).*

**Interpretation:** The methodology used allowed us to deepen the conceptualization of the WTHD and reach a sufficient agreement in terminology. The proposed operational definition should facilitate the sharing of knowledge among clinicians and researchers thereby fostering improved understanding of the WTHD and the development of strategies for early therapeutic intervention.

**Funding:** Instituto de Salud Carlos III; AECC.

**Abstract number:** P21

**Abstract type:** Poster

**A Clinical Study on the Hope of Rehabilitation for Advanced Cancer Patients in Palliative Care Setting whose Performance Status was 3-4**

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**Aim:** The goal of rehabilitation for advanced cancer patients is to improve their ADL and QOL. There were several studies on the hope of rehabilitation for these patients.

However, there was not any study for advanced cancer patients in palliative care setting whose performance status (PS) was 3-4. This study aimed to examine the hope of rehabilitation for these patients.

**Method:** This was a retrospective chart review.

Subjects were 66 consecutive patients (PS3: 44, PS4: 22, male 43, median age 78.5; range 46-93) who admitted to the general wards and palliative care unit of our hospital and then were consulted to occupational therapist (OT) for the last 1 year.

OT asked these patients what were their hope for rehabilitation at the early session. We examined the ratio of the patients who expressed their hope and the contents of hope.

**Result:** Forty-nine patients (PS3: 35, PS4: 14) expressed their hope at the early session, and contents of their hope were to improve/maintain ADL and to palliate physical symptoms (fatigue, dyspnea, edema, etc.).

Among 17 patients who did not express their hope at the early session, two of them did not want to continue the rehabilitation. The other 15 patients wished to continue the rehabilitation, and they accepted passive exercise and massage for relieving physical distress offered by OT. Five of 15 patients expressed their hope such as to discharge the hospital and to spend their lives at home, to go outside a hospital room, etc. afterwards.

**Conclusion:** In this study, 26% of patients didn't express their hope at early session, but finally, 97% hoped to continue the rehabilitation by an offer of the rehabilitation program for relieving pain and distress. During this process, it could enable the patients who didn't express their hope at early session to express new hope, and it may lead to high quality of palliative care.

The author received no financial support.

**Abstract number:** P22

**Abstract type:** Poster

**Comparison of Thirst-alleviating Interventions in a Human Surrogat Model of Xerostomia**

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**Background:** Xerostomia of dying patients is often linked to the burdening experience of thirst and a concurrent decrease in quality of life. Nevertheless, there is no significant evidence supporting the effectiveness of mouth care compared to infusion therapy for relieving thirst in palliative patients so far. As research in dying patients is an ethical challenge this study focuses on thirsty healthy subjects as a human surrogate model.

**Method:** In a randomised controlled cross-over trial 16 healthy subjects received combinations of mouth care (spraying chilled (7° Celsius) water intraoral) or sham mouth care (wetting lips with water at room-temperature) in 30 minute intervals and either 500ml (intervention) or 50ml (sham infusion) of sodium chloride 0.9% intravenous over four hours at four investigations. Each subject had a 12h interval of restricted fluid intake before and was requested to perform oral breathing during the test. Assessment of the interventions' effects on thirst was carried using a 0-100 numerical rating scale. Data were analysed using repeated measurement ANOVA.

**Results:** There have been no effects from intravenous sodium chloride on the sensation of thirst in healthy participants irrespective of the applied volume per hour. In subjects with baseline thirst > 40/100 NRS a decrease in thirst due to intraoral mouth care >20% was found.

**Conclusion:** Spraying chilled water intraorally can alleviate the sensation of thirst rather than infusion therapy. Extrapolated to the situation of dying patients with thirst, this finding points to the important role of nursing offering effective mouth care.

**Abstract number:** P23

**Abstract type:** Poster

**Are Symptoms Bothersome - Do We Really Ask the Right Questions? Graphical Display of Patient Nominated Symptoms, their Bother Factor and Interference on Individual Quality of Life Can Significantly Improve these Same Outcome Measures over Time**

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**Background:** Patients receiving chemotherapy for advanced cancer are frequently examined by the clinician. We hypothesised that some symptoms may bother the patient but may not be appreciated as bothersome to the clinician. The aim of this study was to measure the impact of symptom bother/interference on quality of life (QoL) and evaluate the impact of sharing that information with the clinician.

**Methods:** A randomised controlled trial of 65 patients receiving chemotherapy for advanced cancer was conducted to measure differences in symptom bother/interference on QoL over 4 time-points using the Schedule for the Evaluation of Quality of Life (SEIQoL) Direct Weighting (DW). Patients self nominated symptoms along with the impact of symptom interference on their subjective QoL was reported to the clinical team in a colourful visual info-graph format (intervention group) and was compared to patients whose symptom information was not reported (controls). The primary objective was to compare differences in symptom bother on QoL between groups over time.

**Results:** A significant number of patients experienced symptom bother ( $P=0.000$ ). The most frequently nominated symptoms were fatigue (40%) pain (29%) shortness of breath (19%) and weakness (16%). Findings demonstrated a highly significant difference in symptom interference between groups ( $P=0.000$ ). Symptom interference experienced by the control group increased by 38% from baseline to time point 4 whereas that reported by the patients in the intervention group decreased by 10% over time.

**Interpretation:** Increased awareness of patient's perception of symptom bother and symptom interference with quality of life by the clinician can significantly decrease symptom burden on QoL over time. Presenting patient's views on a graph accessible to the multidisciplinary team may improve the outcome of symptoms, their bother as well as interference on their subjective QoL.

**Abstract number:** P24

**Abstract type:** Poster

### Use of Dexmedetomidine Continuous Subcutaneous Infusion (CSCI) in a Palliative Care Service in Ireland

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**Background:** Dexmedetomidine, a pure  $\alpha_2$  adrenergic agonist, is licensed in Europe since 2011 for sedation and analgesia. It allows "conscious sedation", attenuates hypertension and tachycardia. The hypnotic action is similar to normal sleep with facilitated arousal. It causes no respiratory depression. It blocks the "sympathetic storm" arising in stressful situations.

**Aims:** The aim of this study is to assess whether continuous subcutaneous infusion (CSCI) of Dexmedetomidine could be safely and effectively used to support patients in a Palliative Care Inpatient setting.

**Methods:** Noted were:

- Diagnosis at referral
- Underlying diseases
- Preexisting anxiolytic, antidepressive, antipsychotic, analgesic medication
- Other current medication
- Follow up
- Outcome

Special attention was given to the skin site.

**Results:** 12 patients were treated up to 26 days aged 49 to 86 years. The main indications for dexmedetomidine were cooperative sedation: 11, arterial hypertension: 2, withdrawal symptoms: 2 patients. The underlying diseases were a malignancy in 6, addiction in 4, COPD in 4, intracerebral bleed in 2 patients. High levels of anxiety were prominent in 6 patients. Depression and delirium were observed in 2 patients each. One patient was extremely angry.

Dexmedetomidine doses varied between 0.1 to 0.9  $\mu\text{g}/\text{kg}$  per h. 9 patients died. 3 patients could be weaned of dexmedetomidine where the indications were addiction in 2 patients, delirium in one patient. In 2 patients CSCI had to be stopped after 3 hours because of hypotension. In 2 patients the antihypertensive medications had to be adjusted.

The subcutaneous access was well tolerated without any local irritation.

**Conclusion:** Dexmedetomidine induced an excellent level of reduced anxiety with improved ability for patients to communicate. This helped to spend meaningful time with family. It is effective treating malignant arterial hypertension. The limitation of its use are patients having or developing hypotension and bradycardia.

**Abstract number:** P25

**Abstract type:** Poster

### Shortcomings in Medical Care of Patients with Refractory Breathlessness in Germany

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**Background:** Refractory breathlessness is a disabling symptom in advanced diseases. Comprehensive care is based on pharmacological and non-pharmacological interventions provided by multidisciplinary experts to support patients as well as carers. In Germany, little is known about the medical care of patients with refractory breathlessness due to advanced disease.

**Aims:** To explore patients' experiences with care provision for refractory breathlessness in the German health care system and identify shortcomings.

**Methods:** Semi-structured qualitative interviews were conducted with patients, carers and professionals coming from respiratory medicine, cardiology, oncology and palliative medicine. Topics were interviewees' experiences in the management of breathlessness and their views on the idea of a breathlessness service. Interviews were transcribed and analysed using Qualitative Content Analysis developed by Schreier.

**Results:** 10 patients (3 chronic obstructive pulmonary disease (COPD), 3 cancer, 2 pulmonary fibrosis, 2 chronic heart failure (CHF)), 3 carers (COPD, cancer, CHF) and 10 professionals (7 respiratory and other specialists, 2 therapists and 1 social worker) were interviewed. Patients' main themes were lack of information, reduced access to health care practitioners due to immobility, unclear responsibilities for breathlessness and unmet psychological needs. Carers felt unable to cope with their spouses' breathlessness. Professionals noted insufficient treatment concepts and limitations of treatment due to characteristics of the German health care system.

**Conclusions:** The medical care of patients with refractory breathlessness in Germany shows significant shortcomings. To improve health care, multidisciplinary concepts should be tested, similar to breathlessness services in the UK. Focus should be on education of patients, support for carers and the implementation of sustainable therapy concepts for refractory breathlessness.

**Abstract number:** P26

**Abstract type:** Poster

### Which Symptoms Are Problematic in Hospitalised Older Adults with Palliative Care Needs? A Cross-sectional Study in the UK

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**Background:** The UK is experiencing unprecedented population ageing with more people suffering multi-morbidity and complex symptom burden, and requiring hospital care. A better understanding of the symptom burden of hospitalised older adults with palliative needs, and their families is required, to identify areas for improvement in care.

**Aims:** To explore the symptom burden of older adults ( $\geq 65$  years) accessing specialist palliative care in hospital, and their families.

**Methods:** Two surveys were completed in the UK during 2012-2014: a face-to-face survey of older adults ( $\geq 65$  years) accessing specialist palliative care in hospital, and a mortality follow-back survey of bereaved carers of older adults ( $\geq 65$  years) who had accessed specialist palliative care in hospital, administered 4-10 months post-death. Symptom burden including quality of care was assessed using the Palliative care Outcome Scale (POS). Descriptive analyses explored severity of symptoms and problems (0=absence; 1-2=moderate; 3-4=severe). Bivariate analyses explored associations between symptom burden and gender and diagnosis.

**Results:** Elevated pain (43% severe) and family anxiety (57% severe) were found among patients ( $n=70$ ). Among bereaved carers ( $n=134$ ), the worst problems were sharing feelings (46% severe) and family anxiety (83% severe). The majority of patients and carers reported no problems with quality of care (information needs, time wasted, and practical matters). Male patients reported worse pain, anxiety, and time wasted ( $p < .05$ ). No differences were found between cancer and non-cancer patients.

**Conclusions:** Substantial family anxiety was reported by patients and carers, regardless of diagnosis. Routine assessment of family anxiety and provision of psychological support in palliative care is needed. Longitudinal research is required to assess symptoms over time.

**Funders:** The Atlantic Philanthropies, Cicely Saunders International, CLAHRC.

**Abstract number:** P27

**Abstract type:** Poster

### Oral Nutritional Supplements: Dietitian Preferences, Acceptability and Prescribing Practices

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**Introduction:** Malnutrition in cancer is a poor prognostic indicator with poor patient outcomes and diminished tolerance of anti-cancer therapy. Oral Nutritional Supplements (ONS) enhance nutritional intake for those at risk of malnutrition. Success depends on patient compliance, palatability and gastro-intestinal tolerance. ONS selection is typically a dietitian-led activity. Factors that influence dietitians ONS prescribing practice are poorly understood.

This study aimed to

- examine dietitian taste preferences and global acceptability of 3 ONS products
- explore if perceived palatability influences prescribing practices
- study phenylthiocarbamide (PTC) sensitivity in relation to ONS taste preferences

**Methods:** Ethical approval obtained from local committee. General clinical practice dietitians in hospital recruited and completed the following

- Prescribing Practice Questionnaire
- Randomly Assigned Taste Tests (5) of 3 ONS products
- Low Volume Milkshake: 125ml/300kcal/12g protein
- Protein Rich Milkshake: 200ml/300kcal/20g protein
- Dessert: 125g/225kcal/12.5g protein
- ONS Taste Questionnaire recorded in the following order; smell, texture, taste, aftertaste, appearance and global impression of each product sample
- A PTC taste strip test applied to tongue

Descriptive statistics and correlation tests were conducted.

**Results:** 16 dietitians completed the study to date. Products were highly rated for taste: 85% liked the low volume milkshake, 80% dessert and 73% the protein rich milkshake. Overall acceptability was 80%. Preferences were flavour dependent. Factors most likely to influence prescribing practice were nutritional value, acceptability, palatability, tolerance and cost.

**Conclusions:**

1. Product palatability and overall acceptability high among dietitians
2. Low-volume, nutrient-dense milkshake rated highest followed by dessert style product
3. ONS are an acceptable and palatable way to assist nutrition
4. Flavour variety important in choice

**Abstract number:** P28

**Abstract type:** Poster

**Nutritional Status of Cancer Patients at Time of Dietitian Referral**

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**Background:** Malnutrition and cachexia are associated with poor prognosis, reduced tolerance of cancer treatment and worse quality of life. Furthermore, malnutrition is associated with increased healthcare costs; early intervention may result in significant savings. There is increased emphasis on the early recognition of people at risk of malnutrition and in the pre-cachexia stage.

**Aims:** Provide a snapshot of current practice and describe:

1. The nutritional status of people with cancer at point of dietitian referral
2. The prevalence of clinically identifiable stages of cancer cachexia (pre-cachexia, cachexia and refractory cachexia), based on the 2011 consensus (Fearon et al)
3. Professional opinion on adequacy of referral timing.

**Methods:** This is a prospective evaluation of current practice. Data is recorded from consecutive cancer referrals to dietitian services in 5 Irish teaching hospitals. Demographic details, nutritional status, barriers to nutrition and timing of referral are noted. The dietitian categorises each patient by stage of cachexia, based on available information, or records which information was missing.

**Results:** Interim results for the first 100 patients are presented. 58% were male and 62% inpatients. Median Body Mass Index (BMI) was 23 kg/m<sup>2</sup> (range 15.6 - 39.5). Two-thirds had lost > 5% of body weight prior to referral. Median number of barriers to nutrition was 2 (range 0-5). 20% were thought to be pre-cachectic, 44% cachectic and 12% refractory. In 55% of cases, it was felt that the person should have been referred sooner.

**Conclusions:** Interim results demonstrate that most people with cancer referred to a hospital dietitian already have significant weight loss, with multiple barriers to nutrition, and are often cachectic. The majority are deemed to be referred too late. The results of this study will inform service planning, education and future research in malnutrition and cancer cachexia in Ireland.

No funding was received.

**Abstract number:** P29

**Abstract type:** Poster

**Medicinal Cannabis Use and Preferred Mode of Administration: Preliminary Results from an Anonymous Patient Survey to Inform Medicinal Cannabis Phase II and III Trials for Cancer-related Anorexia-cachexia**

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**Background/aims:** In Australia the NSW Ministry of Health, is funding phase II and III medicinal cannabis trials. A survey seeking patients' medicinal cannabis preferences for mode of administration, previous and current use, and attitudes and beliefs towards a cancer-related medicinal cannabis anorexia-cachexia trial is being undertaken.

**Study population:** Advanced cancer patients, aged  $\geq 18$  years, with poor appetite, taste problems or weight loss, and who might consider participating in a medicinal cannabis trial are eligible to participate.

**Methods:** A cross-sectional anonymous patient survey. Administered online and in the waiting rooms of participating adult outpatient oncology and palliative care services. Responses summarized descriptively via frequencies.

**Preliminary results:** Responses from 109 participants have been analysed. Half (50%) of the participants are male, with over a third (36%) aged between 41-60 years. While, cannabis tablets (67%) are the preferred mode of administration many participants indicated willingness to use medicinal cannabis via more than one administration route. The most common reasons shaping preferred route of administration were: perceived convenience, familiarity, quicker effect, lower intrusiveness, more precise dosing and fewer side effects. Very few participants were worried about adverse effects (5%) or legal issues (2%), and only a small proportion indicated a need for further information (4%). A small number of participants had used medicinal cannabis (n=15) as a way of managing their: pain (n=5), psychological problems (n=4), appetite loss (n=3) or insomnia (n=3). Two users indicated that they would not participate in a trial if required to stop their usual cannabis use. Two participants believed that cannabis might cure cancer.

**Conclusions:** Comments confirmed strong support for trials of medicinal cannabis and included anecdotal reports of efficacy and perceptions that current evidence is sufficient.

**Abstract number:** P30

**Abstract type:** Poster

**Effectiveness of Gabapentinoids for Treatment of Pruritus in Patients with End Stage Renal Failure. A Systematic Review .**

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**Background:** Uremic pruritus (UP) is a prevalent symptom in patients with end stage renal failure, affecting patients' quality of life and associated with a higher mortality. The pathophysiology is poorly understood, but itch may share some pathways with neuropathic pain. The anti-convulsants gabapentin and pregabalin, widely used for the treatment of neuropathic symptoms, may have a potential role managing UP.

**Aim:** To assess the effectiveness of gabapentinoids (gabapentin, pregabalin) for itch in patients with end stage renal failure.

**Methods:** A systematic literature review to April 1<sup>st</sup> 2015 was performed, using standard methods. The databases CENTRAL, MEDLINE, EMBASE, and CINAHL were searched. Randomized controlled and quasi-experimental trials, studies with a before-after design, and observational studies in English language assessing the effectiveness of gabapentinoids on treating UP were included. The National Collaborating Centre for Methods and Tools (NCCMT) quality assessment tool was used to assess the methodological quality of the selected papers.

**Results:** Of 83 screened references, ten studies were included. Five assessed gabapentin, three evaluated pregabalin, and two studies involved both drugs. All studies were small with methodological limitations. Most studies found that in patients with UP refractory to other therapies, gabapentin reduced mean visual analogue scale UP score significantly ( $p$  values  $< 0.05$ ). Similar results for pregabalin were seen. Both drugs had side effects, primarily somnolence, dizziness, and fatigue, often leading to discontinuation of treatment.

**Conclusions:** This review confirm a role for gabapentinoids in the treatment of refractory UP. However, due to small sample sizes and study limitations, the results must be cautiously interpreted. Initial low drug doses are necessary, with a cautious dosage titration. Well designed larger controlled trials of gabapentinoids for itch in this patient group are warranted.

**Abstract number:** P31

**Abstract type:** Poster

### Muscle Wasting and Relation to Physical Function and Quality of Life (QoL) in Advanced Non Small Cell Lung Cancer (NSCLC)

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**Background:** Cancer cachexia, linked to loss of weight and depletion of skeletal muscle, is frequent in NSCLC. Former studies have shown that weight-losing NSCLC patients report poorer QoL than their weight-stable counterparts. The relationship between muscle depletion and QoL in NSCLC is not previously reported. The aim was to analyse the association between muscle mass and QoL outcomes especially those related to physical function, at diagnosis.

**Methods:** Patients with NSCLC enrolled in three Norwegian randomised trials of first-line chemotherapy ( $n=1305$ ), stage IIIB/IV disease and performance status 0-2 were included. Muscle mass was assessed at the third lumbar (L3) level using Computer Tomography (CT) scans obtained before start of treatment, and quantified as skeletal muscle index (SMI) ( $\text{cm}^2/\text{height-m}^2$ ). QoL was assessed by the EORTC QLQ-C30. Associations between SMI and Physical and Role function (PF/RF) and Global QoL were investigated in men and women separately by linear regression using flexible non-linear modelling.

**Results:** Complete data were available for 734 patients, mean age 65 years. Mean SMI was  $47.7 \text{ cm}^2/\text{m}^2$  (SD 7.6) in men ( $n=420$ ),  $39.6 \text{ cm}^2/\text{m}^2$  (SD 5.7) in women ( $n=314$ ). Significant non linear associations were found between SMI and physical function (PF) (non-linearity: men  $p=0.016$ , women  $p=0.004$ ) and role function (RF) (men  $p=0.020$ , women  $p=0.012$ ) i.e below a turning point of about  $43 \text{ cm}^2/\text{m}^2$  for men and  $37 \text{ cm}^2/\text{m}^2$  for women, lower SMI was related to lower PF and RF. For global QoL a similar significant non-linear association to SMI was found for men ( $p=0.001$ ), but not for women ( $p=0.150$ ).

**Conclusion:** Pronounced loss of skeletal muscle in patients with NSCLC seems to negatively affect functional status and global QoL, but only when muscle mass falls below threshold values close to those formerly observed in association with survival in cancer patients (1).

### Reference

(1) Martin, L. et al. (2013). *J Clin Oncol*, 31(12), 1539-1547.

**Abstract number:** P32

**Abstract type:** Poster

### Pilot Study of Subjective Taste and Smell Changes in Treatment-naive Patients with Solid Tumours

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**Background:** Taste and smell changes (TSCs) are common in head and neck (H&N) cancer and during or after chemotherapy (CT) or radiotherapy (RT). It is an area that has been under-investigated, particularly in the treatment-naïve. TSCs may present as part of a symptom cluster, with anorexia, dry mouth, early satiety and fatigue, which can negatively impact nutritional status.

**Aim:** To examine the prevalence, severity and characteristics of TSCs in non-H&N solid tumours, before CT or RT, and their relationship with concurrent symptoms.

**Methods:** A prospective observational study was conducted. Forty consecutive, treatment-naïve, non-H&N cancer patients were recruited over a 6 week period at a Radiation Oncology outpatient clinic. Data on TSCs, symptoms, dietary intake and nutritional status were collated using the 'Taste and Smell Survey' and the 'abridged Patient-Generated Subjective Global Assessment' (abPG-SGA). Body mass index was measured. SPSS® was used for statistical analysis; two-sided P values < 0.05 were statistically significant.

**Results:** Most were newly diagnosed (n=28, 70%). 19 (48%) reported TSCs. 9 noted stronger sweet and 7 stronger salt taste. Of those, 4 reported stronger and 4 weaker smell sensation. Those deemed at nutritional risk by the abPG-SGA tended to have more TSCs (P=0.057). TSCs were significantly associated with dry mouth (P< 0.01), early satiety (P< 0.05) and fatigue (P< 0.05).

**Discussion:** TSCs preceded treatment in almost half of the study population, notably with stronger sweet and salt tastes; most of these were at nutritional risk. These changes may be tumour-induced. TSCs were significantly associated with other symptoms and may be part of a symptom cluster.

**Conclusion:** TSCs are a frequent, poorly addressed problem in the treatment-naïve cancer population. Further research and clinical guidelines for the assessment, diagnosis and management of TSCs in cancer are needed.

**Abstract number:** P33

**Abstract type:** Poster

### Effectiveness of Exercise Interventions for the Management of Sarcopenia in Patients with Advanced Solid Tumors: A Systematic Review

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**Background:** Sarcopenia (loss of muscle mass and physical function) is common in patients with advanced solid cancers, with prevalence estimates 28-67%. It limits prognosis, treatment response and quality of life (QoL), but limited evidence exists on best treatment approaches.

**Aim:** To explore the effectiveness of exercise programs to counteract sarcopenia in adults with advanced solid tumours.

**Methods:** We searched 3 databases (Medline, Embase and Cochrane Library, April 2015) and conference proceedings of the Multinational Association of Supportive Care in Cancer (2010-2014). Outcomes of interest were sarcopenia, survival, disease progression, fatigue and QoL. We assessed risk of bias of randomised controlled trials (RCTs) using the Cochrane Collaboration's tool and classified studies as low, high or unclear risk. Results were analysed using descriptive and narrative data synthesis.

**Results:** We identified 4 studies: 2 RCTs with a usual care control arm and 2 observational

(403 patients). Three studies (376 patients) used combined resistance and aerobic training and one study (27 patients) used resistance training alone. Compliance, safety, muscle function, fatigue and QoL were reported in all 4 studies whereas lean body mass was reported in 2 studies. The exercise interventions had no adverse events and high completion rates (63%-94%). All studies identified benefit relating to the assessed components of sarcopenia, and two showed improvements on fatigue and QoL. However, both RCTs were classified as high risk of bias.

**Conclusion:** Despite the emergent data with positive findings, robust RCTs are needed to support the use of exercise for sarcopenia in advanced cancer in clinical practice.

**Abstract number:** P34

**Abstract type:** Poster

### Clinical Outcomes after Infection among Outpatients with Advanced Cancer

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Useful data to guide antimicrobial use among outpatients with advanced cancer (OAC) are limited. The benefit of anti-infective treatment on clinical outcomes other than survival was barely addressed.

**Objectives:** To determine the impact of infection and its management on the 14-day survival of OAC. Changes in functional status and inflammation markers (modified Glasgow prognostic score - mGPS) in survivors are evaluated.

**Methods:** Prospective cohort; all OAC referred to a hospital-based palliative care service over a 24-month period; demographics, clinical condition [primary cancer, ongoing treatment, Charlson index (CI), Palliative Performance Scale (PPS), steroid use, admission proposal], lab results (C-reactive protein, serum albumin) at visit 1, by the time of the 1st infective episode (sepsis or organ-related) and thereafter, as well as anti-infective use were recorded; survival was calculated from the point of infection diagnosis (infected group, IG) or from the initial PC consult (non-infected group, NIG). Multivariate regression explored predictors of the 14-day survival.

**Results:** Of the 457 OAC (52% female, median 70 years old, 44% gastrointestinal tumours, median PPS 50%, median survival 73 days) 70% had a confirmed/suspected infection (14% sepsis). An anti-microbial was used in 67%. Eighty-two percent of IG (60% with sepsis, 87% with organ-related) vs 90.4% non-infected were alive 14-days after ( $p=0.017$ ). PPS was the only independent predictor of 14-day survival in NIG. Low PPS, steroid use, sepsis, no active cancer treatment and admission refusal were poor survival predictors in the IG. Elevation in the mGPS score was more common in survivors previously infected (14%

vs 10.5%,  $p=0.046$ ). No relation was found between recent infection and a lower PPS score afterwards.

**Conclusion:** Infection but not the use of anti-microbials affected the short-term survival in our cohort. The prognostic value of mGPS changes after infection resolution should be clarified.

## Assessment and measurement tools

**Abstract number:** P36

**Abstract type:** Poster

### Adaptation and Reliability of a Needs Assessment Tool for Progressive Disease - Cancer (NAT:PD-C) in Primary Care

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**Research aims:** Australian NAT: PD-C is a tool to help clinicians (oncology, palliative, general practitioners [GPs]) identify and triage palliative care needs of cancer patients and carers. Use has been shown to reduce unmet needs. We aimed to adapt it for use in UK primary care and test reliability and face validity.

**Table 1.**

Needs Domain		Number of Observations	No Concern (%)	Some Concern (%)	Significant Concern (%)	Weighted Kappa
<i>Patient wellbeing</i>	Physical symptoms	100	7.0	52.0	41.0	0.34
<i>Patient wellbeing</i>	Activities of daily living	99	22.2	45.5	32.3	0.49
<i>Patient wellbeing</i>	Psychological symptoms	98	42.9	43.9	13.3	0.47
<i>Patient wellbeing</i>	Spiritual/existential issues	94	71.3	22.3	6.4	0.43
<i>Patient wellbeing</i>	Cultural/social issues	91	68.1	28.6	3.3	0.22
<i>Ability of carer to care for patient</i>	Distress about patient's symptoms	90	43.3	33.3	23.3	0.34
<i>Ability of carer to care for patient</i>	Difficulty providing physical care	88	62.5	28.4	9.1	0.32
<i>Ability of carer to care for patient</i>	Difficulty coping	87	50.6	36.8	12.6	0.48
<i>Ability of carer to care for patient</i>	Family problems	84	69.1	21.4	9.5	0.30

**Study design and methods:** We adapted the tool using literature. An expert group (clinicians; patients; carers) assessed face validity. Inter-rater reliability was tested:

- 1) video-recorded 9 consultations of GPs using the tool to assess cancer patients (+/- a carer);
- 2) each video rated using the tool by different GPs and nurses.

A simulation exercise estimated a sample size of 100 ratings to give 80% power to detect moderate agreement. Method of statistical analysis: quadratic Kappa weights, (to give more weight to disagreements of two categories) were used to assess agreement for each tool domain using Cohen's values of substantial (0.61 - 0.8); moderate (0.41 - 0.6); fair (0.21 - 0.4); poor agreement (< 0.21).

**Results and interpretation:** The expert group confirmed face validity of the adapted tool. 42 GPs (with various experience) and 6 nurses provided 11-12 different ratings for each video to give 101 ratings. Kappa scores indicated fair to moderate agreement for most (9 out of 13) palliative care concerns (Table 1). The adapted tool has face validity and despite variable clinician experience, has useful reliability. Further validation is ongoing.

**Abstract number:** P37

**Abstract type:** Poster

### Establishing Cut-off Points for Defining Symptom Severity Using the Edmonton Symptom Assessment System-Revised Japanese Version

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**Background:** Screening symptoms is important for appropriate symptom management. It remains uncertain which

scores on the Edmonton Symptom Assessment System-Revised (ESAS-r) comprise the optimal cut-off points to determine symptom severity for Japanese cancer patients.

**Objectives:** To investigate optimal cut-off points for individual ESAS-r items for detecting symptom severity and evaluate the screening performance of the ESAS-r depression item, in Japanese cancer patients.

**Methods:** We recruited palliative care cancer patients from five tertiary acute hospitals in Japan. We asked participants to complete the ESAS-r Japanese version, Verbal Rating Symptom Severity Scale (VRS), and Quick Inventory of Depressive Symptomatology-Self-Report (QIDS-SR) Japanese version. We calculated sensitivity and specificity for detecting severe and moderate/severe symptoms evaluated by VRS at different cut-off points of ESAS-r. We also calculated sensitivity and specificity for detecting both the presence of depression and moderate/severe depression evaluated by QIDS-SR at various cut-off points of depression item of the ESAS-r Japanese version.

**Results:** 292 participants completed the questionnaire. For most of ESAS-r symptoms, cut-off points to achieve the best balance between sensitivity and specificity were 5-7 for determining severe intensity, and 3-4 for determining moderate/severe intensity. For the ESAS-r depression item, a cut-off points of 2 achieved the best balance between sensitivity and specificity for detecting both presence of depression and moderate/severe depression.

**Conclusions:** The ESAS-r Japanese version can accurately represent the severity of many symptoms. The cut-off points established for determining the level of symptom severity using ESAS-r provides a guide for symptom management in Japanese cancer patients.

**Abstract number:** P38

**Abstract type:** Poster

### Validation of the Edmonton Symptom Assessment System (ESAS) and ESAS-r in an Ambulatory Palliative Care Clinic

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**Background:** The Edmonton Symptom Assessment System (ESAS) numeric rating scale (NRS) is used widely in oncology palliative care, but has only been validated as a visual analogue scale in a general oncology outpatient setting. We aimed to validate the NRS for ESAS and a revised version, ESAS-r, in an ambulatory palliative care setting, and to assess patient preference for either format.

**Methods:** Outpatients with advanced cancer (N=252) completed three assessments during a single clinic visit: ESAS, with an added time window of "past 24 hours";

ESAS-r, with a “now” time window and symptom definitions; and the Memorial Symptom Assessment Scale (MSAS). Internal consistency was calculated using Cronbach’s alpha. Paired t-tests compared ESAS and ESAS-r scores; these were correlated with MSAS using Spearman correlation coefficients. Test-retest reliability was assessed in 50 patients at 24 hours using intraclass correlation coefficients (ICC).

**Results:** Cronbach’s alpha was 0.83 for ESAS; 0.86 for ESAS-r. ESAS and ESAS-r overall scores correlated well with total MSAS (Spearman’s rho 0.64 and 0.65, respectively). Correlation of individual symptoms with MSAS ranged from 0.45-0.81 (ESAS) and 0.46-0.77 (ESAS-r). Nausea correlated better for the ESAS than for the ESAS-r (0.71 vs. 0.60); pain and shortness of breath showed strong correlation with both versions (ESAS: 0.71 & 0.81, respectively; ESAS-r: 0.66 & 0.74). Participants preferred the symptom definitions for the ESAS-r (86.4% versus 13.6%), but the “past 24 hours” time window (55.5%) was favoured over “now” (20.2%). The 24-hour test-retest showed strong reliability (ICC=0.84 for ESAS, 0.87 for ESAS-r).

**Conclusions:** Both ESAS and ESAS-r NRS are valid and reliable tools for outpatients with advanced cancer. Strong correlations with MSAS were seen in both versions for pain and shortness of breath, symptoms which are commonly assessed by numerical rating scales. Use of a wider time window may better capture fluctuating symptoms.

**Abstract number:** P39

**Abstract type:** Poster

### **Predicting the Survival of Egyptian Patients with Incurable Gastrointestinal Malignancies Using the Chuang’s Prognostic Score**

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**Background and aim:** Prediction of survival of incurable cancer patients has many applications to improve end-of-life care for this group of patients. Cancer patients present usually in an advanced cancer stage in limited-resources countries including Egypt. Finding simple reliable tools to predict survival in these countries is important. The Chuang’s Prognostic Score (CPS) was developed to predict the survival of terminally-ill cancer patients. Our aim was to assess the usefulness of the CPS in predicting the

survival of Egyptian incurable gastrointestinal cancer patients.

**Methods:** The CPS was assessed prospectively in 117 patients with incurable gastrointestinal malignancies. The CPS score ranges from 0 to 8.5 and is based on eight items: ascites, edema, cognitive impairment, liver and lung metastases, the Eastern Cooperative Oncology Group performance status, tiredness and loss of weight during the last 3 months. The maximum CPS score (8.5) denotes worst prognosis. Survival of patients was calculated from the date of CPS assessment to the date of death or last contact.

**Results:** The median age of patients was 55 years (range: 24-77), 52% of them were females and 51% had colorectal cancer. The estimated median survival for the whole group was 120 days (95%CI: 82-159). Patients were divided using two CPS cutoff scores (3.5 and 6) into 3 groups: group 1 with a score  $\leq 3.5$  (52 patients), group 2 with a score  $> 3.5 - < 6$  (49 patients) and group 3 with a score  $\geq 6$  (16 patients). The estimated median survival for the three groups respectively was 166 days (95%CI: 122-210), 106 days (95%CI: 90-122) and 84 days (95%CI: 35-133). The difference in survival between the three groups was statistically significant ( $p=0.044$ ).

**Conclusions:** Although it was developed to predict short term survival, the CPS may be useful in predicting the survival of incurable cancer patients who are not eminently dying. The CPS may be helpful in decision making in Egyptian incurable cancer patients.

**Abstract number:** P40

**Abstract type:** Poster

### **The Use of the Integrated Palliative Care Outcome Scale (IPOS) as a Service Evaluation Tool**

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The Integrated Palliative Care Outcome Scale (IPOS) is a tool that has been validated globally in measuring patients’ physical as well as psychosocial needs. This tool is especially valuable in evaluating change in symptoms over time. The aim of our study was to use the questionnaire to evaluate impact of the services offered at our hospice, and also identify areas of care that should be developed further.

An intention to treat study was undertaken over a 6-month period including all patients admitted to the Marie Curie hospice, Glasgow. Participants were given the IPOS questionnaire to complete on first contact with the hospice, then 7 days later.

Of 164 patients whose information was collected 54% of patients completed at least one questionnaire. The results demonstrated an average of a 28% improvement in

physical symptom scores and a 25% improvement in psychosocial symptoms, on completion of the final questionnaire. The 12 patients with the highest anxiety scores were studied further. In their documentation 11 patients were recognised as being distressed, however only 7 acknowledged their distress with a member of the palliative care team, and only 5 to a doctor. Interestingly, the patients referred to the hospice with a non-cancer diagnosis had average physical and psychosocial symptom scores 13% and 21% higher respectively, than those with a cancer diagnosis.

The study demonstrates the positive impact of hospice care on multiple aspects of patients' lives. The questionnaire also demonstrated its utility in being used as a starting point for difficult discussion topics such as anxiety. The higher symptom scores of those with a non-cancer diagnosis could be due to multiple factors and this highlights the need for further investigation in this area.

**Abstract number:** P41

**Abstract type:** Poster

**Evaluating the Association between Phase of Illness and Resource Utilization; A Potential Model for Demonstrating Clinical Efficiency in Palliative Care? The Results of a Prospective Observational Cohort Study of Consecutive Admissions to a Specialist Palliative Care Unit in Ireland**

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**Background:** Technical efficiency in healthcare involves demonstrating clear and flexible inter-relationships between resource utilisation (capital or labour intensity) and patient need (*Torgerson D. BMJ 1999*). In Palliative Care, five phases of patient illness have been identified: stable, unstable, deteriorating, terminal and bereaved (Eager 2003). In a Specialist Palliative Care Unit (SPCU) research evaluating the association between phase of illness and intensity of nursing care could be used to demonstrate clinical efficiency.

**Aim:** The aim of this study was to evaluate the association between phase of illness and intensity of nursing care in a SPCU.

**Methods:** This was a prospective, observational cohort study of consecutive admissions (n=400) to a SPCU. Phase

of illness was documented by medical staff on admission and daily thereafter. A 'nursing dependency tool' was developed scoring direct daily nursing interventions (Physical, psychological and family care and symptom control). This score was called the nursing total scores (NTS) and reflects the intensity of nursing activities. Data was entered into SPSS and descriptive statistics generated.

**Results:** 342 (85%) of patients had full data recorded on admission. Stable, unstable, deteriorating and terminal phases were associated with progressively increasing median NTSs on days 1, 2, 3 and 4 (all  $p < 0.01$ ). Phase stabilization from the unstable to the stable phase during this timeframe resulted in reductions in Physical care ( $p=0.038$ ), Symptom management ( $p=0.007$ ), and near significant reductions in family support ( $p=0.06$ ).

**Conclusion:** In this study, a clear association was demonstrated between phase of illness and intensity of direct nursing activities and these activities were sensitive to phase stabilization from the unstable to the stable phase. This demonstrates technically efficient resource utilization in a SPCU and identifies a potential phase and NTS based efficiency model for inpatient palliative care.

**Abstract number:** P42

**Abstract type:** Poster

**Comparison of Indicators for Achievement of Pain Control with Personalized Pain Goal in a Comprehensive Cancer Center in Japan**

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**Background:** Indicators to quantify achievement of pain control is important for quality improvement; and pain intensity is one of the most frequently used indicators. However, the achievement of personalized pain goal (PPG) is recently being recognized as a potential indicator.

**Aims:** The objective of this study was to compare the indicators for pain control and additionally to analyze the characteristics of the PPG.

**Methods:** This was a single-center cross-sectional study. Cancer patients over 20 years of age who visited the outpatient clinic at the National Cancer Center Hospital East between March 2015 and September 2015 and had received opioid medications over two weeks were consec-

tively enrolled. The patients rated self-reported questionnaire. We analyzed the prevalence of pain using

- (1) the average pain intensity over the previous 24 hours (PI),
- (2) pain interference with daily activities (Interference),
- (3) the presence of breakthrough pain, and
- (4) the achievement of PPG, defined as a lower PI than the PPG.

We compared the PPG scores among patients with different backgrounds.

**Results:** We evaluated 347 (median age 64, female 38%) patients. The median PI was 2 (interquartile range [IQR] 1-4); the median interference, 2 (IQR 0-5); and the median PPG, 2 (IQR 1-3). The prevalence of achievement of pain control was 68.5% with PI < 4; 69.8% with Interference < 4; 45.5% with no breakthrough pain; and 45.2% with the achievement of PPG. The PPG values were significantly lower in patients with PI < 4, Interference < 4, and an underachievement of PPG (P < 0.001); patient demographics including age, gender, and primary tumor sites were not significantly associated.

**Conclusions:** The present study showed that the achievement of pain control varied depending on indicators adopted. The median PPG was 2, and the achievement of PPG was 45.2% among the enrolled patients in our comprehensive cancer center in Japan.

**Abstract number:** P43

**Abstract type:** Poster

### Systematic Symptom Assessment: Taking the ESAS to the PROM

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**Background:** Cancer patients experience a high symptom burden during their illness. Use of systematic, standardized patient-reported outcome measurement (PROM) tools like the Edmonton Symptom Assessment System (ESAS) may help to enhance symptom identification and control, stimulate discussion, and improve patient satisfaction.

**Aim:** Investigate the attitudes of clinicians toward standardized symptom assessment and the use of PROM tools, particularly to:

- Explore different providers' self-reported ESAS use;
- Understand barriers and facilitators; and
- Identify ways to improve the collection and management of PROMs.

**Methods:** Anonymous, self-administered electronic questionnaire toward clinicians in all of Ontario's Regional Cancer Centres (Canada).

**Results:** 960 eligible surveys were analyzed (response rate 36%), the majority from nurses (37%), physicians (27%), and radiation therapists (25%). 76% of respondents deemed standardized assessment "best practice" (range 66% for physicians to 93% for psychosocial oncology staff), 8% 'disagreed' or 'strongly disagreed'. 69% of respondents reported 'always' or 'often' looking at their patients' ESAS scores (lowest: radiation therapists (29%)). 60% of respondents 'always' or 'often' talk to their patients about the ESAS score, 52% 'always' or 'often' incorporate it into the care plan. Technology-related barriers (such as easy access to ESAS scores in clinic) ranked high, followed by time-related ones (e.g., adding time to busy clinics).

**Conclusion:** Despite high regard toward the usefulness of PROM tools and recognition as "best practice", there is a gap between self-reported utilization and inclusion into the care plan. Use of further, short PROMs that address individual needs, could supplement the ESAS within a person-centred approach to care, while routinely providing higher utility for clinicians and patients.

**Funding:** Support provided by the Ontario Cancer Symptom Management Collaborative, a Cancer Care Ontario program.

**Abstract number:** P44

**Abstract type:** Poster

### Using Existing Population-level Administrative Data to Identify Indicators of Appropriate and Inappropriate End-of-Life Care in Patients with Cancer, COPD or Alzheimer's Disease

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**Introduction:** Appropriate care at the end of life implies that expected health benefits of care exceed possible negative outcomes. Monitoring appropriate and inappropriate care at the end of life is an important public health challenge. To address this, we aimed to identify indicators of appropriate and inappropriate end-of-life care for people with cancer, COPD or Alzheimer's disease that can be measured using existing population-level administrative data.

**Methods:** Potential indicators for three disease groups were identified by literature review and clinical expert interviews, selecting on

- (1) measurability with Belgian health care and medication claims data,
- (2) validity and
- (3) reliability.

Potential indicators were assessed by expert survey scoring, using a modified RAND/UCLA appropriateness method. Indicators for which no consensus was reached in the survey were taken into group discussions. Indicators with consensus among the experts were retained for the final quality indicator set.

**Results:** We identified 14 indicators of appropriate and 17 indicators of inappropriate end-of-life care for patients with cancer, 10 indicators of appropriate and 22 of inappropriate end-of-life care for patients with COPD and 8 indicators of appropriate and 23 of inappropriate end-of-life care for patients with Alzheimer's disease. Indicators concerned 5 topics: aggressiveness of care, pain and other symptom treatment, specialized palliative care, place of dying and continuity of care.

**Conclusion:** A comprehensive set of disease-specific quality indicators for end-of-life care was identified that allows monitoring of the quality of end-of-life care in the full Belgian population for three clearly distinct disease groups. This set is relevant for several other countries that may have similar full-population administrative health claims data. A next phase could be to have international comparative sets of quality indicators for end-of-life care in cancer, COPD and Alzheimer.

**Abstract number:** P45

**Abstract type:** Poster

### Low Transthyretin Levels Predict Poor Prognosis in Cancer Patients in Palliative Care Settings

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**Objectives:** Low levels of transthyretin indicate malnutrition; these levels might be affected by inflammation, in particular in cancer patients in palliative care settings. The aim of this study was to investigate the correlation with low transthyretin levels and survival among cancer patients in palliative care settings.

**Methods:** This was a sub-analysis of a multicenter, prospective, cohort study. Patients who had advanced cancer and who were first referred to a palliative care service were eligible. Patients receiving anti-tumor therapy were excluded. Survival analyses were performed to elucidate predictors of poor prognosis.

**Results:** A total of 144 patients were enrolled in this analysis (45.1% female; median age, 72 years). Cox regression analysis revealed that low transthyretin levels (< 10.9 mg/L) (hazard ratio [HR] 1.64, 95% confidence interval [CI], 1.02 - 2.69;  $p = 0.043$ ), poor muscle power (HR, 1.87; 95%CI, 1.06 - 3.33;  $p = 0.032$ ), the present of liver metastasis (HR, 1.72; 95%CI, 1.03 - 2.88;  $p = 0.039$ ), and use of home-based palliative care (HR, 2.87; 95%CI, 1.14 - 7.56;  $p = 0.025$ ) were predictors of poor prognosis. Median survival in patients with low transthyretin levels (< 10.9 mg/L) was 26 days, which was significantly shorter than in patients with high transthyretin levels ( $\geq 10.9$  mg/L) (50 days;  $p < 0.001$ ).

**Conclusions:** Low transthyretin levels predictor poor prognosis among cancer patients in palliative care settings.

**Abstract number:** P46

**Abstract type:** Poster

### Embedding Patient Reported Outcome Measures (PROMs) into the Inpatient Hospice Setting: What Do they Tell us?

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**Background:** PROMs are important to determine changes in symptoms (SY) & quality of life (QOL) of patients in specialist palliative care (SPC) settings. A validated questionnaire (SKIPP:St Christopher's Index of Patient Priorities) has been embedded into two UK hospices for 3 years. SKIPP is given to every patient admitted on day 3 (SKT1) & 10 (SKT2). SKT1 can be used as a PROM in itself; comparing SY prior to & since admission. Little literature exists around completion & impact of SPC using PROM. Our aim was to explore changes in SY & QOL during a hospice stay. **Methods:** Retrospective review of 150 admissions to 2 UK inpatient hospices. Phasing score & SKIPP data were described using counts (%) for categorical data & mean (SD) for continuous variables. Data analyzed with Pearson's Chi Squared or ANOVA as appropriate. Statistical significance accepted if  $p < 0.05$ .

**Results:** Mean age 68 years, male (56%) & cancer diagnosis (96%). Majority of patients phased as unstable (55%) or deteriorating (26%). Average length of stay 16.7 days. 57% died in the hospice, 41% discharged home & 2% transferred to acute hospital. 59% completed SKT1. For those who stayed 10 days or longer, 34% completed SKT1 & 34% SKT2. At SKT1, 45% & 34% respectively of patients rated their key concern (pain, moving around/breathlessness/nausea) 'had got much better' or 'a little better'. There was variability on impact of service on key concern; most physical SY got much better & less improvement in moving around; likely to be representative of the changing disease trajectory in this cohort of patients. Patients rated a positive change in their QOL on SKT1; mean increase from 2.6 to 4.65 on a 8-point scale ( $p < 0.05$ ) (& change maintained at SKT2).

**Conclusion:** Nearly 60% of patients completed SKT1. Patients reported an improvement in SY burden within 3 days of admission and increase QOL scores. We are mindful the cohort of patients who were unable to complete SKIPP may have had a different experience of SY burden and QOL.

**Abstract number:** P47

**Abstract type:** Poster

### Spanish Short form of the Schedule of Attitudes towards Hastened Death in Palliative Care

#### Population: Preliminary Results

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**Introduction:** The most used instrument to measure the wish to hasten death (WTHD) in patients with life-threatening conditions is the Schedule of Attitudes towards Hastened Death (SAHD), a self-report instrument with 20 true/false items. However, some authors highlighted that the length of the SAHD might exhaust patients with advanced conditions, and the wording of some items might be too direct in some cultures where speaking openly about death is sometimes avoided.

**Aims:** To compose a SAHD-short form and study the psychometric properties of this new set of items.

**Method:** Data from a previous study on Spanish palliative inpatients were analyzed with a Rasch model. The item reduction process followed next three steps:

- (1) after fitting data into a Rasch rating scale model, those items with low discrimination (point bi-serials  $< 0.70$ ) were removed,
- (2) items with fit statistics (Infit and Outfit) outside the range 0.7-1.4 were assessed and removed, and
- (3) quality and criteria of the final set of items were studied.

We examined the test probability function of the final set of items to establish an empirical score to screen patients at risk of suffering WTHD. Convergence tests between the original and the reduced set of items were carried out.

**Results:** Fifteen items were removed because their low discrimination or poor fit. The final set of 5 items had all quality conditions. The 20.8% of participants had higher risk of suffering WTHD ( $P > 50\%$ ). Correlation analysis revealed that the results from the original set of items and the reduced form were almost equivalent.

**Conclusions:** The short form of the SAHD could allow us to detect patients at risk of WTHD. The cut-off point of 3 seems to be a valid measure which may aid healthcare professionals in helping patients at risk and establishing effective healthcare plans.

**Funding:** Instituto de Salud Carlos III; AECC-Barcelona.

**Abstract number:** P48

**Abstract type:** Poster

**Effectiveness of a Physiotherapy Led Rehabilitative Programme and Suitability of Functional Outcome Measures in Palliative Care Patients**

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**Background:** Optimising physical function is a primary aim of physiotherapy in palliative care. Research using validated and service specific outcome measures is necessary to demonstrate the effectiveness of therapeutic interventions.

**Aim:** The primary aim of this research was to determine the effectiveness of a physiotherapy led therapeutic rehabilitative programme (TRP) in patients attending specialist palliative day care (SPDC). Secondary aim was to assess the suitability of 4 different functional outcome measures in this population.

**Method:** Retrospective observational cohort study of patients attending an 8 week SPDC programme. The studied intervention involved a TRP; a combination of strength and balance exercises modified to suit individual patients. Pre and post outcome measures utilised: Edmonton functional assessment tool (EFAT-2), 5 Times Sit to Stand Test (FTSST), Timed Up and Go (TUG) test and researcher's own tool for scoring Mobility. This tool was locally developed and measured patient mobility and assistance required, based on an 8 point scale. The tools measured function by analysing falls risk, lower limb strength and independence with functional tasks.

**Results:** 7 patients (64%) completed the 8 week intervention with full data recorded for 6 (54.5%). 4 failed to complete due to clinical deterioration.

Functional/Balance improvement was demonstrated by a reduction in all average scores. TUG fell from 25.8 to 17.2 seconds, 3 subjects (50%) subsequently fell below falls risk indicator (13.5 seconds). FTSST fell from 24.8 to 19.6 seconds, EFAT-2 from 7.5 to 5.2 points, and Mobility Measure 4.5 to 3 points.

**Conclusion:** Although a significant attrition rate, as is common in a palliative care setting, this study demonstrates the effectiveness of a physiotherapy intervention for patients able to complete the programme through improved physical function and balance. It also introduces a new tool documenting patients' mobility to the literature.

**Abstract number:** P49

**Abstract type:** Poster

**Complexity in Advanced Palliative Care at Home: Testing an Assessment Tool**

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**Background:** A tool for the assessment of the complexity ("IDC-Pal") developed in Spain includes elements that assess the clinical and psychological situation of the patient, family, environment and health organization, to be classified as "complex" (C) or "highly complex" (HC). An appropriate assessment of complexity is supposed to be useful for the management of resources and the decide which kind of professionals in an interdisciplinary team should be involved.

**Aim:** To describe the elements of complexity in a specific palliative hospital-based home care department in a cancer center.

**Method:** Descriptive, prospective, observational study. Population: Patients in need of palliative care admitted to home care department. Consecutive sampling. Data collection: out of clinical reports and interviews between researchers and clinicians. Tool: dichotomic answers (yes/no) to elements of complexity.

**Results:** Between January and February 2015, 92 of 134 patients admitted to our service met inclusion criteria. Of these, 82 were included 37 men and 45 women. The mean age was 65.9 years (SD = 13.0). 68 had at least one HC situation and 14 only C. The median was 6 elements HC or C per patient, mainly due to their clinical situation. The most common items were "sudden change in performance" (n = 51), "difficulty to control symptoms" (n = 42) and "determinant social or family role" (n = 40). In the psycho-emotional situation, the most common element was "not competent family and / or caregivers" "existential distress and / or spiritual suffering" (n = 27), and dependent family and environment was (n = 15).

22 patients had 10 or more elements of C or HC.

**Conclusions/discussion:** Clinicians in advanced palliative care should be able to assess and manage the most frequent situations that are considered as C or HC. This includes social, psychological and spiritual distress, competencies of family and caregivers at home and difficult symptoms.

**Abstract number:** P50

**Abstract type:** Poster

**The Prognostic Role of C-reactive Protein and Albumin in Advanced Cancer Palliative Care Inpatients: A Retrospective Study**

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**Introduction:** Accurate prognostication facilitates appropriate cancer management. C-reactive protein (CRP) and albumin may have prognostic value. The CRP/albumin ratio (CAR) and modified Glasgow Prognostic Score (mGPS) incorporate these parameters. Recent studies used a lower cut-off in the mGPS (CRP < 5mg/L, instead of < 10). The utility of these scores in palliative care is unclear.

**Aim:** To assess the prognostic value of CRP, albumin and CRP-based scores (CAR, mGPS with standard and low cut-offs) in cancer admissions to a Specialist Palliative Care Unit (SPCU).

**Methods:** A database of all cancer admissions to the SPCU from September 2014 to February 2015 was reviewed. Serum CRP, albumin and survival time were recorded. CRP and albumin were analysed as categorical variables (high CRP > 10mg/L, low ≤ 10mg/L; normal albumin ≥ 35g/L, low < 35g/L). CAR and mGPS (with CRP thresholds of both 10mg/L and 5mg/L) were calculated. Association with survival (at 7, 30 and 180 days) was examined. Statistical analysis was performed with SPSS.

**Results:** Of 226 admissions, complete data were available for 123. 13 were still alive; their data was censored. 85%(n=94) had CRP > 10mg/L and 96%(n=106) albumin < 35g/L. There was a significant mean survival difference between high and normal CRP (80 v 29 days; p< 0.001) and low and normal albumin (35 v 87 days; p< 0.01). CAR was above published cut-offs for 84% (n=92). A significant survival difference was found between mGPS groups at 7(p=0.01) and 180(p=0.02) but not 30 days. Lowered CRP cut-off for mGPS found a significant difference between groups at 7 days(p=0.04).

**Conclusion:** A clinically and statistically significant survival difference existed between high and low CRP, high and low albumin and between mGPS groups at specific timepoints. Lower CRP threshold did not improve prognostication. Blood results may not be available for all patients in this setting. Large prospective studies are needed.

No funding was received for this study.

**Abstract number:** P51

**Abstract type:** Poster

### Quality Indicators for Evaluating Palliative Care Day Services: Systematic Review

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**Background:** With an ageing population and increasing numbers of people with life-limiting illness, there is a growing demand for palliative care day services. There is a need to measure the quality and value of these services but little agreement on which aspects of care should be used to do this. Development and implementation of quality indicators would offer a means of defining, measuring and comparing care quality across a range of diverse settings and locations.

**Aims:** To identify existing quality indicators relevant to evaluation of palliative care day services and examine the evidence base in support of their use.

**Design and methods:** After an initial scoping review, a full systematic review was conducted following PRISMA guidelines. Five databases (Ovid MEDLINE, Ovid EMBASE, CINAHL, PsycINFO, Cochrane Central Register of Controlled Trials) were searched from January 2000 to June 2015. Grey literature sources were also searched for unindexed technical reports and practice guidelines. Development of the quality indicators was evaluated using the Appraisal of Indicators through Research and Evaluation (AIRE) Instrument. The GRADE approach was used to assess overall quality of the included evidence.

**Statistical analysis:** Analysis was primarily descriptive.

**Results and interpretation:** 96 papers were included in the review. Following removal of duplicates and grouping of similar indicators, 185 unique quality indicators were identified and classified into 17 separate domains. The majority related to physical and psychological care and support or co-ordination of care. Quality varied considerably but AIRE scores were typically low to moderate while overall methodological quality was also moderate. A substantial number of quality indicators for evaluating palliative care day services are available, but evidence supporting their use, particularly in terms of outcomes after implementation is limited.

**Abstract number:** P52

**Abstract type:** Poster

### Unmet Needs for Key Interventions Palliative Cancer Care (KI-PCC) in Patients with Advanced Cancer: Comparison of Romanian and Swiss Patients

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**Aim:** The integration of Palliative Care in oncology is challenging, particularly in resource-restricted and regulatory disperse settings with variable training of health care professionals (HCPs). We aim to identify gaps of defined KI-PCCs in order to apply tailored improvement programs.

**Methods:** The reported data is part of a larger prospective study in Romania and Switzerland (250 and 40 evaluable adult stage IV cancer pts from different care settings with defined palliative care (PC) needs based on POS, ECOG 1-3). Needs for 7 “Key Interventions of Palliative Cancer Care” perceived by pts and their recalled delivery by hcp were collected monthly by a nurse-led assessment. Gaps were defined as patient expressed need for a KI-PCC and lack of perceived delivery by any hcp. The gaps are compared descriptively for baseline and one month later.

**Results:** An unmet need for Illness understanding (*Do you have all the information you need to understand your illness?*) was in Romania at BL 49% and at 1 months 41%, in Switzerland 3% and 0%; for symptom control (*Did you have distressing symptoms?*) 59%/66% and 42%/32% (not for pain, but for fatigue, anorexia), for decision processes (*Did you have a change in the anticancer treatment? Did you have side effects that would have required a reconsideration?*) 55%/23% and 5%/10%, for care network (*Did you have to go to the ER or did you need/would you have needed care at home?*)

71%/45% and 51%/54%, for family members (*Does your family play an important role in your care?*) 44%/49% and 44%/56%, for end of life preparation & care (*Did you have the need to address EoL worries, like that life time is limited, family is not prepared to cope?*) 34%/18% and 27%/25%, for spirituality (*Did you have the need to address spiritual issues?*) 58%/63% and 43%/40%.

**Conclusion:** Our data suggest that unmet needs for KI-PCCs perceived by patients reflect differences in between Romanian and Swiss patients and oncologist.

**Abstract number:** P53

**Abstract type:** Poster

### Use of the Edmonton Classification System for Cancer Pain (ECS-CP) to Validate Location of Care in a Comprehensive Integrated Palliative Care Program

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**Aim:** The ECS-CP is used on initial assessment in all locations of care in our palliative care program. The Tertiary Palliative Care Unit (TPCU) is our best resourced location and is intended as a referral site for the most complex patients. Included components of the ECS-CP have been shown to predict complexity of care required to achieve stable pain control.

Our aim was to use our comprehensive database to demonstrate that more complex patients, as defined by the ECS-CP, are being admitted to the TPCU.

**Methods:** The program database was accessed to compare patient demographics and ECS-CP components across all locations of care for the period April 1, 2014-March 31, 2015 (n=3863).

**Results:** There were 2148 consults in acute care, 919 consults in the community, 620 consults at the cancer clinic, and 176 admissions to the TPCU. For those patients with a pain syndrome (n=2306), patients admitted to the TPCU had significantly higher frequencies of neuropathic pain (39%), incident pain (45%) and psychological distress (23%) compared to other locations of care (p < 0.001). In other sites, the range of ECS-CP scores was: neuropathic pain 9-20%, incident pain 20-38%, psychological distress 9-22%. There was no significant difference in addictive behavior across sites (range 2-5%). The frequency of normal cognition was significantly higher for patients at the cancer clinic 83% than other sites (p < .001). There were some unexpected variations for incident pain and psychological distress across similar locations of care.

**Conclusion:** The ECS-CP was able to differentiate between patients with more complex pain syndromes referred and admitted to the TPCU and patients at other sites. The unexpected variations are quality assurance and educational opportunities requiring follow up and education to improve the use of the ECS-CP in clinical practice to assess patients and guide management.

**Abstract number:** P54

**Abstract type:** Poster

### Development and Evaluation of a Comprehensive Tool (MPCAT) for Patient Assessment in Palliative Care Settings

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**Background:** All palliative care patients should have a comprehensive systematic assessment at the initiation of a service and as needs change thereafter.

**Aim:** The development and testing of evidence based multidisciplinary in-patient assessment proforma (MPCAT) with accompanying guidelines and training package.

**Methodology:** This is a single site study using a convergent parallel mixed method design involving extensive consultation with clinicians. A systematic approach was used to search Medline, CINAHL and PsychINFO to identify palliative care specific assessment instruments, tools and questioning guidelines. Admission assessment documentation systems from Hospices in Ireland and Britain were collated, compared and contrasted. An adapted Delphi technique was used with a group of clinical experts to choose tools for inclusion in the MPCAT from the tools identified in the literature review and survey of Irish and British documentation systems. Semi-structured qualitative Interviews were conducted with staff to evaluate the implementation of the MPCAT.

**Results:** The MPCAT includes 8 evidence based clinical tools which had been previously published in the literature. Graduated interviews to screen for patients psychosocial and carers needs were developed further to consultation with clinical experts. Three higher order themes were identified from the interview data:

- Care Planning and communication is facilitated
- Assessment of psychosocial and spiritual needs is complex
- Changing practice takes time

**Conclusion:** Implementation of a comprehensive evidenced assessment proforma was feasible in the clinical environment. This process and proforma should be tested in other Hospices, to determine if results can be replicated.

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**Abstract number:** P55

**Abstract type:** Poster

### Measuring Outcomes through Point-of-Care Data

#### Collection: Comparison of Two Outcome Initiatives in Australia and the UK

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**Background:** The Palliative Care Outcomes Collaboration (PCOC) in Australia (AU) and the Outcome

Assessment and Complexity Collaborative (OACC) in the UK are initiatives that support the routine use of assessment tools and outcome measures in palliative care practice. Both provide routine feedback, enabling clinical teams to make effective use of the data collected, when planning individual patient care and for quality improvement.

**Aim:** To contrast two clinical data registries to identify key issues in measuring and improving patient outcomes in palliative care.

**Methods:** Data are collected at point of care through standardised assessment tools. In AU, 115 palliative care services have submitted data 6 monthly since 2009. In the UK, two palliative care services have submitted data monthly since Jan 2015. Comparison is made between the two data collections over 6 months in 2015.

**Results:** Between Jan-June 2015, PCOC and OACC collected data on 16,408 and 2,200 patients; 20,318 and 2,672 episodes of care; and 46,068 and 4,262 phases of illness; respectively. Patients in both countries were a similar age but non-malignant patients were proportionally more in the UK (42.3%) than in AU (22.0%). In both countries, community episodes were longer (mean [sd] UK 35.1 [33.3] days; AU 28.4 days), than in hospice (UK 16.5 [15.8] days; AU 11.3 [13.0] days) or hospital consult episodes

(UK 6.4 [12.4] days; AU 5.2 [7.0] days). The distribution and duration of phase varies according to settings in both countries. Hospital consult and hospice services reported a similar proportion of 'terminal patients'.

**Conclusion:** PCOC is an established program, OACC is comparatively newer. Despite this phase and episode level data, collected at point of care, demonstrates consistency between AU and the UK, within the constraints of different populations, models of care, and stage of initiative. Consistency between clinical registries in both countries provides opportunity for international benchmarking.

**Abstract number:** P56

**Abstract type:** Poster

### What Are the Core Programme-level Principles in Outcome Measurement Interventions in Palliative Care? A Comparison of Outcome Measurement Interventions in Australia and the UK

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**Background:** Globally, the need to monitor and report on patient outcomes is increasing, and large-scale outcome measurement interventions will help palliative care report on these. However, adequate descriptions of the components of large-scale outcome measurement interventions are rare. This limits national implementation, and international comparisons and evaluations.

**Aims:** To identify core programme-level principles in two outcome measurement interventions: the Outcome Assessment and Complexity Collaborative (OACC) in the UK and the Palliative Care Outcomes Collaboration (PCOC) in Australia.

**Methods:** Deductive analysis of the core and subcomponents of the intervention, and its primary functions was conducted to identify similarities and differences. Findings were confirmed with implementation and design staff.

**Results:** Similarities in the development of the intervention include methods designed to: build capacity, engage stakeholders; review evidence; develop/refine the intervention and associated resources; capture, analyse and report on data; and educate, train and motivate stakeholders. Differences across countries include: a larger-scale stakeholder engagement in Australia and an emphasis on governance; and a primacy of research in the UK.

**Conclusions:** The similarities in core programme-level principles outnumber the differences. The similarities relate to the intervention itself. The differences concern adaptation in response to local and national context, priorities, funding requirements and resources. International comparisons and evaluations are possible. Established intervention components should be adopted to support global monitoring of outcomes in palliative care

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**Abstract number:** P57

**Abstract type:** Poster

### Usability and Users' Experience of Eir - A Computerized Tool for Symptom Assessment and Decision Support in Cancer Care

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**Background:** Eir is a computerised tool for symptom assessment and decision support, developed for patients and physicians. In Eir, patients enter data about their

current symptoms on an iPad, prior to the consultation. The data is wirelessly transferred, summarised and immediately available for the physicians on their computers. A computerised assessment tool must be adapted to and perceived as useful by the target users if it is to be endorsed and implemented into daily clinical use.

**Aim:** To investigate the usability of Eir and patients' and physicians' experience of using Eir.

**Methods:** Patients and physicians at the Cancer Clinic at St. Olavs Hospital, Trondheim University Hospital were eligible for the study, and were asked to test Eir. Recruitment was based on the principle of maximum variation. Data was collected by observation, think-aloud-protocol and interviews according to predefined templates and guides, and qualitatively analysed by means of a simple content analysis.

**Results:** 10 patients in a palliative phase and 5 physicians participated. The patients had 1-14 symptoms (median = 7). Most patients found Eir easy to use with little or no instructions. Patients said Eir could help them keep track of symptom development over time, and that it would be useful to fill in Eir at home. Since more symptoms leads to more questions, filling in Eir became very time consuming and tiring for some of the patients with high symptom burden.

Physicians said Eir gave them a good overview of patients' symptoms, especially for patients with many symptoms. Eir identified symptoms they otherwise would not have addressed, without consultation time extension.

**Conclusions:** Eir was found to be user friendly and useful by physicians and most of the patients. However, Eir needs adjustments in order to improve usability for patients with a high symptom burden.

**Funding:** Norwegian University of Science and Technology and St. Olavs Hospital, Trondheim University Hospital, Norway.

**Abstract number:** P58

**Abstract type:** Poster

### Does the EQ-5D Capture the Concerns Measured by the POS?

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**Background:** Studies assessing the effectiveness of palliative care interventions commonly use palliative care-specific instruments e.g. the Palliative Care Outcome Scale (POS). But, for economic evaluations, utility data is necessary. Mapping algorithms translate scores from condition-specific instruments into values from generic preference-based instruments like the EuroQol 5-dimension (EQ-5D).

However, mapping approaches rely on the conceptual overlap between both instruments.

**Aims:** To develop a model to predict mean EQ-5D utility values from the POS.

**Methods:** We combined data from 3 studies which collected data on both POS and EQ-5D, and then randomly divided these into estimation ( $n = 392$ ) and validation ( $n = 391$ ) samples. Relationships between the instruments were estimated using 3 modelling techniques. Models were fitted to the overall EQ-5D index using linear regressions estimated by ordinary least squares (OLS), and censored least absolute deviations (CLAD). Further models were fitted to the individual dimensions of the EQ-5D using multinomial logistic regression (M-Logit). The predictive performance of models was evaluated using mean absolute error (MAE) and root mean squared error (RMSE).

**Results:** External validation found considerably high errors for all three models (MAE = 0.31 for OLS; 0.30 for CLAD; and 0.32 for M-Logit), which suggests that the models do not produce reliable estimates. Furthermore, all three models appeared to overestimate low EQ-5D values and underestimate high EQ-5D values.

**Conclusion:** Despite exploring three models, it appears there are certain aspects of the POS that the EQ-5D does not capture, likely due to a lack of conceptual overlap between the two measures. Further research should focus on deriving preference weights for the POS, rather than using mapping algorithms that appear to be unreliable.

**Funders:** The Atlantic Philanthropies, Cicely Saunders International.

**Abstract number:** P59

**Abstract type:** Poster

### Measures to Assess Commonly Experienced Symptoms for People with Dementia in Long-term Care Settings: A Systematic Review

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**Background/aims:** High symptom burden is common in long-term care residents with dementia and results in distress when undetected. Assessment measures may support symptom detection in people unable to self-report due to advancing dementia. We aimed to identify proxy-completed measures of symptoms experienced by people with dementia, and critically appraise the psychometric properties and applicability for use in long-term care settings by direct caregivers.

**Methods:** We searched Medline, EMBASE, PsycINFO, CINAHL and ASSIA from inception to June 2015, supplemented by citation and reference searches. We included studies that evaluated psychometric properties of symptom measures for people with dementia, or those of mixed cognitive abilities residing in long-term care settings. Measures were included if they did not require clinical training, and used proxy-observed signs for assessment of verbally compromised people. Data were extracted on study setting and sample, measurement properties and psychometric properties. Measures were independently evaluated by two investigators using quality criteria for measurement properties, and evaluated for clinical applicability in long-term care settings.

**Results:** Of the 19,942 titles and abstracts screened, 40 studies were included evaluating 32 measures to assess pain ( $n=12$ ), oral health ( $n=2$ ), multiple neuropsychiatric symptoms ( $n=2$ ), depression ( $n=8$ ), anxiety ( $n=2$ ), psychological wellbeing ( $n=4$ ), and discomfort ( $n=2$ ). Of the pain assessments, the PAINAD and PACSLAC had the strongest psychometric properties. Measures assessing other common symptoms were identified but require further validation in this setting.

No multi-symptom measure was identified for this population.

**Conclusions:** A multi-symptom measure to support systematic detection of common symptoms in this population is urgently required. Of the measures identified, most require further validation.

**Funders:** Cicely Saunders International, Atlantic Philanthropies, CLAHRC.

**Abstract number:** P60

**Abstract type:** Poster

### A Measure to Support Systematic Assessment of People with Dementia in Care Homes: The Palliative Care Outcome Scale (POS) for Dementia - Assessment (POS-DemA)

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**Background/aims:** Proxy-completed measures may provide a solution to detecting symptoms and problems in verbally-compromised care home residents with dementia. However, little is known about the use of these measures by non-clinically trained carers working in care home settings. We aimed to explore the comprehensibility and acceptability of a new proxy-completed measure, the Palliative care Outcome Scale for Dementia - Assessment

(POS-DemA) to support systematic assessment of care home residents with dementia.

**Methods:** Carers working in three London residential (non-nursing) care homes were purposively sampled. Think-aloud and probe techniques were used in two phases of cognitive interviews to elicit problems with the instruction manual and measure. Interviews were audio-recorded and analysed using content analysis. Refinements to POS-DemA were made at each phase through expert consensus.

**Results:** Ten carers were recruited, five in each phase. Problems identified related to comprehension of written instructions and medical terms e.g. delusions; assessment of residents with complex or fluctuating symptoms, particularly those unable to self-report; and consistency in interpreting and responding to items. POS-DemA was refined to minimise problems in comprehension and response through layout changes, and provision of non-medical terms and item descriptors. Presentation of proxy-observed signs were refined to support assessment of symptoms and problems in verbally-compromised residents. Changes were made to the instruction manual, and presented in alternative video format to support completion of POS-DemA and its use in routine care.

**Conclusion:** Measures used to support objective systematic assessment of people with dementia by carers should include non-medical terms, and support observational assessment. Provision of instructions in written and video formats aids comprehension of use in routine care.

**Funding:** Cicely Saunders International, Atlantic Philanthropies, CLAHRC.

**Abstract number:** P61

**Abstract type:** Poster

### Delirium Assessment in a Specialist Palliative Care Inpatient Unit

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**Background:** Delirium is a serious neuropsychiatric syndrome that impacts on functional ability, quality of life and causes distress for patient's families. Its prevalence on admission to a specialist palliative care unit (SPCU) varies from 13%-42%. The 2010 NICE guidelines reports that a patient is at risk of delirium if any of the following are present; age  $\geq$  65 years, cognitive impairment, current hip fracture or a severe illness. All patients admitted to a SPCU should be screened due to the presence of at least 1 risk factor, e.g. a serious illness.

**Aims:** To assess the percentage of patients screened for delirium and risk factors present on admission to a SPCU over one month.

To implement a delirium screening tool, assess compliance and analyse results.

**Methods:** A chart review was performed retrospectively for all admissions to a SPCU in July 2015 to assess risk factor profile and performance of delirium screening. Following this review, the Bedside Confusion Scale; a validated screening tool in the palliative care population, was included in all admissions over a one month period. A repeat chart review was conducted to assess results and compliance with the intervention.

**Results:** 56 patients were admitted in July 2015. All patients had one risk factor, i.e. a serious illness, 61% had two and 7% had three risk factors present. No patients were screened for delirium on admission.

Following the implementation of the Bedside Confusion Scale in October 2015, 53% of admissions were screened. 45% of these patients scored  $\geq$  2 concerning for a confusional state, 23% scored 1 and 31% scored 0, indicating borderline and normal mental states respectively.

**Conclusion:** Patients admitted to a SPCU are at risk of delirium. Perhaps some patients scored high as they were unable to perform the test due to illness. Identifying and treating delirium may lead to improved quality of life. Following this review, a delirium management protocol will be developed.

**Abstract number:** P62

**Abstract type:** Poster

### Reliability and Validity Evidence for the Revised Edmonton Symptom Assessment System (ESAS-r) in a Diverse Palliative Care Population

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**Aim:** The Edmonton Symptom Assessment System (ESAS) is a widely used symptom assessment tool originally developed for advanced cancer patients. To address concerns regarding potential reporting errors, a revised version, the ESAS-r, has been developed. The aim of this study was to gather reliability and validity evidence in a diverse palliative care population, using our comprehensive program database.

**Methods:** The following admission data were extracted from the database for the period, April 1, 2014-March 31, 2015: patient demographics, ESAS-r, Edmonton Classification System for Cancer Pain (ECS-CP), location of care (n=3863). Only cognitively intact patients with a completed ESAS-r were included in the analysis.

**Results:** 1492 cognitively intact patients (Mini-Mental State Exam  $\geq$  24) completed the ESAS-r on initial consult or admission to the following sites: acute care (n=721,

48%), cancer facility (n=358, 24%), community (n=296, 20%) or tertiary palliative care unit (n=117, 8%). Most patients had advanced cancer (n=1411, 95%) with an average age of 66 years (SD 14). Internal consistency was moderately high (Cronbach's alpha=.72). Spearman rho correlation ( $\rho$ ) between wellbeing and the other 8 ESAS-r items was modest ( $\rho$ =.48). Performance status correlations were highest for fatigue ( $\rho$ =-.25); appetite ( $\rho$ =-.25) and drowsiness ( $\rho$ =-.21). The ESAS-r discriminated between cancer and noncancer patients (Mann Whitney U,  $p$ =.000, pain and shortness of breath), locations of care (Kruskal Wallis,  $p$ =.000, all symptoms) and psychological distress (ECS-CP, 1-way ANOVA,  $p$ <.05, all symptoms except appetite and shortness of breath).

**Conclusion:** The ESAS-r items are moderately inter-related (good internal consistency) and are able to discriminate between cancer and noncancer patients, locations of care and psychological distress within the context of pain. Further validation studies, particularly with larger noncancer samples and non-palliative cancer patients, are warranted.

**Abstract number:** P63

**Abstract type:** Poster

#### **Pain Assessment during Last Week of Life - A Useful Tool or a No Need?**

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**Background:** Pain is a common symptom in end-of-life (EOL) care. The Swedish Register of Palliative Care (SRPC) systematically collects data on EOL care since 2005 and argues that the use of pain assessment tools during the last week of life is important.

**Aim:** To study the use of pain assessment tools and related differences in treatment outcomes during last week in life.

**Method:** Using data from SRPC, the use of pain assessment tools and outcome of pain treatment during last week in life was analysed in different care settings from 2012 - 2015. Only patients dying an expected death were included in the analyses.

**Results:** Since 2012 approximately 60 % of all deaths in Sweden were reported to SRPC of whom 84 % were expected.

The use of pain assessment tools in the studied population increased from 21 to 38 % between 2012 and 2015, with specialized palliative care 33 - 62 %, hospitals 12 - 22 %, nursing homes 18 - 38 % and general home care 17 - 40 %.

Pain was detected in 80 % of assessed patients and reported in 64 % of those not assessed with a validated pain assessment tool. This difference was most pronounced in hospitals and nursing homes.

Complete pain relief was achieved to a higher degree in patients who had been assessed for pain as compared to those not assessed with a validated pain assessment tool, with a difference of 8 % in 2015.

**Discussion:** Systematic pain assessment during the last week of life increases detection of treatable pain but is still underused in Sweden, even within specialized palliative care. This calls for even more systematic education and perhaps an open debate aiming for a change in attitudes both among staff, patients and next of kin.

**Abstract number:** P64

**Abstract type:** Poster

#### **Translation and Cultural Adaptation of the Integrated Palliative Care Outcome Scale for Use in Sweden**

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**Background:** Patient-reported outcome measurements are important for measuring changes in patients' health over time, evaluating the quality of care given, and improving the quality of care service. The Integrated Palliative care Outcome Scale (IPOS) is one such measure, capturing clinically important physical, psychological, social, and existential aspects of patients' palliative care needs. When patients are unable to complete the IPOS questionnaire themselves with or without assistance, a staff version is also available.

**Aim:** To translate and culturally adapt the IPOS Patient and Staff versions for use in the Swedish context.

**Method:** The process comprised forward and backward translations, cultural adaptation, and expert group reviews. To validate the resulting Swedish version of IPOS, cognitive interviews were conducted with 13 patients and 15 staff from various care contexts.

**Preliminary results:** The Swedish expert group changed some words and grammar due to minor discrepancies in the back translation process. The participants in the cognitive interviews responded positively overall to the questionnaire. Deteriorating health and not having Swedish as the native language did not cause problems in completing the questionnaire. After the first round of cognitive interviews, problematic questions and answer options were rephrased, and redundant text was deleted.

**Conclusion:** The Swedish IPOS (Patient and Staff versions) has been validated linguistically and culturally, and is now available for clinical use. The next final step in the validation process will be to test the psychometric performance of the Swedish questionnaires.

**Abstract number:** P65

**Abstract type:** Poster

### Translation of the Edmonton Classification System for Cancer Pain and “Quick User Guide” into Spanish

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**Aim:** The Edmonton Classification System for Cancer Pain (ECS-CP) is used by our Spanish-speaking clinical group in different palliative care settings. To improve the value for Spanish-speaking clinicians, we proposed to translate the ECS-CP and its corresponding “Quick User Guide” (QUG) into Spanish and gather preliminary readability and test-retest reliability evidence.

**Study design and methods:** The study was designed in three phases.

Phase I: Two independent translators translated the English version of the ECS-CP and QUG into Spanish. The investigation team reviewed and agreed with this document leading to the first Spanish version (ECS-CP CAS v1). This first version was revised grammatically (ECS-CP CASv2), and then translated back to English, resulting in the third version (ECS-CP CASv3).

Phase 2: The third version was analyzed for readability levels, using the freeware INFLESZ. Two reliability indices - the Flesch-Szigriszt readability index (FSRI) and the Fernandez-Huertas Index - were obtained, resulting in a fourth version (ECS-CP CASv4).

Phase 3: 25 different clinical scenarios of patients with pain syndromes were given to 20 clinicians. They answered

the scenarios twice with a gap of 15 days in between. Before the third phase was initiated, we performed a one-hour formation session. When the whole process ended, participants completed a qualitative interview. The Kappa coefficient was used to calculate test-retest reliability using SPSS v20.0.

**Results:** The FSRI was 54.61 (high school literacy level). The Fernandez-Huertas Index score was 60.02 (10-12 years of age literacy level). The Kappa coefficient was 0.83.

**Conclusion:** With the methodology used, we obtained the translated Spanish version of the ECS-CP and QUG that fulfils the readability, practicability and reliability criteria expected to be used by Spanish-speaking health professionals to assess difficult pain in our population.

**Abstract number:** P66

**Abstract type:** Poster

### Do Palliative Care Patients and Staff Report the Same Main Problems and Concerns? A Textual Analysis of the Opening Question on the Integrated Palliative Care Outcome Scale (IPOS)

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**Background:** The IPOS patient and staff versions assess palliative care symptoms and concerns; the first item asks patients or staff to report patients’ main problems/concerns.

**Aims:** To determine patients’ main problems/concerns, compare concurrent staff responses using IPOS, and compare how these correspond to subsequent IPOS items.

**Methods:** Cross-sectional survey of patients/staff and textual analysis of the free text question ‘what have been your main problems or concerns over the past 3 days?’, across palliative care settings. Data was double entered, categorised, independently analysed and discussed until agreement by two researchers. Patient and staff reported main problems/concerns elicited concurrently were compared.

**Results:** 222 UK patients completed IPOS questionnaires, mean age 65.8 years (range 20-92), 45% male, and 85% white. 42% stable, 34% unstable and 16% deteriorating. 204/222 (92%) completed the first item, giving three (n=81), two (n=61), or one (n=81) response. In total 356 problems were reported; 234/356 (66%) were reflected in subsequent items of IPOS. The highest reported were pain (n=81), anxiety/worry (n=35) and shortness of breath (n=30). 32 categories were identified, including ‘other physical symptoms’ (n=30) and ‘unique concerns’ (n=30) these were individual to patients e.g. “wanting to be able to eat normally” and “being on oxygen all the time”. Staff

completed IPOS' for 211/222 patients, correctly identifying 46% (192/416) of patient reported main problems/concerns.

**Conclusion:** A diverse range of main problems/concerns were identified using IPOS. Staff identified 46% of patient reported main problems and concerns. The IPOS questionnaire reflects 66% of patient's main problems/concerns and the IPOS open question enables patient's main problems to be captured, which can be difficult for staff to identify and IPOS allows patients unique concerns to be captured.

Independent research funded by NIHR (project number RP-PG-1210-12015).

**Abstract number:** P67

**Abstract type:** Poster

### Quality of Life Outcome Measures - A Way to Drive Personalised Medicine: From Bedside to Bench?

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**Background:** The preferred method of measuring quality of life remains controversial and choice is often driven by clinical objectives, methodological concerns and practical constraints. Health Related QoL (HRQoL) tools are prescribed tools that focus on how the patients' health is affecting QoL. The Schedule for Evaluation of Individual Quality of Life Direct Weighting (SEIQoL DW) recognises the individual and his values. We aimed to examine the important QoL issues for patients with advanced cancer and compare subjective QoL and HR QoL measures over time.

**Methodology:** 65 consecutive patients receiving chemotherapy for advanced cancer were interviewed at time of first treatment. The assessment was repeated at 3 subsequent time points. At each time QoL was measured using SEIQoL DW and the EORTC QLQ -C 30.

**Results:** The most common cues were health 92%, social activity 64% and keeping active 58%. The mean SEIQoL DW score at T1 was 58.5 +/- SD 23.1 and T 4 was 64.25 +/- SD 22.5 with a high mean internal validity ( $R^2 = 0.75$ ). The mean EORTC HR QoL score at T1 was 50.10 SD +/-28.3 and T4 was 60.36 +/-SD 22.63. Although QoL scores rated lower when QoL measure was anchored by health rather than being individually driven, a comparison of QoL scores derived by both instruments across time demonstrate statistically significant improvement in QoL ( $P < 0.05$ ).

**Conclusion:** In this study both subjective QoL and HRQoL measures improved significantly over time with individual QoL measures higher than HR QoL. While the number of cues commonly assessed by HRQoL instrument were also elicited using SEIQoL, other cues, unique to the individual were also additionally elicited with SEIQoL. Subjective QoL measures is a patient centred approach, which in harmony with HRQoL measures, may be considered invaluable in contributing toward personalised medical care.

**Abstract number:** P68

**Abstract type:** Poster

### Validation of the Integrated Palliative Care Outcome Scale (IPOS) to the Portuguese Population - Preliminary Results

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**Background:** IPOS is a patient-centered outcome measure developed by merging two existing measures: the Palliative care Outcome Scale and the Palliative care Outcome Scale-Symptoms.

**Aim:** To validate the previously culturally adapted Portuguese IPOS version to the Portuguese population.

**Methods:** Multi-centred observational study with 2 assessment points. Data is being collected in 8 centres using convenience sampling. All patients attending the participant services are screened for eligibility. Inclusion criteria:  $\geq 18$  years, mentally fit to give consent, diagnosed with an incurable, potentially life-threatening illness, read, write and understand Portuguese. Exclusion criteria: patient in distress, cognitively impaired. A standard operating procedures manual was developed and distributed to all centres in the person of the facilitator/champion leading the study locally. Descriptive statistics summarise demographics and clinical data. For psychometric testing the COSMIN checklist was followed.

**Results:** 1376 individuals were screened between July 1<sup>st</sup> and October 15<sup>th</sup>. 70 (5.1%) were included. Mean age of the sample is 65.9 years (SD 12.3), 42 (60%) are male, 42 (60%) have up to 4 years of formal education, 37 (52.9%) are from the Northern region. 25 individuals (35.7%) were recruited in a primary care service, 25 from a non-specialised palliative care hospital service and 20 (28.6%) from 2 palliative care services. Most patients had a cancer diagnosis (73%). Internal consistency (excluding open questions) Cronbach's alpha was 0.753. For reliability between patients and healthcare professionals scores, intraclass correlation was higher for pain (ICC=0.734) and mobility (ICC=0.833) and lowest for practical problems (ICC=0.043).

**Conclusion:** Preliminary results seem to suggest that the Portuguese IPOS is a reliable measure. Once all data has been collected further validity testing will be conducted for all psychometric properties.

**Funding:** Calouste Gulbenkian Foundation.

**Abstract number:** P69

**Abstract type:** Poster

### Cancer Malnutrition: Bioelectrical Impedance and Body Composition

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**Introduction:** Cachexia, defined by loss of skeletal muscle mass +/- fat mass, is common in advanced cancer but remains poorly evaluated. Weight or body mass index give no indication of body composition and underestimate malnutrition.

Bioelectrical impedance analysis (BIA) presents an ideal solution. It is a rapid, non-invasive, bedside body composition assessment tool. BIA measures phase angle (PhA). Low PhA represents poor cell membrane integrity, an indicator of malnutrition. Feasibility of routine use in palliative care inpatients is unclear.

**Aim:** Evaluate feasibility and patient acceptability of BIA to assess body composition in a specialist palliative care unit (SPCU).

**Methods:** A prospective observational study recruited consecutive cancer admissions. Patient Generated Subjective Global Assessment (PG-SGA) assessed nutrition. BIA recorded body composition on 2 consecutive mornings under real-world conditions. Ideal test conditions were identified (bladder voided, fasting, right-side electrode placement, supine). Acceptability was evaluated by questionnaire. Descriptive statistics generated by Microsoft Excel.

**Results:** 50 participants recruited, 25 male. Mean age 67 years (range 39-94). Median European Co-operative Oncology Group performance status was 3 (range 0-3). All but 2 had metastatic cancer. 96% (48/50) were at high risk of malnutrition on PG-SGA. Low PhA on BIA recorded in 74% (37/50). Participants reported 100% device acceptability.

### Conclusions:

1. High acceptability supports clinical use
2. Difficult to accomplish recommended test conditions

**Table 1.**

FEASIBILITY	N of TOTAL	%
Right-side electrode placement	44	88
Bladder Voided	44	88
Supine	41	82
Fasting	32	64
<b>PhA VARIANCE DAY 2- DAY 3</b>		
Variance Mean & Range (%)	10.6	0-65

3. PhA result may vary daily
4. High malnutrition prevalence in SPCU

**Abstract number:** P70

**Abstract type:** Poster

### Assessment and Classification of Cancer Pain: An Update of the Systematic Literature Reviews

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**Background:** The lack of a universal standard for pain assessment and classification may be one explanation for undertreated cancer pain. This study aims to update our previous systematic reviews on cancer pain assessment tools (PATs) and cancer pain classification systems (PCSs).

**Methods:** A narrative systematic review (PROSPERO 2014:CRD42014009150) was carried out. MEDLINE Ovid, Embase Ovid, and the Cochrane Library were searched for articles published during 2008-2014 for PATs, and from 2006 to 2014 for PCSs. The reviews included clinical studies developing or validating new PATs or PCSs in adult cancer populations.

**Results:** 3690 and 959 hits were obtained for PATs and PCSs, respectively. All abstracts were screened according to the inclusion criteria, yielding 34 and 36 studies for full-text screening. Nine studies were retained, incl. seven PATs and two PCSs. In 5/7 PAT-studies, patient and/or professional expert groups were involved in the development,

but only two were extensively validated or cross-culturally tested. All but one PAT were multidimensional. Four of 7 PATs focused on breakthrough pain (BTP), incl. pain intensity, duration and response to pain treatment. The two PCSs were based on single pain characteristics; treatment response (1) and temporal pattern (1). None was formally developed or validated.

**Conclusions:** Few new PATs were developed, and extensive validation was lacking for all. For BTP, there seems to be consensus on inclusion of pain intensity, duration and response to pain treatment. No new, validated cancer PCSs were identified. Results will be used in the update of EAPC guidelines for cancer pain.

## Research methodology

**Abstract number:** P72

**Abstract type:** Poster

### Managing Evidence on Palliative Care: Are Realist Reviews Feasible?

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**Background:** Synthesizing evidence on interventions is often done through the use of an effectiveness approach. Its focus is to measure and report on the effectiveness of the interventions. A limitation is that they provide little explanation why the intervention works (or not) when applied in different contexts. Palliative care interventions may be complex, where outcome highly depends on the interaction between people and the context in which the intervention occurs. Realist reviews are important and innovative strategies to synthesize research results on complex interventions. So far however, few realist reviews are conducted within the domain of palliative care.

**Aim:** To evaluate the feasibility of realist review as approach to synthesize research results in palliative care.

**Methods:** Comparison of realist review with other review designs, its strengths and weaknesses.

**Results:** Simple interventions in palliative care (e.g. medication), can be measured through effectiveness reviews. Comparing to other systematic reviews, realist reviews focus on understanding the causal mechanisms by which complex interventions in a particular context produce certain outcomes. It borrows techniques of 'traditional' systematic reviews (e.g. its rigor), while articulating and testing theories, though the steps in the review process are overlapping and iterative. Moreover, data are synthesized to determine "what works, for whom, in what circumstances, in what respects and how?". As such a realist review is theory-driven and has an explanatory rather than an evaluative focus.

**Conclusion:** The realist review approach may be useful when synthesizing evidence on complex palliative care interventions or programs. It offers the opportunity to gain insight in the key factors which affect success or failure of the interventions through its analysis of both context and mechanisms. The resulting insights can be used when planning and implementing interventions at local, regional or national level.

**Abstract number:** P73

**Abstract type:** Poster

### Off-label Prescribing in Palliative Care - A Cross-sectional Survey of Spanish Palliative Medicine Doctors

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**Background:** Regulatory bodies including the European Medicines Agency register medications (formulation, route of administration) for specific clinical indications. Once registered, prescription is at clinicians' discretion. Off-label use is beyond the registered use.

**Aim:** The aim of this study was to document off-label use policies (including disclosure and consent) in Spanish palliative care units and current practices by palliative care clinicians.

**Design:** A cross-sectional survey was conducted online following an invitation letter. The survey asked clinicians their most frequent off-label medication and unit policies.

**Setting/participants:** Spanish palliative medicine doctors.

**Results:** Overall, 47 clinicians responded (60% response rate). The majority did not have policies on off-label medications, and documented consent rarely. The most frequent off-label medications is attached in Table 1. The verbal consent from the patient wasn't obtained "never" in 14%, whereas the written consent in 71%. The respondents at 11% of the times never document in their notes, when prescribing off-label the reasons for this,

**Conclusions:** Off-label prescribing in Spanish palliative medicine clinicians is poorly recognised. More research is required to determine the prevalence and clinical consequences of off-label prescribing in palliative care.

**Abstract number:** P74

**Abstract type:** Poster

### Development of a Method to Systematically Review YouTube Videos Documenting People's Experience of Terminal Illness

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**Background:** Patients are increasingly using social media to share their experiences of terminal illness. An appreciation of what patients are sharing is of interest to healthcare workers caring for these patients. Methods for identifying and analysing videos are not well established, and there are no studies reporting on the use of video blogs (“vlogs”) by this specific population.

**Aims:** To propose a method to systematically review YouTube videos of patients talking about their experiences of terminal illness.

**Methods:** A comprehensive search strategy was developed. Resulting videos were included if: they were a testimonial of a patient talking about their experience of terminal illness; the patient identified him/herself as having a terminal illness; the patient was aware they were being filmed; the video was in English language; the video was not commercial or educational. Data was systematically extracted including descriptive characteristics (authorship, length, popularity), and content analysis. Given the visual nature of the data, non-verbal communication and objective signs of illness were also examined.

**Results:** A total of 33 videos were included. The mean length of videos was 9 minutes 45 seconds (range: 1:15 - 27:55). 30 out of 33 of videos were from patients who had been diagnosed with stage IV cancer. Themes identified through content analysis included symptoms, treatments, motivation for vlogging and thoughts about dying.

**Conclusions:** This method for analysing the YouTube videos of patients approaching the end of their lives was developed through a collaborative approach and the joint screening and analysis of videos reduced bias. Traditional systematic review methods seem to be applicable to review YouTube content, although some adjustments were needed. The results of this review offer a valuable insight into people’s experience of terminal illness.

**Abstract number:** P75

**Abstract type:** Poster

### Deterministic Linking of Administrative Databases and Disease-specific Databases to Study End-of-Life Care in Belgium

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**Background:** From a public health perspective, monitoring the characteristics, quality and costs of end-of-life care in populations are important challenges. The vast amount of routinely collected data available in full-population administrative databases creates opportunities to address that challenge. Using the case of Belgium, we aimed to explore:

- (1) which databases are available that provide information about end-of-life care?
- (2) what are the procedures to obtain/use these data? and
- (3) what is needed to integrate separate databases and protect privacy?

**Methods:** We explored existing Belgian administrative databases and disease registries. Technical and privacy-related aspects of linking and accessing databases were explored in cooperation with the associated database administrators and privacy commission bodies. For all relevant databases, we explored and followed procedures in cooperation with database administrators to link the databases and to access the data.

**Results:** Three database administrators were identified as fitting to study the use, quality and costs of end-of-life care in Belgium, providing five databases: the national InterMutualistic Agency’s registry of health care claims data; the Belgian Cancer Registry on incidence of cancer; and Statistics Belgium’s death certificate database, data from the socio-economic survey, and fiscal data. To obtain access to the data, approval from all database administrators, the relevant supervisory bodies and two separate national privacy commissions was required. The databases were linked by two Trusted Third parties (TTP) using a deterministic match using encrypted social security numbers.

**Conclusion:** Linking and accessing various routinely collected population-level databases includes challenges but offers the opportunity to study patterns in the use, quality and costs of end-of-life care in the full population and for specific diagnostic groups.

**Funding:** Agency for Innovation by Science and Technology (140009).

**Abstract number:** P76

**Abstract type:** Poster

### Recruitment of Participants to Research with a RCT Design in Palliative Homecare Settings - Health Care Professionals Experiences

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Performing research within a palliative care context includes many ethical and practical challenges, in particular regarding recruitment. Randomised controlled trials (RCT) are notorious difficult to complete in palliative care (PC), due to physical, psychological, social and existential symptoms and challenges of patients and family caregivers. The research conducted, was a project studying effects of a psycho-educational intervention, aiming to support family caregivers, caring for a severely ill family member at home. The intervention was delivered at 10 specialized palliative home care units in a metropolitan area in Sweden.

**The aim** was to study how the health care professionals' (HCP) experienced recruiting participants to a RCT testing a psycho educational intervention for family caregivers. An inductive qualitative inquiry with interpretive description methodology was used to analyze two datasets. 5 focus group discussions were carried out with 23 HCP's, to capture experiences from recruiting patients as well as family caregivers to the study and delivering the intervention. After intervention completion, 9 interviews with 11 group leaders were performed, since they were mainly responsible for the recruitment to the intervention.

**Results:** Overall the HCP's experiences of recruiting participants to the research project were colored by

- 1) handling the inclusion criteria's of the study - estimate phase of disease,
- 2) Assessing participant's burden and needs, and deal with ethical dilemmas, and
- 3) contributing to evidence based clinical practice.

**Conclusion:** HCP's are trained to assess and meet family caregiver's needs; randomization collides with the general approach to offer best possible support. Collaboration and dialogue between researchers and HPC's is of importance when addressing challenges and benefits when carrying out clinical RCT in PC.

**Abstract number:** P77

**Abstract type:** Poster

### **Inclusion of Patients with Severe or Very Severe COPD in a Randomised Controlled Study on Early Specialised Palliative Care: Is-it a Challenge?**

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**Introduction:** COPD is a progressive lung disorder with mortality rates between 36-50%, within 2 years after admission for an acute exacerbation. Randomized controlled trials (RCT) are necessary to analyse the benefit provided by early intervention of palliative care specialists in these patients. A RCT was initiated in a tertiary center to determine the effectiveness of introducing specialized palliative care on hospital, intensive care unit and emergency admissions in patients with severe and very severe COPD. Several difficulties were encountered during the inclusion process.

**Methods/design:** Systematic review of all reasons why screened patients were not included in the study.

**Results:** During the inclusion period (October 2013-February 2014), 315 patients were screened and 51(16%) were included: 137 (45%) patients declined to participate; 30 (10%) were already included in another research protocol; 6 (2%) patients died during the inclusion process; 91 had exclusion criteria: 28 (9%) patients had cognitive impairment (MMSE  $\leq$ 23) and 63 (20%) had active cancer.

**Conclusion:** Inclusion of these patients is challenging. First, because of the high rate of persons who declined to participate to the study. Second, because of the high prevalence of cancer in this population, but possibly also because of the prevalence of cognitive impairment. The next step should be to better understand the reasons for their refusal (home visits? misrepresentation of the palliative approach? being randomized to the control group?) and to develop strategies to increase the inclusion rate for these patients.

**Abstract number:** P78

**Abstract type:** Poster

### **What Should we Report? Safety Reporting in Palliative Care Interventional RCTs**

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**Background:** Safety reporting is the process by which researchers gather information about adverse events (AE) which affect participants during the trial. An AE is any untoward medical occurrence that does not necessarily have a causal link to the intervention. The requirements for serious adverse event (SAE) reporting in clinical trials of investigational medicinal Products (CTIMPs) for Data Safety Monitoring Committees (DSMC), is outlined in international law. Safety reporting guidance for undertaking interventional palliative care trials such as psychological interventions like advance care planning (ACP) is however less clear.

**Design and methods:** The ACTION study, a complex ACP cluster trial for patients with advanced cancer, is taking place in 6 European countries, where it is expected patients may die or be admitted to hospital while they are on the trial. A safety reporting policy was developed by the study consortium in conjunction with an independent DSMC to meet the needs of the study and to comply with each nation's research ethics regulations.

**Results and interpretation:** It was recognised that given the study population it would not be unusual for participants to experience SAEs while taking part in the trial but for the majority these would be unrelated to the intervention. Routine hospital admissions and expected deaths are to be recorded but not reported as SAEs. SAEs to be reported in this study are defined as those events that take a course that is significantly more unfavourable to study participants than foreseen in the normal course of the illness such as severe psychological distress. Items from the EORTC questionnaires completed by patients in both arms of the study related to distress are to be reviewed by the DSMC as well as the reported SAEs.

**Conclusion:** Having appropriate procedures in place for the management of SAEs for all studies, not just CTIMPs is important, as participants of interventional studies can also be potentially affected by SAEs.

**Abstract number:** P79

**Abstract type:** Poster

### **Engaging Nursing Homes (NHs) in the PACE Study: Comparing Recruitment in Observational and Intervention Research Designs**

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**Background:** NH residents are often excluded from epidemiological studies, demonstrating a need for representative, internationally comparable research in this area. Data

on palliative care provided by NHs is reported to the Care Quality Commission in England, but the quality of care is often locally determined.

**Aims:** To review the challenges encountered in engaging and recruiting NHs across England to the European Commission funded PACE research project; a two part study comprising of a retrospective, cross sectional survey of deaths and a cluster randomised controlled trial (RCT) of the 'PACE Steps to Success' end of life training intervention.

**Methods:** Study 1 collected quantitative data from NH staff, general practitioners and relatives of 200 deceased NH residents in 50 NHs. Study 2 aimed to recruit twelve NHs, six in each arm of the RCT. The research team encountered challenges throughout the research process, including developing a representative sampling framework, obtaining ethical approvals, advertising the study and recruiting NHs.

**Results:** Study 1 has recruited 44 NHs resulting in data on 92 deceased residents from 32 research visits made so far. Identifying NHs through random sampling resulted in fewer NHs recruited compared to advertising through the ENRICH NHs research networks. Average death rates per NH were lower than expected (3.1 per three months). Study 2 is in the process of recruiting twelve NHs with the support of local ENRICH teams by January 2016. Lack of time and resources, concerns regarding data protection and fear of opening up to potential criticism were identified as barriers to participation.

**Conclusions:** Observational and RCT research designs in NHs require distinct recruitment processes. Whilst representativeness was attained in study 1, ensuring a rigorous random sample was not possible. In both studies, the engagement with NH research networks and informal contacts improved the rate and extent of research involvement.

**Abstract number:** P80

**Abstract type:** Poster

### **Grant Mapping: Taking the Palliative and End of Life Care Priority Setting Partnership Forward**

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**Background:** In January 2015 the Palliative and end of life care Priority Setting Partnership (PeolcPSP), facilitated by the James Lind Alliance (JLA), published 83 unanswered research questions relating to palliative and end of life care. These questions were guided by responses from people in the last years of life, current or bereaved carers and professionals working with people at the end of life. The purpose of this initiative was to inform future research direction.

**Aim:** In this project we present the findings of grant mapping to enhance our work on the PeolcPSP, highlighting how current and recently funded research addresses the priorities identified by the JLA methodology, allowing research funders, charities and researchers to see which priorities are the subject of current research and which receive little or no research funding.

**Methods:** Marie Curie grants and those of other funders were mapped onto a colour-coordinated system in which the colour increases with intensity with the brightest representing interventional research, and the faintest showing indirect links. These have been reviewed by several members of a working group to ensure accuracy and consistency.

**Results:** Through mapping each grant against the 83 unanswered questions the mapping process has generated a visual representation of gaps in research. The system has for instance highlighted that end of life care research in general shows strong relations to Advance Care Planning and place and type of care, but comparatively less interventional research currently addresses out of hours care.

**Conclusions:** Through mapping current grants against the long listed priorities, this analysis is able to inform the funding strategies of project partners and other funders, ensuring that future research is relevant to palliative care populations. This reduces the risk of using limited future funds on research where an earlier or current grant may already have/ will answer the research question.

**Abstract number:** P81

**Abstract type:** Poster

**'Nothing about me without me' How to Achieve Meaningful Patient and Public Involvement (PPI) in an RCT?**

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**Background:** PPI in health research is seen to lead to research findings that have relevance to patients. Internationally, funders and Institutes have developed recommendations supporting involvement (eg the Innovative Medicines Initiative: EU; the Patient-Centered Outcomes Research Institute: USA; and the National Institute for Health Research: UK), but despite this it undervalued and tends to be tokenistic.

**Aims:** To explore the benefits of PPI in palliative care research and identify how these can be achieved.

**Methods:** An RCT of analgesia is being conducted in the North West of England. PPI contributed to the protocol and patient information design. Within the RCT a nested qualitative study of patient experiences, informed by the

principles of grounded theory, was undertaken over a 12-month period. Theoretical sampling was used to recruit a subset of participants. A constant comparative approach was used for analysis which included a PPI analysis event. In this patient representatives and researchers used innovative tools to explore emergent codes and raw data in order to give new insights to the raw data and initial coding.

**Results:** Recruitment (n=20) was completed 4 months early. As a result of PPI involvement in the analysis new insights were brought to the raw data and synergies between initial codes were identified, unpacked and redeveloped. The initial coding framework was developed to include anticipatory experiences of pain. The representatives reported feeling valued and developing greater understanding about the research.

**Conclusions:** PPI involvement brings benefits to palliative care research and researchers. Embedding it throughout the whole research process (from development to analysis) has impact: assisting recruitment through appropriately designed information, developing suitable data collection schedules, and bringing new insights to analysis. Meaningful PPI requires investment but leads to benefits which enhance research conduct and findings.

**Abstract number:** P82

**Abstract type:** Poster

**Breathlessness in Patients with Advanced Diseases: A Model to Characterise Non-pharmacological Interventions**

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**Background:** Breathlessness is a common and distressing symptom in advanced diseases. A wide range of non-pharmacological interventions exist including singing therapy, physical exercise and complex interventions such as breathlessness services.

**Aim:** To develop a theoretical model to assign non-pharmacological interventions in breathlessness to clearly defined groups using a concept of underlying mechanisms of effect.

**Methods:** Studies from an updated literature review of a Cochrane Review on non-pharmacological interventions in breathlessness published in 2009 were analysed regarding the specific type of intervention as described in their methods sections and allocated according to the structure

or process of their delivery and the predominant underlying mechanism of effect.

**Results:** 20 different groups of non-pharmacological interventions for breathlessness were identified. The three underlying mechanisms of effect were:

cognition/emotion for music, singing, humour, psychoeducation, psychological & psychotherapeutic interventions;

respiration for breathing training, fan, chest wall vibration, acupuncture & acupressure;

physical functioning for NMES, mobility aids, physical exercises. Meditative movements were assigned to multi-dimensional mechanisms of effect. Health programmes which make use of structural programmes and different intervention tools were subsumed under

structure-orientated programmes, with a distinction between interventions with/without tailoring to individual needs.

**Conclusion:** Characterisation by underlying mechanisms of effect is a useful and viable tool to organise non-pharmacological interventions for breathlessness. Nevertheless, there are limitations for interventions without a clear underlying mechanism of effect, such as acupuncture. This categorisation will help to structure future reviews on non-pharmacological interventions and will provide an opportunity to tease out the relative importance of the three underlying mechanisms of effect.

**Abstract number:** P83

**Abstract type:** Poster

### Developing and Testing Discrete Choice Experiment on Home Palliative Care

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**Background:** Discrete choice experiment (DCE) is a quantitative method for eliciting preference by asking

people to choose between 2+ products/services. It helps determine which attributes of the product/service contribute the most to people's choices and thus to their utility.

**Aim:** To develop and test a new DCE on home palliative care (HPC).

**Methods:** Cross-sectional pilot survey study. Attributes and levels were based on a Cochrane review, a meta-ethnography and published DCEs on HPC. An experimental design was developed on SAS. The survey was piloted using cognitive interviewing with adult patients and their family carers from 3 HPC services in Portugal with 1+ follow-up home visits by the HPC team. Interviews were analysed for difficulties using Tourangeau's model of information processing. Logistic regression (LR), random-effects LR, conditional fixed-effects LR and alternative-specific multinomial probit were tested for choice modelling.

**Results:** The experimental design resulted in 24 choices (8 choice sets in 3 blocks) with 2 service alternatives, combining 5 attributes of HPC (family support, information/planning, type of home support, accessibility, waiting time (WT)). Including WT attribute allows willingness to wait calculations. The DCE was tested with 21 participants (11 carers, 10 patients with median PPS=45; interviews 26-120mins) out of 37 eligible. Median difficulty evaluated on a Likert scale was 2 (easy), though 2 patients did not finish the exercise. The statistical model converged (probit). Key difficulties related to comprehension (e.g. WT was sometimes understood as response time for every visit instead of time from referral to beginning of HPC) and judgement (e.g. indecision due to similarities between service alternatives).

**Conclusion:** The DCE method is feasible and acceptable, but not all patients are able to participate. In the main study we will place more attention on the explanation of the WT attribute.

**Funding:** Calouste Gulbenkian Foundation.

**Abstract number:** P84

**Abstract type:** Poster

### To what Extent is Retrospective Research in Nursing Home Residents Limited by Non-response-Bias?

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**Background:** Although the risk of non-response bias is a serious concern for retrospective surveys, there is little empirical evidence on the extent of this problem,

particularly in the context of end-of-life care research in nursing homes using proxy respondents.

**Methodology:** Both the Dying Well with Dementia study (DWD, 2010) and the ongoing PACE study 1 (2015) used randomized cluster-sampling to identify a representative sample of nursing homes in Flanders, Belgium. In PACE, all residents of these facilities who died over a 3 month period were reported (n=328); in DWD, only residents with dementia were reported (n=205). For each resident, the nurse and relative most involved in care and the general practitioner (GP) were given a structured questionnaire. Demographic and care-related characteristics of the resident extracted from the nurses' questionnaire (response rate DWD: 88%, PACE: 80%) were used to compare residents for whom the GP and/or relative did not complete the questionnaire with those for whom they did.

**Results:** Response rates for relatives and GPs were 53% in DWD and 61% for relatives and 67% for GPs in PACE. In DWD, there were no differences in demographic characteristics, stage of dementia or nursing care received between residents for whom the GP and/or the relative did or did not complete the questionnaire. Nurses perceived more consensus on care among relatives in cases where the GP completed a questionnaire (p=.004) than in cases where the GP did not. Non-response of relatives was not related to this characteristic. Results of PACE will be presented at the conference.

**Conclusion:** For both GPs and relatives there appears to be no non-response bias based on resident and care characteristics, though non-response by GPs may lead to bias based on consensus among relatives. These results suggest that non-response bias is not a barrier for the use of retrospective studies in research on end-of-life care in nursing homes.

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**Abstract number:** P85

**Abstract type:** Poster

### Handling Adverse Events in Palliative Care Nondrug Trials

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**Background:** Compliance to the Good Clinical Practice (GCP) guideline is a controversial topic for less regulated nondrug trials. Due to dissimilar structures a one-to-one transfer of GCP is neither possible nor reasonable. Arrangements have to be made to assure data quality and patient safety. In this context, Adverse Events (AE) assessment is particular challenging in palliative care (PC) research as patients are expected to have many disease related events during study course.

**Aims:** To evaluate current AE implementation in studies investigating nonmedical interventions in the domain of PC.

**Methods:** Keyword and MeshTerm based literature search in Medline and Embase (Oct. 2015) using synonym combinations of 'nonpharmacological intervention' and 'palliative care' with restriction to randomized controlled trials published since year 2000. Abstracts were reviewed for adequacy (study population, type of intervention) and, if so, full text was searched digitally for terms related to 'Adverse Events'. Respective passages were evaluated according to pre-specified criteria.

**Results:** 115 articles out of 462 references were identified. Almost all addressed AEs either in a deficient manner or not at all. Only 6 cases clearly described AE recording/reporting processes permitting critical evaluation. Those can be characterized by the following features: Restricting assessment either to predefined occurrences or to Serious AEs and excluding events due to natural disease progression. Appropriate criteria for distinction between intervention and disease relation were often lacking.

**Conclusion:** Findings highlight the need for a commitment to AE reporting and more transparency on AE recording procedures within the analyzed kind of trials, particularly regarding the evaluation of disease or intervention relatedness. Applicable and comprehensible criteria have to be discussed for a more harmonized approach which meets necessary quality standards and considers PC research conditions.

### Statistics

**Abstract number:** P86

**Abstract type:** Poster

### How Do Patients Die in the Czech Republic - Population-based Data about Last Hospitalization

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**Background:** Over 100 000 persons die annually in the Czech Republic, of which 68.5% die in an inpatient health care facility. Information about last hospitalization before death may bring highly desirable information about the organization of health care for patients in terminal stage of a disease.

**Aim:** To describe last hospitalization from the perspective of health care system in order to identify potential weak

points and search for opportunities for systemic changes and improvements.

**Methods:** Data from the National Database of Palliative Care was used. This database contains joined data from Death Certificates and from the National Register of Hospitalized Patients.

**Results:** Proportion of deaths occurring in tertiary teaching hospitals, acute care hospitals, post-acute hospital and inpatient hospices are 9.2%, 38.7%, 10.4% and 2.5%, respectively.

The data indicate that 69.4% of patients with cancer, 68.2% patients with chronic heart disease, and 44.2% of patients with dementia die in tertiary teaching hospitals and acute care hospitals.

Further 10.6% of patients with cancer, 17.1 % patients with chronic heart disease, and 42.5% of patients with dementia die in long-term care hospitals.

The number of hospitalizations during the last year of life of patients who died in a hospital was 1, 2, 3, and  $\geq 4$  in 32%, 26.2%, 16.9% and 24.7% of cases respectively.

**Conclusion:** Most patients with chronic progressive disease, who require the palliative approach, die in acute care settings. Therefore, there is a critical need to develop palliative services in the field of acute care to meet these needs adequately.

Repeated hospitalizations of patients in advanced stage of chronic disease during the last year of life are a common pattern of patient trajectory. It is important to identify these patients early and to start the comprehensive palliative care in due time to prevent undesired and potentially preventable admissions to acute and intensive care settings.

## Translational research

**Abstract number:** P87

**Abstract type:** Poster

### A Process to Dying? Metabolomic Changes in Urine towards the End of Life

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**Background:** Recognising when someone is in the last days of their life is an ongoing difficulty for clinicians. There is very limited evidence regarding biological or biochemical changes that occur in the last weeks and days of life.

**Aim:** To collect urine samples from patients towards the end of life and analyse these using metabolomic approaches.

**Method:** Within a specialist palliative care centre, urine was prospectively collected from patients with an expected prognosis < 4 weeks. Samples from a Control group were also collected: patients with advanced cancer and expected prognosis > 3 months, 4 normal volunteers and one patient with a non-malignant diagnosis. Samples were analysed for volatile metabolites (Volatile Organic Compounds VOCs) by Gas Chromatography Mass Spectrometry (GC-MS), and water soluble metabolites using Nuclear Magnetic Resonance Spectrometry (NMR). Data was analysed using MetabolAnalyst, a set of online tools for metabolomic data analysis and interpretation.

**Results:** Samples from 19 patients were collected: 11 experimental group, 8 control. GC-MS analysis identified over 390 VOCs. 84 VOCs were detected at significantly different levels in the last weeks and days of life. The number of statistically significant VOCs increased from 12 at four weeks before death, to 43 at 3-5 days before death. A trend analysis for the individual VOCs showed that of these VOCs, 1 was significant at four weeks before death and 22 VOCs were significant at 3-5 days before dying. The steepest rise in significant VOCs was seen in the last week of life. Results from the NMR studies will be ready for presentation at the conference.

**Conclusion:** Metabolomic studies and analysis may generate VOCs that can be used as a potential prognostic indicators.

**Abstract number:** P88

**Abstract type:** Poster

### Applying Knowledge Transfer in Palliative Care Settings: Findings from a Systematic Scoping Review

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**Objective:** Despite increasing levels of research evidence being generated in palliative care, there appear to be several barriers to the implementation of research in practice. The aim of this project was to review knowledge transfer and exchange (KTE) frameworks used in health settings and assess their relevance to palliative care.

**Methods:** In line with PRISMA guidelines, a systematic scoping review was developed to search articles included in six electronic databases (including MEDLINE, EMBASE, CINAHL and PsycINFO) for four terms (knowledge, transfer, framework, healthcare) and their variations.

**Results:** The search identified 4288 abstracts, with 294 eligible for full-text screening, resulting in 79 papers analysed. Studies were published between 1985 and 2014 (two thirds since 2006); the majority were conducted in North

America. In total 87 models were indicated, with the Promoting Action on Research Implementation in Health Services Framework (PARIHS) being the most common (n = 15).

The key components of the models include a partnership or collaborative approach to KTE, focus on the needs of the audience, and an awareness of different modes of communication. The papers were appraised for relevance to the palliative care and it was found that the study or the target population were relevant in many of the papers. The components most relevant to palliative care were used to establish a proposed model of KTE for palliative care.

**Conclusions:** The model offers guidance as to effective ways of translating different types of research knowledge to care providers and stakeholders, and could be utilised in hospital, community and home based settings as well as to inform future research. It is recommended that researchers adopt this model of KTE for palliative care in future research to ensure that research is conducted with knowledge transfer in mind.

**Abstract number:** P89

**Abstract type:** Poster

### Examining Delirium Epidemiology, Systems and Nursing Practice in Specialist Palliative Care Inpatient Units: A Mixed Methods Study

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**Background/aim:** Delirium is an under-recognised acute neurocognitive disorder frequently experienced by older inpatients. This research aimed to identify what is required to improve the capabilities of specialist inpatient palliative care nurses to recognise and assess delirium.

**Methods:** A two-phase mixed methods design examined delirium in palliative care inpatient settings from epidemiological, systems and nursing practice perspectives. During Phase one a systematic review on delirium epidemiology, cross sectional study and an environmental scan were completed, while Phase two employed Critical Incident Technique and focus groups to explore nurses' delirium experiences, perceptions and capabilities. Data were integrated at project conclusion to identify opportunities to improve delirium outcomes for patients receiving care in this setting.

**Results:** Internationally, delirium prevalence in palliative care units ranged from 26% to 62% during admission, increasing to 88% in the last hours of life, while one in five Australian palliative care inpatients with a mean age (SD) of 74 years ( $\pm 10$ ) were diagnosed as delirious in a 24-hour period. Almost all delirium guidelines exclude evidence and recommendations related to end of life care, and delirium systems are missing from palliative care units. Ambiguous terminology and nurses' poor conceptual and diagnostic understanding contributes to delirium under-recognition and inadequate assessment. The Nursing Delirium Screening Scale is feasible for use, yet optimal recognition and assessment by nurses also requires rapport with patients, engagement of family, validation of delirium tools in this setting, point-of-care guidance, educational strategies and interdisciplinary teamwork.

**Conclusion:** More careful navigation of patients away from an episode of delirium and building the capacity of nurses to provide exemplary delirium care must become core business within specialist palliative care inpatient units.

**Abstract number:** P90

**Abstract type:** Poster

### Are Serum Concentrations of Cytokines Associated with Symptom Intensities or Response to Corticosteroids in Advanced Cancer Patients Receiving Opioids?

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**Background:** Studies have linked cancer related inflammation with symptom intensity in cancer patients with advanced disease. We conducted a randomized controlled trial assessing corticosteroids' (CS) effects on pain, appetite and fatigue in cancer patients.

This was a post hoc exploratory analysis to investigate whether inflammatory markers at baseline were associated with symptom intensity; or with level of response to CS.

**Methods:** Adult cancer patients on opioids with average pain intensity last 24 hours  $\geq 4$  (NRS 0-10) were randomized and received methylprednisolone 16 mg or placebo twice daily for 7 days. Patients were evaluated at inclusion and day 7 using the EORTC QLQ-C30. At randomization sedimentation rate (SR), CRP, and the cytokines IL-1 $\beta$ , IL-1ra, IL-2, IL-4, IL-6, IL-8, IL-10, IL-12, IL-18, INF- $\gamma$ , TGF- $\beta$ 1, MIF, MIP-1 $\alpha$ , MCP-1, TNF- $\alpha$  and sTNF-r1 were analysed.

**Results:** 49 patients with mean Karnofsky Performance index 67 (CI 63-71), median survival 86 days, and mean opioid consumption 259 mg / day (oral morphine equivalents) (CI 178-339) were included. Eight cytokines: sTNF-r1, IL-1 $\beta$  IL-6, IL-18, MIF, MCP, TGF- $\beta$ , IL-1ra, and CRP and SR were elevated. Physical and role function were highly correlated to CRP and sTNF-r1, and IL-6 and SR, respectively. Medium correlations were found between appetite and CRP, IL-6, and IL-1 $\beta$ ; fatigue and IL-1ra; cognitive function and TGF- $\beta$ 1; and dyspnoea and IL-1 $\beta$ .

In 38 patients receiving CS, regression analysis suggested a non-significant association between sTNF-r1 and MCP at baseline and improvement of appetite and pain after 7 days of CS-treatment, respectively.

**Conclusion:** Inflammatory markers CRP, SR, sTNF-r1, IL-1 $\beta$  IL-6, IL-18, MIF, MCP, TGF- $\beta$ , and IL-1ra were elevated in this post-hoc exploratory analysis in advanced cancer patients. The concentrations of some cytokines were associated to role function, physical function, appetite, fatigue, cognitive function and dyspnoea.

**Funding:** Telemark Hospital Trust.

**Abstract number:** P91

**Abstract type:** Poster

### Cancer Pain: Bridging the Evidence-practice Gap

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**Background:** An evidence-practice gap exists in the management of cancer pain. This study aims to evaluate the effectiveness and cost-effectiveness of a suite of cancer pain guideline implementation resources designed to improve pain outcomes for patients attending ambulatory oncology and palliative care. This translational research program aims to facilitate evidence uptake in the clinic.

**Methods:** This trial employs a stepped-wedge cluster randomised controlled design. The clusters will be participating ambulatory oncology and palliative care services. Patients will be eligible if they present to a participating service with cancer and pain during the study period. During an initial control phase, services will be equipped with a system for screening patients for pain. During a training phase, 'clinical champions' and clinical staff at each centre will be supported to tailor the implementation resources to their centre's needs. In the intervention phase, services will be given procedures to feedback screening results to medical teams prior to consultation and the following guideline implementation strategies:

- 1) a patient goal setting tool, pain management plan and diary;
- 2) QStream health professional education program; and
- 3) audit and feedback regarding centre performance on key standards of care.

The trial's primary outcome will be patients' pain severity one week after presenting with moderate pain, defined as  $\geq 5$  on a 0-10 numerical rating scale. Secondary outcomes will include quality of life, carer experience, and cost-effectiveness. Eighty-two patients per centre at 6 sites (N=492) will provide >90% power to detect the main effect. Cost-effectiveness analysis will estimate the incremental cost per extra quality adjusted life year.

**Conclusion:** Better management of pain has potential to increase quality of life and caregiver experience. The trial design and experience of implementation in first two sites will be reported.

**Abstract number:** P92

**Abstract type:** Poster

### Salivary Diurnal Cortisol Profiles in Patients Receiving Palliative and Supportive Care Services: A Cross-sectional Study

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**Background/aims:** Cortisol secretion has a marked circadian rhythm, characterised by high morning and low evening levels. Reduced diurnal variation, represented by a flatter rate in the decline in cortisol across the day ('slope'), is indicative of hypothalamic-pituitary-adrenal (HPA) axis dysregulation, and has been found to be associated with

frailty, poor physical performance and shorter survival in a range of populations. Its prevalence and meaning in the palliative care context has not been established. This cross-sectional study aimed to explore the prevalence of HPA axis dysregulation in community-dwelling patients receiving palliative or supportive care services.

**Methods:** Patients were compared against an age-matched healthy control group. Those on systemic steroids in the preceding 4 weeks were excluded. Saliva samples were collected over 2 consecutive days at 3, 6 and 12 hours after waking. Diurnal slopes were calculated by regressing log-transformed cortisol values on collection time. Slopes were categorised as 'declining', 'flat', 'ascending' or 'inconsistent' using established criteria.

**Results:** 61 patients with advanced malignant (n=23) and non-malignant (n=38) disease (mean age  $\pm$ SD: 73.1 $\pm$ 9.1 years, males=34) were compared against 50 healthy controls (mean age $\pm$ SD: 74 $\pm$ 7 years, males=16). Diurnal cortisol patterns differed significantly between the two groups

( $\chi^2=13.9$ ,  $p<0.01$ ): 20.3% of patients had aberrant (flat or ascending) patterns versus 0% of healthy controls. In a one-way ANCOVA, controlling for age, gender and socioeconomic status, the mean diurnal slope was significantly flatter in the patient group relative to the healthy group [adjusted mean slopes: -0.07 (CI: -0.08 to -0.05) versus -0.16 (CI: -0.18 to -0.15),  $p<0.001$ ]. Slopes did not differ significantly between malignant and non-malignant subgroups.

**Conclusions:** HPA axis dysregulation may be common in advanced disease. Further work is necessary to establish its clinical implications.

## Palliative care organisation and health care services

**Abstract number:** P94

**Abstract type:** Poster

### A Review of Contact between Inpatient Palliative Care Services in St. James's Hospital, Dublin and General Practitioners

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**Aims:** The project aimed to review practice within the palliative care team to ascertain if the goal of contacting patients' GPs on discharge from hospital, as recommended by the Standard Operation Procedure (SOP) of the Team, was being met. The SOP is derived from The National Clinical Programme for Palliative Care Guideline May 2014 (Standard 2.3). It recommends that: '*Service users receive integrated care that is coordinated effectively within and between services*'.

**Method:** A retrospective review of records using the Electronic Patient Record (EPR) System

A list of all patient discharges from the specialist palliative care inpatient services from January 1<sup>st</sup> 2015 to April 21<sup>st</sup> 2015 was generated from The EPR System. The data sought from each EPR was as follows:

1. Was the GP contacted: Yes or No
2. If the GP was not contacted, why not?

Initial data collection showed:

- Total number of patients discharged = 102
- Total number of GPs contacted = 16/102 (15.7%)

Results were presented at a Multi-Disciplinary Team Meeting. A discharge algorithm was created. Team members discussed difficulties in contacting the GPs and agreed that the algorithm could reduce workload without compromising patient care.

On July 7<sup>th</sup> 2015 the audit was repeated looking at discharges between May 1<sup>st</sup> and July 6<sup>th</sup>. Comparing results of the two rounds shows that number of calls to GPs where required increased from 15.7% to 53.8% following intervention.

#### Points for consideration for future practice:

Contacting GPs remains a major challenge due to the time-consuming nature of telephoning GPs.

Verbal feedback from GPs suggests that contact from the SPC Team once a patient is discharged is appreciated and contributes positively to patient care.

A final algorithm was developed to reflect the findings of the complete audit cycle and encourage team members to continue to liaise with our colleagues in the community.

**Abstract number:** P95

**Abstract type:** Poster

### Combining Research Generated Performance Data with National Economic Data to Promote the Hospice Based Model of Palliative Care. A Systems Analysis Case for Enhanced National Funding in Ireland

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**Background:** Sixteen counties in Ireland have no access to inpatient hospice palliative care. It is essential to promote the case for further development of hospice based services using sound evidence from research on the clinical effectiveness and efficiency of hospice care along with national economic data.

**Methodology:** A systems analysis combining data from the Irish Economic Evaluation of Palliative Care (ESRI 2015) with the results of a prospective, observational cohort study of consecutive admissions (n=400) to a specialist palliative care unit (SPCU) in Ireland.

**Results:** Admission to a SPCU is clinically effective, inducing phase stabilization in 70.7% of unstable patients within 72 hours, and progressively improves pain ( $p=0.007$ ), other symptoms, psychological and carer distress ( $p=0.001$ ). Stable phase also results in improved performance status ( $p<0.001$ ). Hospice care is clinically efficient, with phase driven intensity of nursing interventions resulting in patients in the unstable, deteriorating and terminal phases receiving progressively higher intensity of nursing care but when stabilized, lower intensities ( $p=0.001$ ). In addition, 90% of hospice based care days are provided in the home setting outside of the unit through hospice at home services, facilitating care at home. ESRI and local data shows that the hospice model reduces A&E visits by 60-70% in the last 3 months of life, greatly reduces the number of deaths in hospital and reduces the use of hospital resources by 50% in the last 3 months of life. However, service wide, in the last year of life, the hospice model of care is no more expensive than the non-hospice based model demonstrating systemic technical and productive efficiency.

**Conclusion:** Hospice inpatient care is clinically effective, systemically efficient and is a cost equivalent model that reduces hospital resource utilization and facilitates patients being cared for at home. Investment in this model of care is a national imperative.

**Abstract number:** P96

**Abstract type:** Poster

### **An Intervention to Improve Supportive Care for Family Caregivers of Patients with Cancer: Design, Acceptability and Planned RCT for its Effectiveness**

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**Aim:** To describe a pragmatic intervention designed to improve supportive care for family caregivers (FC) of lung cancer patients, and its planned effectiveness assessment.

**Methods:** The intervention was developed from the knowledge gained from previous studies, a literature review and the distress screening program already in place for cancer patients in Quebec, Canada. The distress screening tool currently used for patients was adapted to the FC context. It includes a distress thermometer and a problem checklist. Its convergent validity with the Hospital Anxiety Depression Scale (HADS) was tested in 29 FC of patients at different phases of their lung cancer. Individual interviews with 12 FC and 2 focus groups with members of an oncology team and with 8 family physicians (FP) from diverse practice settings were conducted to assess the usefulness and acceptability of the intervention and finalize it accordingly.

**Results:** Correlation between the distress thermometer score and the HADS was good ( $r=0.64$   $p=0.0002$ ), as with the number of problems checked ( $r=0.65$   $p=0.0001$ ). The intervention was well accepted by FC, the oncology team and FP. It includes:

- 1) systematic FC distress screening and problem assessment near their relative's cancer diagnosis, and every 2 months;
- 2) privileged contact with an oncology nurse away from the patient to further identify and address FC problems;
- 3) liaison by the oncology nurse with the family physician of FC reporting high distress (thermometer score  $\geq 5/10$ ), or problems relying on FP expertise.

An ongoing randomized trial supported by the Quebec Health Research Fund is assessing the intervention effectiveness on FC distress and needs.

**Conclusion:** Prior to implementation, any intervention aiming to produce practice change needs to be accepted and endorsed by all involved stakeholders. Based on inter-professional collaboration between primary care and oncology care, this intervention has the potential to improve cancer supportive care.

**Abstract number:** P97

**Abstract type:** Poster

### **Organisational Factors Affecting Transition from Children's to Adult Services by Young Adults with Life-limiting Conditions in Ireland**

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**Research aims:** To provide an overview of the transition services provided to young adults with life-limiting conditions in Ireland, identifying models of good practice and the factors influencing the quality and continuity of care.

**Study population:** Service providers in statutory and non-statutory organisations providing care to young adults with life-limiting conditions; young adults with life-limiting conditions and their parents.

**Study design and methods:** A realist evaluation approach using a mixed methods design with four phases of data collection: a questionnaire survey of health, social, educational and charitable organisations providing transition services to young adults in Northern Ireland and one Health Service Executive area in the Republic of Ireland with 104 individual responses from 29 organisations; interviews with eight young adults, two focus groups with parents/carers and 17 interviews with service providers.

**Method of analysis:** Data from the survey, interviews and focus groups were thematically analysed seeking to explain the impact of services and interventions, and to identify organisational factors influencing the quality and continuity of care. The two jurisdictions were analysed separately and a comparative analysis undertaken.

**Results:** Eight interventions were identified associated with a successful transition to adult care: an early commencement, effective communication between children's and adult services, orientation of the young adult to adult care; person centred approach, a transition coordinator, using an interdisciplinary and interagency approach, developing the young adults' autonomy, and supportive parents. Factors influencing the quality and continuity of care included the presence of a capable and willing adult service; and children's services using the time made available by an early commencement to support parents in ceding control to facilitate development of the young adults' autonomy.

**Abstract number:** P98

**Abstract type:** Poster

### What Are Physicians' Reasons for Not Referring People with Life-limiting Illnesses to Specialist Palliative Care Services? A Nationwide Survey

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**Background:** Many people who might benefit from specialist palliative care services are not using them.

**Aim:** We examined the use of these services and the reasons for not using them in a population in potential need of palliative care.

**Methods:** We conducted a population-based survey regarding end-of-life care among physicians certifying a large representative sample (n = 6188) of deaths in Flanders, Belgium.

**Results:** Palliative care services were not used in 79% of cases of people with organ failure, 64% of dementia and 44% of cancer. The most frequently indicated reasons were that

- 1) existing care already sufficiently addressed palliative and supportive needs (56%),
- 2) palliative care was not deemed meaningful (26%) and
- 3) there was insufficient time to initiate palliative care (24%).

The reasons differed according to patient characteristics: in people with dementia the consideration of palliative care as not meaningful was more likely to be a reason for not using it; in older people their care needs already being sufficiently addressed was more likely to be a reason. For those patients who were referred the timing of referral varied from a median of six days before death (organ failure) to 16 days (cancer).

**Conclusions:** Specialist palliative care is not initiated in almost half of the people for whom it could be beneficial. The reasons for not using palliative care found in our study inform future health policies regarding palliative care in at least two ways. Firstly, strategies to tackle palliative care needs within the population should not only focus on specialist palliative care services but also on adequate palliative care skills in regular caregivers. Secondly, there is still a need to promote awareness of the benefits of early palliative care, including its potential and meaningfulness in non-cancer conditions such as dementia.

**Abstract number:** P99

**Abstract type:** Poster

### Working Methods of Hospice and Palliative Care Networks - Results of a Status Quo Analysis

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**Background:** Networking of palliative care (PC) and hospice providers is vital to ensure local high-standard

support and care for seriously ill and dying patients and their relatives. However, little is known about beneficial strategies of collaboration within networks. This study aims to investigate the general conditions under which hospice and PC networks in Bavaria, Germany, perform. Modes of working, forms of organisation, and communication channels are explored.

**Methods:** This project is the initial phase of a larger mixed-methods study. Data were collected in semi-structured interviews with 10 coordinators and chairpersons of 10 Bavarian hospice and PC networks. The interviews, conducted between March and June 2015, were audiotaped, transcribed verbatim, and analysed by 3 investigators with the aid of the computer-assisted qualitative data analysis software MAXQDA.

**Results:** Five central themes emerged:

- 1) historical development of the network;
- 2) network conception, objectives, and mission;
- 3) ways of working;
- 4) partners in own network; and
- 5) other networks.

Networks are organised in different ways, ranging from rather informal, loose connections to more formalised frameworks. Respondents emphasised the importance of direct contact with network partners via person-to-person media, regular meetings, and joint events. Non-bureaucratic cooperation on a basis of mutual trust and communication on eye-height between volunteers and professionals and at the interface of ambulatory and inpatient services was considered critical for the often mentioned objective to provide patient-centred care.

**Conclusions:** Well-trying and established practices of networking are present in the networks included in the study, but they are not systematically documented and hence not easily accessible to those outside the own network. The gained data will foster the development of a best practice recommendation for regional hospice and PC networks.

**Abstract number:** P100

**Abstract type:** Poster

### **DRG and Inpatient Palliative Care - Does it Fit? Looking for Factors that Influence the Case Related Cost**

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**Background:** More and more Palliative Care (PC) Services in Germany are paid on the basis of diagnosis related

groups (DRG). PC professionals suspect the German DRG system to not really represent the case related cost. This study presents a first approach to compare total cost of inpatient PC service to the revenues generated inside the German DRG system.

**Methods:** The calculated case-related cost of 51 patients admitted directly to an inpatient PC service was compared to the revenues generated inside the DRG system. Additionally, the cases were screened for factors that may be related to higher total cost (age, symptom load measured by HOPE-SPCHL or ECOG status at admission). Total cost per patient was calculated according to the cost object controlling guidelines by the German DRG Institute (InEK, Institut für das Entgeltsystem im Krankenhaus). Statistical calculation was executed using IBM SPSS Statistics software (Mean, Chi Square, linear regression).

**Results:** Mean cost per day was generally higher on the first days of the stay. Linear regression of the absolute cost and the revenues calculated by the DRG system revealed a regression coefficient of 1.21. The coefficient of determination is 0.719. Of 51 cases, only 10 reached a cost-covering remuneration. Mean cost per day was not directly associated to age, symptom load at admission or ECOG status at admission.

**Conclusions:** These results support the suspicion that the German DRG system does not reproduce the complexity and the cost per patient of inpatient PC treatment. Larger number of cases is necessary to better examine factors accounting for the total cost of treatment and to provide a base for case related reimbursement.

**Abstract number:** P101

**Abstract type:** Poster

### **Standard Operating Procedures for Symptom Management in a Palliative Care Unit**

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**Background:** In palliative care it may help to standardize repeating processes like pharmacological symptom oriented treatment. Therefore a multiprofessional panel of experts in the field developed standard operating procedures (SOP) for symptom oriented treatment of dyspnea, pain, anorexia and nausea. The SOP are used primarily in the palliative care unit and are based on the best existing evidence and clinical experience. Feasibility foretold to be well in a pilot study, but efficacy of these SOP is unknown.

**Method and patients:** All patients admitted to our ward between February 2014 and May 2015 (n=276) were either treated according to SOP or the reasons for deviation from the SOP were recorded. Symptom burden was routinely assessed by proxies (HOPE Symptom & Problem Checklist, 4241 points of assessment) and by patients (MIDOS\_2, 1245 points of assessment). Both tools use a 4 - point Likert scale (0=none / 1= mild / 2=medium / 3= strong).

Differences were computed by single factor variance analyses with repeated measurement (Greenhouse-Geisser, Huynh-Feldt), statistical significance was set to  $p < 0.05$ .

**Results:** Patients admitted suffered from pain (40% of all recorded assessments), nausea (15%), dyspnea (37%), and anorexia (67%). Treatment according to SOP was possible in the majority of cases: pain (99%), nausea (97%), dyspnea (96%), and anorexia (71%).

Treatment following the SOP led to therapeutic success regarding pain, nausea and dyspnea with the effect of changing moderate to severe symptoms to none to light symptoms in pain (95% of all recorded assessments), nausea (93%), dyspnea (94%).

**Conclusions:** Treatment according to our proposed SOPs is feasible and efficient in managing pain, nausea/emesis, and dyspnea in a palliative care concept.

**Abstract number:** P102

**Abstract type:** Poster

### Postmortal Cornea Donation in Palliative Care - A Structured Approach

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**Background:** About 5000 cornea are transplanted every year in Germany, enabling functionally blind patients to see again. However there is still a constant shortage of transplantable cornea. One of the antagonists may be the communication about donating tissue in face of a terminal illness. In our palliative care service we introduced a structured approach and report on the outcome in tissue donation and its effect on health care professionals (HPR).

**Methods:** We introduced as a standard operating procedure on admission a discussion about tissue donation (SOPtd) with the patient and/or next of kin. The structured

approach implemented the question alongside the inquiry on advanced directives (health care proxy, living will, organ donation). HPR were prepared to empathically react on patients and families emotions and distress. We assessed the number of donations and the emotional strain and willingness to partake of HPR, both measured by a 6-point Likert scale before and after the implementation, and conducted a semi-structured interview.

**Results:** In 12 months prior to SOPtd we recruited 2 donors in 315 patients of whom 212 died in our care; in 12 months after we recruited 13 donors in 347 patients of whom 202 died. The SOP td was carried out in 82% of all admissions. We interviewed 17 HPR. Strain on HPR was reduced significantly by SOP td (median pre 4, post 2,  $p < 0.05$ ) as willingness to partake increased (median pre 5.5, post 1.5,  $p < 0.01$ ). Most common reasons for emotional strain were "association with death", "lack of training", and "being out of place". Perceived benefits were "maintain patient's autonomy", "to help/ inform in making the decision".

**Discussion:** The SOPtd proved to be feasible and lead to an obvious increase in cornea donations in our palliative care service. Above that the structured approach helped health care professionals to decrease emotional strain and increase willingness to partake in tissue donation discussions.

**Abstract number:** P103

**Abstract type:** Poster

### Identifying Unmet Palliative Care Need: Audit of Acute Hospital Inpatient Referrals

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Audit of hospital referrals to specialist palliative care (SPC) is needed to identify if patients are overlooked/ referred late resulting in unmet needs. Published literature was reviewed to develop evidence-based audit standards and identify screening tools/questions in the absence of nationally mandated standards for referral.

**Objectives:** To identify unmet need in hospital inpatients; To assess if needs require education/up-skilling of generalist workforce and/or SPC direct patient contact.

**Population:** Medical records from 5th occupied bed on given day for 6 purposively selected specialty wards.

**Analysis:** Unmet need identified through application of: current SPC referral criteria; published tools H-CAT (trigger tally system) and SPICT (indicators in non-malignant diseases); SPC auditor/ward nurse judgment of needs.

**Results:** 49 cases sampled (8 known to SPC). 17/49 had cancer. Ward nurses considered 13/49 to require SPC but auditors identified 18/49. Therefore, 37% of patients needed SPC, but only 21% had been referred. Potential referral triggers included pain, (67.3% of patients, with 155 trigger entries (t) confusion (40.8%, t=61); nausea and vomiting (38.8%, t=43) and constipation (36.7%, t=55). Per patient, those not needing SPC (ward could address need) averaged t=6.1 physical symptoms, 0.8 psychological and 0.7 information/planning needs (IPN). Those referred for SPC averaged t=20.5 physical, 4.8 psychological and 4.4 IPN per patient. Those with SPC need but not referred averaged t=9.7 physical, 1.5 psychological and 1.5 IPN per patient indicating intermediate need exceeding ward care but not triggering referral. Upskilling potential was identified in 21 cases (13 also needing direct SPC) including advance care planning (n=12) and symptom management (n=8).

**Conclusions:** 22.4% of patients had unmet needs requiring improvements in skill mix and identifying need for referral. No tool was superior for identification. Outcomes of our action plan will be reported.

**Abstract number:** P104

**Abstract type:** Poster

### Keeping the Doors Open: A Current State Assessment of Palliative Care Units in Ontario (Canada)

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**Background:** Jurisdictions known internationally for full integration of palliative care stress a systems approach and

service provision across sectors - including palliative care units (PCUs). An absence of these components might result in bottlenecks and sub-optimal access to services.

**Aim:** As part of a larger research program toward services across settings, the goal of the study was to gather data related to PCUs in the Province to guide health care planners and providers.

**Methods:** Comprehensive electronic survey (including human resources, utilization statistics and services provided) of all facilities identified as likely hosting PCUs/palliative beds between late 2014 and early 2015. Residential hospices were excluded.

**Results:** 29 out of 43 facilities responded; 21 self-identified as PCUs and 8 had “floating beds”. Of these, 14 were housed in acute care hospitals and 7 in complex continuing care (CCC) facilities, including Veterans Affairs. Variability was noted toward staffing ratios; only 13 facilities had access to psychologists. Data regarding service utilization was scarce; 19 facilities reported admission wait times (median 3 days); 14 reported length of stay (median 21 days) and 18 occupancy rate (mean 92%). Most facilities provided interventions such as parenteral hydration (25/29) and methadone treatment (24/29); fewer thoracenteses (20/29) and intraspinal block maintenance (11/29) - services often not provided in residential hospices. Many facilities flagged challenges related to funding; a key issue was the current Ministry funding formula for CCC-based PCUs.

**Conclusion:** PCUs are a key component of the health care system. Standards regarding staffing levels to meet the needs of patients with complex problems are required and remuneration needs to be fine-tuned to better reflect the care provided.

**Funding:** Support provided by Cancer Care Ontario’s Palliative Care Program and a Summer Student Award from the Technology Evaluation in the Elderly Network.

**Abstract number:** P105

**Abstract type:** Poster

### Status Quo of Palliative Care in the Cantonal Health Care Setting of St. Gallen: A Cross-sectional Study

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Given the national strategy for palliative care, corresponding structures should be developed in all Swiss cantons. For quite some time, the Health Department of St. Gallen has been developing a cantonal concept for palliative care, though several challenges, including missing palliative care data, have delayed the project. It is thus necessary to

evaluate all areas of health care in St. Gallen with respect to palliative care. To evaluate the status quo of palliative care in the cantonal health care settings of St. Gallen, the results of which can catalyze the development of the cantonal concept. Several cross-sectional survey studies have been conducted with eight hospitals, 550 primary care physicians, 117 long-term care facilities, 61 home care services, and 10 volunteer services. The response rate was lowest at family doctors (21.6%), 67.5% for long-term care, 49.2% for home care services, and peaked at 100% for hospitals and volunteers services. Analysis shows that St. Gallen exhibits strong basic health care offerings in palliative care, though its quality varies considerably in the different areas of health care. Fragmentation among the different settings induced different perceptions of what palliative care should be, which has caused a heterogeneous health care structure. Overall, the palliative care situation in St. Gallen is satisfactory, though realizing homogenous. Equitable palliative care will require additional efforts for further activities. From the present study, it is possible to formulate adequately targeted goals for the palliative care concept in the canton St. Gallen.

**Abstract number:** P106

**Abstract type:** Poster

### **Integration of Oncology and Palliative Care: Setting a Benchmark**

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**Introduction:** Integration of oncology and palliative care (PC) should be standard for patients with advanced cancer. To clarify the concept, an expert panel has developed 13 minor and 30 major criteria. The PC service at this hospital works in close association with oncology. In-patients receive shared care from both teams and a PC outpatient clinic runs alongside the oncology clinic. We consider our cancer service to be "integrated". The aim of this study was to determine whether we meet the criteria of integration as defined by the expert panel.

**Methods:** Based on the expert criteria, a survey was undertaken to determine the perceived level of integration by all health care professionals (HCPs) within our cancer centre. An objective determination of integration was obtained from chart reviews of all patients who died in the first 6 months of 2015. Integration was defined as : >70%

of all respondents answered "agree" or "strongly agree" to each distractor and >70% of patient files supported each criteria.

**Results:** Preliminary data show that >90% of the HCPs are aware of the outpatient PC clinic, a PC interdisciplinary team and a PC specialist with a senior leadership position. 58% consider that patients are referred early to PC, 8% don't agree, 34% don't know. Only 50% is aware of combined PC and oncology educational activities. 86% of patients were seen by the PC team, either in the outpatient or the inpatient clinic. The median time from referral to death was 78 days (range 8-546). Symptom assessments were documented in 83% of the charts. Of the patients admitted to the intensive care unit within 30 days before death, none had a PC consultation.

**Conclusion:** Our cancer service meets the criteria of an integrated oncology and PC service and can be considered as a benchmark. The knowledge of the level of integration is not equally distributed amongst HCPs. Awareness of those areas in which integration is lacking provides an opportunity for service development.

**Abstract number:** P107

**Abstract type:** Poster

### **Introducing a System to Prioritize Inpatient Admissions (SPIA) to Hospice: Evaluation of a Service Improvement Initiative**

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**Background:** Demand for admission to our 18 bed hospice inpatient unit (IPU) is high; frequently 10-15 patients await admission at one time. Priority is given to those perceived as having greatest unmet specialist needs. Provision of information regarding specialist needs using standardised referral form is variable, and comparison of needs challenging. We adopted a System for Prioritizing Inpatient Admissions (SPIA) whereby referral data is augmented by assessment of level of need in a number of weighted domains, as assessed by referrer, resulting in a total score. This is completed upon referral, at weekly intervals and when a patient's condition changes.

**Methods:** We measured the behaviour and attitudes of clinical staff involved in admissions meetings regarding the allocation inpatient beds. This was done by questionnaire at baseline and 3 months following introduction of the SPIA. The SPIA in use in another institution was adopted with minor adaptations following local consultation. We retrospectively reviewed the SPIA data of patients referred during June 2015. Data analysis was descriptive.

**Results:** 9/16 staff returned baseline and 7/16 the post-intervention questionnaire. Compared with baseline,

post-intervention expressed ease in describing prioritization process increased from 56 to 100%; perceived efficiency of the process as very good/good was 100% versus 78% expressing it as fair pre-intervention; confidence that beds are always allocated according to need increased from 0% to 43%; 71% versus 45% felt that the method of allocation was consistent and 71% felt that the SPIA provided useful additional patient information. 25 patients were referred, mean duration on list was 8 days. 52% were admitted, 32% died prior to transfer or too unwell to transfer. Change in physical symptoms and prognosis were most common reasons for changes in score.

**Conclusions:** SPIA was perceived to increase transparency, consistency, efficiency and confidence in process.

**Abstract number:** P108

**Abstract type:** Poster

### Analysis of the Experience of Integrated Palliative Care Work in the West Area of Madrid

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**Background:** Integrated Care Model comes with the intention of promoting coordinated and interdisciplinary processes for patients with advanced disease and their families. It brings together all the specific palliative care teams providing services in a geographic area.

**Objectives:** To evaluate the performance our Integrated Unit in its first 4 months. To evaluate the use of videoconference as a facilitator element for sharing all information of the patients included in the program.

**Methods:** West Palliative Sector consists of 7 specialist Palliative Care Teams for a population of 714.000 people: 2 hospital teams, 3 domiciliary teams and 2 Inpatient Care Units, 1 public and 1 private. Integrated Unit provides care for a population of 206.000 people, consists of the following resources: 1 hospital team, 3 domiciliary teams, 2 Inpatient Care Units, 1 public and 1 private. Formal professional interaction happens through weekly videoconference in which all multidisciplinary teams (doctors, nurses, nursing assistants, psychologists, social workers) coordinate to draw up the patients Multidisciplinary Action Plan involved.

**Results:** Between 21/5/2015 and 27/8/2015, 14 videoconferences were held. 101 patients aged  $\geq$  18 years, 64 males (63%) and 37 women (37%) were discussed; 82% oncologic patients, 18% non-oncologic. 159 consultations were carried out (34 patients were discussed in more than 1 meeting). A median of 11 cases per meeting (range 5-21) were presented. Reasons for inclusion were: referral to another team (22,8%), monitoring (60,0%), preparation/monitoring of mourning (14,5%) or hospitalization (2,8%).

**Conclusions:** In our experience, the use of new technologies facilitates communication between teams involved in the Integrated Unit. Videoconferencing permits a multidisciplinary assessment of the patient's situation, and allows interactive participation of different professionals. It has been a very useful tool in the continuous monitoring of many of our patients.

**Abstract number:** P109

**Abstract type:** Poster

### Part 2: Measuring Complexity of Needs in Palliative Care: A National Qualitative Study of Stakeholder Perspectives

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**Background:** Although measurement is increasing in palliative care, there is limited standardisation in measuring complexity. Meaningful measurement is important for comparative evaluation and benchmarking.

**Aim:** To appraise stakeholders' views on measuring complexity in palliative care to determine a standardised approach.

**Study design/methods:** Face-to-face semi-structured interviews with UK stakeholders from hospital, hospice and community settings, purposively sampled by geographical location, background and experiences of models of care. Techniques to enhance trustworthiness were informed by COREQ guidelines. Framework analysis was conducted, with data handled in NVivo.

**Results:** Interviews were completed with 65 of 67 stakeholders, including 10 patient/carer representatives, 38 clinicians (i.e. medical, nursing, allied, spiritual care, social care and welfare), 8 national leads and 9 managers. Initial themes include:

- i) **Need for measuring complexity:** Participants indicated a need to measure complexity to standardise practice, manage caseloads, justify service activity and reduce inequity;
- ii) **Acceptability/feasibility of measuring complexity:** Participants had mixed views about whether complexity can be measured. Most suggested a scoring system, such as hierarchies or composite scores. Regardless, the need to include both individual needs and interactions with services when measuring complexity was deemed important; and
- iii) **Challenges/concerns in measuring complexity:** Losing sight of individual needs, variability of scoring between health professionals, frequency of assessment, data collection and storage, and increased staff workload were identified.

**Conclusion:** There is broad support for measuring complexity in palliative care but there are varied views about how this can be achieved. Future measurements need to be clear, brief but meaningful, and take account of individual needs, service interactions and address inequity.

**Funder:** NIHR PGfAR (RP-PG-1210-12015).

**Abstract number:** P110

**Abstract type:** Poster

#### Interim Analysis of Outcomes for Transfer of Patients from Hospice to Hospital

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**Background:** There is focus on the cost of admission to hospital for patients in the last year of life and a drive to reduce admissions. For some patients in the last year of life, admission to hospital for acute management is required, appropriate and beneficial.

Transferring patients from hospices to hospital can be complex and many factors are taken into consideration, most of all patients' wishes.

There is little evidence regarding outcomes for palliative care patients transferred from hospice to hospital.

**Aim:** To add to the evidence base on utilisation of hospital resources for patients at the end of life and explore decision making processes and outcomes for patients transferred to hospital from hospice.

**Method:** A survey of demographics, decision making processes and outcomes for patients transferred acutely from 3 hospices to hospitals over 9 months was recorded prospectively, gathering real time data.

**Results:** Interim results show that 26 patients were transferred to hospital. Average age was 61 years. 21 had

advanced cancer and most had an ECOG performance status of 3. Most patients had been admitted to the hospices for symptom control of pain, 4 were admitted for terminal care. 3 were receiving chemotherapy and one of these was in a Phase 1 trial.

Only 2 patients had opted not to be transferred to hospital at the time of admission to hospice but agreed to be transferred following unexpected events.

Most transfers were due to sepsis, 2 for falls resulting in fractures, 5 for invasive procedures and 3 for investigations not available in the hospices. 21 patients were discharged, 5 on the same day following management in the emergency department. 5 patients died in hospital. Average length of stay was 6.8 days. Of the 5 patients that died in hospital 3 had unexpected reversible acute conditions. All 5 patients had capacity to agree to transfer to hospital.

**Conclusion:** Admission to hospital for some patients at the end of life is appropriate and of benefit with good outcomes.

**Abstract number:** P111

**Abstract type:** Poster

#### Developing a Model of Short-term Integrated Palliative and Supportive Care for the Frail Elderly with Non-cancer Conditions in Community Settings: Perspectives of Older People, Carers and Key Stakeholders (OPTCare Elderly Study)

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**Background:** Improving access to palliative care (PC) for frail older people with non-cancer conditions is an international priority. Short-term integrated palliative and supportive care (SIPS) is one proposed model, but little is known about the views of health professionals (HP), older people and carers.

**Aim:** To develop the SIPS model of care for older people with non-cancer conditions by synthesising recommendations from key stakeholders with views of older people and carers.

**Methods:** Transparent Expert Consultation using nominal group technique to generate recommendations for SIPS

model, and consensus survey (1-9 low to high agreement) involving HPs, voluntary sector and carer representatives, and researchers. Focus groups with older people and carers using vignettes to facilitate discussion. Data analysis comprising descriptive statistics for survey data and content analysis for focus group transcripts. Synthesis across *a priori* areas of uncertainty:

- 1) timing of SIPS delivery; and
- 2) processes of integrated professional working (IPW).

**Results:** Two consultations with 63 stakeholders generated 30 recommendations. We conducted 3 focus groups with volunteer carers, day centre members/carers, and nursing home residents (n=17).

**Main findings:**

- 1) Timing - stakeholder consensus that SIPS is of maximum benefit at points of high emotional/physical symptom burden e.g. advanced disease (median 9, IQR 8-9). However, older people and carers advocated referral early in the disease trajectory for future planning and familiarity with PC team.
- 2) Priorities for IPW are HPs' timely access to PC advice via a single contact (median 8.5, IQR 8-9) and a nominated skilled key worker for patients and carers to coordinate care (median 8, IQR 7-9).

**Conclusions:** There is a tension regarding suggested timing of SIPS between participant groups, with older people and carers advocating earlier delivery. IPW requires an emphasis on a nominated skilled key worker to coordinate care.

**Funder:** NIHR RfPB

**Abstract number:** P112

**Abstract type:** Poster

**Knowledge of Hospice and Attitude towards Hospice in Patients with Advanced Cancer in Palliative Medicine Setting in a Developing Country**

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**Background:** Despite potential benefits of hospice enrollment, hospice facilities are underutilized among advanced cancer patients. No study has been done which reflects the current knowledge of and attitude of advanced cancer patients receiving palliative care towards hospice in a developing country.

**Aim:** To evaluate knowledge of hospice, attitude towards it and factors associated with knowledge and attitude among advanced cancer patients receiving palliative care.

**Methods:** A cross sectional survey was conducted on 75 advanced cancer patients receiving palliative care in dept of palliative medicine in a premier tertiary cancer institute using convenience sampling & a specially prepared questionnaire with 7 questions for knowledge (response as yes/no/don't know) and 12 for attitude (response from strongly agree to strongly disagree). Relevant analysis was done for descriptive statistics. Chi square test was applied to detect significant differences.

**Results:** 27(36%) participants had knowledge of hospice. Of them, 9(33%) had positive attitude, 12(44%) felt that staying in hospice is giving up and 14(52%) wouldn't go to stay in hospice as they believed that they wouldn't be able to leave it. Other 64% participants who had no knowledge of hospice were given brief information on hospice. Analysis of their attitude revealed that 23(48%) favored hospital admission to hospice, 22(46%) had doubts regarding hospice admission. Only 6(8%) of total were willing to stay in hospice and they had low finances or no family support. Level of education was significant factor associated with knowledge of hospice(p=0.03) and positive attitude(p=0.035) towards it.

**Conclusion:** Awareness of hospice is limited among palliative care patients in our study. For improvement of hospice care in developing countries, educationally and culturally appropriate measures need to be implemented to bring about a positive change in understanding of hospice among palliative care patients & general public.

**Abstract number:** P113

**Abstract type:** Poster

**Home-based Specialized Palliative Care in Patients with Advanced Cancer: A Systematic Review**

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**Background:** World-wide there is an urgent need for specialized palliative care (SPC) for patients with advanced cancer. Therefore, an overview of available information on organisation of home-based SPC and its effects are mandatory.

**Aim:** This systematic review aims at giving an overview of available information on organization and effects of home-based SPC for patients with advanced cancer. Furthermore, outcomes regarding place of death, survival time, quality of life, performance status, and symptom management are included.

**Design:** PICO search strategy consisting of terms related to cancer, palliation and home care.

**Data sources:** The search was conducted in PubMed, EMBASE, and Cochrane (1<sup>st</sup> of January 2000 to 27<sup>th</sup> of January 2015). Further, hand search in the reference list of the included studies was performed.

**Results:** Five articles out of 2080 abstracts were selected for analysis. Three additional studies were added by hand search. Six observational studies (four longitudinal and two cross-sectional) and two interventions (before and after) were evaluated.

In all studies the description of the SPC service was limited to composition of employees. No other organizational aspects were outlined. One study mentioned specialized training of staff. Forty-four to ninety percent of the patients receiving home-based SPC died at home. Studies including survival and quality of life had divergent outcomes and over-all performance status did not improve, but some symptoms were better controlled. One study showed better symptom control with SPC when compared to other settings.

**Conclusion:** There is a lack of controlled clinical trials regarding home-based SPC for patients with advanced cancer, resulting in poor evidence for the effect of home-based SPC. Generally, the description of the organizational content of the SPC is vague. Home-based SPC programs for advanced cancer patients should be assessed in randomized controlled trials.

**Abstract number:** P114

**Abstract type:** Poster

#### **Palliative Rehabilitation: Time to talk about it?**

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**Background/aims:** Whilst the benefit of a rehabilitative approach to palliative care for some patients with advanced cancer is now widely accepted, the optimal timing of introducing such services remains unclear. The aim of the APRIL (Active Palliative Rehabilitation in Lung cancer) study was to determine the feasibility, acceptability and potential impact of palliative rehabilitation, for people commencing systemic therapy with palliative intent, for stage IIB or IV non-small cell lung cancer (NSCLC).

**Methods:** A six week individualised programme of moderate intensity cardiovascular and resistance exercise and nutritional guidance, to promote function, well-being and

quality of life, was undertaken. The study was designed to be introduced to people as soon as the decision to commence systemic therapy was made. Individual goals were revised and agreed weekly using transtheoretical model of behaviour change (TTM). On completion, patient participants and healthcare professionals (HCPs) were asked about programme timing.

**Results:** Eight of the 11 participants completed all study outcome measurement points (baseline, six weeks, 12 weeks). Time to commence APRIL from starting systemic therapy varied from minus one to 84 days. Delays in study introduction by the trials nurse, physical symptom burden and psychosocial barriers faced by patients all affected APRIL commencement. None of the participants reported discontent with palliative rehabilitation being discussed early in their treatment journey.

**Conclusions:** Findings are contrary to views held by many HCPs that discussions about rehabilitation are best delayed until after cancer treatment is established or completed, so as not to overburden patients. Early conversations regarding rehabilitation may enable a focus on what is currently important to the individual, rather than investing all effort on future focused goals.

**Funding:** Doctoral Fellowship awarded by the AIIHPC and the HSC R&D Division, PHA, Northern Ireland.

**Abstract number:** P115

**Abstract type:** Poster

#### **How Empowering is Hospital Care? Challenges and Solutions from A Cross-national Ethnography in Ireland, the UK and the USA**

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**Background:** Patient empowerment is embedded within policy guidance globally. Empowerment is associated with determining one's own goals and making effective decisions in line with them, so comes into sharp focus in advanced disease, in which decision-making is often

complex. Most care in this population occurs in hospitals, yet the extent to which patients feel empowered in this setting is unknown.

**Aim:** To explore the extent to which hospital care empowers patients with advanced disease and identify challenges to and facilitators of empowerment in this setting.

**Methods:** A multi-method ethnography was conducted in 6 hospitals in 3 countries: Ireland, the UK and the USA. Patients age  $\geq 65$ , unpaid carers and generalist and specialist palliative care (PC) staff were interviewed and observational field work completed. Directed thematic analysis used Aujoulat's theory of empowerment.

**Results:** Analysis of 92 interviews and 377 hours of observations across 10 medical specialties revealed patients use a range of strategies to maintain/gain control and coherence, e.g. challenging staff, leading decision-making or choosing not to make decisions, maintaining independence. Threats to empowerment included poor continuity of care and information provision, staff shortages and quality assessment based on throughput. Deference to authority was a challenge in Ireland; in the USA, reimbursement biased towards procedural care had a negative impact. Facilitators of empowerment included accurate, tailored information provision, proactive identification of needs, access to PC, and multidisciplinary meetings exploring psychosocial concerns.

**Conclusions:** Opportunities exist to improve empowerment in inpatient settings. Hospitals should focus on quality of life as well as cure, and prioritise relational care and communication. Systems and training that promote collaborative relationships between staff and access to PC are needed.

**Funding:** Cicely Saunders International, The Atlantic Philanthropies.

**Abstract number:** P116

**Abstract type:** Poster

### Changes in Volunteering - What Does this Mean for Hospice and Palliative Care Services in Europe?

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**Introduction:** Hospices and palliative care services in many countries rely heavily on volunteers and research suggests that without their contribution some services may be unsustainable. A new generation of volunteers have different expectations to those of their predecessors.

**Aims:** This paper aims to explore the:

- Changing influences on volunteering in different countries
- Changing expectations of volunteers

- New challenges facing organisations who involve volunteers in Europe

**Method:** Drawing upon a scoping of the literature, and a multidisciplinary Symposium held in 2015 with the aim of developing consensus around the above topics. With 160 delegates from 13 countries information was generated by presentations and group discussion. Qualitative data were recorded in writing and checked with presenters and session leaders for accuracy. Data were analysed thematically.

#### Outcomes:

- Political and economic changes affect volunteering in all countries.
- New laws in some countries either present barriers to or empower volunteering.
- Volunteers are becoming involved with new patient groups such as children and people with dementia.
- New types of volunteers are emerging including the involvement of young people and prisoners
- In some countries more men are volunteering; others are finding men difficult to recruit
- Volunteers' motivations perceived to be less altruistic
- Organisations face challenges in recruiting and retaining volunteers

**Conclusion:** With continued dependence on volunteers and increasing demand for services for patients with complex needs, hospice and palliative care services face challenges from a new generation of volunteers. These volunteers are no longer content with traditional roles and seek to use their skills in different and more meaningful ways. If volunteering is to flourish, organisations must address the changes taking place within volunteering and ensure that they match the expectations of volunteers with those of the service.

**Abstract number:** P117

**Abstract type:** Poster

### Healthcare Professionals' Experiences of Providing Palliative Care to Children: A Review of the Literature

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**Background:** Staff who provide palliative care to children work in a challenging environment where they must assist families coming to terms with the loss of a child whilst managing their own sense of grief. Currently, there is a lack of clarity regarding how we can best support staff in

this role and help them cope in these demanding circumstances.

**Aim:** This review aims to explore how health care professionals who work in paediatric palliative care cope with the unique challenges of their role.

**Method:** A mixed methods review was employed. A systematic search of bibliographic databases such as CINAHL, MEDLINE, Web of Science, EMBASE, PsychINFO, and The Cochrane Library was undertaken. Further studies were identified through searching reference lists of retrieved papers and through direct contact with experts in paediatric palliative care. Study selection, appraisal and data extraction were conducted by two independent researchers and findings were synthesized using an integrative thematic analysis.

**Results:** Thirty papers met the studies inclusion criteria: 18 studies employed a qualitative design, six quantitative, and six used a mixed-method design. A range of themes were identified including: the rewards and costs of 'staff experience'; 'impact on personal/professional life'; 'coping strategies'; and, 'recommendations for practice'.

**Conclusions:** Education to help staff deal with the unique challenges of their role, the importance of self-care, and supporting staff via multidisciplinary debriefing were identified as key features in supporting professional staff. Findings of this review will be valuable for guiding the future development of services and interventions to improve the quality of end-of-life care for children, families and healthcare professionals.

**Abstract number:** P118

**Abstract type:** Poster

**A Randomized Trial Aiming to Evaluate the Impact of a Systematic Dialogue between Oncologists & Supportive Care Team about the Use of Additional Chemotherapy (CT) Line in Metastatic Breast Cancer (MBC) Patients (pts). (OSS Study, NCT00905281)**

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**Statement of aims:** The evaluation of the benefit/risk ratio of successive lines of CT in MBC remains difficult. Lines tend to be less effective but are nevertheless often prescribed. The set up of an early concerted coordination

between supportive care teams (SS) and oncologists (O), such as "early palliative care" developed especially in lung cancer, could limit the use of additional CT lines often ineffective and toxic.

**Methods:** This randomized, multicenter study evaluated the impact of a concerted management (O-SS) versus conventional pts care (CPC) on the prescription of a 4<sup>th</sup> or 5<sup>th</sup> CT line among MBC pts being treated by a 3<sup>rd</sup> or 4<sup>th</sup> CT line. Secondary objectives were feelings of pts in terms of symptoms, anxiety, satisfaction or quality of life (QoL) (Edmonton, HADS, QLQ-C30 QSSP and F-PMH / PSQ MD scales), the impact of the disease on their family environment (GHQ-28 questionnaires), and the satisfaction of oncologists (Likert scales). 100 pts were planned to show a 30% decrease in the rate of prescription of a 4<sup>th</sup> or 5<sup>th</sup> CT line (80% to 50%) with  $\alpha=5\%$  and 80% power.

**Results:** Between Jan. 2009 and Nov. 2012, 98 pts were included: 50 pts in CPC arm (including 27 in 3<sup>rd</sup> CT line) versus 48 pts in O-SS arm (26 in 3<sup>rd</sup> line). Preliminary results show that

- 1) 10% of pts have presented an objective response under the CT line ongoing at the time of inclusion and
- 2) the rate of prescription of an additional CT line was similar between the 2 arms (70% CPC versus 75% O-SS). The analysis of the impact of the concerted care on how pts feel as well as their QoL is ongoing.

**Conclusion:** In this study, concerted O-SS consultation has no impact on CT prescription, which remains a major issue. This multidisciplinary approach should be expanded in subsequent studies taking into account the characteristics of the pathology (disease with slow evolution, often asymptomatic, for which many therapies are available, high media coverage) and include medico- economic endpoints.

**Abstract number:** P119

**Abstract type:** Poster

**Do Weekly Teleconsultations between Palliative Patients and a Specialist Palliative Care Team Improve Palliative Care at Home? - An RCT**

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**Background:** most patients with life-limiting illnesses wish to be cared for and die at home. As palliative care can become rather complex, support from specialist palliative care teams may be needed. Teleconsultations (TCs) may bridge the physical gap between patients at home and hospital-based palliative care consultation teams (PCTs).

**Aim:** To evaluate whether weekly TCs between home-dwelling palliative patients and a hospital-based PCT reduces patient-experienced symptom burden in comparison with ‘care as usual’.

**Design:** Randomized controlled trial.

**Methods:** Inclusion criteria: patients with a progressive oncological disease, Karnofsky-score of  $\leq 60$  and life-expectancy  $\leq 3$  months. As inclusion fell short of expectation, inclusion criteria were broadened to: any patient with a progressive oncological disease visiting the palliative care outpatient clinic.

After completing baseline measurements, participants were randomized to:

- 1) intervention group, receiving weekly TCs for 12 weeks or
- 2) control group receiving “care as usual”, generally consisting of primary care and outpatient palliative care. Primary outcome: symptom burden based on ESAS and HADS-scores.

**Statistical analysis:** differences in primary outcomes for both groups were calculated using General Linear Models, repeated measures.

**Results and interpretation:** 74 participants were analyzed. Mean age was 62.3 yrs in the intervention group vs. 61.9 yrs in the control group. In the intervention group, 11 participants were female (28.9%) vs. 14 (38.9%) in the control group. Other baseline characteristics did not differ between groups (marital status; family composition; educational level). Preliminary data analysis showed no difference in Total Distress Score (sum of ESAS-sub-scales) between both groups. Currently, HADS-scores have not been analyzed. Based on preliminary data, applying weekly TCs between home-dwelling patients and a hospital-based PCT does not seem to improve patient-experienced symptom burden.

**Abstract number:** P120

**Abstract type:** Poster

**Prospective Cohort Study of Palliative Care Consultation for Hospitalized Adults with Advanced Cancer: New Evidence on the Association between Complexity and Cost**

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**Background/aims:** Specialist palliative care consultation teams (PCCT) have been shown to reduce hospital costs for adults with serious illness, and the cost-saving effect is

larger for patients with more comorbidities. Identifying the hospital costs and palliative care impact on those costs for specific comorbidities is an important next step in developing the economic evidence on care for patients with complex multimorbidity.

**Methods:** Clinical and cost data were collected on 1023 adults admitted to four United States hospitals with an advanced cancer diagnosis. 288 patients (28%) were seen by a PCCT; 735 received usual care (UC) only. PCCT and UC patients were matched using propensity scores. Comorbidities were measured and identified using the Elixhauser index. Costs associated with specific comorbidities and cost-effects of PCCTs were estimated using generalised linear models with a gamma distribution and a log link.

**Results:** Substantive differences between costs associated with specific comorbidities, and between cost-effects for different comorbidities, are identified. The Elixhauser index is shown to be an inexact measure of multimorbidity and complexity in economic analyses, and a weighted version of the Elixhauser is shown to be superior.

**Conclusions:** Health care provision and health services research are entering an era defined by complex multimorbidity: the co-occurrence of more than one serious illness for a large number of patients. New methods of accounting for comorbidities can improve the accuracy and sophistication of planning and finance in care for serious illness, as well as future studies in this field.

**Abstract number:** P121

**Abstract type:** Poster

**Barriers and Facilitators to Implement the Needs Assessment Tool for Interstitial Lung Disease Patients: A Qualitative Study**

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**Background:** The Needs Assessment Tool for Interstitial Lung Disease (NAT:PD-ILD) aims to facilitate non-palliative care specialists to identify and triage palliative care (PC) concerns and needs of patients and their family carers. Such tools can promote good clinical practice but can be difficult to implement.

**Aim:** To identify challenges and facilitators to future clinical practice implementation of the NAT:PD-ILD.

**Method:** Video and audio-recorded data from i) focus group of 8 multi-professional respiratory clinicians and ii) expert consensus group (n=18) of respiratory physicians, PC physicians, nurse specialists, research staff and patient/carer representatives, were transcribed and analyzed using i) cognitive mapping and ii) thematic framework analysis.

**Results:** Thematic framework analysis identified two main themes:

- 1) clinical concerns and
- 2) training needs. Lack of resources were identified as major barriers; the clinical need, content validity of the tool, the structure, objectiveness, flexibility and fast “aid memoire” were identified as facilitators.

Communication training needs were highlighted by clinicians to improve their ability to talk about spiritual and psychosocial concerns with patients and carers. Cognitive mapping identified that most interaction was classed as “positive” - despite clearly identified barriers, these were presented alongside suggestions to address these.

**Conclusion:** NAT:PD-ILD was seen as a good, necessary and practical tool to be included in the everyday practice of ILD clinical teams. Training for clinicians, and adequate time in clinic were seen as the main requirements for successful implementation. It was acknowledged that the tool might identify the need for increased resources (e.g. psychology) and should be used during clinical consultations as a clinical guide.

This study was funded by a Marie Curie Cancer Care Research Grant.

**Abstract number:** P122

**Abstract type:** Poster

### **Patient and Public Involvement in Palliative Care Research: A Qualitative Study to Identify Motivators**

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**Background:** Patient and public involvement is gaining in popularity in palliative care research. However, little evidence exists concerning the reasons why patients, their

families, the public (service users) or researchers engage in this type of work. This gap hinders collaboration.

**Aim:** To identify and compare the different motivations among service users and researchers to establish a basis for future collaboration between the two parties.

**Methods:** Focus groups were conducted with palliative care patients / unpaid carers and palliative care researchers. Data was audio recorded and transcribed. Mayring’s approach to content analysis was adopted to analyse the data. The main categories after inductive analysis were compared and contrasted.

**Results:** 24 service users and 9 palliative care researchers were approached. Seven service users and 6 researchers participated in three focus groups (two patient / carers, one palliative care researcher). Preliminary results identified the following motivators for service users: involvement as a way of carrying things forward, of feeling empowered and being useful in channelling thoughts away from the physical aspects of disease. Whereas for researchers, the scope of motivators ranged from a commitment to participatory methods of involvement, personal values and compliance with governance and funding policies.

**Conclusion:** We identify differences in motivations to work together on research projects between service users and researchers. This new evidence informs palliative care researchers about motivations from both parties, which are powerful key fundament in the modelling of a collaborative framework in its true sense. Recognition and concordance of motivations is critical.

**Funders:** The Atlantic Philanthropies, Cicely Saunders International, NIHR Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London).

**Abstract number:** P123

**Abstract type:** Poster

### **Person-centred Palliative Care in Five European Countries: The Experiences of Patients and Family Carers**

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**Background:** Integrated palliative care (IPC) should be responsive to patients' needs. However, knowledge about the best way to provide IPC is scarce. Evidence is mainly based on perspectives of professionals and family carers. The InSup-C project examined patients' and family carers' experiences of care provision in several IPC initiatives in five European countries.

**Methods:** IPC initiatives, transmural collaborations between professionals to provide palliative care, were selected in five European countries (Belgium, Germany, Hungary, The Netherlands and the UK). From these initiatives patients with cancer, COPD and heart failure (with a prognosis less than 12 months) and their family carers were recruited. Semi-structured interviews were conducted focusing on how IPC initiatives respond to patient's palliative care problems and needs and how they collaborate. Interviews were transcribed verbatim and coded using an internationally agreed codebook.

**Results:** 157 patients and 90 family carers were interviewed. Main themes were *availability of professionals* (knowing who to contact when having needs), *compassionate care* (dealing with the person beyond the illness), *patient-centred information* (honestly responding to informational needs in times of uncertainty), *close inter-professional contacts*, and *information transfer* (resulting in being up-to-date and involved). Respondents highlighted the importance of a person-centred approach in the care received. Although respondents were quite satisfied in general, they frequently reported examples of professionals only focusing on the illness or not collaborating properly.

**Conclusion:** According to patients and family carers IPC means that professionals are person-centred in their thinking, communication and collaboration. Further analysis of the study results will provide more insight into the mechanisms of the IPC initiatives that contribute to person-centred care and gaps that may exist in quality service provision.

**Abstract number:** P124

**Abstract type:** Poster

### What Makes the Patients' Situation Complex? Complexity and Resource Needs in German Palliative Care - A Qualitative Interview Study

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**Background:** Palliative care (PC) funding in Germany is based on diagnosis-related groups (DRGs) or remuneration per day. Internationally, the complexity of patients' situations is proposed to predict the resources (time, drugs, medical equipment) and costs of PC.

**Aim:** To explore which factors describe complex patient situations in PC in Germany.

**Methods:** 42 semistructured qualitative expert interviews (27 clinical, 15 economical/political background) were conducted between June and October 2015. Interviews were audio-taped, transcribed and analysed by the framework method using NVivo. The second stage of analysis (identifying recurring and important themes) is finalised. Themes were developed both deductively based on the interview guide and inductively.

**Results:** According to the experts' opinion, factors describing complex patient situations refer to four major domains of the care system: the patient (e.g. certain physical symptoms, psychological burden, biography, communication barriers), family (e.g. other sick family members, psychological burden), team (e.g. identification with patients of younger age), and to the structural/system level (e.g. non-availability of care facilities and services). Complexity results from a combination of several factors which affect and are affected by each other. Experts confirmed interdependence between complexity of a patient's situation and resource needs.

**Conclusions:** Due to the interdependence between resource needs and the level of complexity of patients' situations, factors causing complexity will also be resource use and cost drivers. Because of the reciprocal relation of several factors, statements on the impact on needed resources cannot be made easily. The final set of complexity factors will be tested against actual resource use in patient care.

This article represents independent research funded by a private charity.

**Abstract number:** P125

**Abstract type:** Poster

### Integrated Palliative Care Practices in Seven European Countries: The Experiences of Experts

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**Background:** Empirical evidence suggests that integrated palliative care (IPC) increases the quality of care at lower costs. However, little is known about best service models and how to successfully implement these. The European InSup-C project investigated experts' experiences with local IPC practices in both oncology and non-oncology in seven European countries. The study focused on scopes, organisational processes, facilitators and barriers of these practices.

**Methods:** A qualitative interview study was conducted between December 2013 and May 2014. Interviews were transcribed verbatim and coded using a coding framework. Key categories were core elements of IPC practices, facilitators, barriers and recommendations to achieve successful IPC.

**Results:** Thirty-four experts in primary and secondary palliative care (PC) or public health from Belgium, Germany, Hungary, Ireland, the Netherlands, Spain and the UK were interviewed. The majority were physicians in either oncology or non-oncology. IPC practices differed considerably in settings, professions and diagnostic groups involved. Core elements were a multidisciplinary team approach and cross-sectional coordination. Facilitators towards integration of PC were trust, cultural change, basic PC education and financial reimbursement schemes. Barriers were problems in communication and cooperation, insufficient knowledge and education, cultural problems, lack of resources and capacities and structural disincentives to implement IPC. Recommended improvements to achieve IPC were place and timing, communication and cooperation, basic education in PC, patient-centeredness, decision-making and financing.

**Conclusion:** The reported IPC practices depended much on local resources, e.g. networks and caregivers' extraordinary engagement. In order to transform local IPC practices in Europe into sustainable IPC services at larger scale, securing legal and financial support at the level of national healthcare systems are indispensable.

**Abstract number:** P126

**Abstract type:** Poster

### Core Functions of Regional Palliative Care Networks in the Netherlands: The State of the Art

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**Background:** In the Netherlands palliative care (PC) is approached as non-specialized care, providing equitable access for all. To improve the quality of PC across the country, 66 regional palliative care networks (RPCN) were established. These RPCN vary in participants, practices, and results, but both the RPCN and the Ministry of Health Affairs emphasize the need for more consistency. Half 2014 a set of Minimum Requirements was introduced in all RPCN, describing four core functions, i.e. COORDINATING, INFORMING, MONITORING, and FACILITATING PC in the region.

**Aim:** To investigate the extent to which the RPCN meet these requirements before implementation of improvements.

**Methods:** Between June and September 2015 in all RPCN coordinators and chairs, and one delegate per organization (n=931) were invited to complete an online questionnaire measuring various aspects of the four core functions. Non-parametric tests were used for analysis.

**Results:** 263 participants (28%) completed the questionnaire, representing 55 out of 66 RPCN, including various care settings and disciplines. Of the respondents 78% were familiar with the set of Minimum Requirements. The best implemented core function was 'Informing' according to 46%, whereas 'Monitoring' was seen as best implemented by 5%. A large majority (85%) reported that the interests of PC organizations, and of patients and relatives were served in their network. Facilitating educational programs was the most reported activity (93%). Regarding the continuity of care across care settings, 21%-28% of the respondents agreed that their RPCN contributed effectively to these processes.

**Discussion:** The implementation of the core functions and the impact of the RPCN on the provision of PC vary across RPCN. Most RPCN put emphasis on networking between organizations and on dissemination of knowledge.

**Conclusion:** RPCN do not meet all minimal requirements and largely vary in performing the core functions. Improvements will be initiated.

**Abstract number:** P127

**Abstract type:** Poster

### Differences in Ambulatory and Inpatient Hospital Use and Costs in the Last Year of Life by Patients' Characteristics

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**Background:** Patients who die in hospital services have specific characteristics that influence patterns of use of health care in the last year of life (LYOL). The identification of these patterns is useful to prepare patients and family to face end of life issues and to develop palliative care.

**Objectives:** We examined the role of patients' characteristics on use and costs of hospital ambulatory and inpatient care, including ambulatory (emergency room and outpatient visits) and inpatient care in the last year of life.

**Methods:** Population included adult patients deceased in 2013 in a medium-size hospital. Claims data and electronic medical records were used to determine utilization. To estimate costs, prices were used as proxy. Patients' attributes were sex, age, principal diagnosis, and number of secondary diagnoses. Due to non-normality of use and costs variables, differences between groups of patients were assessed with Mann-Whitney, Kruskal-Wallis and Pearson's Chi-squared tests.

**Results:** For the 484 patients included, each patient in the LYOL had 2,69 ( $\pm 2,49$ ) emergency room (ER) visits and 4,8 ( $\pm 9,64$ ) outpatient visits. Each patient was hospitalized 1,79 times ( $\pm 1,6$ ) for about 20 days, of which 10 in episode of death. Patients in the LYOL had an average cost of 9.973€ ( $\pm 15.053$ €) of which 9.318€ ( $\pm 15.045$ €) in inpatient services. Older patients presented lower use and costs of inpatient care and ER visits but higher use of outpatient visits. Women have higher ER use and cost. Diagnoses related to cancer presented a much higher use and cost of outpatient visits. Patients with more secondary diagnoses had higher use and costs in inpatient care.

**Conclusion:** Significant discrepancies, influenced by patients' characteristics, were found for resource utilization and costs of hospital treatment in the last year of life. It is possible to profile patients according to their characteristics and set priorities for the development of end of life care.

**Abstract number:** P128

**Abstract type:** Poster

### Redefining DRGs for Palliative Care in Germany

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**Background:** Hospital treatment costs and cost drivers in palliative care (PC) are poorly analysed. It remains unknown whether current German Diagnosis related groups (G-DRGs), merely accounting for the main diagnosis, reproduce costs adequately in Germany.

**Aim:** To analyse costs and reimbursement for inpatient PC and to identify relevant cost drivers.

**Setting/participants:** 2 German hospitals, 2151 patients (group A = total group, hospital care including, but not exclusively, PC) and subgroup of patients receiving PC only (group B, n = 784).

**Methods:** Two-center, standardised, micro-costing approach with patient-level cost calculations and analysis of the reimbursement situation 7/2012 - 12/2013. Patient and care characteristics predictive of inpatient costs of PC were derived by generalised linear models and investigated by classification and regression tree analysis.

**Results:** Mean total costs per case were € 7392 (SD = 7897) (group A) and € 5763 (SD = 3664)

(group B), mean total reimbursement per case € 5155 (SD = 6347) (group A) and € 4278 (SD = 2194) (group B). For group A/B, 58%/53% of the overall costs and 48%/53%, 65%/82% and 64%/72% of costs for nursing, physicians and infrastructure were reimbursed, respectively. Main diagnosis was not predictive of costs. However, duration of PC and length of total stay (as expected due to the cost calculation method) were identified as significant cost drivers.

**Conclusions:** G-DRGs do not reproduce costs in PC adequately and cause a financing gap. Probable reasons are

- 1) PC patients differ from patients on normal wards regarding their complexity and the care they need and
- 2) cost classifiers currently used for DRG-grouping poorly reflect resource use. Studies collecting resource-use based cost data as well as data on cost drivers reflecting the complexity of the patients' situation are needed as a basis for further development of the costing and reimbursement system for PC.

Independent research funded by a private charity.

**Abstract number:** P129

**Abstract type:** Poster

### Barriers and Facilitators to Accessing Specialist Palliative Care in Hospitals for Older Adults: A Multi-method Cross-national Ethnography

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**Background:** The World Health Assembly has called for palliative care integration within health systems, equitably across disease groups, and throughout all levels of care. Specialist palliative care services in hospitals are expanding although access varies.

**Aims:** To identify barriers and facilitators to accessing specialist palliative care in hospitals.

**Methods:** A multi-method ethnography, underpinned by a theoretical framework, was conducted in six hospitals in three countries: the Republic of Ireland, the UK and the USA. Interviews were completed with: patients, unpaid carers, and generalist and specialist staff. Prolonged observations and open, axial and selective coding was conducted. Findings were clustered and tabulated. Data saturation, triangulation and standardised protocols were used. Outliers were sought.

**Results:** Analysis of 92 interviews and 377 hours of observations across medical specialties, during 2012-2014, identified 3 facilitators, 11 barriers, and 14 factors that operated as either a barrier or facilitator. Consistent facilitators were integrated generalist-specialist models of care, universal health coverage and patient characteristics (death proximity, need for pain control, identifiable deterioration, cancer diagnosis). Barriers spanned: individual; service delivery; organisational; and societal levels. Three inter-related themes showed that factors were influenced by: individual understandings concerning palliative care; hospital systems that prioritise survival; and funding and policy imperatives that emphasise cure.

**Conclusions:** Barriers to accessing specialist palliative care in hospitals outnumber facilitators, but most barriers can be modified into facilitators. Policy makers and clinicians should adopt the facilitators and modify the barriers to improve access.

**Funding:** The Atlantic Philanthropies, Cicely Saunders International, CLAHRC.

**Abstract number:** P130

**Abstract type:** Poster

### Quality of Care Provided within a Model for Early Palliative Care Integration in Advanced Lung Cancer Patients

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The integration of palliative care (PC) and medical oncology (MO) in the clinical pathway of patients (pts) with advanced cancer is the goal of simultaneous care models where pts are seen contemporarily in medical oncology and palliative care outpatient clinics. Our model aims to ensure continuity of care between hospital services that provide specific anticancer treatments and palliative care services according to pts' needs for symptom control and psychosocial support, also considering the choice of setting of care and prognosis. Aim of this study was to describe the model adopted for advanced lung cancer pts and to assess the quality of care provided applying the ASCO Quality Measures for Aggressive EOL Care.

**Methods:** All consecutive pts with lung cancer followed by MO and PC outpatient clinics from 1.01 to 31.12. 2014 were retrospectively evaluated. Data on disease stage, performance status, symptoms, date of the last CT cycle, admission to hospital, hospice, or home care programs in the last 3 months of life, date and place of death were collected.

**Results:** Among the 464 pts followed by the MO in 2014, 151 were also seen in PC as outpatients; the average time from the first visit in MO and the first visit in PC was 30 days. Pts' characteristics were: ECOG 1 42%, Stage IV 80%; 82% received chemotherapy, and 94% had symptoms (pain 84.8%, dyspnea 24%, fatigue 23.8%, cough 15.2% and loss of appetite 9.3%). 56 pts died in 2014: 10 died in hospital, 19 in hospice and 8 at home (19 missing data). The overall average time from first PC visit to death was 185 days, the average time spent in home care 21 days, in hospice 14 days and in hospital nine days. The median time since the last chemotherapy and death was approximately 100 days for both pts cared at home and in hospice.

**Conclusions:** These data show that our model provides aspects of continuity of care, early palliative care integration with oncology and compliance with the ASCO Quality of EOL care indicators.

**Abstract number:** P131

**Abstract type:** Poster

**A Palliative Care Resource Matching Program:  
A Strategy to Improve Access, Availability and  
Integration of Palliative Care Beds**

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**Background:** Palliative care services are often challenged by the poor integration of palliative care across health care sectors and by the lack of a systems approach to service provision.

**Aim:** The Toronto Central (TC) region in Ontario, Canada, developed an electronic referral sending and matching software to improve access, availability and integration of its palliative care beds (RM&R PC).

**Methods:** A current state assessment was conducted and each participating organization defined its processes for referral. Several stakeholder sessions were held to solicit feedback and help identify, prioritize, finalize and validate project systems and subsequent reporting. Outcomes were leveraged to develop the current state workflow, and to understand palliative referral volumes and processes across TC. Finally, a program was developed to support the process of referral and matching, and to collect data for quality improvement.

**Results:** The program manages the referral and admission processes of 207 palliative care beds, spread across 9 palliative care units and 1 residential hospice. In the first year of its implementation (Sept 2014-Aug 2015), the RM&R PC processed 3957 applications for 2030 patients, resulting in 1422 admissions to palliative care beds. The mean time for referral matching ranged from 4.9-10.9 days depending on the unit, including time for application completion (mean 2.3 days), requests for additional information (total 743), follow-up (mean 2.4 days) and time between referral acceptance and bed admission (mean 2.6 days). Applications were denied for 520 patients, most often because the clinical prognosis extended beyond the unit's referral criteria.

**Conclusion:** This program streamlined the application process, improved communication between organizations, and provided transparency regarding bed referral, availability, wait-times and admission.

**Abstract number:** P132

**Abstract type:** Poster

**A Survey of Attitudes towards Palliative Medicine  
amongst Doctors Working in an Irish Emergency  
Department in 2015**

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**Background/aims:** The Three Rs (Recognition/Response/Reflection) Project is a quality improvement initiative integrating Palliative Care in the Emergency Department. The three objectives of the project are to improve the recognition of palliative care needs of patients presenting to the emergency department, to improve the response of staff to these needs and to embed reflective practice. Our aim was to assess doctor's understanding of patients' palliative care needs, behaviour in practice, their previous training and preferred educational modalities.

**Methods:** A survey was designed with closed and open-ended text questions. 34 questionnaires were administered. All replies were anonymous. Data was analysed using SPHINX software package.

**Results:** 23 (68%) of recipients completed the survey. Almost universally, the doctors favoured increased availability of the Palliative Medicine Team in the ED, guidelines for referral and making protocols available for the management of palliative care patients. Whilst 41% of staff felt the ED was a place to provide aggressive rather than palliative medical care, the remainder disagreed or strongly disagreed with this. Only 5/22 rated their ability as good to handle difficult ethical end of life decisions. 15 (68%) rated it as fair and 1(4.5%) as poor. 19/21 staff felt the existence of an advanced care directive would be helpful in deciding appropriate care in the ED.

Only 4/21 of staff had any previous training in Palliative Medicine. Whilst most staff rated themselves as having good skills in managing pain, almost all mentioned pain management as an important education topic to be covered. Respondents favoured case presentations and workshops over videoed role play and lectures.

**Conclusions:** ED medical staff had a clear perception of the role of Palliative Medicine, valued its potential in the ED and were positively predisposed towards further education and training, with preferences for case presentations and workshops.

**Abstract number:** P133

**Abstract type:** Poster

**Mixed Method Evaluation of a Palliative Care (PC)  
Project in Rural North India**

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**Background:** Provision of palliative care (PC) is a challenge for health services in India. An estimated 34 million people need PC but less than 1% have access to it. Over the last couple of decades PC services have rapidly developed in parts of south India, but there is slow progress in rural north India. In this resource-poor setting where cancer cure is often impossible due to late presentation and limited treatment options there is a great need for PC services.

**Aim:** Evaluating the impact of a community based PC program, developed and funded by a UK agency and set up in five hospitals in rural north India.

**Method:** Mixed method rapid realist evaluation, with data collected from documents, activity records; field observation of services and 44 in-depth interviews with hospital leaders and staff, patients, carers and community members. All teams were assessed against *Pallium India* PC Standards and overall program approach through WHO Public Health for PC.

**Results:** Each team had implemented a community based model of care, with local contextual modifications, mainly for cancer patients but few with HIV, paraplegia and other non-communicable diseases. All teams achieved most *Pallium* markers apart from morphine utilization; despite great effort only 2/5 had secured morphine licenses. The program demonstrated compliance with WHO principles. Staff had been carefully selected and had completed a PC course. Remarkable synergy was emerging between PC and community health, supporting the community-based approach. Hospitals were exploring 'social enterprise' approaches to achieving sustainability e.g. small profits from surgical services utilized to fund PC.

**Conclusion:** The model developed, exemplifies a locally appropriate, evidence based, iterative approach to PC development. Further education and targeted research could enhance the services and the model could be extended to similar sites. The overall approach has wider applicability for PC service development.

**Abstract number:** P134

**Abstract type:** Poster

### Palliative Care in Dutch Hospitals, Results of a National Survey

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**Background/aim:** Involvement of palliative care teams (PCTs) in care for patients with a serious illness in hospitals has been shown to have positive effects on patients' quality of life. In the Netherlands, professional standards state that each hospital should have a PCT by 2017. The aim of this study was to investigate the number of hospitals that have a PCT or other palliative care services and to study characteristics of the PCTs and possible differences between teams in different types of hospitals.

**Methods:** In April 2015, questionnaires were mailed to key palliative care professionals in all general, teaching and academic hospitals in the Netherlands. Out of 92 hospitals, 74 responded (80%).

**Results:** 57 of 74 hospitals (77%) have a PCT. Other palliative care services are relatively scarce, except for palliative care labeled beds (50%) and outpatient clinics (50%) in academic hospitals. The number of PCTs increased over the past 3 years. The most common disciplines participating are nurses (100%), internal medicine specialists (90%), anesthesiologists (75%) and spiritual counselors (65%). In most cases, medical specialists do not have hours available for their work as palliative care consultant, this in contrary to nurses and nurse practitioners. Most PCTs (77%) do not provide an out-of-hours service yet. Half of the PCTs state that the number of referrals is less than their capacity. Teams that started before 2012 have more referrals compared to younger teams. Teams in academic hospitals tend to have started earlier and have more referrals.

**Conclusion:** The number of Dutch hospitals with palliative care teams is rapidly increasing. Participating disciplines, procedures and number of referrals vary within teams.

**Table 1.** Number of referrals in 2014 (N=43).

	General hospital (n=19)	Teaching hospital (n=17)	Academic hospital (n=7)	All hospitals (n=43)
	Median (Range)	Median (Range)	Median (Range)	Median (Range)
Number of inpatient referrals in 2014	44 (2-415)	83 (25-680)	145 (20-236)	77 (2-680)
Number of outpatient referrals in 2014	22 (0-384)	23 (0-91)	16 (0-47)	20 (0-384)
Number of home visits in 2014	20 (0-74)	5 (0-10)	25 (0-47)	6 (0-74)

**Abstract number:** P135

**Abstract type:** Poster

### A National Program for Palliative Care in the Netherlands

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**Introduction:** As advanced cancer and chronic disease increase, the anchoring of palliative care (PC) in national policy programs gains importance, as has been done before in Ireland. A Dutch national program with a funding of 51 million euro's has been launched to stimulate PC. The aim of this paper is to describe the constituent key factors of this program.

**Methods:** The program was initiated by the Netherlands Federation of UMCs (NFU) in conjunction with the Dutch core group (PC representatives). A position paper was developed early 2013. In 2013, round table meetings were organized with representatives from Dutch PC organizations to reach consensus on the main themes of the program. Additional policy meetings were organized with the Dutch Ministry of Health, leading to Parliament letters in 2013 and 2015. Regional palliative care networks were involved via their platform Fibula, supported by the Comprehensive Cancer Organisation. The program aims to improve PC for patients and relatives and will run until 2020, with periodic project calls and a national committee.

**Results:** Three success factors appeared constituent for the development of the Dutch national program. Firstly, consensus emerged among PC representatives about leading themes. Based on this, a matrix was developed comprising 4 themes (Table). Secondly, policy consensus was reached to allocate budget to this national program proposal. The negotiations with the Dutch Ministry of Health

**Table.** Dutch National Program Matrix.

Themes:	Research	Education	Implementation
1. Awareness & Culture			
2. Organisation & continuity of care			
3. care-innovation & quality			
4. Patient/relative participation			

were led by NFU/core group combining professional experience with policy impact. The third feature was the strengthening of regional collaborations between UMC centers of PC expertise and local palliative care networks, including regional PC organizations.

**Conclusions:** It is possible to identify constituent factors for the development of a national program for palliative care. This leads to a new phase in palliative care in the Netherlands and may also inspire other EAPC members.

**Abstract number:** P136

**Abstract type:** Poster

### Implementation of PaTz Palliative Home Care Groups Improved the Way General Practitioners and District Nurses Define Patients Eligible for Palliative Care

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**Background:** In PaTz-groups general practitioners (GPs) and community nurses have regular meetings to improve palliative home care, inspired on GSF. A central aim is to timely identify patients in need of palliative care. PaTz participants should realize that patients can be eligible for palliative care

- (1) when they would not be surprised if the patient would die within a year or 6 months, and
- (2) also before all curative or life-prolonging treatments have stopped.

**Aim:** To study whether the implementation of PaTz had an effect on elements PaTz participants mention in defining who is eligible for palliative care.

**Methods:** Questionnaire study before and 14 months after implementation of PaTz in 40 PaTz groups. In the pretest 235/361 (65%) of GPs and 54/119 (45%) of community nurses responded; corresponding figures for the post test: 197/358 (55%) and 58/111 (52%). For all respondents who answered the open ended question on the definition of patients eligible for palliative care both times (n=164) the answers were coded; pre/posttest differences were tested with a McNemar test.

**Results:** After implementation of PaTz participants mentioned significantly more often the life expectancy of a patient being limited to a year or six months as element of being eligible for palliative care

(from 28% to 41%). The element 'no more treatment options' was mentioned significantly less often in the post-test (from 46% to 33%). Also for GPs and community nurses separate the same results were found. Other

elements mentioned most (posttest) were having a disease one would die from (36%), functional status or symptom burden of the patient (12%) and content or intensity of care (10%).

**Conclusion:** PaTz resulted in has brought about a positive change, with a palliative care definition more in line with the one of WHO. Possibly because of the attention in PaTz for among others the surprise question. Yet, the results also show room for further improvement.

**Funding:** ZonMw, PvF stichting.

**Abstract number:** P137

**Abstract type:** Poster

### The Role of General Practitioners and Integrated Palliative Care at the End of Life from a Patients Point of View

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**Research questions:** The early integration of palliative care treatment for patients with life limiting diseases is an important topic improving the efficiency level and quality of care. General practitioners (GPs) are part of this process because of their close contact to the patients that in many cases persists long term. But does the role of GPs change with the engagement of integrated palliative care (IPC) initiatives and if so, how is this perceived by patients and family care givers?

**Methods:** In the framework of the mixed methods InSup-C study 157 patients and 90 family care givers at the end of their life being treated by one of the 18 palliative care initiatives from four countries

(NL, BE, DE and the UK) were interviewed using a semi-structured approach. The transcripts of these interviews were qualitatively analysed in the light of an internationally agreed codebook.

**Results:** The role and engagement level differs from country to country. In Germany and the UK this data demonstrated that GPs often assume an administrative role when specialists (IPC teams, oncologist or other) get involved, limiting the work of GPs to making referrals and prescribing medications. Some GPs remain in their function as the primary person of trust. In Belgium and the Netherlands more GPs seem to continue their close contact and intensive treatment after the onset of palliative care treatment

which only holds an advisory role. Patients and family care givers are sometimes disappointed if the role of the GPs changes to less engagement.

**Conclusion:** The role of GPs after the onset of IPC can change in a more pronounced ways than might have been expected. What is most important to patients and family care givers, is to have a person of trust who can be contacted 24/7. It is necessary to evaluate how far the role of a GP can be compensated by an integrated palliative care initiative. Structural reorganisation might be necessary to prevent an overload of IPC initiatives.

**Abstract number:** P138

**Abstract type:** Poster

### Development of a Database for Drug Compatibility

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**Background:** The parenteral route of drug administration is an essential alternative for patients where other routes are not feasible due to various causes. Mixing several drugs in one infusion device in order to achieve symptom control in a low-technology setting is common practice in palliative care although it is associated with the risks of drug incompatibility. Laboratory data on drug compatibility in palliative care is scarce. Due to a variety of influencing factors neither the laboratory data nor the clinical experiences alone can cover all aspects of drug compatibility.

**Aim:** To set up a database for collecting compatibility data as well as clinical experiences in order to increase knowledge on drug admixtures in palliative care.

**Methods:** The database was set up including a questionnaire for a structured clinical compatibility assessment. This was based on a review of the literature, databases and books for compatibility data relevant for the palliative care setting. The questionnaire was developed and piloted among in- and outpatient palliative care teams. Results from the literature review were integrated into the same database that is used by clinicians entering the compatibility data.

**Results:** In October 2015, compatibility data for 32 drugs relevant to palliative care and a total of 130 datasets on different drug admixtures have been included into the database so far. The database will be accessible for clinicians starting in December 2015. As data collection is ongoing during the preparation of this abstract, the final results will be presented at the conference.

**Discussion:** The combination of laboratory data and clinical experiences on drug compatibility can help to increase knowledge in this area and thus help to improve drug safety in palliative care infusions therapy.

**Abstract number:** P139

**Abstract type:** Poster

### **Integrating Palliative Care into National Health Systems: An Emergent Framework from 4 African Countries**

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**Background:** The WHA Resolution 2014 requested member states to “integrate evidence-based cost effective and equitable palliative care services in the continuum of care, across all levels” The 3 year *IntegratePC* programme “**Strengthening and integrating Palliative Care in 4 African countries**” is a UK Government funded initiative through the Tropical Health Education Trust led by the University of Edinburgh, Makerere University, and Africa Palliative Care Association. It worked with the Government and National Associations of Palliative Care in Zambia, Malawi, Kenya and the Government in Rwanda to build local models of palliative care in 12 major hospitals.

**Aims:** To document the evidence base and develop a framework of integration emerging from the 12 models of palliative care in the 12 hospitals and their community systems.

**Methods:** We conducted a baseline assessment, ongoing review and dialogue with regards to the vision for palliative care service provision to help map the process we facilitated. For each hospital a matrix was developed which built on core constructs including staffing, setting, services provided, types of patients seen, referral process, and management.

**Results:** The process of defining and developing models of care was unique for each setting, A set of common overarching themes emerged captured in an 11 P framework which identified the essential components - Programme of palliative care (whether through link nursing, separate unit, a hospital wide approach) Policies, Preceptorship, Pathways, Protocols, purposeful Prescribing, Procurement and Performance systems, Partnerships, Pastoral care and visible Presence.

**Conclusion:** Defining a model of care is challenging, but integral to service development. The common themes of the framework provide a systematic way of identifying activities, and organising systems to achieve integration within an existing service. The framework is relevant to more economically developed countries.

**Abstract number:** P140

**Abstract type:** Poster

### **Telephone Triage: Experience of a Community Specialist Palliative Care Team in Northern Ireland**

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**Background:** A community specialist palliative care nursing team (CSPCT) based at a hospice in Northern Ireland has piloted a telephone triage assessment (TTA) tool in response to increasing demand and discrepancy between level of urgency at the time of referral and time of first assessment by the CSPCT. The aim of this pilot was to assess if TTA improves prioritisation of newly referred patients and service delivery.

**Methods:** A TTA tool assessing pain, other symptoms and psychosocial issues was developed by the CSPCT following review of triage tools in use elsewhere in the UK. The TTA was then piloted for a 12 week period in 2013, with triage being undertaken by one member of the team each week. The triage system has been continued and was reassessed in 2015.

**Results:** A total of 45 TTAs of patients referred in February/March 2013 of the pilot were reviewed. Referrers had deemed 40% of these referrals as high priority, 38% as medium, 11% as low and had not prioritised the remaining 11%. Following TTA, only 13% were triaged as high priority, 44% were triaged as medium and 9% as low. 6% of patients declined input from the team at triage. Other referrals did not require TTA. In January to March 2015, 85 new referrals were triaged. 26% were graded as high priority, 56% as medium and 18% as low. All high priority patients (and a further 39% triaged as being lower priority), were seen within the target timeframe of 1-3 working days.

**Conclusion:** A CSPCT telephone triage system has been found to be user friendly and ensures prioritisation of referrals based on a standardised and up-to-date assessment of needs. All patients triaged as high priority are seen at home without delay. It is a more efficient way of identifying patients who no longer require, or wish to have input from the CSPCT. In the midst of static resources, the triage system is allowing the CSPCT to manage an increasing workload more effectively and improve delivery of care to patients and families at home.

**Abstract number:** P141

**Abstract type:** Poster

### **A Road Map for Integrated Units: Operational Policy for Running MDT Meetings**

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**Background:** Integrated Unit model has been developed with the aim of improving communication between PC Teams at different Care Settings in an specific geographic area. Multidisciplinary meetings are held on a weekly basis using videoconference and the result of interdisciplinary evaluation of needs is documented on an Individualized Care Plan.

**Aim:** To develop a protocol for conducting MDT meetings with the aim of defining objectives and methodology during the meetings. To create a standardized data collecting sheet of all the cases discussed during the meetings for further evaluation.

**Methods:** The protocol and the Data Collecting sheet were developed with mixed methods:

- (1) A literature review,
- (2) A Conceptual framework designed by a multidisciplinary team
- (3) A pilot study developed with the first 2 Integrated Units.

**Results:** A preliminary protocol was developed by the research team, based on relevant literature that revealed that international standards and criteria recommend multidisciplinary meetings to be held two to four times per month with a length of two hours. Then a Conceptual Framework was designed by a multidisciplinary team, establishing the responsibilities of the Clinical and Admin Coordinators of the meetings, classification of the type of cases to be discussed, time for discussion of each case depending on if they are new, follow ups or for bereavement care and which items need to be discussed for each case: evaluation, assessment of needs and an action plan

and who is the responsible team for documenting in the MDT meeting. Later on the protocol was refined after conducting a pilot study with the first two integrated units looking at structure, process and outcome measures.

**Conclusion:** The operational policy helps to identify which areas need improving to promote professional coordination from different levels of care and to set up a framework for optimizing MDT meetings. The framework developed is reproducible and can be extended easily.

**Abstract number:** P142

**Abstract type:** Poster

### **Improving the Effectiveness of MDT Meetings: Information Technology Service Infrastructure Provision**

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**Background:** No single Palliative Care Service can provide the answer for all a patient and their family might need to satisfy their End of Life needs. Conscious of this fact a model of interrelationship for multidisciplinary teams working around the patient in our region has been proposed: the Integrated Unit. Multidisciplinary team meetings using videoconference offer an effective way of interaction and coordination for Palliative Care Teams.

**Aim:** To develop an operational policy and provide PC teams with video-collaboration facilities to improve communication and effectiveness at MDT meetings.

**Methods:** We describe the operational protocol designed, which establishes several stages and tasks to provide teams with the infrastructure and the equipment necessary for

video-collaboration facilities and the ongoing support from Information and Technology Services.

**Results:** This model went live in September 2014 and since then the Integrated Unit model has been implemented in 3 PC Sectors in our region and 9 Subunits have been set up. We are starting with the 10<sup>th</sup> at this moment. From a total of 108 planned MDT meetings, 93 have been held (86%). 5 virtual rooms have been created and 22 participant PC teams have been trained. 7 Incidences have been reported.

**Conclusions:** Besides the benefits of improving patient symptom control and continuity of care, technology support with the use of video-collaboration offers other important benefits to MDT meetings from the point of view of professionals:

- A significant improvement in communication between professionals
- Time and Money savings as professionals don't have to get around

The operational protocol to give technology support to the implementation of the Integrate Unit model is reproducible and can be extended easily to other Regions.

**Abstract number:** P143

**Abstract type:** Poster

### **Palliative Care “Dedicated Swing Beds”: Needs, Perceived Competencies and Empathy of Non-palliative Care Professionals**

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**Background:** In May 2015, the Lausanne University Hospital introduced five new “dedicated swing beds” for palliative care across all adult clinical departments except psychiatry. Patients in these beds remain in their primary inpatient units, but the medical responsibility and supervision is taken over by the Palliative Care Service. This ongoing study aims to assess the personal needs, perceived competences in palliative care as well as the empathy levels of the partner services’ physicians, nurses and other professional caregivers.

**Method:** We are currently performing an exploratory prospective study. A questionnaire has been developed in order to assess health care professionals’ specific needs and perceived competences in palliative care (numerical scale from 0-10). The *Jefferson Scale of Physician Empathy* (JSPE) is administered to measure empathy levels (total score ranging from 20-140).

**Results:** So far, 41 physicians, 96 nurses, and 56 other caregivers completed the questionnaires. Descriptive data analyses showed that the highest needs were in “pain management” ( $M=7.4 \pm 2.1$ ), “patients’ psycho-social support” ( $M=7.31 \pm 1.9$ ), and “family members’ psycho-social support” ( $M=7.38 \pm 2.0$ ). The lowest perceived competences were in “delirium management” ( $M=5.11 \pm 2.3$ ), “acute symptom management” ( $M=5.22 \pm 2.4$ ) and “spiritual care” ( $M=5.32 \pm 2.1$ ). JSPE total score is significantly higher in nurses than physicians and “other caregivers” ( $M=114.7 \pm 10$  vs.  $M=110.0 \pm 12.1$  vs.  $M=104.7 \pm 12.3$ , respectively;  $F=9.431$ ,  $p=.000$ ).

**Discussion:** These results show that the opening of palliative care “dedicated swing beds” throughout the hospital might indeed respond to existing health care professionals’ needs. The data might also inform educational strategies aimed at improving professional competencies in palliative care. The needs, competences and empathy will be evaluated again after 6 and 18 months in order to test these assumptions.

**Abstract number:** P144

**Abstract type:** Poster

### **Integration of Early Palliative Care Services for Patients with Advanced Lung Cancer**

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**Aim:** In 2013 a palliative care support service (PCSS) for lung cancer patients from diagnosis of advanced disease, was started in the outpatient oncology unit at a University Hospital. The first two years’ experiences are described.

**Method:** PCSS is provided by nurses in the hospital palliative care team (HPCT) with backup from a PC physician. The first appointment is 4-6 weeks after a diagnostic interview with the oncologist and every 4-6 weeks until patient’s death or discharge to a palliative care home team (PCHT). The first interview focuses on assessing the patients understanding of disease, prognosis and goals of treatment. Each interview includes an assessment of distress and symptoms using the NCCN Distress Thermometer (DT) and the Revised Edmonton Symptom Assessment Scale (ESAS-r). Tailored information and recommendations are provided for symptom management and other resources.

**Results:** Over 20 months 80 patients were referred to the PCSS, 13 did not attend and 3 died before first

appointment. Interviews were 165, telephone calls 131, physician's advice 100 and 28 discharged to PCHT. Overall results on DT showed that 46 (76%) patients scored  $\geq 3$  on distress. Most frequent reported problems were physical (100 %) and emotional (50%). Problems with fatigue (65%), pain (50%), breathing (46%), sleep (41%), tingling in hands/feet (36%), constipation (36%) and worries (36%) were most common. Overall results on ESAS-r showed: tiredness 88%, shortness of breath 75%, well-being 71%, anxiety 56%, pain 54%, appetite 49%, drowsiness 46%, depression 42% and nausea 38%. The frequency of ESAS-r symptoms scored  $\geq 3$  in severity were: tiredness 72 %, shortness of breath 57%, wellbeing 45%, drowsiness 39%, lack of appetite 32%, pain 31%, anxiety 27%, depression 21% and nausea 15%.

**Conclusion:** The overall experience of PCSS is positive. Oncology clinicians have shown interest in this service for other advanced cancer patients. Two research projects are ongoing.

**Abstract number:** P145

**Abstract type:** Poster

### The Hospice Care Concept, a Cross Sectional Study

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**Introduction:** Worldwide, hospice care is defined inconsistently.

**Aim:** To explore hospice care in the Netherlands to develop a sustainable definition of hospice care.

**Methods:** An explorative cross sectional study was performed, from June 2014 - June 2015. Members of the Dutch Association of Hospice Care (43) were recruited. An electronic survey was mailed to all participating hospice administrators.

Primary outcomes: population, concept of care, staffing and services. The survey was based on the current (inter) national standards of care. Face validity and feasibility were established by 5 experts, hospice administrators and researchers; 2 changes were made.

Descriptive statistics were performed using SPSS.

**Results:** 39 hospices (286 beds, 2797 patients) were included. The population was patients with a life expectancy < 3 months, families, caregivers and the community. Only 4 hospices (10%) used a casemix: complexity, specific patient groups or age. All hospices provided inpatient care. In addition patients were admitted for respite (70%), crises (50%), home- (40%) and day care < 10%. Patient care focused on individual physical, psychological, social and spiritual needs and caregivers (over)burden and bereavement. Patient care was provided by formal (25%) and

informal (75%) caregivers. The multidisciplinary teams consisted of nurses, physicians and spiritual counselors in all hospices, complemented with various paramedics. Nurses were available 24/7 in all hospice. Knowledge development and dissemination was facilitated through 1) consultation: local 64%, hospital 42% and national 57%, 2) education: independent 85% or collaboration 76%, and 3) research: participant 79% and initiator 36%.

**Conclusion:** Hospice care in the Netherlands developed from inpatient facilities in the '80s to a broad concept of specialized palliative care in 2015, expanding the responsibilities to hospice care for all patients and families in need for palliative care in the community.

**Abstract number:** P146

**Abstract type:** Poster

### Advance Care Plan for Palliative Patients: Preferred Start and Content

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**Background:** Since the 1990s there has been an increasing awareness of the challenges according to early decision making in palliative care and of the poor knowledge and documentation of patients wishes and hopes. Apart from progress in palliative care, the focus to deal with these needs has been the development of advance care planning.

**Aims:** We explored the preferred start and content of Advance Care Plans for palliative patients from the perspective of health care professionals.

**Methods:** An online survey was sent to all hospital doctors, general practitioners and specially trained palliative care nurses (n=151) in the district of Romsdal in Norway.

**Results:** 51 health care professionals responded (34%). Most of the responders worked more than 10 years within health care (70%).

They suggested the right starting point of an Advance Care Plan to be; time at which a non-curable disease is diagnosed (64%), estimated time of survival below one year (50%), below 6 months (29%) and below 2 weeks (6%), repeated hospital admissions during the last 6 months (42%), reduced functional level (ECOG 2-3)

(29%). The majority preferred a proactive and early approach to an Advance Care Plan. Free comments emphasized that a continuous updating of the plan is essential.

The responders suppose it important that an Advance Care Plan contains: patient's wishes, hopes and worries (100%), responsibility in further treatment (98%), intensity of further treatment and resuscitation status (98%), status quo of disease (90%), patients and relatives acceptance of prognosis (89%), how to reach health care professionals 24/7 (89%).

**Conclusion:** The participants strongly support early and systematically decision-making and recommendations in advance care planning. An Advance Care Plan with continuous updating is crucial in empowering health care professionals to face the challenges in provision of care to palliative patients during the whole course of disease.

**Abstract number:** P147

**Abstract type:** Poster

### Early Palliative Care and Its Translation into Oncology Practice in Canada: Barriers and Challenges

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This project reviews the progress Canada has made integrating palliative care into oncologic practice. Key clinical practice guidelines have influenced and have been translated into Canadian oncology policy and operations. Comprehensive accreditation standards exist to guide oncology practice in institutional and ambulatory care settings. Common barriers and challenges are discussed: education and attitudes, compassion fatigue, terminology, paucity of research, aggressive cancer care, and organization and operational considerations. As a result eight made-in-Canada innovations emerged and are described. This inventory of best practices provides a foundation for a structured environmental scan of oncology beds and services. The behavioural domains framework is also concurrently being used to inform the construction of a survey developed to assess the knowledge, skills and attitudes of oncologists across Canada. Lessons learned and recommendations describe a plan for action.

**Abstract number:** P148

**Abstract type:** Poster

### The Economics of Advance Care Planning

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**Background:** Advance care planning (ACP) encompasses discussion and documentation of patients' future health care wishes. Previous reviews on economic impacts of ACP have been limited in scope or have not provided quantitative synthesis of results. The aim of this study is to assess the impacts of ACP on healthcare resource use from a societal perspective.

**Methods:** Systematic review and synthesis based on an electronic search strategy of the following databases: MEDLINE, CINAHL, EMBASE. PsycINFO, EBM Reviews and Social Work Abstracts. Scopus and Google Scholar were searched to capture grey literature.

**Results:** Review of 40,960 records resulted in a total of 236 articles eligible for full review. Inclusion criteria included study design (experimental or observational), setting, whether or not only decedents were sampled, and the use of ACP indicators. Of the resulting 36 studies, 18 represented documentation-based interventions, 2 were discussion-based, 14 were for both documentation and discussion or institutional ACP programs, and 2 involved proxy measures. Studies varied in length of data collection period for cost or charge assessment from 48 hours to periods of up to 18 months. Only 4 studies included costs of the ACP intervention itself. Twenty-eight studies showed decreased charges or costs in the ACP intervention groups, 6 showed cost increases, and 2 showed no effect or inconclusive results.

**Discussion/conclusion:** Given significant heterogeneity between the types of resources costs among studies and the measures used to compute the published cost data, comparative cost analysis and synthesis was challenging. Nonetheless, our analysis suggests that ACP interventions lead to reduced use of resources. The bulk of these savings were observed in inpatient, outpatient, and other (home, long term, and hospice) care settings. The impact on out-of-pocket and private costs is inconclusive.

**Abstract number:** P149

**Abstract type:** Poster

### Distress, Psychological Morbidity and Coping Strategies among Palliative Professionals: A Longitudinal Study in a Single Unit

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Hospice and palliative care practitioners (HPC), despite facing the trauma of patients' death daily as part of their work, are described to report less work-related stress symptoms compared to other health workers. This seemingly paradoxical finding has been related to a number of

putative protective factors at the organizational and individual level (e.g. team working and coping strategies). Palliative staff's resilience and vulnerability at these two levels has not been much searched longitudinally.

This study aimed to monitor the prevalence of work-related stress, psychological morbidity, and their associations with workplace and individual factors in a single palliative unit, 6 months after hospice opening (t1) and 6 months later (t2).

Both qualitative and quantitative methods were used, tackling factors such as perceived work climate, workload, trust in colleagues' competence and support, work-life balance, coping strategies and psychological well-being (with HSE by Edwards et al, 08, GHQ by Goldberg, 72, Cope by Carver et al., 89, ASQ by Feeney et al., 94)

Results showed a strong association between workplace factors and psychological morbidity. Repeated measures Anova showed remarkable worsening at t2 especially for control (on her own work), support by supervisors, and change (how organizational change is managed and communicated); psychological morbidity, on the other hand, increased from 0% to 50%. Though good work-life balance and constructive coping were present at t1 and t2 in most staff, team working dropped severely at t2, and the management exhibited a stable avoidant coping strategy.

Results seem to confirm the importance of organizational stressors in hospice like in other workplaces (Koh et al., 15): protective factors at the individual level, which are present in this palliative unit too, may not suffice, alone, to dispel burn-out.

## Bereavement and family care givers

**Abstract number:** P151

**Abstract type:** Poster

### Family Caregivers' Experience of Providing End of Life Homecare in Advanced Cancer: A Grounded Theory Study

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**Research aims:** The provision of end-of-life homecare involves the organization of multiple resources and supports for patients and families. The purpose of this study was to examine family caregivers' experience of providing care in the home for patients with advanced cancer. Study Population: Family caregivers of patients who completed a randomized controlled trial of early palliative care versus standard oncology care were recruited 6 months to 5 years after the patient's death.

**Study design and methods:** Utilizing the method of grounded theory, the researchers asked 61 participants to

explore their experiences with care in semi-structured interviews from April 2012 to March 2015.

**Analysis:** The constant comparison technique guided the analysis of interviews. Analysis involved an iterative process until theoretical saturation was achieved.

**Results and interpretation:** Study results yielded four conceptual themes:

- (1) *Taking charge* (caregivers' assumption of active roles in the organization of homecare, which was initiated by the desire to contribute, but also because they felt the need to ensure good care);
- (2) *Feeling supported* (participants gathered therapeutic supports from visiting homecare personnel to provide a sense of reassurance and emotional comfort);
- (3) *Preparing for death* (participants expressed the importance of being prepared for the final phases of dying, in particular obtaining knowledge of how to play a more meaningful role) and
- (4) *Managing bureaucratic details* (the need to manage multiple administrative responsibilities following death).

**Conclusion:** Although they often did not have the necessary information and training to fully participate in this process, family caregivers played an active role in providing homecare to ensure the best possible care at the end of life. Examining caregivers' perceptions can inform educational and training interventions to facilitate this role, and reveal aspects of homecare that require more formal support.

**Abstract number:** P152

**Abstract type:** Poster

### „It is Good to Be Remembered.“ A Survey on Sending Anniversary Commemorative Cards to the Bereaved of Deceased Palliative Care Patients

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**Background:** What do bereaved family members feel and think about receiving a commemorative card from the palliative care facility where their relative died the year before? Studies indicate that condolence letters generate positive effects on the grief work of bereaved persons. However there is a lack of studies inquiring specifically about the feelings and opinions of bereaved family members on receiving a commemorative card one year after their relative deceased.

**Questions:** What are the effects of a commemorative card on its recipients?

Does it serve the purpose of expressing appreciation and sympathy?

Are there any further aspects (e.g. regarding layout or text) which need to be considered?

**Methods:** A questionnaire relating to these questions was sent out to each recipient of a commemorative card in the time frame from October 2014 (starting point of sending commemorative cards in our unit) to June 2015. Data were analysed descriptively and via qualitative content analysis.

**Results:** From 87 questionnaires 19 were undeliverable. From the remaining 68 questionnaires 24 were returned completed (35 % response rate). The sample included 14 spouses and 7 adult children of deceased patients. 22 out of 24 respondents felt pleased receiving the card. 21 responded they felt consoled. For 9 respondents the card initiated sadness but simultaneously a feeling of gratefulness. The current format of the commemorative cards, layout, text and date of mailing were assessed as adequate or right.

**Conclusions:** The results clearly indicate that receiving a commemorative card affects the recipients positively. Hence, this approach is an important component of a palliative care facilities' work, which after all does not end by the time of the patients' death, but includes supporting the family members in dealing with the loss thereafter. Further research on effects of condolence from the caregiver to the bereaved family members with larger samples is needed.

**Abstract number:** P153

**Abstract type:** Poster

### Rounding the Circle of the Continuum of Palliative Care

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This study describes and interprets lived experiences of non-medical professionals (NMP) (funeral directors, florists and solicitors) as they interact with the bereaved and dying. The philosophy of palliative care focus on family centred care. Its core value, collaboration of interdisciplinary and multidisciplinary teams within the Continuum of Palliative Care (CoPC).

This research identifies the need for extending these partnerships. The work establishes how integrating NMP's into CoPC strengthens the approach to care in communities, particularly at the post-mortem interval.

A phenomenological study using triangulation, semi-structured in-depth interviews and surveys. The study identified the *lived experiences* of a community; funeral director

(n=5), florist (n=6) and solicitor (n=45) documenting obvious and imperceptible services offered to the dying and bereaved. Interviews and surveys were analysed using NVivo & SPSS software. Van Manen's 'holistic' and 'selective' approaches were used to identify the main themes.

**Major themes:**

- Death is difficult for all NMP's
- The bereaved are not prepared for the practical side of death.
- NMP's view themselves as outsiders & subordinate to health professionals despite having vast experience
- Timing from death to disposal adds pressure, to both NMP's and families
- NMP's boundaries juxtaposed with empathy and compassion
- NMP's have a distinct lack of recognised coping mechanisms

Findings have relevance to health professionals and question the effect of their sudden disconnect following the death of their patient to the bereaved family. Embedding NMP's into the CoPC can address social/practical issues coupled with bereavement thus enabling a holistic approach to the post-mortem interval. Health professionals should learn to tap into the NMP's valuable experience. Enabling and giving a voice to the NMP's will help the bereaved feel better, less alone, and get access to support in their communities thus rounding the circle of CoPC.

**Abstract number:** P154

**Abstract type:** Poster

### Understanding Quality of Life among Caregivers of Patients with Advanced Cancer: A Qualitative Study within a Trial of Early Palliative Care

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**Background:** Palliative care can improve the quality of life (QOL) of patients when introduced early in the course of advanced cancer; however the effect on caregivers is less clear. The purpose of this study was to report qualitatively on caregiver QOL following a trial of early palliative care, exploring from a caregiver perspective areas of QOL and impact of early palliative care on these domains.

**Methods:** 461 patients with advanced cancer and 182 caregivers were recruited to participate in a cluster-randomised

controlled trial of early palliative care versus standard oncology care<sup>1</sup>. Following completion of the trial, 23 family caregivers (14 intervention, 9 control) were sampled selectively to participate in semi-structured interviews to discuss their QOL. Interviews were analysed using a grounded theory approach.

**Results:** Five major themes of caregiver QOL emerged from the interviews: burden; confidence and supports; self-growth and relationships; confronting mortality; and coping strategies and life perspective. Apparent differences in QOL emerged between intervention and control participants that were not evident from the quantitative results. In particular, the intervention group reported increased access to practical supports, resulting in greater confidence as a caregiver; more prevalent self-care strategies; a greater willingness to discuss mortality and advance care planning; and a change in life perspective through caring for the patient with cancer.

**Conclusions:** This study revealed five major areas of caregiver QOL, on which early palliative care could have an impact. Current QOL questionnaires designed for caregivers may not fully address the domains that were described. Consideration should be given to the construction of a caregiver QOL measure that is specific to the early palliative stage.

1. Zimmermann, C et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *Lancet* 2014;383:1721-30

**Abstract number:** P155

**Abstract type:** Poster

### **Who Needs Bereavement Support and who Provides Bereavement Support? A Mortality Follow-back Survey**

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**Background:** Palliative care services struggle to make appropriate decisions about providing, or not providing, bereavement support due to the lack of evidence-informed approaches.

**Objectives:** This study identifies and describes the profiles of bereavement risk and support needs of a population based sample in Australia and tests the fit of the data with the three-tiered public health model for bereavement support.

**Method:** Family members who were bereaved 6-30 months prior to the survey and who were clients of six funeral providers participated (2013-15). A postal survey was used to collect information about bereaved people's

experience of caring and perceived satisfaction with any bereavement support provided.

**Results:** A total of 1133 bereaved people responded. The low risk group (59.6%) were typically grieving for a parent, the moderate risk group (35.2%) were typically grieving for a spouse, and the high risk group (5.2%) typically grieving for a child or a young spouse. 63% of deaths were due to terminal illnesses and 64% of deceased care recipients used palliative care services. The majority of the bereaved in each of the 3 risk groups received support predominantly from family and friends, followed by funeral directors and general practitioners. The higher the risk group, the more likely there was a perceived lack of support.

**Conclusions:** Support needs of bereaved people at different risk levels may be met using different combinations of strategies. Rather than a 'one-size-fits-all' approach to bereavement care, there is merit in providing flexible and targeted bereavement services, many of them informal and within local communities as well as formal offerings of health services. As promoted by the public health model, the emphasis needs to be on partnerships between palliative care services and the wider community.

**Abstract number:** P156

**Abstract type:** Poster

### **Family Caregiver Participation in Palliative Care Research: Is Gatekeeping Necessary?**

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**Background:** It is important to seek the perspectives of patients and their family caregivers to improve the evidence base in palliative care. However their participation in research is limited by inappropriate gatekeeping and paternalistic attitudes.

**Objective:** To examine the impact of research involvement on family caregivers of terminally ill people in home-based palliative care.

**Method:** The sample consisted of 322 family caregivers of palliative care patients in Western Australia (2013-14), who participated in a stepped wedge cluster trial of an intervention on identifying and addressing carer support needs using the CSNAT. A 3-item questionnaire was administered by phone post-intervention for both groups, the intervention (n=233) and the control (n=89), seeking their views on the positive and negative aspects and their ratings of the benefit of their research participation. Quantitative and qualitative analyses were undertaken.

**Results:** 98% of participants completed this post-intervention interview. The majority in both groups (even the

control group who only completed outcome measures) rated their research involvement as very or extremely beneficial (77% control and 83% intervention) and 97% in both groups perceived positive aspects to their experience. Themes pointed to 3 benefits: intrapersonal and inward directed “helped me” where caregivers felt acknowledged, valued, reassured and less isolated; connection with others and outward directed “helps other carers” leading to service improvement; interpersonal where the researcher-participant relationship has created “a safe place” for caregivers to impartially and safely express feelings.

**Conclusion:** Gatekeeping can be minimised by better understanding the factors influencing decisions to participate in research at the organisation, practitioner and caregiver levels, by developing a collaborative research design with an identified ‘champion’ from within the organisation and ongoing education and training.

**Abstract number:** P157

**Abstract type:** Poster

### Transitions Experienced by Families in Palliative Situations: A Qualitative Meta-study

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<sup>3</sup>Universität Witten Herdecke, Witten, Germany

In receiving palliative care, patients and their families experience changed life situations, in which they must negotiate challenges in daily life, increased care, and new roles. With limited time, they also experience emotional changes corresponding to the uncertainty of the future. Transitions experienced in such situations are often studied by focusing on individual aspects, which are synthesized in the following study. To assess patients’ and their families’ experiences with palliative care situations to gain a multifaceted view on transitions to palliative care. After completing a systematic research and review, a qualitative meta-study was conducted involving 14 qualitative studies. Analysis was supported by MAXQDA. The approach involved initial open coding, followed in order by axial and selective coding, in a process during which categories and concepts were synthesized. Results were validated using the model by Penrod that seeks normalcy through the end of life. The central phenomenon observed among palliative care patients and their families was maintaining normalcy during transitions. Transitions are initially experienced unconsciously until a crisis occurs and responsive actions are necessary, which encourages patients and families to perceive the situation consciously and develop strategies for negotiating it. With caregiving, new roles evolve

and patients remain caught between hopelessness and valuing their remaining time alive. With the progress of illness, caregivers reprioritize and balance their roles, and after death, family members inevitably find themselves in changed roles and are influenced by distressing and supportive factors. In palliative care situations, transitions are experienced differently by patients, their families, and professional care providers in a constant phenomenon that oscillates between unconscious and conscious perceptions of transitions. A differentiated view on emphasizing patients’ and families’ perspectives is given.

**Abstract number:** P158

**Abstract type:** Poster

### Hope as Determinant for Psychiatric Morbidity in Family Caregivers of Advanced Cancer Patients

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**Aim:** The increasing tendency for home care of advanced cancer patients often results in considerable burden and responsibilities for family caregivers (CG), in many cases leading to adverse effects for CG on their own physical and mental health. The aims of this study were, in a sample of CG of advanced cancer patients:

- 1) to assess the course of psychiatric morbidity and potentially associated CG characteristics over time,
- 2) to identify the influence of the patients’ death on CG, and
- 3) to explore predictors for psychiatric morbidity over time.

**Method:** This multi-institutional, prospective study assessed the psychiatric morbidity (i.e. posttraumatic stress disorder (PTSD), anxiety, depression and alcohol abuse) and its possible predictors (i.e. hope, burden and coping mechanisms) of CG of advanced cancer patients. CG at follow-up were categorized into one of two groups, depending on whether the patient had died since baseline or not.

**Results:** Overall, 80 participants completed both assessments. The prevalence of PTSD and anxiety decreased significantly over time ( $p=.007$  and  $p=.001$  respectively), all

other variables remained constant. There were no significant differences in psychiatric morbidity in grieving CG compared to non-grieving CG. Hope at baseline was significantly lower in CG with PTSD ( $p=.011$ ), alcohol abuse ( $p=.021$ ), anxiety ( $p\leq.001$ ), and depression ( $p\leq.001$ ) at follow-up.

**Conclusion:** CG are known to have a high prevalence of psychiatric disorders. Nevertheless, some disorders seem to decrease over time, maybe due to adjustment to the stressful situation. Most strikingly, the death of the patient had no influence on psychiatric morbidity whereas hope during caregiving seems to be the only predictor for the development of psychiatric disorders over time. Interventions to foster hope should be the focus of future research in CG of advanced cancer patients.

**Abstract number:** P159

**Abstract type:** Poster

### Hearing the Voice of Bereaved Parents - Service Users Influence Change in an Irish Hospice Community Bereavement Service

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**Background:** The Public Health Approach to bereavement care (Rumbold et al,2014) advocates that service providers should build the capacity of communities to support bereaved people. Despite this, Irish research with bereaved parents has focussed mainly on mothers whose young child died either peri-natally or following a life limiting illness. Research is needed to identify the supports of most benefit to both parents when their child dies.

**Aim:** The aim of this study was to identify the supports that bereaved parents found to be most helpful in the aftermath of the death of their child. Specific objectives included identification of parents' unmet needs in bereavement and opportunities for potential service improvement.

**Method:** This was a mixed methods study of parents who had sought support from the bereavement service between 2009 and 2014 ( $n=184$ ), with invitations to participate in a postal survey and/or a focus group made via telephone contact. Descriptive statistics and thematic content analysis (Burnard et al, 2008) were employed for data analysis.

**Results:** The postal survey achieved a 24.4% ( $n=45$ ) response rate. Median age of children when they died was 19.75 years (Inter Quartile Range=27). The respondents included 13 fathers (27.3%). Sources of support most commonly availed of were practical ( $n=36$ ) and emotional support ( $n=33$ ) from family and friends. Formal supports that were most frequently rated as very helpful were

couple counselling (44%,  $n=8$ ) and a support group with other bereaved parents (50%,  $n=11$ ). Focus group data identified three higher order themes:

- A feeling of being unsupported by informal networks
- Individual or couple counselling improved coping
- Meeting other bereaved parents enhanced coping.

**Conclusion:** Service providers must strive to develop interventions which strengthen parents' informal support networks, by raising awareness of parental grief. Early support that meets the long-term needs of this vulnerable group is vital.

**Abstract number:** P160

**Abstract type:** Poster

### Ehealth Initiatives for Family Carers in Pall Care: A Review of the Literature

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**Background:** Ehealth is defined as the use of Information and Communication Technologies (ICT), such as smart telephones, email or the internet, in health care. Research on how family carers in palliative care use ehealth has been sparse and de-centralised.

**Aims:** To present the results from a literature review exploring the use of ehealth by family carers in palliative care.

**Methods:** Six databases were searched: MedLine, Embase, PsycInfo, AMED, CINAHL and PROSPERO. The search strategy was a combination of the terms 'carers', 'ehealth', 'Information and Communication Technology' and 'palliative care'. Records were included if they reported original research of the use of ICT in the provision of palliative care for family carers.

**Results:** A total of 430 publications were identified through the multi-database search, and a further 4 were found by examining reading lists. The full text of 37 articles was assessed, and 10 papers, pertaining to five different studies, were included in the review. All studies assessed the use of ICT by family carers who were in the same household as the patient. Eight publications explored the use of video conferencing systems that allowed the carers to interact with health care staff. The majority of these studies reported positive results, especially through qualitative findings.

One study reported the use of a web-based support service for caregivers of people with NSCLC, and another one explored the use of a digital pen for pain assessment. The quality of these studies was variable.

**Conclusion:** The majority of the research on the use of ICT by family carers in palliative care has focussed around the use of video conferencing systems. There is a lack of studies looking at how carers in palliative care use the internet: how do they search for health-related information online; how does that impact on their well-being as caregivers, and what mechanisms do they use to differentiate from 'good' and 'bad' information.

**Abstract number:** P161

**Abstract type:** Poster

### **Intensive Procedure Use in the Last Month of Life is Associated with More Depressive Symptoms in Surviving Male and Female Spouses**

*Ornstein, Katherine<sup>1</sup>, Aldridge, Melissa<sup>1</sup>, Garrido, Melissa<sup>1</sup>, Bollens-Lund, Evan<sup>1</sup>, Siu, Albert<sup>1</sup>, Langa, Kenneth<sup>2</sup>, Kelley, Amy<sup>1</sup>*

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**Background:** Family caregivers of individuals with serious illness who undergo intensive medical procedures at the end of life may be at risk of negative consequences including depression.

**Aim:** To determine the association between patients' use of intensive medical procedures at the end of life and depressive symptoms in their surviving spouses.

**Methods:** Longitudinal cohort study of 1253 decedents and surviving spouses using data from the Health and Retirement Study, a survey of U.S. adults linked to Medicare claims. Decedents were mean age 77.7 and predominantly male (74.5%). With propensity score matching, we compared change in depressive symptoms (measured by the Center for Epidemiologic Studies Depression Scale (range= 0-8)) of spouses of individuals who underwent at least one intensive, life-sustaining procedure (i.e., intubation/mechanical ventilation; tracheostomy; gastrostomy tube insertion; enteral/parenteral nutrition; and cardiopulmonary resuscitation) in the last month of life, to spouses of individuals who did not use intensive procedures.

**Results:** 18% of decedents underwent one or more intensive procedures in the last month before death (n=225), with intubation and mechanical ventilation being most common (78.7%). In fully-matched analyses, those whose spouses underwent intensive procedures had a significantly greater increase in depressive symptoms after death (1.4 vs. 0.9; p=0.02). Among surviving male spouses, use of intensive procedures vs. no procedures was associated

with a one point higher increase in depressive symptoms (1.6 vs .6; p<.01).

**Conclusion:** While depressive symptoms increase overall following a spouse's death, surviving spouses of those who underwent intensive life-sustaining procedures experience an even greater magnitude of increase in depressive symptoms. This effect appears to be stronger for surviving male spouses. These family members should be targeted for potential support services to reduce depressive symptoms.

**Abstract number:** P162

**Abstract type:** Poster

### **Complicated Grief, Depression, Sleep Disorders and Alcohol Consumption of Bereaved Families of Cancer: A Nationwide Bereavement Survey in Japan**

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**Background:** Bereaved family members are at higher risk of psychological and/or physical health impairment.

**Aim:** The aim of this study was to explore the frequencies of complicated grief (CG), depression, sleep disorders, and the change in alcohol consumption in family members after bereavement.

**Methods:** We conducted a nationwide, cross-sectional, questionnaire survey for bereaved family members in 175 institution between May and July 2014 in Japan. The questionnaire included demographic characteristics, bereaved family grief (Brief Grief Questionnaire; BGQ) and depression (Patient Health questionnaire-9; PHQ-9) status, sleep conditions including use of hypnotics, and amount and frequency of alcohol intake and changes in alcohol consumption after bereavement.

**Results:** The analysis included 9,126 (response rate 67%) family members' questionnaires. In total, 14% and 17% of the participants suffered from complicated grief assessed by BGQ and at risk of major depression disorders (MDD) assessed by PHQ-9 respectively. Moderate correlation

( $r=0.59$ ;  $p < 0.0001$ ) was observed between the BGQ and the PHQ-9 score. In addition, 59% of the CG participants and 45% of the high risk MDD participants suffered from both CG and MDD symptoms. Ten percent of the participants used hypnotics and 69% felt disturbed in their daily activities by their current sleeping conditions. In total, 18% drink alcohol everyday, and 15% and 17% reported the changes in alcohol consumption after bereavement respectively. The use of hypnotics, disturb in daily activities by their sleep conditions and change in alcohol consumption was significantly related to CG and risk of MDD (all  $p < 0.0001$ ).

**Conclusion:** Current study have shown that in almost half of the possible CG or MDD participants had those symptoms independently and the other cormobidly have those symptoms. Bereaved families in high level of grief or depression could also be at high risk of sleep disorders or excessive alcohol intake.

**Abstract number:** P163

**Abstract type:** Poster

### Does Quality Dying Matter after Death? A Population-Based Study of Bereaved People

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**Background:** Some experience extreme bereavement grief; with factors contributing to this needing to be determined. People who believe a bad death happened may experience more severe grief.

**Research aim:** A descriptive-comparative study to answer questions:

1. To what extent is perceived quality of death related to the current level of bereavement grief?
2. To what extent are the perceived quality of death and the current bereavement grief level related to whether or not help was obtained for bereavement grief?

**Methods:** A bereavement study was completed in 2014 using the University of Alberta Population Research Laboratory's random-digit dialing telephone call system for population-representative answers from 1208 adult Albertans.

**Findings:** 31% were bereaved within the last year and another 15% in the last 1 to 2 years; with 78% currently feeling some grief. On rating scales of 0-10, the mean score for bereavement grief was 2.9 - indicating relatively

minimal grief, while the mean score for perceived quality of death was 5.9 - indicating it was slightly more good than bad. In adjusted analyses, the level of bereavement grief was lower when the perceived quality of death was higher. The level of bereavement grief was higher when the respondent was female, Protestant or Catholic, when the death grieved over was  $< 2$  years ago, and when it involved a spouse, parent, or child. The odds of seeking and obtaining help for bereavement grief were higher among females, when the deceased was a child, and with more severe bereavement grief. The odds of obtaining help were lower when the perceived quality of death was higher. 22% had obtained help for their bereavement grief.

**Conclusion:** Bereavement grief was common and the perceived quality of death was found to be linked to grief intensity. Research is needed to confirm these findings elsewhere, and to determine how to ensure high quality deaths as quality appears to be as important after death as it is before death.

**Abstract number:** P164

**Abstract type:** Poster

### Developing an Educational Intervention on Breathlessness in Advanced Disease for Informal Carers

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**Background & aim:** The evidence-base for educational interventions to support informal carers and enhance their caregiving capacity is limited. Our aim was to develop an evidence-based educational intervention on breathlessness in advanced disease for carers.

**Method:**

Stage 1: Qualitative in-depth interviews with purposive sample of 25 patient-carer dyads from two disease groups (COPD and cancer) to identify educational needs and intervention preferences.

Stage 2: One-day multidisciplinary workshop with 13 clinical experts to identify evidence-based content and acceptability and feasibility of potential delivery modes.

Stage 3: Two half-day workshops (one COPD and one cancer) with 10 carers and seven patients to review intervention content, format, and language. Qualitative data analysis used a Framework approach.

**Results:** Carers wanted to learn about breathlessness. Six key topics emerged from patient-carer dyad interviews: understanding breathlessness, de-escalating anxiety and panic, keeping active, living positively, managing infections (in COPD), and knowing what to expect in the future. There was wide variation in how carers wanted to learn, but written resources were less popular than face-to-face, group, video and web-based learning. Carers wanted an intervention that drew on both clinical expertise and peer-carer experience. In general, they wanted to learn with the patient. Building on these findings, the clinical expert workshop identified evidence-based content for the six topics and discussed a potential web-based platform to facilitate multiple modes of access e.g. via clinicians, established support groups, or by carers independently. Carer workshops endorsed the need for the intervention, its content and format, and refined its language and presentation style.

**Conclusion:** Developed with carer, patient and clinician expertise this educational intervention on breathlessness has the potential to be highly relevant and acceptable to carers.

**Abstract number:** P165

**Abstract type:** Poster

### Will Only Death Bring Relief? - Burden and Needs of Family Care Givers of Patients with COPD.

#### Qualitative Interview Study

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**Research aim:** To explore and understand what it means to care for a relative suffering from progressed COPD, and to outline the burden and needs of family care givers.

**Study population:** Family care givers (n=8, age 48-79, female 6, ongoing study) of patients with progressed COPD in Germany.

**Design and methods:** Qualitative design; open guided interviews using narrative interview techniques to gain a broad and deep insight into the family care givers' experiences; analysis according to Grounded Theory (Strauss; Strauss/Corbin) using abductive reasoning.

**Results:** First results suggest that relatives who care for patients suffering from progressed COPD experience ongoing psychological strain caused by organisation of both daily routine (e.g. physical care, visit to the doctor) and formalities (e.g. application for financial support of home care or medical aids). Relatives feel obliged to care for the ill person and focus attention on them; because it is unpredictable when the next dyspnea crisis will occur, they find themselves in constant distress and tension. As a result, they try to be always available and disregard their own needs and interests. Further, the family care giver's role changes from partner to carer and they try to become an expert on COPD, switching between distanced professional and empathic relative. Family care givers suffer from psychosocial overload, and, at the same time, tend to reject professional care. It seems as if, from their perspective, the patient's death would be their only chance of relief.

**Conclusion:** As informal care givers do not receive regular psychosocial support, for them, as well as for patients, early integration of the bio-psychosocial palliative care concept and/or a non-kin-care concept (Wosko/Pleschberger 2015) might be relieving. Awareness of family carers' needs to be strengthened, e.g. by implementing the carer support needs assessment tool (CSNAT) (Aoun et al. 2015).

**Abstract number:** P166

**Abstract type:** Poster

### Family Nursing in Specialized Palliative Home Care: The Benefits of a Therapeutic Conversation Intervention

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**Background:** Family caregivers (FCGs) caring for a family member with advanced cancer are at risk for psychological distress. Less evidence is available regarding effective interventions to improve caregivers' outcomes. A study is ongoing on the effect of a therapeutic conversation intervention in three phases.

**Aim:** To evaluate the effectiveness of a family therapeutic conversation intervention (FAM-TCI) to improve caregiver outcomes for home-based FCGs of a family member with advanced cancer (phase I).

**Methods:** The theoretical frameworks that guide the intervention are the Calgary Models from the Family Systems Nursing. Phase I is a quasi-experimental; one-group pretest-posttest design. Sixty family caregivers answer a set of 7 questionnaires at three time points (baseline, after two

sessions of FAM-TCI and two to four weeks later). Three study hypotheses regarding positive outcomes of psychological distress, caregiving burden and perceived support were tested using repeated measures ANOVA.

**Results:** In total 26 FCGs were included in the preliminary analysis of phase I. FCGs receiving the intervention evidenced significant improvements in perceived support ( $P < .001$ ) and depression symptoms ( $P < .05$ ). However, the results of appraisal of caregiving were not statistically significant. Large effect sizes favouring the intervention were found for perceived support and other effect sizes calculated ranged from medium to small.

**Conclusion:** These preliminary results support that the FAM-TCI is an effective intervention for home-based FCGs where a family member has advanced cancer and two out of three study hypotheses were confirmed.

**Abstract number:** P167

**Abstract type:** Poster

### **Losing a Parent to Cancer as a Teenager: Comparison of Self-reported Family Cohesion in Cancer-bereaved and Non-bereaved Youth**

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**Background/aims:** Family cohesion plays a role in children's and teenagers' wellbeing after the death of a parent. However, little is documented about how it changes over time or the relationship between bereavement and family cohesion as reported by youths themselves. This study aims to investigate the level of family cohesion during childhood, teenage years and in young adulthood, as reported by youths that lost a parent to cancer in their teenage years compared to their non-bereaved peers.

**Methods:** In this nationwide population-based study, 622 (73%) youths (aged 19-26) filled in a questionnaire 6-9 years after losing a parent to cancer during teenage (ages 13-16) and 330 (78%) non-bereaved peers from a matched random sample. Associations were assessed using multivariate logistic regression with various combinations of confounder variables.

**Results:** Few reported poor family cohesion during childhood, with insignificant difference between the groups. Regarding the teenage years, both groups had a higher proportion of those reporting poor family cohesion. However, the cancer-bereaved youth were more likely to report poor family cohesion compared to their non-bereaved peers (adj. OR:2.1, 95%CI:1.4-3.2). Looking more closely at the cohesion trajectory in the bereaved youth, the highest proportion of poor family cohesion occurred during the teenage years, after the loss. At the time of the survey, both groups had a lower proportion of poor family cohesion. However, the cancer-bereaved youth were again more likely to report poor family cohesion compared to the non-bereaved youth (adj. OR:1.6, 95%CI:1.0-2.5).

**Conclusion:** Compared to their non-bereaved peers, cancer-bereaved youth are at higher risk of reporting poor family cohesion during their teenage years, especially after the loss of a parent. Although some of the families seem to re-unite as the time passes, cancer-bereaved youth are still, 6-9 years after the loss, more likely to report poor family cohesion.

**Abstract number:** P168

**Abstract type:** Poster

### **Caregiver Burden: Inside and Out Palliative Care Units**

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**Background:** The research conducted so far does not allow us to conclude that the caregiver burden is higher when the patient is in the palliative care units or at home, even with contradictory data.

**Aims:** To identify the prevalence of caregiver's burden and to compare it in inpatients and outpatients.

**Methods:** Cross sectional descriptive and analytical study about caregivers of palliative patients, combining quantitative and qualitative approaches. This abstract is a part of an ongoing larger research about caregivers. The sample includes 130 family caregivers of patients receiving palliative care at home or in the Madeira Palliative Care Unit. Data collection has been conducted from April 2014 to April 2015 through structured questionnaire with open and closed questions about context of caregiver's profile and Zarit Burden Interview (validated for palliative portuguese caregivers.) Data analysis are being processed with the

SPSS 20 and content analysis. The study was approved by the ethic committee of the Madeira Health Service.

**Results:** This study is still under development therefore we will present at the conference the final results. Trough the preliminary data we found high prevalence of caregiver's burden and there seems to be no difference between the burden on caregivers inpatients and outpatients. The variable "admitted patient" does not seem to contribute to a lower level of caregiver's burden. However, other variables such as social and financial support, caregiver's age, and global health perceived by caregivers seems to have a high impact on it.

**Conclusions:** The caregiver's burden is currently one of the admission criteria in palliative care units. The preliminary data from this study shows that inpatient caregiver's do not have a fewer burden, so health professionals should continue to intervene by supporting the caregiver in this process, taking into account other variables that contribute to this phenomenon.

**Abstract number:** P169

**Abstract type:** Poster

### Key Messages from a Metasynthesis of Qualitative Research to Honor the Voices of Bereaved Family Caregivers

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**Aim and background:** Bereavement can be extremely challenging for people who were family caregivers of a palliative care patient. Up to 25% of them will face complicated grief or debilitating symptoms such as depression and anxiety, especially if they had a difficult caregiving experience. Even though palliative care guidelines identify the importance of support for family, extending into bereavement, very little is known about their experiences or how to support them. The aim of the research was to

- a) complete a metasynthesis of qualitative research with bereaved family caregivers,

- b) identify a set of key messages, and
- c) produce a series of videos as interventions for bereaved caregivers.

**Method:** By applying Sandelowski and Barroso's approach, a metasummary and a metasynthesis of qualitative research with bereaved caregivers were completed by an interdisciplinary team of international researchers, clinicians, policy-makers, and community members. A set of key messages and recommendations from the findings was developed and formed the basis of a series of videos that feature participants who were bereaved caregivers.

**Results:** A model of the findings from qualitative research was developed, describing the factors that impact a continuum of experiences ranging from feeling traumatized to experiencing personal growth. Key messages from the metasynthesis include the need to:

- a) consider the entire caregiving trajectory,
- b) respect the diversity of caregivers' experiences, and
- c) acknowledge that each person needs different kinds of support.

The videos that were developed with bereaved caregivers integrate these messages and were found to be very helpful and meaningful in focus-group evaluation.

**Conclusion:** Addressing the needs of caregivers during bereavement requires taking a person-centred approach that respects diversity and unique experiences. Evidence-based video interventions with and for bereaved caregivers encourage knowledge mobilization.

### Education research

**Abstract number:** P171

**Abstract type:** Poster

### End of Life Care Educational Programme on the Intensive Care Unit Increases Staff Confidence

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**Background:** Studies have demonstrated that end of life care (EoLC) on the intensive care unit (ICU) is not always optimal. Whilst staff recognise the need for compassionate EoLC, they are not always confident in managing terminally ill patients.

**Aim:** To compare staff attitudes and confidence around EoLC on ICU in a tertiary cancer hospital, before and after the implementation of a specific targeted educational programme.

**Method:** A 4-week intensive EoLC educational programme was designed and implemented for all ICU clinical staff. This consisted of twelve teaching sessions in four key areas: withdrawal of treatment, symptom control, care of the dying and communication. This was integrated with 'de-brief' sessions to allow discussion around issues pertaining to individual patient deaths. Staff participated in an anonymous online questionnaire before and after the programme. Each question was scored on a four point categorical scale. Chi-Square analysis compared responses before and after the educational programme.

**Results:** 50 staff members participated in the initial questionnaire and 36 in the questionnaire post programme. There were 117 attendances overall to formal teaching sessions. In both questionnaires a high proportion (80%) of staff felt supported in dealing with EoLC. After the educational programme, more staff felt involved in the decision making around withdrawal of treatment ( $p=0.047$ ). A greater proportion of staff understood the reasoning behind this decision making ( $p=0.03$ ). Staff felt more confident in assessing pain in EoLC patients ( $p=0.018$ ). Despite the educational programme, 40% felt there were conflicting messages about patients' EoLC plans.

**Conclusion:** EoL sessions tailored to ICU staff have increased confidence towards managing EoLC patients. Clear communication between all staff is key to clarify EoLC plans. Ongoing regular updates and de-brief sessions will be implemented to optimise patient care and ensure staff are well supported.

**Abstract number:** P172

**Abstract type:** Poster

### Is the Out-of-Hospital Emergencies our Unfinished Business? A Nationwide Survey of Educational Skills about End-of-Life Care among Professionals

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**Background/aims:** The Out-of-hospital Emergency service is an area of frequent and delicate assistance of our patients in palliative care. Some research suggest the absence of qualification in end-of-life care in the educational background of this professionals. We wonder if they (the out-of-hospital emergency professionals -OOHEP) also detect needings in end-of-life care.

**Methods:** A descriptive cross sectional study. We launched a nationwide survey supported by "google drive formularies" through national professional associations and vocational

schools of OOHEP. We made a descriptive analysis and crosstabs, using SPSS 21.0. Informed consent was not needed.

**Results:** 110 people answered, with 109 valid questionnaires. The standard profile was a median-aged (30-50 years old) and experienced (median of >10 years worked) male, 2/3 professionals, mostly of basic life support, with a good satisfaction degree (Mean=6.84/10, DS=2,98), and with training in out-of-hospital emergencies by a vocational school. Among 12 available educational skills, 71% chose topics directly related to palliative care (communication skills, family support, or ethical aspects like palliative sedation or limitation of therapeutic efforts), with a 40% that specifically chose a topic called "End-of-life care and palliative care"(FIGURE 1). About motivation, most of them expressed the desire of helping others, and this was associated with the perception of less educational needings in communication skills (chi-square=4.6;  $p=0.032$ ). In addition, this needing (communication skills) was demanded more among professionals (33%) than volunteers (14%)(Chi-square=4.46;  $p=0.035$ ). There were no statistically significant differences on age, years of experience working, satisfaction degree or civil state.

**Conclusions:** We believe that this study confirms what bibliography suggests: end-of-life care is an educational needing among OOHEP.

**Abstract number:** P173

**Abstract type:** Poster

### The Impact of Teaching Techniques on Undergraduate Students Perception of Palliative Medicine as a Challenge

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**Background:** While palliative medicine (PM) still expands, it is still perceived as challenging by students and doctors. It is unknown, whether different teaching techniques as modular teaching (MT) and case-based learning (CBL) have different impacts on the perception towards palliative medicine of undergraduate students.

**Methods:** Medical students ( $n=398$ ) assessed on a 6-Point-Likert scale before and after a course in PM (a) "whether" and "why" PM is challenging and (b) their preparedness for caring for terminally ill patients, and (c) their perceived capabilities to treat and to communicate palliative patients

on a 100mm visual analogue scale. PM was taught according to the recommendation by the EAPC of 2013. In cohort 1 (C1, n=217) MT and in cohort 2 (C2, n=181) CBL were performed.

**Results:** PM was perceived as rather difficult (3.5), because of “complex diagnosis/comorbidities”, “emotionally challenges” and “communication”.

In answer to “will this course be helpful in my future practice” implementation of CBL led to a significant improvement in “psychosocial/spiritual aspects” ( $p=0.001$ ), “symptom assessment/quality of life” ( $p<0.05$ ), and “ethical aspects” ( $p<0.001$ ).

Preparedness for caring for the dying was low in C1 and C2 (mean 3.8, 3.9 respectively, 0 = well prepared to 5 = not prepared at all) and improved significantly in C2 (2.9 after,  $p<0.001$ ).

Assessment of self-perceived preparedness to treat symptoms and communicate showed a significant increase in C2 (30mm and 66mm, and 25mm and 56mm respectively, both  $p<0.001$ ).

**Discussion:** PM is a challenging subject for medical students. Challenging aspects include complex diagnosis and comorbidities, emotions, and communication. CBL is adequate to prepare students for PM practice and superior to MT, especially in regard of bearing and ethical and spiritual questions.

**Abstract number:** P174

**Abstract type:** Poster

### For whom Should we Care? - A Teaching Program for Residents to Foster End-of Life Care

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**Background:** In Austria, end-of-life care is mostly delivered by physicians who have had no specialised training in palliative care as this is not mandatory in the local medical curriculum. Based on EAPC recommendations, a program to enable physicians starting their career to offer end-of-life care was designed.

**Aim:** Residents’ competencies to care for the dying have been improved.

**Methods:** The teaching program for end-of-life care was offered to all residents of an Austrian tertiary care hospital starting 2015. This program was evaluated after 8 months using the „test for palliative competence“ (PKT), a recently validated German questionnaire to check physicians’ palliative knowledge and self efficacy.

**Results:** A teaching program was designed consisting of 19 units in palliative care and monthly death debriefing rounds in small groups. Palliative training took place 11

times during the 8 months of observation with 44 persons participating. 9 of 10 new residents - the main target group - took part. Using the PKT, an increase in palliative knowledge of all residents was shown from 14 +/- 4 to 16 +/- 2 of 28 ( $p=0,01$ ); the palliative self efficacy showed a trend to rise: from 30 +/- 6 to 33 +/- 6 of 54 ( $p=0,08$ ). Especially those persons having taken part in the death debriefing rounds experienced an increased palliative self efficacy.

**Conclusions:** Even experienced physicians often do not feel sufficiently prepared to deliver professional end-of-life care. This can be changed by a mixture of teaching and debriefing rounds. Reflecting their own clinical experiences in end-of-life care in small groups was effective for self efficacy in end-of-life care. Starting to work as a physician might be the crucial moment for establishing an attitude which comprises end-of-life care as a physician’s core competence.

**Abstract number:** P175

**Abstract type:** Poster

### Can a One-day Workshop Improve Health Care Assistant’s Knowledge and Self-efficacy in Palliative Care?

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**Background/aims:** Evolution of the Health Care Assistant (HCA) role places them at the centre of the direct provision of hands-on care to dying patients, as well as acknowledging them as a key informant to the wider team regarding the person’s condition. Competency Frameworks for palliative care highlight the need for HCAs to have knowledge of and apply the principles of palliative care. Therefore, providers of palliative care education should incorporate a framework to support HCAs in achieving those competencies. In the Irish context, there has been no evaluation of whether palliative care education supports HCAs achieve the competency levels required.

**This study aims** to evaluate whether a one-day palliative care education programme, designed to introduce essential hospice and palliative care concepts to HCAs working across all practice settings, can impact positively on HCAs knowledge of palliative care and self-efficacy with 14 core skills relevant to their role

**Methods:** A quasi-experimental pretest-posttest follow-up design was used. Thirty-five HCAs enrolled on the one-day programme covering 14 key areas relevant to the HCA

role (e.g. discussing hospice and palliative care, non-drug therapies, care of the body following death). Knowledge (assessed using the Palliative Care Study Day Knowledge Questionnaire) and confidence (measured using the Ersek Efficacy Questionnaire) was assessed pre and post course, and again at six weeks post course.

**Results:** There was significant improvement in HCAs knowledge ( $t(34) = -5.197, p < 0.000$ ) and overall self-efficacy ( $t(29) = -5.457, p < 0.000$ ) post course. Improved confidence in 13/14 key skills was detected. HCAs completed the six week follow up and improvements were sustained over time.

**Conclusions:** This study demonstrated significant improvement in palliative care knowledge combined with an increase in confidence levels for health care assistants after attending a one-day palliative care education program.

**Abstract number:** P176

**Abstract type:** Poster

**Can a Palliative Care Education Intervention Improve and Sustain Participants' Confidence and Professional Development in Palliative Care and Does this Translate to Care Delivery?**

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**Background:** It is becoming increasingly recognised that in order to improve palliative care provision there must be a strong focus on education and training with the need for educational initiatives to be effectively evaluated and learning sustained over time. The European Certificate in Essential Palliative Care (ECEPC) is an eight week home-study based programme for generalist and palliative care professionals currently run in Hospices in the UK, Republic of Ireland, and Malta.

**Aims and objectives:** To evaluate the impact of the ECEPC on candidates' confidence in palliative care and determine if this is sustained over time; to establish if learning from the course influences professional growth; to explore the translation of learning and experience to care delivery.

**Population:** All consenting candidates (n186) undertaking the ECEPC over a 12 month period.

**Study design:** A longitudinal mixed method approach using an online survey as baseline, 3 and 6 months (using a validated self-efficacy scale). Semi-structured interviews with a sub-sample of 15 candidates at the same time points.

**Methods of analysis:** The survey was analysed using frequency, correlation and multiple regression analysis. Interviews were examined using thematic analysis.

**Findings:** Survey response rate was 65%. The self-efficacy scale found confidence increased at 3 months and was sustained at 6 months. Qualitative analysis supported the survey findings that increased knowledge improved confidence in decision making and management at the end of life, and enhanced communication between patient, family and professionals. Some influenced the practice of others through education, or became a resource for their colleagues enhancing both their own and their team's palliative care practice.

**Conclusion:** The findings suggest that the ECEPC course improves candidates confidence, which is sustained at 6 months influencing clinical practice, professional development, and care delivery.

**Abstract number:** P177

**Abstract type:** Poster

**Training General Practitioners in Timely Identification of their Palliative Patients and in Anticipatory Care Planning Enhances their Awareness**

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**Background:** Palliative care is often restricted to terminal care. For that reason, general practitioners (GPs) were trained in timely identifying palliative patients with cancer, COPD or heart failure with the help of the RADboud indicators for Palliative Care needs (RADPAC) and to make a proactive, structured care plan. They were offered two additional training sessions, in which they practiced with simulation patients to talk about the future, and per patient, a consultation with a palliative care consultant to fine-tune the care plan.

**Aim:** To study how GPs and consultants evaluated the several aspects of the training, and its impact on their daily practice.

**Design:** Two years after the training took place we performed semi-structured interviews with the GPs, and a focus group interview with the consultants and did a thematic content analysis.

**Results:** Six consultants and nine GPs participated. Most GPs mentioned positive changes in their thinking or acting regarding early palliative care. Part of them still used the tool to identify patients; most of the others had internalised the indicators. Although half of them still considered discussing end-of-life aspects difficult, particularly in patients

with organ failure, the others more easily discussed the future with their palliative patients.

**Conclusion:** Although most GPs and consultants were positive about the training and applying it in daily practice, timely identify of palliative patients with COPD or CHF and how to discuss the future with them should have more attention in future training.

**Abstract number:** P178

### Beginning the Conversation in High School: Talking about Death Improves the Awareness of Palliative Care and Bereavement? Se+ Project

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**Background:** There is few research about education in end-of-life care (EOLC) in high school, and its results in improving the awareness of the living of patients and families in palliative care (PC).

**Aim:** To analyze the impact of a session about end-of-life care in the own perception of change of high school students about EOLC and PC.

**Method:** A pre/post prospective study during the last 2 years in Navarre. A 3-hour session was prepared about

EOLC, including a testimony of a relative in grief. 2 surveys were designed for before and after the session, collected by the teachers. The score went from 1 to 4, being 1-2 less adaptive answers, and 3-4 more adaptive. The main objective was to achieve a statistically significant mean difference in the first 4 questions, before and after the session, with a confidence interval of 95%. Informed consent was not needed, but we signed an agreement with each school.

**Results:** 947 students of 12 schools (7 private, 5 public) answered the surveys along 22 sessions. The main objective was achieved (TABLE 1), with a greater mean difference in the PC image (2.56 pre vs. 3.13 post,  $p < 0.0001$ ). The overall rating was 3.28/4 (SD 0.64). There were statistically significant differences between private vs public school (slightly lower in public). 2/3 of those with less adaptive answers in the first four questions perceived change in their attitude toward patients and families; 83% took awareness about their ability to help others in this situation; 59% affirmed that it is necessary to talk about this at school; and 93% scored 3 or 4 out of 4 to the session. About palliative care, those who answered less adaptively in question 2 believed that the session helped them to take awareness of their ability to help others (85%).

**Conclusion:** Beginning the conversation about end-of-life with high school students has demonstrated impact in the image of PC, and improved the awareness of their ability to help.

**Table 1.** Survey and results.

QUESTIONS	TOTAL (%)	MEAN (SD) BEFORE SESSION	MEAN (SD) AFTER SESSION	p value	NNT (CI 95%)
When you hear the Word "death", you...	892 (94.2%)	2.65/4 (1.047)	3/4 (1.071)	<0.0001	9,5 (6,6-17)
When you hear that somebody is in palliative care, you...	899 (94.4%)	2.56/4 (0.92)	3.13/4 (0.82)	<0.0001	2,6 (2,4-2,9)
A relative of your best friend is dying. You...	900 (95%)	3.41/4 (0.84)	3.5/4 (0.79)	<0.023	25,2 (13,2-286,3)
Your relative is dying. You...	895 (94.5)	3.6/4 (0.9)	3.72/4 (0.72)	0.003	8,5 (6,7-11,7)
Do you believe that the session have helped you to learn something you did not know previously?	900 (95%)		2.87/4 (0.75)		
Do you believe that the session changed your attitude towards patients and families in EOL?	899 (94.4%)		2.7/4 (0.87)		
Do you believe that the session has improved your awareness that you are able to help this people in EOL?	900 (95%)		3.07/4 (0.72)		
Do you believe that it is necessary to talk about this at school?	897 (94.7%)		2.78/4 (0.85)		
Which is your overall assesment of the sesión?	892 (94.2%)		3.28/4 (0.64)		

**Abstract number:** P179

**Abstract type:** Poster

### **Nursing Students' Attitudes toward Caring for Dying Persons - Development during Nurse Education**

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**Background/aims:** Most nurses will care for dying patients in their work and nursing education need to prepare students for this task. The attitudes toward dying and death, and communication with patients and families are important issues in palliative care education. The aim was to describe nursing students' attitudes toward caring for dying patients during undergraduate education, factors influencing changes in attitudes, and how prepared students feel to perform end of life care.

**Design/methods:** This is a longitudinal study exploring the development of nursing students' attitudes to care for dying patients with the questionnaire Frommelt Attitude Toward Care of the Dying Scale (FATCOD) first, at the beginning of their education (T1), second, at the beginning of the second year (T2) and finally, at the end of the third year of education (T3). FATCOD is a 30 item questionnaire exploring attitudes to care for dying patients; items are rated on a five-point Likert scale. Total FATCOD score, all items summated ranging from 30 to 150, for T1, T2 and T3 was analyzed with ANOVA. Length of theoretical and presence of practical palliative care education were hypothesized to influence changes in attitudes. Students also evaluated support and preparation from education. At all three occasions, 117 nursing students from six universities in Sweden participated.

**Results/interpretation:** The total FATCOD increased from 126 to 132 from T1 to T3. Theoretical palliative care education became significant predictor of changes in attitudes towards caring for dying patients in that five weeks education better predicted changes in attitudes than three weeks. Students with five weeks theoretical palliative care education also felt more prepared and supported by the education to take care of a dying patients. Students did not feel prepared to take care of a dead body or meet families. Although nursing students' attitudes increased, they need more preparation in palliative care.

**Abstract number:** P180

**Abstract type:** Poster

### **E-Learners in Palliative Care Education - What Do they Really Need?**

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“Education is a core component of specialist palliative care (DOHC 2001). E-learning provides flexibility to learn regardless of location allowing self-paced learning to occur at a time and place that suits the learner. How do learners perceive e-learning in palliative care education and what are the challenges to its uptake?”

**Aim:** To understand the barriers to adopting e-learning in palliative care in Ireland by clinical staff and to examine how we can facilitate e-learning for those undertaking e-learning courses.

**Methods:** Postal and online questionnaires were distributed to hospice services on the Island of Ireland inviting clinical staff from specialist palliative inpatient units, homecare / community and palliative day care services to participate in the study.

**Results:** The average response rate obtained across six sites was approx 35% (n= 397). Respondent's perceived confidence carrying out a number of computer tasks was high with 62% feeling confident using E-Learning even if they had never used it before. Sixty-seven per cent indicated that having limited time would be a challenge and analysis of open-ended responses highlighted not having protected time during work as an inhibitor. There was a preference for face to face interaction by 54%. Nearly one third indicated that remaining motivated would be a challenge. Approx 27% indicated lack of computer skills, lack of confidence and a requirement for technical or other support as factors preventing them using E-Learning. Relating to course design, modules should be short and “E-learning needs to be interactive & a sharing of ideas with ones in your personal field”.

You can tick more than one

Booklet	28%
Face-to-face assistance	50%
Video demo	25%
Telephone contact	33%
Online assistance	47%
Hands-on training session	50%

*[Support you would like to receive as a learner]*

**Conclusions:** Critical facilitators for e-learners ranked in order of importance are:

- 1) Dedicated protected time to participate in E-Learning
- 2) Quick technical and administrative support
- 3) Dedicated computer training before completing an E-Learning course

- 4) Regular contact with the educator in online course work.

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**Abstract type:** Poster

### The Last Aid Course - First Experiences and Review of the Literature

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**Background/aims:** Most people do want to die at home. In the future many people will therefore need Palliative Care at home. This increasing demand for Palliative Care cannot be met by specialized Palliative Care Teams alone. Therefore the public needs basic knowledge and skills in Palliative Care and care at the end of life in order to participate in end of life care.

**Methods:** An international working group from Norway, Denmark and Germany with experts in the field of Palliative Care from different professions designed a short basic *last aid course* with 4 teaching hours (each lasting 45 minutes) only. The four modules are about:

1. Care at the end of life,
2. Advance Care planning and decision making,
3. Symptom management,
4. Cultural aspects of death and bereavement.

Pilot courses have been established in all three countries. First experiences are presented. In addition an overview about the literature will be given.

**Results:** The results showed that most participants appreciate the course and talking about death and dying in a comfortable atmosphere. Most of the participants would recommend the course to others.

**Conclusions:** First experiences with the *last aid courses* are very promising. Education of instructors and a wider distribution of last aid courses have already started in autumn 2016. Further research on the implementation of the last aid course is planned.

#### Literature:

1. Bollig G, Kuklau N. Der *Letzte Hilfe* Kurs - ein Angebot zur Verbesserung der allgemeinen ambulanten Palliativversorgung durch Information und

Befähigung von Bürgerinnen und Bürgern. *Z Palliativmed* 2015; 16: 210-216.

2. Bollig G. Der Letzte Hilfe Kurs - Eine sorgende Gemeinschaft braucht Allgemeinwissen über Palliativversorgung und Palliative Care. *Praxis Palliative Care* 26/2015: 36-39.
3. Bollig G, Kuklau N. Sistehjelpskurset! Et kurs for folk flest om død og omsorg ved livets slutt, palliasjon. *Omsorg* 2015; 2: 66-71.

**Abstract number:** P182

**Abstract type:** Poster

### The Relevance of Emotional Intelligence in End-of-Life Care

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**Background:** Nurses have an important role in the provision of end-of-life care, and nursing students often find death and working with dying people to be some of the most difficult aspects they face in their training. In this context it is important to obtain information about undergraduate nurses' perceived abilities to interpret and manage emotions when interacting with dying patients.

**Aims:** The aims of the study were to examine the relationship between emotional intelligence in respect to nurses' attitudes towards caring for terminally ill people and members of their families, and death anxiety.

**Methods/subjects:** Participants were 377 nursing students (81 males and 291 females, 5 not specified) with a mean age of 21.87 years (SD= 4.60, range 17-47).

**Instruments:** Participants responded to a questionnaire that contained the Spanish versions of the following instruments: a) Trait Meta-Mood Scale (TMMS-24), that assesses attention to feelings, clarity of feelings and mood repair; b) Frommelt Attitudes Toward Care of the Dying Scale (FATCOD-S), constituted by two factors: "positive attitudes toward caring for dying patients" and "perceptions of patient and family-centred care", and c) Death Anxiety Inventory-Revised (DAIR).

**Procedure:** A cross-sectional design was used. The students' participation was voluntary and all answers would remain anonymous and confidential.

**Results:** Linear regression analysis confirmed that emotional clarity (TMMS) is a significant predictor of FATCOD. In addition, the correlation coefficients showed a significant positive association between death anxiety and

emotional attention, and negative with the positive attitude toward caring for the dying patient.

**Discussion:** The findings indicate that a greater understanding of the emotional process modulates the death distress which involves the end-of-life care. The results suggest the convenience of including emotional training and death-education programs in nursing curriculum.

**Abstract number:** P183

**Abstract type:** Poster

### Introducing Palliative Care in University Medical Education - Student's Perspective

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**Purpose:** To present an analysis of the academic activity within the discipline of palliative care performed from the students' perspective.

**Material and method:** An individual survey, comprising 12 open-ended and closed-ended questions, was applied on the 3<sup>rd</sup> year students in Medicine, in May 2015.

**Results:** 199 valid surveys were collected. 60 students (30%) rated the informational content of the course as "excellent", and 88 (44%) considered it to be "very good". The training methods were assessed as "excellent" by 80 (41%), and "very good" by 69 (35%) of the students, respectively. The usefulness of the information conveyed during internships was considered to be "excellent" and "very good" by 85 (43%) and 69 (35%), respectively, of the respondents. The students rated the following as "excellent": the atmosphere during internships - 100 (54%), the professors' amiability - 132 (67%), the students' involvement during internships by professors - 122 (62%) and the presentation of a representative casuistry by 88 (46%). The learning climate and the course and internship programs were assessed as "excellent" and "very good" by 116 (59%), 149 (76%) and 111 (56%), respectively, of the students. The usefulness of the Palliative Care discipline and its degree of "attractiveness" were rated above 8 (on a scale from 1 to 10) in a ratio of 131 (69%) and 107 (58%), respectively, of the students. This paper further comprises examples of the most representative answers to open-ended questions: "which session provided the newest / most useful information?", "was there any particular occurrence during internships that impressed you most?", or "what do you assess as being positive/negative within this discipline?".

**Conclusions:** The academic performance conducted within the discipline of Palliative Care was generally assessed as positive by the students who have expressed interest in this subject.

**Abstract number:** P184

**Abstract type:** Poster

### Helping improve Out of Hours End of Life Care: Educational intervention for Emergency Service Nurses

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**Background:** Our 24hr palliative care platform provides continuity of specialist care for patients and families. Initial contact is by phone. Most consulting reasons can be dealt with telephone advice; other times, Pal24 professionals request a Emergency Services Nurse or Doctor for a face to face assessment or intervention. In 2012, 6 educational workshops on using the Subcutaneous Route, were organized after a significant event occurred.

**Aim:** Establish the perceived impact that SC route workshops or any other Palliative Care training Courses have had on nurses perception on their confidence when attending End of Life situations.

To assess the evolution of number of Nursing Units needed mobilizing by Pal24 over last 4 and a half years.

**Methods:**

- (1) A descriptive study of the number of ER nursing Units mobilized from the 24hr platform
- (2) Analysis of a telephone survey undertaken over a 3 day period by Pal24 professionals to 20 nurses working in Emergency Services.

**Results:** For nearly 90.000 contacts since Pal24 went live, 410 Nursing Units were mobilized in 2011, 631 in 2012,

581 in 2013, 803 in 2014 and 410 from 1<sup>st</sup> of January to 30<sup>th</sup> of June 2015. Results from the survey have shown that 65% of nurses felt comfortable managing end of life situations always or nearly always. 70% had completed a Palliative Care training course, 50% of these, the SC Route Workshops. 50% felt that training had changed the way they worked with Medical Units. All of them would like to receive further training.

**Conclusions:** A progressive increment in the number of nursing units mobilized is observed, in parallel with the increasing number of Pal24 interventions. This study shows how a single educational intervention can help improve perception of confident management of end of life situations and of better coordination with other professionals. Further impulse of accredited educational activities is essential to promote a continuous improvement and development of Palliative Care.

**Abstract number:** P185

**Abstract type:** Poster

### Interprofessional Palliative and End of Life Care Education of Medical Students in the United Kingdom and United States: A Tale of Two Programs from the Nurse's Perspective

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**Background:** Traditionally medical students are taught by doctors, but patient care is delivered in interprofessional teams.

**Aims:** To explore the perceptions of non-medical health care professionals regarding their role in medical student instruction in palliative and end of life care.

**Methods:** Focus groups were held across four sites in the UK and USA. Non-medical staff who have facilitated medical student teaching in hospice or other palliative care settings were purposively sampled. Groups were recorded and transcribed verbatim. Constant comparative analysis by two authors identified themes and subthemes which were verified by all authors and the final themes agreed by consensus.

**Results:** Two major themes were identified:

1. Perceived benefits and value of the experience and how the non-medical health care professional contributes to achieving those benefits by:
  - A. Showing a different perspective of palliative care;

- B. Providing a greater understanding of the significance of multidisciplinary teams and
- C. Giving patients a feeling of importance and opportunity to contribute to medical student education.

2. The challenges and limitations of such experiences with suggestions for overcoming these challenges:
  - A. Supporting the medical students with variable experience and interest in palliative care;
  - B. Respecting patient autonomy and C. Managing the clinical reality in order for the students to make the most of the experience.

**Conclusions:** This is the first study to ascertain the views of interprofessional team members involved in medical student education in palliative and hospice care. Despite distinct international settings, the experiences were remarkably similar. Interprofessional education of medical students appears to be rewarding for staff, patients and students. This interprofessional patient care experience provided medical students a transformative experiential learning opportunity in palliative care.

**Abstract number:** P186

**Abstract type:** Poster

### Reflecting on Palliative Care Clinical Practice. A Qualitative Analysis of Medical Student's Experience

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**Background:** There are evidence about the benefits of including Palliative Care (PC) in medicine curriculum, and experiences of students claiming for practices in PC has been shown in the literature.

**Aim:** To explore the reflections done by medical students after their first experience in PC clinical practice.

**Method:** PC is taught in the 6th course of Medicine at the University of Navarra, including one clinical practice day integrated in a multidisciplinary PC team. Each student (n=197) was asked for sending to the teachers their own written reflections (WR) about the clinical experience in the following 48 hours. Each WR was anonymized and included in a database. Through NVivo10 software a content analysis with a phenomenological approach was conducted triangulated by 2 researchers.

**Results:** Response rate was 84%, 167/197 students sent WR. Six major themes emerged: **1) *The way to work in PC***; highlighting the holistic approach (56%), teamwork (52%), support to the family (49%) and proximity (44%). **2) *Professional learning experience (the learned)***; emphasizing the need (43%) and innovation (34%) of these practices, and its complexity (33%). **3) *Personal learning experience (the lived)***; students highlight their emotional experience (34%) and their gratitude feeling (30%). **4) *Student's perception related to the patient and family***; identifying changes of view toward the dying process (21%) and their gratitude to the PC team (19%). **5) *Students also reflect on deeper aspects of PC*** as a part of the essence and purpose of Medicine (16%). **6) *In contrast with student's previous ideas about PC***, the experience made disappear their prejudices.

**Conclusion:** Students describe the PC clinical experience as positive, reflecting on depth about essential issues of PC in spite of the short duration of the practice. The emerged themes and explicit comments in the texts suggest that an early exposure to PC practice in medical degree could be useful to all future doctors

**Abstract number:** P187

**Abstract type:** Poster

#### **From Fear to Confidence: Changing Providers' Attitudes about Pediatric Hospice Care**

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**Background/aims:** Children have limited access to hospice care: few existing hospice programs have dedicated pediatric teams and adult hospice providers feel inadequately trained to care for children. The aim of this study is to increase access to pediatric hospice care by empowering adult hospice providers to care for children through a comprehensive education program. Education empowers providers by changing their attitudes from inadequacy to confidence.

**Methods:** We developed a two-day education program to train interdisciplinary teams of adult hospice providers in pediatric care. The curriculum consists of thirteen modules to improve participants' knowledge, skills, and attitudes. Sixty-two providers in Boston and San Francisco learned via multiple teaching methods including lectures, discussions with bereaved parents, and role-play with actors. Learning was evaluated with assessments given before, immediately after, and 6-months following the program. Responses were compared using a one-sided, two-sample T-test with a significance level of  $\alpha=0.05$ .

**Results:** After the education program, providers' knowledge increased and self-reported confidence levels

improved significantly in eleven of thirteen modules ( $p<0.05$ ). 63% of providers improved in managing symptoms, 60% in having difficult conversations with children, 67% in providing culturally competent care, and 73% in introducing hospice to families. Qualitative data reinforced that learners felt more prepared to care for pediatric patients. Analysis of 6-month follow up data is pending.

**Conclusions:** A two-day, high intensity education program can improve adult providers' knowledge of and skill level with pediatric care, leading to a change in attitude from fear to confidence. This model has the potential to dramatically increase access to pediatric hospice care as it utilizes the untapped resource of existing adult hospice infrastructure.

**Funding:** Care Dimensions; Judith Revis Foundation.

**Abstract number:** P188

**Abstract type:** Poster

#### **Pronouncing Death: How prepared Do Junior Doctors Feel to Perform this Role?**

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**Background:** Pronouncing a patient death is an important clinical skill, commonly performed by the most junior members of the medical team. It is imperative that all doctors feel confident in performing this role. Research has shown that educational intervention can markedly improve new doctors' confidence and self-assessed competency in this area (*Amos Bailey, Williams 2005*).

**Aims:** The aim of our study was to ascertain whether newly qualified doctors feel prepared to perform this role hence help to improve current practice.

**Methods:** Following ethical clearance approval, a questionnaire survey was distributed to the interns, working in one teaching hospital.

**Results:** A total of 36 responses from target of 76 (48% response rate). Respondents had trained in 5 different medical schools. Only 22% reported having received teaching on pronouncing death. At the time the survey was conducted (fourth month of work), 24 (66%) had pronounced at least one patient death. 62% of these reported they did not know what was required when asked to pronounce death. Respondents indicated they were unsure of the specifics of the examination required, what must be documented, legalities, among other concerns. When asked if they had gone to anyone for advice, 71% reported they had consulted senior doctors, 25% consulted nursing staff, and 21% sought advice from co-interns. In response to whether they had consulted any reference or guidelines, 17% reported they had used online guidelines. Regarding

whether they believe more teaching is needed for new doctors on this area, respondents were in favour of more teaching during medical school (61%), during internship (83%), and at intern induction (92%).

**Conclusions:** Our study found that junior doctors reported feeling unprepared to pronounce patient death and that guideline will help improve their level of comfort and competency. These findings will help us to structure the future education and induction for newly qualified doctors.

**Abstract number:** P189

**Abstract type:** Poster

### Content of Health Care Provider (HCP) Education during Implementation of an Integrated Oncology and Palliative Programme in a Rural District in Norway

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**Background:** Integration between oncology and palliative care improves cancer care. Indicators of integration were recently published by Hui et al. (Ann Oncol 2015) covering e.g. routine symptom screening, education, and place of death consistent with patient's preference. Within the implementation of an integrated cancer care programme in Norway, knowledge and practice in cancer palliative care (CPC) among HCPs are investigated and examined to identify areas for customising their education.

**Methods:** Physicians (P), nurses (N) and nurse assistants (NA) working with cancer patients at a local hospital and in 13 municipalities were included by e-mail invitation. Questions to knowledge, skills and attitudes in CPC were asked. Responses were given on a four point verbal scale from strongly disagree/not at all (=1) to strongly disagree/very often (=4).

**Results:** Among 1365 HCPs invited, 353 (26%) provided analyzable responses, P 21 (6%), N 180 (51%), NA 152 (43%). Mean scores for how often P, N, and NA ask patients to fill in numerical rating scale to assess symptom intensity were: 2.6, 2.1, 1.3, and similar for pain body map: 2.2, 1.9, 1.3. Scores of P, N, and NAs self-reported confidence in treating cancer pain were: 3.4, 2.9, 2.4. Scores for the statement "patients who prefer, should be allowed to die at home" were: 4.0, 3.8, 3.8.

**Conclusions:** HCP do not use symptom assessment regularly, but feel relatively confident in treating cancer pain. The latter is contradicted by a recent cancer patient survey in the same region, concluding that < 50% achieved pain control. Most HCP support that patients who would like to die at home, should be able to. However, in Norway, about 13 % of cancer patients die at home. A selection bias in the sample is likely; only highly motivated HCPs might be included. HCPs' needs and patient reported outcomes are recommended to guide the content of training and teaching.

### End of life care and quality of dying

**Abstract number:** P191

**Abstract type:** Poster

### Preferences for Life-sustaining Treatments Are Mostly Stable in Terminally Ill Cancer Patients' Last 6 Months of Life

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**Context:** A key to high quality end-of-life (EOL) care for terminally ill patients is acknowledging their right to choose their own life-sustaining treatments (LSTs) and to receive care tailored to their needs throughout the dying process. However, the stability of preferences for LSTs at EOL has not been well established for terminally ill cancer patients nor have transition probabilities been explored between different types of preferences.

**Objective:** To assess the stability of terminally ill cancer patients' LST preferences at EOL by identifying distinct states of LST preferences and examining the probabilities of each state staying at the same state and transiting towards other states between consecutive time points.

**Methods:** Stability of LST preferences (cardio-pulmonary resuscitation [CPR], intensive care unit [ICU] care, cardiac massage, mechanical ventilation, intravenous nutritional support, and nasogastric tube feeding) was examined among 298 terminally ill cancer patients in their last 6 months of life by hidden Markov modeling (HMM).

**Results:** Our HMM identified six distinct states (initial size) for LST preferences: uniformly preferring (9.4%), uniformly rejecting (31.0%), uniformly uncertain (22.9%), favoring intravenous nutritional support but rejecting other treatments (22.8%), and favoring (8.2%) or uncertain about (5.7%) nutritional support and ICU care while rejecting

other treatments. The shifts between LST-preference states in our study were relatively small between any two time points (transition probability of staying at the same state was 92.4% to 97.7%), except for the two states characterized by uncertainty about preferences.

**Conclusions:** Preferences for LSTs among approximately three-fourths of terminally ill cancer patients were stable even when death approached. Tailoring interventions to the unique needs of patients at each state not only providing personalized EOL care but also may avoid potentially futile aggressive EOL care.

**Abstract number:** P192

**Abstract type:** Poster

### Comfort Experience in Palliative Care: The Patient's Voice

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**Background:** Palliative care aims to provide maximum comfort to the patient. However it is unknown what factors facilitate or hinder the experience of comfort, from the perspective of inpatients of palliative care units. This lack of knowledge hinders the development of comfort interventions adjusted to these patients.

**Aim:** Describe the experience of comfort and discomfort experienced by inpatients at palliative care units.

**Design:** A phenomenological descriptive study was undertaken. Data were collected using individual interviews. Data were analysed following the method of Giorgi.

**Setting/participants:** 10 inpatients were recruited from a Spanish palliative care unit and 7 from a Portuguese palliative care unit. Dying patients were excluded.

**Findings:** Four themes reflect the essence of the lived experience: The Palliative Care as a response to the patient's needs with advanced disease, attempt to naturalize advanced disease, confrontation with their own vulnerability, openness to the spiritual dimension.

**Conclusions:** Informants revealed that they experience comfort through humanized care, differentiated environment, symptomatic control, hope and relationships. The discomfort emerges from the losses and powerlessness against their situation. Even if such findings may seem intuitive, documenting them is essential because it invites us to reflect on our convictions about what it means to be

comfortable for these patients, and allows incorporating this information in the design of focused interventions to maximize the comfort experience

**Keywords:** palliative care, inpatients, qualitative research, phenomenology, comfort.

**Abstract number:** P193

**Abstract type:** Poster

### Aggressiveness of End-of-Life Care for Hospitalized Cancer Patients with and without Dementia: A Nationwide Matched Cohort Study in France

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**Aims:** To compare the aggressiveness of end-of-life care in hospitalized cancer patients with and without dementia in France.

**Methods:** Nationwide, retrospective study using data from the French national hospital registry, which systematically collects administrative and medical information about every inpatient admission and outpatient visit in France. Cancer patients aged  $\geq 65$  years with a diagnosis of dementia were matched 1:1 with cancer patients who were not diagnosed with dementia, using sex, age and primary malignancy as matching variables.

**Results:** Overall, cancer patients with dementia (n=26,782) were less likely to receive aggressive treatments in their last month of life than patients who were not diagnosed with dementia (n=26,782 matched controls). Hence, dementia was associated with a significant decrease in the receipt of chemotherapy (2.8% vs. 8.5%,  $P < 0.001$ ). In addition, patients with dementia were less likely to receive radiation therapy (OR= 0.49, 95%CI= 0.43-0.56), blood transfusion (OR=0.67, 95%CI= 0.64-0.70), artificial nutrition (OR=0.79, 95%CI= 0.73-0.85), or invasive ventilation (OR= 0.62, 95%CI= 0.57-0.68) during the last month before death. However, cancer patients in the 'dementia' group were found to be more likely to remain hospitalized over their entire last month of life (adjusted OR= 1.42, 95%CI= 1.37-1.48) and to have more than one emergency department visit during their last month of life (adjusted OR= 1.18, 95%CI= 1.07-1.29).

**Conclusion:** Hospitalized older cancer patients with dementia are less likely to receive aggressive treatments near the end of life than patients without dementia. Such discrepancies raise an important question for clinicians and healthcare policy makers: is the propensity of cancer patients with dementia to receive less aggressive treatments the sign of a form of under-treatment, or is this - on the contrary - an indication that patients without dementia were over-treated near the end of life?

**Abstract number:** P194

**Abstract type:** Poster

**Paediatric End-of-Life Care Needs in Switzerland - PELICAN (2012-2015): Description of Current Practices (PELICAN I) and Assessment of Parental Perspectives (PELICAN II quantitative)**

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**Aims:**

**PELICAN I:** Retrospective chart review in order to

- (1) describe the current practice of end-of-life (EOL) care in Switzerland for children/adolescents having a cardiological, neurological or oncological disease, or who died during the neonatal period, and to
- (2) explore differences in EOL care between the four diagnostic groups.

**PELICAN II:** Quantitative assessment of parental perspectives of EOL care in order to

- (1) describe specific parental experiences in relation to the underlying medical condition causing the child's death,
- (2) explore differences in parental perspectives between four common medical conditions responsible for childhood death.

**Methods:**

**PELICAN I:** Variables collected included characteristics of patients, circumstances of death and information about several domains of EOL care (last 4 weeks of life).

**PELICAN II:** The Parental PELICAN Questionnaire (PaPEQu) was newly developed and its validity was tested. Parents gave their informed consent to participate in the PELICAN I and II studies separately.

**Results:**

**PELICAN I:** Data of 149 children that deceased in the years 2011 or 2012 has been collected in 13 hospitals, 10 community care organizations and two long-term institutions. More than 60% of the children died in an intensive care unit. A palliative care approach was documented in 89% of patients. Circumstances of death, and EOL care however differed between diagnostic groups.

**PELICAN II:** 200 parents completed the PaPEQu. Parents reported generally positive experiences and high

perceived satisfaction with care. Parents of children with cancer showed the highest ratings, and parents from the neurology group the lowest.

**Conclusion:** Our baseline data provides needed information on current care practices and the parental perspective in order to close existing gaps in service provision and to improve quality of care. Further research is needed to develop and test interventions targeting meaningful outcomes of paediatric EOL care.

**Abstract number:** P195

**Abstract type:** Poster

**Involvement of Palliative Care in People Receiving Euthanasia**

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**Background:** In Belgium, where euthanasia was decriminalized in 2002, the viewpoint of euthanasia embedded in palliative care (PC) has been promoted by the Federation for Palliative Care Flanders, accepting the option of euthanasia at the end of a PC pathway.

**Aim:** To examine the extent to which PC is involved in the euthanasia practice in Flanders.

**Methods:** In cases of euthanasia (N=349) identified in a nationwide survey of physicians certifying a random sample of deaths in 2013 in Flanders we studied the use of specialist PC services, the attending physician's PC expertise, consultation of a PC specialist, and the occurrence of euthanasia in PC units.

**Results:** In 72% of the people who received euthanasia at least one specialist PC service was used. Those dying from cancer (84%) and those dying in hospital (83%) had the highest rates of specialist PC service use. Hospital-based PC (incl. PC unit) (38%) and PC support at home (32%) were the most used specialist PC services. The most frequently indicated reasons for not using specialist PC services in euthanasia cases were that

- 1) the care already sufficiently addressed the patient's palliative and supportive care needs (57%),
- 2) the patient did not want it (29%) and
- 3) PC was not deemed meaningful (23%).

In 50% of people who received euthanasia, the attending physician had followed PC training or was working in a palliative team. In 69% of euthanasia cases a PC specialist was consulted to evaluate the euthanasia request and 7% of the patients died in a PC unit. Overall, PC was involved in 92% of people who received euthanasia.

**Conclusion:** People who died by euthanasia often received palliative care and palliative care physicians are frequently involved in decision making and performance. This suggests that having access to and using PC does not necessarily alter requests for euthanasia, and that euthanasia and PC are de facto not incompatible in Flemish end-of-life care practice.

**Funding source:** IWT & FWO.

**Abstract number:** P196

**Abstract type:** Poster

### General Practitioners' Experiences with Advance Care Planning for Elderly People

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**Background and aim:** Advance care planning (ACP) has shown to prevent unnecessary and unwanted care, increases patient satisfaction and reduces costs. However, previous research shows ACP seems to focus on end-of-life palliative care and appears to have no systematic place in health care for elderly people. Two thirds of all patients who died of terminal illness did not participate in ACP. A better understanding of general practitioners (GPs) experiences with ACP could be used to develop tools that contribute to a broader, earlier and possibly more systematic way of practicing ACP. The aim of this qualitative study among GPs is to explore their experiences with two important aspects of ACP; occasion for ACP and the topics addressed in ACP with elderly people.

**Methods:** We conducted semi-structured interviews with 19 Dutch GPs from 2012 to 2015 and thematically analyzed the interview transcripts.

**Results:** GPs mentioned two types of occasions for ACP: making use of systematic care, for example when care is handed over or during a periodic check-up, and making use of non-systematic care, such as requests from the patient or family, when the GP experiences dissatisfaction about current care or when the GP perceives signs that indicate a risk of further deterioration. GPs addressed ACP topics in five categories: views on quality of life and dying, wishes and preferences, possible future care scenarios, information about what to expect from the GP and healthcare, and practical issues concerning the situation after death.

**Conclusion:** This is the first study that shows an overview of occasions for ACP and topics addressed in ACP. It shows ACP is already taking place, mostly in a non-systematic way, and much earlier than only in end-of-life palliative care. These results may fuel efforts to develop tools to improve practicing ACP and contribute to better care for all elderly people.

This research is funded by ZonMw, <http://www.zonmw.nl/en/>

**Abstract number:** P197

**Abstract type:** Poster

### Effects of an Advance Care Planning Programme among Chinese Patients with Advanced Disease: A Randomized Controlled Trial

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**Research aim:** This study aimed to evaluate the effects of an ACP programme in Chinese patients with advanced diseases and their family carers.

**Study population:** Patients who met the criteria of the Gold Standards Framework, are mentally competent and being discharged to home, and their family carers were recruited from a hospital.

**Study design and methods:** A randomized controlled trial was conducted between Mar 2014 and Oct 2015. An ACP programme was delivered to the experimental group by a nurse facilitator through home visits. Patients' preferred and family predicted end-of-life care goal were collected at baseline, and at 1-month and 6-month.

**Methods of statistical analysis:** The programme was evaluated by comparing the two arms based on intention to treat. Kappa statistics was used to examine congruence in care goal in the dyads.

**Results and interpretation:** A total of 236 dyads participated, with a response rate of 70.9%. The mean patient's age was 77.7 years, with the majority living with family. Their 6-month mortality rate was 13.6%. Family carers were mainly adult children. Nearly none of them had heard of ACP. By the end of the study, more than two-third of patients in the experimental group preferred comfort care for end of life. Twenty-eight patients wanted to sign an advance directive, but eight of them could not get family consensus. Six dyads withdrew from the study because the family carers were upset with the discussion. The proportion of having discussed end-of-life care were significantly higher in the experimental group ( $p < 0.001$ ), and the concordance in the dyads was statistically significant ( $k=0.309$ ,  $p=0.003$ ). This is one of the first studies to engage Chinese patients and their families in ACP. It appears that Chinese patients are receptive to ACP, but their wishes sometimes may not be respected as treatment decision is often regarded as a collective decision. More family education is needed as they tend to avoid the discussion.

**Abstract number:** P198

**Abstract type:** Poster

### Reasons for Terminal Hospital Admissions: Results of a Survey among Family Physicians

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**Background:** Many terminally ill patients are admitted to an acute hospital setting at the end of life. We aimed to examine the reasons for terminal hospital admissions and other aspects that play a role in the decision-making about the admission according to family physicians (FPs), and the extent to which these reasons and aspects are related to the characteristics of the patient, the care they received prior to admission and the circumstances of the admission.

**Methods:** Survey among FPs about their patients who had died non-suddenly in a university hospital in Belgium between January and August 2014. Questions were asked about the circumstances of and reasons for the terminal hospitalization and about aspects that played a role during decision-making about the admission, as well as items regarding the patient's situation and illnesses (e.g. cause of death) and characteristics of care prior to the admission.

**Results:** We received 245 completed questionnaires (response rate 70%); 77% of those hospital deaths (n=189) were considered to be non-sudden. FPs indicated that 55% of terminal hospital admissions were for palliative reasons and 26% were for curative or life-prolonging reasons. The patient feeling safer in hospital (35%), family members believing care to be better in hospital (54%) or an inadequate care setting (85%) played a role in the decision to admit the patient to hospital. When patients were admitted with a limited anticipated life expectancy, FPs were more likely to indicate that the admission had been for palliative reasons ( $p < 0.001$ ) and that an inadequate caring capacity of the care setting had played a role in the decision to admit the patient to hospital ( $p=0.002$ ).

**Conclusions:** The majority of terminal hospitalizations in a Belgian University hospital was for palliative reasons. Better support for out-of-hospital palliative care services may be needed.

**Funding:** IWT SBO 100036.

**Abstract number:** P199

**Abstract type:** Poster

## Sexuality Issues in Specialist Palliative Care (SPC): A Retrospective, Observational Cohort Study

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**Background:** Palliative care patients experience changes of sexuality due to disease and treatment. As sexuality is important for QoL, changes in sexuality may represent palliative care needs.

### Aim:

1. To study health care professionals' documentation of sexuality in records of pts receiving SPC.
2. To investigate if documentation depended on patient characteristics, or the palliative care setting.

**Method:** A retrospective, observational cohort study of 60 consecutive pts receiving SPC. Thirty hospice and 30 palliative care team (PCT) pts were included in two regions. Demographics were recorded and patient records analyzed for documentation of sexuality (sexual contact, intimacy and body image). Duration of follow-up was till time of death or for a maximum of three months.

**Results:** Of the 60 pts, 52% were male and 48% female. Median age was 71.3 yrs and median follow-up 20 days. 95% had malignant disease. 73% were in a relationship. Sexual orientation was never documented. In 38%, sexuality issues were documented. Documentation of sexuality was higher in the hospice than the PCT setting (53% vs. 23%). The difference could be ascribed to one hospice documenting sexuality issues in 73% of pts. Focus was on intimacy rather than body image or sexual contact. Documentation of sexuality was related to age (57% vs 20% for pts < vs. > median age) and relationship status (53% vs. 0% for pts in relationship vs. single pts).

**Discussion:** Documentation of sexuality issues in patient records may not accurately reflect staff awareness. However, our study does suggest that awareness of sexuality is lacking in SPC. The approach of health care professionals seems biased by assumptions about sexuality in different age and relationship status groups.

**Conclusion:** Sexuality issues were infrequently documented. The awareness of sexuality issues varied considerably with patient characteristics and the palliative care setting. Further research and education on sexuality are warranted.

**Abstract number:** P200

**Abstract type:** Poster

## Is Quality End of Life Care Provided in the General Medicine Inpatient Setting in Canada?

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**Background:** Many Canadians die in hospital, but there is limited information on the quality of end of life (EOL) care in Canadian hospitals.

**Aim:** To characterize the quality and timing of EOL care in a tertiary care centre and to identify whether palliative care (PC) involvement was associated with quality EOL care.

**Methods:** We conducted a retrospective chart review of 150 patients who died on an inpatient internal medicine unit in 2012. Information was extracted on patient demographics; cause of death; diagnosis of dying; goals of care (GOC) discussion; involvement of PC, social work and spiritual care; and prescription of medications for symptom management.

**Results:** Of the 150 deaths, the median age was 79.5 (range 22-101), 58% were male, 69% spoke English, and median length of stay (LS) was 8 days (1-206). A total of 41% deaths were from cancer, 50% were coded as anticipated by clinicians, 37% occurred without social work or spiritual care involvement, and 66% occurred with prior PC team involvement. PC patients had a GOC discussion median 6 days prior to death (vs 2 days without PC,  $p < 0.0001$ ), during which the patient was present 49.5% of the time (vs 25%,  $p = 0.007$ ). PC patients tended to have earlier discontinuation of: blood work (median 2 days before death vs 1,  $p < 0.001$ ); vital signs (1 vs 0,  $p = 0.007$ ); and IV fluids (1 days vs 0,  $p = 0.002$ ). PC deaths were more likely to have an order of an antiemetic (46.5% vs 27.5%,  $p = 0.03$ ), analgesic (95% vs 71%,  $p < 0.0001$ ), anticholinergic agent (41% vs 18%,  $p = 0.003$ ) and/or antipsychotic (65% vs 32%,  $p = 0.001$ ). On multivariate analysis controlling for length of hospital admission and expected death, PC intervention was associated with earlier discontinuation of bloodwork and vital signs, and with earlier opioid and antipsychotic orders (all  $p < 0.05$ ).

**Conclusion:** Quality of EOL care is variable for hospital inpatients; palliative care involvement is associated with better care in this population.

**Abstract number:** P201

**Abstract type:** Poster

### Transitions Experienced by Carers on the 'Living-Dying' Journey of a Relative with Dementia

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**Background:** The experience of care transitions for family carers of a relative living with dementia do not necessarily lessen once their relative is admitted to a care home. Goals of care and end of life care decisions need to be made. The process of reaching these decisions can be significantly challenging.

**Aim:** To explore the experience of family carers responsible for decision-making on behalf of a relative living with advanced dementia through their transitions from the community into a care home.

**Method:** Carers of a resident living with dementia were offered an individual interview in a qualitative study within a randomised trial evaluating an Advanced Care Planning intervention in care homes in Northern Ireland, UK. Twenty participants completed a semi-structured audio recorded interview, from which transcripts were thematically analysed.

**Results:** Interviews highlighted that carers were at different stages of the decision-making process for their relative's care when they were admitted to the care home. Some had previously discussed end of life care wishes with their relative, whereas others had to make an informed choice for the care without prior discussions. The emotional impact of this transition varied from high levels of stress and extreme guilt, to a sense of relief that their relative was content and safe in their new setting. Some carers reported that this decision process left them feeling isolated due to family conflict, but support was also available for others from their new 'family': the care home staff. However, reports of poor communication with and amongst staff, and inconsistencies of health care provision were an additional source of distress.

**Conclusion:** Key findings which require further investigation include: holding goals of care decision-making earlier in the dementia disease trajectory; recognition of family dynamics; the need for improved knowledge to facilitate informed decision-making, and improving communication with and between staff.

**Abstract number:** P202

**Abstract type:** Poster

### Natural Preference of Body Posture in the Dying Process: A Preliminary Study in a Hospice Care Setting

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**Background:** All people have different body postures during sleep, most people prefer a lateral position. Nevertheless in the terminal phase patients are mostly placed in a

supine position. So far in literature it has never been questioned whether this is the most comfortable posture for dying persons and its possible consequences for the quality of dying. We hypothesize that the preferred sleeping position creates advantage for dying and bereavement.

**Aim:** To investigate whether the preferred sleeping posture can be realized in the dying process in hospice care and whether it contributes to an improvement of quality of dying.

**Methods:** In an explorative, observational study hospice patients with immanent risk of dying were questioned about their favorite position during sleep. Besides they were asked whether they would like to be put in this position in the last hours of life. After a confirmative answer, patients were promised to be nursed in their favorite posture during their final hours. To evaluate the maintenance of this promise, photographs were taken to capture the wanted position directly following the interview and after dying.

**Results:** 17 patients agreed to participate, relatives of 3 patients were interviewed and asked about their experiences with the procedure. 10 out of 17 patients died in their posture of preference; one person died acutely, 3 patients returned home and 3 patients were still alive at the end of inclusion. All relatives reported that seeing their beloved one dying in a familiar and comfortable posture provided support and comfort. The natural position diminished relatives impression of suffering dying.

**Discussion/conclusion:** This unique study with visualized wishes about the wished body posture supports the assumption that hospice patients have the possibility to die in a posture of preference. Relatives are positive about this attempt to improve the quality of dying. Further studies to reach conclusive answers are in preparation.

**Abstract number:** P203

**Abstract type:** Poster

### **The Dying Trajectory of Hematological Cancer Patients: The Need for a Two-track Approach**

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**Introduction:** Patients with hematological cancers have acute exacerbations of illness interspersed with aggressive curative therapy regimes. Their disease trajectories may continue over many years, and are often ending with a rapid and unexpected death. In the last months of life, crisis visits

to the emergency department (ED) are frequent. A retrospective study was started to identify hematological patients visiting the ED, to analyze proactive actions of treating hematologists, and, to develop interventions to reduce unnecessary aggressive treatments at the end of life.

**Methods:** All patients with hematological cancers visiting the ED of a large university hospital between May 2011 and January 2013 and dying within three months after this visit were included. Data on patient and visit characteristics were obtained from Electronic Patient Records.

**Results:** A total of 79 patients was included, 68% was male, median age was 61 years. When visiting the ED, 60% was still on curative treatment, 50% had an ECOG performance status >2, and in 6% orders on limiting life sustaining treatment had been documented. Ninety percent was admitted, 74% died within four weeks, of whom 39% on the intensive care unit (ICU) and only 13% at home. Although 90% of hematologists had informed the general practitioner in the three months before death, only 15% had documented a pro-active plan for symptoms and 1% had consulted the palliative care consultant.

**Conclusion:** When patients with hematological cancers visit the ED in the last months of life they are at high risk to die within the hospital, even on the ICU. It seems difficult to recognize the start of the terminal phase, and, the focus of hematologists is towards curation. A two-track approach with the goal on disease treatment and on support for quality of life and advanced care planning including place of death will probably improve care for patients with hematological cancers and their family.

**Abstract number:** P204

**Abstract type:** Poster

### **Use of a Palliative & End of Life Care Pathway in a Canadian Acute Care Setting: A Quality Improvement Project in Academic General Internal Medicine Units**

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**Background:** Patients nearing end of life (EOL) are often under-recognized in acute care settings, resulting in poorly defined patient goals of care and a high incidence of futile, aggressive care at EOL. Pathways are now being developed to facilitate early identification of patients in their last year of life, to promote early advance care planning, and to build capacity for EOL care in acute care settings.

**Aims:** This project is a stakeholder analysis for a palliative screening and care pathway and aims to gain an understanding of the thoughts of General Internal Medicine (GIM) team members on its integration in acute care units.

**Methods:** Semi-structured interviews via a grounded theory framework were conducted with key GIM stakeholders in an academic center to explore their opinions of the pathway, and on suggestions for integrating the pathway into GIM patient care practice. Interview transcripts were analyzed for emerging themes by two research team members.

**Results:** Eleven multidisciplinary GIM stakeholders were interviewed. The proposed pathway was well received and emerging themes included: timing of implementation (i.e. key times in the admission where the tool should be used), relevance (highly relevant to their patient population), and ownership of the tool (i.e. tool should be interdisciplinary and used by multiple GIM clinician groups). GIM members also saw the tool as providing an opportunity to teach and to gain advance care planning skills and expect increased inter-professional communication following its implementation.

**Conclusions:** This study is the first in Canada to allow for an understanding and integration of the elements important to an acute care specialty service in the development of a Palliative & EOL care pathway. More importantly, this project will serve to build capacity amongst multidisciplinary GIM health care providers to increase advance care planning discussions and improve quality palliative and EOL care for patients.

**Abstract number:** P205

**Abstract type:** Poster

### Specialized Palliative Care in Sweden - For whom and How Well?

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**Background:** The Swedish Register of Palliative Care (SRPC) aims to register the quality of end-of-life care for all dying persons in Sweden irrespective of place of death, age or underlying diagnosis. During 2014 the coverage was 68 % of all deaths, with almost 100 % coverage of deaths occurring within specialized palliative care.

**Aims:** To present the patient population dying in specialized palliative care together with results of key quality indicators of end-of-life care.

**Methods:** All deaths registered in the SRPC from specialized palliative care units during 2014 were analyzed regarding demographics, underlying diagnoses and nine quality parameters.

**Results:** 8858 deaths were registered from 142 specialized palliative care units representing 10 % of all deaths in

Sweden. There was an equal gender balance and mean age was 73 years. 87 % of all deceased had a cancer diagnosis with lung-, pancreatic-, breast-, prostate- and colon cancer being the most common in descending order. Cardiac/pulmonary diseases were most common non-malignant diagnoses. 38 % retained ability to express his/her will and take part in decision-making until hours before death. 75 % died at their preferred place of death; 13 % of all patients died alone. 85 % received information about transition to end-of-life care from a physician. 27 % died with pressure ulcers; 6 % with grade 3 or 4. 57 % had a documented pain assessment during last week of life but only 31 % had a documented assessment of symptoms other than pain. 34 % experienced severe pain at any time during last week in life. More than 98 % had an individual prescription of injectable PRN drugs towards pain on the drug list before death.

**Conclusion:** As in most European countries, cancer is still the predominating diagnosis within Swedish specialized palliative care. Quality of end-of-life care in this context is satisfactory, but there is still room for improvement. An excellent national coverage yields valid data through the SRPC.

**Abstract number:** P206

**Abstract type:** Poster

### Factors Associated with Preference for and Actual Place of Death among Older Patients with Advanced Disease: A Prospective Study in the UK, USA and Ireland

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**Background:** Dying in one's preferred place is proposed as a more patient-centred quality indicator than dying home. However, patients' experiences and expectations may influence preferences and little is known about this.

**Aim:** To identify factors influencing preferences for place of death (POD) among older populations and compare these with actual POD.

**Design:** Cross sectional survey and death records

**Setting:** Hospitals in 3 cities (London, Dublin, and New York City)

**Data collection:** Face-to-face survey with patients aged  $\geq 65$  receiving specialist palliative care to collect preferences, demographic, clinical and symptom data, and death record.

**Analysis:** Dependent variables: most preferred POD (either home or hospice/palliative care unit (H/PC)); actual POD. Multilevel multivariable analyses assessed the factors associated with preferred and actual POD. Factors entered were determined by univariate analyses and a theoretical model.

**Results:** 163 patients (70 London, 70 Dublin, 23 New York) completed the survey: mean age 73; 49% women. 85% had cancer and 78% a primary unpaid carer. Home was the most preferred POD (56%) with H/PC being the second (23%). The main factors associated with preference for home death were cancer diagnosis (OR 3.69, 95% CI 1.45-9.41) and living with someone else (OR 2.37, 95% CI 1.30-4.31). Better functional independence was associated with a slightly lower preference for home death, and non-cancer diagnosis and better cognitive ability with preference for H/PC. Out of 119 deaths 16% of patients died at home, 30% in a H/PC and 21% in hospital. Better functional independence and valuing quality and extension of life were associated with actual home death.

**Conclusions:** Factors affecting place of death were different to preferences and functionally independent patient did not prefer to die home, dying more often at home. Improvement in services, especially with home support and in-patient palliative or hospice units would closely meet preferences.

**Abstract number:** P207

**Abstract type:** Poster

### **A Care Bundle to Improve Care of the Dying in Acute Medical Wards**

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**Background/aims:** Despite the fact that most Australians die in acute hospitals, the quality of care dying patients receive is highly variable with the situation even more complicated by a sparsity of well conducted research to inform care of the dying. This work aimed to systematically document the need for and then develop and pilot systems to improve the reliability of care processes available to dying patients.

**Methods:** A step-wise approach was used to move from a preclinical theoretical basis to developing and piloting a solution through a series of connected subprojects.

**Results:** The subprojects' results are summarised in consecutive publications including an initial literature review highlighting that hospital deaths are not uncommonly

characterized by inadequate communication between health professionals, patients and families; poor symptom control; and dissatisfaction with the environment. Similar problems were expressed by bereaved family members in face-to-face interviews. Lastly, an audit of care reinforced the lack of attention to quality. These projects informed the solution: a care bundle for the dying. This was developed according to existing recommendations and includes: a track and trigger observation chart; regular monitoring of patients and families; introduction of prescribing algorithms. This was trialled over six months and resulting in significant improvements in assessment of people's symptoms and family distress. Staff and family were interviewed both to confirm the feasibility of including the opinions of these groups and to test for any impact. While this was shown to be acceptable, no real changes in staff attitudes or families' opinions were noted.

**Discussion:** This project highlights that it is possible to systematically develop and pilot solutions to improving care processes at the end of life. This work is important as it supports the feasibility of the solution and the approaches implemented to test the solution.

**Abstract number:** P208

**Abstract type:** Poster

### **Safety in Palliative Home Care in a Norwegian Municipality: A Comparison of the Patient's Perceptions Compared with those of Family Member's**

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Palliative care encompasses patients and their families. Family members may feel supported when they know that the care is of high quality and in accordance with the patient's interests. A strategy in Norwegian health-care policy is to give palliative care in the patient's home. To realize this plan, it is vital that patients and their family members feel safe with the care.

The aim is to compare the relationship between the patient/family member's perceptions of safety of palliative home-care.

Sixty patients receiving palliative home-care in Norway and 38 family members participated. Of these, 32 were matching pairs; patient/family member. A patient and family member version of a modified QPP (Quality from Patients' Perspectives) was used for measuring aspects of

safety: symptom relief, availability of help, continuity of care, user-involvement, information, cooperation and coordination of the care, competence of staff and respect. The questions encompass two response-scales: perceived safety and subjective importance. The SPSS and Wilcoxon's signed rank test were used to identify potential differences within the patient-family member dyads of safety ratings ( $P < 0.05$ ).

Preliminary results show that patient/family dyads have high levels of agreement in ratings of perceived reality and subjective importance of safety with palliative home-care. The patients show statistical significant higher scores on perceived safety (eight out of 61 items). The family members show statistical significant higher scores in subjective importance (three out of 61 items) and patients show statistical significant higher scores on subjective importance (one out of 61 items).

The results should be valuable for politicians in developing palliative care, and may also influence health professionals in performing palliative care to obtain common care-related experiences of safety for patient/family members.

This study is funded by Regional Research Funds and Hamar Community in Norway.

**Abstract number:** P209

**Abstract type:** Poster

### Sedation in Palliative Care Questions the Competency in Caring

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**Aims:** Refractory symptoms and intractable distress of a dying patient may require palliative sedation which could make health carers uncomfortable, inducing moral or emotional distress. Morita pointed out the major factors leading to nurses suffering. These included professional skills and working organization. But the study by questionnaire did not allow the full understanding of these factors. Our study was therefore aimed at exploring perceptions and experiences of the use of Midazolam (MDZ) and the practice of sedation in PCU to understand how the sedation is represented to the carers and what the impact is on their care practices.

**Methods:** The qualitative study conducted by a multidisciplinary research team associated 3 methods: 6 focus groups and 3 weeks participant observations involving health carers and their teams; 12 personal written narratives were collected

40 voluntary health professionals and 3 PC teams of 3 PCU participated.

**Results:** The cross-sectional thematic analysis has shown carers uncertainty:

of the symptom refractoriness, showing difficulties in interpreting the clinical signs, fearing that their emotions impaired the symptom assessment, doubting the beneficial effect of sedation about the quality of the caring relationship, feeling submitted to the patient's demands or being a manipulator themselves about the therapeutic significance of their action. The major point was that nurses were anxious to hasten death when injecting MDZ. Anticipation of the consequences of their act showed a gap between the intentional decision of sedation and its implementation.

To reduce uncertainty the whole health care team invented practical and organizational working rules.

**Conclusion:** In PCU sedation deeply questions the carers relation to their professional competency. Uncertainty of the action is the key factor of carers suffering. The link between intention and consequence of the action has to be thought during the decision of sedation.

**Funding:** Fondation de France.

**Abstract number:** P210

**Abstract type:** Poster

### Quality of Care during the Last Week of Life: Symptom Prevalence and Relief Profiles Based on a National Palliative Care Register Data

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The aim was to identify predictors of symptom relief profiles as quality indicators of care for patients during the last week of life.

Professionals' reported data of patients were obtained from the Swedish Palliative Care Registry. Sample: all deceased adults with expected deaths in 2011 and 2012 (53% and 63% of the deceased population). Descriptive and latent class analyses were performed to identify

symptom relief profiles, and regression analysis to predict latent class membership.

38329 men and 48697 women were included. Neoplasms (37%), cardiovascular diseases (31 %) and dementia (12%) were the most common causes of death, and nursing home (40%), hospital wards (28%), and specialised palliative care units (11%) most common places of care. Results suggest 5 latent classes representing unique symptom relief profiles, with total relief of a symptom varying from 10% to 90%, see Table 1. Important predictors of symptom profile classes include place of death, cause of death, and having PRN prescriptions for anxiety and other symptoms.

Groups of patients (class 4 and 5) present predominantly unrelieved symptom profiles indicating need for quality improvement in hospitals, nursing homes, as well as across other places of care and a range of diagnoses. Symptom prevalence and relief profiles can help to re-define how we think about quality of care and thereby inform policy for end of life care.

	Class 1	Class 2	Class 3	Class 4	Class 5
Proportions of patients in the sample	31%	25%	20%	14%	9%
Total relief among those having the symptom					
Pain	90%	76%	79%	65%	32%
Breathing rattles	54%	53%	49%	27%	28%
Nausea	63%	41%	57%	49%	22%
Anxiety	93%	82%	75%	44%	10%
Breathlessness	33%	65%	47%	25%	26%
Confusion	29%	38%	18%	30%	21%

[Classes: distribution of symptom relief (n= 87026)]

**Abstract number:** P211

**Abstract type:** Poster

### Transition to Palliative Care for Patients with Metastatic Prostate Cancer: How Well Have we Integrated?

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**Aims:** There is increasing focus on timely integration of palliative care for people with advanced cancer to enable benefits in symptom control, communication and care planning. Limited data have described the current landscape for men with metastatic prostate cancer (mPCA), including timing of- and access to- palliative care. This study aims to identify transition points where palliative care referral may benefit patients with mPCA.

**Methods:** This was a retrospective population cohort study of mPCA cases that died between 2003 and 2010 (n = 4349). Linked hospital inpatient, emergency, and death registration data were used to track health service use and survival from first multi-day admission to death. Descriptive statistics on service use, symptoms, procedures, survival, and place of death are presented.

**Results:** Following multiday admission with metastatic disease, the cohort survived a median of 3 months (IQR 1, 10). During this interval cases had a median of: 3 admissions (IQR 1, 9); 1 emergency visit (IQR 0, 2); 35 bed days (IQR 18, 63); and 5 (3, 8) cancer or treatment-related complications, such as LUTS (50%), fluid & electrolyte disorders (38%), anaemia (47%), infections (52%), constipation (32%). At least one indicator of aggressive end-of-life care was recorded in 3583 (82%). While 2648 (61%) had a palliative care approach in place by the time of death, this first occurred in the final admission for 1695 (64%), dying a median of 31 days (IQR 12, 78) after initial engagement. Just 22% died outside hospital while 78% died in hospital, of which 55% were in an acute bed.

**Conclusions:** Half of all men admitted with mPCA survived less than 3 months, with a marked symptom burden, multiple procedures and admissions. Many did not receive any hospital-based palliative care, and a majority were referred in their final admission. Admission with mPCA is a significant indicator for palliative care referral ensuring timely integration of palliative care.

**Abstract number:** P212

**Abstract type:** Poster

### Exploring the Landscape of Palliative Care for People with Non-Hodgkin's Lymphoma: Do they Receive Quality End of Life Care?

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**Aims:** The interface between palliative and haematological care is receiving increased attention. Difficulties with prognostication and expanding novel treatments for haematological cancer raises challenges for integration of palliative care and planning for the end of life. This study aims to examine quality end-of-life care indicators for people who die from non-Hodgkin's lymphoma (NHL).

**Methods:** A retrospective population cohort study of NHL cases that died between 2001 and 2010 (n = 4337) was conducted. Linked hospital inpatient, emergency, and death registration data was used to describe health service use, symptoms, and procedures in the last 12 months of life. Descriptive statistics were used to profile established international quality end-of-life care indicators.

**Results:** The sample comprised 4337 patients (58% male) with NHL, predominantly diffuse large-B cell lymphoma (32%). In the last 30 days of life, 3857 (88%) had at least one, and 1865 (43%) had two or more of the following indicators: >1 acute hospital admission (56%); length of stay  $\geq$  14 days (57%); receipt of chemotherapy (17%);  $\geq$  1 intensive care admission (11%); and >1 emergency room visit (8%). Just 1819 (42%) were identified as having a palliative approach by the time of death, and 984 (22%) accessed a palliative care bed. Most people (79%) died in hospital, of whom 187 (5%) were in a palliative care bed and 3188 (92%) were in the acute setting.

**Conclusions:** The quality of dying in this NHL cohort based on established international indicators demonstrates clear opportunities for optimising end of life care and improving access to palliative care. Of note, these data will include patients who die of treatment-related complications and who die receiving appropriate life-saving treatment. Nonetheless, future work must examine patient perspectives, referral guidelines and collaborative partnerships in order to improve the quality of end of life care for patients with NHL.

**Abstract number:** P213

**Abstract type:** Poster

### **Integration of Palliative Care for Patients with Metastatic Breast Cancer: Have we Achieved Quality End-of-Life Care?**

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**Background:** Integration of palliative care into the trajectory of patients with advanced cancer is a current priority, with established benefits for patients and family carers. Although the timeliness of palliative care integration is important to achieve benefits, uncertainty remains about when this should occur. This study aims to identify transition points to enhance integration of palliative care for patients with metastatic breast cancer (mBR).

**Methods:** This was a retrospective population cohort study of mBR cases that died between 2003 and 2010 (n = 3205). Linked hospital inpatient, emergency, and death registration data were used to track health service use and survival from first multi-day admission to death. Descriptive statistics on service use, symptoms, procedures, survival, and place of death are presented.

**Results:** Following a multiday admission with metastatic visceral disease, the cohort survived a median of 3 months (IQR 1, 12). While 1936 (60%) had a palliative care approach in place by the time of death, this first occurred in the final admission for 1333 (69%), dying a median of 24 days (IQR 9, 59) after initial engagement. This occurred despite the cohort having a median of 3 admissions (IQR 1, 12) and 31 bed days (IQR 15, 59) in this period. At least one indicator of aggressive end-of-life care such as chemotherapy use or hospital stay  $\geq$  14 days in the last 30 days of life was recorded in 2611 (81%). Most people (81%) died in hospital, and the majority of these (58%) were in the acute setting.

**Conclusions:** Women dying from mBR have late engagement with palliative care, despite increasing evidence supporting early integration. Given half of all women admitted with visceral metastases survive less than 3 months

thereafter - routine referral and communication about the practices of palliative care at this point (if not already in place) may assist to identify and support those likely to benefit from palliative care engagement.

**Abstract number:** P214

**Abstract type:** Poster

### Confidence in Danish General Practitioners about Provision of Terminal-phase Care

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**Background:** General practitioners (GPs) are crucial in palliative care as they are responsible for all at-home treatment and care. To ensure sufficient care, which meets the individual patient's needs, the GP must feel confident about the role as key worker in the end-of-life trajectory and must also know the patient's end of life preferences.

**Objectives:** To explore GPs' confidence being the key-worker, how they report awareness of patients' preferences and confidence in providing medical care in the terminal phase of life.

**Material and methods:** Data are based on a postal questionnaire study in 2014 among all 843 GPs in the Central Denmark Region (previously used questions and existing literature). Descriptive statistics was used and GPs grouped according to their answers were compared using chi<sup>2</sup> test.

**Results:** Of the 570 (68%) participating GPs 76% reported to feel comfortable/very comfortable with their role as key worker in palliative care. 58% agreed/strongly agreed to initiate talks with their patients about dying, and 56% agreed/strongly agreed to know where patients with severe diseases preferred to die. The GPs who reported to talk to their patients about dying differed significantly from the GPs who reported to know where their patients wanted to die ( $p=0.001$ ). With regard to medical care in the last phase of life 56% felt confident/very confident about administering medicine subcutaneously, while 60% felt confident/very confident using the just-in-case box. These two groups also differed significantly ( $p=0.001$ ).

**Conclusion:** Most GPs felt confident about being the key worker in palliative trajectories. However, this study indicated a need to focus on patient preferences and to improve GPs' medical skills as only approximately half of them reported to fulfill these tasks. The identified differences among the GPs might indicate diversity in skills and attitudes, which should be targeted in future interventions.

**Funding:** Danish Cancer Society and TrygFonden.

**Abstract number:** P215

**Abstract type:** Poster

### Trends in Family Involvement in End-of-Life Decision-making: Results from Repeated Population-based Nationwide Surveys

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**Background:** Deaths of people with chronic illnesses are frequently preceded by potentially life-shortening end-of-life decisions (ELDs). A patient and family centered care perspective calls for these decisions to be discussed with both patients and family members. When patients are incompetent, family members may act as surrogate decision-makers. In this study we aim to describe

- (1) trends in family involvement in ELDs and
- (2) the relationship between family involvement and patient competency at the time of the ELD.

**Methods:** Repeated nationwide postal questionnaire survey of physicians who certified a large random sample of Flemish deaths in 2007 ( $n=6202$ ) and 2013 ( $n=6188$ ). Certifying physicians were asked whether they had discussed ELDs with the patient and/or the patient's family.

**Results:** Response rate was 58% in 2007 and 61% in 2013. Of all deaths, 47.8% were preceded by an ELD in both 2007 and 2013. The prevalence of ELDs discussed with family members increased from 67.7% of cases in 2007 to 71.8% of cases in 2013 ( $p=0.012$ ). Hierarchical logistic regression models showed that the higher likelihood of family involvement in 2013 compared to 2007 was fully explained by the increased degree of patient involvement in 2013. Patient involvement was in turn fully explained by the observed increase in patient competency between 2007 and 2013.

**Conclusion:** We found the increase in family involvement between 2007 and 2013 to be due to an increase in patient competency in that period, which may indicate earlier discussion of ELDs with patients and family. Further research is needed to better understand this increase in patient competency and its relationship with patient and family involvement in end-of-life decision-making.

**Funding:** This study was supported by Strategic Basic Research grant 140009 from the Agency for Innovation by Science and Technology.

**Abstract number:** P216

**Abstract type:** Poster

### Supporting People with Dementia to Die at Home in Ireland

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**Background:** The Irish Hospice Foundation has funded a night nursing service for people dying at home with non-malignant conditions since 2007. The number of people with dementia referred to this service has risen significantly since 2007 with 86 people with dementia accessing the service in 2014.

**Aim:** The aim was to explore components of care which support a person with dementia who accessed the night nursing service to die at home.

**Method:** Supplementary information was gathered from specialist palliative care teams (SPCT) for 50 dementia referrals to the night nursing service between May and December 2015. This information included demographic information, type of dementia, living situation, informal and formal care supports, out of hours supports and co-morbidities.

**Results:** Preliminary analysis of the sample to date (n=41) indicates the following:

1. 80% of the sample were women with an average age of 85. Two of the sample had young onset dementia (under 65years)
2. A significant proportion of people accessing the night nursing service (61%) lived in urban areas
3. 63% of the sample had 2 or more reported co-morbidities
4. Families provided between 12- 24 hours of care per day to people with dementia dying at home with some formal paid supports.
5. GP support and/or availability to do home visits to the person was reported to be a significant support in 60% of the sample
6. The Public Health Nurse was involved in 100% of cases
7. Most people were referred to specialist palliative care teams in the last week of their life.

**Conclusion:** This audit demonstrates the range of supports and services that people with dementia need to die at home. Earlier referral to specialist palliative care teams may support and enable more people with dementia to remain at home. There is a need to increase awareness of the palliative care needs of people with dementia.

**Abstract number:** P217

**Abstract type:** Poster

### Quality of End-of-Life Care of Patients with Lymphoma: A Retrospective Analysis

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**Background:** Available data regarding the quality of end-of-life care for patients (pts) with hematologic malignancies is scarce compared to solid malignancies. That is also the case at the OI and in Slovenia.

**Methods:** 53 pts with lymphoma that died at OI in 2014 were included in the study. The quality of care in the final 30 days was assessed with indicators of aggressive treatment: hospitalization, intensive care unit (ICU) admissions, deaths at the ICU and systemic cancer therapy (SCT) use. Indicators which enable prediction of life expectancy were analyzed: Glasgow prognostic score(GPS) and performance status(PS). The results were compared with the available data on care of patients with solid tumors.

**Results:** In the final 30 days, 32/53 pts (60,4% vs. 43,1%) received SCT, 15(28,3 % vs. 5,9 %) were treated at the ICU, 11(20,8% vs. 3,5 %) also died at the ICU. There were on average 20,2 days (vs. 13,0 days) of hospitalization. The analysis showed that most of the pts had indicators of short survival (GPS 2, PS 3-4): 31/36 pts (86,1%) had albumins below 35 g/l, 51/52 pts (96,2%) had CRP over 10 g/l. Glasgow prognostic score (GPS) could be determined for 35 patients. 6 (17,1%) had GPS 0 or 1 and 29(82,9%) had GPS 2. WHO PS was noted for 36 pts; PS was 2 or less for 12 (33,3% vs. 78%) PS 3 or 4 for 24(66,7% vs. 22%). 8 pts were included in palliative care (15,1% vs. 5,9 %). End-of-life pts also received red blood cells in 52,8%, platelets in 34%, and fresh frozen plasma in 15,1%. 84,9% of the pts received antibiotics.

**Conclusions:** The results shows that pts care was carried out according to principles of curative medicine, including frequent laboratory tests, administration of numerous medications, and the continuation of SCT, in spite of the presence of indicators of irreversible damage to vital systems. At that stage that kind of treatment is pointless and harmful, while symptoms, psychosocial needs of the patients and their close ones are not considered.

**Abstract number:** P218

**Abstract type:** Poster

### Practice of Palliative Sedation in a Specialized Unit for Acute Palliative Care in a Tertiary Swiss University Hospital: A Three Years Retrospective Study

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**Background:** Palliative sedation (PS) is a last resort treatment aimed at relieving refractory symptoms in patients at end-of-life. There is a lack of knowledge regarding the practice of PS due to the impossibility of conducting randomized controlled trials for ethical and methodological reasons. This study aims to describe the practice of PS and its modalities and indications, in a Swiss specialized acute palliative care unit and to explore whether patients who received PS differed from patients who did not.

**Methods:** A retrospective analysis of the computerised medical and nursing records of all 186 patients who died in the unit between 2011 and 2014 was performed. The following data were searched: patients and PS characteristics and PS monitoring documented by Rudkin Score (RS).

**Results:** PS was used for 24.7% (n=46) of all deceased patients. Most common indications for PS were dyspnea (28.3%, n=13/46) delirium (28.3%, n=13/46) and existential suffering (ES) (21.7%, n=10/46). Midazolam was widely used to achieve PS (97.8%, n=45/46). Mean dose was 2.25 mg/h. Parenteral hydration has been withheld in 3 of 26 patients who received it before PS. RS was documented in only 30.4% (n=14/46) of patients on the first day of PS and 19.6% (n=9/46) the day of death. Sedated patients were significantly younger (mean age=62.3 vs. 69.2,  $p=0.003$ ) and were hospitalized longer in the unit (mean=14.5 vs. 10 days,  $p=0.000$ ). In both groups, patients were mostly men diagnosed with a metastatic cancer, admitted for the management of physical symptoms.

**Conclusion:** Use of midazolam as the main sedative drug for PS. ES is a controversial indication in the literature; surprisingly it was frequently used for PS. To improve the monitoring of PS, RS should be documented more regularly. Except for age and duration of stay, no significant differences were observed between sedated and non-sedated patients. It is essential to perform others studies to better understand the practice of PS in Switzerland.

**Abstract number:** P219

**Abstract type:** Poster

### Quality of End-of-Life Care in Residential Care Homes. Perspectives of Family Members Using the VOICES Questionnaire

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**Background:** In Europe, hospitals are replaced by other care facilities for elderly, e.g. residential care homes (RCHs) as the place where most death occurs, and they play an increasing and important role in end-of-life (EOL) care.

**Objective:** The aim was to describe experiences of quality of care as reported by family members of those who died in RCHs.

**Design:** A retrospective survey design.

**Methods:** Deaths (n=189) at 19 RCHs in one municipality in northern Sweden were included. Family members were sent the VOICES questionnaire one month after their relative had died. Descriptive statistics were used.

**Results:** Almost all residents (94.1%) were reported to have died at their preferred place, and the majority (86.2%) of family members were informed about the imminent death. Regarding care in the last 3 days before death, most family members reported that there was enough help with nursing care (93%) and personal care (78.5%). About half of the dying residents were reported to have pain (46.5%) and 86.4% received pain treatment; more than half (55.9%) were reported to have breathlessness and 39.7% received treatment for it.

**Conclusion:** Family members reported an overall positive picture of received personal care, nursing care and communication indicating high quality of EOL care for their dying relative. However, inadequacies in symptom relief the last three days in life at RCHs, suggest that more attention to this aspect is needed.

**Keywords:** elderly, end of life, family members, palliative care, quality of care, residential care homes, VOICES questionnaire.

**Funder:** This work was supported by the Strategic Research Program in Health Care Sciences (SFO-V), "Bridging Research and Practice for Better Health," Sweden; the Rönnbäret foundation, Skellefteå municipality; and the Umeå University Fund and Foundation of Medical Research, Skellefteå.

**Abstract number:** P220

**Abstract type:** Poster

### Temporary Resident Care Home Deaths

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**Background:** One third of deaths in care homes are temporary residents; people for who the care home is not the usual place of residence. This study examines the underlying causes of death, age, gender for temporary care home residents who died in care homes between 2004 and 2013 in England.

**Methodology:** Mortality data were extracted from ONS Mortality for the registered years 2004-2013. To determine

if a person dying in a care home (nursing or residential), was a resident, place of residence on the death certificate was matched to ONS Communal Establishment database. If the postcode matched, it was inferred this person was a resident of a care home. If it did not match the person was classed as a temporary resident.

**Results:** From a cohort of 846,146 care home deaths 283,876 deaths (33.5%) were temporary residents. Temporary residents accounted for 52% of care home deaths in persons aged under 75 (35,196 deaths), 42% of deaths in persons aged 75-84 (96,793 deaths) and 28% of deaths in persons aged 85+ (151,887 deaths). Males accounted for 42% of temporary resident care home deaths compared to 26.5% of deaths in care home residents.

30% of temporary residents die from cancer (85,626 deaths) compared to 11% of care home residents (60,975 deaths). Temporary residents accounting for 58% of all cancer deaths in care homes; 64% of deaths from cancer of the trachea, bronchus and lung, 60% of deaths from cancer of the digestive organs and 59% of deaths from prostate and urinary cancers.

**Conclusion:** Care homes become the place of death for many people who are not residents. Are these people dying where the best quality of care can be delivered, dying in their place of preference or are the findings of this study a reflection of how end of life care services are structured for people in England.

**Abstract number:** P221

**Abstract type:** Poster

### End-of-Life Decision-making in Different Types of Cancer: Results from a Nationwide Survey among Treating Physicians

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**Background:** Cancer patients are more likely than other patients to face end-of-life decisions that have possible or certain life-shortening effects (ELDs), which could be related to differences in disease trajectory and access to palliative care services. Since differences in disease trajectory and access to palliative care services also exist across cancer types, we examined whether the incidence and types of ELDs differ between cancer types.

**Methods:** A random sample of 2669 cases was drawn from all death certificates with cancer as the underlying cause of death in Flanders, Belgium, from January 1 until June 30, 2013. The certifying physician of each death was sent a questionnaire about medical end-of-life decisions.

We used Pearson's  $\chi^2$ -tests to assess whether cancer type (breast, gastrointestinal, respiratory, genitourinary, head and neck, hematologic, other) was related to the incidence and types of ELDs ( $\alpha$ -level set at 0.05).

**Results:** After removing 277 cases in which responding was impossible from the sample, the response rate was 58.3% (N=1394). The physicians assessed 77% of those deaths as non-sudden. In 85% of non-sudden deaths, at least one ELD was made. ELD rates did not vary significantly between cancer types. Overall, 18% of all ELDs were non-treatment decisions, 63% were intensified alleviation of pain and symptoms, 3% were life shortening without explicit patient request, and 16% were euthanasia or physician-assisted suicide. Types of ELDs did not differ significantly between cancer types.

**Conclusion:** Despite evidence about differences in disease trajectory and access to palliative care services, our results showed no variation in the incidence and types of ELDs among people dying from different cancer types. More research is needed into the decision-making process and involvement of patients with different types of cancer and their caregivers in ELDs.

**Funding:** Strategic Basis Research grant 100036, Agency for Innovation by Science and Technology.

**Abstract number:** P222

**Abstract type:** Poster

### Think Ahead: An Advance Planning Tool

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**Aims:** To engage the public and health professionals to use Think Ahead as an advance planning tool.

**Methods:**

**A range of processes were engaged in:**

- **Consultation with members of the public through focus groups**
- **GP research:** involving 120 people up to 70 years of age, examined people's experiences of using the Think Ahead form using interviews
- **Nursing home research:** involving interviews with staff and 510 residents in 8 nursing homes between 28 and 100 years in Kildare in 2014. Residents ranged from normal to severe cognitive impairment.

**Results:**

- GP research: 74% of patients reported that they were not distressed by anything in the Think Ahead form and 87% said that Think Ahead should be made more publicly available.

- Nursing home research: The baseline level of documentation of end of life wishes was: 58% had no documentation; 22% had full documentation and 20% had some wishes documented. Following the Think Ahead intervention, levels of documentation rose from 20-47% depending on the level of cognition of the resident
- 80% of public believed that Think Ahead would be of interest to the general public. 89% said that they would have conversations with family members or loved ones following learning about Think Ahead and 52% said that Think Ahead had caused them to rethink their wishes around end of life care
- Over 40,000 forms distributed since 2011 and 2,000 have registered on [www.thinkahead.ie](http://www.thinkahead.ie)
- Think Ahead is partnered with 15 organisations and state agencies
- National organisations now rolling out Think Ahead

**Conclusion:** The research and public engagement activities have shown that Think Ahead is a practical tool which people value as part of their planning for end of life. More research is required into how people are using Think Ahead and which professionals, if any, they are turning to for support.

**Abstract number:** P223

**Abstract type:** Poster

### ‘Grasping or Letting Go?’ Reflections on ‘Inner Space’ of Patients in Palliative Care

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**Aim:** Studies that enlighten the patient’s perspective in palliative care are often performed from a perspective of needs, wishes or satisfaction. This study wants to enlighten the patient’s perspective in the last phase of life. What is the essence of those experiences?

**Method:** We performed a phenomenological analysis based on interviews with 40 respondents. These interviews appeared in a series called ‘Het laatste woord’ (‘The last word’), published in an important Dutch newspaper (*NRC Handelsblad*) on a weekly basis during two years. The 40 interviews were read intensively, coded and cross coded. The three researchers double checked their interpretations and conclusions.

**Results:** The analysis showed a phenomenological core category of grasping and (gradually) letting go. After the first shock patients felt more intensively connected to what really mattered in their lives. This could be children, spouses, nature, art or philosophy. They tried to manage their reality by letting go of everything in different ways.

Some patients offered no resistance, while others experienced intense struggling. For many of them moments of easiness and struggle alternated. This process of letting go could be recognised in all stories, although patients differed in the easiness of their letting go.

**Discussion:** The differences between patients in the easiness of their ‘letting go’ and accepting reality were understood from three different theoretical perspectives: coping theory, stages of grief (Kübler-Ross) and the *ars moriendi* traditions connected to the concept of inner space (as described by Carlo Leget). Based on the results, input for reflection sessions and competency development of volunteers was designed. Coordinators and coaches of volunteers might use this material for creating moments of reflection with volunteers in palliative care settings and improve their skills to change perspective with patients.

Funding came from PiN (Project in The Netherlands, KNR).

**Abstract number:** P224

**Abstract type:** Poster

### Improving Sensitivity of Volunteers for Spiritual Stress with Patients in Palliative Care

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**Aim:** Volunteers in care focused roles are definitely the persons in palliative care who most spend time with patients. But are they sufficiently equipped to recognise signals of spiritual restlessness, stress or suffering? In the Netherlands one hospice received a grant to develop a method to increase volunteers’ sensibility and learn them how to call attention to situations in which patients are not comfortable at spiritual level. A one year project was performed in which researchers and hospice staff worked together intensively, guided by a group of 8 experts and a group of 10 volunteers, providing feedback on the whole process.

**Method and results of the development project:** We developed a method based on intensive literature research, case discussions, narratives and expert consultations. A model from the spiritual care guideline in palliative care was chosen that enables recognition of physical, psychological, social and spiritual concerns in patients. Based on this model an observation method was developed that stimulates volunteers to look at patients more intensively and to evaluate and write down their interpretations of patients’ situations after each shift. Afterwards exchange of information with other volunteers and coordinators was encouraged by having them decide on an either positive or negative assessment. The observation method was tested

in five hospices by ten volunteers, followed by an evaluation via interviews (n=4) and focus groups (n=2).

**Reflection:** This observation method was embraced by volunteers, coordinators and experts involved. The method can be used for individual volunteers, for a whole volunteering community or for integration in general trainings for volunteers at national level. The method reinforces the layer of reflection on patients' struggles in volunteering organisations. Special clues are included for referral to further steps in care, e.g. asking assistance from spiritual counsellors.

**Funding:** The Helffer Kootkar Price.

**Abstract number:** P225

**Abstract type:** Poster

**“The Potential versus’ the Reality”: Findings of a Cross-sectional Survey Examining Health Care Professional Perspectives of Advance Care Planning for People with Dementia in Long Term Care Settings**

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**Background:** Evidence suggests ACP can improve the care provided to people with dementia in long-term care settings (LTCSs), facilitating their participation in care decisions. However, few people with dementia have engaged in ACP, despite it being advocated by international policy. The role of health care professionals is integral to addressing this deficit, therefore further understanding of their perspective is needed.

**Aim:** To examine registered nursing home managers (RMs) knowledge & attitudes in relation to ACP for people with dementia in LTCSs.

**Design:** A cross-sectional postal survey was carried out as part of a larger scale sequential explanatory mixed methods study. An adapted survey instrument was used, developed through incorporation of results from an in-depth analysis of the literature & consultation with key experts in ACP & dementia. Principal component analysis was conducted, revealing 6 components.

**Setting/participants:** All registered nursing home managers employed by homes caring for people with dementia across Northern Ireland (n=178).

**Results:** Response rate of 66% achieved (n=116). The level of knowledge in relation to ACP was poor, with corresponding low levels of confidence reported. A lack of clarity surrounding who should lead the process was evident. Varying levels of support impacted on practice. The

positive influence of ACP training was evident, with subsequent increased perceived control reported. However, RMs struggle with the ethical dilemma created when outweighing the potential benefits of ACP to the person with dementia with the desire to protect them.

**Conclusions:** Whilst RMs recognise the potential benefits of ACP, intention to engage is influenced by several inter-related factors, making implementation in practice complex. Enhanced understanding of the factors which influence their perspective will contribute to the development of future educational support and guidance, in order to improve facilitation of ACP in this setting.

**Abstract number:** P226

**Abstract type:** Poster

**How and when to Ask for Patients’ End-of-Life Preferences - A Matter of Importance?**

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**Background:** A priority in end-of-life (EOL) care is exploring and fulfilling patients' preferences. However, how and when to ask for EOL preferences are not fully explored. One issue is whether patients are taking practical issues into concern (real preference) or whether they report on preferences that mirror their genuine wish (ideal preference). Furthermore, many studies report on preferences for place of death (POD) but patients were actually asked about place of care (POC). We aimed to examine patients' EOL preferences according to

- 1) timing,
- 2) differencing between real / ideal preferences and
- 3) differencing between POC / POD.

**Methods:** Incurably ill cancer patients were recruited from seven hospital departments in a University hospital. A structured interview was performed at inclusion and questionnaires with identical questions regarding real/ideal preferences for POC and POD were sent one month later. Answers were compared using congruence in percentages and weighted kappa statistics. A kappa-value (k) larger than 0.6 was interpreted as substantial agreement or better (Landis JR, Koch GG. Biometrics 1977).

**Results:** In all, 96 cancer patients were included. Mean age was 68 years and 58% were men. Congruence between preferences at inclusion and one month later was 40.4-65.1%, k:0.14-0.40 and congruence between real and ideal preferences was 66.2-94.9%, k:0.49-0.88, with a tendency

to increasing congruence as time passes. Finally, congruence between preferences for POC and POD was 84.3-90.7%,  $k:0.76-0.85$ .

**Conclusion:** This study shows that how questions were asked was important especially early in trajectories. Also, time had an impact on EOL-preferences and the patients reported preferences for POC and POD as two different issues. These differences are important to remember both for clinicians and researchers. When reporting patients' preferences detailed information on what and how patients were asked is important.

**Abstract number:** P227

**Abstract type:** Poster

### The Meaning of Compassion in Palliative Care. A Systematic Review

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**Justification:** The vulnerability of the patient and what his illness involves require irreplaceable compassion of the health professionals. The recommended use of compassion in clinical practice requires defining its terminology to know in depth its meanings in order to perform further studies.

**Methodology:** A systematic search in 25 Bibliographic Databases and Key terms used are Compassion and Empathy, MeSH term. Boolean operators AND and OR search in the title (TI) as descriptor (SU) were combined. The search strategy was

**(SU (empathy)) OR (TI (empathy)) OR (TI (compassion)) OR (SU (compassion)) NOT (((SU (self-compassion)) OR (TI (self-compassion)) OR (SU (compassion meditation)) OR (TI (compassion meditation)) OR (SU (compassion fatigue)) OR (TI (compassion fatigue)) OR (SU (burnout)) OR (TI (burnout)) OR (SU (compassionate use)) OR (TI (compassionate use)) OR (SU (compassion focused therapy)) OR (TI (compassion focused therapy)) OR (SU (figley compassion)) OR (TI (figley compassion)) OR (SU mindfulness)) OR (TI mindfulness)))**

This primary search was supplemented by consulting experts about the defining characteristics of the term "compassion" in clinical practice and Snowball method was used.

**Results:** After removing duplicates and applying the inclusion criteria, 28 items were identified.

**Discussion:** The need for compassion among health professionals is becoming a cause of reflection for many authors. The term "compassion" has different

interpretations and nuances in health literature. Found aspects could be grouped in categories:

- Etymology
- Process
- Feeling
- Attitude
- Supportive
- Antagonists
- Different Concepts

**Conclusions:** Compassion could be defined as the sensitivity, the ability to perceive and understand the suffering of others and it allows the personal assistance to provide relief, decrease or complete elimination of that situation. Subsequent studies are required in order to find out how to increase compassion in everyday activities of health professionals

**Abstract number:** P228

**Abstract type:** Poster

### Identifying the Scope and Impact of Opioid Medication Errors in Adult Palliative Care and Oncology Settings: A Systematic Review

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**Background:** Opioids are used routinely to manage pain and other symptoms at the end of life in palliative care and oncology services. Opioids pose a greater risk to patient safety than other drug classes if they are prescribed or administered incorrectly, and are the most frequently reported drug class in medication errors causing patient harm. Despite their widespread use, little is known about the scope and impact of opioid medication errors in adult palliative care and oncology settings.

**Aim:** To identify opioid error incidence, types and patient impact in adult palliative care and oncology settings reported in the peer reviewed literature.

**Methods:** A systematic review identifying empirical studies published in English, between 1980 and 2014, reporting data on opioid error incidence, types or patient impact, in adult palliative care and/or oncology settings.

**Results:** This is the first review to systematically identify opioid errors reported in adult palliative care and oncology settings. Five studies met the inclusion criteria, reporting data from the clinical setting, the home care setting and palliative care clinicians' perceptions of opioid errors. The predominant opioid error type related to deviations from

opioid prescribing guidelines (81% of patients), including: incorrect dosing intervals, incorrect route or formulation for pain type, and no 'as needed' analgesia ordered for patients on regular opioids. Notably, this review did not identify any studies reporting opioid administration errors in the clinical setting, nor was patient harm from opioid errors reported in the included studies.

**Conclusions:** This review highlighted that, in adult palliative care and oncology settings, opioid error incidence, patient impact and identification of error types, are under-explored areas of patient safety. Defining and quantifying opioid error types and identifying opioid error reporting practices in these settings will benefit future quality and safety initiatives.

**Abstract number:** P229

**Abstract type:** Poster

### **End-of-Life Care and Costs for Patients with Dementia, Cancer, Heart Failure and COPD: A Retrospective Cohort Study Using Administrative Data**

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**Background:** Care at the end of life differs between diagnostic groups, probably related to limited recognition of poor prognosis and palliative care needs in non-cancer patients. Our aim is to compare the care and care costs in the last year of life for the four main diagnostic groups for palliative care provision; patients with cancer, COPD, heart failure or dementia.

**Methods:** Health insurance data containing all medical expenses financed by the Dutch Health Insurance Law from Insurance Company Achmea were used. 22% of the Dutch population is insured by Achmea. The Achmea Health Database 2009-2010 was linked to information on long term care at home or in an institution, the National Hospital Registration, and Causes of Death-Registry from Statistics Netherlands. For patients who died in 2010 of cancer (n=8658), COPD (n=1637), heart failure (n=1505) or dementia (n=3586), frequencies and means were calculated to describe use and cost of care.

**Results:** The proportion of decedents with hospitalizations increases nearer to death. In the last year of life, for cancer patients 44% of total mean costs are for hospital admissions; this is 27% for COPD; 20% for heart failure; and 4% for dementia patients. Stay in a nursing home is low for people with cancer (peak at last 30 days; 11%), COPD (peak at last 30 days; 19%), and heart failure (peak at last 30 days; 21%), and high for people with dementia (peak at last 30 days; 71%). In the last year of life, for cancer

patients 7% of total mean costs are for nursing home care; this is 21% for COPD; 25% for heart failure; and 70% for dementia patients.

**Conclusion:** Decedents with dementia show the most distinct pattern of care, and costs of care are highest for this group due to nursing home care. Most studies in palliative care focus on hospital care, and while this is a very important place of care with regard to palliative care, it doesn't offer a complete picture, especially in non-cancer patients.

**Abstract number:** P230

**Abstract type:** Poster

### **How about Autonomy? The Role of Relatives in the Care for Patients Dying in the Hospital**

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**Background:** Hospital care and communication tend to be focused on the individual patient and the decision-making is typically based on the principle of individual autonomy. It can be questioned whether this approach is adequate in terminally ill patients, as many patients want a close relative to be involved in decisions at the end of life.

**Aim:** To investigate the experiences of relatives concerning their role and position during the last days of the patient's life in the hospital.

**Methods:** This study was embedded in a retrospective questionnaire study on the quality of dying of a consecutive sample of patients who died in a university hospital in the Netherlands (2009-2012). 451 relatives of 951 deceased adult had completed the questionnaire. We performed a qualitative analysis of the comments and answers of relatives to open questions.

**Results:** Relatives expressed a need for 'comprehensible, timely and sensitive information and communication', 'involvement in decision-making', 'acknowledgement of their position', 'being able to trust healthcare staff', and for 'rest and privacy'. When relatives felt that their role had sufficiently been acknowledged by healthcare professionals (HCPs), their experiences were more positive.

**Discussion:** These themes largely match with one of the eight dimensions of patient-centered care, i.e. 'involvement of family and friends', including providing accommodation for relatives, involving them in decision making, supporting them as caregivers, and recognizing their needs and contributions. In the care for patients dying in the

hospital relatives have an important role. An approach of HCPs to care that is exclusively based on individual patient needs and autonomy seems inadequate.

**Conclusion:** The role of relatives might be better addressed by the concept of relational autonomy, which creates opportunities to involve relatives in providing patient-centered care and adequately addresses the needs of patients.

**Abstract number:** P231

**Abstract type:** Poster

### Implementing the Care Programme for the Last Days of Life in an Acute Geriatric Hospital Ward: A Phase 2 Mixed Method Study

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**Background:** To improve the quality of end-of-life care in geriatric hospital wards we developed the Care Programme for the Last Days of Life. The aim of this study is

- (1) to determine the feasibility of implementing the Care Programme in the acute geriatric hospital setting and
- (2) to explore its preliminary effects on end-of-life care.

**Methods:** A phase 2 mixed methods study according with the MRC framework was performed in the acute geriatric ward of Ghent University Hospital between 1 April and 30 September 2013. During the implementation process a mixed methods approach was used including participant observation and the use of a quantitative evaluation tool.

**Results:** The evaluation tool showed that implementing the Care Programme in the geriatric ward was successful and thus feasible: a steering group was formed consisting of two facilitators, health care staff of the geriatric ward was trained in using the Care Guide for the Last Days of Life, which was subsequently introduced onto the ward, and approximately 57% of all dying patients were cared for according to the Care Guide for the Last Days of Life. Nurses and physicians experienced the Care Guide as improving the overall documentation of care, improving communication among health care staff and between health care staff and patient/family and improving the quality of end-of-life care. Barriers to implementing the Care Programme included difficulties with the content of the documents used and the low participation rate of physicians in the training sessions and audits.

**Conclusions:** Results of this study suggest that implementing the Care Programme for the Last Days of Life is

feasible and that it has favorable preliminary effects on end-of-life care as reported by health care professionals. Based on the identified barriers during the implementation process, we were able to further refine the Care Programme before implementing and testing it in a phase 3 cluster randomized controlled trial.

**Abstract number:** P232

**Abstract type:** Poster

### Who Will Make my Decisions When I No Longer Can? A Survey Examining Hospitalised Older Adults' Preferences in Scenarios of Incapacity

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**Background:** Up to 70% of hospitalised older adults lack decision-making capacity. Establishing surrogate decision-makers may help identify who to support in decision-making.

**Aims:** To explore patients' preferences for the involvement of surrogates in scenarios of incapacity.

**Methods:** A survey with older patients  $\geq 65$  years in the UK and Republic of Ireland with univariate and bivariate analysis, and fixed-/mixed-effects regression, as required.

**Results:** Of 215 patients approached, 140 completed the survey (65%), and 122 (87%) answered the decision-making question concerning incapacity. Most patients preferred not to make decisions before losing capacity ( $n=73$ , 60%). Of these, most preferred to delegate their decision-making to one other person ( $n=50$ , 69%). Two thirds wanted a relative, other than their spouse or partner, to make their decisions ( $n=49$ , 67%). A minority wanted their spouse or partner to make decisions ( $n=26$ , 36%). Approximately one in five preferred a doctor to make their decision ( $n=14$ , 19%). Of the patients that wanted to make decisions before losing capacity to do so, most wanted one other person also involved in making these decisions ( $n=27$ , 64%). Of these, most preferred to involve relatives, other than their spouse or partner ( $n=30$ , 71%). Patients with a primary unpaid carer were less likely to want to have a doctor involved in their shared decision-making than patients without a primary carer  $\chi^2(1) = 7.088, p < .05$ .

Patients in the UK were more likely to want to be involved in making decisions than those in Republic of Ireland  $\chi^2(1) = 24.228, p < .001$ .

**Conclusion:** Although the popularity of advance care planning has increased, legislation and guidelines need to account for scenarios where hospitalised older adults prefer to delegate decisions to others. The role of culture, unpaid carers and doctors need investigation in scenarios of diminished capacity and decision-making.

**Funders:** Atlantic Philanthropies, Cicely Saunders International, CLAHRC.

**Abstract number:** P233

**Abstract type:** Poster

### Are Different Factors Associated with Preferred versus Actual Place of Death in Advanced Diseases? A Three Country Comparison

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**Background:** Although achieving preferred place of death (POD) is proposed as a quality indicator, little is known about the factors which effect patients' and carers' preferences for place of death (POD), and how preferences are influenced by diagnosis and experiences of care.

**Aims:** To determine factors associated with patients' and family carers' preference for POD across 3 countries and whether these factors are similar to or different from the factors associated with actual place of death.

**Design:** Mortality follow-back survey.

**Setting:** Hospitals in 3 countries: UK (London), Ireland (Dublin), and the USA (New York and San Francisco).

**Data collection:** Postal survey using self-completion questionnaires among bereaved caregivers of patients aged  $\geq 65$  who accessed specialist palliative; plus extraction of patient record data.

**Analysis:** Dependent variables: patient's and carer's preference for POD (home; other; no preference); actual POD (home; other; no preference); change in preference for POD. Variables entered were selected using univariate analyses and a theoretical model.

**Results:** 721 questionnaires were returned. Patients were: 53% women, mean age 79.9. 46% of patients had cancer;

68% lived with someone else; mean number of carer 2.7. Main factors associated with patients preferring home as POD: carer's preference, older age and cause of death. Positively associated with carers preferring home were being white, care arrangements and patient's preference. Patients with cancer or a carer who preferred home as POD more often died at home. Patients with more hospital admissions were less likely to die at home. Hospital stay was associated with patients' and carers' changing preference for POD.

**Conclusions:** Factors associated with preferred POD differ from the factors associated with actual POD. Cancer patients are more likely to die at home and those with more hospital admissions are less likely to. The experience of patients in hospital may change preferences.

**Abstract number:** P234

**Abstract type:** Poster

### Survey of Bereaved Relatives in Two Academic Adult Hospitals

*Korn, Bettina<sup>1</sup>, Ó Coimin, Diarmuid<sup>2</sup>, Prizeman, Geraldine<sup>3</sup>, Codd, Margaret<sup>4</sup>, Curran, Mairead<sup>5</sup>, Hynes, GERALYN<sup>3</sup>, Donnelly, Sarah<sup>6</sup>, Fahey, Tony<sup>6</sup>*

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Our two hospitals have over the past five years invested in programmes to improve the quality of end of life care (EOLC). In collaboration our sites undertook research to 1) establish how we are meeting the needs of dying patients from the perspectives of relatives, and 2) test the feasibility of utilising post bereavement surveys in acute hospitals in Ireland. This paper presents combined quantitative data of the mixed methods study. VOICES<sup>1</sup>, established in the UK was adapted for this study.

This post-bereavement study gathered data retrospectively from bereaved relatives between June and August 2015. A total of 860 deaths occurred in the period. 781 questionnaires were distributed to bereaved relatives 3-9 months after death of their relative with an information pack. Reminder letters followed 2 and 4 weeks later. A helpline was provided in each site during the data collection period. 356 questionnaires were returned giving an overall response rate of 45.6%. The survey tool consisted of a 36 item questionnaire. Data was inputted in MS Excel and converted to statistical package IBM SPSS statistics v. 22

(IBM 2013) for analysis. Frequency and distribution tables were prepared for closed questions.

Example key findings relate to overall quality of EOLC on last admission being good to outstanding (87.3%), with 81% of bereaved believing their relative died in the right place. However, 28.5% wanted but did not receive bereavement care and only 24% of respondents knew about their deceased relatives preferred place of death. 45.6% response rate compares well with other studies using VOICES methodology. The helplines received 36 phone calls.

For the first time we have comparable data from the user perspective providing feedback on EOLC in two large Irish acute academic hospitals. Data provides the opportunity to compare EOLC nationally and internationally, benchmark, clearly identifies gaps in current care provision and provides direction for future development.

**Abstract number:** P235

**Abstract type:** Poster

### **Understanding Continuation of Potentially Inappropriate Medications at the End of Life: Perspectives from Patients, their Relatives and Physicians**

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**Aim:** To obtain in-depth information about the perspectives of patients, relatives and physicians towards potentially inappropriate medications (PIMs) at the end of life.

**Methods:** A secondary analysis of in-depth interviews with 17 patients who were diagnosed as having a life expectancy of less than three months, 12 relatives, and 20 medical specialists and 12 general practitioners who cared for them. Analyses were done independently by two researchers (EG, MT), using the constant comparative method, which is part of the grounded theory approach.

**Results:** Patients, their relatives and physicians felt that PIMs should ideally be discontinued in patients with a limited life expectancy. Patients and their relatives are prepared to discontinue medications, even those with sentimental value to patients. Still, some patients reported that stopping might give them the feeling that their attending physician has already thrown in the towel.

Physicians mentioned several reasons for not stopping PIMs: little awareness, low priority, and unknown consequences. Other reasons were concerns - when discussing

the discontinuation of PIMs - about 1) facing patients with the approach of death, and 2) the possibility that patients might think they do not get the best medical care.

If physicians communicate with patients about the possibility of discontinuing medications, they seem to emphasize the inappropriateness of continuing PIMs in light of the limited life expectancy.

**Conclusions:** The continuation of PIMs at the end of life can be explained by several pragmatic reasons. Another important reason for continuing PIMs is concerns about the reaction of patients and relatives when discussing the discontinuation. However, patients may be open to discontinue PIMs. A change in communication may be helpful: physicians should communicate about the usefulness of PIM discontinuation instead of the uselessness of continuing these drugs.

This study is supported by ZonMw grant 80-82100-98-210.

**Abstract number:** P236

**Abstract type:** Poster

### **Identification of Priority Areas for Improvement of Medication Management in the Last Phase of Life: A Delphi-study**

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**Aim:** The goal of this project was to identify possible solutions for difficulties concerning medication, and formulate recommendations to be addressed in guidelines for medication management at the end of life.

**Methods:** We conducted a two-round Delphi study with 23 international and 19 Dutch experts in palliative care. We made a questionnaire with 58 possible solutions addressing problems regarding medication management at the end of life identified in previously performed studies (patient records, interviews and survey); this questionnaire was reviewed and tested. The recommendations were related to awareness and organization, education, research and development, tools, roles, decision-making and communication.

**Results:** Response rate in the first round was 93%, mean agreement between experts 87% (range 62-100%); additional suggestions for solutions were given by 51% of experts. For the second round, 31 solutions with >87% agreement, 12 new and 7 adapted solutions were

presented. Experts were asked to give a top 10 ranking of the most relevant recommendations for a guideline. The response rate to this round was 77%.

Top five solutions based on their ranking score:

#### Table .

- |   |
|---|
| (1) Physicians should discuss the wishes, treatment goals and priorities regarding medication management at the end of life with the patient in a timely manner. (Roles)          |
| (2) A medication review should be an integral part of the care for patients at the end of life. (Awareness)   |
| (3) Physicians should discuss the end of life with the patient in a timely manner. (Roles)  |
| (4) Medication management at the end of life should be individualized, based on the patient's clinical situation. (Newly added in round 1)  |
| (5) Health care professionals should be trained in communicating with patients and/or their family about decision-making on medication management at the end of life. (Education) |

**Conclusions:** In our Delphi-study experts identified the aspects of different domains that should be addressed in guidelines for medication management at the end of life.

This study is supported by ZonMw grant 80-82100-98-210.

**Abstract number:** P237

**Abstract type:** Poster

#### What we Should Achieve: Core Outcomes Set (COS) for Care in the Dying Phase

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**Background:** A recent systematic review conducted by members of the COMET team did not identify any relevant COS developed for Palliative Care, or more specifically care for the dying.

The aim of this pilot study was to test a set of potentially relevant outcome parameters in care for the dying patient and families modified from results from previous research for consensus among experts.

**Methods:** Two groups of interprofessional experts from Europe were asked to rank the list of these parameters according to GRADE proposal (inclusion into COS with grading > 70% of experts with 7, 8 or 9= critical as outcome): one international group (n = 48), and one national

group of palliative care experts (n = 26) in 11/2014 and 02/2015 respectively.

**Results:** Highest ranking with > 70% of experts ranking 7, 8 or 9 were seen for: pain, nausea/ vomiting and dyspnea, anxiety and in-time communication about dying among patient, family and professionals. Both expert panels, despite being blinded for the results, ranked items identically high.

**Conclusions:** Interprofessional experts show very high agreement on what should be regarded as most important outcomes for best care in the dying phase. Further work on the core outcome set is required to examine which outcomes are most pertinent and to incorporate views on what should be identified as core outcomes from patients and their families including cultural variance.

**Abstract number:** P238

**Abstract type:** Poster

#### More Care, Less Pathway: Transformation of International Guidance into National Recommendations on Best Care for the Dying

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**Background:** With the Liverpool Care Pathway (LCP) approach ending in 2014, users in various countries who had successfully introduced LCP earlier needed to redefine content and format according to national norms or to stop using such guidance.

**Aim:** The Swiss association for Palliative Care mandated a group of experts from across the multilingual country to develop a national clinical practice recommendation for best care of the dying patient.

**Methods:** In a two- cycle interprofessional expert Delphi process, evidence based content derived from literature including LCP- and OPCARE9- results, various international guidelines and clinical expertise were ranked according to GRADE proposal (inclusion with grading > 70% of experts with 7, 8 or 9= critical), and merged to a national recommendation document. A sounding board of professionals from non- specialist background and selected family members who had close contact to some of the institutions reviewed and commented the document.

**Results:** Control of physical symptoms and anxiety ranked highest according to GRADE proposal. Special emphasis was given to quality and content of communication between professionals and patient/ family including wording how to address difficult issues such as discussing prognosis/ recognizing in a sensitive way. Whereas medical issues

dominated the first version of the document, feedback from the sounding board broadened content towards cultural and spiritual challenges. Family members' feedback raised new questions about timing and comprehensibility of communication about dying and death.

**Conclusions:** The method combining international evidence, clinical experience and feedback from non-professionals turned out to be effective in redefining guidance for care for the dying on a national level in a multicultural country.

**Abstract number:** P239

**Abstract type:** Poster

### Palliative Care Team Consultation and Quality of Dying in the Hospital

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**Background/aims:** In Western countries many patients die in hospital. Several studies have reported on a lack of quality of care and unmet needs of patients dying in the hospital. Palliative care team (PCT) consultation has shown to improve quality of life for patients with incurable disease. Little is known about the relation between PCT consultation and quality of dying (QoD) as evaluated by relatives. The aim was to assess the association between PCT consultation and QoD as evaluated by relatives.

**Methods:** We conducted a retrospective cross-sectional questionnaire study among relatives of cancer patients who died in a university hospital in the Netherlands between June 2009 and March 2011.

**Results:** 175 out of 343 relatives responded to the questionnaire (response 51%). They reported about 77 and 98 patients for whom a PCT was or was not consulted, respectively. The mean score (on a 0-10 scale) for QoD for patients with PCT consultation was 6,7 compared to 5,8 for patients who did not receive consultation ( $p=0.05$ ). There was no significant difference in quality of life during the last 3 days of life.

**Table 1.** PCT consultation and QoL and QoD

	n	Without PCT consultation Mean (sd)	With PCT consultation Mean (sd)	T-test	P-value
Quality of life (QoL)	164	3.72 (2.57)	3.26 (2.76)	1.086	0.28
Quality of dying (QoD)	156	5.82 (2.73)	6.68 (2.64)	-1.976	0.05
Diff QoD-QoL	156	2.11 (3.07)	3.34 (2.99)	-2.517	0.01

Patients who received PCT consultation more often discussed preferences for medical treatment (82% versus 62%,  $p=0.01$ ) and were more often aware of imminent death (39% versus 22%,  $p=0.03$ ), as was the relative (59% versus 40%,  $p=0.05$ ). Further, patients who received PCT consultation more often were able to say goodbye (56% versus 40%,  $P=0.02$ ). For relatives these percentages are 62% versus 46% ( $p=0.05$ ). Finally, patients who received PCT consultation more often were at peace with imminent death (58% versus 38%,  $p=0.03$ ).

**Conclusions:** For patients dying in the hospital, palliative care team consultation is associated with several aspects of a favorable quality of dying.

**Abstract number:** P240

**Abstract type:** Poster

### Patient Activation in Frail Older People

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**Aims:** There is an increasing awareness that people need to be more active in expressing healthcare needs and managing their health(care). We aimed to assess to what extent frail older people are equipped to do so by assessing their level of patient activation, i.e. having the knowledge, skills and confidence to manage their health. Patient activation is a strong predictor of a range of health-related outcomes.

**Methods:** Older people residing in Rotterdam (NL) were asked to participate in a c-RCT on the effect of advance care planning (ACP). Inclusion criteria were being competent (score of  $>16$  on MMSE), frail (score of  $\geq 5$  on Tilburg Frailty Index) and  $\geq 75$  years. Patient activation was assessed by the Patient Activation Measure (PAM). The PAM score distinguishes four levels of activation, with level 4 being the highest level of activation. Physical and mental health were assessed by the SF-12.

**Results:** Of 653 eligible people, 200 (31%) consented to participate. The mean age of participants was 87 years; 70% was female and 19% lived with their partner. 45% was institutionalized, 55% community-dwelling. The mean score of the PAM was 52, which is lower than those earlier reported in mentally competent cohorts. Of the older people, 39% were classified as level 1 activation, 31% as level 2, 26% as level 3, and 5% as level 4. This means that 62% of participants had the “confidence and knowledge to take health-related actions”, while 31% actually “took action to improve their health status”. Patient activation was positively associated with mental capacity (.151), mental health (.144), physical health (.224) and negatively with being institutionalized (-.032).  
**Conclusion:** Many frail older people had low levels of patient activation, especially those who were institutionalized and in worse health. In the near future, our RCT will show whether engaging in an ACP program can increase the activation levels of older people.

The study is funded by ZonMw, Stichting Theia and Laurens.

**Abstract number:** P241

**Abstract type:** Poster

### Implementing an Individualised End of Life Care Plan in a Tertiary Referral Cancer Hospital

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**Aim:** The Liverpool Care Pathway (LCP) was phased out in July 2013. In June 2014, the Leadership Alliance for the Care of Dying People set out a new approach with a focus on five priorities of care (One Chance To Get It Right, 2014). The London Cancer Alliance (LCA) developed a document based on these five priorities that has been adapted as an electronic individualised end of life care plan, “The Principles of Care for Dying Patients” (POCD). The aim was to determine whether the five priorities of care recommended by the Leadership Alliance were being captured by the document.

**Method:** This involved sequential case note review (7 pre-implementation of POCD and 10 post-implementation of (POCD).

**Results:** In both groups all patients had anticipatory medications prescribed, all had both physical and psychological symptoms reviewed, medications and interventions reviewed and rationalised with documented discussions with both patients and family.

In both groups, 50% of patients who had capacity and 100% of their families had a documented discussion about the diagnosis of dying.

In the post implementation group, documentation of discussions around hydration and nutrition was present in 90% and 50% of cases, respectively. This compares to 57% of cases in the pre-implementation group.

In the post implementation group, place of care (PPC) was discussed in 85% of cases and place of death (PPD) in 100%, compared with 71.4% and 57% respectively, in the pre-implementation group.

The spiritual needs of all patients and 50% of their families was documented in the post-implementation group. This compares to 42.9% of patients and 0% of families respectively, in the pre-implementation group.

Families’ needs were assessed in all cases in the post-implementation group compared to 71.4% in the pre-implementation group.

**Conclusion:** Benefit was seen with the POCD with respect to discussions regarding hydration, PPD and PPC. Improvement was seen in documentation of spiritual and family needs.

**Abstract number:** P242

**Abstract type:** Poster

### Artificial Hydration: The Decisions and the Difficulties

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**Background:** The use of artificial hydration (AH) in the last days of life has been under increasing scrutiny in recent years. Most guidelines now state that it should be considered on an individual basis and be discussed with the patient and those important to them. It is important to better understand the difficulties perceived by healthcare professionals (HCPs) in order to fully address them.

**Research aims:** We surveyed HCPs working with patients at the end of life with the primary aim of understanding their views on aspects of AH, including the timing and discussing of AH.

**Methods:** Using an online survey, we recruited 61 HCPs with experience in end-of-life care via advertising on social media. Structured answers and free text questions were used. Data was analysed independently by two researchers using SPSS. We compared perceived differences in AH discussions with different parties using  $\chi^2$ .

**Results:** HCPs felt there is likely to be more benefit for AH in the last weeks of life compared with the last days ( $p=0.000313$ ). 86% saw discussing AH with patients as necessary. HCPs found discussing AH with relatives more difficult than with patients ( $p=0.006278$ ). HCPs felt relatives found AH discussion more distressing than patients

( $p=0.000156$ ). The major themes that emerged were that the focus should be the patient's decision and relatives often disagree with HCP plans.

**Interpretation:** HCPs feel that AH is likely to be more beneficial in the last weeks of life rather than the last days. HCPs view discussing AH with relatives as more difficult than with patients. This appears to arise from treatment disagreements, which seem less common with patients.

Decisions regarding AH can be difficult, distressing and influenced by conflicting views. Improving education and support of all involved may help improve care.

Further research should focus on better understanding barriers to discussing AH with relatives and ways to overcome them.

This study received no funding.

**Abstract number:** P243

**Abstract type:** Poster

### Patients' Acceptance of Approaching Death According to General Practitioners in 4 European Countries

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**Background:** Acceptance of approaching death is often seen as an aspect of a good death and it is suggested to be influenced by palliative care. Aim is to study the extent to which patients who died non-sudden accepted approaching death according to their general practitioner (GP) in four European countries and whether country, patient and care characteristics were associated with this.

**Method:** Nationwide representative mortality follow-back study among GPs, who filled in a weekly questionnaire regarding all their patients who died. Included people had died non-sudden ( $n=3056$ ) in Belgium, the Netherlands, Italy and Spain in 2013, 2014 or 2015. Associations were analysed with multiple logistic regression analyses.

**Results:** In all countries most GPs did assess the patients acceptance of approaching death: from 66% in Spain to 94% in the Netherlands (as opposed to filling in unknown). Logistic regression revealed that this occurred less in patients with severe dementia, and more in case of more GP patient contacts, having discussed diagnosis, approaching death and end of life or proxy preference. Country did

not remain significant. Of all cases in which the GP assessed the patient's acceptance the percentages of patients completely or for most part accepting impending death differed per country: Italy 64%, Spain 69%, Belgium 80% and the Netherlands 89%. The multivariate model revealed that, next to country, age, having discussed end of life or proxy preferences, and having discussed approaching death were positively associated with acceptance; sex, diagnosis, GP patient contacts, discussing spiritual issues, provision of palliative care by GP or a specialist palliative care initiative were not.

**Conclusion:** In all 4 countries most patients were in acceptance of approaching death, although it varied per country. Especially care characteristics related to communication on end of life issues between GP and patient were related to acceptance.

**Funding:** NL None.

**Abstract number:** P244

**Abstract type:** Poster

### Identification and Implementation of Indicators to Monitor Successful uptake of Advance Care Planning in Alberta: A Delphi Study

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**Introduction:** In April 2014, Alberta Health Services and Covenant Health implemented Advance Care Planning (ACP) and Goals of Care Designation (GCD) across Alberta. This is a formal way to register patient's opinion on care details, especially in emergency, when communication with the patient is impossible. Now there is a need to find methods of characterizing the quality of its functioning in a large, complex, multi-sector health care system.

**Objective:** To identify the most informative indicators to monitor ACP/GCD across Alberta.

**Methods:** 132 potential indicators were found in the literature through systematic review and environmental scan. A Delphi consensus-based approach is used to evaluate, reduce and refine them. We performed one face-to-face meeting and three Delphi rounds. The topics were: defining domains for the indicators (18 IOM×Donabedian), reduction and refinement of the list of indicators, determining most appropriate care settings.

**Results:** Preliminary mapping of the indicators to the domains has selected 54 indicators with highest level of agreement, which were used in Delphi rounds. R.1. Invited 73 panellists, 16 completed responses. No consensus in 5

domains, therefore, 26 indicator(s) with highest evaluation remained. An additional 5 indicators suggested by panelists, 3 continued to subsequent round. R.2. Invited 72 panelists, with 9 completed responses evaluated. The resulting 18 distinct indicators used Round 3. R.3. Invitation for Round 3 was sent to 62 specialists from 7 types of care settings, with 24 complete responses. Results show indicators covered all levels of details and setting types; none of the indicators received too low applicability score.

**Conclusion:** The results allow us to proceed to the next phase of our program: defining data sources, testing and validating the ACP/GCD indicators.

**Abstract number:** P245

**Abstract type:** Poster

### Implementation and Evaluation of Electronic Medical Orders for Goals of Care and End of Life

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**Purpose:** Calgary Health zone is a pioneer in introducing goals of care designation both in paper and electronic form. Our purpose was to evaluate the level, trends and determinants of these medical orders.

**Patients/methods:** We examined electronically recorded medical orders for goals of care at end of life for adults admitted to acute care settings between December 2008 and December 2014. Evaluation of determinants required patient's DOB, gender, admission and discharge dates, location, attending physician, electronic order start and stop dates. The physician's attending group we used to classify the patients into 5 groups by specialization: medicine, surgery, psychiatry, obstetrics and other.

**Results:** We analyzed 525,000 electronic GCD records. The percentage of patients with an electronic order varied from 54% in 2009 to 81% in 2014. The percentage of patients with medical and comfort care orders (excluding resuscitation) increased from 12% to 14%. More than 60% of patients had only one order during the study period. The intervals between the orders varied from several hours to more than a year. Per encounter, more than 40% of orders had duration less than 1 day. The main determinants for the percentage of patients with an order were patient's age at admission and the presence of a physician order set (of which these medical orders were automatically included). Order sets increased documentation of goals of care from 64% in 2012 to 81% in 2014 in selected settings. For individuals below 40 presence of orders varied from 65% increasing to more than 90% for ages over 90.

**Conclusion:** Electronic orders and order sets have been successfully implemented in a large health region.

Advanced age is a significant determinant in the documentation of medical orders concerning goals of care. The inclusion of goals of care within an order set leads to increased use without documentation of contributory discussions warranting further research.

### Epidemiology and public health

**Abstract number:** P247

**Abstract type:** Poster

### Differences in Out-of-Pocket Costs of Healthcare in the Last Year of Life of Older People in 13 European Countries

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**Background/aims:** One of the most costly periods of healthcare provision is the last year of life, but research has so far focused on insurer costs rather than out-of-pocket costs. Out-of-pocket costs may be important to patients making medical decisions. This paper aims to investigate the self-reported out-of-pocket costs associated with healthcare in the last year of life of older adults in Europe.

**Methods:** Proxy respondents for 2,501 deceased adults of 55 years or over filled in a post-death surveys part of the Study of Health, Aging, and Retirement in Europe (SHARE). Data from 13 European countries and four waves from 2005-2012 was used.

**Results:** The proportion of people with out-of-pocket costs for healthcare in the last year of life ranged from 21% to 96% in different EU countries. Out-of-pocket costs ranged from 2% to 25% of median household income. Secondary and institutional care was most often the largest contributor to out-of-pocket costs, with care received in a care home being the most expensive type of care in 11 out of 13 countries. Multilevel analyses showed that limitations in more than two activities of daily living (coefficient =6.47, 95% CI 1.81-11.14) and a total hospitalization time of three to six months (coefficient 14.66, 95% CI 0.97-28.35) or more than six months (coefficient 31.01, 95% CI 11.98-50.15) were associated with higher out-of-pocket costs. Twenty-four per cent of the variance on a country level remained unexplained.

**Conclusion:** The variation in out-of-pocket costs for healthcare in the last year of life between European countries indicates that countries face different challenges in making healthcare at the end of life affordable for all.

SHARE is funded by the European Commission, the US National Institute on Aging and national sources.

**Abstract number:** P248

**Abstract type:** Poster

**Trends in Continuous Deep Sedation until Death between 2007 and 2013: A Repeated Nationwide Survey**

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**Background:** Continuous deep sedation until death is a highly debated medical practice, particularly regarding its potential to hasten death and its proper use in end-of-life care.

**Objective:** To examine the prevalence and characteristics of continuous deep sedation until death in Flanders, Belgium from 2007 to 2013 and to determine whether performance and decision-making varies depending on the physician's degree of palliative training.

**Design and setting:** A population-based death certificate study regarding deaths in 2013 and 2007 in Flanders, Belgium.

**Participants:** Physicians attending a random sample of deaths in Flanders, Belgium.

**Measurements:** Characteristics of continuous deep sedation (patient characteristics, drugs used, duration, estimated effect on shortening life and palliative care training of attending physician).

**Results:** After the initial rise of continuous deep sedation to 14.5% in 2007 (95% confidence interval 13.1% - 15.9%), its use decreased to 12.0% in 2013 (95%CI 10.9% - 13.2%). Compared with 2007, in 2013 opioids were less used as sole drug and the decision to use continuous deep sedation was more often preceded by an explicit patient request. Compared to non-experts, palliative care experts more often used benzodiazepines and less often opioids, withheld artificial nutrition or hydration more often and sedation was more often performed after a request from or with the consent of the patient or family.

**Conclusion and relevance:** Worldwide, this study is the first to show a decrease in the prevalence of continuous deep sedation. Despite positive changes in performance and decision-making towards more compliance with due care requirements, there is still room for improvement in the use of recommended drugs and in the involvement of patients and relatives in the decision-making process.

**Primary funding source:** Flemish government agency for Innovation by Science and Technology (SBO IWT nr. 100036) and Research Foundation Flanders (FWO).

**Abstract number:** P249

**Abstract type:** Poster

**Survival and Level of Care among Breast Cancer Patients with Brain Metastases Following Whole Brain Radiotherapy (WBRT)**

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**Background/aims:** Brain metastases are associated with great suffering and poor prognosis. Whole brain radiotherapy (WBRT) is commonly used when stereotactic radiosurgery or surgery are not feasible. The benefit of WBRT for patients in late palliative stages can however be questioned.

The aim of this study is to evaluate survival and level of care (hospital/home) following WBRT among breast cancer patients with brain metastases.

**Methods:** We identified 242 patients with brain metastases due to breast cancer, receiving WBRT at the Karolinska University hospital, Sweden, 1999-2012. Through review of medical records, we collected data on clinical factors including level of care before and after WBRT, and survival.

**Results:** The median age at WBRT was 58 years (range 30-88 years). The majority of the patients, n=129 (53%) had WHO performance status score 0-1, whereas 71 (29%) were symptomatic with WHO 2 and 41 (17%) with WHO 3-4 before WBRT, and 96 (40%) patients were staying in hospital while 146 (60%) were at home. Most patients (n=209, 86%) were treated with 4 Gy x 5. Median survival following WBRT was 2.9 months (interquartile range 1.1-6.6 months). Fifty-seven patients (24%) were never discharged from hospital after WBRT. Among the patients that were hospitalized before WBRT, 45 (47%) died in hospital with no stays at home, whereas this was true for 12 patients (8%) among those who were at home before WBRT (p< 0.0001). Among patients with WHO 0-1 before WBRT, 125 (97%) came home again, whereas if the WHO was 2, 46 (65%) patients came home, and if the WHO was 3-4, 14 (34%) came home (p< 0.0001). These associations were not explained by age.

**Conclusions:** One in four breast cancer patients with brain metastases could not be discharged from hospital following WBRT. When deciding about WBRT, the patients' WHO score, level of care before WBRT and the patient's choice of level of care in the end-of-life period should be considered.

**Abstract number:** P250

**Abstract type:** Poster

**Methicillin-resistant *Staphylococcus aureus* (MRSA) and Multi-resistant Gram-negative Bacteria (MRGN) at a German Palliative Care Unit - A Single Service Analysis**

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**Background:** Diagnosis of MRSA or MRGN and the resulting protective measurements might affect patients with life-limiting disease, family caregivers and staff in many ways during a palliative care unit (PCU) stay. Little is known about the prevalence of MRSA and MRGN on PCUs.

**Aim:** The study's aim was to describe patients' risk factors and to identify the prevalence of MRSA or MRGN amongst in-patients at a German PCU.

**Methods:** The study took place in a PCU (10 beds) at a university hospital. Patients were assessed for individual MRSA and MRGN risk factors and were screened following the hospitalwide criteria. Between 02/01/2014 and 01/31/2015 patients were routinely tested within 48 hours following admission. Samples were taken from the nasal atrium and - if applicable - from chronic wounds. Swabs were investigated by standardized laboratory examination via conventional microbiological cultures.

**Results:** 325 patients (93.9%) of 346 admitted PCU patients fulfilled one or more of the MRSA screening criteria (e.g. hospital stay >3 days within last 12 months; chronic wounds; indwelling catheter). From 322 patients samples were taken and tested for MRSA and MRGN. Altogether 3.5% of the patients (n=12) were diagnosed with MRSA, 4.0% with MRGN (n=14) and one patient with both (0.3%).

**Discussion:** PCU patients are at increased risk to be carrier of MRSA or MRGN. Compared to previously reported MRSA prevalence rates among PCU patients (range: 3% - 10.7%) the MRSA prevalence was rather low in this study. The frequency of colonisations with MRGN was similar. Altogether 7.8% of patients were affected (n=27) by multidrug resistant bacteria and required hygiene measurements. Ongoing analyses focus on the ensuing consequences for both patients and caregivers.

**Acknowledgment:** The study presented is part of the project "M-EndoL - MRSA in end-of-life care" that is funded by the Bundesministerium für Bildung und Forschung (BMBF).

**Abstract number:** P251

**Abstract type:** Poster

**Polypharmacy in Older People Near the End of Life: A Population-based Study in Sweden**

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**Aim:** We aimed to evaluate the frequency of polypharmacy over the course of the last year of life of older people in Sweden.

**Methods:** Nationwide, register-based study in the entire Sweden, including all individuals who died at age 65 years or older between January 1, 2007 and December 31, 2013. Drugs register records were linked with the Cause of death register, the Patient register and the social services register in order to create one comprehensive dataset covering the entire Swedish population. Multivariable logistic regression models were computed to examine factors independently associated with polypharmacy.

**Results:** During the study period, 453,058 older individuals died from non-sudden causes and were therefore included in the analysis. The average number of dispensed medications varied from 4.5 (SD= 4.0) during the 12<sup>th</sup> month before death to 5.9 (SD= 4.5) during the last month. Between the 12<sup>th</sup> and the last month before death, the proportion of older adults receiving 10 different medications or more ("excessive polypharmacy") increased from 12.2% to 21.3% (p< 0.001). During the last month of life, women were more likely to be exposed to excessive polypharmacy than men (adjusted OR= 1.18, 95%CI= 1.16 to 1.20). While controlling for possible confounders, younger age, higher number of morbidities, institutionalization and multi-dose dispensing system were found to be associated with an increased likelihood of receiving ≥10 medications (p< 0.001).

**Conclusion:** During the last month before death, 21% of older adults who died from non-sudden conditions were dispensed ≥10 different medications. Considering the potential for serious and harmful drug-drug interactions, these findings raise important questions regarding the adequateness of medication use in older people near the end of life.

**Abstract number:** P252

**Abstract type:** Poster

**Multimorbidity Near the End of Life: A Register-based Study in Sweden**

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**Aims:** This study aimed to estimate the frequency and patterns of multimorbidity in older adults near the end of life in Sweden.

**Methods:** Nationwide, register-based study in the entire Sweden, including all individuals who died at age 65 years or older between January 1, 2007 and December 31, 2013. Chronic diseases were captured using both the death certificate register and the hospital register, using the 10<sup>th</sup> revision of the International Classification of Diseases (ICD-10).

**Results:** During the study period, 475,828 older individuals died from non-sudden causes. These decedents had an average of 3.0 chronic diseases (SD=1.6) at time of death. While adjusting for age and living arrangement, men were found to have a higher number of chronic diseases ( $\beta=0.14$ , 95%CI= 0.13 to 0.14) and a higher Charlson Comorbidity Index score ( $\beta=0.22$ , 95%CI= 0.21 to 0.23). The six most prevalent chronic diseases were hypertension (39.6%), congestive heart failure (39.1%), chronic ischaemic heart diseases (33.1%), solid cancer (32.2%), cerebrovascular diseases (27.6%) and dementia (24.9%). We found considerable variation between institutionalized and community-dwelling older people. In addition, chronic multimorbidity ( $\geq 2$  chronic diseases) affected 81.0% of the deceased. 57.4% of patients had  $\geq 3$  chronic diseases, 34.9%  $\geq 4$  and 18.4%  $\geq 5$ . For instance, among older people who died from solid cancer (n=153,353), 23.2% experienced chronic ischaemic diseases, 26.1% had congestive heart failure, 11.1% were diagnosed with dementia, 12.9% with COPD and 15.0% with II diabetes.

**Conclusion:** This nationwide, population-based study in Sweden gives an unprecedented insight on the burden of diseases for older people near the end of life. The prevalence of chronic multimorbidity among decedents requires a holistic approach of care near the end of life. It also raises serious methodological questions regarding the validity and the relevance of mortality studies relying on single-cause of death.

**Abstract number:** P253

**Abstract type:** Poster

### Increase over Time in the Use of Palliative Care Provided By General Practitioners and Specialist Palliative Care Teams: A Population-based Study in Belgium

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**Background:** Many countries have implemented strategies to increase access to palliative care. Yet no population-based data are available on changes in palliative care use over time. We studied differences over a 5-year period in the use of palliative care provided by general practitioners (GPs) and specialist palliative care (SPC) teams in the last three months of life in the Belgian population.

**Method:** Population-based mortality follow-back study. In 2009/10, and 2013/14, GPs of the Belgian nationwide epidemiological surveillance system (Sentinel Network) weekly registered every death among their patients ( $\geq 18$  years) using a standardised form surveying the care in the patient's last three months of life. Analysis included descriptive statistics and bivariate significance tests. Deaths that GPs described as sudden were excluded.

**Results:** The GPs registered 2388 deaths in 2009/10 (1604 (67%) non-sudden deaths) and 2432 deaths in 2013/14 (1592 (65%) non-sudden deaths). GPs stated that they provided palliative care to 50% of patients in 2009/10 and to 62% in 2013/14 ( $p < .001$ ). The increase was larger for people who died from non-cancer disease (43 to 57%) than for people who died from cancer (63 to 69%) ( $p < .001$ ). In 2009/10, 47% of patients received SPC, which rose to 62% in 2013/14 ( $p < .001$ ). SPC use increased more strongly for people who died from non-cancer disease (36 to 53%) than for people who died from cancer (65 to 74%) ( $p < .001$ ). The rise in SPC use by non-cancer patients was due to higher use of palliative home care (25% increase) and palliative care in nursing homes (54% increase) (both  $p < .001$ ).

**Conclusion:** Use of palliative care in the last three months of life in Belgium rose significantly between 2009/10 and 2013/14, and most strongly for patients who died from non-cancer disease. Identifying the drivers of this development could inform policy-making that aims to increase the use of palliative care in the population, both in Belgium and internationally.

**Abstract number:** P254

**Abstract type:** Poster

### Barriers and Opportunities to Integrated Palliative Care in Europe and its Relationship with the Level of Service Provision

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**Background:** Palliative care (PC) development in Europe does not always correspond to general trends of health system performance or economic development. As part of the European Commission's INSUP-C project, we explored the factors conditioning PC integration in European health systems.

**Aim:** To characterise PC development and integration in Europe in terms of what barriers and opportunities are present at each stage of PC service provision.

**Design:** Mixed methodology, based on the 2013 Atlas of PC development in Europe surveys: qualitative data from the Eurobarometer survey on barriers and chances to PC, and quantitative data on PC service provision, as collected in Facts Questionnaire. Responses were divided into general or integrated care, and then classified according to the WHO public health model for PC. An analysis followed according to 4 levels of service provision using a distribution of frequencies.

**Results:** A total of 135 barriers and 133 opportunities were reported. Most barriers (68%, n=92) had to do with general development, while opportunities were divided between general development (51%, n=68) and integrated care (49%, n=65). Main barriers to general development are funding and social or professional awareness, whereas specifically to integrated PC, a lack of undergraduate or basic education stands out. Major opportunities to reach general development of PC are related to the increase of resources while to integrated PC is an improvement in regulatory framework. Countries with diverse service provision levels show differences, including a trend towards integrated care and research opportunities in higher strata, as well as opportunities in international collaboration among countries at lower provision levels.

**Conclusions:** Lack of undergraduate or basic education and wideing the regulatory framework, are respectively the main barrier and chance to integrate PC according to national leaders. These findings may inform long-term planning and policy work.

**Abstract number:** P255

**Abstract type:** Poster

### Communication and Quality of Life on People with Head and Neck Cancer: A Literature Review

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**Background:** The diagnosis and treatment of head and neck cancer affect the quality of life regarding health of the

affected subjects, since the realization of the laryngectomy may affect directly and even hinder their ability to communicate.

**Aims:** To summarize the main results of researches related to quality of life regarding health of head and neck cancer patients submitted to laryngectomy.

**Method:** This is an integrative literature review study, conducted in the electronic databases: PubMed, LILACS, SCIELO and CINAHL, through the descriptors: "Head and Neck Neoplasms", "Quality of Life" and "Communication".

**Results:** 14 articles were selected. 5 were published in Brazilian journals and 9 on international journals, being categorized in two analysis units: I: Impact of the illness, in quality of life, physical and functional aspects and symptoms, II: Psychosocial aspects related to the treatment of head and neck cancer. The results indicated that people with cancer suffer from the impact of treatment on functional, psychological and aesthetic aspects with body, speech and feeding changes, which are manifested in the daily life of these subjects. Emotional and verbal communication difficulties in the post-laryngectomy which difficult the social interactions, particularly in relation to their families and the health team and constitute a highly stressful situation, and sometimes traumatic. The use of alternative communication resources may favor the active social participation of these people, allowing them to express their choices, according to their wishes, thus favoring their quality of life.

**Conclusion:** The treatment by the multidisciplinary health team and the care of the family are quite complex and there is need for further researches, with greater methodological rigor of the scientific evidences on quality of life related to health of people with head and neck cancer and submitted to laryngectomy with communication skills commitments.

**Financial Support:** CAPES-Brazil

**Abstract number:** P256

**Abstract type:** Poster

### Caregivers Burden of People in Palliative Care: An Integrative Literature Review

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**Background:** The illness of a family member brings many changes in family structure, such that the family caregiver of people in palliative care could/MAY face physical, emotional and social burden.

**Aims:** To summarize the main research findings and critically analyze the evidence on the burden of caregivers of people in Palliative Care.

**Methods:** Bibliographic search in the electronic databases: MEDLINE, LILACS, CINAHL and the virtual library SciELO, with crosses between the descriptors: "Caregivers", "Palliative Care", "Hospice Care", "Terminal Care" and the keywords "Burden", "Supportive Care" of articles published from January 2004 to June 2014, in Portuguese, English and Spanish. 10.296 articles were identified and 23 articles were selected.

**Results:** The material was categorized into three units of analysis: 1. the task of caring and consequences to the life of the caregiver (N=7); 2. the caregiver's burden before the approach of death (N=8); 3. programs and support services to caregivers (N=8). The articles indicate that the caregiver burden varies according to their experience of care task and the evolution of the cared person's illness. Caregivers may face familiar conflicts, financial difficulties and burnout symptoms, decreasing their quality of life. The support offer by others members of family, friends, faith, could be considered protection factors to reduce burden. Their needs should be met to reduce the burden and improve both caregiver's quality life as the assisted one. However, scientific evidence is considered fragile according to Stetler (1998), being 65.2% rated level 4, 21.8% level 5 and only 13% of studies considered of strong evidence.

**Conclusion:** The issue of burden on caregivers of people in palliative care is relevant for research and for clinical practice, but studies with higher methodological quality and scientific evidence are required to support this vulnerable population.

**Financial support:** CAPES - Brazil

## Ethics

**Abstract number:** P257

**Abstract type:** Poster

### Has the Patient/Family Refusal to Be Treated or Diagnosed Influence in the Implementation of Therapeutic and Diagnosis Procedures in Terminally Ill Patients in Nursing Homes?

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**Aim:** Determine if patient's refusal to be treated or diagnosed influence in the number of therapeutic and diagnostic procedures implemented in terminally ill patients in nursing homes, and in the use of ER services.

**Methods:** Descriptive cross-sectional study. Terminally ill patients of 12 nursing homes of Granada (Spain) were followed-up by nurses during 3 months. Inclusion criteria for professionals were; work full time in the nursing homes for at least 6 months. To identify the terminally ill patients SECPAL criteria were used. Professionals were asked fill one questionnaire each month.

**Results:** 64 patients were followed up, 10,9% died. Average age was 83 years (SD=7,68), 60,9% of them were women. 54% had dementia, 22% heart failure, 15% cancer, 5% hepatic failure, and 4%, renal failure. In 40,6% of the cases, patients or families refuse to undergo more diagnosis procedures, and 26,6% refuse to receive more therapeutic procedures.

The most frequent therapeutic procedures were; antibiotic prescription 24,3%, aerosols 17,9%, and peripheral venous catheter 17,3%. For most of the procedures analysed, no differences were found between those who reject therapeutic procedures, and those who not. Paradoxically, some of the procedures, like aerosols (p=0,00) or oxygen therapy (p=0,00) were more frequent in those who refused to be treated.

The most frequent diagnosis procedures were blood tests 20,5%, and urinary tests 16%. No differences were found between those who refuse to undergo diagnosis procedures, and those who not.

42,2% patients were assisted by ER services, and 28,1% were hospitalized during the follow-up. Also in this case, no differences were found between those who refuse to undergo diagnosis or therapeutic procedures, and those who not.

**Conclusion:** Few differences in therapeutic and diagnosis procedures and use of ER services were found between patients who refuse to be treated/diagnosed and those who did not make explicit their opinion.

**Abstract number:** P258

**Abstract type:** Poster

### The Patient Will-tessellation: Values and Attitudes of Physicians Related to Decisions about withdrawing Treatment for Incompetent Patients

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**Background:** Based on the 2001 WHO definition palliative care (PC) aims to improve the quality of life of patient and their families. With this aim questions of the individual organization of treatment and the general access to PC provision arise. Therefore, beside clinical research improving evidence based practice, ethical issues need to be addressed, e.g. factors influencing decision making (DM) or attitudes of involved persons.

**Aim:** To explore and to typify the value systems of physicians working on PC or Intensive Care units with regard to the relevant influencing factors related to decisions about withdrawing treatment for incompetent patients.

**Method:** This study integrates an online factorial survey (FS) and a qualitative interview study. The data collection of the FS combines the key benefits of survey research with the benefits of experimental designs. It enables to identify effects of single influencing factors often mixed and biased in reality. The qualitative Data add participants' self-reflections and reasoning.

**Results:** N=199. 51% women, average age is 46y. Most of them care for more than 6 incompetent patients per month (33%). The average age of the 23 physician participated in the qualitative interviews is 48y. Factors influencing the DM about withdrawing treatment for incompetent patients are the age of the patient, his/ her stated will and the status of custodianship. That means the higher the age the lower the willingness of the participants to agree to use maximal therapy. The qualitative data complement this result by explaining it: a higher age is not a factor itself, but it is connected with little prognosis, multimorbidity, etc. In general, participants show some flexibility in their DM considering the individual situation of the patient.

**Discussion:** The study contributes to the understanding of ethical reasoning of physicians working on Palliative Care or Intensive Care units and experiencing frequently situations with incompetent patients.

**Abstract number:** P259

**Abstract type:** Poster

### **Moral Emotions in Palliative Care: Empirical Insights from Austria and Canada**

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**Research aims:** Moral emotions as one specific group of emotions play a vital role in delivering palliative care as e.g. ethical issues and moral distress belong to daily routine.

Moral emotions are oriented to the welfare of other persons or the society as a whole. To better understand moral emotions in Palliative Care the aims of the presented study are to analyze care situations from Austria and Canada in different care settings and identify families of moral emotions on one hand and describe influencing contextual factors on the other hand.

**Methods:** Within a qualitative study design a reanalysis of Austrian narratives on ethical issues and Canadian narratives on moral distress were conducted. Data in Austria encompass 36 narratives that were generated through qualitative questionnaires in nursing homes. Canadian data are based on qualitative interviews with home care palliative specialists and encompass 47 critical incidents. The reanalysis of data was conducted with narrative analysis.

**Results:** Preliminary results show that moral emotions in palliative care can be found in families around "empathy and relatedness", "sadness, isolation and bereavement", "anger, frustration and powerlessness", "guilt and shame" and "being touched and feel close". Contextual factors influencing moral emotions can be summarized as "suffering and decline of client", "expectations and dynamics of family", "structural conflicts and power issues" and "lack of resources and information".

**Conclusion:** The diversity of moral emotions reflects the everyday experiences in palliative care. It became obvious that most of the moral emotions that have been expressed appear to be interconnected within a bundle of other emotions. Contextual factors influencing moral emotions in palliative care are relatively independent of care settings. In Palliative Care moral emotions and their contextual factors constitute an important source of insight for reflection in organizational ethics.

**Abstract number:** P260

**Abstract type:** Poster

### **Assumptions on Dignity and the Value of Life in Terminally Ill Patients. A Review of Argument-based Ethics Literature**

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**Aims:** The purpose of this study was twofold: to explore the ethical and philosophical assumptions underlying the expressions of terminally ill patients and their carers about dignity and the value of life, and examine the relationship between these premises and proposed approaches from studies in this area.

**Method:** We carried out an argument-based ethics literature analysis using the McCullough et al. approach. Especially focusing on the assessment of the adequacy of the ethical arguments, and the identification of conclusions and positions of the authors. Twenty-one studies were included all of which were retrieved from a prior systematic review of qualitative studies which explored the role of autonomy and control in the perception of dignity in patients at the end of life.

**Results:** Two extreme positions regarding the sense of dignity and the value of life were identified. Those patients who demonstrated an intrinsic notion of dignity associated their answers with a transcendental or spiritual attitude to life. Said patients maintained a certain positive value of life which bestowed meaning to it. On the contrary, where patients showed a strong desire for control over their circumstances and the process of dying, they highlighted values like respect, autonomy and self-determination. Upon losing this autonomy they expressed a loss of value to life.

**Conclusions:** The included studies state that the assumptions about the sense of dignity and the value of life influence the approach to and perspective of the illness (patients and professionals respectively). The underlying premises in the studies result in concrete actions: in some cases understanding that a person in some circumstances has lost their dignity due to a loss of autonomy can lead to ideas of euthanasia or physician assisted suicide. Bearing in mind that an intrinsic sense of dignity protects from the loss of value of life should foster this view of inherent dignity on a clinical and societal level.

**Abstract number:** P261

**Abstract type:** Poster

#### Attitudes towards Dying with Dignity and Physician-assisted Suicide - A Representative Population Survey in Germany

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**Background:** The relation between palliative care and physician-assisted suicide has been subject of professional discourse in the international palliative care community for several years. In Germany, political and public debate has more recently intensified since a law on physician-assisted suicide is anticipated to be passed in November 2015.

**Aim:** To investigate German population perspectives on dying with dignity and physician-assisted suicide.

**Methods:** In a representative population survey conducted yearly by a leading authority in the field of health policy

monitoring, n=1,598 German citizens were asked about health-related topics. A module on dying with dignity and physician-assisted suicide was included, being carefully piloted beforehand. Data were analysed descriptively.

**Results:** Being free from pain (54%), dying at home (48%), and being surrounded by their loved ones (47%) were reported to be the most significant prerequisites for a death with dignity. Nearly 40% of the respondents, under certain conditions, could imagine having a wish for hastened death despite good palliative care delivery. As to the expected consequences if physicians were explicitly allowed by law to assist their patients with suicide, the majority (77%) thought that unnecessary suffering could be diminished and physicians were better able to act in line with the patients' values (66%). At the same time, nearly half of the respondents (46%) feared the risk of misuse. For many questions, a considerable proportion of respondents chose the "I cannot judge this" option (up to 30%) or did not reply to a question at all.

**Conclusion:** Overall, the results reflected diversity as well as a high level of uncertainty with regard to what constitutes dying with dignity. Palliative care professionals and other stakeholders should explore how a society can adequately respond to a variety of individual values regarding the end of life while at the same time ensuring good palliative care provision.

**Abstract number:** P262

**Abstract type:** Poster

#### Disease Awareness, Health Issues Connected to End of Life and Advance Directives Knowledge in Italian Patients Affected by Different Chronic Diseases

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**Introduction:** Chronic diseases are one of the most frequent causes of death worldwide. Its management at end of life requires the active participation of pts and their caregivers in the decision-making process of care. Aim of this cross-sectional observational study was to assess chronic disease pts on disease awareness, health issues connected to end of life and Advance Directives knowledge.

**Method:** 115 pts (30 advanced cancer, 30 Chronic Heart Failure, 23 with Amyotrophic Lateral Sclerosis and 32 with chronic renal failure) underwent a 12-item semi-structured interview aimed at evaluating pts' disease knowledge, and opinions on their right to be informed and on their consent to treatment.

**Results:** 74% of ALS pts and 84% of those with CHF stated that the information received on diagnosis and disease progression had been useful to take decisions on subsequent choices, compared with 47% of pts with advanced cancer ( $p < .001$ ). More than 60% of pts, regardless of the diagnosis, were not able to provide the correct definition of "aggressive therapy", as well as of "invasive therapy" except for pts with CHF and with chronic renal failure who were familiar with these definitions in 57% and 69% of cases, respectively. More than 70% did not know the meaning of advance directives. Once informed on the definitions of "Advance Directive" and "Advance Declaration of Treatment", only ALS pts would prefer a formulation of advance directives that are legally binding ( $p < .005$ ).

**Conclusions:** Despite the limited size of this cohort, our data provide relevant points of interest. Although we observed, as already described in literature, a different diagnosis and prognosis knowledge among different diseases, also a general lack of knowledge on health issues connected to end of life was evident, regardless of the disease. There is still no adequate health information about therapeutic procedures and tools that may enable the pt to be an active participant in disease management at end of life.

**Abstract number:** P263

**Abstract type:** Poster

### Preferences on Forgoing Treatment Are Stable over Time with People owning an Advance Directive; A Cohort Study

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**Aims:** Stability of preferences about end-of-life (EOL) care is one of the most important subjects when it comes to the use and validity of advance directives (ADs). We aimed to investigate the stability of EOL preferences of people owning an AD and the influence of health status and the experience of life-events on this.

**Methods:** A longitudinal cohort study with a population owning different types of ADs, consisting of members of

Right to Die-NL (NVVE, n=4279) and the Christian orientated Nederlandse Patiënten Vereniging (NPV, n=1014), answered written questionnaires between 2005 and 2010. We used hypothetical scenarios about cancer and dementia to assess preferences for continuing or forgoing resuscitation, mechanical ventilation, artificial nutrition and hydration, and antibiotics. Using a multi-state model we analysed whether health status and life events influenced changes in preferences.

**Results:** From the NPV majorities ranging from 67-76% and for the NVVE from 76-98% had stable preferences about either forgoing or continuing treatment for the different treatments and scenarios. In both groups preferences were most stable when it came to resuscitation and least stable when it came to mechanical ventilation. Mostly the experience of different life-events was not associated with instability of preferences. We did find that a person's own health, a change in the health and the death of a loved one were associated with a change in preferences concerning some of the treatments.

**Conclusions:** Preferences concerning continuing or forgoing treatment at the end of life stay stable for a majority of people owning ADs. Higher percentages of instability in the NPV group might be related to their AD (a will to live statement) neither clearly in- or excluding forgoing treatment at the end of life.

The high stability found supports validity of Ads. However, on-going communication about their content is recommended.

**Funding:** The Netherlands Organization for Scientific Research.

**Abstract number:** P264

**Abstract type:** Poster

### Decision-making at the End-of-Life and the Recommendations of the Council of Europe: Results from a Qualitative Secondary Analysis of Interviews and Observation Field-notes

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**Background:** End-of-life decisions are embedded in clinical, socio-cultural, humanistic, political, organizational and economic concerns. The making of such decisions is complex and demanding. In 2014, the Committee on Bioethics, Council of Europe, launched the "Guide on the decision-making process regarding medical treatment in end-of-life situations", aiming at improving decision-making processes and empowering professionals in making such decisions.

**Aim:** To analyze if end-of-life decision-making by specialized palliative care teams is aligned with this Guide.

**Methods:** A secondary data analysis of nineteen interviews and nine team observation field-notes from a previous study with palliative care teams in Portugal was conducted. An analysis grid based on the abovementioned guide was created considering three dimensions: Ethical and legal framework; Decision-making process; Disputed and controversial issues.

**Results:** Thirteen professionals considered the ethical principle of autonomy paramount when making end-of-life decisions. This was registered in seven field-notes. Other ethical principles valued were justice (mentioned by twelve professionals and observed in seven teams) and beneficence/non-maleficence (stated by seven professionals and in five field-notes). The majority of the interviewees and field-notes referred to the collective and inter-professional dimension of the decision-making process. Palliative sedation was the disputed issue most mentioned by professionals. The wish of hastening death emerged as an ethical challenge to excel common care approaches.

**Conclusions:** The ethical decision-making process followed by Portuguese palliative care teams seems to be aligned with the guidelines of the Council of Europe. The nature, limitations and benefits of qualitative secondary data analysis are discussed. Further research is needed to evaluate the actual use, effectiveness and impact of guidelines for end-of-life decision-making for all parties involved.

**Abstract number:** P265

**Abstract type:** Poster

### Is Artificial Nutrition Appropriate for this Seriously Ill Patient? An Analysis of the Consultations of the Clinical Ethics Committee of a Tertiary Care Hospital

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**Introduction:** When patients suffering from advanced stage diseases or dementia are unable to eat, the question of the appropriateness of artificial nutrition may arise. In the University Hospitals of Geneva, health carers can apply to the Clinical Ethics Committee (CEC) to help them solve ethical dilemmas regarding the care of hospitalized patients.

**Aim:** To assess the arguments used by the CEC and determine if a general ethical reasoning process can be identified.

**Methods:** Retrospective comparative analysis of the CEC reports concerning the initiation or withdrawal of artificial nutrition (AN) in adult patients.

**Results:** 15 reports were included covering a time span of 14 years. Most patients (n=12) suffered from a neurological problem, either medical (n=10) or post-traumatic

(n=2). Median age was 76 years (range 17 to 91). In 8 cases the question concerned withdrawing AN, in 5 cases initiating AN. Altogether 7 main arguments have been used by the CEC; the median number of arguments per case is 2. None is found in all the reports. Patient presumed wishes is mostly used (n=8), followed by the principles of non maleficence and beneficence. Patient preferences combined to non maleficence are justification enough to renounce AN in some cases. The principle of distributive justice is the least mentioned (n=2). Time appears as a value - time to let the family come to terms with his loved one's situation - and as a practical mean to negotiate and involve the family in the patient's care - determination of a delay to assess if defined goals of care have been reached. **Conclusion:** We can identify a general ethical reasoning process regarding AN in seriously ill patients. Determination of patient preferences is paramount. To allow time can be considered a value in the solving of ethical dilemmas.

**Abstract number:** P266

**Abstract type:** Poster

### Symptom Relief and Continuous Deep Sedation at the End of Life in Germany. A Cross-sectional Survey and Clinical-ethical Analysis of Decision Making Practice

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**Background:** Symptom relief and continuous deep sedation (CDS) are frequent practices at the end of life in Germany. Empirical studies on decision making are scarce.

**Aim:** To analyse ethically relevant aspects of decision making practice.

**Methods:** Cross-sectional survey among a random sample of German physicians in five physicians' chambers, using the questionnaire of the EURELD Consortium. Statistical analysis with SPSS 23,  $\alpha$ -level < 0.05.

**Results:** As published elsewhere, 734/1998 physicians completed the questionnaire (response rate 36.9%), 403 had cared for a dying adult patient in the last 12 months.

In 31/105 patients (30%) who received CDS, artificial nutrition and hydration were withheld. Patients with CDS were significantly younger than patients without CDS (median age of patients with/without CDS 75/78 (range 26-93/40-98;  $p=0.02$ ). There were no significant differences ( $p>0.05$ ) regarding patients' gender, disease or physicians' palliative medicine qualification.

Of the 123 physicians who had provided symptom relief with expected shortening of life, 79 provided additional information: n=34 estimated the life-shortening

effect between 1 and 7 days, n=3 between 1 and 4 weeks and n=1 more than 4 weeks. n= 27 estimated that there was no life-shortening. In 41/79 cases (52%) the possible life-shortening had been discussed with the patient immediately (n=9) or some time (n=32) prior to the decision. With 38/79 patients (48%) the possible life-shortening effect had not been discussed. There was no significant difference ( $p>0.05$ ) between the patients who received symptom relief with expected shortening of life and those who had symptom relief without this expected consequence regarding age, gender and physicians' palliative medicine qualification.

**Conclusion:** Further research is needed to explore the role of physicians' and patients' values relevant in these decisions.

**Abstract number:** P267

**Abstract type:** Poster

### The 'Choice Funnel' of Life - Starts Wide but Ends up Narrow: Easy Conclusions from Big Numbers

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**Background/aims:** In England, patient choice is enshrined in the NHS Constitution and recently End of Life Care Policy documents: One Chance to Get it Right & What's Important to Me: A Review of Choice In end of Life Care. While the importance of patient focussed care is not questioned there are increasing concerns that the promotion of choice as an end in itself raises unrealistic expectations especially as the population ages and are increasingly frail for a prolonged period before death. The 'State of Care' report by Care Quality Commission (CQC) reports demand for social care increasing with projected further steep increases.

**Methods:** A review of National (England) statistics on age, cause and place of death contextualising with what we know about what is important to patients.

**Results:** There are estimated to be 386,000 people living in approximately 17,000 nursing or residential homes. ~20% of care home residents are aged 85+, average length of stay 9 and 18 months. Care home residents have greater and more complex health needs with multiple co-morbidities. Over 100,000 deaths take place in care homes each year. In a decade 2004-13 the % of people dying at 85+ years increased from 32% to 40%. The % dying aged 85+ in care homes increased 32% to 38% and in 75-84 year olds from 13% to 15%. There has also been an increase in deaths in care homes after hospital admission for those not normally resident at home. Yet surveys suggest less than 2% of patients wish to die in care homes. More people are dying of non-cancer, non-CHD causes with multiple morbidity. At least three-quarters of all those who are dying have reduced agency- physical and/or mental and/or social.

**Conclusions:** Simply analysing national data clearly demonstrates that as the population ages the range of choices related to end of life become reduced. Policy should be circumspect about the reality of choice and place more emphasis on quality of end of life care whatever the circumstances.

## Psychosocial care and spirituality

**Abstract number:** P269

**Abstract type:** Poster

### A Systematic Review: Spirituality Assessment Tools in Adult Palliative Care

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**Background:** Spirituality often underpins the experience of advanced illness. It is a complex concept that is multidimensional and embraces both the existential realm, as well as value-based and religious considerations. The necessity to assess and support patients' spiritual needs is significant to patients themselves, and can impact on their quality of life. However, it is unclear what is the most suitable tool to assess the spiritual wellbeing of adult palliative care patients.

**Aims:** To systematically identify and critically appraise the evidence on spirituality assessment tools for adult palliative care patients.

**Methods:** The Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidance was adhered to. Eight electronic databases were searched and additional sources of evidence were located through relevant websites, grey literature, hand searching, contacting experts in the field, cited and cross-referencing. The search was conducted in October 2014.

Data was extracted into a tailored Data Extraction Form and methodological quality was assessed using the Method Score. The psychometric quality rating of the tools was evaluated according to Terwee's quality framework and Selman et al's framework.

**Results:** 6,573 papers were identified from the electronic databases and additional sources. Three studies met eligibility criteria:

1. Spanish Society of Palliative Care GES Questionnaire;
2. European Organisation for Research and Treatment of Cancer, Quality of Life Group Spiritual Well Being 36 item scale;
3. Spiritual Needs Inventory.

**Conclusions:** There was a lack of evidence in both the methodological and psychometric aspects of these three tools, to be able to confidently propose a spirituality

assessment tool. For this reason, only a recommendation could be made about the GES Questionnaire being most favourable. Despite the paucity of tools, there were encouraging preliminary findings that warrant further robust evaluation.

**Abstract number:** P270

**Abstract type:** Poster

**Doctors and the Breath of Life: Exploring Awareness of Spirituality in Physicians Working in an Inpatient Specialist Palliative Care Unit**

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**Background:** Physicians are expected to be aware of and acknowledge the spiritual dimension of illness and pain as part of their overall assessment and care of palliative care patients. This study aimed to examine how doctors in an inpatient specialist palliative care unit recognised and recorded the spirituality of patients in their care.

**Methods:** A retrospective audit of medical documentation was performed to ascertain how and if doctors recorded spirituality as part of their assessment of patients. Subsequently an interactive spirituality workshop intervention was provided with 100% attendance by doctors. Following the workshop a repeat unannounced audit was conducted on all inpatient medical notes to see how spirituality was recorded by doctors following educational intervention. (Participants were not aware that an audit would be conducted).

**Results:** The baseline audit recorded a 48% recording of the religious denomination and 76% free text script about spirituality by doctors. Content analysis of free text revealed that the language used was heavily religious-based. Following the workshop intervention there was an 82% recording of religious denomination and 88% recording of free text concerning spiritual matters. Content analysis of free text post-intervention revealed an increase of recorded free text and significantly broader reference to meaning, value and spirituality in tandem with religious expression.

**Conclusions:** The provision of an interactive spirituality workshop contributed significantly to the ability of doctors to discuss and record spiritual issues beyond religiosity in palliative care patients. The results of the spirituality workshop intervention broadened the enquiry and recording of spirituality from a predominantly religious expression to represent the broader spiritual realm in an increasingly spiritually diverse population.

**Abstract number:** P271

**Abstract type:** Poster

**Spiritual Well-being at the End of Life: An Exploratory Study on Advanced Cancer Patients in Home-care Setting in Italy**

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**Background:** In home care cancer patients, spiritual issues can play a central role in individual experience. Spiritual well-being is a key aspect, strictly related to global quality of life that has to be evaluated independently from both physical and psychosocial well-being.

**Aims:** We investigated the feasibility of FACIT-Sp and FACT-G administration in a cohort of home care cancer patients in Italy. Our study evaluated patients' spiritual well-being, quality of life, the relationship between them and with socio-demographic variables.

**Methods:** Spiritual well-being of 961 advanced cancer patients, enrolled in a home palliative care program in 9 different Italian regions, was assessed with the FACIT-Sp-12 composed by three domains: Meaning, Peace and Faith. Quality of life was evaluated with the FACT-G.

**Results:** 683 patients (46% male) completed both questionnaires. Global spiritual well-being was statistically significantly higher in patients from Central Italy, subjects with higher Karnofsky Performance Status and patients fully participating to religious rituals.

Faith subscale scores were higher in patients from Southern Italy and relatively independent from quality of life subscales.

Pearson correlation coefficients between subscales of spiritual well-being and total quality of life scores were positive and statistically significant (Pearson's  $r$  for Peace=0,71; Meaning=0,52; Faith=0,27;  $p < 0,01$ ). Results from the hierarchical regression analysis showed that 51% of the variance in quality of life was explained by the three spiritual wellbeing subscales, with Peace as the best predictor (Peace unique contribution=23,2%,  $p < 0,001$ ).

**Conclusion:** FACIT-Sp resulted an appropriate and reliable instrument for the assessment of spiritual well-being in home care cancer patients. Our findings confirmed the value of the spiritual well-being as an independent domain of quality of life and recall the need to support patients with spiritual distress at the end of life.

**Abstract number:** P272

**Abstract type:** Poster

### What Do Nurses Know, Do and Need in Caring for Hospice Care Patients with Anxiety?

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**Background:** Anxiety is prevalent in 30% of hospice care (HC) patients. Since nurses report to rarely have appropriate competencies to identify and respond to anxiety a reflection hereupon is essential. This study is set up to develop an intervention using the Medical Research Council framework in order to achieve a fit between current practice and the intervention.

**Aim:** To explore nursing practice in HC: what do nurses know, do and need caring for patients with anxiety?

**Methods:** A mixed method design was conducted. 336 nurses caring for patients in hospices and palliative care units were invited to complete the survey and participate in focus groups (FG) to get a more in-depth view. Data collection continued until saturation was reached. Descriptive statistics were computed using SPSS. The  $\chi^2$  and t- test were performed to compare among groups. The FG were transcribed verbatim and thematically analyzed.

**Results:** 79% completed the survey, in 65.3% without missing items; 5 FG were conducted. Most nurses had >10 years working experience in HC, mean age was 51.7 years. In 59% nurses were convinced that they were equipped with sufficient knowledge. Most impeding factors were lack of time (50%) and knowledge (31%). Identification of anxiety was found difficult due to the variety in expressions. Tools to identify anxiety were used by 37%. Although a range of interventions were mentioned, reasons for selecting a specific intervention were unclear. A major responsibility is experienced when caring for patients with panic attacks out of office hours, making prompt decisions necessary.

**Discussion/conclusion:** This study highlights the struggle and needs of nurses caring for HC patients with anxiety. The intervention set should consist of guidelines in applying assessment tools, effective communication strategies and decision models to select intervention based on patients' needs and causes of anxiety to accomplish a worthwhile effect in anxiety management for HC patients.

**Abstract number:** P273

**Abstract type:** Poster

### Conceptualization, Development and Psychometric Validation of the IBesFEMS

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**Objective:** Life-threatening illnesses in children have a significant impact on the lives of siblings. Consequently, special attention must be paid to the specific needs of these siblings to help them cope with the situation. To address this issue, a research program was elaborated. The first three phases involved the conceptualization, development and content validation on a initial version of *Inventaire des Besoins de la Fratrie d'Enfants Malades Sévèrement (IBesFEMS)* [Needs Inventory for Siblings of Critically Ill Children]. The fourth phase represented a preliminary validation study.

**Method:** The first phase in this instrument development was conducted using qualitative methodology (focus groups: 6 siblings; 8 parents). The second phase consisted of validating the content of a pool of items developed according to the needs identified in the first phase. Twenty-one participants (3 psychometricians, 3 researchers, 3 clinicians, and 6 siblings) evaluated each item. During the third phase, the acceptability and administration procedures of the preliminary version were assessed qualitatively by 5 siblings. Lastly, the fourth phase represented a prospective study, the new instrument was administered via website or paper to 58 siblings.

**Results and interpretation:** The first phase led to the production of a typology made up of 43 needs in 10 different environments. The second phase allowed the selection of the items, based on expert opinion. This procedure gave rise to a first version of *IBesFEMS* consisting of 48 items. The psychometric validation study revealed that the measure has an estimated internal consistency of 0.96 and a temporal stability intraclass correlation coefficient (ICC) of 0.86 ( $p < .01$ ). Its convergence validity was also satisfactory. The findings suggest that the *IBesFEMS* is highly relevant for pediatric palliative care clinicians and researchers. Future studies should investigate the factorial structure and predictive validities of the *IBesFEMS*.

**Abstract number:** P274

**Abstract type:** Poster

### Geographic Variation in Antidepressant Prescriptions for Seriously Ill United States Veterans

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**Background:** Untreated depression is disabling and exacerbates perceived pain among seriously ill patients. Within the US Veterans Health Administration (VHA), a national integrated healthcare system of 21 service networks serving >5 million US military veterans, 20% of seriously ill veterans have comorbid depression. Detecting patterns of variation in depression care for seriously ill veterans is the first step toward understanding and improving mental and physical outcomes for this large, vulnerable group of patients.

**Aim:** To determine the extent of geographic variation in depression treatment among hospitalized veterans with advanced physical illness and depression.

**Methods:** We analyzed 2011-12 VHA administrative data for a random sample of hospitalized veterans with advanced cancer, heart failure, pulmonary disease, and/or HIV/AIDS. Logistic regression tested associations between service network and antidepressant receipt before discharge among patients with a depression diagnosis in the inpatient record (and no dementia/delirium). To account for network-specific patient differences, we calculated marginal effects for each network at the mean of all other covariates (age, race, depression type, comorbidities, and past antidepressant use).

**Results:** Of 2,312 depressed veterans (91% male, mean age=65), 6% had psychotherapy and 70% received antidepressants before hospital discharge. Antidepressant receipt rates varied by network (range=41-87%, interquartile range[IQR]=67-76%,  $p < .001$ ); differences remained after adjusting for patient characteristics (range=35-89%, IQR=72-81%).

**Conclusions:** High quality palliative care includes psychological distress management, but geographic differences in antidepressant receipt may reflect clinical uncertainty in how to best manage depression. Future studies should explore whether differences in practice guideline knowledge, organizational culture, or clinical priorities are responsible for the observed patterns.

**Funding:** US VHA.

**Abstract number:** P275

**Abstract type:** Poster

**‘He Tries to Get Me to the Place where I Can Get my Wholeness Together again’ - An International Study of Patients’ Views and Preferences Regarding Spiritual Care**

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**Background:** Spiritual distress is highly prevalent in advanced disease, and associated with poor health outcomes and increased costs, but evidence to inform the provision of spiritual care (SC) in palliative care is limited. Building on the SC research priorities identified in the 2014 EAPC survey, we explored patients’ views, preferences and research priorities in relation to SC.

**Methods:** Experienced researchers conducted focus groups (FGs) with adult patients receiving palliative care in 9 countries. Purposive sampling aimed for diversity in diagnoses, age, gender and belief systems. FGs were recorded, transcribed and, if necessary, translated into English. Data were analysed thematically.

**Results:** 74 patients participated in 11 FGs in South Africa, Kenya, South Korea, USA (3 sites), Canada, UK, Belgium, Finland and Poland: 48 women, mean age 61. 53 had cancer. 21 were Catholic, 22 Protestant, 5 spiritual but not religious, 4 Buddhist, 2 Muslim, 2 Jewish, 2 atheist, 7 other. Five themes are reported: experiences and understandings of SC, preferences regarding SC, descriptions of effective SC, and research priorities. Human connection was perceived internationally as essential. Religious patients saw SC as integrating faith into the illness experience. Preferred SC providers were mainly trained specialists or other spiritually attuned staff. Effective SC was described as putting the patient first, going the extra mile and integrated into care. Research priorities included understanding the qualities of human connectedness (e.g. compassion, empathy) and how to foster them in staff, and how to initiate SC.

**Conclusions:** Patients across the world describe human connection, patient-centredness and integration in healthcare as fundamental to SC. While SC specialists play important roles, particularly for religious patients, patients emphasised the benefit of other staff recognising and being comfortable with the spiritual domain.

**Funders:** Sir Halley Stewart Trust, UCT.

**Abstract number:** P276

**Abstract type:** Poster

### **Digging in the Dirt: Findings and Lessons Learned from A Comprehensive Scoping Review of Compassion within Clinical Care**

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**Background:** Recent concerns about suboptimal patient care associated with a lack of compassion have led to healthcare reform and recommendations to enhance compassion within clinical practice. Palliative care patients expect compassionate care and while the majority of palliative care providers desire to provide such care little exists by way of empirical evidence to guide them in this important facet of their work. The purpose of this scoping review was to map the literature on compassion in clinical care.

**Methods:** Searches of eight electronic databases and the grey literature were conducted to identify empirical studies published over a 25 year period (1990-2014) in accordance with the scoping methodology of Arksey and O'Malley. After title and abstract review, full-text articles were screened and extracted by two reviewers independently. A narrative approach to synthesizing and mapping the literature was used.

**Results:** Of the 36,637 records that were initially identified, 648 studies were retrieved, with 44 studies being included in the review. Six themes emerged from the reviewed studies: nature of compassion, development of compassion, interpersonal factors related to compassion, action and practical compassion, barriers and enablers of compassion, and outcomes of compassion.

**Conclusions:** Although compassion is a liberally employed term in the healthcare literature, there is a limited understanding of compassion within healthcare, particularly in palliative care. A deeper examination of the key healthcare provider behaviors and attitudes associated with compassion, including the inclusion of patient and family perspectives regarding the nature of compassion, is necessary.

**Abstract number:** P277

**Abstract type:** Poster

### **'She Listened to my Sister's Stories Very Carefully' - An International Study of Caregivers' Views and Preferences Regarding Spiritual Care**

*Selman, Lucy<sup>1</sup>, Brighton, Lisa<sup>2</sup>, Sinclair, Shane<sup>3</sup>, Egan, Richard<sup>4</sup>, Karvinen, Ikali<sup>5</sup>, Speck, Peter<sup>2</sup>, Vermandere, Mieke<sup>6</sup>, Glajchen, Myra<sup>7</sup>, Puchalski, Christina<sup>8</sup>, Adler, Shelley R.<sup>9</sup>, Gikaara, Nancy<sup>10</sup>, Hunter, Joy<sup>11</sup>, Powell, Richard A.<sup>12</sup>, Deskur, Ewa<sup>13</sup>, Yong, Jinsun (Sr. Juliana)<sup>14</sup>, InSpirit Collaborative*

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**Background:** Although research into the spiritual care (SC) needs of family carers is lacking, high levels of spiritual distress have been reported, particularly when their loved one has a poor prognosis. Building on the priorities for SC research identified in the 2014 EAPC survey, we explored carers' views and preferences regarding SC.

**Methods:** Focus groups (FGs) were conducted with adult unpaid informal carers of patients receiving palliative care in 9 countries. Purposive sampling aimed for diversity in age, gender, belief system and patient diagnoses. FGs were recorded, transcribed and, if necessary, translated into English. Data were analysed thematically.

**Results:** 71 caregivers participated in 11 FGs in South Africa, Kenya, South Korea, USA (3 sites), Canada, UK, Belgium, Finland and Poland: 56 women, mean age 59. 23 were Catholic, 21 Protestant, 6 other Christian, 9 no belief system/agnostic/atheist, 5 Muslim, 3 Buddhist, 2 spiritual but not religious, 1 Jewish. Data arose in five categories: carers' spiritual concerns, patients' spiritual concerns, experiences of SC, preferences regarding SC, research priorities in SC. Carers described patients' problems accepting illness, stress, worry, guilt, asking 'why me?' and questioning God. Carers' main spiritual concerns were relationship problems, worry, stress, and asking 'why them?' Carers reported a lack of SC, but good experiences when received. SC was seen as a responsibility of all staff. Volunteers and peer support were valued. Research priorities included staff training, improving assessment, and making SC suitable for diverse populations.

**Conclusions:** Participants' descriptions of patients' and carers' spiritual distress highlight the importance of attending to spiritual concerns in palliative care and the current inattention to spiritual needs in practice. Training and supporting all staff and volunteers in the provision of SC in palliative care must become a priority.

**Funders:** Sir Halley Stewart Trust, UCT.

**Abstract number:** P278

**Abstract type:** Poster

**Frequenting Death's Doorstep: A Mixed Method Study on Issues Related to Patients' Spiritual Well-being and their Healthcare Providers' Ability to Address Spiritual Needs within a Bone Marrow Therapy Clinic**

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**Background:** The benefits of early integration of palliative care into the cancer trajectory are increasingly recognized in research and practice. Diagnosis and treatment of a blood and/or marrow cancer evokes spiritual issues associated with mortality, whether in the early stages of the disease or at the end of life. An understanding of the nature of spiritual wellbeing, associated psychosocial factors, and how to effectively address spiritual issues within this population is severely limited.

**Methods:** In the qualitative phase, semi-structured focus groups were held with patients and healthcare providers to determine the nature, impact and barriers associated with addressing issues of spiritual wellbeing in the context of an interdisciplinary bone marrow transplant clinic. Data were analyzed using the qualitative approach of latent content analysis. In the cross-sectional phase, 100 patients were administered measures of quality of life (FACT-BMT), post-traumatic growth (PTGI), and spiritual well-being (FACIT-SP). Data analysis included descriptive statistics, correlational analysis and independent sample t-tests.

**Results:** Four major categories emerged from the qualitative data: addressing spiritual well-being, impact of illness on spiritual well-being, routine and specific clinical time points for addressing spiritual issues, and enhancing spiritual well-being in the clinical setting. There were a number of differences between test items and spiritual and religious factors, including income level, being attached and living situation. Patients who identified as somewhat religious

demonstrated significant differences in several subscales of the PTGI and the FACIT-SP.

**Conclusions:** Quantitative and qualitative results provide insight into what contributes to patients' quality of life, including spiritual well-being. Qualitative data identified clinical and interpersonal factors related to effectively addressing spiritual issues within this population.

**Abstract number:** P279

**Abstract type:** Poster

**Music Therapy to Promote Relaxation and Well-being in Palliative Care: Results of a Randomized Controlled Trial**

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Music therapy has been part of palliative care treatment for more than 30 years. Despite promising clinical experience regarding the support of symptom management, emotion regulation, communication, and spirituality, little is known about the effectiveness and underlying mechanisms. Therefore, the aim of the present study was to investigate, whether a standardized, live music therapy relaxation intervention could promote relaxation and well-being in terminally ill patients.

84 patients from a palliative care unit were randomly assigned to either two sessions of live music therapy using monochord music and vocal improvisation or two sessions of listening to a prerecorded verbal relaxation exercise. The primary outcomes were patients' self-reported levels of relaxation, well-being, and acute pain. Heart rate variability (HRV) and quality of life (QOL) were assessed as secondary outcomes. Analysis of covariance with pre-intervention values as covariates and post-intervention scores as outcomes was used to detect significant between-group differences.

The music therapy group showed significantly greater improvements than the control group regarding relaxation ( $p < .001$ ) and well-being ( $p = .01$ ), with medium to large effect sizes. No significant differences were observed for acute pain ( $p = .53$ ). Examination of HRV data revealed a significant increase in high-frequency (HF) variations of heart rate ( $p = .01$ ). In addition, the music therapy intervention showed to be superior concerning the reduction of QOL-“fatigue” subscale ( $p = .03$ ).

Results from both self-reported and objective data indicate that music therapy is an effective treatment to promote relaxation and well-being in palliative care patients.

Low baseline values on acute pain may explain the lack of significant effects on pain reduction. Future research may address the promising effect on fatigue symptoms.

**Abstract number:** P280

**Abstract type:** Poster

### Dignity Therapy in Palliative Care: A Comprehensive Systematic Review of the Literature

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**Background:** Patients with advanced disease experience a variety of needs. There are few systematic psychological interventions to help manage their emotional and spiritual needs. Dignity Therapy (DT) emerged as a brief psychotherapy to relieve psychoemotional and existential distress in patients whose lives are threatened by illness.

**Objective:** To conduct a systematic review of experimental studies involving DT for patients in Palliative Care (PC).

**Method:** Systematic search of the literature from 2002 to 2015 in PubMed, CINAHL, Cochrane Library and PsycInfo. All research articles that included the use of DT in PC patients were selected. Article quality was also assessed.

**Results:** 25 of 97 studies were included. Quality of studies is high. Findings speak about patients, families and professional perceptions on DT. Acceptability and feasibility and how DT has adapted to other cultures and types of patients is also reviewed. Various types of studies have assessed DT's effectiveness. Nonrandomized studies suggest statistically significant improvements in existential and psychosocial

measurements such as suffering or depression. A randomized study shows significant improvement in depression and anxiety after DT. Patients, relatives and professionals consider DT useful and have a positive view of it. DT is starting to be used in patients with motor neuron diseases and in the elderly. This review provides a comprehensive view of DT including perspectives from all the people involved on it. It goes a step further than other reviews as not only analyses the primary outcome of the studies, but also considers different studies' adaptations of DT to patients with different pathologies and in different cultural contexts.

**Conclusion:** Further evidence is needed regarding the use of DT. It is important to better understand how DT works in order to establish a means for measuring its impact and assessing whether patients with high levels of emotional distress can benefit most from DT.

**Abstract number:** P281

**Abstract type:** Poster

### A Study on the Effect of Being Spiritual and Religious among Advanced Cancer Patients to their Symptoms Burden and Quality of Life

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**Background:** Despite conceptual differences, researchers acknowledge that spirituality ± religiosity may have positive health outcome in patients with life-limiting illnesses. This study aimed to ascertain spiritual and religious characteristics of advanced cancer patients from a multi-ethnic background, and their correlation with symptoms burden and quality of life.

**Methods:** 80 oncology patients completed self-rated spiritual (FACITSp12) and religious (DUREL) intensity scores. The scores were correlated to symptoms burden (ESAS-R) and quality of life (FACT-G7) scores. Non-parametric and

**Table 1.** Median scores according to race and religion.

	FACITSp12 [0-48] (IQR/min-max*)	DUREL [5-27] (IQR/min-max*)	ESAS-R [0-90] (IQR/min-max*)	FACT-G7 [0-28] (IQR/min-max*)
<b>Race: Malay (n=56)</b>	46.0 (7) p<0.05	26.0 (3) p<0.05	12.0 (13) p=0.566	16.0 (6) p=0.789
<b>Chinese (n=19)</b>	32.0 (17)	19.0 (10)	14.0 (22)	17.0 (6)
<b>Indian (n=5)</b>	40.0 (12)	25.0 (7)	16.0 (25)	18.0 (7)
<b>Religion: Islam (n=56)</b>	45.5 (7) p<0.05	26.0 (3) p<0.05	12.0 (13) p=0.149	16.0 (6) p=0.417
<b>Christianity (n=5)</b>	38.0 (27)	24.0 (9)	24.0 (18)	12.8 (7)
<b>Buddhism (n=12)</b>	34.5 (12)	23.0 (9)	13.5 (20)	16.5 (5)
<b>Hinduism (n=2)</b>	42.0 (40-44)*	26.0 (25-27)*	9.0 (3-15)*	20.58 (19-22)*
<b>Atheism (n=2)</b>	28.5 (23-34)*	19.5 (16-23)*	19.0 (4-34)*	16.0 (15-17)*

correlation tests were used to examine the relationship between the variables.

**Results:** Malay patients scored higher than Chinese patients in spirituality and religiosity subscales ( $p < 0.01$ ). Muslim patients have a higher degree of meaning, peacefulness and faith compared to Buddhists ( $p < 0.01$ ). Spirituality and not religiosity, is correlated with less symptoms burden ( $r_s = -0.313$ ,  $p < 0.01$ ) and better quality of life ( $r_s = 0.323$ ,  $p < 0.01$ ).

**Conclusions:** In this study we found that spiritual/religious needs in advanced cancer patients differ according to race and religious background. Spiritual well-being may affect the quality of life and symptoms control of advanced cancer patients. We postulate that the differences in patients' ethnicity and beliefs present a unique entity for future research in cancer care.

**Abstract number:** P282

**Abstract type:** Poster

### What Can Be the Effect on PROMs of Spiritual Care Training to Hospital Staff in the Netherlands? (SPIRIT-NL)

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**Background:** Spirituality is reported as important for palliative patients. There is an increasing demand for spiritual care training. In a multicentre trial, healthcare chaplains of 7 non academic teaching hospitals implemented a pilot training (SC) in palliative care (PC) to 9 multidisciplinary clinical teams on regular curative departments where also palliative patients receive treatment.

**Aims:** Measuring the effect of the intervention training SC on the perceived care and treatment as experienced by patients. Assessment of the spiritual needs and attitudes of hospitalized palliative patients in the Netherlands.

**Methods:** In an explorative multicentre trial, we have collected data of 85 palliative patients on pilot and control departments, pre and post intervention, using questionnaires on physical symptoms, spiritual distress and the perceived focus of caregivers on their spiritual needs, quest for meaning or existential questions, spiritual involvement and attitudes (SAIL), followed by a single open question 'how was it for you to fill in the questionnaire?'. Quantitative and qualitative methods were used to analyse the effects of the intervention.

Quantitative and qualitative methods were used to analyse the effects of the intervention.

**Results:** All patients scored highly on spiritual themes and involvement. They reported attention to their spiritual needs as highly important. No significant effect of training staff on spiritual distress of patients and proxies was measured. There was a significant effect on the attention to spiritual and existential needs that patients experienced, and a possible effect on patients' sleeping. Half of the patients reported a degree of reflection on spiritual or existential questions as a result of filling in the questionnaire.

**Conclusion:** Training spiritual care can be measured in patient reported outcome measures and seems to have a positive effect on the quality of care. Further research should focus on how to optimize training spiritual care for hospital staff so that an effect on spiritual distress is possible.

**Abstract number:** P283

**Abstract type:** Poster

### Impact of Existential and Psychological Determinants on the Perceived Quality of Life in Palliative Care Patients

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**Background:** Existential and psychological issues became central in recent years in the palliative care domain. This study aims to assess to what extent these non-physical determinants can be considered as significant predictors of perceived quality of life (QOL) in palliative patients.

**Methods:** We performed a cross-sectional study involving face-to-face interviews with Swiss palliative patients. Existential issues were assessed with the *Schedule for Meaning in Life Evaluation* (SMILE), the *Spiritual Subscale of the Functional Assessment of Chronic Illness Therapy* (FACIT-Sp, "meaning", "peace", and "faith" scores). Psychological issues were assessed with the *Hospital Anxiety and Depression Scale* (HADS, "anxiety" and "depression" scores) and the *Schedule of Attitudes toward Hastened Death* (SAHD). QOL was measured with a single item scale (0-10). Multivariate analyses were performed.

**Results:** Between September 2012 and January 2015, 206 patients consented and completed the protocol (51.5% were female and mean age=67.5 ± 10.9). The best predictive model for QOL explained 37.4 % of the variance of the perceived QOL and included the “peace” and the “faith” scores of the FACIT-Sp, the total score of the SMILE, the “depression” score of the HADS and the total score of the SAHD (adjusted R<sup>2</sup>=.374, AIC=681.449, p=.000). Among these variables, only the “faith” dimension of the spiritual wellbeing ( $\beta$ =.085, p=.023) and the “depression” dimension of the psychological distress ( $\beta$ =-.190, p=.000) appeared as significant predictors of QOL.

**Conclusions:** Existential and psychological determinants, particularly depressive symptoms contributed to a large extent to the perceived QOL of life of palliative care patients. There is an urgent need to improve psychosocial and existential interventions, taking into account the fragility of the palliative patients in palliative care, and to clarify the criteria used for identifying depression in the palliative care setting.

**Abstract number:** P284

**Abstract type:** Poster

**Breast Cancer Patients Treated with Chemo-therapy Reports More Unmet Supportive Care Needs in the Early Treatment Phase, than Patients Treated Only with Radio-therapy**

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**Aims:** The purpose was to identify unmet supportive care needs in the early treatment phase of women treated for breast cancer and to investigate differences in needs between groups treated with chemo-therapy and radiation-therapy. If it is possible to identify early unmet needs, it may be possible to predict levels of unmet needs in the post-treatment phase and target an early rehabilitation to specific groups and with specific interventions.

**Population:** Over a six-month period, 123 Danish women treated with mastectomy or lumpectomy, were assessed for eligibility in the midst of their primary treatment period. Eighty-five percent agreed to participate and 100 women filled out the baseline questionnaire. Forty-five women were under treatment with radiation-therapy, forty-nine with chemo-therapy and four women were treated with both radiation- and chemotherapy.

**Design and methods:** As part of a large battery of self-administered questionnaires, the women filled out at home, the Supportive Care Needs Survey (SCNS-SF34) together with demographic items (socioeconomic status, working hours, marital status etc.). The SCNS-SF34 includes 5

different domains of needs: Psychological-, Health system & information-, physical & daily living-, patient care & support-, and sexuality needs.

**Analysis:** The subscales of the SCNS revealed good reliability (Cronbach’s alpha: .79 - .96) and the summated scores were skewed and therefore log-transformed. An independent samples t-test was conducted to compare the need scores for radiotherapy-group (R-group) and chemotherapy group (C-group).

**Results and interpretation:** There was a significant difference between the C-group and R-group on physical and daily living needs [t(93)=-3,24, p=0,002] and sexuality needs [t(90)=-3,36, p=0,001], but the magnitude of the differences in the means were small (eta squared=0,10 & 0,11).

The women treated with radio-therapy showed significant less unmet needs than the women treated with chemotherapy.

**Abstract number:** P285

**Abstract type:** Poster

**Out of Hours Spiritual Care Provision: Two Phase Survey Undertaken Round Christmas Time**

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**Background:** An individual’s health and well-being benefit when spiritual needs are addressed. Continuity of care in our setting for patients included in the Specialist PC Register and Program, is provided by a service that gives support to patients and their families 24/7 either by phone, or at patient’s homes as needed.

**Aim:**

- Establish whether out of hours, Christmas spiritual interventions can advance *Spiritual Care* provision.
- Assess whether training and experience have impact on spiritual issues.

- Assess patient's, family carer's and professional's spiritual needs.

**Methods:** Analysis of a phone survey undertaken in two phases by the 24hour Specialist PC Team. Cases were selected for inclusion when professionals objectively assessed that "Spirituality was somehow addressed in relation both to patients and/ or carers". Data Collecting Sheet were filled during telephone contacts.

**Results:**

In Phase 1, a total of 2429 contacts were registered with a media of 515 calls per week, 15 patients were included. Surveys were completed in a period of 4 weeks around Christmas.

In Phase 2, surveys were undertaken 3 months later for a period of 3 weeks. 36 patients were included. Despite that most of the consultations were for symptom control, we have observed that in many of them, there were hidden needs that went beyond the symptom.

**Conclusions:**

- The 24h service enables families and carers to reassure their loved ones promoting their spiritual wellbeing and enhancing their quality of life at home.
- Most of the consulting reasons related to specific symptoms, most of them common in situations of last days or hours of life, such as loss of oral route, agitation, worsening of general deterioration.
- The need for protocols, training and updating in spirituality is essential for a better care for patients and families, as well as for better identification of need.

We work to impulse *Spirituality* approach in our setting at times of particular vulnerability and need.

## Communication and information

**Abstract number:** P286

**Abstract type:** Poster

### Hypothetical versus Actual Decision-making in Hospitalised Older Adults: A Cross-national Mixed Methods Study

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**Background:** Studies that examine how people make decisions about their care mostly use hypothetical decision scenarios. The use of hypothetical scenarios raises the issue of applicability to clinical practice

**Aims:** To examine hypothetical preferences for shared decision-making and associated factors in hospitalised older adults, and to appraise these preferences in relation to how decisions were actually made

**Design:** Mixed methods involving a face-to-face survey and nested qualitative interviews completed 2012-2014 in five hospitals in the UK and the Republic of Ireland. Univariate, bivariate and regression with sensitivity analysis was completed. Descriptions of actual decision-making were analysed using content analysis

**Results:** Of 215 patients approached, 140 completed the survey (65%). Most preferred shared decision-making in hypothetical scenarios (74%, 90/122). A preference to die at home or in hospice was significantly associated with wanting to be involved in shared decision-making (95% CI, 0.02-0.61;  $p < 0.05$ ), compared with preferring to die in a nursing or residential home or hospital. Age, gender, financial hardship, quality versus quantity of life, preferred place of death, and educational attainment had no statistically significant effect on the likelihood of preferring shared decision-making. In qualitative interviews, 18/20 preferred shared decision-making, yet actual decision-making varied due to patient and staff factors and the decision itself. Of 87 decisions discussed, 33 were patient-led, 34 were doctor-led and 20 were shared with the doctor or family

**Conclusions:** Hypothetical preferences are not simply retrieved in clinical settings as patients may calculate their preference at the time of making their decision. Examining patient, staff and decision factors may help identify how patients determine their preferences in clinical settings, where complexity is the norm

**Funders:** The Atlantic Philanthropies, Cicely Saunders International, CLAHRC.

**Abstract number:** P287

**Abstract type:** Poster

### Are our Discharge Summaries Fit for Purpose?

Hart, Caroline, Stevens, Toria, Girling, Natalie

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**Background:** Handover is a vital part of safe and effective healthcare provision, and discharge letters form a key part

of this. The complex needs of palliative patients make this document central to their on-going care. A previous audit at Severn had shown that a great deal of clinical information was not being communicated in the discharge summary. A discharge summary template was introduced to prompt the medical team to improve documentation.

**Aims:** To improve the information given to GPs and other healthcare professionals on discharge from the Severn Hospice by assessing the effect of the discharge summary template.

**Method:** The discharge summaries of all patients who were admitted between 1<sup>st</sup> January 2014 and 30<sup>th</sup> June 2014 were reviewed, and their content audited against a modified version of the Academy of Royal Colleges discharge summary checklist.

**Results:** 86 discharge summaries were reviewed, and showed that documentation of all areas has improved. Many fields are documented in over 90% of discharge summaries, this includes patient allergies, changes made to medication, specific GP requests on discharge. The number of days to completing the discharge summary has also improved with 24% being completed by the day of discharge.

Although some areas have improved with the template, they are still poorly documented including patient follow up [72%] and DNAR status [80%]

**Conclusions:** The implementation of the discharge summary template has led to vast improvement in documentation of vital information, and has therefore improved the communication between the Hospice and community services.

Further recommendations have been made to improve documentation of specific fields, including 'suggested phrases' included in the template to guide the medical team and encourage the secretarial team to include the date of follow-up if known.

**Abstract number:** P288

**Abstract type:** Poster

### **Training Palliative Care Teams to Improve Communication with Patients, Families, and Colleagues**

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Although palliative care is a team-based enterprise, few team members receive formal instruction on communication as part of their clinical training. In the United States,

care coordination and patient/family satisfaction impact reimbursement rates, placing more focus on the communication skills of providers. In an effort to improve patient-centered communication, we developed an interprofessional palliative care communication curriculum known by the acronym COMFORT. The curriculum was created for a two-day training course for implementing evidence-based communication skills into practice. Using the National Consensus Project's Clinical Practice Guidelines for Palliative Care, the curriculum was built by a team of interprofessional faculty. The COMFORT Curriculum for Palliative Care Teams includes teaching materials, training videos, and supplemental resources to integrate communication skills building into existing clinical settings. Hospital-based palliative care teams (2 providers from different disciplines) were competitively selected from across the state. Statewide interprofessional communication training took place with 30 palliative care teams (60 providers in total). Physicians, nurses, social workers, and chaplains rated the course as excellent with a mean score of 4.81 (on a scale of 1=poor to 5=excellent), found the course stimulating (4.91), and met expectations (4.76). At six months post-course, participants reported that they provided communication training to an additional 731 providers, mostly nurses (n=373). The module on family communication was rated as the most useful module for their practice (mean 8.78 out of 10). This statewide training provides healthcare professionals with education on team-based care and communication, developing the skills needed to integrate palliative care into hospital systems and improve access and services to patients and families. This project was funded by the Archstone Foundation.

**Abstract number:** P289

**Abstract type:** Poster

### **"Thank you All for Being Involved in my Life." How People Share their Experience of Terminal Illness Online: A Content Analysis of Youtube Videos**

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**Background:** During the last decade, social media has become mainstream in many areas, including healthcare. A large number of videos made by individuals who are facing a terminal prognosis are freely available online for anyone with internet access. These videos usually stay available online for years and can be watched freely,

raising some concerns amongst clinicians who may not be familiar with this phenomenon, and bringing new ethical challenges to the palliative care arena.

**Aims:** To conduct a qualitative analysis of how individuals share their experience of terminal illness through Youtube videos.

**Methods:** Content analysis was conducted exploring the testimonials of individuals who posted videos on Youtube. The videos were identified through a systematic review. Two independent researchers coded the data from each video and discussed the findings to minimise bias. Disagreements were discussed with a further two researchers until a consensus was found. Based on the codes and categories identified, a set of themes was defined.

**Results:** Themes identified through content analysis were around symptoms, treatment options (including complementary and alternative medicine), family support and emotional difficulties. Whilst a few individuals presented only a single video, many of them had created Youtube channels in which they posted several videos on a regular basis until death.

**Conclusion:** The qualitative content analysis of the videos offers a valuable insight into people's experiences of terminal illness. The intimate portrayal of patients' experiences in YouTube presents clinicians with a novel perspective, resource and challenge. We suggest a number of implications for clinicians, policy makers and researchers in order to increase awareness, and suggest strategies for clinicians who may be faced with patients watching these videos. Ethical implications are also discussed.

**Abstract number:** P290

**Abstract type:** Poster

#### **Unmet Informational Needs of Family Care-givers of People with Learning Disabilities who Require Palliative Care: A Literature Review**

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The worldwide population are living longer, and palliative diagnoses are increasing. This population includes people with learning disabilities (LD) who are often cared for by a family member. Health and Social Care services advocate involvement and support of family caregivers, notably in relation to the LD and palliative care fields as historically the LD terrain has been flawed with barriers and inequities. Despite this, European (EU) level literature shows inadequate support of family caregivers of people with LD.

The aim of this review was to explore the family caregiver role and establish what unmet informational needs

exist when meeting the demands of both LD and a palliative prognosis.

A systematic approach led by Aveyard (2014) utilising electronic databases, reference lists and suggested literature from policy and reports was employed. Key search terms were: family caregivers, intellectual/learning disability, palliative/end of life care and unmet/informational needs.

Literature findings on family caregivers revealed similar themes emerging from both the LD and palliative care studies. Lack of information and signposting to services and support was the overarching theme. This was regarding financial entitlements, respite, psychosocial support and educational guidance. The specific service and support needs are collated under the informational need blanket as it is all encompassing.

Root cause analysis identified poor partnership working between services and with the caregiver alongside a paucity of comprehensive carer's needs assessments. As a result caregivers report feeling unprepared, stressed, isolated and unsupported emotionally and financially. EU recommendations state a need for further research at the LD and palliative care interface in respect of family caregivers. Conclusively a gap has been exposed; no literature was identified explicitly researching the unmet informational needs of family caregivers of people with LD who require palliative care.

**Abstract number:** P291

**Abstract type:** Poster

#### **Advance Directives: Prevalence and Barriers in Patients with Advanced Cancer**

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**Background:** Patients with advance directives (ADs) are more likely to receive care in line with their preferences, receive less aggressive end-of-life care, and are less likely to die in hospital. Our aim in this survey of patients with advanced cancer was to identify factors associated with AD initiation and barriers to AD completion.

**Methods:** Patients with advanced solid tumour malignancy receiving palliative treatment at the Chemotherapy Day Unit, Princess Margaret Cancer Centre, Toronto, Canada, between September 2011 and May 2012, were approached for recruitment. They completed an onsite questionnaire about their demographics and ADs. Multivariate analyses

identified predictors of AD initiation. Electronic medical records were reviewed to detail cancer care and assess documentation of do-not-resuscitate (DNR) orders.

**Results:** 208 patients were enrolled, with 193 surveys available for analysis. Fifty-eight percent were female (112/193) and 52% (100/193) were  $\geq 60$  years old. Participants reported initiation of an AD in 106/193 (55%) of cases. ADs included a living will in 63/193 (33%), a power of attorney in 95/193 (49%), and a DNR order in 35/193 (18%). Medical record review identified documentation of the DNR order in 5/35 (14%) of cases. Multivariate analyses identified increasing age ( $p=0.0003$ ) and palliative care referral ( $p < 0.0001$ ) to be associated with AD initiation, while patients identified lack of knowledge of ADs as the strongest barrier to AD completion.

**Conclusion:** Although more than half of the patients surveyed had initiated an AD, lack of knowledge was reported as the greatest barrier to AD completion; palliative care referral was associated with increased AD initiation. Lack of AD documentation in medical records could prevent patients receiving care in line with their preferences. Education and timely palliative care referral may increase AD completion in this population.

**Funding source:** Ontario Ministry of Health and Long Term Care.

**Abstract number:** P292

**Abstract type:** Poster

### What Sticks? An Exploration of Students' Understanding of Hospice and Palliative Care a Year After an Education Session

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**Background/aims:** The catalyst for this research was witnessing patients' and families' fears around accessing specialist palliative care services and hearing them say they would have accessed services sooner if they had been more informed. Recent research indicates a lack of public awareness in relation to hospice and palliative care (McIlfatrick et al 2013). There are more than 360,000 secondary school-aged children in the Republic of Ireland (CSO 2012) so this was considered to be an ideal target audience to receive education about hospice and palliative care. The aim of this research is to evaluate the effectiveness of an educational session on hospice and palliative care delivered to secondary school students a year after the original delivery to extrapolate what information and understanding was retained.

**Methods:** Evaluative description qualitative study inviting students to fill out a questionnaire through Survey Monkey. The 268 students are now in 5th year and attended

an educational session delivered by the researcher in the last school year when they were transition year students.

**Results:** Students were invited to complete a pre-talk and post-talk questionnaire at the time of the education session. The results of those questionnaires demonstrated that students' knowledge and attitudes towards hospice and palliative care changed and improved. This research is designed to ascertain the level of retention, if any, in the next academic year, of the knowledge and attitudes gained by the students during the session. An additional question will explore whether students have shared the information, and with whom. This phase is commencing in November 2015 and will be completed in February 2016.

**Conclusion:** Preliminary results indicate that the education session had a positive impact on students' understanding of hospice and palliative care. The results of the next questionnaire will indicate the level of long-term retention of knowledge and attitudes gained.

**Abstract number:** P293

**Abstract type:** Poster

### How to Achieve Successful Implementation of Advance Care Planning (ACP) in Nursing Homes: A Rapid Review

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**Aim:** Despite growing evidence of the potential effectiveness of Advance Care Planning (ACP), important knowledge gaps remain regarding the process through which it can be successfully implemented. Using the Aspen Institute's Theory of Change, we aim to identify the *intermediate outcomes* required for successful ACP in nursing homes. Intermediate outcomes are defined as "building blocks of a change process", i.e. conditions that must be in place at different stages of the change process for long-term goals to be reached.

**Methods:** Rapid review. We searched four databases for empirical studies about ACP in nursing homes published between 2004-2015 and reviews concerning ACP in general. Two authors independently screened the studies. One author assessed quality and extracted and categorized data using thematic synthesis.

**Results:** We included 38 studies (13 qualitative, 6 quantitative, 1 mixed-method, 18 reviews) that identified more than 30 intermediate outcomes on different levels: resident, family, staff or facility. Most were facility level outcomes.

	Resident	Family	Staff	Facility
To have knowledge about ACP	X	X	X	
To be willing to participate in ACP	X	X		X
To be appropriately skilled as an ACP facilitator			X	
To conduct a series of ACP conversations	X	X	X	
To have a clear documentation, storage and retrieval system				X
To have a monitoring, feedback and reviewing system in place				X

[Identified intermediate outcomes]

The table shows the intermediate outcomes most frequently mentioned in high or medium quality studies.

**Conclusion:** We identified numerous intermediate outcomes to be achieved on four levels to successfully implement ACP in nursing homes. Our findings support the idea that a successful ACP intervention must consist of a whole-system approach in which the facility plays an important part. Building on this, we will develop a chronological framework of change to be used in the development and evaluation of ACP interventions in Belgian nursing homes.

**Funding:** Research Foundation-Flanders.

**Abstract number:** P294

**Abstract type:** Poster

### Oncologic Specialists and General Practitioners Use the Patient as Intermediary in End-of-Life Communication

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**Background:** Timely end-of-life (EOL) discussions between patients and physicians are considered essential for high-quality EOL care, but they frequently do not occur or occur late. In oncology, one barrier for timely EOL discussions is poor collaboration between oncologic specialists and general practitioners (GPs).

**Aim:** To explore interprofessional communication and coordination between oncologic specialists and GPs on EOL discussions and to analyze if this effects the practice of EOL discussions.

**Methods:** In-depth interviews were conducted with 16 GPs and 14 oncologic specialists. Purposive sampling was used to ensure maximum heterogeneity. Interviews were recorded, transcribed verbatim and analyzed using qualitative content analysis.

**Results:** In general, EOL discussions are mainly considered the role of the GP, but oncologic specialists vary about their own roles in discussing EOL issues. Interprofessional coordination on who discusses what and when is mostly absent. Interprofessional communication of EOL issues mostly proceeds using the patient as intermediary. This can function well as long as some conditions are met: proactivity of the GP in building a relationship with the patient and in initiating EOL issues; the oncologic specialist facilitating by being realistic to patients about prognosis and limits of treatment and informing the GP adequately. When these conditions are not met, EOL discussions might stay absent either due to lack of initiative by the GP or to lack of accessibility for such discussions by the patient.

**Conclusion:** If timely EOL discussions needs to be implemented into regular care, proactiveness of the individual GP and realistic communication about prognosis and treatment of the oncologic specialist are essential. Both professions should be aware of these conditions.

**Main source of funding:** Stichting Stoffels-Hornstra.

**Abstract number:** P295

**Abstract type:** Poster

### 'Having a Laugh': Cancer Patients' Use of Online Humour

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**Background:** Common public and health professional representations of cancer and end of life experiences are relentlessly depressing and gloomy. Yet somewhat surprisingly the majority of cancer patients are not depressed and manage to cope well with advanced disease. Theories of humour describe typologies and functional outcomes but little is known about how cancer patients use humour in online cancer contexts.

**Aims:**

1. How do cancer patients use humour during online exchanges?
2. What functions does humour use appear to have?

**Methods:** Drawing upon a secondary analysis of data from the project 'Metaphor in End-of-Life Care' (funded by the UK Economic and Social Research Council; grant number: ES/J007927/1; <http://ucrel.lancs.ac.uk/melc/>). Data included 500,000 words from cancer patients who contributed to public online cancer fora in the UK. Analysis involved quantitative and qualitative corpus linguistic methods to identify humorous discursive threads.

**Results:** Three (nonexclusive) types of humour use were identified:

- 1) 'gallows' humour which was self-disparaging ('laughing in the face of death');
- 2) socially taboo humour ('bum' or 'toilet' humour) specifically adopted by a patient group with colorectal cancer; and
- 3) group specific humour which promoted social cohesion and group identity; Humour took the form of teasing, anecdotes and fantasy scenarios.

For example, mutual support was engendered by asking for advice and sharing difficult or embarrassing experiences.

**Conclusions:** Humorous and serious content was found to be interwoven. Although it perhaps takes insider knowledge to identify humour, it appears to function to promote group solidarity and mutual support, and for individuals enhances coping, and potentially offers empowerment in the face of adversity. Joking and laughing about their cancer helps patients turn serious, threatening and unpredictable experiences into objects of non-serious play and thereby reducing their psychological impact.

**Abstract number:** P296

**Abstract type:** Poster

**Advance Care Planning and Advance Healthcare Directives with People with Dementia**

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**Aim:** Dementia is a progressive life limiting illness. People with dementia value planning ahead as it allows them to express wishes and preferences, put affairs in order, reduce anxiety and help family members to know wishes and preferences for the future. Additionally healthcare staff are often uncertain and lack confidence with regard to carrying out advance care planning and use advance healthcare directives. The aim of this work is to develop guidance in relation to advance care planning and advance healthcare directives with people with dementia based on literature review findings.

**Methods:** A systematic literature review was completed by searching the online databases of CINAHL and PubMed. Grey literature was also accessed. The literature was reviewed and four themes identified. These themes directed the scope of the guidance.

**Results:** The themes from the literature include:

1. Advance Care Planning & Advance Healthcare Directives with People with Dementia  
Advance care planning is difficult to engage in due to fluctuating capacity
2. Decision Making assistants, co-decision makers and representatives  
Proposed legislation outlines these 3 levels of decision making assistant and guidance about these roles is required.
3. Professional Uncertainty  
Time constraints, lack of knowledge and understanding of dementia, advance care planning and legal responsibilities are factors.
4. Advance Care planning tools

**Conclusion:** Guidance for use in all care settings will be developed based on the above themes.

**Abstract number:** P297

**Abstract type:** Poster

**Physicians' Experience and Expectation on Prognostication in Palliative Care. A Qualitative Approach in South Korea**

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**Background:** Prognostication is the one of most challenging tasks for physicians in palliative care. Although there have been many prognostic scores for palliative care providing useful information, prognostication is still difficult because of its uncertainty. Little is known about what physicians' experience and expectation for prognostication in their daily practices in Oriental countries.

**Aim:** To explore palliative physicians' experience and expectation on prognostication.

**Design:** Qualitative study using semi-structured individual interviews which were analyzed using a constant comparative method.

**Participants:** Convenience sample of 11 attending palliative physicians, 4 oncologists and 7 family physicians in South Korea from May to July in 2015.

**Results:** Four areas were discussed.

- 1) Importance of prognostication: All physicians agreed that prognostication is essential in palliative care. The reasons were categorized into three groups as follows:
  - i) to help patients and their families prepare death,
  - ii) to decide appropriate treatments,
  - iii) to facilitate communication with patients and their families on dying and death.
- 2) Difficulties in prognostication: Physicians experienced that inaccuracy is an inevitable aspect of prognostication. They felt uncomfortable to predict the final days because there were lack of prognostic factors for one week's survival.
- 3) Basis of prognostication: Most physicians used various prognostic tools such as clinical signs, clinical prediction of survival, and prognostic scores.
- 4) Future expectation for prognostication: Physicians hoped simple and accurate indicators to predict the final days.

**Conclusions:** Korean palliative physicians fully recognized the importance of prognostication. In practices, they regarded the prognostication as a meaningful method to enhance communication with patients and their families for the end-of-life care. Simple and accurate factors are needed for prognosticating the final days.

**Abstract number:** P298

**Abstract type:** Poster

### Who Really Makes the Decisions? A Survey Examining Decision-making Preferences and Associated Factors in Hospitalised Older Adults

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**Background:** Most decision-making studies in palliative care research focus on the doctor-patient relationship. An examination of who patients would like to share decisions with more broadly is lacking.

**Aims:** To examine patients' preferences for whom to involve in shared decision-making, including associated factors concerning the involvement of doctors.

**Methods:** A face-to-face survey conducted with older patients ( $\geq 65$  years) in the UK and the Republic of Ireland during 2012-2014. Chi-square tests for categorical data and Kendall's tau-b tests for ordinal data were used, and regression as required.

**Results:** Of 215 patients approached, 140 completed the survey (65%) and 122 answered the preference question. Most survey respondents were white (92%), female (46%), had cancer (86%), were educated to secondary level 78%), and were comfortable or coping on their income (83%). Most preferred shared decision-making ( $n=90/122$ , 74%), and, of these, half wanted more than one other person involved in making their decisions ( $n=45$ , 50%). The majority preferred that relatives other than their spouse or partner be involved ( $n=63$ , 70%), and a large minority preferred that their spouse or partner be involved ( $n=40$ , 44%). Nearly one in three wanted a doctor involved in their decision-making ( $n=27$ , 30%). Patients with a primary carer were less likely to want to a doctor involved in their shared decision-making, compared to patients without a primary carer  $\chi^2(1) = 4.286$ ,  $p < .05$ . Analysis revealed little difference across countries.

**Conclusions:** A distributed model of decision-making, in which decision-making is distributed across a range of people, is preferred by patients receiving palliative care. The doctor-patient dyad may form part of this. Preferences for the involvement of doctors may have been previously over-estimated due to not asking patients who they would like to share decision-making with more broadly.

**Funders:** The Atlantic Philanthropies, Cicely Saunders International, CLAHRC.

**Abstract number:** P299

**Abstract type:** Poster

### Primary Care Staff Knowledge of CPR Survival Rates

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**Background/aims:** There is an ongoing push for primary care staff in the UK to implement Advance Care Plans for terminally and chronically ill patients, including DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) orders as appropriate. Recent UK legal judgements have underlined the importance of involving patients or families, and also established the ‘prudent patient’ approach to informed consent.

Studies in secondary care have demonstrated poor staff (as well as patient) knowledge of CPR survival rates. This study investigates primary care staff knowledge of CPR survival rates: this is important if patients and their families are to be informed and involved in DNACPR orders.

**Methods:** A forced-choice questionnaire was administered to primary care staff attending relevant educational events and via service providers in a London borough.

The questionnaire asked about responsibility for DNACPR orders and other more contextualised resuscitation decisions. It also asked about perceived survival rates in out-of-hospital, and in-hospital CPR; including in patients aged over 70, and in those with advanced cancer.

**Results:** Very few primary care staff in this survey accurately estimated CPR survival rates: there were substantial under- and over-estimates, for all patient ages. Most staff have signed off five or less DNACPR orders. Those who have signed more did not always have more accurate knowledge about survival rates.

**Conclusions:** If ‘prudent’ primary care patients are going to be able to fully embrace the new approach to consent, they need to know more about the outcomes of CPR, especially out-of-hospital. It must therefore be of concern that so many primary care staff had such limited knowledge about CPR survival rates. Both under- and over-estimates may inappropriately influence decision-making.

The upcoming UK national approach considers decisions about CPR within overall goals of care, but may produce new gaps in knowledge for primary care staff.

**Abstract number:** P300

**Abstract type:** Poster

### Delphi Study and White Paper Defining Optimal Advance Care Planning (ACP): Results from the EAPC Taskforce

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**Aims:** ACP is increasingly implemented but its concept and content vary considerable and are often not evidence-based. We aimed to develop a definition of and recommendations for ACP, supported by scientific evidence and expert opinion, and appropriate to a variety of cultural values.

**Methods:** Systematic consensus was searched through a 3 round Delphi study. In round 1, which was qualitative, 11 experts from 5 countries established a draft definition and core domains in a two-day invited expert meeting. Subsequently, 33 draft recommendations were formulated pertaining to recommended core elements of ACP, roles and tasks, timing, regulation, and outcome measures. The recommendations were based on 41 identified literature reviews, additional literature searches, and expert opinion. Round 2 and 3 of the Delphi study concerned an online survey, asking respondents to indicate their agreement with our ACP definition and the 33 recommendations on a 7-point scale (1 indicating strongly agree; 7 indicating strongly disagree); qualitative comments could be added.

**Results:** In round 2, the survey was completed by 102 of 140 addressed experts (response 71%) from 14 countries, including physicians, nurses, psychologists, ethicists, scientists, policy makers, and patient representatives. For 25 of the 33 recommendations, there was immediate agreement, indicated as a mean score of  $\leq 1.8$ . The qualitative comments of the experts will be used to adapt all recommendations and potentially add new ones. In round 3 the adapted set of recommendations will be re-evaluated by the expert panel. The final results are ready to be presented, for the first time, at the EAPC conference in Dublin.

**Conclusion:** Reaching consensus on a definition of and recommendations for ACP in a panel of experts with varying professional and cultural backgrounds seems feasible. The ultimate ACP framework, based on evidence and consensus, can provide guidance for clinical practice, policy and research.

**Abstract number:** P301

**Abstract type:** Poster

### The ‘Message’ of Palliative Care in the Spanish TV and Radio. A Mix-method Analysis

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**Background:** Mass media are the main agent in the process of building public opinion. Often Palliative Care (PC) appears in television (TV) and radio (RD) programs contributing to build its image and social perception.

**Aims:** To explore and describe the circulating ideas and messages about PC in the Spanish TV and RD.

**Methods:** The five main Spanish open-access TVs (TVE; Tele5, Cuatro; Antena3; La Sexta) and the main four RDs (RNE; SER; Onda 0; COPE) were selected. The terms “palliative care” and “palliative medicine” were introduced into the search tool of each media website, looking for all broadcasted programs between 2009 and 2014. Two analysis on the collected information were performed:

- 1) quantitative analysis through a questionnaire;
- 2) qualitative content analysis.

**Results:** 31 results were identified in TV and 114 in RD. After identifying duplicates and programs where search terms were used in a figurative way unconnected with the study's aim, 28 were selected from TV and 23 from RD. Nearly all documents identified had an informative approach (TV=96%, RD=87%), where opinion and subjective interpretations related to PC were common (TV=68%, RD=70%) addressing the general public. Most of the documents include PC professional testimonies (TV=64%, RD=74%). In TV, relatives and patient testimonies are frequent (39% and 36%, respectively). Nearly half of the RD documents (52%) include testimonies from politicians, being lower in TV (25%). Qualitative analysis showed how TV provides a positive PC image seeking its own promotion and diffusion. Due to RD's nature, where talk shows and live programs are frequent, PC is dealt analytically explaining themes in depth and with a claiming approach.

**Conclusions:** There is a substantial presence of PC in Spanish TV and RD, but sometimes it is named figuratively. Ideas and messages associated with PC in TV and RD are related with the need of explaining and promoting PC, what could reflect a poor social awareness about PC.

**Abstract number:** P302

**Abstract type:** Poster

### In the Loop? Audit of Hospital Discharge Letters for Patients with Palliative Care Needs

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**Background:** It is often during a hospital admission that a patient is first identified as having palliative care (PC) needs. The hospital discharge letter (HDL) is crucial in conveying this to primary care and other teams. If done badly, this may impact on the patient's care and transition between healthcare settings. This audit aims to establish baseline data regarding the quality of HDLs for PC patients from the local hospital.

**Method:** A retrospective audit was undertaken of 50 consecutive HDLs (to home, hospice or other hospital) in 2014 for an inpatient stay when the patient was first referred to the hospital liaison PC team. 11 locally agreed standards assessing key information were developed against which the HDLs were evaluated.

**Results:** Patients were under the care of various specialties. 90% had advanced cancer. All HDLs documented diagnosis and 70% identified PC needs. Almost half of the HDLs had information about current symptoms. 50% stated whether or not PC follow up was planned. 44% detailed anticipatory medications, but only 8% had a plan for these. A quarter of HDLs relayed the patient's and/or family's understanding of diagnosis. Only 18% of HDLs documented the patient's understanding of prognosis and 8% documented that of the family. 8% stated the patient's preferred place for end of life care. 84% had no documentation of resuscitation status. Only half of the HDLs documenting resuscitation status relayed patient/family's understanding of this.

**Conclusion:** This audit has highlighted that HDLs for PC patients need to improve. Most HDLs identify that patients have PC needs, but are particularly deficient in terms of documenting what patients and families understand, their future care preferences and resuscitation decisions. It may not be possible or appropriate to clarify these issues during a single admission, but documentation of that in itself would be useful. Reaudit is planned once a PC HDL template and/or discharge policy/protocol is in place.

**Abstract number:** P303

**Abstract type:** Poster

### How to Create an ICT System for Palliative Care: Methods for User Involvement during Design and Development

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**Background:** Information and communication technology (ICT) is emerging as a mode for delivering new and enhanced models of palliative care. Different ICT interventions are being developed, but methods for involving palliative care patients and health professionals are not

well reported. Increased reporting of methods for user involvement across all stages of development can encourage ICT systems that target needs and requirements of patients and clinicians. We present the user involvement approach taken for an ICT system to support routine pain monitoring in community-based palliative care patients.

**Method:** The ICT system was designed to facilitate two-way communication between patients and health professionals; consideration of both users' perspectives was essential. Qualitative interviews and web surveys provided rich data to inform early, exploratory work, which was paired with a usability method called 'think-aloud protocol', taken from the research field of human-computer interaction.

**Results:** Early qualitative work with patients (n = 20) and health professionals (n=105) provided key information on i) how patients interact with palliative care services, ii) how health professionals assess pain, and iii) the acceptability of ICT interventions for both groups. This led to the generation of a list of system specifications, written in lay language, which supported discussions and decision making around system requirements between social scientists, health professionals and developers. Following prototype development, the 'think-aloud protocol' generated data on system usability issues.

**Conclusion:** A structured approach to user involvement in ICT system development in palliative care can generate rich and meaningful data to drive design. Consideration of how to communicate findings with developers is an essential component of this process. Methods available from other research disciplines can be utilised to supply valuable information to inform system development.

## Palliative care in specific groups

**Abstract number:** P305

**Abstract type:** Poster

### Research and Education of Cultural Competence in Hospice and Palliative Care

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The need for support from hospice and palliative care (HPC) services by minority ethnic groups is increasing in Germany. In Stuttgart for example in 2014, 42,2% of registered inhabitants had a migration background compared to 37,2% in 2000. A review of international literature revealed the lack of cultural competence by the HPC providers as one of the main problems.

This paper seeks to address the question of what are the main cultural competences in HPC for those working in Germany today, and whether these competencies can be developed into a training program for HPC staff.

Qualitative methodology using Grounded theory was used to explore cultural competences. Data was collected from seven interviews and one focus group. The interviews explored the experience of those working in HPC services from different disciplines, as well as one patient with Arabian ethnicity and one relative of a deceased patient from an African background. The focus group consisted of a HPC service team who were caring for an Asian migrant.

Core competencies emerged from the qualitative data and related to personal skills (perception, openness and empathy), teamworking skills (exchange of information and people-centered care) and skills in the interactions with carers and patients (communication, relationship building). The results were used to develop a training program for HPC staff. Evaluation of a pilot workshop showed that the training of a trans-cultural attitude, which focuses on building human relationships beyond cultural differences, was the most important skill for the participants.

The research was conducted only at one place in Germany with limited participants. Nevertheless the study and the workshop showed, that an education for cultural competence should have primarily the goal to encourage palliative care specialists to overcome the distance to people with an unfamiliar cultural background.

This research project was part of the EUPCA.

**Abstract number:** P306

**Abstract type:** Poster

### Whose Priorities? An Ethnographic Exploration of Recognising Needs in Dying Older People in the Acute Hospital Setting

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**Background:** Older people with comorbidities spend a significant proportion of their last year of life in acute hospital settings, with many actually dying there. However end of life care in this environment is frequently reported as being of poor quality. In order to improve care we need to understand the patient experience, but this has traditionally been a challenging area to research.

**Aim:** To investigate prioritization of needs in dying older people in acute hospitals

**Methods:** This study reports on an ethnographic observational research project undertaken in 2015 in an acute care of the elderly ward in the UK. 186 hours of observations of clinical practice were undertaken, producing over 97,000 words of field notes. From these, experiences of 16 patients with multiple comorbidities were extracted, examining contrasting narratives between patients, families, and members of the multiprofessional team.

**Analysis:** Data is being analysed using NVivo, drawing out individual narratives as well as overarching themes.

**Results:** The analysis highlights fundamental differences in understanding within and between participant groups. Early themes include:

- Contrasting health professional goals in relation to withholding and withdrawing treatments
- Defensive practice and risk aversion prioritised over compassion
- Over-treatment of patients with complex comorbidities leading to late recognition of dying
- Under-estimation of family and patient understanding of prognosis
- Structural changes in hospital management (post-Francis) impact on perception and monitoring of care quality

**Conclusion:** Findings demonstrate differences in priorities within and between health professionals, patients and families, with implications for understanding how and why things can go wrong. This is essential if interventions and education are to be grounded in real life clinical practice. The patient narratives offer powerful and vivid examples of these tensions and challenges.

**Abstract number:** P307

**Abstract type:** Poster

### Clinical Characteristics that Influence Therapeutic and Diagnosis Procedures in Terminally Ill Patients in Nursing Homes

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**Aim:** To determine which clinical characteristics influence in the number of therapeutic and diagnostic procedures implemented in nursing homes terminally ill patients, and in the use of ER services.

**Methods:** Descriptive cross-sectional study. Terminally ill patients of 12 nursing homes of Granada (Spain) were followed-up by nurses during 3 months. Inclusion criteria for professionals were; work full time in the nursing homes for at least 6 months. To identify the terminally ill patients SECPAL criteria were used. Professionals were asked fill one questionnaire each month.

**Results:** 64 patients were followed up during 3 months. 10,9% died during the follow-up. Average age was 83 years

(SD=7,6), 60,9% of them were women. In relation to the disease, 54% had dementia, 22% heart failure, 15% cancer, 5% hepatic failure, and 4%, renal failure. 28,1% patients were rated as high comorbidity. The most frequent therapeutic procedures were; antibiotic prescription (24,3%), aerosols (17,9%) and peripheral venous catheter (17,3%). Nasogastric tube, enteral nutrition and aspiration were used only in dementia patients. No differences in the use of therapeutic procedures were found between patients with low or high comorbidity index. The most frequent diagnosis procedures were blood tests (20,5%), and urinary tests (16%). X-Ray ( $p=0,02$ ), blood test ( $p=0,00$ ), and ECG ( $p=0,01$ ) were used more frequently in patients with high comorbidity. No differences were found regarding diagnosis procedures in relation to cognitive impairment or disease. 42,2% patients were assisted by ER services, and 18 (28,1%) were hospitalized. Cognitive impaired patients were hospitalized more frequently than other patients ( $p=0,37$ ).

**Conclusion:** Cognitive impairment and comorbidity influence in the use of diagnosis and therapeutic procedures. Further studies must deepen in why dementia patients undergo a greater number of therapeutic procedures and hospitalizations.

**Abstract number:** P308

**Abstract type:** Poster

### A Systematic Review of Prognostic Factors in the Final Three Months of Life for People with a Haematological Malignancy

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**Aim:** The aim of this review was to identify 'bedside' prognostic factors associated with increased mortality in the final three months of life for people with a hematological malignancy.

**Methods:** A systematic review of the literature was performed across: PubMed; CINAHL; PsycINFO; and the Cochrane Library with inclusion criteria:

- 1) prognostic cohort studies;
- 2) published 2004-2014;
- 3) sample  $\geq 18$  years;
- 4)  $>50\%$  sample had a hematological malignancy;
- 5) reported 'bedside' prognostic factors;

- 6) median survival of < 3 months; and
- 7) English language.

**Keywords included:** haematological malignancy; prognostic factors; and end of life.

**Results:** The search returned 4,860 studies of which 28 met inclusion criteria. Critical appraisal was performed using the Quality in Prognostic Studies Tool. Most studies were set in the intensive care unit (n=24/28) and were retrospective (n=25/28). Forty 'bedside' prognostic factors were identified in the following broad categories:

- 1) demographics;
- 2) physiological complications or condition;
- 3) disease characteristics;
- 4) laboratory blood values; and
- 5) interventions.

The most commonly reported factors in univariate and multivariable analyses included: mechanical ventilation; vasopressor support; sepsis/infection; older age; haemodynamic instability; elevated liver enzymes; multi-organ failure; respiratory distress; and elevated urea/urea. Performance status, symptom burden, anorexia-cachexia syndrome, quality of life, multi-morbidity and clinician judgement were not tested in any study.

**Conclusion:** This review has identified factors that are useful for prognosticating for people with a hematological malignancy who have deteriorated and have been admitted to the intensive care unit. There is an urgent need for research that will identify people at risk of dying prior to acute deterioration, in a range of settings.

**Abstract number:** P309

**Abstract type:** Poster

### Any Old Disease: Do Older People with Cancer Receive Different End-of-Life Care than those Without?

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**Background:** Palliative care has traditionally focused on people with cancer, but the majority of older people will die from other causes. This research investigates differences in end-of-life care between older people who died with or without cancer in Belgium.

**Method:** Nationwide representative mortality follow-back study among GPs, who filled in a weekly questionnaire

and follow-up questionnaires regarding all their patients who died. The study included people who died non-suddenly over the age of 75 (n=1662) in 2009 and 2010.

**Results:** Of people 75 or older, 22% died with cancer. Older people who died without cancer more often lived in a care home (38%) and more often had severe dementia (23%) than older people who died with cancer (14% and 5% respectively). Controlled for these differences, having a palliative treatment goal during the last 3 months of life was more common among older people with cancer (up to 93%) than among older people without cancer (up to 77%), whereas curative or life prolonging treatment goals were less common among older people with cancer. The GP was more often aware of preference for a place of death (51%; OR=1.94, 95%CI=1.47-2.55), preference for medical treatment(s) at the end of life (35%; OR=2.02, 95%CI=1.52-2.67), or preference for a proxy decision maker (20%; OR=1.57, 95%CI=1.32-2.18) for people with cancer than people without cancer (34%, 18% and 13% respectively). Communication between GP and patient regarding diagnosis, possible complications and physical, psychological, social or spiritual problems was more common among older people with cancer than older people without cancer.

**Conclusion:** Compared with older people without cancer, GPs of older people with cancer recognize different treatment goals for them and communicate more with them. These results suggest cancer is an important trigger, also for older people, to communicate about care at the end of life and to initiate palliative care.

**Funding:** Flemish League against Cancer.

**Abstract number:** P310

**Abstract type:** Poster

### Symptom Prevalence and Quality of Life of Advanced Dementia Patients in a Homecare Setting: A Prospective Cross-sectional Study

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**Background:** Dementia prevalence is expected to increase with an ageing population. Patients become increasingly dependent as dementia progresses. Many spend their last days in institutions due to the burden of care. Advanced dementia (AD) is a terminal illness requiring palliative care. A home hospice programme allows them to be cared for in a place which is familiar and comfortable for them. This study aims to investigate the symptom prevalence of AD patients living at home and factors affecting their quality of life (QOL).

**Methods:** Patients at FAST© (Functional Assessment Staging Test) Stage 7A and beyond with one of the following: hypoalbuminemia (< 35g/L), feeding tube, or pneumonia were recruited and followed up. Patients' demographics and medical histories were obtained from medical health records. The Pain Assessment in Advanced Dementia Scale (PAINAD), Neuropsychiatric Inventory Questionnaire (NPI-Q) and Quality of Life in Late Stage Dementia Scale (QUALID) were administered on the first home visit.

**Results:** Pain was present in 67.5% while challenging neuropsychiatric behaviours were noted in 75.3% of patients (n=77). NPI-Q severity correlated moderately with QUALID ( $r=0.36$ ,  $p<0.05$ ). Patients with lower albumin levels had significantly higher median NPI-Q scores (Median=3, n=65) than those with albumin >35g/L (Median=0.5, n=10),  $p<0.05$ .

**Conclusion:** Pain and neuropsychiatric behaviours were prevalent in our patients. Patients with severe neuropsychiatric behaviours were more likely to have lower albumin levels as behaviours such as depression may lead to loss of appetite. Consequently, they may be perceived as having low QOL. Home palliative care may address the high symptom burden and improve their QOL. Limitations include administration of QUALID to family instead of patients, and interviewer bias when scales need to be translated and administered by different healthcare professionals.

**Acknowledgements:** This study is funded by Temasek Cares.

**Abstract number:** P311

**Abstract type:** Poster

### What Do Previously Homeless People in London, UK, Think about Advance Care Planning (ACP) and End of Life Care (EOLC)? A Qualitative Investigation

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**Background:** The mean age of death of homeless people in the UK is 47, and many die with complex unaddressed needs, frequently complicated by substance misuse. However, little

research has explored the thoughts or personal experiences of homeless people regarding end of life care (EOLC) or advance care planning (ACP).

**Methods:** As the first stage of a wider study, we conducted semi-structured interviews and focus groups with people with past experience of homelessness, exploring their own thoughts and experiences, their perceptions of the experiences of other homeless people, and the implications for care and support of currently homeless people, particularly those with substance misuse issues, who consequently risk death related to liver disease.

**Results:** We interviewed eight people with personal experience of homelessness, all currently working with homeless people in London. Five then took part in a focus group. While recognising the potential value of ACP, most participants, similarly to the general population, did not wish to think about it while the need was perceived as still hypothetical. Instead, they preferred to focus on hope and keeping optimistic that people with liver disease, even when seriously ill, would recover and not die. Their main concern was that professional caregivers, rather than offering ACP to specific individuals, should persevere with providing ongoing compassionate care to all homeless people. They suggested this would enable the development of trust over time, which they saw as a prerequisite for initiating any discussion of EOLC or ACP.

**Conclusions:** Homeless people may be considered more vulnerable and more in need of ACP than the wider population. However, our previously homeless interviewees thought that homeless people primarily need compassionate care and support, not ACP discussions, unless the end of life is extremely pressing. Ongoing caring relationships may build trust and so facilitate broaching EOL issues with homeless people.

**Abstract number:** P312

**Abstract type:** Poster

### Palliative Care in the Context of Services for Children with Neurodevelopmental Disabilities and Their Families: A Delphi Study

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**Background:** Overlap exists between the care required by children with a life-limiting illness and children with complex disabilities. The needs of children with life limiting neurodevelopmental disabilities (LLND) and their families require consideration to enable the appropriate delivery of care. Palliative care is well positioned to contribute to services.

**Aim:** This study explored service providers' perspectives of services, including palliative care, for children with LLND and their families.

**Study population:** Participants were expert professionals with no less than five years' experience in paediatric, intellectual disability and/or palliative care. Thirteen participants were sampled from across these areas, including statutory, voluntary and charity organisations.

**Study design/methods:** A Delphi design was employed with three questionnaire iterations, and respondents were provided with information between rounds. The questionnaires examined the goals of care for children with LLND and changes which would improve care.

**Analysis:** Scores from previous rounds were provided, with agreement expressed as a median (threshold = 80%) and consensus reported as interquartile ranges. Non-parametric tests were used to measure stability.

**Results:** The primary goals of care for children with LLND disabilities and their family included achievement of the child's full potential, optimum symptom management and home based care. The most important changes to services included a single care plan for use across all services, greater coordination and integration of the services, and specialist paediatric palliative care when required.

**Conclusion:** This study highlighted high agreement on the goals of care for children with LLND and their families, with less consensus regarding the changes required to current services. There was evidence of the contribution of palliative care in this context, though future research is needed to further examine these issues.

**Abstract number:** P313

**Abstract type:** Poster

### High Symptom Burden and Low Functional Status in the Setting of Multimorbidity

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**Aims:** We sought to enhance understanding of the relationship between diagnosis, multimorbidity, symptom burden and functional status.

**Methods:** Secondary analysis of baseline data from a trial conducted in the Palliative Care Research Cooperative Group (PCRC). Eligibility criteria: adults with life-limiting illness on statin for  $\geq 3$  months, life expectancy  $>1$  month, declining functional status. Cancer diagnosis= solid organ and hematologic malignancies; multimorbidity= $>2$  on Charlson Comorbidity Index (CCI); high symptom (sx) burden= a) number of sx with a severity score  $>4$

and b) any score  $> 7$  on Edmonton Symptom Assessment Scale (ESAS); functional status measured by Australia-modified Karnofsky Performance Scale (AKPS). Group differences were tested with a t-test; multivariate regression analysis was used to determine effect of multiple variables on AKPS and on sx burden.

**Results:** Of 381 patients, 51% had a primary diagnosis of cancer, mean age 74.1 years (SD 11.6). Patients had multiple comorbid illnesses (mean CCI=4.9 (SD 2.8)), multiple sx (mean 9-item ESAS score=27.2 (SD 15.9)) and reduced functional status (mean AKPS=53 (SD 13)). The most common non-cancer comorbid illnesses were chronic obstructive pulmonary disease (32%), congestive heart failure (26%) and cardiovascular disease (22%). In both univariate and multivariate analyses, multimorbidity was associated with sx burden (4.2 vs.3.1 moderate or severe sx ( $p=0.003$ ); 12% vs. 6% with severe sx ( $p< 0.001$ );  $F= 7.0$ ,  $p=0.008$ ), while cancer diagnosis was not (4.1 vs. 3.8 moderate or severe sx ( $p=0.42$ ); 10% vs. 11% with severe sx ( $p=0.96$ );  $F= 1.19$ ,  $p=0.28$ ). In both univariate and multivariate analyses, sx burden was associated with functional status ( $F = 11.6$ ,  $p< 0.001$ ) while multimorbidity was not.

**Conclusions:** Sx cannot be attributed solely to a diagnosis of cancer. The association between sx burden and functional status underscores the importance of meticulous attention to sx in patients with multimorbidity.

**Abstract number:** P314

**Abstract type:** Poster

### Symptom Relief during the Last Week of Life among Patients with Heart Failure - A Registry Study

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**Background:** Cardiovascular disease is the most common cause of death in Europe and heart failure is the final common stage of many diseases of the heart. Patients with heart failure experience symptoms as severe and distressing as those of cancer patients. Still, they do not have equal access to palliative care.

**Aim:** The aim was to describe symptom relief during the last week of life among patients with heart failure.

**Methods:** Data was retrieved from the Swedish Register of Palliative Care, for deaths occurring 2011 and 2012 (n=3981). During this period, the register covered 58% of all deaths in Sweden. Inclusion criteria were; heart failure as underlying cause of an expected death (ICD-10 codes I50.0, I50.1 & I50.9) and for patients 18 years or older. Variables about symptom experiences and assessments were described using univariate statistics.

**Results:** Symptom relief was most prominent for pain and anxiety. Still, 25% and 38% respectively, of the patients had only partial or no symptom relief during the last week of life. Poorer relief was found for patients with shortness of breath, nausea and respiratory tract secretions. More than half of these patients (61%, 58% and 55% respectively) were partly or not relieved. Poorest symptom relief was shown for patients with confusion: 85 % were partly or not relieved. Validated self-rating scales were seldom used to assess symptoms, pain was more often assessed (12%) than other symptoms (8%).

**Conclusions:** The findings indicate that symptom control needs to be improved in end of life care of patients with heart failure. Structured clinical use of symptom rating scales can be one way to reach a better symptom control.

**Abstract number:** P315

**Abstract type:** Poster

### Exploring Patients' Interest in Complementary Therapies during their Inpatient Stay in a Specialist Palliative Care Unit

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**Background:** The use of complementary therapy has become increasingly integrated into Specialist Palliative Care Units (SPCUs), however, few studies have explored patients' interest in this.

**Aim:** To evaluate patients' interest in and experience of complementary therapies during their inpatient stay in a SPCU.

**Methodology:** All 179 patients admitted to the SPCU over the 3 month period January - March 2015 were assessed on admission. Those deemed suitable to participate by the researcher / Clinical Nurse Specialist were invited to participate in this ethically-approved research project. Details of the study were explained by a researcher / Clinical Nurse Specialist and written informed consent was obtained. A standardised paper questionnaire was completed by participating patients and this information was later transferred to an electronic database for storage and analysis.

**Findings:** Seventy-one patients (40%) completed the study of which only 27% had previous experience of using complementary therapies in the past 12 months. Sixty percent were deemed unsuitable to participate because they were imminently dying, had significant cognitive failure or had major communication / language difficulties. The age profile and diagnostic groups in the study were representative of the typical SPCU population. The majority (52%) were 'very interested' in receiving complementary therapy, whilst 13% reported having 'no interest'. Massage and reflexology were identified as the most popular forms of complementary therapy. The primary anticipated benefits associated with complementary therapy were relaxation and improvement in general wellbeing.

**Conclusion:** This research has indicated a high level of interest in complementary therapies in the study population.

**Abstract number:** P316

**Abstract type:** Poster

### The Harsh Realities of the Patient Journey: A Pilot Study of Patients and Carers Experiences and Reflections of Advanced Head and Neck Cancer

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**Background:** Advanced head and neck cancer (AdvHNC) patients frequently experience treatment side-effects which may manifest as physical and/or psychological distress. Similar symptoms can be experienced by carers and relate to being unprepared for the care-giving responsibilities.

**Aim:** To explore patients and carers experiences relating to treatment intent (curative v. palliative) and outcome to assist future decision making for cases of AdvHNC.

**Methods:** AdvHNC patients and their carers were invited to participate. Semi-structured interviews (patients n-7, carers n-5 and 1 joint-patient/carers) detailing treatment decision making, treatment outcome and management of care were digitally-recorded and transcribed verbatim. Content analysis was conducted to identify key themes.

**Results:** Analysis identified 4 key themes:

1. Decision-making - treatment received was deemed to be the only option though neither patients nor carers were prepared for its severity and would re-consider options available should the cancer re-occur.

2. Timely information - wealth of information available if you knew where to look or who to ask.
3. The harsh realities of the patient journey - practicalities of travelling for treatment, time spent waiting for treatment to be completed, and concerns over weight loss were expressed concerns.
4. Establishing effective support systems - inadequacies of local services resulted in patients being unable to gain necessary assistance; support services concentrated on patients and offered insufficient support and advice to carers who became inadvertent managers of care.

**Conclusions:** Patients and carers highlighted that additional support is essential to provide both emotional and practical assistance, especially for carers who are not prepared for such a challenging role. Although survival was key priority, effective communication to understand disease severity and support decision-making is essential.

**Abstract number:** P317

**Abstract type:** Poster

#### **Hospice Management of Tracheostomy Ventilated Motor Neuron Disease Patients: A Questionnaire Study**

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**Background:** In the UK and Ireland a small but increasing number of patients with motor neurone disease (MND) are managed using long term tracheostomy ventilation (TV). Due to the symptom burden and progressive nature of MND, the National Institute for Health and Clinical Excellence recommends specialist palliative care input is available to all patients. TV MND patients require highly specialised medical and nursing care which may be beyond the remit of inpatient palliative care units. Despite this there is a dearth of research relating to the support of such patients in the palliative care setting.

#### **Aims:**

- (1) To shed light on UK and Irish hospice experience of managing MND patients using assisted ventilation, including the withdrawal of TV.
- (2) To highlight factors that prohibit the admission of MND patients on tracheostomy ventilation to hospices.
- (3) Finally, to describe the experience of senior palliative care physicians in managing this patient group.

**Methods:** An electronic questionnaire will be sent to approximately 180 medical directors of hospices/specialist

palliative care units across UK and Ireland. Hospices were identified using the UK and Irish hospice directories. The questionnaire has been developed on the basis of a literature review and the experience of two palliative medicine consultants and has been piloted with 5 palliative care consultants. The questionnaire includes 23 items which broadly relate to three themes: Hospice policy for admission and management of tracheostomy ventilated MND patients; the relevant experience of senior palliative medicine physicians; and demographic data.

**Results:** Results of the questionnaire will be presented. Data relating to both admission experience of hospices and experience of individual hospice medical directors in managing TV MND patients, will be presented.

**Abstract number:** P318

**Abstract type:** Poster

#### **Ensuring Adequate Care for Frail Older People in General Practice - A Focus Group Study on General Practitioners', Nurses', and Medical Assistants' Perspectives**

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**Background:** In general practice, end-of-life care for frail older people is an increasingly important responsibility. Thoughtful approaches are needed to ensure that frail older persons' wishes are respected, and to avoid undesirable interventions in the last phase of their lives.

**Aim:** To gain insights into nurses', general practitioners' (GPs), and medical assistants' perspectives on the needs and challenges in the care for frail older people at the end of their lives.

**Methods:** Three mono-professional focus groups were conducted with nursing experts (n=11), GPs (n=5), and medical assistants (n=6) in 2014. The discussion guide included: enhancing older people's resources; continuity of care; collaboration and networking; proactive care planning; last phase of life and dying at home. Data were analysed using a combination of structured-thematic and formal-qualitative content analysis.

**Results:** Three core themes were identified as a synthesis from the professionals' perspectives:

- (1) autonomy and self-determination;
- (2) proactive care planning; and
- (3) a culture of care. Autonomy was depicted as a field of tension between the older people's desire to preserve their independence and the limits to self-determination in every day life observed by the participating health professionals. Next

to structural factors of the health system, the care providers' attitude and a palliative care approach were highlighted as essential to facilitate proactive care planning and to prevent panic-stricken interventions in ambiguous situations.

**Discussion and conclusions:** The focus group discussions highlighted that despite increased public debate about end of life issues, tension prevails between emphasis on curative, life-saving treatment and acknowledging the wishes and needs of frail older persons facing conditions inevitably associated with limitations and loss. Based on the participants' experience, timely involvement of a palliative care approach can be considered expedient.

**Abstract number:** P319

**Abstract type:** Poster

### End-of-Life Treatment Decisions in Patients Dying with Dementia in The Netherlands

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**Context:** In western countries, the large majority of patients with dementia die in long-term care settings and families and professional caregivers are often faced with complex treatment decisions. However, few physician reports on end-of-life decisions are available.

**Objectives:** To investigate the prevalence of living wills, and to describe end-of-life treatment decisions in patients dying with dementia in long-term care settings in the Netherlands with medical treatment provided by elderly care physicians.

**Methods:** We present data collected in the nationally representative Dutch End of Life in Dementia study (2007-2011). Within two weeks after death, 103 physicians completed questionnaires about living wills, care goals and end-of-life treatment decisions in 330 patients with dementia who resided in one of 34 participating long-term care facilities. We used descriptive statistics.

**Results:** Living wills were rare (4.9%), and in one case death was due to a physician-assisted suicide. Most patients had a palliative care goal (91.1%) and the most

important trigger for starting palliative care actions was an event related to health problems such as infections or heart failure (85.7%). In more than half of the patients (53.7%), decisions were made to withdraw potentially life-prolonging treatment. A minority was hospitalized (8.9%) in the last month (mainly for fractures), or received antibiotics (24.2%) in the last week (mainly for pneumonia), four patients received tube-feeding or rehydration therapy in the last week, and resuscitation was attempted in two patients. Dementia was listed as a cause of death for most (88.2%) and non-natural deaths were rare (1.5%).

**Conclusions:** Although living wills were rare, physicians are inclined to withhold potentially burdensome life-prolonging treatment in patients dying with dementia in the Netherlands. Physicians may feel that patients die due to the dementia and that a palliative approach is more appropriate at the end of life.

**Abstract number:** P320

**Abstract type:** Poster

### Implementing Facilitated Case Conferencing for Aged Care Residents with Advanced Dementia - Development of a Palliative Care Planning Coordinator Role

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**Background:** Care for people with advanced dementia requires a palliative approach however this is often not delivered to high quality in nursing home settings. This research aimed to inform understanding of perceived benefits and drawbacks of a facilitated case conferencing intervention, as well as barriers and facilitators to its implementation.

**Methods:** We trained registered nurses at 10 nursing homes in the role of Palliative Care Planning Coordinator (PCPC) 0.4FTE for 18 months. The PCPCs' role was identify residents with advanced dementia at a time-point likely to benefit from a case conference; organise and facilitate case conferences with optimal involvement from

family, multi-disciplinary facility staff and external health professionals; oversee implementation of palliative care plans; and train other staff in person-centred palliative care. This was a qualitative sub-study focusing on the intervention arm of a cluster randomized controlled trial. The success of the PCPC role was evaluated via semi-structured interviews with PCPCs, families, facility staff and physicians involved in case conferencing. Analysis used a thematic framework approach which was both deductive and inductive, using two independent coders and a constant comparative method.

**Results:** Interviews were conducted with 11 PCPCs, 18 nurses, 8 allied health staff and 3 physicians. The themes included key benefits (multidisciplinary involvement, better communication between staff and families); barriers (time pressures, staff resistance); and facilitators (staff and general practitioner support, positive family feedback, dedicated PCPC role).

**Discussion:** These themes highlighted the importance of funded support and structured approach to family case conferencing and involvement of diverse perspectives in decision-making about care. Success of the PCPC role varied according to support from management and staff and PCPC motivation and aptitude for change management.

**Abstract number:** P321

**Abstract type:** Poster

### **Palliative Care in Dutch Mental Health Facilities. The Perspectives of Nurses**

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**Aim:** Not much is known about the palliative care needs of psychiatric patients. Since nurses are important in the provision of palliative care this study explores nurses' experiences with providing palliative care to psychiatric patients in Dutch mental health facilities, and elaborates on perceived barriers.

**Methods:** Mixed-methods. Nurses of the Dutch nurses' association division of psychiatric nursing were invited to complete a survey (164/537; 31%). Nine nurses participated in an in-depth interview. Data was analysed according to elements of palliative care: early recognition, care

domains, family care and multidisciplinary approach. Analyses: descriptive statistics and thematic coding.

**Results:** In a two year period, thirty percent of nurses had had experience with providing care to patients with somatic comorbidity in the last phase of life. The mean age of deceased patients was 63 years and 62% was male. 53% of nurses recognized the patients would die in the near future at least six months before death. 63% of patients received physical care before death, 46% psychosocial care and 33% spiritual care. One-fourth received care from all domains. Half of the relatives received aftercare. In 91% care was provided by multidisciplinary teams of at least 4 disciplines. Barriers included different pain perception and expression and decreased effectiveness of symptom treatment, which were reported to hamper timely and adequate palliative care provision especially in this group. Psychiatric disorders were also reported to impede fruitful end-of-life conversations.

**Conclusion:** Only 1 in 3 of psychiatric nurses had experience with providing palliative care. All elements of palliative care are recognized and there is relatively much attention for spiritual and psychosocial care in comparison to palliative care for patients without psychiatric disorders. Specific characteristics of this group make cooperation between psychiatric and palliative disciplines necessary.

**Funding:** None.

**Abstract number:** P322

**Abstract type:** Poster

### **Praying, Not Planning: Elderly Malaysians' End-of-Life Care Attitudes and Preferences**

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**Introduction:** Malaysia, like many middle-income countries, has an ageing population and an increasing number of older people live alone.

**Aim:** To explore the social and health care arrangements of elderly people living alone in rural Malaysia.

**Methods:** Semi-structured interviews with a purposive sample of 20 Malay and 20 Chinese Malaysians aged over 65. Interviews were conducted with an interpreter, recorded, transcribed and translated. A thematic approach identified cross-cutting themes.

**Results:** Amongst others, future illness and care were important themes. Subthemes included: avoidance of discussion about illness and death; family care expectations; lack of advance care planning; and achieving a good death through prayer and deeds. Participants avoided thoughts about illness and death, which could make them depressed or even sick. Talking about or arranging future care was rare. There was a preference for care in their own home with support from adult children or, as a last resort, in an adult child's home. Residing with adult children in large cities was particularly undesirable. Planned care tended to be sought by those without children and involved care by extended family, applying for financial support or even, in one case, contemplating suicide. Instead of planning care, participants generally prayed for good health and a quick death. Muslim, Christian, Taoist and Buddhist participants alike, appealed to the appropriate deity for good health (Chinese Buddhists, contrary to some Buddhist teachings, recognized various gods). Taoists and Buddhists attributed a quick death to good conduct, and illness to the karmic effect of bad deeds.

**Conclusion:** Cultural sickness and death taboos, and the belief that the end of life is the preserve of religion, hindered advance care planning. There was an expectation that care would be provided within families, but changes in family structure and rural-urban migration have implications for the fulfilment of these expectations.

**Abstract number:** P323

**Abstract type:** Poster

**Pilot Study to Test the Feasibility of Introducing Palliative Care as Part of a Psychological Support Workshop for Patients Newly Diagnosed with Idiopathic Pulmonary Fibrosis (IPF) and their Families**

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**Background:** IPF is associated with a poor prognosis, high symptom & psychological burden & limited treatment options. NICE guidelines recommend introducing supportive & palliative care early on in the disease trajectory, including information, support & symptom relief. Advanced care planning is also paramount. There is an

urgent demand for development of services to meet these needs. This pilot study aims to test the feasibility of a workshop approach to introduce palliative care to patients with newly diagnosed IPF & their families.

**Methods:** ILD physicians identified patients recently diagnosed with IPF. Patients were invited to attend a workshop with a 'guest'. Led by a clinical psychologist & palliative care clinical nurse specialist, workshops included didactic teaching, interactive discussions & experiential learning. Topics related to palliative care included: defining palliative care; symptom control; planning for the future; support services available. Participants completed a semi-structured questionnaire at the end of the workshop. Framework analysis identified themes on the impact of attending a workshop.

**Results:** Data from 3 workshops is currently available. Demographics: 27 patients (m=21; f=6); 25 family members (m=3; f=22). Participants reported benefiting from peer support; learning about symptom control, practical coping & accessing support. Participants reported that more information about IPF, its progression & prognosis & treatment options, including oxygen therapy, would be useful. However, the extent to which participants engaged with information related to palliative care varied strikingly between groups.

**Conclusions:** Attendance at a workshop is perceived as a positive experience. Continued development of support services to meet the palliative care needs of patients diagnosed with IPF & their families is required. A flexible, patient-led approach to introducing and discussing palliative care is essential.

**Abstract number:** P324

**Abstract type:** Poster

**The Effects of an Ageing Prison Population: Increasing Prisoner Palliative Care Needs and Some Consequences for Prisoners and Prison Staff**

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**Background:** The UK prison population has doubled over the past decade and, with men over 60 the fastest growing group, the need to improve palliative care in prisons is increasingly urgent. The majority of older prisoners have multiple and complex healthcare needs and many will die in prison.

**Aims:** This paper reports on Phase 1 of an action research project in which a situational analysis explored palliative care in one prison in England.

**Methods:** The study is being conducted in partnership with prisoners and staff in a prison with a high number of older and disabled prisoners. This has involved 32 interviews and 5 focus groups with people both inside and outside the prison including healthcare staff, governors, prison officers, chaplains, prisoners, and specialist palliative care staff (n=62). In addition, a case study was undertaken centred on a prisoner who was approaching the end of his life and four people involved in his care and support. Interview and focus groups have been transcribed and analysed using a thematic network approach and the software package Nvivo 10.

**Results:** As a result of an ageing prison population and increasing palliative care needs, prisoners and prison staff are living and working in increasingly close proximity to illness and death, with a number of consequences for both groups. The roles of prison staff are changing as they balance safety and security with meeting prisoner care needs. Prisoners report an increasing awareness of their own mortality and fears about dying in prison. For prison staff, it can be difficult to deal with illness and death in the workplace when also dealing with it in one's personal life.

**Conclusions:** Drawing on data from one prison with a high number of older and disabled prisoners, this paper illustrates some of the effects on prisoners and prison staff of an ageing prisoner population with increasing palliative care needs.

**Abstract number:** P325

**Abstract type:** Poster

**A German Nationwide Palliative and Hospice Care Hotline for People Severely Affected by Multiple Sclerosis: A One-year-Report**

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In order to facilitate cooperation between neurology and palliative and hospice care (PHC) and to ease patient's access to these structures, a nationwide hotline for people affected by multiple sclerosis (MS) was established in Germany, and the experience of the first year analysed.

The hotline was designed and introduced to the MS community in cooperation with the German Multiple Sclerosis Society (DMSG). Calls were documented using a standardized case report form supplemented by personal notes after each call. In cases where PHC services were recommended, follow-up calls were intended. Data was analysed descriptively.

During the first year (09/2014 - 08/2015), 156 calls (79 patients, 37 caregivers, 5 members of patient associations (e.g. DMSG), 5 health professionals, one other hotline, 29 unknown) were documented and analysed. Patients (mean age: 50.7 years; range: 28-84; 54% male) had an average illness duration of 19.63 years (range: 2 month - 50 years). 82% of the patients were living in their own homes, 12% in nursing homes, 6% in other places (one patient was homeless). Main symptoms reported by callers were

- 1) symptoms evolving due to MS (49%): e.g. limited mobility, impairment of speech;
- 2) typical palliative symptoms (28%): e.g. severe pain, breathing difficulties; and
- 3) psychosocial problems (35%): e.g. inadequate living conditions, psychological distress and burden of relatives.

In 6% of cases the caller brought up the topic of death and dying. 10% of callers reported difficulties in accessing PHC structures. 40% of all calls were deemed eligible for PHC and recommendations for available services were given.

Results indicate that the hotline is broadly accepted. Although patients expressed a wide range of problems showing the need for PHC, in some cases they were refused these structures. The hotline now helps to facilitate access to palliative and hospice care structures.

The hotline is funded by the Gemeinnützige Hertiestiftung.

**Abstract number:** P326

**Abstract type:** Poster

**Do Palliative Patients Have Early Access to Drugs Used for Symptom Control?**

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**Background:** Uncontrolled symptoms are one of the main reasons for patients being admitted to a palliative care unit (PCU). Providing adequate pharmacotherapy plays a central role in palliating symptoms. Early access to relevant drugs can be crucial to decrease the symptom burden and to prevent unnecessary hospitalisations.

**Aims:** Evaluation of the time point when palliative drug therapy focusing on symptom control is initiated.

**Methods:** Cross-sectional study of patients admitted to a German PCU. Six common drugs in Germany were identified by conducting a literature search and a consumer analysis: dipyrone, morphine, hydromorphone, fentanyl, dexamethasone, metoclopramide. From January to June 2015 all prescribed drugs were recorded at six different points: before T0, during T1-T4, and after the in-patient stay T5.

During the in-patient stay and at discharge from the PCU, pharmaceutical consultations with physicians, nurses, as well as patients and their family members took place. All patients discharged from the PCU were included in the evaluation. Findings were analysed using the McNemar test.

**Results:** 65/160 (41%) admitted patients were discharged from the hospital (n=34 men, median age 66 years, min-max 21-93 years, cancer diagnoses n=59). During the PCU stay, the proportion of prescribed drugs changed as follows compared to the time before admission T0 vs. T3: morphine from 31% to 42%, hydromorphone from 6% to 18%, dexamethasone from 26% to 63%, metoclopramide from 17% to 42% and dipyrone from 46% to 74%. The prescribing of fentanyl decreased from 17% to 15%. Hydromorphone, dipyrone, dexamethasone and metoclopramide showed a significant difference (T0 vs. T3,  $p < 0.05$ ).

**Conclusion:** Patients admitted to a PCU already receive a number of drugs for symptom management before admission. However, for optimisation of symptom relief, additional drugs are necessary with the strongest increase in dexamethasone and dipyrone.

**Abstract number:** P327

**Abstract type:** Poster

### Scoping the Level and Extent of Service Provision to People with Intellectual Disabilities at the End of Life

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**Background:** Concerns exist about the end of life care that people with intellectual disabilities receive. This population are seldom referred to palliative care services and inadequate data sets exist about their place of death.

**Aim:** To scope the extent of service provision to people with intellectual disabilities at the end of life by specialist palliative care and intellectual disability services in one region of the United Kingdom.

**Methods:** As part of a larger doctoral study a regional survey took place of a total sample (n=66) of specialist palliative care and intellectual disability services using a postal questionnaire containing forty items. The questionnaire was informed by the literature and consultation with an expert reference group. Data were analysed using SPSS to obtain descriptive statistics.

**Results:** A total response rate from services of 71.2% (n=47) was generated. Findings showed a range of experience among services in providing end of life care to people with intellectual disabilities in the previous five years, but

general hospitals were reported the most common place of death. A lack of accessible information on end of life care for people with learning disabilities was apparent. A few services (n=14) had a policy to support this population to make decisions about their care or had used adapted Breaking Bad News guidelines (n=5) to meet their additional needs. Both services recognised the value of partnership working in assessing and meeting the holistic needs of people with intellectual disabilities at end of life.

**Conclusions:** A range of experience in caring for people with intellectual disabilities was present across services, but more emphasis is required on adapting communication for this population to facilitate them to participate in their care. These findings could have international significance given that studies in other countries have highlighted a need to widen access to palliative care for this group of people.

**Abstract number:** P328

**Abstract type:** Poster

### "An Odyssey without Receiving Proper Care" Expert Opinions on Underrepresentation of Migrants in Palliative Care

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Migrants and their families, including the 2<sup>nd</sup> and 3<sup>rd</sup> generation (M+), are a vulnerable group facing various barriers to healthcare (HC). Studies on accessibility of palliative care (PC) for M+ in Germany are lacking.

**Aim:** We aim to explore factors influencing access to PC for M+, as experienced by experts from different fields in HC.

**Method:** Guided interviews with experts on HC for M+ (palliative/hospice care, geriatric care, research, training for HC professionals, psychiatry, hospital and ambulatory nursing management) exploring factors influencing accessibility. Interviews were conducted (2013) and analysed according to Meuser & Nagel.

**Results:** According to the experts (n=13), access is hindered a) on the sociopolitical level, b) within the HC system, and c) on the user level (M+). Ad a), institutions specifically developed for M+ emerged parallel to the regular (HC) system; the M+ population lacks participation in social progress; and intercultural opening of institutions is time consuming and laborious. Ad b), information about care services and options hardly addresses M+; and even the general public is little aware of PC which is a relatively new field, let alone M+. Ad c), M+ might lack trust in institutions generally. Even though traditional family structures are dissolving, M+ families are still required to

care for sick members. Adult M+ in need of PC rather belong to the first generation that is perceived as more traditional and less integrated in society, therefore suffering most from restricted access to PC.

Experts propose increased networking with services addressing M+, and migrant communities in general. Information regarding PC needs to be improved. Native-language media may be used to disseminate information about PC services.

**Conclusion:** PC services should actively establish collaboration with services frequented by migrant communities, and the communities themselves. Customized information should be developed and disseminated in such networks.

**Abstract number:** P329

**Abstract type:** Poster

### Is Palliative Care Possible in Prison? National Study about Inmates with Terminal Illness in France

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**Research questions:** In France, in 2011, 125 inmates died in prison because of illness. Since 2002, the French law allows disabled inmates or inmates with terminal illness to request a suspended sentence for medical reasons. However, some requests are not granted and some inmates do not even request such a release. The PARME national study aims to describe and understand the trajectories of dying inmates in French prisons.

The purpose of this presentation is to highlight the needs of inmates nearing the end of life in prison (UCSA) or in special unit for inmates in hospital (UHSI), and to identify eventual barriers to a dignified EOL care.

**Methods:** A national census of terminally ill inmates with a life expectancy of less than 1 year was first conducted across France (192 medical units). From this census, a qualitative research was conducted on 14 situations of dying inmates chosen for their representativeness in order to provide in-depth analysis of the dying inmates' trajectories. Interviews were conducted with the dying inmates, physicians, judges and social and probation workers.

**Results:** Our results reveal that dying inmates did not benefit from a comprehensive palliative care approach despite the existence of UCSA and UHSI. An end-of-life global care is impossible because of the difficulties to provide care in custodial settings and because of the absence of families who cannot accompany the patients until their death.

**Conclusion:** The end of life of inmates with terminal illness is not dignified. The French law doesn't address every situation that medical staffs are likely to encounter. This study shows an imbalance between the needs of palliative care and the possibility to develop them in prison. It would be important in the future to consider how to facilitate the application of the law and the relevance to develop interventions of mobile palliative care teams in prisons.

*PARME study is funded by the Foundation of France (philanthropic foundation)*

**Abstract number:** P330

**Abstract type:** Poster

### What is the Role of Palliative Care Specialists in Managing Distress among Patients with Metastatic Breast Cancer?

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**Introduction:** Current evidence for palliative care/oncology integration derives from cancers with either very short prognoses or relatively limited treatment options (e.g. pancreas). Little is known about the role of palliative care in metastatic breast cancer, where prognosis may be measured in years and the treatment option portfolio is continuously expanding.

**Methods:** The Cancer Support Community Metastatic Breast Cancer Experience Registry is a voluntary, patient-reported, online registry of patient experiences with cancer. We evaluated data reported by patients from March 2013 to March 2014. The registry includes demographic information and data regarding physical, emotional, social, and financial distress measured using Likert scales. We calculated descriptive statistics and Pearson's chi-squared.

**Results:** We evaluated 599 patients. The sample median age was 56; 93% were White; 61% had a bachelors degree or higher. Median time from diagnosis of metastatic cancer was 3 years. Regarding physical distress, over 50% reported "moderate" or higher issues with sleep, nutrition, and fatigue. Depression and anxiety prevalence increased by 15% and 20%, respectively, from pre-treatment to post-treatment. Among social distress, 25% felt alone, 62% worried about burdening their family, and over 50% limited contact with others 30% or higher desired more

assistance with: diagnostic and treatment information, making decisions, managing symptoms and emotions, and managing disruptions to family and work life. Respondents were more likely to have been asked about distress if they received part or all of their care at an academic or comprehensive cancer center ( $p < 0.001$ ) or treatment through a clinical trial ( $p = 0.012$ ).

**Discussion:** We identified high prevalence of unmet needs across several supportive care domains. About one-third of respondents indicated wanting more help with distress considered core components of specialty palliative care.

**Abstract number:** P331

**Abstract type:** Poster

### Care and Illness Characteristics of People with Intellectual Disabilities Receiving Home Palliative Care and Hospice Care

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The increasing longevity of people with intellectual disabilities (ID) stresses the importance of excellent palliative care. In the Netherlands a hospice specifically for people with ID was started. In this study, characteristics of the palliative care provided in a care organisation for people with ID are presented. People admitted to hospice care and home care are compared.

Data are collected of 52 people with ID in a care organisation for whom palliative care was indicated and a medical ID specialist was involved. A retrospective cohort study design is used in which data are extracted from the patient records between October 2012 and October 2015. Data on duration of palliative care, indication for palliative care, involved disciplines and transfers are presented. Differences between hospice and home care are tested using multiple logistic regression analysis.

28 patients were admitted to the hospice, 23 died in an institution group home and one died at home. We included 40 men and 12 women; mean age at death was 65.3y. 9 patients had a profound level of ID, 13 severe, 17 moderate, and 10 mild (3 unknown).

Main diagnoses were cancer (25%), organ failure (33%), stroke (7%) and other chronic illness (31%) (4% unknown). Mean duration of the palliative care trajectory of hospice patients was 91 days; all other patients 133 days. Physicians recognised the palliative care phase in 63% of all patients; 37% was recognised by other staff members, family and the patients themselves. Only one hospice patient was admitted to the hospital within this period; three of the remaining patients were hospitalised at least once. A multidisciplinary team was involved in all patients, but more disciplines were involved in hospice care, including a hospice ID physician.

All patients had relatively long palliative care trajectories. The relatively low number of cancer patients may hamper recognition of the palliative care phase. Hospice admissions may prevent hospital admissions.

**Abstract number:** P332

**Abstract type:** Poster

### Intervention in the Emergency Department of a Hospital Palliative Care Team

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**Background:** Palliative care patients often need urgent attention because of complex symptoms. An early assessment by an expert team who knows the patient medical history and the symptom management may be useful in the Emergency Room (ER) in topics such as indication or withdrawal of therapies, the need of certain laboratory or imaging tests. They may also contribute in relieving pressure in the ER. When patients call to our unit for medical emergencies, they are often referred to de Oncology Day Hospital (ODH) and visited by our team avoiding overcrowding the ER.

**Aims:** To describe the urgent activity of a hospital oncologic Palliative Care Team (PCT) in the ER and the ODH during a five months period. To describe the patient's characteristics, the reason for consultation, and the destination of the patients.

**Methods:** Descriptive study including all patients seeking emergency assistance by our PCT during five months.

**Setting:** University tertiary hospital with 656 beds.

**Measurements:** Age, gender, cancer diagnosis, Urgent setting:ER, ODH, Reason for consultation, Patient Destination:Home, Hospital Admission

**Results:** A total of 128 patients were visited, 83males(64,8%), 45females(35,2%), Median Age 71 years(Range 44-91).

**Cancer diagnosis:** Pancreatic:6,2%, Gastric-esophageal:8,5%, Bowel-rectal:19,5%, Lung:27,3%, Breast:27,3%, Genitourinary:14%, Sarcoma:4%, Hepatic-Biliary:4%, Haematologic:4%.

**Reasons for consultation:** Pain:21%, Gastro-intestinal symptoms:13,3%, Respiratory symptoms-Dyspnea:13,3%, Haemorrhage:8,6%, Fever:7%, Ascites:4%, Genitourinary symptoms:3,1%,Functional decline:6,25%,2 cases of opioid toxicity.

**Destination:** Home 77(60.2%),Hospital admission 51(39.8%).

**Setting:** ER 30%,DH 70%.

**Conclusions:** There is a significant number of urgent visits of palliative care in the hospital. The most common

reasons for consultation are gastro-intestinal, respiratory symptoms and pain. In our case, less than 40% of urgent interventions ended in admission to the Palliative Care Unit.

**Abstract number:** P333

**Abstract type:** Poster

### Upskilling Aged Care Workers on Advance Care Planning and Palliative Care in Long Term Care: Effectiveness of a Blended Learning Model

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Decision Assist is a national program, enhancing the provision of palliative care and advance care planning (ACP) services to older people in long term care. This presentation reports interim results from the blended learning program delivered to clinical staff working in long term care. Participants were asked to complete two hours of online learning modules prior to attending two, one-day workshops two months apart. Participants rate knowledge and confidence; pre online modules (T1), immediately post online (T2), at the completion of workshop 2 (T3) and six months after the online modules (T4). Pre online (T1), post online (T2) and post workshop 2 (T3) ratings have been completed by 1851, 965, and 381 participants respectively to date (October 2015). No data for T4 was available but will be completed by March 2016. These interim results indicate that the online modules significantly increased participant knowledge in relation to timing of a palliative care case conference (PCCC) ( $p < 0.001$ ), timing of ACP

( $p < 0.001$ ), end of life care pathway approvals ( $p < 0.001$ ), recording end of life decisions for residents with dementia ( $p < 0.001$ ), and signs of approaching death ( $p < 0.001$ ). Most of these significant changes were maintained at T3. Self-rated knowledge levels also significantly increased between T1 and T2 in relation to: ACP ( $p < 0.001$ ), PCCCs ( $p < 0.001$ ), and using an end of life care pathway ( $p < 0.001$ ) and were maintained at T3. Change in practice was recorded by a self-reported activity and completed by 1182 workshop participants (October 2015). Approximately 71.9% of participants reported they had conducted an ACP discussion with at least one existing resident, and 52.7% reported having this discussion with a newly admitted resident. PCCCs were facilitated and attended by 40.2% and 34.1% of participants, respectively. The blended learning approach improves participant's immediate knowledge and confidence and this is further reinforced by workshops.

**Abstract number:** P334

**Abstract type:** Poster

### What Are the Differences among Occupational Groups Related to their Educational and Supportive Needs in Providing Palliative Care In Long-term Care Homes?

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**Aims:** The purpose of this study was to compare the differences across occupational groups of educational and supportive needs to provide palliative care in long-term care (LTC) homes.

**Methods:** A cross-sectional survey (End of Life Professional Caregiver Survey) was administered at four LTC homes in Ontario, Canada using a modified Dilman's approach. The survey included three domains: patients and family-centered communication, cultural and ethical values, effective care delivery. In total, 697 LTC staff were given surveys, including 317 personal support workers (PSWs), 219 support staff, 128 licensed nurses, and 20 allied health care workers.

**Analysis:** Stepwise linear regressions were completed on mean responses calculated for each of the three survey subscales. Between groups ANOVAs with Tukey post hoc analyses then compared differences in individual survey responses among the significant predictors from the regression models.

**Results:** Overall, 317 participants completed the survey with a response rate of 45%. ANOVAs revealed significant differences among occupational groups for the three subscales. Nurses rated their comfort and ability in providing palliative care higher than both PSWs and support staff but there were no significant differences between nurses and PSWs on items such as "I am able to be present with dying patients", "I am able to deal with my feelings about working with dying patients" and "I feel my workplace provides resources to support staff who care for with dying patients". In contrast, support staff rated their comfort of working with dying patients significantly lower than both nurses and PSWs, and provided lower ratings on the existence of workplace resources available to them.

**Conclusions:** These study findings suggest there are differing needs of LTC staff, specific to occupational group. Optimal palliative care may require resources to increase the availability of support for all staff involved in the care of patients.

**Abstract number:** P335

**Abstract type:** Poster

**Equality of Care: Love, Care and Solidarity Relations for Older Adults with Intellectual Disability in Ireland at End of Life**

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**Background:** Currently, there is not a clear picture of the scale and breadth of the experiences and challenges that are experienced by people with intellectual disability (ID) and their carers supporting them at end of life. IDS-TILDA study presented an opportunity to explore these issues in those deceased since wave 1 of data collection.

**Methods:** A Mixed Methods approach is employed, with an emphasis on quantitative analysis with an embedded qualitative data collection element. Experiences were captured through face-to-face interviews, using an adapted version of the Views of Informal Caregivers Evaluation of Services questionnaire (VOICES), regarding last year of life with 45 close caregivers interviewed as proxy. Analysis was carried out using descriptive statistical and text analysis and discussed in the context of Lynch et al's (2004) framework of social justice.

**Results:** A profile of ID service residential setting dwelling adults (80.4%), multi-morbid (87%) with primarily moderate, severe or profound IDs (89.1%), supported by paid caregivers at end of life (95%) was established across 19 services. Qualitative data generated was heavily influenced by the impact of relationships established with caregivers at this time, in particular love and caring relationships.

**Conclusions:** Findings provide an insight into the profile of death and dying as an older adult with ID in Ireland and the systems underpinning end of life care (in)equalities experienced. In particular, the system of affective (in) equality and the domain of love care and solidarity relationships supporting people with ID on life's final journey impacts on access to and quality of care provided.

**Abstract number:** P336

**Abstract type:** Poster

**Retrospective Study of Antenatal and Neonatal Referrals to an Irish Paediatric Specialist Palliative Care Service and also of Patient Outcomes**

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**Background:** There is growing recognition of the role of Specialist Palliative Care (SPC) in the care of patients diagnosed in the perinatal period with life limiting conditions and also of their families.

**Aim:** To assess the needs/patterns of service utilisation of antenatal and neonatal patients referred to SPC at an Irish paediatric hospital and at an Irish maternity hospital over a 4 year period together with patient outcomes.

**Methods:** Retrospective electronic database and chart review. All consecutive patients referred to the SPC service over a 4 year period were included and data collected on patient outcomes to September 2015. Data was entered onto Microsoft Excel.

**Results:** 83 perinatal referrals were received over 4 years of which 20% were antenatal and 80% neonatal, with an increase in antenatal referrals in recent years.

Reasons for referral included antenatal advice and planning; meeting expectant parents; preparing for compassionate extubation; symptom control and discharge planning.

The most prevalent diagnoses prompting referral were chromosomal abnormalities (most frequently trisomy 18 & 13); complex congenital cardiac abnormalities and multiple severe abnormalities.

A very small number of patients survived the first year of life, with the majority dying in the acute hospital setting (mean 40 days after referral).

Physical symptoms were well managed with the recommended initial dose of as required or regular medications. Few patients required dose titration.

**Conclusions:** The SPC response to antenatal and neonatal patients has evolved and referrals have become more common. Perinatal patients and their families required extensive multidisciplinary SPC support. Discharge home required extensive planning and liaison with multiple community services. This has significant resource utilisation and funding implications. Further study is required identify the needs of particular patient populations.

**Abstract number:** P337

**Abstract type:** Poster

**Symptoms, Care Needs and Diagnosis in Palliative Cancer Patients in Acute Care Hospitals**

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It can be challenging to provide palliative care in hospitals where the care is focused on curative interventions. The aim

was therefore to describe and compare symptoms, care needs and diagnosis in palliative cancer patients in acute care settings in regions with no 24-hours specialist palliative care services. This population-based study with a cross-sectional design was carried out in two acute care hospitals, in 2007 with 142 one-day inventories (N=2972) and in 2012, with 139 (N=2843). Due to few differences these two dataset were combined. To analyse the relationships, multiple logistic regression models were used. In total, 589 patients

(10,1%) were assessed as being palliative (mean age 74; mean number of symptoms/patient: 3). The two most common non-gender related diagnosis were colorectal (12,1%) and lung cancer (11,7%). Among men, prostate cancer (23,1%) was most common and among women, gynaecological (15,4%) and breast cancer (14,3%). The most common symptoms were pain (42,3%) and deterioration (42,3%). In the table, the relationships between the most common diagnoses and symptoms/care needs are presented.

**Table I.**

Diagnosis	Symptoms and care needs	p-value	OR	95%CI	Nagekerke R-Square
Breast	Radiotherapy	0,003	3,6	1,5-8,2	0,371
	Pleuracentes	0,002	7,8	2,1-28,7	
Colorectal	Abdominal surgery	0,000	8,4	3,8-18,6	0,137
Gynaecological	Abdominal surgery	0,015	4,9	1,4-17,9	0,416
	Blood transfusion	0,007	3,8	1,4-10,3	
	Paracentes	0,000	6,1	1,7-22,2	
Lung	Obstipation	0,006	3,0	1,4-6,7	0,149
Prostate	None				

Our results show that several symptoms, such as pain and deterioration, are not strongly associated with specific diagnoses. This indicates that focus in palliative care should be on treating symptoms irrespective of diagnosis. Several symptoms and care needs may also be resolved in advanced palliative home care instead of in acute care settings. The study was funded by The Kamprad Family Foundation, Sweden.

**Abstract number:** P338

**Abstract type:** Poster

### Public, Patient and Family Carers' Views on Palliative and End of Life Care in India: An Integrated Review

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**Background:** The Global atlas of palliative care shows that around 80 countries remain under the category of patchy or generalised development. Despite recent economic progress in India, provision of palliative and end of life care remains in the development stage, and there is limited synthesised evidence on service user (public, patients and carer) views which could inform emerging national policy and practice guidelines.

**Aim:** To synthesise published evidence relating to the views, preferences and experiences of Indians in relation to palliative and end of life care.

**Design:** An integrative review.

**Data sources:** Five databases (MEDLINE, PsychINFO, CINAHL, EMBASE, and Google Scholar). Hand searches of key journals and reference citation tracking were also carried out to identify studies reporting the views of Indians on palliative and end of life care. Extracted data were synthesised using thematic analysis.

**Results:** In total, six studies were included. Reviewed studies elicited perspectives from terminally ill patients, family care givers, palliative patients, outpatients and also the general public. Five themes were identified; role of social and economic factors, influence of cultural and traditional factors, religious and spiritual concerns, preferences in relation to place of care and family care giving as a choice.

**Conclusions:** Considering the geographical and cultural diversity and demographic size of the Indian population, there is minimal evidence around user perspectives on palliative and end of life care. More research is crucial at this time of national consensus towards policy development in palliative care in India.

**Abstract number:** P339

**Abstract type:** Poster

### A Scoping Review of Palliative Care for those with Severe Persistent Mental Illness

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**Background:** Severe persistent mental illnesses (SPMI), such as schizophrenia, bipolar disorder, and major

depression, are strongly linked with poor physical health. Despite this, access to healthcare is poor: those with SPMI die younger, have more chronic diseases, and greater disease severity. Symptoms of advancing illness are often unseen in the presence of SPMI, leading to late presentation, diagnosis, and referral. Access to care for those with SPMI is poor, yet little is known about palliative care for this population.

**Aims:** To determine the extent, range, and nature of research activity about persons with SPMI approaching, and at, end of life, and to identify gaps and opportunities for future research.

**Methods:** The author conducted a rigorous Scoping Review of peer-reviewed literature. Search terms included variations of 'palliative', 'mental health', 'mental illness', and specific psychiatric diagnoses. A comprehensive database search yielded 36 studies. Studies were charted to extract salient data and a descriptive analytical process was used to reveal key issues, themes, and gaps.

**Results:** Fragmentation in care systems between specialties and settings limits access to both medical and psychiatric care. Studies were seldom set in residential care or shelters where those with SPMI are typically cared for. SPMIs were seldom differentiated from other psychiatric diagnoses after onset of life-limiting illness, despite an increasing number of studies in the last decade. This recent rise in literature about the treatment of mental illness in palliative settings has neglected those with SPMI.

**Conclusion:** Findings of this review provide an overview of literature on the topic of those with SPMI approaching, and at, end of life. Such an overview is fundamental to identifying the gaps in knowledge and future directions for research. This study exposes a dire need for more research in order to inform policy and practice.

## Non-cancer

**Abstract number:** P341

**Abstract type:** Poster

### A Pilot Study Examining Predictors of Short Term Mortality in Advanced COPD - Importance of Nutritional, Systemic Inflammatory and Physical Performance Indices

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**Background:** Challenges in prognostication results in patients with advanced COPD being referred to palliative services only when terminally ill. We aim to compare the prognostic capabilities of functional, nutritional, physical

performance and inflammatory indices, against disease-specific measures including the BODE index, which comprises: BMI, FEV<sub>1</sub>, Modified Medical Research Council dyspnoea scale (MMRC) and the 6-minute walk test.

**Method:** 83 patients with stage 3 or 4 COPD were recruited. COPD severity was assessed using FEV<sub>1</sub>, BODE and use of long-term oxygen therapy (LTOT). We evaluated nutrition using Subjective Global Assessment (SGA), weight loss, BMI and serum albumin. Physical performance was measured using the 2-minute (2MWT) and 6-minute walk test (6MWT), as well as grip strength. C-Reactive Protein (CRP) was used to measure systemic inflammation. We performed Kaplan Meier survival analyses and significant predictors were examined using Cox-regression analyses.

**Results:** Subjects were followed up for a median duration of 749 days (IQR 654-804). 13 (15.7%) subjects died, their median survival was 391 days (IQR 256-496). Disease-specific markers such as BODE, FEV<sub>1</sub>, exacerbation frequency and ICU admissions were not predictive of survival. Age, LTOT, 2MWT, 6MWT, weight loss >5% over 6 months, SGA grading, serum albumin level, grip strength and MMRC scores were found to predict survival (all p< 0.05). Analyses on serum CRP was near statistical significance (p=0.05). In our Cox-regression analysis, weight loss >5% in 6 months (HR 11.77, p< 0.005), MMRC ≥3 (HR 9.90, p< 0.05), age group (HR 8.28, p< 0.05) and CRP> 4.9mg/L (HR 4.88, p< 0.05) predicted shorter survival, independent of other covariates.

**Conclusion:** Despite a modest sample size, age, nutrition, inflammation and physical performance predicted survival, when conventional disease-specific markers did not. A prognostic model integrating these measures will improve predictive accuracies in advanced COPD.

**Abstract number:** P342

**Abstract type:** Poster

### Receiving the News of a Diagnosis of Motor Neurone Disease: What Does it Take to Make it Better?

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**Background:** Breaking the news of the diagnosis of MND is challenging for both neurologists and patients. The

manner in which the patient/family learn of the diagnosis has implications for the way they move on from the devastating news of their diagnosis to the actions required for support throughout the illness trajectory.

**Objectives:** To identify the experiences of people with MND/family carers in receiving the diagnosis and to determine which aspects of breaking this bad news were associated with greater satisfaction with the way the diagnosis was delivered to them.

**Method:** An anonymous national postal survey was facilitated by all MND associations in Australia, in 2014, and centred on the SPIKES protocol for communicating bad news.

Results provided a comprehensive insight from the patients' (n=248, response rate 29%) and family carers' perspective (n=194): 36% were dissatisfied with the delivery of the diagnosis and gave low ratings on the ability/skills of their neurologists to deliver the diagnosis. It was evident that the longer the patients spent with their neurologists during breaking such bad news, the more they were satisfied and the higher they rated the neurologists' ability/skills. The largest significant differences between neurologists rated as having high or low skills in delivering the diagnosis were in four domains: Responding empathically to the feelings of patient/family; sharing the information and suggesting realistic goals; exploring what patient/family are expecting or hoping for; making a plan and following through. Family carers reported similar experiences to patients.

**Conclusions:** With over a third of patients/family carers dissatisfied with their experience, there is room for improvement in the practice of neurologists in specified areas which could form the basis for changing practice, and the development of standards and protocols likely to have implications at the international level.

**Abstract number:** P343

**Abstract type:** Poster

### **The Management Symptoms during the Withdrawal of Assisted Ventilation in MND/ALS**

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**Aims:** People with motor neuron disease / amyotrophic lateral sclerosis (MND/ALS) are increasingly receiving ventilation, usually non-invasive ventilation via a mask, to

manage respiratory failure from respiratory muscle and diaphragmatic weakness. As the disease continues to progress some who are ventilator dependant, ask for the withdrawal of the ventilation. This study has looked at the withdrawal process and the symptoms patients experienced.

**Method:** Interviews with 17 relatives, 24 doctors and 26 nurses and allied health professionals, involved in the withdrawal of assisted for 30 patients, were analysed thematically.

**Results:** To avoid distressing symptoms doctors discussed the need to use medication before the assisted ventilation was withdrawn. Additional medication was administered if symptoms subsequently occurred. The health care professionals intended that medication doses should be sufficient to avoid symptoms but were concerned that they could be seen to hastening death if high doses were used. The majority of patients were given morphine or diamorphine and midazolam - usually by a subcutaneous infusion, subcutaneous injections or via an intravenous line- to manage breathlessness and anxiety. Some patients received medication via their gastrostomy.

One third of the patients experienced symptoms after the assisted ventilation was removed, and on two occasions this required the mask to be temporarily replaced as well as administration of further medication. The distress experienced by some patients was difficult for all concerned - families and professionals.

**Discussion:** During the withdrawal of assisted ventilation in MND/ ALS distressing symptoms may occur if the doses of sedating medication are insufficient and the presence of uncontrolled symptoms was distressing to all concerned. There was a need for a clear guidance, from people with experience, to provide details of the medication required to prevent distress.

**Abstract number:** P344

**Abstract type:** Poster

### **“We Could Do Better”: The Nature and Meaning of Information-giving in End-stage COPD**

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**Background:** End of life in Chronic Obstructive Pulmonary Disease (COPD) is typically difficult to predict, and although palliative care initiatives are developing, active treatment in the acute hospital setting often continues up to death. Staff delivering care but who may not be part of the treatment decision-making process express frustration at the lack of a palliative approach in end-stage disease and

cite part of their role is to give information to assist decision-making for those in their care.

**Overall study aim:** To understand the meaning and experiences of information-giving of staff caring for acute severe COPD within the social context of the acute hospital setting.

**Methods:** In this exploratory, qualitative study, interviews and focus groups were undertaken with nurses and physiotherapists (n=10) who care for people with severe COPD in acute hospital settings in the North of England. A grounded theory approach to analysis was aided by the software NVivo.

**Results:** Although staff can act as information-givers to support their patients, time constraints lead to hesitancy on their part, and they often wait for the patient to express concerns for their future before intervening. Once the conversation is initiated, staff express a sense of responsibility to do the job well, and this is often difficult. More experienced staff feel better equipped to give information and discuss decisions on behalf of their patients, but the success of this is rooted in inter-disciplinary relationships and the nature of the ward hierarchy.

**Conclusion:** Inter-disciplinary relationships, professional experience and time constraints all create a challenge to effective information-giving in clinical practice when considering treatment decision-making for people with acute severe COPD.

**Abstract number:** P345

**Abstract type:** Poster

### The Experiences of Palliative Care Service Provision for People with Non-malignant Respiratory Disease: An All-Ireland Qualitative Study

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**Background/aim:** Palliative care is recommended for people with advanced non-malignant lung disease. Yet there is limited evidence regarding the integration of palliative care for people with interstitial lung disease, bronchiectasis and COPD. This study aimed to explore specialist and generalist palliative care provision for people with non-malignant respiratory disease and carers, in rural and urban areas in the North and Republic of Ireland.

**Methods:** Qualitative study involving a convenience sample of 17 bereaved carers and 18 healthcare professionals

recruited from 2 rural and 2 urban sites on the Island of Ireland. Data collection consisted of semi-structured interviews with carers of patients with COPD, interstitial lung disease or bronchiectasis who had died 3-18 months previously; and 4 focus groups with healthcare professionals. Data analysed using thematic analysis.

**Results:** Three key findings included:

- 1) Geographical location influenced local palliative service provision, not only due to rurality but also health jurisdiction;
- 2) Lack of consensus amongst healthcare professionals regarding when specialist and generalist palliative care is appropriate for patients with non-malignant respiratory disease;
- 3) The unpredictable nature of the disease caused uncertainty about disease progression amongst all participants, especially carers who experienced a lack of awareness of the life limiting nature of the disease.

**Conclusions:** The management of patients with non-malignant respiratory disease is complex and challenging with a clear need for a more integrative model of practice, incorporating palliative care in a responsive and dynamic way. This research informed a potential model of care which may help healthcare professionals introduce palliative care, and specialist respiratory care, early in the disease trajectory, whilst also encouraging the involvement of specialist palliative care for complex symptom management.

**Funded:** Department for Employment and Learning

**Abstract number:** P346

**Abstract type:** b

### Attitudes to Palliative Care and the Care of People with Intellectual Disability in the UK, Portugal and Nigeria

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**Aims:** The aim of this study was to compare the attitudes of medical and nursing staff towards palliative care across Portugal, Nigeria and the UK with the objective of looking at the attitudes to PC for people with intellectual disability (ID) in particular.

**Method:** Focus groups were held at the end of a study day for medical, nursing and social care professionals - UK 25, Nigeria 8, and Portugal 15 and semi-structured, open-ended questions were used.

**Results:** Profound differences in attitudes towards palliative care exist between the three countries.

In the UK there was greater awareness of palliative care, although this was often associated with end of life care. The awareness of palliative care of people with ID was variable. Few people had received any training in ID care and it was felt that people with ID could be excluded from decision making within palliative care and there were concerns about how to involve people with ID in their care plans.

In Portugal there was generally little understanding of palliative care and there was limited discussion of the topics of death and dying, with patients and families often having unrealistic expectations of treatment. People with ID were often cared for within institutions, although some were cared for at home.

In Nigeria there was awareness of palliative care, particularly for people with HIV and AIDS. Local developments are occurring, e.g. in Nigeria a Hospital Palliative Care Team has been established within the local Federal Hospital. People with ID were viewed as “different” and there were few resources to help in their care.

**Discussion:** There are profound differences in attitudes to palliative care, reflecting and affecting the development of services. Local developments may occur but there are often deeper cultural attitudes regarding the discussion of diagnosis and the discussion of care in different countries. The care of people with ID varies greatly and may reflect societal taboos.

**Abstract number:** P347

**Abstract type:** Poster

### Is there Room for Improvement? Assessing Skills and Confidence of Staff in a Renal Unit to Facilitate Advance Care Planning Discussions with Patients with End Stage Renal Disease?

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**Aims:** People with end stage renal disease (ESRD) at the end of life should be supported to live as fully as possible and enabled to die with dignity in a setting of their own choice. Advance care planning (ACP) allows people to discuss and outline their wishes and priorities of care. In the UK, 74% of people say they would prefer to die at home; in 2013, 49% of people died in hospital, in the dialysis population this is higher at 73%. We plan to pilot an ACP initiative in the renal unit. Prior to this, to assess

current practise we have shown in a retrospective case note review that ACP is poorly documented; a survey of health care professionals (HCP) has been performed to assess HCP's current views and confidence in regard to ACP. We report on the results of the survey.

**Methods:** An electronic 10 question survey was sent to HCP's within the renal team of a teaching hospital via email and weblink. Ethical approval was sought from Liverpool University ethics committee.

**Results:** 120 HCP's were contacted, with 59 respondents (29% doctors, 55% nurses and 16% allied HCP's). 70% felt ACP conversations were extremely beneficial. 34% felt confident/very confident in discussing prognosis, 28% confident /very confident in discussing death and dying and 29% confident/very confident in discussing that death may be imminent. HCP's reported having a discussion regarding; a patient's wishes for the future (51%), preferred place of death (50%), a patient refusing treatment (58%) and nominating a lasting power of attorney (25%). 35% of participants reported never having facilitated these discussions. 11 (22%) had completed an advanced communication skills course.

**Conclusion:** HCP's in nephrology recognise benefits of ACP, however confidence could be improved. Although HCP's report having had ACP discussions, from a recent review of case notes this is poorly documented. The effectiveness of ACP discussions is dependent on good communication and coordination of care.

**Abstract number:** P348

**Abstract type:** Poster

### Can We Enable Patients to Express Support Needs in Advanced Non-malignant Disease? Testing a Prototype Tool for Use within a New Support Needs Approach for Patients

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**Background:** The population-based Living with Breathlessness Study identified limited reporting of support needs to health care professionals (HCPs) by patients with advanced chronic obstructive pulmonary disease (COPD) and, crucially, the difficulties patients face in expressing their needs. This has important implications for support needs identification and response by HCPs.

**Aim:** To explore the feasibility and acceptability of a tool to enable expression of support needs in clinical practice by patients with advanced COPD.

**Methods:** Informed by, and modelled on, the evidence-based Carer Support Needs Assessment Tool approach (CSNAT) we developed a prototype tool to enable expression of support needs by patients. The prototype was self-completed by 147 patients with advanced COPD. The potential role of the tool in clinical practice was explored in qualitative interviews with a purposive sample of HCPs and in a stakeholder workshop. Data analysis included frequency counts (quantitative) and a framework approach (qualitative).

**Results:** The prototype tool enabled patients to consider and express a range of support needs: knowing what to expect in the future (36%), practical help (36%), understanding their illness (35%), looking after other health problems (35%), knowing who to contact if concerned (30%), managing symptoms and medications (30%), dealing with feelings and worries (27%), and accessing equipment (27%). Patients were also able to prioritise their needs. These unmet support needs existed despite (or because of) living with COPD for a median of 10 years. The prototype was well received by patients, HCPs and stakeholders who could envisage use in practice.

**Conclusions:** The tool is now being formally developed, grounded in patient data from the Living with Breathlessness Study, and will be tested within a person-centred approach for identifying and responding to patient-identified support needs.

**Funders:** Marie Curie & NIHR CDF.

**Abstract number:** P349

**Abstract type:** Poster

### End-of-Life Care of Patients with Idiopathic Pulmonary Fibrosis Shows Conflicting Practices

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**Background:** Idiopathic pulmonary fibrosis (IPF) is a progressive disease with median survival ranging from two to seven years. Since lung transplantation is the only curative treatment available early integrated palliative care should be offered to IPF patients.

**Aim:** The aim of the study was to describe the treatment practices and decision making during end-of-life (EOL) care of IPF patients in real life data.

**Methods:** Our study population consisted of 257 patients that were included in the Finnish IPF registry starting from January 2011 until May 2014, 61 patients had died during this time period. The final population consisted of 59 (two died abroad and thus data was missing). Death certificates and medical records from the last six months of life were analysed. We divided patients into three groups according

to place of death. The comparison between groups was made with X<sup>2</sup>-test.

**Results:** 51 (86%) patients died in hospitals and eight (14%) patients died at home. Palliative care or EOL-care decisions were made in 19 (32%) and DNR in 34 (58%) patients. All together 39 (66%) patients had one of three EOL-decisions made and from those 18(46%) were made ≤ 3 days prior to death. Seven patients were resuscitated, and 37 (79%) received antibiotics during the final hospital stay. During the last 24 hours of life, X-rays or laboratory tests were taken in 19% and 53% of the hospitalized patients, respectively (in tertiary hospitals 31% and 69%, in community hospitals 5 % and 33 %, p< 0.05). Opioids were prescribed to 71% of the patients during the last week before death.

**Conclusion:** Majority of IPF patients died in a hospital with life-prolonging procedures on going until the death. Frequent use of opioids describes the intention to relieve symptoms, but decisions on advanced directives were made very late. Early palliative care consultation and better recognition of the dying patient could improve EOL-care in IPF.

**Abstract number:** P350

**Abstract type:** Poster

### Retrospective Comparative Cohort Study of Patients With COPD and Lung Cancer Receiving Specialist Palliative Care: Symptom Burden and the SPC Response

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**Background:** Specialist Palliative Care (SPC) is of proven benefit for cancer patients. The expansion of SPC for patients with Chronic Obstructive Pulmonary Disease (COPD) has been recommended. At present our service provides SPC for patients with COPD and has tailored its response. The symptom burden of patients with COPD and Lung cancer in receipt of our SPC service has not been described, nor has the SPC response.

**Aims:** To describe the symptom burden of patients with COPD and lung cancer receiving SPC and to examine the SPC response.

**Methods:** A retrospective cohort comparative study was undertaken. A retrospective electronic database and chart review was performed. A specifically designed proforma was used to collect information regarding patient's demographics, symptoms, comorbidities and medications, and to examine each documented interaction for key words or concepts. Data was entered onto SPSS.

**Results:** Forty-seven patients with COPD were identified. A random sample of patients with lung cancer under the care of the service was generated. Here we present a

section of data from the larger study. Both cohorts had a high level of symptom burden. Patients with COPD had higher reported incidence of breathlessness, anxiety and depression. The lung cancer cohort was less likely to receive non pharmacological management of their symptoms. The COPD cohort were more likely to receive targeted therapy for symptoms e.g. breathlessness management and to have Physiotherapy and Occupational therapy input.

**Conclusion:** The SPC response to patients with COPD has evolved and become more tailored.

Further research is required to evaluate the effectiveness of the response.

**Abstract number:** P351

**Abstract type:** Poster

### Recruitment Challenges Experienced with Patients with Advanced Chronic Heart Failure

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**Background:** There is a paucity of research on the palliative care needs of advanced chronic heart failure (ACHF) patients and recruitment is recognised as challenging.

**Aim:** To describe the recruitment challenges experienced in identifying ACHF patients and describe solutions to address these.

**Methods:** ACHF patients and their unpaid caregivers were recruited as they attended 2 nurse-led heart failure disease management clinics for a feasibility patient-reported outcome study using a longitudinal design.

**Results:** The New York Heart Association (NYHA) functional class subjectivity undermines its use in inclusion criteria for ACHF patients. Neither it nor the European Society of Cardiology's ACHF definition capture the progressive but fluctuating nature of ACHF, where symptomatically stable patients have a high mortality risk and potential palliative care needs. Inclusion of NYHA functional class II and removal of a heart-related hospitalisation in the preceding 6 months substantially increased the median monthly numbers of eligible patients approached

(8 to 20) and median numbers recruited (4 to 9). With these inclusion criteria adjustments, recruited patients still had a median 1-year mortality risk of 22.7 using a validated cumulative risk score. Eligible patients could only be approached as they attended the clinic which necessitated a prolonged recruitment period of 6 months.

**Conclusion:** Potential solutions to increase recruitment include; a validated cumulative risk score to identify patients with a 1 year mortality score of > 20% regardless of symptom burden with potential palliative care needs and a research register of ACHF patients to facilitate direct researcher-patient contact to identify potential patient participants.

**Abstract number:** P352

**Abstract type:** Poster

### Improving Care in the Community for People with Advanced Liver Disease: Feasibility Trial of a Nurse-led Intervention

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**Background and aims:** Liver disease is the third commonest cause of premature death in the UK, but palliative care for these patients is poorly developed. We tested the feasibility of delivering and evaluating an innovative complex intervention provided by a supportive care liver nurse specialist to improve care coordination, anticipatory care planning and quality of life for people with advanced liver disease and their carers.

**Study population:** Patients with advanced, progressive liver disease with one or more unplanned hospital admissions due to decompensated cirrhosis from any cause, and their family carers.

**Study design and methods:** Mixed-methods feasibility trial. Patients/carers received a 6-month intervention from

the nurse specialist who acted as case manager and coordinator, supported patients and carers to live as well as possible with the illness, and enhanced care delivered by community-based professionals. We used validated questionnaires and routine data to assess resource use, care planning processes and quality of life outcomes. Qualitative interviews with patients, carers and professionals explored acceptability, effectiveness, feasibility and refinements to the intervention.

**Results:** The intervention and evaluation were acceptable and feasible. The supportive care liver nurse specialist improved the care experienced by patients and families by facilitating continuity of care, care coordination and better communication across health and social care settings. Patients' poor understanding of the life-limiting nature of their condition made initiating care planning conversations difficult. Cost-effectiveness was indicated by the nurse's potential to reduce unplanned hospital admissions.

**Conclusion:** We successfully tested recruitment processes, candidate primary and secondary outcome measures and refined an acceptable intervention for a future multi-site RCT.

**Funder:** Chief Scientist Office Scotland.

**Abstract number:** P353

**Abstract type:** Poster

### Screening for Poor Prognosis Identifies Patients with Advanced Liver Disease who Stand to Benefit from Timely Palliative Care Intervention

*Hudson, Benjamin<sup>1</sup>, Verne, Julia<sup>2</sup>, Forbes, Karen<sup>3</sup>, McCune, Anne<sup>1</sup>*

No. of criteria positive	Number of patients (n=47)	Sensitivity (1 yr mortality)	Specificity (1 yr mortality)
2 or above	37	100	62
3 or above	21	81	81
4 or above	3	10	96

*[Accuracy of tool for predicting 1 year mortality]*

**Conclusions:** The tool has been successfully trialled over the past year. Patients who screen positive are highlighted for discussion at a weekly hepatology MDT. Assuming MDT agreement this triggers a consultant led poor prognosis discussion with the patient, a poor prognosis letter to the GP, and involvement of the palliative medicine team.

**Abstract number:** P354

**Abstract type:** B

### A Pharmacist Led Falls Prevention Focused Medication Review in a Specialist Palliative Care Inpatient Service

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**Introduction:** Liver disease is the 3rd commonest cause of premature death in the UK. Recent UK data demonstrated that only 19% of patients assessed unsuitable for liver transplantation were referred to palliative care services, a median of 4 days before death.

We aimed to design and validate a tool to identify inpatients with liver disease who stand to benefit from palliative care assessment and advanced care planning, and to create a model of care for such patients.

**Methods:** The department of health document 'Getting it Right: improving end of life care for people living with liver disease' identifies evidence based factors which are predictive of death in liver disease. Five of these factors (Childs Pugh C, >2 admissions within last 6 months, continued use of alcohol, unsuitable for liver transplantation, pre-admission WHO performance status >2) were assimilated into a simple screening tool for use by junior doctors admitting patients to the hepatology ward.

**Results:** The tool was retrospectively applied to all patients admitted to the Bristol Royal Infirmary with a diagnosis of cirrhosis over 90 consecutive days from 1st July 2013 (n=47). Mortality one year post admission was calculated. Sensitivity and specificity for predicting one year mortality when 2, 3 or 4 poor prognostic criteria were positive were analysed. On this basis, an admission score of 3 or more criteria was considered a "positive" poor prognosis screen.

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**Background:** Falling is a multifactorial event with a wide range of risk factors, including medications and polypharmacy. A study found that 50% of adults with advanced cancer will experience a fall associated with a high risk of physical injury.

**Aims:** To evaluate the implementation of a pharmacist led falls prevention focused medication review in a specialist palliative care inpatient service.

**Methods:** 55 consecutive admissions to the specialist palliative care inpatient service underwent medication review focused on falls prevention by the clinical pharmacist. The total number and type of falls risk medications (FRM) and the total number of medications in use for each patient were reviewed with the multi-disciplinary team.

**Results:** The mean number of medications prescribed to each patient was 10.9 ( $\pm 4.3$ ). The mean number of falls risk medications prescribed to each patient was 3.5 ( $\pm 1.6$ ). Changes were made to 11% of prescribed FRM. Cardiovascular drugs accounted for 82% of medication changes, namely, beta-blockers (31.8%), ACE/ARB (18.1%), diuretics (13.6%), alpha blockers (9.1%), antianginal agents (4.5%), and calcium channel blockers (4.5%). In all of these cases the medication was stopped and not switched to another agent.

**Conclusion:** Medication reviews aimed at falls prevention in the specialist palliative care population involve balancing the need for minimising medications associated with falls with managing co-morbidities and ensuring effective symptom control.

We found that 11% of falls risk medications identified were suitable for change; 82% of changes were to cardiovascular drugs. Medication reviews focusing on cardiovascular drugs have the potential to yield most of the results of more extensive falls prevention focused medication reviews. This finding will inform the development of future falls risk medication review programmes specific to this patient cohort, increasing their feasibility in the hospice setting.

**Abstract number:** P355

**Abstract type:** Poster

### **A Physical Exercise Programme for Patients with Parkinson's Disease in an Outpatient Palliative Care Setting - A Feasibility Study**

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**Introduction:** Parkinson's disease (PD) is a neurological disorder that leads to progressive disability. Exercise programmes may be an effective strategy to delay or reverse functional decline for patients with PD.

**Aim:** To assess the effectiveness of a physiotherapy led exercise programme on outcomes (gait, bed mobility, balance, frequency and fear of falls and quality of life) for patients with PD.

**Design:** A small scale feasibility study with a single patient cohort using a pre-test and post-test design.

**Methods:** The programme which ran for eight weeks was undertaken in Marie Curie Hospice Belfast. Initially each patient was assessed at baseline using standardised tools. These included the Lindop Parkinson's Assessment Scale (LPAS), Fall's Efficacy Scale (FES-I), Falls Event Questionnaire and EQ-5D-5L. The treatment was group based, the exercises were evidence based and tailored to each patient with a focus on progressively increasing intensity and complexity. Following the programme patients were re assessed using the same set of standardised tools.

**Results:** Four patients with mild to moderate Parkinson's Disease were invited to participate in the study (3:1 female:male; median age 55 years; Hoehn & Yahr stages 11 and 111). All patients completed the 8 week programme. Three out of four patients improved in their Quality of Life (QoL) scores and reported an improvement in their overall health. All patients reported a decrease in their concern regarding falling during everyday tasks and the frequency of recurrent falls and near misses fell during the period of the exercise programme. All the patients performed the tasks related to bed mobility quicker and displayed an increase performance in their balance measures.

**Conclusions:** Overall the results of this feasibility study indicate that this patient population would be able to participate in a large scale trial allowing formal assessment of this therapeutic intervention.

## EAPC 2016: Print Only Abstracts

### Pain

**Abstract number:** PO1

**Abstract type:** Print Only

#### Improving the Safety Profile of Alfentanil in a UK Cancer Centre

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**Background:** Alfentanil is an synthetic opioid used in cancer pain. Indications include

- (i) *renal impairment* (inactive metabolites) and
- (ii) *'switching'* due to opioid toxicity.

Local guidelines were published in 2013 to improve safe prescribing and use of alfentanil.

**Aims:** Retrospectively audit use of alfentanil in the PC setting against local guidelines introduced in 2013.

**Methods:** Patients prescribed subcutaneous alfentanil were identified (January to December 2014). Notes were reviewed against standards:

- Alfentanil should be initiated in consultation with the PC or pain team
- Indication should be documented
- In opioid naïve patients, the starting dose should be 0.5-1mg/24hrs
- If converting to alfentanil from another strong opioid, document calculation
- The PRN alfentanil dose should be 1/10<sup>th</sup> background dose.

**Results:** 57 patients were identified: 52 patient notes were available. Alfentanil was started following discussion with PC team in 96% (50/52) in 2014 (98% (39/40) in 2012). Starting indication was documented in 77% (40/52) compared with 85% (34/40) in 2012:

- (i) Renal impairment, 54% (28/52), average eGFR 32ml/min/1.73m<sup>2</sup> compared to 60% (24/40) in 2012 (median creatinine was 188mmol/L)
- (ii) Opioid 'switch' in 22/52 (42%) in 2014 (16/40 (40%) in 2012).

Conversion calculations were documented in 62% (29/47) in 2014(16% (5/32) in 2012). Appropriate dose of PRN alfentanil was prescribed in 28/33 cases(85%).

**Conclusions:** Alfentanil prescribing practice has changed since local guidelines were published, with more prescribers documenting conversion calculations and prescribing appropriate 'as required' doses. Fewer patients had the starting indication for alfentanil indicated in the notes despite a similar proportion being initiated on PC team advice - this is an area for improvement More patients were discharged on alfentanil in 2014 (25% (2014),10% (2012) which suggests need for specialist support for community palliative care teams and GPs.

**Abstract number:** PO2

**Abstract type:** Print Only

#### The Efficacy and Safety of Oral Methadone Conversion Using the Blackburn Method in an Acute Hospital Setting: A Case Series

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**Background:** Methadone is a commonly used opioid for the treatment of refractory pain due to advanced cancer. In the UK, most methadone conversions take place in a specialist palliative care unit, due to variations in half-life, relative analgesic potency and duration of action. A number of methods for methadone conversion have been described. **Objectives:** To evaluate the safety and efficacy of the Blackburn method of methadone conversion in a tertiary hospital in the United Kingdom for patients with advanced cancer whose pain is not controlled on strong opioids.

**Methods:** Retrospective case note review of patients undergoing conversion to methadone from an alternative opioid. We calculated the initial and discharge dose ratio between the admission morphine-equivalent daily dose (MEDD) and oral methadone dose. Pain assessment was made daily with reference to a 5 point Likert scale. Serious adverse events and side effects were recorded.

**Results:** Data from 25 patients was evaluable. The mean MEDD prior to methadone conversion was 240mg. The mean dose ratio between the admission MEDD and oral methadone on discharge was 9.6. 80% of patients required less PRN analgesia on day 3 than on admission. No episodes of significant pain flare were associated with the methadone conversion and no patient's pain was worse on discharge than on admission. On discharge, 36% of patients reported that their pain was significantly better than on admission, 48% of patients reported that their pain was moderately better and 12% of patients pain was slightly better and 4% did not notice a difference in pain.

No significant adverse events were noted. The most common side effect was drowsiness, affecting 40% patients. In none of the patients was the drowsiness sufficient to warrant omission of next methadone dose. The average length of stay was 6.6 days.

**Conclusion:** The Blackburn method provides a safe and efficacious way in which to change patients to oral methadone in the acute setting.

**Abstract number:** PO3

**Abstract type:** Print Only

### The Effectiveness of the Symptoms Other than Pain for the Start of Opioid Therapy

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**Background:** The management of cancer pain by opioid treatment is one of the important cures in maintenance of highly quality-of-life for cancer patients. Tapentadol (TAP), a new dual-action opioid, is a recommended drug for the initial use of opioid to cancer pain in the newest EAPC cancer pain guideline.

**Aim:** To explore the best starting timing of TAP treatment for the management of cancer pain by identifying some symptoms other than pain intensity that are effective for recognizing the proper starting timing of TAP treatment.

**Methods:** This study was investigated in 58 cancer patients. They were treated with TAP twice daily from August 2014 to June 2015. They were divided into two groups with (group1, n=26) or without (group2, n=32) pain at the beginning of TAP treatment. Patients in the group2 were started with minimum TAP when they have several symptoms such as anorexia, abdominal distention insomnia, fatigue and irritation. Pain was scored by the numeric rating scale (NRS) averaged for a day.

**Results:** There were no significant differences in the observation period between group1 and 2 ( $32.2 \pm 15.6$  and  $34.7 \pm 21.1$  days). In group2, the average dose of TAP was lower than that in group1 ( $70.7 \pm 47.1$  mg/day vs.  $115.4 \pm 75.3$  mg/day). The maximum length of period with NRS0 was significantly longer in group2 than that in group1 ( $19.3 \pm 17.0$  days vs.  $3.6 \pm 3.9$  days,  $p < 0.0001$ ). Moreover, the percentages of the days with NRS0 into total observation days were also significantly higher in group2 than in group1 ( $54.5 \pm 27.1\%$  vs.  $15.7 \pm 21.8\%$ ,  $p < 0.0001$ ). In this study, side-effects of TAP treatment were hardly observed and thus any therapeutic medicines for constipation or vomiting were not used.

**Conclusion:** The present results suggest that some symptoms other than pain are also useful sign for the start of

TAP treatment. In addition, TAP is effective and well tolerated in opioid-naïve cancer patients.

**Abstract number:** PO4

**Abstract type:** Print Only

### Practice and Factors Associated with Pain Management among Physicians, Addis Ababa, Ethiopia

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**Introduction:** The practice of pain management by health professionals is poor and is a Public Health problem. This study aimed to measure pain management practice and determined factors associated with pain management among physicians working in public hospitals, Addis Ababa.

**Problem statement:** Pain is poorly treated in Ethiopia. Furthermore, there is fear of prescribing opioids, poor pain assessment, and pain rating practice amongst physicians. Professional and system related factors are amongst the main issues that hamper pain management.

**Methodology:** A cross sectional study design was conducted on 344 physicians. A single population proportion formula was used to determine sample size and convenience sampling was used. Data were collected using a pretested self-administered questionnaire. Descriptive statistics are used to present the data. Odds ratio with 95% confidence interval and logistic regression analysis were employed to measure the degree of association between the practice and factors associated with pain management.

**Conclusion:** Pain management practice is poor in 285 (83%) of participants. Hence, 198 (58%) of physicians do not measure pain using a scale and 109 (32%) do not perform physical examination whilst assessing patients for pain. Moreover, 280 (81%) of physicians do not prescribe opioids for pain management even if a patient requires.

Factors such as poor level of knowledge, insufficient time, inadequate training in medical school, unavailability of pain relieving drugs, and poor attitude are associated factors hampering the practice of pain management in public hospitals, Addis Ababa.

**Recommendations:** Improve knowledge of physicians regarding pain management through training. The number of clinical officers and

**Abstract number:** PO5

**Abstract type:** Print Only

### Interdisciplinary Pain Management Programmes for Chronic Pain: A Systematic Review of effectiveness and Development of a Programme for Palliative Care

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**Background:** As patients live longer with life-limiting conditions and present earlier to palliative care services, the prevalence of chronic pain will increase. Interdisciplinary programmes offer comprehensive management, where the treatment target may be to improve function without changing symptom intensity.

**Aims:** To evaluate the effectiveness of interdisciplinary pain management programmes (PMP) on pain intensity, psychological wellbeing, physical function and quality-of-life in patients with chronic pain, to inform a programme for study in palliative care.

**Methods:** Studies were identified from systematic searches of Medline, Embase, Cinahl and PsycINFO databases to Oct. 2014, citation searches and conference proceedings. Included studies were randomized controlled trials for all conditions and causes of chronic pain, where PMPs consisted of a physical and psychosocial component. Quality assessment was carried out using the Cochrane Collaboration tool for assessing risk-of-bias. Narrative synthesis was performed. The 'single-trial-based choice' method was used to aid intervention selection.

**Results:** 12 studies involving 1528 participants (age 26-95 years) met the inclusion criteria across low-back pain (5 studies, n=607), fibromyalgia (2 studies, n=338) and chronic pain of mixed-origin (5 studies, n=583). There was moderate and high risk-of-bias in 2 and 10 studies respectively. Effect sizes ranged from 0.14–0.43 (pain) 0.05–0.95 (physical function) 0.37-0.93 (psychological outcomes/quality-of-life). A moderate-intensity PMP used in older adults was selected for modified use in palliative care.

**Conclusion:** PMPs can lead to improvements in physical function and aspects of quality-of-life in people living with chronic pain, which do not necessitate a concurrent reduction in pain intensity. Heterogeneity and methodological limitations limit the strength of evidence. Further modelling and feasibility testing is required to begin evaluation within palliative care.

**Abstract number:** PO6

**Abstract type:** Print Only

### Opioid Conversion Ratios: An Audit of Practice

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**Background:** There is no absolute mathematical formula that may be consistently applied to give a precise 'equivalent' dose when converting from one opioid to another.

All published 'conversion ratios' serve to provide a rough indication of the approximate potency equivalence.

**Aim:** To examine current practice in our specialist palliative care unit regarding opioid conversion ratios in common use.

**Standard:** that there should be just one such ratio for each opioid in use.

**Methodology:** All opioid to opioid conversions over 6 week period were documented.

Start/end opioid, along with ratio used, calculation made & dose adjustments were included.

**Findings:** 29 overall conversions resulted in 42 interdrug calculations.

Most common rotations:

Oxycodone > Morphine (5)

Oxycodone > Hydromorphone (5)

Morphine > Fentanyl (4)

Morphine > Oxycodone (3)

Ratios in use:

**Morphine > Oxycodone 2:1 (17); 1.5:1 (1)**

**Morphine > Hydromorphone 7.5:1 (5); 10:1 (2)**

Morphine > Alfentanil 30:1 (3)

Morphine > Codeine 1:10 (1)

Morphine > Fentanyl 100:1 (7)

**Morphine > Buprenorphine 75:1 (1); 62.5:1\* (3); 83:1\* (2)**

\*Conversions using equivalence chart

**Conclusion:** There were multiple ratios in use for three different opioid to opioid conversions. This could lead to patient risk & unsafe practice. To improve practice, we propose new opioid conversion guidelines & have designed a new opioid conversion chart which can be used to aid staff in safely converting from one opioid to another. This will be supplemented by education sessions for all medical & nursing staff. Reaudit is currently in progress to assess the effectiveness of our intervention.

**Abstract number:** PO7

**Abstract type:** Print Only

### Intrathecal Analgesia in Cancer Pain - Is it Worth it?

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**Background:** Intrathecal analgesia is known to reduce pain in patients where conventional systemic analgesia has

been ineffective or intolerable. However there is little evidence on how this intervention affects quality of life (QOL).

**Aim:** To explore how intrathecal analgesia affects QOL in patients with advanced progressive cancer and severe uncontrolled pain and/or intolerable side effects.

**Methods:** Qualitative interviews were undertaken with relatives of deceased individuals who had intrathecal analgesia (external system) as part of their pain control. Interviews were analysed using thematic analysis.

**Results:** 11 interviews were conducted in two UK centres with established intrathecal services. The emerging themes were:

- i) 'making the decision to have the intrathecal' (relatives described desperate situations with very severe pain and/or sedation, in which the suffering individual would try anything);
- ii) 'knowing they were having the best' (intrathecal analgesia, with the associated increased access to pain and palliative care services, meant relatives felt everything possible was being done, making the situation more bearable);
- iii) 'was it worth it?' (the success of the intrathecal was judged on whether it enabled the individual to be themselves through their final illness and dying phase, not simply on improved pain control); and
- iv) 'not without its problems' (a range of significant side effects were described, however these were considered to be acceptable, if the intrathecal acted to enable self expression).

**Conclusion:** Intrathecal analgesia was perceived to be of greatest value when it achieved quality of time by controlling pain and enabling individuals to be themselves through their final illness and dying phase; under these circumstances significant side effects were judged to be acceptable.

**Abstract number:** PO8

**Abstract type:** Print Only

#### Adhesion Levels of Fentanyl Transdermal Products

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**Objective:** We reported that the remaining drug rate varies even when applying a fentanyl transdermal product

(Fentos® Tape) to the same patient. The present study examined variations in the adhesion levels of such products among different methods of attachment.

**Methods:** With cooperation from 15 adults, an experiment was conducted using the following materials: sample Fentos® Tape without containing drugs (tape), MiTAC Label® (label), General Sol Carbon Paper (carbon paper), and arm simulator. The label or tape was attached, adopting one of the following 4 methods, and its adhesion level was evaluated using the carbon paper placed on the simulator:

- (1) attaching without any special technique;
- (2) mildly holding the target site with the hand for 30 seconds after attachment;
- (3) applying pressure on the entire target site using the fingers after attachment; and
- (4) applying pressure on the entire target site using the fingers and holding it with the hand for 10 seconds after attachment.

The pasting surface of the label or tape was separated from the carbon paper, and scanned. Obtained images were analyzed, and coated areas were calculated. Tukey's multiple comparison test was conducted.

**Results:** Significant differences between the following methods were observed: label: (1)(2), (1)(3), (1)(4), (2)(3) and (3)(4); tape: (1)(2), (1)(3), (1)(4) and (3)(4).

**Conclusion:** Method (1) showed significant differences from (2), (3) and (4), supporting the usefulness of manual techniques to increase the adhesion level. When adopting methods (2) and (3), it is still difficult to cover the entire target site with the hand. Based on these findings, it may be appropriate to regard (4) as the most effective method to increase the adhesion level. The skin condition varies among patients, and the skin surface at the site of attachment may be rough. The results of this study suggest that (4) may contribute to appropriate attachment.

There is no conflict of interest.

**Abstract number:** PO9

**Abstract type:** Print Only

#### The Process of Pain Assessment in Elderly Cancer Patients with Dementia

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**Background:** Reports state that pain is underestimated and undertreated in cancer patients with dementia, and thus in order to successfully manage pain in elderly cancer patients with dementia, detailed and continuous nursing assessments are essential.

**Purpose:** To elucidate the process in which cancer pain is determined in elderly cancer patients with dementia.

**Research approach:** Qualitative

**Setting:** Palliative care wards, general care wards, and visiting nursing stations in Japan

**Participants:** Nine nurses in their fifth or more years as nurses who have experience of successfully managing pain in cancer patients with dementia aged  $\geq 65$  years.

**Methodologic approach:** Participant observations of care settings and semi-structured interviews.

**Findings:** The following nine categories were extracted from the collected data.

- 1) Understanding the patient's essential personality traits;
- 2) Picking up on comparative changes in everyday status indicators;
- 3) Determining whether the patient is at peace or experiencing discomfort;
- 4) Assessing the patient's characteristic means of expressing pain and ability to express pain;
- 5) Looking for the patient's characteristic pain indicators;
- 6) Determining whether an observed symptom is pain or another symptom;
- 7) Observing the patient with consideration of the possibility of cancer pain;
- 8) Determining cases in which there are multiple, continuous pain indicators to indicate an increase in pain; 9) Sharing information regarding the patient's individual traits and pain with team members.

**Interpretation:** Nurses determined the presence or absence and degree of pain using individualized indicators for each patient based on diverse information about the patient. These indicators highlighted the instincts and wisdom that constituted the experiential knowledge of the nurses. However, more data must be collected in the future in order to convert this experiential knowledge into explicit knowledge.

**Abstract number:** PO10

**Abstract type:** Print Only

### **The Pain of the Elderly in Nursing Homes: A Descriptive Study**

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By 2050, estimates indicate that more than one quarter of the population of the European Region will be aged 65

years and older. In Spain, this is likely to rise to more than one third of the population\*. Authors found that 45-80% of nursing home residents have substantial pain that is undertreated.

**Aims:** To analyze the socio-demographic, clinical profile and management of pain of elderly patients with need for palliative care in a nursing home.

**Study population:** In the period of study, a total of 170 residents lived in nursing home and 29 patients met the inclusion criteria: clinical deterioration evaluated by nurses and  $\leq 50$  points score Karnofsky Index (KPS).

**Study design and method:** A descriptive, longitudinal and prospective study, in a nursing home of southeastern Spain, between March and August 2015. Socio-demographic, clinical variables were collected using the patient's clinical history and observation with the VAS pain scale and PAINAD. The descriptive statistical analysis was carried out using SPSS v.17.

**Results and interpretation:** 79.3 % were females, who had a mean age of 86 years (79% was more 90 years old). 84.6% who died was in the nursing home. Most had pluripathology with 4 to 7 chronic pathologies (69%) and the totality suffered pathology musculoskeletal so it increases the risk of pain. The chronic pain with pain episodes breakthrough is the most prevalent (44.8%). 13.8% was in the last step of WHO stepwise (48.3% use morphine and 96.6% use adjuvants). The average pain without activity was reduced from 3.37 to 1.63 ( $p=0.001$ ); and in activity from 4.79 to 3.37 ( $p=0.02$ ). The patient with severe pain in activity was reduced from 46.2% to 5.3%. Palliative care should be integrated into chronic disease management in nursing homes.

\*Palliative care for older people: better practices. Copenhagen. Publications WHO Regional Office for Europe, 2011.

**Abstract number:** PO11

**Abstract type:** Print Only

### **“ Living with Pain - The Life from Childrens and Adolescents in Palliative Care”**

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**Background/aims:** Pain is a stressful event for children and adolescents and can have some negative consequences even more when is accompanied by a chronic disease with no possibility of cure. The pain it is quite experienced by children and adolescents in situation of chronic disease

and in the end of life care, sometimes it is necessary since childhood until adulthood. The focus on Palliative Care is to provide the highest quality of life possible to children, adolescents and their families while minimizing suffering and pain. The main objective of this study is knowing the daily experience of children and adolescents in Palliative Care, and knowing how they manage pain in their daily lives.

**Methods:** Considering the uniqueness of the experience of children and adolescents in Palliative Care, we chose to develop a qualitative study. We use the Oral History as a methodological framework, these framework allow that children and adolescents (from 6 to 17 years 11 months and 29 days), have a voice.

**Results:** We have interviewed six children and adolescents, all have chronic disease and pain. We found three themes: Describing pain; Using a variety of alternatives for pain control and; Being normal despite pain and disease.

**Conclusion:** Despite the difficulty of interviewing children and teenagers, we have realized that they deal with pain in their daily lives. Although pain is a limiting factor in the lives of children and adolescents, we found that they faced their daily pain and still had a life beyond pain and illness. In addition, we highlight the relevance of nurses understanding that effective management of pain in children is essential for a normal life and less suffering.

**Abstract number:** PO12

**Abstract type:** Print Only

### Oral Health Assessment of Cancer Patient in Exclusive Palliative Care in Barretos Cancer Hospital, Brazil

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Pain is a major problem for patients with terminal cancer. Pain control is a key to the understanding of "good death" and should be associated with work of the multidisciplinary team, where the dentist is present. This study aimed to evaluate the oral health status of 93 (100%) patients under palliative care exclusive admitted to the Barretos Cancer Hospital, in the Palliative Care Unit. Tests were performed to evaluate the plaque index (PI) (Silness and Loe, 1964), DMFT index (decayed, missed, blocked off and destroyed) (Klein and Palmer, 1937), gingival bleeding index (IS) (Loe and Silness, 1963), presence of intra and extra oral lesions, use of intra oral prosthesis, the presence of oral candidiasis and xerostomia. Among the results found, 63 (67.7%) patients aged 65 or superior 65, 61 (65.6%) patients were caucasian and 66 (71%) patients

had low education. 43 (46.7%) patients had gingivitis and 23 (24.6%) patients had high DMFT index. 46 (49.5%) patients presented xerostomia and 16 (17.2%) oral candidiasis in the intra oral examination. From the observed results, it was concluded that the presence of the dentist in the multidisciplinary team is of great importance in the treatment and prevention of oral and systemic complications that may trigger pain, which can further compromise the health of patients under oncology palliative care compromising even more the quality of life.

**Abstract number:** PO13

**Abstract type:** Print Only

### Cultural influence on Chinese background cancer patients' pain management beliefs, needs and practices: a Systematic Review of both Chinese and English Language Research Literatures

*Xu, Xiangfeng<sup>1</sup>, Luckett, Tim<sup>1</sup>, Wang, Yueping Alex<sup>1</sup>, Lovell, Melanie<sup>2</sup>, Philips, Jane L.<sup>1</sup>*

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**Background/Aims:** More than half of cancer patients experience unrelieved pain. Chinese background cancer patients' cultural beliefs and attitudes may influence their pain reporting and management practices which requires better understanding. This study aims to explore Chinese background cancer patients' experiences, attitudes, beliefs and needs concerning pain and its management; and barriers/facilitators to optimal pain management.

**Methods:** A systematic review adhering to the PRISMA Statement conducted in mid-2015. The comprehensive search was undertaken to identify peer reviewed articles published in English or Chinese between 1990-2015 with self-reported primary data on pain and management in Chinese background adult cancer patients.

**Results:** Of the 3904 identified manuscripts, 19 primary studies from Chinese (n=8) and English database (n=15) included which involved Chinese adult cancer patients from mainland China (n=3714 inpatients), Hong Kong (n=86 inpatients) and Taiwan (n=2208 inpatient and 102 outpatients). The barriers prevented Chinese background cancer patients from reporting their pain, using analgesic/adherence to pain treatment and resulted in uncontrolled cancer pain were: 1) patient/family related barriers: beliefs to cancer pain and/or to analgesics, 2) health provider related barriers, 3) system barriers. Few of these articles reported Chinese cancer patients' use and/or beliefs to non-pharmacological or traditional Chinese mediations for pain management and none of them explored the pain management perspectives of Chinese patients living in high income English speaking countries, including Australia.

**Conclusion:** The literature suggests that Chinese background cancer patients' beliefs may present barriers to pain relief even in their home country. Research is needed to understand whether these barriers are compounded further when patients migrate to Western countries and use of non-pharmacological and traditional Chinese mediations.

**Abstract number:** PO14

**Abstract type:** Print Only

### Opioid Analgesics Accessibility in Poland

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Opioid analgesics play key role in the management of cancer pain. Most of them are accessible for in Poland, however still their consumption is much lower than in many other European countries and USA. Referring to this fact there were investigated opioid analgesics consumption level and its dynamics in Poland in 2000-2013, current treatment pattern and the barriers to the adequate and in time cancer pain treatment.

The annual sales data 2010-2013 were analyzed. The qualitative analysis of the possible barriers to easy access of opioid analgesics was performed. The opioid analgesics consumption per capita was continuously growing and was 3-fold higher in 2013 than in 2000. Yet the therapy pattern does not reflect the EAPC 2012 cancer pain pharmacotherapy guidelines. The most frequently used analgesics remains fentanyl, followed by morphine and buprenorphine. Buprenorphine is the most quickly growing opioid analgesic, mostly due to favorable reimbursement status and the fact it is the only strong opioid analgesic provided by a regular prescription form in Poland. Financial and non-financial barriers to opioid analgesics accessibility in Poland were indentified. The evident barrier to analgesics accessibility is the effective patient price as a result of the reimbursement status of medicine. The consistent insisting on the authorities in Poland, based on the EBM and the current EAPC guidelines, resulted in achieving reimbursement for some new opioid formulations. Still there is unequal accessibility to opioid analgesics between cancer and non-cancer patients, as well as between outpatient and inpatient care patients. Some of them, like formal and legal, were successfully disposed of after close cooperation with the Ministry of Health. This might appear helpful for other countries struggling against similar obstacles.

### Symptoms other than pain

**Abstract number:** PO15

**Abstract type:** Print Only

### Presentation to the Emergency Department by Breathless Patients: A Qualitative Study

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**Background:** Chronic breathlessness is common in cardiorespiratory conditions and is associated with emergency department (ED) attendance. We aimed to explore the clinical pathways used by breathless people and how they made the decision to present to the ED.

**Methods:** Semi-structured interviews with people who had recently presented to the ED because of acute-on-chronic breathlessness, their carer and a nominated clinician were conducted. The experience of living with, or caring for people with, breathlessness, help-seeking for symptoms and the decision to present was explored. The interviews were recorded, transcribed verbatim and analysed using thematic analysis. Data were managed using NVivo.

**Results:** Eighteen patients were interviewed, nine with a carer. Eight clinicians were interviewed later. Six major themes were found: biopsychosocial effects of breathlessness, coping style, help-seeking pattern, clinician response to patients' breathlessness (as distinct from the underlying disease), access to help, help-seeking tension and the need for "rescue". The person's coping style, help-seeking pattern and clinician responsiveness to breathlessness influences their life with breathlessness. The decision to present to primary care clinicians or to the ED involves tension on the part of the patient and carer. Presentation occurs when urgent "rescue" is needed, when access to primary care clinicians is limited, or when directed by a clinician.

**Conclusion:** ED attendance by people with chronic breathlessness is in the context of their daily lived experience. The person's coping style, help-seeking pattern and the responsiveness of their clinician to the symptom frames the way they live with breathlessness. It is important that patients, carers and clinicians work together to manage breathlessness to optimise quality of life and to minimise the need for emergency presentation.

**Abstract number:** PO16

**Abstract type:** Print Only

### The Impact of Taste Testing of Products for the Treatment of Xerostomia on the Prescribing Practice of Palliative Clinicians

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**Background:** Xerostomia (dry mouth) has an incidence of 60-80% in patients with advanced cancer. Palliative practitioners use a variety of products for treating xerostomia, often based on familiarity.

**Aim:** With an absence of a clear evidence base, issues such as taste are important when considering compliance. We hypothesise that if palliative practitioners were more familiar with the taste of these products then this would impact positively on their prescribing practice.

**Design:** Palliative practitioners were invited to participate in taste testing of commonly used products for xerostomia. Rankings of prescribing preferences were taken before, immediately after and at one month post taste testing. Products were ranked for their taste, palatability, and perceived effectiveness.

**Participants:** Nine consultants and three registrars in palliative medicine, and thirty Community Hospice Nurses from across Northern Ireland.

**Results:** Pre-taste testing the most popular products were Biotène Oralbalance® gel, Biotène moisturising® mouthwash, Glandosane® natural spray, sugar free chewing gum, and sips of water. The saliva replacement sprays were most frequently scored as unpleasant during testing. Following tasting the most popular products were Biotène Moisturising® mouth wash, sugar free chewing gum, Salivix® pastilles, sips of water, and Biotène Oralbalance® gel. A sustained change in prescribing practice was demonstrated during follow up.

**Conclusions:** This study highlights the positive impact of taste testing on the prescribing practice of palliative specialists, with sustained changes that should result in improved patient compliance with treatments. This can form the basis for further research into the effectiveness of these products in palliative patients with xerostomia.

**Abstract number:** PO17

**Abstract type:** Print Only

**Retrospective Study of Referrals to a Specialist Palliative Care Breathlessness Management Programme Our Lady's Hospice and Care Services (OLH&CS) Dublin and of Patient Outcomes**

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**Background:** Specialist Palliative Care (SPC) is of proven benefit for cancer patients. The expansion of SPC for patients with non-malignant chronic lung disease has been recommended. This institution provides SPC for patients with COPD and Idiopathic Pulmonary Fibrosis (IPF) and runs a nurse specialist led breathlessness management programme (BMP) offering multidisciplinary care.

**Aim:** To assess the needs/patterns of service utilisation of patients referred to the BMP during 2012 together with patient outcomes over a 30 month follow up period.

**Methods:** Retrospective electronic database and chart review. All consecutive patients referred to the BMP over a 12 month period during 2012 were included and data collected on patient outcomes to June 2015. Data was entered onto SPSS

**Results:** 15 patients attended the BMP (8 female, 7 male); mean age 73 (63-86 years). 80% had a diagnosis of COPD; 20% IPF. COPD patients were referred on average 7 years post diagnosis

(1-7 years). All IPF patients were referred within a year of diagnosis. 66% of patients completed the programme; 12.5% (all IPF) died during the programme. On completion of the BMP, 20% were discharged while 80% continued to attend a nurse led OPD. After completion of the BMP, 42% were ultimately referred to a community palliative care team (CPCT), 30% referred to day hospice, and 58% subsequently admitted to the specialist palliative care inpatient unit (SPCIPU). Those referred to the CPCT attended for an average of 71 weeks (15-120 weeks) and those attending the day hospice attended for an average of 34 weeks (17-40 weeks). Of those who died by 30 months follow up, 83% had died in the SPCIPU. 17% died at home.

**Conclusions:** The SPC response to COPD and IPF patients has evolved and become more tailored. The provision of such a tailored service has significant resource utilisation and funding implications. Further study is required to evaluate the effectiveness of the breathlessness intervention.

**Abstract number:** PO18

**Abstract type:** Print Only

**A Profile of Dietetic Interventions in Specialist Palliative Care**

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**Background:** Dietitians are believed to play a role in Specialist Palliative Care (SPC) but there is no research supporting this.

**Aim:** To provide a profile of dietetic interventions in a SPC setting.

**Methods:** Retrospective chart review (Jan-Mar 2015) of patients discharged from the inpatient and day units of an Irish SPC facility. Patients referred to dietetics were included. Data was extracted manually from charts and entered into SPSS. Descriptive statistics were generated.

**Results:** 63 patients were referred to dietetics from the inpatient unit. 93% (n=52) had cancer, 7% (n=4) had

non-cancer diagnoses. 11% (n=7) were not assessed due to clinical deterioration, 89% (n=56) were assessed and treated. The most common rehabilitation interventions were recommendations of therapeutic diet (89%) and of food fortification (79%). The most common symptom management interventions were recommendations for palliation of anorexia (73%) and for early satiety (46%). Psychosocial interventions were provided for 98% of patients and/or families, 46% received support to alleviate eating or weight loss-related distress. 93% of patients and/or families received dietary education.

Nine patients were referred from the day unit. 86% (n=6) had cancer, 14% (n=1) had non-cancer diagnoses. Two declined assessment, 78% (n=7) were assessed and treated. The most common rehabilitation interventions were recommendation of therapeutic diet (100%) and of food fortification (100%). The most common symptom management interventions were recommendations for palliation of anorexia (71%) and for early satiety (57%). 100% of patients and/or families received psychological support, 43% to alleviate eating or weight loss-related distress. 100% of patients and/or families received dietary education.

**Conclusions:** This is the first known study to assess the role of dietitians in a SPC setting. Dietitians provided rehabilitation, symptom control and psychosocial support to patients and families.

**Abstract number:** PO19

**Abstract type:** Print Only

### A Retrospective Evaluation of the Effectiveness of a Breathlessness Rehabilitation Programme in a Palliative Care Service in Ireland

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**Background:** Dyspnoea is a prevalent symptom amongst patients receiving Specialist Palliative Care (SPC). It is important to investigate dyspnoea treatment options. Pulmonary rehabilitation is safe and effective in the management of dyspnoea, but has not been sufficiently investigated in the SPC population.

**Aim:** To investigate the impact of an exercise and education intervention on dyspnoea in SPC patients.

**Study population:** Data was obtained from all consenting participants of the SPC Physiotherapy-led Breathlessness Rehabilitation programme, who completed the programme between January 2012 and October 2015 (n = 8). 7 participants had a non-malignant primary diagnosis.

**Study design and methods:** This was a prospective observational cohort study. The intervention delivered by the

researcher over 4 weeks, was based on international Pulmonary Rehabilitation guidelines (Spruit et al, 2013), consisting of aerobic and strengthening exercise and education. Outcomes were assessed before and after the programme using validated scales including disability associated with dyspnoea (Modified Medical Research Council Dyspnoea Subscale [MMRCDS], Stenton, 2008), dyspnoea-related distress levels (Distress Thermometer<sup>3</sup> [DT], Mitchell, 2010), and exercise capacity (Six Minute Walk Test [6MWT], Holland, 2014).

**Results and interpretation:** Changes in average scores in all measures show improvement following the intervention (MMRCDS pre-test=3.25, post-test=2 [change=-1.25]; 6MWT pre-test=417.1m, post-test=484.3m [change=+67.2m]; DT pre-test=6; post-test=3.5 [change=-2.5]), demonstrating improvements in the symptom of dyspnoea, functional capacity, exercise tolerance and quality of life scores following the intervention.

**Conclusion:** Data from this small study support the provision of exercise and education in the management of dyspnoea in SPC. Further research is required. Given the high attrition rates in SPC, multi-centre trials may be required to investigate statistical significance.

**Abstract number:** PO20

**Abstract type:** Print Only

### Risk-factors for Development of Pressure Ulcer in the End of Life Care - A Register Study

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The scientific knowledge and research about pressure ulcers in caring science is growing, but the shortage of studies of skin changes at life's end (SCALE) is problematic. The aim in palliative care is to increase quality of life and relieve suffering. However, sometimes turning the patient would rather increase than decrease suffering in the dying patient.

In The Swedish Register of Palliative Care (SRPC) there is a question if the patient died with pressure ulcers (and category). During 2014, 60 415 deaths were reported to the register Pressure ulcers (graded from 1 to 4) had been reported for 13 213 patients at the time of death, however in nursing homes the prevalence was 21% and the corresponding figures in specialized palliative care were 42%. The big difference in proportion of death with pressure ulcer, raise the question if this reflect a difference in quality of care or that the two care context, care for patients with dissimilar risk for pressure ulcers in the end-of-life.

The research questions is to identified correlations between some background variables and dying with

pressure ulcers and to explore if patients dying with pressure ulcers, have more pain than patients without pressure ulcers.

**Methods/material:** The study is a retrospective register study and the population is all patients registered in the SRPC during 2014. The material consists of reported data to SRPC. Data are collected through a online questionnaire with items based on different essential aspects of end-of-life care. In the present study the items concerning; health-care units, gender, age, disease that caused the death, pain, confusion, pressure ulcers at admission and/or last week in life, patients decision-making capacity, parenteral/enteral nutrition, will be used. This study was approved by the ethics committee at Uppsala University in Sweden.

**Results:** No results are present yet.

**Abstract number:** PO21

**Abstract type:** Print Only

### Symptom Cluster in Men with Castrate Resistant Prostate Cancer (CRPC)

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**Introduction and aims:** Men with CRPC experience significant physical and mental health morbidity along with impaired quality of life. Symptoms often co-occur in clusters and are inter-related. They interact and influence each other and may be dependent on a number of factors (e.g. time point, treatment factors or genetics). Symptom clusters are clinically more rational and relevant than individual symptoms. The aim of this study was to detect symptom clusters in men with CRPC followed over 6 months in a pilot feasibility study.

**Methods:** Exploratory factor analyses were conducted based on individual symptom severity ESAS-scores (Edmonton Symptom Assessment System) obtained monthly from a pilot prospective, longitudinal consecutive patient cohort study of men with CRPC.

**Results:** Thirty-four participants with a mean age of 74 (+/-10) years were included. Thirteen were followed for at least 6 months and 7 are still active participants with less than 6 months follow-up. Two symptom clusters were extracted at different time points. The core symptoms in the clusters with the highest correlation were consistent

over time. Core symptoms were Depression & Anxiety for the "Mood Cluster" and Tiredness & Drowsiness (+/-Breathlessness) for the "Fatigue Cluster".

**Conclusion:** Men with CRPC have a high symptom burden. Symptoms occur in clusters and we have identified two clusters with stable core symptoms. The knowledge of these clusters can be used to improve symptom assessment and management and direct future symptom research.

**Abstract number:** PO22

**Abstract type:** Print Only

### Significance of Specialized Palliative Care Concurrently with Anticancer Treatment for Advanced Cancer Patients

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**Purpose:** Recent studies on "early palliative care" have shown its efficacy as exemplified by an improvement in quality of life (QOL), reduction in physical and psychological symptoms, and prolongation of survival. The purpose of this study was to evaluate the effectiveness of specialized palliative care (PC) concurrently with anticancer treatment.

**Methods:** This was a prospective study. Participants were patients who underwent chemotherapy for advanced and recurring cancer during a period of 3 years. Patients who received regular specialized PC concurrently with chemotherapy, and subsequently admitted and died in the palliative care unit (PCU) were assigned to the PC group. Patients who were transferred to the PCU after discontinuation of chemotherapy were assigned to the SC group. Primary endpoints were quality of palliative care using the Support Team Assessment Schedule and QOL using the Good Death Inventory. Secondary endpoints were implementation rate of chemotherapy immediately before death (60, 30 and 14 days) and short-term mortality in the PCU. Statistical analysis was performed using Mann-Whitney U test and chi-square test. This study was approved by the institutional review board of the hospital and was conducted in accordance with the Declaration of Helsinki.

**Results:** A total of 35 and 184 patients were assigned to the PC and SC groups, respectively. Physical symptoms, anxiety, communication scores, and QOL scores were significantly higher in the PC group ( $p < 0.01$ ). Implementation rate of chemotherapy 60 and 30 days before death was significantly higher in the SC group ( $p < 0.01$ ). Short-term mortality (both at 7 days and 14 days) was significantly higher in the SC group ( $p < 0.01$ ).

**Conclusion:** This approach may facilitate high-quality palliative care for terminally ill cancer patients. The

authors received no financial support for the research, authorship, and/or publication of this study.

**Abstract number:** PO23

**Abstract type:** Print Only

**Lower Extremity Oedema of Advanced Disease Treated by Short Stretch Compression Bandaging Combined with Furosemide in Hypertonic Saline Infusion - A Retrospective Pilot Study**

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**Background:** The extremity oedema of advanced disease is a common, multifactorial feature, which impairs patient activities and quality of life. The most frequently chosen management is based on the various techniques of combined decongestive physiotherapy or pharmacotherapy (with diuretics or steroids). In some cases this single treatment is poorly tolerated or inefficient.

**Objective:** To assess the effectiveness and tolerability of combined physiotherapeutic and diuretic therapy.

**Methods:** A group of ten patients in advanced disease (cancer and chronic heart failure) with severe oedema resistant to diuretic therapy were treated for three days with a combination of multilayer short stretch compression bandaging and furosemide (40-100 mg a day) in hypersaline intravenous infusion.

**Results:** Within a short period of time the clinically meaningful decrease in limbs volume calculated by using circumference measurements was noticed (from mean 9.862 to 7.831 ml;  $P < 0.0001$ ). The treatment was well tolerated; an improvement in pain, dyspnoea, weakness and patients' Palliative Performance Status were observed. The stable blood pressure measurements, laboratory kidney profiles (potassium, sodium, creatinine clearance) were seen and serum albumin elevation was achieved.

**Conclusions:** The novel method of massive, resistant oedema treatment by the combination of compression with hypersaline diuretic seems to be safe and valuable for patients with far advanced disease.

**Abstract number:** PO24

**Abstract type:** Print Only

**The Factors of Delirium by Opioid Administration in Super Elderly Patients**

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**Background:** Opportunities to prescribe opioids for elderly cancer patients are increasing more and more each

day. The number of reports available of super elderly cancer patients (octogenarians and nonagenarians) is very limited so we investigated the psychosomatic effects on patients over 80 to determine why delirium occurs after the administration of opioids.

**Method:** Records of patients who were over 80 years old were investigated for the period starting on 31/7/2014 and ending on 1/8/2015,

Observation were as below,

- 1) Type of opioids
- 2) Opioids switch due to side effects
- 3) If delirium after prescribed opioids was present or not?
- 4) Serum Na<sup>+</sup>, Ca<sup>+</sup>, Creatinine and D-dimer level
- 5) EKG at prescribing
- 6) Administration of oxygen
- 7) Co-existing disease

**Result:** 67 patients were prescribed in the period (28 transdermal fentanyl, 8 morphine, 18 oxycodone, 6 tapentadol, 7 tramadol orally). Initial use opioid: 14 transdermal fentanyl, 9 oxycodone, 8 tramadol, 8 morphine and 3 tapentadol. Opioid switch was needed when the pain worsened by initial opioid: 8 tramadol and 3 tapentadol. The following were used to treat drowsiness: 3 oxycodone to fentanyl and 2 fentanyl to tapentadol. Delirium occurred in 10 patients: 3 morphine, 3 fentanyl, 3 oxycodone, 1 tramadol. Those patients had atrial fibrillation (100%). Opioid switch was effective in 6 patients (60%). 1 patient who have both of atrial fibrillation and cerebral infarction got delirium when used any opioid and could not recover by opioid switch with other therapy. Low oxygen saturation, serum high creatinine, and low Na<sup>+</sup> level were independent on delirium in this study.

**Conclusion:** We expected that opioids are useful for pain relief but strong opioids have a tendency to pose a risk of delirium in super elderly patients. The use of opioids for the patients with cardiac problem also suggest a risk factor of delirium in these patients. Prospective study should be needed for large number subjects.

**Abstract number:** PO25

**Abstract type:** Print Only

**Palliative Care Oedema: Treatment Goals and Interventions**

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**Background:** Little is known about the treatment of oedema in palliative care patients. Goals and treatments may vary compared to oedema treated in an oncology or general community setting.

**Aim:** To outline the interventions used to treat oedema in palliative care patients, and to determine the goals of treatment.

**Methods:** 6 month retrospective chart review of patients referred to a specialist palliative care physiotherapy oedema service.

**Results:** 63 patients were included. 92% (n= 58) had a cancer diagnosis. 46% (n= 29) had a mixed oedema type comprising of lymphoedema and non-lymphatic oedema, 28.6% (n=18) had primarily lymphoedema, 15.9% (n=10) had primarily non-lymphatic oedema, and 9.8% (n=6) had lymphorrhoea.

Thirty nine patients (61%) were treated in their homes, 14 (22%) in the inpatient specialist palliative care unit, 3 (5%) in palliative day unit, The remainder were seen in more than one setting.

The most common interventions were education around oedema (100%, n=63), compression garments (58%, n=37), bandaging (51%, n=32), exercise (38%, n=24), lymphatic massage and kinesiotaping (35%, n=22 each). Kinesiotaping (elastic skin tape applied to stimulate skin lymphatics) and lymphatic massage were used only for those with a lymphatic component to their oedema. The most common treatment goals were: to maintain skin quality (54%, n=34), to reduce limb volume (52%, n=32), improve QOL (48%, n=30), improve skin quality (36.5%, n=23) and improve physical function (36.5%, n=23).

Treatment duration ranged from 1-176 days (median 7) and was shortest for those with mixed oedema (median 2). The number of treatments ranged 1-14 (average 3.5, mode 1) and was longest for those with primarily lymphoedema (average 5).

**Conclusion:** Palliative care oedema can be treated using the above manual methods. Treatment goals involve maintaining or improving skin quality, limb volume and QOL. Treatment regime differs depending on the type of oedema present.

**Abstract number:** PO26

**Abstract type:** Print Only

### **Indwelling Tunnelled Catheters for the Management of Pleural and Peritoneal Effusions in Patients with Advanced Cancer: A Novel Clinical Experience in Southern Switzerland**

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**Background:** Malignant pleural and peritoneal effusions are common manifestations of advanced cancer, generating an important symptom burden often requires repeated thoracentesis and paracentesis. Indwelling Tunnelled Catheters (ITC) are implantable devices used to treat symptomatic malignant effusions and can be a safe and effective alternative to repeated evacuations.

**Aim:** To review the novel clinical experience of refractory effusion management with ITC in advanced cancer patients in Southern Switzerland.

**Methods:** This retrospective study was conducted in two major University hospitals in Southern Switzerland. Medical charts, electronic patients' records and follow-up reports of advanced cancer patients presenting pleural or peritoneal effusions requiring repeated needle evacuations treated with ITC were collected and analysed.

**Results:** From April 2014 to October 2015, 13 ITC were positioned for refractory malignant pleural (5) and peritoneal effusion (8). Mean age was 68 years, most common neoplasms were gynecological (5), gastrointestinal (5) and lung (3). Patients main complaints before ITC were abdominal tension and pain in ascitis and dyspnoea in pleural effusions. Mean Palliative Performance Scale at time of positioning was 55%. Neither placement failures nor acute or delayed infectious complications were observed. Patients' mean survival after ITC was 30 days (15-60 days), with 4 patients still alive at present date. All patients reported good symptom control related to the effusions and no rehospitalisations due to the ITC management occurred. All patients were cared for and drained home thanks to a tailored nurse-led short training programme for community nurses and informal caregivers.

**Conclusion:** In our experience, ITC resulted safe and effective in managing refractory pleural and peritoneal effusions. ITC allowed home care drain coupled, with good symptom control without complications related to the ITC itself.

**Abstract number:** PO27

**Abstract type:** Print Only

### **Relevance of Using Intranasal MIDAZOLAM in Palliative Care: About a Literature Review**

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**Purpose:** MIDAZOLAM (MIDA) is a treatment used in standard practice in palliative care. The most frequent

indications are anxiety and sedation for refractory symptoms. When it can't be administered intravenously (IV), sub-cutaneously is generally used. Its effectiveness remains unpredictable. In other disciplines (pediatrics), the intranasal (IN) route is frequently used. In this context we questioned the interest of using IN for administration of this therapeutic, in palliative care.

**Method:** To judge relevance and feasibility of using MIDA IN, we have conducted a literature review (in 10/2015) on the database MEDLINE/PubMed (pharmacokinetics/pharmacodynamics, dose, indications). English keywords were: intranasal midazolam, pediatric, adult.

**Results:** The study of 170 abstracts showed that administration of MIDA IN on adult patients, unlike children, has not been much studied. 92 studies were listed in pediatrics against 26 for adults. In adults, studies show different practices, notably initial doses given [2-10mg]. The most consensual indication in this same population (11 studies) is management of convulsive crisis, with undoubted effectiveness. Studies of pharmacodynamic/pharmacokinetic (15 publications) show that the maximum effective concentration is achieved in about 10 minutes [7.6-25.8min], making this administration method appropriate in emergency situations. In this review, there is not publication in palliative care concerning administration of MIDA IN.

**Conclusion:** This mode of administration is under used/studied in adult medicine. It is interesting to question its use in palliative care, including management of emergency situations (anxiety, agitation...). We have started, in palliative care unit and various care units, a feasibility study of this approach to patients not eligible for MIDA IV. We used a nasal vaporizing device (MAD 300). The evaluation will be about the clinical efficiency (time taken between administration and amendment of symptom).

**Abstract number:** PO28

**Abstract type:** Print Only

#### **A Mixed Methods Study for the Evaluation of a Breathlessness Support Service in Germany: Research Protocol**

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**Background/aims:** Breathlessness services have been established in the UK to support patients with intractable breathlessness due to advanced disease. Based on the UK model, a similar service has been established in Germany. Aim of the study is to assess the effectiveness and cost-effectiveness of this new breathlessness support service and explore patients and carers experiences with this new service.

**Methods:** A mixed method design was chosen with a randomized controlled single-blinded delayed intervention study and an embedded concurrent patient survey and qualitative semi-structured interviews. The intervention comprises two clinic visits of patients and relatives with contact to palliative and respiratory medicine, and four appointments with a physiotherapist between the visits. The control group will receive access to the service after 8 weeks. Primary end points are mastery of breathlessness and quality of life, both measured on the Chronic Respiratory Disease Questionnaire (CRQ) after 8 weeks. To show a difference, n=160 patients are needed for the study (80% power,  $\alpha=0.05$ ). For the patient survey, a questionnaire was developed asking about the breathlessness service and its impact. This will be sent to all patients. A purposive sample of patients and relatives will be interviewed to explore their experiences. Analysis will include descriptive analyses and multiple linear regression analyses based on the change score for the effectiveness. Qualitative data will be analysed by thematic coding and compared with results of the quantitative data.

**Results:** Study recruitment is ongoing. Until October 2015, 38 patients have been included.

**Conclusions:** The interpretation of trial outcomes with process evaluation data from a mixed methods triangulation study will help to clarify how a breathlessness support service works and what works best. This information will help to further implementation of breathlessness services in the German health care system.

**Abstract number:** PO29

**Abstract type:** Print Only

#### **Nurses' Experience of Caring for Patients with Terminal Delirium**

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**Background:** Delirium is a major complication of advanced illness and during the last weeks of life. An improved understanding of delirium from the nurse's perspective has the potential to significantly add to the body of knowledge around recognition, management and treatment of terminal delirium.

**Aim:** The focus of this study is to explore nurse's experience and views of caring for patients with terminal delirium.

**Methods:** A qualitative exploratory design was employed. Semi structured interviews with a purposive sample of 6 nurses from the hospice unit and the homecare team were conducted. The interviews were audiotaped and transcribed verbatim. Transcript data was entered into NVivo to facilitate analysis. A thematic content analysis was performed involving coding and theming of data by three researchers working independently of each other.

**Results:** The palliative care nurses experienced multiple challenges when caring for patients with terminal delirium. Themes identified included;

- The experience of distress
- Pharmacological management of terminal delirium
- Need for further education and knowledge
- Communication and multidisciplinary working.

**Conclusions:** Findings suggest the need for educational initiatives focusing on delirium recognition and medication management. Specific evidence based guidelines/policies to aid comprehensive treatment plans for patients is recommended. Further studies are warranted into the potential effect of educational strategies on care in palliative care settings to deal with the stressful and challenging care issues surrounding terminal restlessness. The introduction of systematic and structured processes in the form of guidelines/policies should be explored. A follow up study has been initiated to investigate the effectiveness of educational and psychological interventions aimed at reducing and preventing compassion fatigue and burnout in nursing staff caring for patients with delirium.

*Funded by the Irish Hospice Foundation*

**Abstract number:** PO30

**Abstract type:** Print Only

### **Percutaneous Transesophageal Gastrostomy: An Effective Tool for Managing Malignant Bowel Obstruction Symptoms**

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**Background:** Malignant bowel obstruction (MBO) a common complication of malignancy, seen in up to 28% and 50% of colorectal and ovarian cancer patients. Gastric decompression is often required for symptom relief. Peritoneal carcinomatosis and refractory ascites are relative contraindications for gastrostomy tube (PEG) placement. Indwelling nasogastric tubes are unsightly and associated with complications. A percutaneous transesophageal gastrostomy (PTEG) tube is a safe, alternate way to decompress the gastric content and to alleviate symptoms in patients with MBO.

**Aim:** The purpose of our study is to measure symptom response and complication rates in patients who underwent PTEG placement for management of MBO.

**Methods:** Patients presenting with symptomatic MBO, who were unresponsive to medication management and had a contraindication for placement of a percutaneous gastrostomy (PEG) tube, were deemed appropriate for placement of a PTEG. Symptom burden was assessed using the Edmonton Symptom Assessment Scale (ESAS) and the Karnofsky Performance Scale. The ESAS and Karnofsky scales were measured at days 0, 7, 14 and 28 after PTEG placement. Complications rates were also recorded.

**Results:** We reviewed a case series of six patients who had placement of a PTEG for MBO. The median ESAS score for nausea measured 4.3 prior to PTEG placement, dropping to 1.1 on day 7 following the procedure. Patients' scores for wellbeing improved from 5.0 at baseline to 2.6 on day 7 following PTEG placement. There was no significant change in pain scores or Karnofsky performance scores.

Two patients had emesis during placement and aspirated. One developed pneumonia. One patient developed a surgical site infection.

**Conclusion:** For patients with MBO that have a contraindication for PEG placement, PTEG is safe and effective tool for gastric decompression and symptom relief of nausea.

**Abstract number:** PO31

**Abstract type:** Print Only

### **The Use of Ultrasound in a Hospice Setting - A Review of the First 200 Cases**

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**Background:** Ascites (both malignant and non-malignant) may cause distressing symptoms but hospital transfer for ascitic drainage may be difficult for hospice patients close to the end of life. Having ultrasound available in the hospice may offer a safe and feasible way of performing ascitic drainage in the hospice.

**Aim:** To review the use of abdominal ultrasound in a 34-bed hospice (performed by "non-radiologist" palliative care physicians), and describe the impact on patients.

**Methods:** Routine data recorded manually in a 'Log Book' kept with the Ultrasound Machine was analysed.

The date, patient demographics, indication for scanning, findings and outcome were recorded for all patients scanned between October 2012 and May 2015 and descriptive statistics were generated. Most of the patients were scanned on the wards, except for 3 patients who were scanned in their own homes.

**Results:** The 2 main indications for scanning at the Hospice were for distended abdomen / suspected ascites [134/200], and for suspected urinary retention [55/200].

Interestingly, on 60 occasions, when a scan was performed for 'abdominal distension' ascitic drainage was NOT performed. This was because in a significant number of these cases, the amount of ascitic fluid present was minimal, loculated and/or deep-seated and inaccessible. In other cases, the cause of the abdominal distension was intestinal obstruction; gross hepatomegaly; or faecal loading.

**Conclusion:** Even though the ultrasounds were performed by "non-radiologists" they answered the clinical question every time. Patients could avoid the upheaval associated with hospital transfer for ultrasound, and a number of potentially unnecessary / risky ascitic taps were avoided. These data suggest that ultrasound scanning in a hospice is both safe and beneficial to patients.

**Abstract number:** PO32

**Abstract type:** Print Only

### How Patients and Doctors Talk about Fatigue in Advanced Cancer: A Mixed-methods Study

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**Background:** Fatigue is a common and distressing symptom in patients with advanced cancer. However, some survey data found that patients can be reluctant to report fatigue to their doctor and the reasons for this are unclear. Further data suggests that fatigue is poorly managed by healthcare professionals, with doctors being the least likely to offer any treatments for fatigue.

**Aims:** To explore how patients and doctors approach fatigue in advanced cancer and to identify communication practices that support the assessment and management of this symptom.

**Methods:** This study used a mixed-methods approach, including the video-recording of routine oncology outpatient consultations to understand how fatigue is communicated, with patients completing a quantitative assessment tool to measure fatigue following the consultation. Qualitative semi-structured interviews were conducted with patients whose scores indicated fatigue and separately with doctors. Participants were recruited across 6 specialist oncology clinics, including: breast, colorectal, lung, upper gastrointestinal and prostate.

**Results:** Data collection is ongoing but to date 50 consultations have been video-recorded. Over half of patient participants were male (54%), with a mean age of 68.2 years old, (ranging from 47 to 93). 31 patients (62%) reported moderate to severe fatigue and a subset of 22 patients were

well enough to be interviewed. 15 clinicians participated in the study and have been approached for interview. Themes that emerged from patient interviews included learning to adapt through lived experience of fatigue and the challenges of exercising with fatigue. Clinicians expressed therapeutic nihilism in their interviews. Further results will be presented.

**Conclusion:** It is hoped that analysis of the data will identify communication practices that facilitate and inhibit the effective assessment of fatigue and lead to a better understanding of how clinicians might discuss fatigue in advanced cancer.

**Abstract number:** PO33

**Abstract type:** Print Only

### Supported: The Development of an Abdominal Support Garment for People with Ascites

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**Background:** Ascites is the build-up of large volumes of fluid in the peritoneal cavity which is usually drained at about 5 litres. If an indwelling catheter isn't possible then living with large volumes of fluid which are intermittently drained, is uncomfortable. A support garment was tested with patients with ascites which increased abdominal pressure by 4cm/H<sub>2</sub>O (Tubigrip). The patients found the garment improved discomfort and provided support to their large distended abdomens. However, the garment was too warm and also 'rode up' making it difficult to wear especially in warmer weather.

**Aims:** To develop a support garment for use with people with gross ascites to offer them support and improve their discomfort.

**Methods:** Five prototypes for a support garment using a range of materials to offer abdominal support were developed with the company Jobskin. The garments were made using guidance from previous research and feedback from ongoing comfort tests. The ongoing study with 8 participants with ascites (alcohol related liver disease and malignancy) will assess wear-ability and support requirements including an assessment of comfort, ease of putting on/off, mobility and acceptability. The garment, shaped like cycling shorts, can be made in a range of sizes and colours.

**Results:** An abdominal support garment was developed with the designers by using light weight breathable materials. There were five sections to the garment offering different types of pressurised support including a main abdominal area which allows for support but can significantly increase to allow for abdominal growth. The support garment supported an increase in abdominal girth from 70 cm to 110 cm in the initial participant yet remained comfortable.

**Conclusions:** A support garment has been created which can allow for increased abdominal girth yet provide abdominal support. Further research is planned to evaluate whether wearing a support garment can delay admission to hospital for treatment.

**Abstract number:** PO34

**Abstract type:** Print Only

**Sexual Counseling for Palliative Care Patients and their Partners: A Single Institution Experience**

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**Introduction:** Sexual wellbeing in Palliative Care (PC) is an underestimated problem. Few studies in literature address this topic and guidelines are missing. Problems in sexuality can impact patients' and partners' quality of life. Sexuality in PC can be affected in multiple dimensions, not only in the physical one.

in 2014 the Oncology Institute of Southern Switzerland (IOSI) implemented a consultation service in all oncological day hospitals for sexual wellbeing to improve patient's referral and offer care encompassing the sexual sphere.

**Objectives:** To review the Institution 21 month experience of sexual counseling, focusing on the PC population accessing this service.

**Methods:** A retrospective study of medical charts and documentation of the sexual counseling offered to oncological patients in four oncological day-hospitals was performed.

**Results:** From February 2014 to October 2015 of the 34 oncological patients seen by the service, six (1 female; 5 males) were PC patients. One patient had breast cancer, two men colon cancer and three prostate cancer. Main complaints were dyspareunia in the female patient and erectile dysfunction in men. All patients, including their partners, complained of low libido and sexual desire. Patients and partners expressed that they would have appreciated to be informed earlier about the sexual counseling service.

**Conclusions:** This study highlights that when investigated, palliative care patients can present different levels of sexual dysfunctions. The specialist counseling was welcomed by patients and their partners and oncologists were prone to address patients to the counseling. The service started to overcome the "social taboo" around sexuality, cancer and end of life. The difficulty and the complexity of an adequate multidimensional assessment of PC patients, including sexual wellbeing, can be addressed by implementing a specific counseling not only in oncological settings but also in PC ones.

**Abstract number:** PO35

**Abstract type:** Print Only

**A Single Centre Evaluation: PleurX® System for the Management of Malignant Ascites and Pleural Effusions**

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**Background:** Recurrent ascites and pleural effusions are common with metastatic disease. They pose therapeutic challenges for physicians and cause distress for patients and families. Repeated thoracentesis and paracentesis were previously advocated options, however high recurrence rates, complications and repeated admissions render them impractical. A tunnelled catheter offers an alternative to symptom management and improved quality of life.

**Aims:**

To develop a patient symptom profile for catheter insertion.

To assess complications of the system.

To examine the provision of education to involved individuals.

**Methods:** Patients were identified by the radiology department to have had a PleurX® catheter inserted between April 2014 to January 2015.

A retrospective chart review was performed and data was collected using a proforma.

**Results:** 21 tunnelled catheters were inserted in 19 patients.

Predominant symptoms included; abdominal distension, dyspnoea and pain.

There were no procedural related complications or mortality. One drain was removed due to infection and five patients reported minor complications.

66% had previous thoracentesis or paracentesis performed.

Education was provided post insertion by a hospital healthcare professional.

Catheter care was largely performed by a relative.

Community teams had limited knowledge of catheter drainage and complications.

**Recommendations:** Devise a guideline in conjunction with the radiology department for PleurX® insertion.

Introduce an education pathway for patient and family, commencing prior to insertion.

Arrange education and information sessions for community nursing staff.

Develop an audit tool to assess compliance with recommendations.

**Conclusion:** PleurX® catheters are inserted safely and appear to be well tolerated with few complications.

Education of patient and staff is pivotal to allow patients maintain care in the community, improving quality of life and reducing hospital attendances.

**Abstract number:** PO36

**Abstract type:** Print Only

### The use of Additional Antiepileptic Drugs with Subcutaneous Levetiracetam for the Management of Seizures at the End of Life: A Case Series

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**Introduction:** Seizures can be distressing for patients and families and can occur in up to 13% of palliative care patients. Levetiracetam possesses a number of advantages for use in palliative care. There is limited literature that suggests it is safe and effective in subcutaneous form but further information is required. Multiple antiepileptic drugs (AEDs) are frequently required to achieve seizure control.

**Aims:** To investigate the use of additional AEDs with subcutaneous levetiracetam for management of seizures at end of life. Underlying diagnosis, number of AEDs required and levetiracetam dose were noted.

**Methods:** We conducted a retrospective chart review of all patients treated with a subcutaneous levetiracetam infusion in regional specialist palliative care services in 2013 and 2014. Data was extracted by reviewing in-patient hospital records and analysed using Microsoft Excel. No funding was obtained for this study.

**Results:** 32 patients were treated with subcutaneous levetiracetam. 60% (n=19) patients required additional AEDs and 5 of these had primary brain tumours. 80% (n=4) patients with primary brain tumours were required 3 or more additional AEDs. 50% (n=4) of patients with non-malignant disease required one additional AED. Midazolam was used in 74% (n=14) and was the most frequently used AED. The mean dose of levetiracetam was 1733mg for brain metastases, 1560mg for primary brain tumours and 1642mg for non-malignant aetiology.

**Conclusion:** Subcutaneous levetiracetam has a number of advantages for use in palliative care but many patients require multiple AEDs for seizure control. Patients with primary brain tumours were more likely to require increased numbers of AEDs. This study adds to the previously published case series of the use of subcutaneous levetiracetam in the management of seizures at end of life.

**Abstract number:** PO37

**Abstract type:** Print Only

### Challenges and Directions in Anticoagulation in Palliative Care of Cancer Patients

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**Introduction:** In patients with cancer there is an increased risk of venous thromboembolism, especially in certain types of solid tumors. Occurrence of venous thromboembolism in patients with cancer is linked to a hypercoagulable state due to synthesis of pro-coagulants factors, constitutive expression of tissue factor by tumor cells or local hypoxia. The risk of thrombotic complications increases during chemotherapy, hospitalization or surgery.

**Material and methods:** Based on data from clinical trials and our own clinical experience, we evaluated the antithrombotic treatment of cancer patients admitted in palliative care unit on the first 6 months of this year.

**Results:** 13.59% (359) patients of inpatients required antithrombotic therapy during hospitalization, antithrombotic treatment was initiated at 62.95% of them. At 81.41% patients, the antithrombotic therapy was initiated for the prevention of thromboembolic events, and at 18.69% patients for recent thromboembolic events. 60% (57) of patients on oral anticoagulant therapy have required the switch of the treatment with low molecular weight heparin (LMWH), cause non-therapeutic metrics serial INR. 2.5% (9) patients presented recurrent thromboembolic episode and 3.89% (15) patients experienced minor bleeding disorders.

**Discussions:** The majority of our patients undergo treatment with vitamin K antagonists which pose particular challenges for maintaining and monitoring therapeutic dose. To increase the quality of life and survival of patients with cancer in advanced stages require prevention of thromboembolic events in immobilized patients and also in patients with history of venous thrombosis. LMWH treatment is an alternative to oral anticoagulant therapy and can be safe to outpatients.

**Conclusions:** Venous thromboembolism is a major cause of morbidity and mortality in patients with cancer, and improving antithrombotic prophylaxis and treatment in this subset of patients may have important prognostic implications.

## Assessment and measurement tools

**Abstract number:** PO38

**Abstract type:** Print Only

### A New Approach of Determining Short-term Prognostic Predictive Methods in Terminal Cancer Patients Based on the Change-point in Laboratory Test Values

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**Background:** In terminal phase, it is important to predict the prognosis precisely for patients and their families. However, there are no methods to predict the prognosis within two weeks of death.

**Purpose:** To find simple short-term methods to predict prognosis by detecting a statistical change-point in laboratory test values.

**Methods:** We retrospectively surveyed 121 cancer patients who were aged  $\geq 16$  years and who died at a university hospital in 2008. We analyzed various laboratory test items.

Change-points were detected by using primary and secondary differential calculus for the changes in laboratory test values. According to our judgment reference values (Tab. 1), we compared our prognostic predictive methods (e.g., the WPCBAL score) to the Glasgow prognostic score (GPS).

**Tab. 1.** Threshold value of test items.

Test item	Threshold	Test item	Threshold
<b>WBC</b>	$\geq 4870$ cells/ $\mu$ L	<b>AST</b>	$\geq 30$ U/L
<b>PLT</b>	$\leq 225000$ cells/ $\mu$ L	<b>LDH</b>	$\geq 264$ U/L
<b>BUN</b>	$\geq 14$ mg/dL	<b>CRP</b>	$\geq 2.75$ mg/L

**Results:** The patients were 67 men (55.4%) and 54 women (44.6%), with a mean age of  $58.1 \pm 17.0$  years. The WPCBAL score that met the thresholds for the WBC and PLT counts and BUN, AST, LDH, and CRP levels, and the WPBAL score that met the thresholds for the WBC and PLT counts and BUN, AST, and LDH levels showed a higher sensitivity, specificity, negative predictive value, and relative risk for the prognosis within two weeks of death compared to those of the GPS considering a less than three weeks prognosis. Moreover, while the WPCBAL and WPBAL scores showed an equivalent positive predictive value to the GPS, both positive and negative likelihood ratio were superior to those of GPS (Tab. 2).

**Tab. 2.** Sensitivity, specificity, predictive values.

Variable	Predictive period	Category	Sensitivity	Specificity	Positive predictive value	Negative predictive value	Relative risk	Positive likelihood ratio	Negative likelihood ratio
<b>WPCBAL score</b>	2 weeks	6	0.88	0.79	0.39	0.98	16.5	4.18	0.16
<b>WPBAL score</b>	2 weeks	5	0.91	0.70	0.40	0.97	14.2	3.00	0.13
<b>Glasgow prognostic score</b>	3 weeks	2	0.68	0.53	0.42	0.76	1.78	1.44	0.61

**Conclusion:** The WPCBAL or WPBAL score may be useful as a method to predict the prognosis within two weeks of death.

**Abstract number:** PO39

**Abstract type:** Print Only

### Development and Psychometric Testing of the Protective Reasons against Suicide Inventory for Assessing Older Chinese-speaking Outpatients

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**Aim:** Tools currently exist to test reasons for living among individuals in western countries, but few are available to assess older adults' protective reasons against suicide in Asia. The purposes of this study were to develop and psychometrically test the Protective Reasons against Suicide Inventory among older outpatients.

**Design:** This study had three phases: instrument development, cross-sectional survey to collect data on instrument items, and psychometric testing.

**Method:** The Protective Reasons against Suicide Inventory was developed based on individual interviews with 83 older outpatients in Taiwan, the literature, and the authors' clinical experiences. The resulting Inventory was examined by content validity, construct validity,

criterion-related validity, internal consistency reliability, and test-retest reliability.

**Results:** The Inventory had an excellent content validity index (1.00). Factor analysis yielded a seven-factor solution, accounting for 87.7% of the variance. Scores on the global Inventory and all its subscales tended to be higher in outpatients diagnosed without suicidal ideation than in outpatients diagnosed with suicidal ideation, indicating good criterion validity. Inventory reliability (Cronbach's  $\alpha$  for the global Inventory was 0.88 and for subscales ranged from 0.85 to 0.99) and intraclass correlation coefficient (0.95) were satisfactory.

**Conclusions:** The Protective Reasons against Suicide Inventory can be completed in 5 minutes and is perceived as easy to complete. Moreover, the Inventory yielded highly acceptable parameters for validity and reliability. The Protective Reasons against Suicide Inventory can be used to assess older Chinese-speaking outpatients for factors that protect them against attempting suicide.

**Abstract number:** PO40

**Abstract type:** Print Only

### Evaluating the Quality of Care Provided by a Specialist Palliative Care Service (SPCS) in Ireland

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**Context:** Specialist palliative care services need feasible processes to monitor the outcome of their services from the patient's perspective using validated outcome measures.

**Objectives:** The purpose of this study was to evaluate the implementation of the St. Christopher's Index of Patient Priorities (SKIPP) in three areas of a specialist palliative care service as a tool to measure impact of care provided.

**Methods:** The SKIPP was administered twice (initial and follow up) to a purposive sample of 52 patients in a hospice (n=25), hospice care at home (n=6) and day-care service (n=21).

**Results:** The initial administration of the SKIPP to all patients detected a significant difference in quality of life after receipt of service. The results identified that contemporaneous rating of quality of life (QOL) was higher (Md=5, IQR - 3, n=52) when compared with the retrospective rating (Md=4, IQR - 3, n=52, p=0.002). Eighty three percent (n=43) of patients reported that the receipt of service had resulted in an improvement in their perception of their condition either to a great extent or a very great extent. Of note 73% (n=38) of the patients requested assistance to complete the baseline SKIPP.

**Conclusion:** This study contributes further evidence that outcome measures which address response shift are valuable when measuring impact of palliative care services. In this study one administration of the outcome measure was sufficient at detecting change in QOL and the symptom of most concern in palliative care patients. The brevity of the tool and the timing of its administration suggest it is a valuable resource to services wishing to evaluate the quality of care provided from the patient's perspective. Further investigation is required to determine if approach by clinicians involved in the care of the patient rather than a researcher not known to the patient impacts rates of completion of SKIPP.

Funding from All-Ireland Institute of Hospice and Palliative Care.

**Abstract number:** PO41

**Abstract type:** Print Only

### Domains Considered Important by Advanced-Cancer Patients Undergoing Chemotherapy and the Individual QOL: The SEIQoL-DW of Outpatients under Palliative Care

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**Objectives:** The purpose of palliative care is to improve the QOL. However, the QOL of each patient widely varies depending on what the patient considers important. The objective of this study was to investigate the characteristics of the domains considered important by advanced-cancer patients undergoing chemotherapy and the Individual QOL.

**Methods:** Of the outpatients under palliative care undergoing chemotherapy as a second-line therapy or later, the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQoL-DW) was carried out on patients who met the inclusion criteria such as PS2 or lower, and pain and other symptoms/anxiety STAS-J 1 or lower. SEIQoL-DW is an evaluation method for calculating QOL scores by selecting five domains considered important by the patient in a semi-structured counseling session and totaling the satisfaction level of each domain (0-100)  $\times$  importance% of each domain (taking the whole as 100). The QOL was analyzed upon looking at the domains considered important by patients, along with the content, satisfaction level, and the importance thereof.

**Results:** A total of 28 patients (mean age of 67 years, among 12 male patients and 16 female patients) were included. Commonly selected domains were "family" at 100%, "cancer treatment" at 75%, "health" at 39%, "friends" at 39%, "house work" at 29%, and "hobbies" at 21%. While the mean importance of "family" and "cancer treatment" was 34% and 33%, respectively, the mean

satisfaction level thereof was 75 and 54, respectively. The mean QoL of each patient was 66.2, with a score of 56.9 in patients placing higher importance (30% or above) on “cancer treatment” and 69.8 in other patients.

**Discussion:** While the domains that patients consider important vary, “family” contributes to QoL as a common domain of importance. Putting higher importance on “cancer treatment” has a negative impact on the QoL of each patient.

**Abstract number:** PO42

**Abstract type:** Print Only

### Using Quality of Life Information as a ‘Clinical Tool’ to Improve the Actual Outcome of Quality of Life

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**Background:** Using an outcome measure as a clinical tool, especially in the area of quality of life (QoL) is uncommon. We hypothesized that individual QoL information may help improve patient’s QoL outcome over time when shared with the multidisciplinary team.

**Method:** A randomised controlled trial of 65 patients receiving chemotherapy for advanced cancer was conducted to measure differences in perception of QoL over 4 time-points. The Schedule for the Evaluation of Quality of Life (SEIQoL) Direct Weighting (DW) was used to assess QoL with the intervention group having their subjective QoL reported to the clinical team in colourful info-graph format compared to patients in the control group whose QoL information was not reported to the clinical team. The primary objective was to compare QoL outcome and examine differences between groups.

**Results:** Although there was an improvement in the QoL of all patients from baseline to time point 4 (P=0.05), there was a significant difference between groups over time in individual cue functioning. 92% of patients selected the cue ‘health’ as important to their QoL. Participants in the intervention group demonstrated a significant improvement in the perception of their health functioning compared to the control group (51% v 19%, P=0.014). However, the weighting of health remained constant over time in the intervention group whereas, in the control group, the weighting increased at T2 and T3 in tandem with a drop in health function at these time points for this group - thus suggesting a shift in values for this group.

**Conclusions:** The translation of QoL information from the individual patient for use in the clinical setting

significantly improved the patient’s perception of their health functioning. The value of regular assessment and graphical display and utilisation of patients’ subjective QoL information in routine clinical practice should be given consideration as a standard of care.

**Abstract number:** PO43

**Abstract type:** Print Only

### Botulinum Toxine in Palliative Medicine - Development of a Screening Tool to Identify Patients who Will Profit from Treatment

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**Background:** Lesions of the CNS lead to spasticity in every third patient, causing pain, bedsores, and infections, making nursing difficult, and increasing symptom burden. Acetylcholine (ACh) in the synaptic cleft leads to postsynaptic excitation, e.g. muscular contraction. Botulinum toxin (BtN) is taken up presynaptically and inhibits ACh release. Locally applied the effect is restricted to the injection site, without systemic adverse effects and ceases within 3 to 6 months. Patients with painful or debilitating spasticity profit from BtN injections as pain subsides, nursing becomes easier and complications are avoided as well-known from stroke patients. But it is rarely applied as patients often remain unidentified and are not referred to a specialist. We developed a questionnaire for patients and next of kin as a screening tool for symptoms due to spasticity and assessed its feasibility in a pilot study.

**Methods:** *Development of the questionnaire:* Experts (n=4) for stroke and spasticity device questions about spasticity and its symptoms. All questions are rated on a 4-point Likert scale by the other experts respectively. Best-rated questions were used in the questionnaire.

*Pilot assessment:* Patients with spastic hemiparesis (n=25) answered the questionnaire; and a semi-structured interview was conducted by one of the experts. Afterward another expert examined and treated the patients.

**Results:** The questionnaire was answered in 12 minutes (mean). 3 of 25 participants left out answers because: they did not see (n=1) and they did not understand (n=2) the question. In all cases (n=25) the experts assessment of spasticity and eligibility for treatment with BtN was correctly predicted by the questionnaire. In most cases treatment

(pattern of spasticity, injection sites) could be correctly deduced from the questionnaire (n=24).

**Conclusions:** The questionnaire is feasible. The questionnaire has a high sensitivity. Further assessments regarding the specificity are necessary.

**Abstract number:** PO44

**Abstract type:** Print Only

### Detecting Cultural Differences before Applying an Irish Instrument on the Quality of End-of-Life Care to a Population in German Speaking Switzerland

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**Background/aims:** Cultural differences might account for respondents' misunderstanding and thus misinterpreting of questionnaire items. This specifically applies to questionnaires translated into another language. In the absence of an instrument in German language measuring the quality of end-of-life care (EoLC), we translated the 'survey of bereaved relatives' (Irish Hospice Foundation, 2015) into German. Discordances throughout this process made us question to what extent the questionnaire embedded in an Irish EoLC context would fit in with our setting in German speaking Switzerland.

**Methods:** We conducted cognitive interviews with 3x5 bereaved relatives who filled in the translated questionnaire in advance. We probed each item that proved to be ambiguous during the translation process. Likewise we asked participants to name any difficulties experienced when completing the questionnaire. After each round we adapted the items, where appropriate.

**Results:** In the interviews, participants revealed several cultural differences in EoLC between both countries. In particular, bereaved relatives felt unable to rate interprofessional team performance, since they perceived little interaction between professional groups in care delivery. Furthermore, they did not show sufficient familiarity with the term 'spiritual needs' to precisely answer the respective item. Ambiguous understanding of either items or response options resulted in questions left unanswered. To enable the rating of team performance, we added items focusing on either nursing team or physician team performance. To enhance clarity, we added explanations in the form of foot notes. In addition, we offered comment fields to allow relatives to explain their response choice, when necessary. The final 5 participants acknowledged the improved clarity of the questionnaire.

**Conclusion:** The validation process executed enabled us to establish adequate cultural equivalence resulting in an understandable and applicable questionnaire.

**Abstract number:** PO45

**Abstract type:** Print Only

### Development and Validation of a Comprehensive Standardized Clinical Assessment Tool for Patient Needs: ACTI-PALLI

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**Aims:** To develop and validate a comprehensive and standardized instrument for Palliative Care (PC) settings, which will be used as an evaluation tool of patient's needs for care plan, outcome measurement and case-mix classification.

**Population:** Adult patients from PC Units, PC mobile support teams, Health network and Home-based hospital care.

**Design and methods:** After a systematic review InterRAI-PC was selected and adapted to the context. For each service, data were collected by 2 trained Health Care Professionals (HCP).

A Multicenter, prospective, observational study was carried out in representative sample of structures of PC, triangulation method was used for collecting data from Patient (observation and interview) at different time: Baseline assessment, 24h after and at 7 days - Interview with his/her family and health care professionals - Additional data were collected from the patient's file. Multiple dimensions were assessed: physical and functional status, health problems, psychosocial and spiritual well-being, social support ...

**Statistical analysis:** Analysis focusing on the instrument's psychometric properties: validity and reliability, using Cronbach's alpha, kappa and Spearman coefficients, intra-class coefficient correlation.

The acceptability will be assessed by using the completion rate per dimension and viewpoint of HCP involved in this study.

**Results:** 25 centers participate, 359/600 patients are already included with 462/850 assessments.

**Table 1.** Example of preliminary results.

Items	%
Pain not adequately controlled by medications	24.7
Anxious	39
Suffering Dyspnea in the 3 last days	50,5
Family conflict	9
Advance directives written	15.6
In-patient PCU from home	36.9

Overall, Professionals attest usability of the instrument and its acceptability, despite their investment in time for assessment.

**Source of funding:** Ministry of health.

**Abstract number:** PO46

**Abstract type:** Print Only

### Estimating the Population who Could Potentially Benefit from Receiving Specialist Palliative Care

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**Objectives:** To estimate the population who could potentially benefit from receiving specialist palliative care in the last year of life taking in account the specific mortality characteristics in Russia.

**Methods:** We studied and refined the existing population-based methods of palliative care needs assessment based on the views of an expert panel and used the refined approach to identify the need for specialist palliative care. Three estimates of the potential specialist palliative care population, Minimal, Mid-range and Maximal, were developed through deep analysis of official causes of death (ICD-10) data from the Regional Center for Medical Statistics by expert focus groups. These estimates were applied to the cohort of adults who died in the Nizhny Novgorod Area in 2013.

**Results:** The expert panel has come to the conclusion that the causes of death are specific in Russia and much differs from those existing in the other countries. The Min-range estimates 31.10% of all adults' deaths, the Mid-range estimates 42.30% and Max-range estimates 58.05% of adults' deaths during the year.

**Conclusions:** This study included cancer and non-cancer conditions in a set of three estimates of a potential specialist palliative care population. The set of identified ICD codes not much but differ from the sets proposed by the other researches. By using population-based data to describe specific characteristics of people who compose specialist palliative care population these results offer a tool for planning palliative medical care services.

**Abstract number:** PO47

**Abstract type:** Print Only

### Developing a Test to Assess the Prognostic Accuracy of Clinicians

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**Background:** Clinicians are not good at identifying when a patient is approaching the end of their life. In order to identify clinicians who are good at this skill, we set out to develop a test of prognostic accuracy based on real-life cases.

**Aim:** To observe the clinical course of patients thought to be in the last few days of life, in order to generate a series of cases with which to test the accuracy of clinicians' prognostic estimates.

**Methods:** This was a prospective observational study of patients at a hospice or under the care of a hospital palliative care team. Recruitment took place between January and October 2015. Any inpatient, over 18 years old, who could speak English, and who was identified by the palliative care team as likely to die within the next two weeks, was eligible to participate. Demographic information, past medical history, Palliative Performance Score (PPS) which varies between 10% [moribund] to 100% [fully active], Richmond Agitation and Sedation Score (RASS) which varies between -5 [unarousable] to +4 [combative], and symptoms during the admission were documented from observations, medical notes, and from discussion with the attending nurse or doctor.

**Results:** 50 participants were recruited; 30/50 (60%) were men, the median age was 74.5 years (IQR 60, 85) and 36 (72%) were white British. The majority (33; 66%) had cancer. The median PPS score was 30% (IQR 10, 40), the median RASS score was -1 (IQR -4, 0). Of the 50 participants predicted to die within two weeks, 40 participants (87%) did so. 29 participants were predicted to die within 3 days, of whom 18 did so. The clinical course of each patient was summarised and used to create a "vignette".

**Conclusions:** Since the vignettes have been derived directly from clinical practice they will offer an authentic platform on which to test the prognostic accuracy of clinicians as well as the effectiveness of future training programs designed to improve the skill of prognostication.

**Abstract number:** PO48

**Abstract type:** Print Only

### Assessment of Hydration in Cancer: Feasibility and Acceptability of Bioelectrical Impedance Vector Analysis

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**Background:** Fluid balance abnormalities are common in cancer. Clinical signs and symptoms may not reliably assess hydration. Bioelectrical Impedance Vector Analysis (BIVA) may be a novel means to assess hydration. Feasibility of its routine use remains unproven.

**Aims:**

**Primary:** Determine feasibility and acceptability of BIVA in hydration assessment in acute oncology admissions.

**Secondary:** Assess correlation between clinical hydration assessment and BIVA.

**Methods:** This was a prospective observational study. Consecutive inpatients were recruited from oncology admissions. They completed a questionnaire on hydration related symptoms (HRS). Clinical and radiological evidence of hydration status was sought. BIVA was conducted at the bedside and results compared to reference values. 4 ideal test conditions were identified - electrodes applied to right side of body, supine, bladder voided, fasting. Tests were done under real-world conditions and any deviation from ideal conditions was noted. Each participant completed an acceptability questionnaire. SPSS® was used for statistical analysis.

**Results:** 14 participants completed the study: 8 women and 6 men, median age 65 years. One was unable to complete the study. Median number of HRS was 5 (range 0-8 of possible 13). 7 had documented or radiological signs of overhydration. BIVA found 6 people to be overhydrated, agreeing with documented or radiological overhydration ( $\kappa=0.857$ ). Clinical signs of dehydration were present in 7. BIVA found none to be dehydrated. Right side electrode placement could not be used in 4 people. 4 participants had fasted, 2 were fully supine; bladder was voided for 1 test. All reported high device acceptability.

**Conclusions:** BIVA was highly acceptable to patients but feasibility issues were identified. Not all ideal test conditions were met. BIVA agreed with conventional assessment for over- but not dehydration. Future studies could examine the validity of alternative standardised test conditions.

**Abstract number:** PO49

**Abstract type:** Print Only

**The Impact of a Novel Tool for Comprehensive Assessment of Palliative Care (MPCAT) on Assessment Outcome at 6 and 12 Months Follow up**

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**Background:** Assessment in palliative care settings should be focused, sensitive, specific and effective in order to minimise discomfort to vulnerable and often highly morbid patients. This report describes the development of an admission assessment protocol for a Specialist Palliative Care Inpatient Unit (SPCU) and its implementation into clinical practice.

**Objectives:** To develop and investigate the impact of the implementation of a Specialist Palliative Care admission assessment tool on documentation of key patient needs.

**Methods:** The outcome of a systematic literature review was used to develop an admission assessment protocol (the intervention) in a SPCU. Mixed methods were utilised to facilitate a comprehensive evaluation pre and post intervention to test the effectiveness, feasibility and acceptability of the intervention.

**Results:** The documented evidence of pain assessment improved from a baseline rate of 71% to 100% post intervention. This improvement was maintained 12 months post introduction of the tool ( $p < 0.001$ ). The documented evidence of screening for spiritual distress increased from a baseline rate of 23% to 70% at 6 months and to 82% at 12 months ( $p < 0.001$ ). The number of referrals made in the first 24 hours after assessment increased post intervention (physiotherapy,  $p=0.001$ , occupational therapy,  $p=0.001$ , social worker,  $p=0.005$ , pastoral care,  $p=0.005$ ), this was maintained at 12 months. Significantly more clinicians (88%) agreed that palliative care domains were comprehensively assessed post intervention in comparison to 59% pre intervention ( $p=0.01$ ).

**Conclusion:** Introducing the MPCAT was associated with significant improvement in assessment of multiple important aspects of patient need.

**Abstract number:** PO50

**Abstract type:** Print Only

**HADS-D for Evaluating Depression Prevalence in Patients Included in a Palliative Oncological Homecare Program**

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**Background:** Depression is a common mental health problem in Palliative Care, yet there are few studies in homecare patients.

**Aim:** To measure depression prevalence in palliative oncological homecare patients using the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D) and to identify influence of other factors in depression.

**Methods:** Prospective, cross-sectional descriptive study of patients included in a palliative home care program from May to August 2015. We performed the HADS-D and included other variables: gender, age, marital status, knowledge of the diagnosis/prognosis, religious belief, history of depression, primary tumor location, symptom burden measured by the total score of the Edmonton Symptom Assessment System (ESAS), palliative performance status (PPS) and survival (measured in days). A descriptive analysis of the sample was performed. We used

the HADS-D as a dichotomous variable ( $\geq 11$  =depression,  $\leq 11$  =not depression), and compared it with each variable by chi-square test or Fisher at low sample, and mean ESAS scores by t Student and Mann Whitney for the rest. We analyze Survival Kaplan-Meier curves according to HADS- D dichotomous variable.

**Results:** A total of 85 patients were included. The mean age was 77 years, 65% were male, 61% were married, 7% had history of depression, 87% knew their diagnosis and 79% their prognosis, 25% had a religious belief. The 22% had a HADS-D score  $\geq 11$ , which is in the normal range of the depression prevalence for a similar population. We found that on the HADS-D  $\geq 11$  group, 67% of the patients had history of depression ( $p=0.021$ ), poor performance status ( $p=0.027$ ), poor survival rate ( $p= 0.027$ ) and also worse symptom burden with a 10 point mean ESAS score difference ( $p=0,0001$ ). The rest of the variables were not significant.

Knowledge of the diagnosis	Yes=74	87,1% (CI 95%: 78.3-92.6)
Knowledge of the prognosis	Yes=67	78,8% (CI 95%: 69-86.2)
Religious Belief	Yes=22	25,9% (CI 95%: 17.8-36.1)
ESAS	Mean= 27,71	S=11,03
PPS	Median=50	IQR (25;75)=50;62,5
SURVIVAL	Median=48	IQR (25;75)= 18 ; 84
HADS-D	MEDIAN=5,5	IQR (25;75)=3 ; 10
HADS-D (DICHOTOMOUS)	<11 points= 66	77,6% (CI 95%: 67.7-85.2)
HADS-D (DICHOTOMOUS)	$\geq 11$ points=19	22,4% (CI 95%: 14.8-32.3)

[Descriptive Results]

**Conclusion:** Although depression is a clinical diagnosis, the HADS-D its a helpful tool to use in homecare advanced cancer patients.

**Abstract number:** PO51

**Abstract type:** Print Only

### Translating Care into Outcomes: A Grounded Theory Study Using the Consolidated Framework for Implementation Research (CFIR)

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**Background:** Many interventions in healthcare fail to translate into better outcomes for patients. Processes of care improve and behaviours change when outcome measures are used routinely in care, but there is uncertainty

concerning whether or not outcome measurement actually makes a difference to outcomes. A model of how outcome measurement works is needed

**Aim:** To develop a model to show how outcome measurement works across palliative care settings

**Design:** A grounded theory study was completed. Semi-structured interviews, developed using the CFIR, were conducted with patients, family and staff. Observational data was collected. Sample size was informed by expert guidelines and theoretical sampling. Interviews were recorded and transcribed. Open, axial and selective coding was completed in NVivo, and analysis stopped when saturation was achieved

**Results:** A model of outcome measurement that includes passive and active pathways in clinical settings was identified from analysis of 38 interviews and targeted observations across medical, nursing and allied health professions, patients and family. Passive outcome measurement pathways have little to no influence on patient outcomes. Active pathways were initiated when staff identified new or modified goals of care from using the measure. Passive pathways can be changed to active pathways by individual exchanges with colleagues, multidisciplinary meetings,

interactions with patients and or their family, and continued assessment and care planning. Both pathways are influenced by staff, patient and family factors

**Conclusions:** Implementing outcome measures alone will not guarantee better outcomes. Multidisciplinary meetings, collaborative approaches to care and accurate interpretation of the findings from the measure are central to guaranteeing this

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**Abstract number:** PO52

**Abstract type:** Print Only

### Facing a Symptom Difficult to Control: Electro-sound-guided Mid-line

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A patient on a Palliative Care Unit might need an IV to administrate medication in order to achieve a good symptom control. Electro-sound-guided mid-line is an alternative to central venous catheters (PICC, HICKMAN, and PORTACATH). Both share the following advantages: only one venopunction, long duration, limited complications, and most of all mid-line is more comfortable to the patient because this procedure can be accomplished in his room and it is not needed a radiological verification.

**Aims:** To describe the advantages of using mid-line on a Palliative Unit.

**Methodology:** Ad hoc database with patient's variables, such as reason for insertion and technique's variables, as complications.

**Results:** A sample of 92 patients. Average age = 66, 2, medium length of stay = 22 days; 88, 2% are oncological patients and 72% of them have receives previously chemotherapy treatment. 34, 4 have an IV when they were admitted. Mid-line needed to be channelled because of dyspnea (36, 6%), high levels of opioids (36, 6%), bad venous resource (92,5%) and comfort (100%). Thus, it was decided to use an IV, channelling it without incidents in 89% of all cases. It was removed because of exitus (60, 2%) and accidental withdraw (21, 1%). Average duration of mid-line = 20, 7 days.

**Conclusion:** The use of mid-line requires an only venopunction to get a venous access that remains during patient's stay on the unit. In this way, this procedure

favours patient's comfort and quality of life because we get a safe and long-lasting route of administration to achieve a good symptom control.

**Abstract number:** PO53

**Abstract type:** Print Only

### Development of a German Measurement Tool to Assess Attitudes towards Death and Dying at the End-of-Life

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**Background:** In current research, attitudes towards death and dying are described most often as a multidimensional phenomenon regarded as a personality trait that is stable over time. The most common attitudes analysed in research are death anxiety and acceptance of death. However, in the last phase of life not only attitudes (meant as stable personality traits) but also attitudes of situational or state-bound nature become more important. Most existing measurement tools so far assess the variety of attitudes as a multidimensional trait in general contexts using questionnaires. Authors of reviews of these measures criticize that attitudes towards death and dying should be assessed using more context-specific, non-questionnaire methods to also fit the requirements of (very) old and ill people and to enable communication on these sensitive topics.

**Aim:** Aim is to develop a first German multidimensional measurement tool to assess attitudes toward death and dying, using additional non-questionnaire methods. Another objective is to design a tool measuring not only personality trait but also state-bound attitudes.

**Methods:** The dissertation project is divided into three parts. In a first step a systematic review (SR) on existing tools to assess attitudes towards death and dying is conducted and items of identified measures are being collected serving as basis for the development of the planned measurement tool. To develop a tool which fits the requirements of research as well as of clinical practice additional qualitative interviews with experts from these fields will be conducted. In a third step the development and validation of the items of the new tool is planned.

**Results:** The poster will focus on the results of the SR so far and present the implications for the characteristics of the measurement tool to be developed and validated.

The project is supported by the Ministry of Innovation, Science and Research of North Rhine-Westphalia (funding scheme 'Fortschrittskollegs').

**Abstract number:** PO54

**Abstract type:** Print Only

### **Palliative Needs of Patients Admitted in a Geriatric Hospital**

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**Research aims:** Failure to identify palliative needs is a common problem to all health services. According to the WHO, only 1 in 10 people who need palliative care have access to the level of care they need.

The non-recognition of the integration of palliative care since the early stages of disease and difficulties in communication between health professionals, patients and family about the diagnosis and prognosis are examples of this problem. The study was developed in a geriatric hospital. Individual care plans are developed in a holistic perspective, integrating all the identified needs. We need a systematized approach to palliative needs, due to the clinical complexity and family dynamic of patients admitted. The aims of the study are: Identify patients admitted with palliative care needs and determine the palliative complexity levels.

**Study population:** Patients admitted at the our Hospital from 01.06.2014 to 11.30.2014.

**Study design and methods:** A prospective and descriptive study. To identify the palliative needs was used Supportive and Palliative Care Indicators Tool and Goldstandards Framework Prognostic Indicator Guidance. It was done the demographic characterization (age, gender, profession, diagnostic, treatments), Palliative Performance Scale and Edmonton Symptom Assessment Scale. Palliative care needs were identified at admission.

**Method of statistical analysis:** Statistic was done with SPSS 19.0.

**Results and interpretation:** There were 116 patients included in the study, 58.6% were females. The mean age was 75 years-old. The mean of hospitalization period was 54 days. 60% had palliative needs, half of which had complex palliative needs. There were 12 deaths.

**Conclusion:** There was a high prevalence of palliative needs in patients admitted. This reinforces the importance of systematically identify palliative needs and the existence of specialized professionals in this field in institutions that provide care to geriatric population.

**Abstract number:** PO55

**Abstract type:** Print Only

### **The Weight Solution: Measuring Controlled Drug Liquids**

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**Background:** Good practice and various international legislation recommend checking balances of controlled drugs (CDs) at least daily. In palliative care opioid CD liquids are commonly used. When measuring liquid controlled drugs, actual volumes can often be marginally different from reported volumes in a controlled drug register due to small but repeated errors in the measuring process. Combined use of a bung and oral dose syringe is the acceptable dose measurement method (Santoro et al 2013). Using a bung means that it is then impractical to accurately measure the volume of controlled drug liquid on a daily basis.

**Aim:** To determine if weighing controlled drug liquids leads to a greater accuracy of measurement during routine checking process of CDs.

**Method:** Two studies were performed. The first lasted two months and looked at discrepancies in liquid CDs using a graduated measuring cylinder to check balances. Data was gathered on a daily basis. The second study evaluated weighing bottles as a different measure for checking liquid CDs. This was carried out weekly over a six month period. The liquid CDs in use during the study period were Morphine Sulphate, Oxycodone and Methadone.

**Results:** When compared to the first study where loss of liquid had been identified during the measurement process as liquid had to be poured from bottle to measure, the second audit identified no loss occurred when weighing sales were being used.

**Conclusion:** Weighing CD liquids as part of a daily check can potentially reduce nursing time for the activity and can potentially lead to greater accuracy of measurement. It can also lead to reduced loss of liquid. It also promoted greater working between pharmacy and nursing departments to find a solution to the checking of liquid CDs.

**Abstract number:** PO56

**Abstract type:** Print Only

### **Evaluating a Novel System to Provide Equitable Community Specialist Palliative Care to Patients with Advanced Non-Malignant Disease**

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**Objective:** The exact role and added benefits of specialist palliative services in the community for patients without malignancy remains unclear. The aim of this study is to examine the efficacy of and compliance with a systematic tool for service delivery, by a Dublin community specialist palliative care team (CSPC), which is based on specialist palliative care need (using palliative care phase, palliative

problem score and PPS to assess complexity) and patient preferences for acute care.

**Methods:** Our study population included patients with non-malignant diseases who received CSPC from 01/08/2014 to 01/05/2015. Data was retrieved from the electronic database at the hospice and a retrospective chart review. Demographic data included primary diagnosis, place of care and source of referral, and palliative care complexity measures.

**Results:** 44 patients were taken on by the CSPCT. 61% of patients were referred from a hospital team. The mean wait time for face to face assessment by the CSPC team was 8 days. 66% were living at home. While 43% of patients were referred to SPC for end of life care, the CSPCT deemed only 16% were in the terminal phase with the majority either stable (40%) or deteriorating (33%). 49% were bed bound (PPS 40%). Only 66% of patients had an out-of-hours plan, of those with a plan, it was for acute hospital care in 37%. The most common symptoms reported were dyspnoea and fatigue.

**Conclusions:** The patient needs-based assessment and service delivery tool is easy but incompletely adhered to. The lack of an out-of-hours plan means the CSPC nurse is unclear as to their role in the event of a decline. Palliative care clinical phase, PPS and PCPSS assisted us in assessing SPC needs for patient groups. Ongoing review of new service delivery systems is essential for evaluating the need/benefit of CSPC for patients without malignancy.

**Abstract number:** PO57

**Abstract type:** Print Only

### Initial Validation of the Palliative Outcome Scale (POS) in Brazil: A Pilot Project

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**Background:** Research work outcomes contribute to evidence-based practice, but they aren't well established in palliative care field. The Palliative Outcome Scale (POS) was originally developed in England (UK) and is a multi-dimensional scale that rates quality of life of people who

have life-threatening chronic diseases. It's a short and simple scale designed for palliative care research and clinical practice.

**Aim:** To present the results of psychometric tests of the pilot project of POS validation process in Brazil.

**Method:** It's a quantitative, cross-sectional, not experimental research which focused the development of a methodologically grounded research. The steps for translation and cultural adaptation presented in literature were followed (initial translation, synthesis of translations, back-translation into original language, analysis by a committee of judges, pretest and submission the produced version to the authors). The final version was used in the pilot project along with clinical and sociodemographic questionnaire and the European Organization for Research and Treatment for Cancer (EORTC QLQ-C30).

**Results:** Data collection was performed with an oncological population, both in scale translation and cultural adaptation process (pre-test) as in the pilot project. This research involved a non probabilistic sample consisting of 50 subjects. The initial psychometric properties of validity and reliability, still in analysis process, and results will be presented at the congress.

**Conclusion:** POS is an important instrument of measuring outcomes on palliative care context and the version culturally adapted to Brazil (POS-Br) is a valid and reliable instrument for data collection on scientific research and as a resource of clinical practices.

**Abstract number:** PO58

**Abstract type:** Print Only

### A Computer Information System for Palliative Care Evaluation and its Contribution to Health Care Networks

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**Background:** The health care of people in palliative care can be improved through the use of an information system.

**Aim:** Establishment of a methodology for identifying the demand and indicators for palliative care based in the development of a computer information system (software).

**Method:** A computer information system (software) was specifically developed for collection, recording and analysis of sociodemographic and clinical data, such as pain, functionality and quality of life related to health care of people with advanced chronic conditions. The project was approved by the Research Ethics Committee (Process N.: 736.991/2014).

**Results:** An integrated database connectivity tool was created (Information Technology), which has several modules, collection, interoperability with the internal system of the hospital complex (interfaces for integration with information system in order to get the data identification of patients by looking at patient record), offline operation capability, custom search, export data in spreadsheet format and automated analysis of the data. Different evaluation tools were selected to compose the software: Sociodemographic and clinical data (includes ICD - International Classification of Diseases), Brazilian Economic Classification Criteria, Karnofsky Performance Status (KPS) or Lansky Performance Status (according to the age of the respondent), Numerical and Analogic Pain Scale and Palliative Outcome Scale - Brazilian version (POS-Br). Other scales were included in the structure of the software (such as ESAS, PaP Score, PPI and PPS), but were not used in the current research.

**Conclusion:** The development of a computer information system will contribute to the establishment of care protocols to patients in palliative care that may be used by different health facilities in the SUS and the growth in the number of palliative care services, favoring the interests of rationalized implementation of national resources.

**Abstract number:** PO59

**Abstract type:** Print Only

### “It’s Like Opening a Can of Worms”: Evaluating a Dignity Care Intervention for People with Life Limiting Illness in the Community Setting

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**Background:** Evidence indicates that people nearing end of life fear loss of dignity and a central tenet of palliative care is to help people die with dignity. The Dignity Care Intervention (DCI), based on the Chochinov theoretical model of dignity care, comprises four components: education manual; patient dignity inventory, reflective questions and care actions.

**Aim:** To evaluate the usability and acceptability of a Dignity Care Intervention (DCI) delivered by community

nurses for people with advanced and life limiting conditions.

**Method:** Mixed methods research design, with three phases.

Phase 1: Semi-structured, face-to-face interviews with patient/carer dyads (n=18),

Phase 2: four focus groups with (n=24) and an online survey with community nurses (n=27),

Phase 3: analysis of completed DCI tools (n=27). Data were analysed using thematic analysis of verbatim transcripts and descriptive statistical analysis.

**Results:** The DCI was acceptable to the community nurses. It contributed to the overall assessment of palliative care patients; identified areas that might not otherwise have been identified; supported communication and assisted the nurses to provide holistic end of life care. Concerns however were expressed that the tool ‘opened a can of worms’ initiating difficult conversations for which the nurses felt unprepared. The patients however found that the tool helped them to identify and consider future needs and were happy to discuss death and dying.

**Conclusion:** The DCI helped nurses to delivered individualised holistic care. Whilst all the nurses wished to continue to use the DCI, there were barriers identified such as the time taken to complete; the identification of suitable patients and the need for more training to enable them to initiate difficult conversations on dignity conserving care and end of life care.

**Funded:** Irish Hospice Foundation and Irish Cancer Society

**Abstract number:** PO60

**Abstract type:** Print Only

### Audit of Depression Screening on Admission to a Specialist Palliative Care Inpatient Unit

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**Background:** Depression is common in palliative care. Given the burden of depression in palliative care, it is advisable to attempt to identify cases in all patients. There is mixed evidence on the ability of screening tools to improve patient outcomes. However, it is unlikely that screening for depression will cause patients harm, and due to the frequency of depression in this population, many palliative care services do screen patients.

**Aim:** To assess compliance with Milford Care Centre’s Specialist Palliative Care Inpatient Unit depression screening standard.

**Method:** Audit approval and chart acquisition was in accordance with Health Service Executive Standards and Recommended Practices for Healthcare Records Management.

A list of patients admitted to the hospice from July 2014 - Nov 2014 was generated from the electronic database iCare. 30 randomly selected patient charts were generated using a computational random number generator. An audit proforma was populated and analysed with Excel.

**Results:** Mean patient age was 72.5 years Mean length of admission was 20.1 days. 10% of patients were screened for depression on admission. 20% of patients taking antidepressants and 33% with a psychiatric history were screened. Two thirds of those who were formally assessed screened positive for depression. 50% of positively screened patients had further action taken.

**Conclusion:** Formal screening for depression on admission is suboptimal. Follow-up of positive screening is inconsistent and not in line with IPU standard.

The 2011 European Association of Palliative Care Guidelines advises that screening tools may be helpful in detecting possible cases of depression, but use should always be complemented by training and comprehensive management strategy. We plan to

1. Revise layout of admission proforma to optimise likelihood of screening tool being completed.
2. Create moodle presentation to accompany changes in admission proforma, including rationale and background to topic.

**Abstract number:** PO61

**Abstract type:** Print Only

### A Review of the Management of Malignant Spinal Cord Compression in a Regional Hospital

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**Background:** Malignant spinal cord compression (MSCC) is a neurological emergency that affects 5% of patients with cancer. Early diagnosis is key in prevention of neurological complications, but frequently there is a delay. Treatment must be implemented early as neurological status at presentation strongly predicts functional outcome. Magnetic Resonance Imaging (MRI) of the whole spine is the investigation of choice and should be performed within 24 hours of suspicion. Management includes immediate administration of corticosteroids in most patients and surgery or radiotherapy.

**Aim:** To identify the current practice in management of MSCC in a regional acute hospital and with particular emphasis on:

- The timeframe from suspicion of MSCC to administration of corticosteroids
- The timeframe from suspicion of MSCC to MRI whole spine

**Methods:** A retrospective review was performed on the medical records of all patients referred to the palliative care team between July and December 2014 with a diagnosis of MSCC. The selected standard was NICE clinical guideline. Data was analysed using Microsoft Excel. No funding was obtained for this study.

**Results:** 11 suitable patients were identified. 44% (n=4) were prescribed corticosteroids within 24 hours of suspicion of the diagnosis. 90% (n=9) of patients had an MRI whole spine. 27% (n=3) of patients had an MRI within 24 hours of suspicion of diagnosis. 90% (n=10) were referred for radiotherapy and 48% (n=5) of patients were referred for consideration for surgery. 45% (n=5) were transferred to a radiation oncology team within 24 hours of MRI diagnosis.

**Conclusion:** This review identifies practice that can be improved in order to optimise patient outcomes. New strategies were adopted to improve practice with the aim of creating regional guidelines for the management of malignant spinal cord compression.

**Abstract number:** PO62

**Abstract type:** Print Only

### Main Prescribed Drugs in a Palliative Care Unit. Are we Loyal to the IAHPIC List of Essential Medicines?

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**Background:** Prescribing appropriately is an important task for doctors which is related to *lex artis*, drug availability, effectiveness and prognosis, among other parameters. The *International Association for Hospice and Palliative Care* (IAHPC) published in 2006 the *List of Essential Medicines* (IAHPC LEM) as a helpful guide for prescription based on efficacy and safety.

**Aims:** Knowing the quality of prescriptions in a palliative care unit (PCU). To compare our prescription pattern versus the International recommendations.

**Methods:** From invoices, we selected the 40 most purchased drugs from January to August 2014. Conversion from mg to *defined daily doses* (DDD) was made. The number of stays of patients in PCU on the same date range were calculated. Finally, a classification of the 30 drugs with highest DDD per stay was made (TOP30 PCU). Those drugs that matched both classifications were identified.

**Results:** Our TOP30 PCU was: **Dexamethasone** (1,97 DDD/patient/day), **Morphine** (0,66), Omeprazol/Pantoprazol (0,63), **Midazolam** (0,60), Lactulose (0,52), Macrogol (0,49), **Paracetamol** (0,49), Ketorolac/Diclofenac

(0,37), **Haloperidol** (0,31), Furosemide (0,27), **Oxycodone** (0,19), **Enema** (0,17), Amoxicillin/Clavulanic (0,17), **Butilescopolamine/Hyoscine** (0,17), **Methadone** (0,17), Espironolactone (0,14), **Metoclopramide** (0,14), Heparine (0,12), Ipratropium Bromide (0,11), Ranitidine (0,10), **Levomepromazine** (0,09) Metamizol/Dipirone (0,06), Cefazidime (0,04), Olanzapine (0,04), Tranexamic Acid (0,04), **Ibuprophen** (0,03), Ceftriaxone (0,03), Paromomycin (0,03), **Lorazepam** (0,03) and Quetiapine (0,02).

**Discussion:** More than 65% of our prescribed DDD of drugs match with the IAHPCL LEM. We have found that some groups as gastric protectors or antibiotics could be over prescribed.

**Conclusions:** Our TOP30 PCU list is well related with IAHPCL LEM. We have to review or correct some prescription patterns in the PCU.

**Abstract number:** PO63

**Abstract type:** Print Only

### Validation of the Integrated Palliative Care Outcome Scale (IPOS) to the Portuguese Population - Completion Assessment of the Open Question Items

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**Background:** IPOS is a patient-centered outcome measure which includes 2 open questions, each allowing for 3 responses.

**Aim:** To assess completion of the open questions for patients and healthcare professionals.

**Methods:** Multi-centred observational study. Data is being collected in 8 centres using convenience sampling. All patients attending the participant services are screened for eligibility. Inclusion criteria:  $\geq 18$  years, mentally fit to give consent, diagnosed with an incurable, potentially life-threatening illness, read, write and understands Portuguese. Exclusion criteria: patient in distress, cognitively impaired. A standard operating procedures manual was developed and distributed to all centres in the person of the facilitator/champion leading the study locally. Descriptive statistics summarise demographics and clinical data. Proportion of completion are presented for each open question.

**Results:** 70 patients included for whom mean age is 65.9 years (SD 12.3), 42 (60%) are male, 42 (60%) have up to 4 years of formal education, 37 (52.9%) are from the North. 25 individuals (35.7%) come from primary care, 25 from a non-specialised palliative care hospital service and 20 (28.6%) from 2 palliative care services. 73% had a cancer diagnosis. There are 30 clinicians participating.

Completion by patients for item 1: 48 (68.6%) for item 1a, 25 (35.7%) for 1b and 11 (15.7%) for 1c. For clinicians, rate of completion was 65 (92.9%) for item 1a, 49 (70%) for 1b and 26 (37.1%) for 1c. In relation to item 2, patients' completion was 24 (34%) for 2a, 1 (1.4) for 2b and 2c. Clinicians: 28 (40%) for 2a, 9 (12.9%) for 2b and 1 (1.4) for 2c.

**Conclusion:** By providing 2 free text items, IPOS allows respondents to add problems, arising in the week prior to completion, whether or not listed in the remaining IPOS items. This allows to emphasise the main problematic issues which might need to be prioritised. Thematic analysis will follow.

**Funding:** Calouste Gulbenkian Foundation.

**Abstract number:** PO64

**Abstract type:** Print Only

### Outcome Measurement in Outpatient Clinic with Edmonton Symptom Assessment Scale: A Retrospective Study

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**Introduction and aims:** Palliative care outpatient clinics aim to provide specialized care for patients with complex symptoms. They fill the gap between home care and inpatient care. Outpatient palliative care could reduce the need for emergency visits or admissions to hospitals. Little is studied regarding the outcomes of these services. The aim was to longitudinally measure patients' symptoms and to examine the use of strong opioids and anti-neuropathic medications in the referred patient population.

**Methods:** Symptoms were documented with the Edmonton Symptom Assessment Scale (ESAS) as a routine part of the newly established outpatient clinic in Pecs, Hungary. Data of the first and second patient visit were retrospectively analysed from January 2013 until December 2014. In addition, data were analysed regarding strong opioid and anti-neuropathic medications usage at the first and second visit.

**Results:** 120 patients were included. The most common symptoms at the first visit were pain (60,5%), anxiety (17,6%), followed by constipation (6,7%). The most severe symptoms at the first visit were pain (5,9), fatigue (2,9), and constipation (2,4). ESAS scores dropped clinically relevant at the second visit: Pain (4,1), fatigue (2,2), and constipation (1,4). Thirty three percent of patient were on strong opioid and 6% of patients with neuropathic pain were on anti-neuropathic medications at the first visit. Strong opioids in 36%, anti-neuropathic medications in 94% were initiated at their first visit.

**Discussion and conclusions:** Patients' main and most severe symptom was pain. Only one third of patients were on strong opioids at the first visit of the outpatient clinic. The majority of patients were not on any anti-neuropathic medications. Combination of medications could result in a significant improvement of symptoms, especially when related to pain. Use of outcome measurements in everyday practice could support clinical follow up and improvement of care.

**Abstract number:** PO65

**Abstract type:** Print Only

### The Influence of Admission Time on the Concordance of Patient - and Proxy Outcome Measures

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**Background:** Not all hospice inpatients are able and willing to self-report their symptoms and the ability to self-report declines in the last weeks of life.

**Aim:** To explore the influence of admission time on the concordance between patient- and proxy reported outcome measures in a hospice facility.

**Method:** A longitudinal research study was performed from January 2012 - March 2016 using prospectively collected data. The Utrecht Symptom Diary, a Dutch adapted translation of the Edmonton Symptom Assessment System, measures the intensity of 12 physical and psychological symptoms and wellbeing. A 0-10 numerical scale, is used for patient measures (USD) filled in twice per week. A 0-4 categorical scale is used for proxy measures (USD-P) filled in daily.

Patients admitted from Jan 2012-Jan 2015, with paired USD-USD-p measures in the 1<sup>st</sup> and 3<sup>rd</sup> week after admission, were enrolled in this study. Only the first paired measurement per week was selected for data analysis.

Primary outcome

1) concordance,

- Agreement: difference in USD and USD-p score
- Sensitivity/Specificity: symptom prevalence (USD>0) and clinical relevance (USD>3)
- Correlation: Spearman rank correlation coefficient<sup>2</sup>) Differences in concordance between 1<sup>st</sup> and 3<sup>rd</sup> week after admission

SPSS was used and an alpha of 5% was applied.

**Results:** Preliminary results of 41/75 patients with paired measurements. Complete agreement was achieved in

31-51%. The USD-p was sensitive (>70%) for pain, dry mouth, and fatigue. Sensitivity for dysphagia, constipation, nausea, shortness of breath and anxiety was < 40%. Specificity was >80% except for dry mouth and fatigue. Specificity was >80% except for fatigue. Correlation was low (.07- .54) but significant for all symptoms.

**Conclusion:** These preliminary results show that nurses were able to assess symptom intensity in concordance with patients. Nevertheless nurses tend to underestimate symptoms, but overestimate fatigue.

Differences in concordance over time will be presented at the EAPC2016.

**Abstract number:** PO66

**Abstract type:** Print Only

### The Clinician's Prognostic Toolbox

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**Introduction:** For patients with life-limiting illness, accurate survival prediction is important for decision-making regarding goals of care, treatment options and dealing with closure on personal family matters.

We aimed to compare the prognostic accuracy of clinician survival prediction (CPS) against 2 functional tools [Palliative Performance Scale (PPS) and Eastern Cooperative Oncology Group Performance Status (ECOG)] and 2 prognostic tools [Palliative Prognostic Scale (PaP), Palliative Prognostic Index (PPI)].

**Methods:** We conducted a 14 months study for this comparison by utilizing the clinical data routinely collected as part of the initial consultation on all patients with advanced illnesses referred to our Palliative Care Consultation Service. Actual survival was calculated using date of death. Descriptive survival analysis was used to determine the patterns of survival. The Kaplan-Meier estimates of the probabilities of survival and median survival were computed for subgroups defined by the tools. The pair wise log-rank test, Cox proportional hazard models for survival prediction and Harrell's c statistics enabled us to compare the tools and their sub-groupings at different cut-off time points. We also examined the impact of using a combination of tools or tools and CPS on the accuracy of prediction of survival.

**Results:** Comparing the accuracy of survival prediction of the functional and prognostic tools as well as CPS demonstrated that the tools had different accuracy at different cut-off time-points. Combining different tools strengthened prediction of survival.

**Conclusion:** The current study will add to the growing literature on prediction of survival for the terminally ill population. It will also strengthen the availability of accurate and timely prognostication information for palliative care patients, their families and the health care providers charged with their care.

## Research methodology

**Abstract number:** PO67

**Abstract type:** Print Only

### Communication in Palliative Care: Designing a Video-based Research Study

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**Background:** Video-based research studies can aid better understanding of healthcare interactions and can contribute to improvements in practice. Studies suggest that the effect of the video-recording process on the doctor-patient dynamic is minimal. This method has been frequently used in primary care research but much less so in palliative care research, where patients with advanced cancer may be considered too frail and vulnerable.

**Aims:** To design a video-based research study that is ethical, acceptable to participants (patients with advanced cancer, their families and healthcare professionals) and feasible to conduct in a hospital outpatient clinic.

**Methods:** A literature review was performed to identify the attitudes of patients to the routine video recording of consultations for research purposes. Service user groups from the local cancer network were consulted to explore their views on the acceptability of conducting video based study with palliative care patients. Cancer healthcare professionals were approached about the design of the study and collaborated to produce the study protocol.

**Results:** The literature review revealed that patients should have the ability to stop the video-recording during the consultation and highlighted concerns regarding the security of data. Patients with fatigue preferred to keep time spent in the clinic and questionnaires to a minimum. The study design carefully addressed patient preferences and concerns. NHS research ethical committee approval followed and to date 50 consultations have been video-recorded. Most participants reported that they forgot about the recording equipment and it was never stopped for interfering with the doctor-patient dynamic.

**Conclusion:** This study confirms that it is feasible and acceptable to undertake video-based research in a palliative care population attending a hospital outpatient clinic. Involving all stakeholders in the design of a healthcare communication study is critically important.

**Abstract number:** PO68

**Abstract type:** Print Only

### The Future of Palliative Care Research

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**Background:** Good clinical care needs an evidence base. Concerns have been raised about poor quality palliative care research.<sup>1</sup> Conference abstracts indicate research activity, but the full publication rate is a measure of quality. 43% of European Association for Palliative Care (EAPC 2005) conference abstracts were fully published.<sup>2</sup>

**Aim:** To assess the publication rate of abstracts (EAPC research conference 2008) by country of origin.

**Methods:** From 505 abstracts, duplicate/invited were excluded leaving 445: 100 oral; 345 poster. Full papers were sought (Medline; Pubmed; Google Scholar) and data extracted: country of origin, study design/population, journal. We report the publication rate by country.

**Results:** Overall publication rate was 57%; 79% for oral presentations. There was wide variation in Abstract numbers by country: range 1-134. Top three countries with the most abstracts were: UK(134); USA(41); Germany(39). Wide variation in publication rate was seen within regions, e.g.: Europe (UK=57%; Continental median 50%; range 0-100%); North America (69%; range 59-94%). Highest and lowest rates for countries with >10 abstracts are seen in table 1. The publication rate was higher in 2008 (57%) than in the 2005 general conference (43%).

**Conclusions:** There is wide variation in full publication. This may be partly due to variation in wealth/health and academic infrastructure, but is also seen amongst countries

**Table 1.** Publication rate.

Highest publication rate if >10 abstracts		Lowest publication rate if >10 abstracts	
Canada	94% (17/18)	Spain	33% (7/21)
Netherlands	72% (21/29)	Ireland	27% (4/15)
Norway	68% (15/22)	Switzerland	25% (3/12)

with established healthcare/education systems, e.g. of the many UK abstracts, only just over half are published. We must identify reasons for variation to ensure that our speciality is supported to produce and publish research of value to clinical practice.

## Reference

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**Abstract number:** PO69

**Abstract type:** Print Only

## Complexity in Palliative Care: Implications for Health Technology Assessment

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**Background:** Palliative care is complex and presents particular challenges for Health Technology Assessment (HTA). An FP7 project, co-funded by the EU, developed concepts and methods to assess complex technologies and applied these in a palliative care case study.

**Aims:** This study examines the complexity characteristics of home based palliative care (HBPC) and considers the implications for HTA methods.

**Methods:** A framework was developed to assess the complexity of health technologies and applied to HBPC. Then, concepts and methods developed in the project were applied to assess HBPC taking the complexity assessment into account. For example, the assessment of effectiveness used harvest plots as these can portray heterogeneous evidence clearly when meta-analysis may be less appropriate. The complexity assessment informed the development of a conceptual model for the economic analysis, based on a systems approach to economic modelling. Interactive participatory HTA approaches were chosen for the assessment of ethical aspects, due to their interactive, flexible nature.

**Results:** HBPC displays all the characteristics of complex health technologies regarding

- a) multiple perspectives (e.g. providers, users);
- b) indeterminate phenomena (as neither the content of HBPC nor the target population is clearly defined);
- c) uncertain causality (relationships between interventions and outcomes are not clear)
- d) unpredictable outcomes (due to a lack of sensitive, reliable and valid tools) and
- e) time/path dependence (historicity) (palliative care has changed over time). The complexity assessment influenced the choice of HTA methods in some assessment aspects.

**Conclusion:** Home-based palliative care is highly complex. Assessing the complexity characteristics of health technologies is an important initial step, enabling HTA researchers to take account of these in their assessment of the technology.

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## Stakeholder Involvement in Health Technology Assessment: A Palliative Care Case Study Exemplar

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**Background:** Internationally, stakeholder involvement is recognised as important in the Health Technology Assessment (HTA) process but little is known about the value of this activity.

**Aims:** To identify the contribution of stakeholder involvement in an EU project, that has developed concepts and methods to assess complex technologies and applied these in a palliative care case study.

**Methods:** Stakeholders (n=155), (commissioners, professionals, academics, patients, caregivers) in England, Germany, Italy, Lithuania, the Netherlands, Norway and Poland took part in the project. Involvement occurred in various ways (i.e. individuals or group, face-face, telephone, email and in Skype meetings) throughout the project.

**Results:** Stakeholder involvement was valuable as they:

- identified priorities in palliative care which led to the focus on home care provision and family carer support early in the project;

- validated findings for patient preferences and moderators of treatment effect, giving additional insights into these;

- informed gaps in the effectiveness evidence;

- provided expert opinion to assist economic modelling to predict the potential cost impact of the introduction of additional carer support;

- informed the assessment of sociocultural aspects which focused on user-professional relationships and decision making;

- took part in a 'mock' decision making meeting to end the case study.

**Conclusion:** The philosophy of stakeholder involvement is consistent with the principles of palliative care, potentially enhancing understanding of the health technology and improving the relevance and responsiveness of research. There is not one model to fit all as involvement needs to be flexible and responsive to specific circumstances. Stakeholder advice can complement and enrich traditional forms of evidence, providing additional insights without creating heavy workloads for researchers or stakeholders.

(co-funded by the European Union under grant agreement 306141).

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### How to Integrate Palliative Care into German Comprehensive Cancer Center? A Delphi Consensus Study

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**Background:** Criteria on integrating specialized palliative care (SPC) in cancer care are increasingly discussed. However, SPC in Comprehensive Cancer Centers (CCCs) certified and funded by the German Cancer Aid varies and best practice criteria have not been yet compiled systematically.

**Aim:** Development of consensus based recommendations (Rec) to develop a best practice model for SPC in CCCs.

**Methods:** A three rounds Delphi study and one roundtable discussion were performed with experts of SPC from all 14 certified CCCs in Germany. Physicians, professional caregivers, researchers and teaching staff (N=52) were invited to review content, relevance and feasibility of 30 statements on a 4-point scale. For consensus 80 % approval on relevance and feasibility was required.

**Results:** From the first to the third round 45/52 (86.5%), 42/45 (93.3%) and 38/42 (90.5%) respondents replied. After the first round recommendations in following domains were approved: *inpatient palliative care consultation service* (3 Rec), *day-care and outpatient palliative care* (2 Rec), *health care proxy and advance directives* (2 Rec), *pathway for dying patients* (2 Rec) and *research* (2 Rec). More than one discussion round was required for the following domains: *schedule of integrating SPC*, *palliative care unit*, *regional networking in palliative and supportive care*, *education and participation in the decision-making process of tumor treatment*. Finally 29/30 recommendations were consented. No consensus was reached on *involvement of SPC in patient case discussion within tumor conference or tumor consultation* (agreement in wording: 100%, relevance: 97.4%, feasibility: 76.3%), e.g. due staff shortage in SPC.

**Conclusions:** All 29 during the Delphi adapted and consecutively approved statements could contribute to provide best possible palliative care in German CCCs and can be used as assessment criteria on integration SPC. Delphi method is a useful tool to conduct acceptance within CCC network.

**Abstract number:** PO72

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### The Development and Validation of a Structured Survey Tool Examining Health Care Professionals' Perspectives of Advance Care Planning (ACP) for People with Dementia in Long-term Care Settings

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**Background:** Evidence suggests that ACP has the potential to improve care for people with dementia in long-term care settings. However to date, despite recommendation from international policy, implementation has been varied. Health care professionals are central to implementing ACP, yet empirical studies indicate they have concerns. There is a lack of validated measures examining the perspectives of health care professionals.

**Aim:** To develop a survey tool to examine to HCP's perspectives of ACP for people with dementia in long-term care settings.

To establish initial reliability & validity of the instrument.

**Methodology:** The tool was developed through adapting a previously validated tool used to measure oncology nurses perception of ACP, underpinned by the Theory of Planned Behaviour. The adaptation process was informed by incorporating the results from an in-depth analysis of literature & consultation with key experts in ACP & dementia. Research variables were grouped into 3 domains: Attitudes, Understanding and knowledge & Current Practice. Open ended questions were included to capture barriers & facilitators to ACP. This tool was administered to a total population of nursing home managers within a region in the UK (n=178).

**Results:** A response rate of 66% was achieved (n=116). Principal Component Analysis was carried out in order to measure construct validity. This revealed the presence of 6 principal components, with each variable loading relatively strongly onto 1 component. The Cronbach's Alpha for the tool was 0.86 indicating good reliability.

**Conclusions:** The results indicate preliminary construct validity of attitudinal and practice sections of the tool. There is potential to enhance understanding by exploring the relationship between the different factors that lead to intention to engage in ACP. This will contribute to the future development of appropriate educational support, resulting in improved care for people with dementia in this setting.

**Abstract number:** PO73

**Abstract type:** Print Only

### Ethics, Reflexivity and the Continuous Conversation Framework

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**Background:** Reflexivity is a strategy to enhance the trustworthiness of a study. It makes transparent the influence of the researcher on research design, data collection and analysis. As part of a doctoral qualitative study of hospice patients and advance care planning using video interview data, reflexivity was utilised to address a range of ethical dilemmas that occurred during the research.

**Methods:** Reflexivity was operationalized by using 3 strategies, through a *Continuous Conversation Framework* (defended subject, video aide memoire and implicit/explicit contract). These provided a systematic proactive lens through which the research process and the participant/researcher interactions could be located, justified and made transparent.

**Results:** The strategies addressed ethical and methodological challenges which arose in the study. Coding and analysis interpretation (video aide memoire), valid informed consent (with a dying participant), participant control (wording of consent form and retrospective cooling off period), explicit contract (family interpretation of use of images after death) and honesty (ambiguity of returned transcript).

**Relevance:** These examples illustrate the challenges and solutions presented in real world research for the ethical researcher. Qualitative research involves creating an interactive, dynamic relationship between participant and researcher. A discussion of the less visible aspects of carrying out research contributes to the methodological and ethical knowledge base of the research and clinical community.

**Conclusions:** Reflexivity through a *Continuous Conversation Framework* offers a systematic approach to identify and make transparent the ethical aspects of research design, data collection and analysis. Sharing the detail of how end of life research is carried out and how ethical and methodological dilemmas can be addressed offers a practical and useful way to contribute to the palliative care research methodological and evidence base.

**Abstract number:** PO74

**Abstract type:** Print Only

### Who Cares? - Scenarios for Future Care Cultures. Reflections on a Participatory Research Project in Collaboration with Schools

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**Background and research aims:** Finding an answer to the question "Who takes care of whom in the future?" is by

no means easy - especially in phases of chronic illness and end of life care. In collaboration with two different types of schools the following research aims are to be reached:

1. Students develop a sophisticated understanding of the importance of care work.
2. Students explore methods of qualitative research as part of participatory collaboration in research.
3. Scenarios for future-oriented care cultures are developed in collaboration between students, teachers, care givers, experts and researchers.

**Study design and methods:** Within a participatory qualitative approach students investigate how and under what conditions care is given in daily life situations. By using a narrative approach to induce the telling of everyday life stories, we intend to provide insights into a diversity of care networks. Questions during the interviews illuminate both the types of contacts and social relations as well as strengths and challenges of specific care networks. In a final scenario-workshop images for care cultures of the future will be developed.

**Results:** Preliminary results reflecting the methodological approach show that participatory research with schools as social systems, teachers, and students the most important factors for collaboration are (1) time and (2) trustful relationships. Time is important as resource that shapes the rhythm of collaboration between universities and schools. Trustful relationships are the necessary starting points for developing shared knowledge.

**Conclusions:** As common time is one of the scarce resources in the project, decisions about the issues that can be part of the participatory discourse vs. giving clear objectives and guidelines for a fruitful collaboration have to be made within the research team. All participants in the project need patience to respect the "otherness" of collaboration partners.

**Abstract number:** PO75

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### Are Patient and Family Priorities Reflected in the Swedish Register of Palliative Care?

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**Background:** High quality palliative care requires a person-centered approach, including communication about end-of-life values, wishes, and priorities. These values, wishes, and priorities should be included in patient reported outcome measures to make them patient relevant.

**Aim:** To explore if the quality indicators in Swedish Register of Palliative Care (SRPC) are relevant for patients and families.

**Methods:** Q-sorting is a method used to elicit subjective perceptions of the meanings and relative importance of concepts, using a set of small cards containing words or phrases which are then sorted and ranked by study participants. An initial set of 62 cards was developed, each containing a short statement about something that could be important to an individual during the last phase of life. The content for the statements was drawn from SRPC, the Swedish version of the "Go Wish" cards, national policy documents, and commonly used palliative care assessment tools. This initial set of cards will be tested by 10 patients and 12 persons from patient organizations who, individually or in focus groups, will assess the appropriateness of the content and language on the cards, as well as the time and emotional burden associated with ranking of the cards.

**Preliminary results:** Initial participants confirmed that the cards were appropriate for discussions of end-of-life priorities, but also suggested some improvements to the content of the statements on the cards and to the facilitation of the ranking process. The priorities of the initial participants to some extent validated the quality indicators in the SRPC, e.g. pain relief and wishes for place of death. Final results will be presented at the conference.

**Conclusions:** Preliminary results showed that the cards were considered appropriate for discussion of end-of-life values, wishes and priorities, and that the Q-sort methodology was feasible when exploring the patient relevance of the quality indicators in SRPC.

**Abstract number:** PO76

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### Novel Method for Determination of Methadone in Cancer Patient Serum by High-performance Liquid Chromatography with Electrochemical Detection

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**Aim:** Serious side effects of methadone are QT prolonged and respiratory depression, therefore it is important to establish a simple and accurate measurement method for methadone concentrations in blood since control of the blood concentration of methadone within safe ranges is indispensable for patients receiving methadone. Furthermore, it is

necessary to ascertain the pharmacokinetics of methadone in blood. Herein, we endeavored to develop a method for measuring methadone concentrations in the blood of cancer patients.

**Methods:** Chromatograms were obtained using a PU-2080 pump equipped with an electrochemical detector. The column was the XTerra® RP18 set at 40 °C. The mobile phase was 50mM Na<sub>2</sub>HPO<sub>4</sub>/CH<sub>3</sub>CN / CH<sub>3</sub>OH(20:19:3). The voltage of the working electrode of the electrochemical detector was set at 800mV. Serum samples (1.0 mL) were extracted in 4 mL butyl chloride. The samples were then mixed, centrifuged for 10 minutes at 2500 rpm, and the butyl chloride (top layer) was transferred to a clean glass tube. The butyl chloride extract was then evaporated to dryness. The dried residue was dissolved in 200µl mobile phase, and 40 µl of the solution were injected into the HPLC column. Furthermore, we measured methadone concentrations during the patient taking methadone (25mg/day) to stop and until death.

**Results:** The methadone peak was detected in 4.7 minutes and separated well from the serum component. The recovery rate was approximately 100 %. A linear-regression analysis of the standard curve from 10 ng/mL to 100 ng/mL yielded the following equation;  $y = 4417.7 x - 18010$  ( $r = 0.998$ ). The lower limit of quantification was 0.5 ng/mL (S/N=3). Methadone concentrations in this patient showed the very high value.

**Conclusion:** The present methadone measurement method is simple and rapid, and detection sensitivity equivalent to that of the conventional method was obtained. Therefore, it should be useful for measuring methadone concentrations in blood from cancer patients.

**Abstract number:** PO77

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### **Methodological Challenges of Exploring Ethical Issues Related to Artificial Nutrition and Hydration (ANH) for People in a Permanent Vegetative State (PVS): Can a Photo-elicitation Interview (PEI) Method Help?**

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**Introduction:** Since the question of withdrawing ANH for people in PVS sparks fierce ethical and legal debates, understanding the elements that influence such decisions is crucial. However, exploring perceptions towards ANH is methodologically challenging because of the emotional state of professionals and families members who are facing an extremely distressing situation, and because this question mirrors representations linked to our ancestral fear of dying of hunger and thirst and because of taboos

surrounding withdrawing a life-sustaining treatment. What method best meets our research needs when it comes to explore in depth such complex situations?

**Aim:** The NUTRIVEGE national study aims to assess the relevance of a PEI method to analyse perceptions and attitudes of professionals and families towards ANH for people in PVS.

**Methods:** The PEI method consists of inserting a photograph into a research interview. An original set of 60 photos was built using Google Images© and participants were asked to choose photos (10 max.) and talk about them. The situations of 32 persons in PVS were explored in 23 dedicated centers across France. 138 interviews were conducted with health professionals and family members. Verbatim were then organized with the support of NVIVO9 software and analyzed by an interdisciplinary research group according to qualitative research methodologies.

**Results:** Our presentation will highlight whether this method 1/is well accepted by the participants, 2/ fosters narration, reflexivity and introspection, 3/offers a sufficient “*unusual angle*” to allow participants to go beyond stereotypes and habits of thinking, 4/could be replicated in other research areas.

**Conclusion:** The use of visual methods currently constitutes an expanding area of research and this is of special interest to strengthen research among populations facing end-of-life and ethical issues.

**Funding:** *National Clinical Research Public Grant (PHRC) from the French Ministry of Health.*

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### **Using Reflexivity to Promote Rigour in Youtube Video Research**

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**Background:** This reflexivity piece stems from a study examining YouTube videos posted by people nearing the end of life. Reflexivity acknowledges how a researcher’s gender, ethnic background, profession and social status influences the choices made within the study, such as the research questions themselves and the methods used within the study. Reflexivity was especially crucial in this review, where the researchers were palliative care clinicians based in the United Kingdom, studying videos by patients from all over the world who were receiving care in different healthcare systems.

**Aims:** To describe the use of reflexive practice in order to limit our cultural and professional biases while undertaking a systematic review of YouTube videos.

**Methods:** The search strategy used the language utilised by patients to describe their advanced disease, rather than professional terminology. Self-awareness was practised at all times and the researchers noted their emotions while analysing videos. Reflexive practice became an integral part of this study and was discussed at every meeting during the research process.

**Results:** Most of the videos were from different cultures and healthcare systems (USA 90.9%) to the researchers' background and experience. While analysing YouTube videos that portrayed strong belief systems or values (e.g. religious or alternative treatments) the researchers reflected on their own potential bias and prejudices. Some videos were campaigning for Physician Assisted Suicide and the researchers took a neutral stance on this issue.

**Conclusion:** We outline the importance of reflexivity in social media video research, where researchers have a dual role of being clinicians and researchers. We feel that, similar to all qualitative research, reflexivity improves rigour and should be explicitly incorporated in the study protocol.

**Abstract number:** PO79

**Abstract type:** Print Only

### **Facilitated Modelling Approach in the Healthcare Research: Example Based on a Palliative Validation Tool**

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**Background:** Interactions between participants are always critical when using problem structuring methods and Facilitated Modelling (FM) workshops in healthcare research. Literature has discussed the role of the facilitator

in shaping workshop trajectories and outcomes, as well as the importance of managing the client-facilitator relationship. However, apart from very few exceptions, limited attention has been paid to the particular dynamics and elements that enable the achievement of consensus within FM workshops in a healthcare context.

**Aim:** To present findings from two workshops that took place in UK respiratory healthcare during the content validation process of an assessment tool developed to identify the palliative care needs of people with fibrotic lung disease in every day clinical practice.

**Methods:** Workshops were audio and video-recorded. Cognitive mapping was used for brainstorming. Entanglements of verbal and non-verbal interactions between workshop participants were identified and the role of the artefacts extrapolated (assessment tool and cognitive map); an iterative/inductive approach to theory building was used.

**Results:** During the workshop, participants were relationally engaged to the production of new knowledge. Challenging, Building and Affirmation statements, accompanied by relevant non-verbal expressions dominated in the participants' communicative practices. No unproductive dialogue patterns were found.

**Conclusion:** The study of verbal and nonverbal interactions in a health research setting highlights the "communication with and about models" issue and the role of artefacts in enabling group processes within FM and appeared to be a useful method in the healthcare setting.

This study was funded by a Marie Curie Cancer Care Research Grant.

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### **Working with Non-clinical Staff to Deliver Research. Lessons from Running a Wait-list Controlled Trial (ELSA) of a Volunteer Befriending Service towards the End of Life**

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**Background:** Many palliative care services involve non-clinical staff such as volunteers and administrative staff, and research in these settings should involve them as active research partners. We provide recommendations on involving these people in research, learning from a wait list trial of a volunteer provided befriending intervention.

**Methods:** A wait-list controlled trial investigating volunteer delivered befriending services across 11 sites in the UK. Non-clinical staff are responsible for site trial management and informed consent procedures. Participants are estimated to be in their last year of life, randomly allocated to receive the befriending intervention immediately or after a four week wait. Data collection at baseline, 4, 8 weeks: WHO QOL BREF, Loneliness scale, mMOS-SS, social networks. Intention to treat analysis includes fitting a linear mixed effect model to each outcome variable at 4, 8 and 12 weeks. ISRCTN 12929812

**Results:** Training for this role includes innovative face to face role play workshops, standard Good Clinical Practice education, and face to face and virtual site visits to check procedural compliance and address issues. Trial initiation matters include acknowledging staff concerns about trial design and involving them trial protocol development, documentation and research procedures. Areas that required acknowledgement and response during the trial include providing support to address issues of informed consent and eligibility, understanding the impact of the 'wait' allocation on participants (n=145), staff and volunteers, and integrating volunteer management and feedback into trial procedures.

**Conclusions:** It is possible to run a rigorous and ethical wait-list trial in partnership with non-clinical site staff and volunteers. Key considerations include assessment of the wait period and data collection timing, understanding providing a service in the context of a trial, and clear responsive communications to support staff.

**Abstract number:** PO81

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### Approaching the Knowledge Generated in a Phenomenological Text: A Path to Improve the Care of Persons with Advanced and Terminal Cancer

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**Introduction:** Van Manen's phenomenology of practice may contribute to the practices and experiences of nurses improving the relationships with patients with Advanced and Terminal Cancer (ATC).

**Objective:** To show the type of knowledge that is generated with Van Manen's Hermeneutical-Phenomenology

Method (HPM) in the context of an inquiry that aimed to study the nature and meaning of the authentic relationship between the oncology nurse and the person with ATC.

**Method:** Van Manen's HPM. 21 persons with ATC hospitalized in the oncology ward of Clínica Universidad de Navarra were phenomenologically interviewed in order to gather their lived experiences. They were asked to describe their relationship with oncology nurses. The principal empirical and reflexive methods and methodological impulses (*vocatio* and *reductio*) were conducted in order to grasp the essence of the relationship between the oncology nurse and the person with ATC.

**Results:** A Phenomenological Text (PT) that grasps the essence of the authentic nurse-patient relationship for the person with ATC was written. The text was divided in 4 parts:

- (1) The nature of the relationship;
- (2) The effects of the relationship in the patient;
- (3) The conditions of the relationship;
- (4) The sense and meaning of the nurse-person with ATC relationship.

The theme 'Relationship means to care with fine and full love', which reveals that the love of nurses to the person the patient is underlines authentic relationships, is presented in order to show the type of knowledge that it is contained in a PT. The knowledge the PT holds may help nurses to act thoughtfully in the interaction with patients with ATC with an active intentional consciousness that may lead them to care for the patients with sensitivity and sensitiveness to the situations and how to behave within them. To understand the essential meaning of the relationship involves grasping better the meaning of an authentic relationship and how to be a good nurse.

**Abstract number:** PO82

**Abstract type:** Print Only

### The Use of QALYs in Cost-effectiveness Analyses in Palliative Care. An Integrative Review

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**Aims/research questions:** In cost-effectiveness analyses (CEA) in health care, Quality Adjusted Life Years (QALYs) are often used as outcome measure. In several countries'

guidelines, the QALY is the prescribed measure of effect. The QALY evaluates the impact on both quality of life and survival time. The use of QALYs in CEAs in palliative care has been subject of much debate. The aim of this review is to integrate and analyze literature on this topic in order to

- (1) provide a more comprehensive understanding of the pros and cons of using QALYs in palliative care and to map suggested alternatives, as well as to
- (2) explore if the problem is recognized in economic research practice and, if so, how it is dealt with.

**Methods:** Both theoretical literature on the topic as well as empirical CEA studies in palliative care were analyzed. An inclusive literature search was conducted in PubMed, EMBASE and CINAHL, in which MeSH terms were *Palliative Care*, *Cost-Benefit Analysis*, *Quality of Life*, and *Quality Adjusted Life Years (QALYs)*. In analyzing the data, the research strategy for integrative reviews of Whitemore and Knafl (2005) was followed.

**Findings and conclusion:** Aside from general arguments about the QALY, e.g. concerning its relation to the intrinsic value of life, several themes regarding the components, features and assumptions of the QALY could be differentiated. These central themes concerned groups of arguments about the 'life years gained', the '(measurement of) quality of life', and the 'valuation and additivity of time' elements of the QALY. Some of which were supported by theories such as the 'Peak End Rule' and the 'Rule of Rescue'. Preliminary findings show that the problem is recognized in economic research practice. Alternative measurement outcomes however, do not seem to be used.

Whitemore R., Knafl K. (2005) *The integrative review: updated methodology*. The Journal of Advanced Nursing 52(5):546-53.

**Source of funding:** EU 7<sup>th</sup> Framework Program.

**Abstract number:** PO83

**Abstract type:** Print Only

**Palliative Care Pharmacotherapy: Continuous Safety through Pharmaceutical Consultation - Study Protocol for a Feasibility Study**

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**Background:** Pharmaceutical supervision of drug therapy can help to identify patient specific risks in pharmacotherapy, to support drug choice and to ensure continuous drug supply.

**Aim:** This study aims to develop and test the feasibility of a standardized pharmaceutical intervention pathway as pharmaceutical consultation for palliative care patients and their health care providers.

**Methods:**

- 1) Development of a pharmaceutical intervention pathway based on clinical experience, expert counseling and scientific data.
- 2) Feasibility testing and method piloting: controlled study to test the standardized pharmaceutical intervention pathway on a palliative care unit at a department of palliative medicine in Germany. Primary endpoint: symptom burden of palliative care patients at admission and after discharge measured with the Integrated Palliative Outcome Scale (IPOS).

Secondary endpoints: drug related problems and changes in drug regimen. Control group: palliative care patients on a comparable institution. The individual components of the pharmaceutical intervention pathway will be audited, e.g. determination of the level of implementation (%), interrater classification of drug related problems.

**Results:** The pharmaceutical intervention pathway consists of medication reconciliation on admission, continued medication evaluation, and discharge planning including patient training and coordination with the general practitioner and local retail pharmacy of the patient.

**Discussion:** Pharmaceutical consultation in palliative care is an approach that is promising to be beneficial for patients and doctors. The effectiveness has yet to be determined. This feasibility study serves as preparation for a randomized controlled study with adequate power.

**Abstract number:** PO84

**Abstract type:** Print Only

**Constructivist Grounded Theory as a Suitable Methodology for Palliative Care Research: A Fit Made in Heaven?**

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**Background:** As grounded theory methodologies have evolved, selecting an approach consistent with the research problem and a palliative care context can be a complex process. Charmaz's Constructivist Grounded Theory (CGT) offers a fitting grounded methodology for understanding palliative care patients' subjective meanings and social contexts, yet little methodological debate exists on using CGT in palliative care.

**Aim:** To demonstrate CGT's relevance to palliative care research by describing its use within a study of palliative care patient's spiritual needs.

**Methods:** CGT's systematic yet flexible methods entailed continual immersion, comparison, memo-writing and scrutiny of the data. 18 adults with life limiting conditions attending palliative care services in an Irish hospice participated in intensive interviews averaging 60 minutes. Following line-by-line coding of transcriptions, initial codes were analysed into continual extended memos, and scrutinised for signs of theoretical categories. Theoretical sampling directed further data gathering until core categories were considered saturated and a grounded theory constructed.

**Result:** CGT is based on researcher and participant co-constructing an abstract understanding of the studied life. The art of intensive interviewing, which is central to CGT, facilitated participants to tap into a spiritual awareness beyond their immediate linguistic consciousness as the researcher became an active participant in the interpretation of their spiritual needs. Experiencing God and eternalising family connections are core spiritual experiences rooted in patients' cultural and religious upbringing and expressed through serving others through God or moral goodness.

**Conclusion:** Within Charmaz's CGT, participant and researcher dyad is key to co-constructing an abstract understanding of the inquiry located in time, place and situation; making it a matching methodology for researching palliative care phenomena in its social context.

## Statistics

**Abstract number:** PO85

**Abstract type:** Print Only

### Importance of Pain Control and Long-term Prognosis in Patients with Urologic Malignancies after Palliative Radiation Therapy for Bone Metastases

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**Aim:** Some patients with urologic malignancies will achieve long-term survival following cancer treatment after an initial diagnosis of bone metastases. We investigated the prognosis of cases with urologic malignancies who received irradiation for bone metastases, while specifically focusing on the clinical features.

**Methods:** From June 2010 to September 2015, we retrospectively collected data of 93 patients with kidney, renal pelvis, ureter, bladder, and prostate cancer who underwent irradiation for bone metastases. Bone metastases were diagnosed by radiography, computed tomography, magnetic resonance imaging, or bone scans. Correlations between clinical parameters and overall survival were statistically analyzed.

**Results:** Of the 93 cases, 48 were alive and 45 were dead at the final follow-up. Moreover, 45 cases (48.4%) had prostate cancer, 27 (29.0%) had kidney cancer, 14 (15.1%) had bladder cancer, and 7 (7.5%) had upper tract (renal pelvis and ureter) cancer. The median overall survival was 31.1 months from the initial diagnosis of bone metastases. Among 17 female cases, no significant difference was observed in median overall survival between those with kidney cancer (n = 11) and those with urothelial cancer (n = 6). Moreover, among the 76 male cases, the median overall survival of cases of prostate cancer (46.0 months; n = 45) was significantly greater than that of cases of kidney cancer (31.1 months; n = 16) and urothelial cancer (11.0 months; n = 15) (P < 0.001). More than 50% of patients with bone metastases from prostate cancer required analgesics such as acetaminophen, nonsteroidal anti-inflammatory drugs, or opioids immediately after radiation therapy.

**Conclusions:** Longer-term follow-up and adequate pain control should be more carefully considered in prostate cancer patients with bone metastases as compared to other urologic cancer patients with bone metastases due to the potential for longer overall survival.

## Translational research

**Abstract number:** PO86

**Abstract type:** Print Only

### The Transfer of New Knowledge into Practice: Exploration of Implementation Plans in Palliative Care Research

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**Background:** One of the most common challenges of public health research today is the optimal integration of new findings into practice. In order to address this challenge, several frameworks have been developed to guide the implementation of evidence-based practice. Despite attempts to identify effective methods for integrating research into practice, evidence is unclear on what works with whom and in what contexts. Therefore, policymakers, practitioners and researchers are often left to their own

judgement. Research on *how* and *if* implementation plans are developed, the utilisation of knowledge transfer models and feasibility of implementation plans is sparse.

**Aim:** To explore knowledge transfer plans developed by palliative care researchers.

**Methodology:** This is an exploratory, descriptive study using one-to-one, semi-structured telephone interviews to explore knowledge transfer plans for research-based evidence, established within key palliative care research projects. Participants included lead Principle Investigators (n=7) conducting research within the All Ireland Institute for Hospice and Palliative Care (AIHPC). Thematic content analysis was undertaken, interviews were transcribed verbatim and an analytic framework was used to organise data based on key components.

**Results:** Thematic analysis revealed several patterns in relation to implementation plans: barriers to implementation, lack of resources for optimal implementation and sequential knowledge transfer.

**Conclusions:** Knowledge transfer plans do not remain static and appear to develop and change as research progresses, often dictated by funders and institutions. Effective utilisation of knowledge transfer guidelines or frameworks is rare.

**Abstract number:** PO87

**Abstract type:** Print Only

### How Could Hematologists and Palliative Care Physicians Better Working Together? Example of Acute Myeloblastic Leukemia in the Elderly

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**Background:** Impact of early palliative care has been demonstrated in patients with solid tumors but those with hematological malignancies benefit less frequently. However, acute myeloblastic leukemia in the elderly over 70 years old (AML70) is an incurable and life-threatening disease.

**Objectives:** To improve collaboration between palliative care and hematology, we sought to identify in what extend a Palliative Care Team (PCT) could support physicians and AML70 patients.

**Method:** The study was retrospective, single-center, including AML70 patients (excluding LAM 3) diagnosed between 2007 and 2013.

**Results:** One hundred and fifty-three patients were included, with 44% of secondary AML. One hundred and

five of them (69%) received chemotherapies. The median overall survival was 3.2 months, ranging from one month (no treatment) to 46 months (intensive chemotherapy). There was no significant difference between oral chemotherapy (3.2 months) and no specific treatment (p=0.11). Seventy-four patients (54%) died at the University Hospital. Blood transfusion had been prescribed in the last month of life in 122 patients (84%). A PCT intervention was required in 36 subjects (24%).

**Discussion:** We confirmed the poor prognosis of AML70, strongly influenced by the prescribed treatment but with uncertain benefit for oral chemotherapy. Three areas of cooperation could be relevant: Therapeutic issues first (patient assessment and decision support, outpatient care and pathways in transfusion support or end of life care). Prognostic issues then (lengthen life or not, anticipation of short term complications). Finally psychological issues (patients and caregivers' difficulties with the experience of incurability, hematological teams' difficulties with poor prognosis).

**Conclusion:** Our study has identified AML70 likely to benefit from early intervention of a palliative care team. Roles and supports of a PCT should probably be better explained among hematologists.

**Abstract number:** PO88

**Abstract type:** Print Only

### Implementation Strategies for Cancer Pain Management Guidelines

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**Background:** Cancer pain is a common problem that is under-treated despite the availability of guidelines due to barriers at the levels of health system, clinician and patient.

**Aim:** We aimed to develop implementation strategies to translate Australian guideline for assessment and management of cancer pain into practice.

**Methods:** Resources developed included patient self-management resources, Q stream health professional education modules and an audit tool to assess guideline adherence. The project used mixed methods, including:

- 1) a national online survey of current practice;
- 2) two systematic reviews;
- 3) a case study of barriers and facilitators to cancer pain assessment and management at a single palliative care unit;
- 4) consultation with stakeholders;
- 5) assessment of acceptability and usefulness via interviews with palliative care and oncology patients
- 6) Pilot testing of resources.

**Results:** Findings highlighted the need for patient self-management resources to be tailored to patients' needs, build patients' sense of control, and support communication with health professionals and coordination of care between services. Patient-held resources were developed to include:

- 1) a pain diary to help patients report pain in a systematic way and better understand exacerbating and alleviating factors;
- 2) a template for setting specific, measurable, achievable, relevant and achievable (SMART) care goals, as well as identifying potential obstacles and ways to overcome them;
- 3) an action plan detailing current strategies for management and contacts for support; and
- 4) a tool for patients to self-evaluate their capacity to self-manage pain and adequacy of support.

Q stream education focussed on key recommendations of the cancer pain guideline and the audit tool assessed adherence to the recommendations.

**Conclusion:** A cluster randomised controlled trial will test effectiveness and cost-effectiveness of the resources.

## Palliative care organisation and health care services

**Abstract number:** PO89

**Abstract type:** Print Only

### Re-thinking Palliative Care Services. Usefulness of an Integrated Care Model

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**Background:** Specialized palliative care services have been introduced in response to the needs of palliative patients. The palliative care population is continuously growing and changing, requiring adaptation of health care organization and delivery. Integrated Care has been described as a method to help the health care sector change into a more demand-driven, client-centered and cost

conscious system, connecting the healthcare system with other human service systems to improve outcomes.

**Aim:** The purpose of this study is to evaluate the current structure and organization of the palliative care services through the lens of the Integrated Care model on a regional level.

**Methods:** A multi-level, multi-disciplinary, multi-method research design is used. A project group was installed with professionals from different settings (home care, hospital, care homes for the elderly, social and educational organizations) and from different disciplines (doctors, nurses, educationalists, social workers, managers) to guide the process. Discussions on norms and values and SWOT analyses were performed in each setting. Chart reviews have been performed during six months to map the patient flow. Patients, family members and professionals in each setting were interviewed.

**Analysis:** Descriptive statistics of quantitative data. Thematic analysis of interviews and focus groups.

**Results:** The functioning of the different palliative care settings was evaluated according to the six integration paths of the model: Normative (vision and mission), Functional, Organizational and System (SWOT analyses and 6-month chart review study) Clinical (interviews with patients and family) and Professional (focus-groups with professionals) Integration. Areas of improvement could be defined towards integration optimization.

**Conclusion:** Using an Integrated Care Framework to evaluate health care services' organisation and functioning is a feasible method to inform quality improvement initiatives.

**Abstract number:** PO90

**Abstract type:** Print Only

### The National Programme Palliative Care in the Netherlands

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The palliative care is well organised in the Netherlands. Still there is room for improvement, for example to smoothen the cooperation in the homecare and hospital care and to improve the quality of education about palliative care for professionals.

The government formulated 13 goals in the national programme (NPPZ) in 2020 and will invest 51 million euro for the improvements (2014-2020). ZonMw (as a governmental funding agency) is asked to formulate a programme to be able to subsidise projects, organised in four themes:

- awareness and culture
- organisation and continuity of care

- innovations and quality of care
- patient involvement and support.

The patient has a central role in the programme, called Palliantie. In the presentation I will explain what the purpose of the government is, which role the regional palliative care plays in this field and how we stimulate new developments and improvements in research, care and education. The organisations involved in palliative care work together in seven regional networks. In the start of this programme we talked to 125 experts about difficulties within the four themes and for different targetgroups in palliative care like children, people with dementia or homeless or psychiatric people. They gave their priorities for important improvements in the palliative care. We will ask them again in 2016 and in 2018 to actualise the priorities. Researchers, education experts and/or carers are invited every year to send in proposals to improve palliative care. In the presentation I will tell more about the differences in priorities by several targetgroups, about the four themes and goals in these themes, the role of the patients in the programme and projects and the impact of the investment we want to achieve in 2020. In a free communication session I'd like to discuss the differences between countries, which are present in the workshop, the difficulties in improvement of palliative care and possible solutions.

**Abstract number:** PO91

**Abstract type:** Print Only

**Progress in International Twinning Partnership between European Palliative Care Centers & Hospice Ethiopia, a NGO in Addis Ababa**

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Palliative care is becoming increasingly important in low and middle income countries with an increasing burden of non-communicable diseases as cancer but also HIV-related morbidity. In 2012 a partnership began between groups in Sweden, the United Kingdom and a small nurse-run NGO delivering community based palliative care in Addis Ababa, the only professional palliative care unit in Ethiopia. Staff trained and supported by Hospice Africa Uganda (led by Professor Anne Merriman).

Memorandums of understanding were signed 2012, using guidance from Help the Hospices, focusing on education, promoting best practice. Goals included exchange visits, teaching, fundraising, networking/advocacy with various existing and potential stakeholders in Ethiopia.

Four years on we reflected on progress made. Each partnership has visited Ethiopia at least annually. Teaching included educational courses at 2 medical schools in Addis Ababa, participating in the "Nine Pain Free Hospitals" educational initiative (joint US & Ethiopian Health Ministry). Home clinical visits by consortium members with hospice staff. Fundraising provided a part time palliative care physician, funded a post-graduate degree for one nurse, contributed to running costs. Strong opioid oral medication was limited to one hospital in Addis Ababa in 2012, now extended to the 9 hospitals. Skype calls every second month with shared minutes, links and updates the partnerships

Partnerships as this require careful planning, clearly documented roles and goals. Facilitating factors include good knowledge of the country. Our experiences have affirmed the need for coordinated approach when different parties are involved in a twinning project. Sharing of experiences, mutual updating of progress save much time in duplication & the important provision of mutual support.

The approach should be replicable across many countries and domains of healthcare.

The project is funded by charitable giving & private donations.

**Abstract number:** PO92

**Abstract type:** Print Only

**Persons Living Alone Have the Highest Admittance to Hospice and the Lowest Admittance to Hospital-based Palliative Care Team/Unit - A Nationwide Study from the Danish Palliative Care Database**

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**Background:** Married individuals have been shown to have higher admittance to specialised palliative care

(SPC). The aims were to investigate the impact of cohabitation status in more detail (subgroups of non-married individuals, e.g., widowed) and to do this separately for the two SPC institution types in Denmark (hospice or hospital-based palliative care team/unit).

**Method:** A register study based on the national Danish Palliative Care Database linked with additional registers including all patients dying from cancer in Denmark 2010-13. The associations were investigated using logistic regression analysis adjusting for sex, age, cancer diagnosis and geographic region.

**Results:** Half of the study population (N=44,480) was married/cohabiting, 25% was widowed, 12% divorced, 7% never married and 3% married but not living together. Compared with persons married/cohabiting, persons living alone were more likely to be admitted to hospice (e.g.,

divorced OR=1.41) and less likely admitted to hospital-based palliative care team/unit (e.g., never married OR=0.64) (Table 1).

**Conclusion:** Cohabitation status was associated inversely with admittance to hospice and hospital-based palliative care team/unit. We hypothesize that better opportunities for care at home (i.e. lower needs) may explain that persons married/cohabiting had lower admittance to hospice. As persons living alone are unlikely to have lower needs than married persons for care from a hospital-based palliative care team/unit we believe that the lower admission of persons living alone reflects that they have less ability to obtain specialist care, possibly because they lack someone to 'talk their case' (inequality). If this is the case, some of the weakest patients have poorer access to SPC, and this should be corrected.

**Table 1.** Institution type specific admittance.

Institution type specific admittance (adjusted for sex, age, cancer diagnosis and region)	Cohabitation status, Odds ratio (Bold = statistic significant)				
	Married/Cohabiting	Married, not living together	Divorced	Widowed	Never married
Hospice	1.00	1.09	<b>1.41</b>	<b>1.20</b>	1.10
Hospital-based palliative care team/unit	1.00	<b>0.80</b>	<b>0.81</b>	<b>0.74</b>	<b>0.64</b>

**Abstract number:** PO93

**Abstract type:** Print Only

### “Outside in the Corridor, Inside in my Mind” - Factors Influencing Nurses’ Decision Making in Severe Breathlessness

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**Background:** Breathlessness is a subjective experience of breathing discomfort. Management comprises pharmacological and non-pharmacological interventions. Nurses have an important role in this context and often use non-pharmacological interventions within their care interaction. At the same time, they need to decide which reaction is right for the individual patient and the situation as well as the setting.

**Aim:** To describe professional nurses’ interactions in situations with patients suffering from severe breathlessness focusing on the factors influence nurses’ decision making.

**Methods:** Participant observation (PO) and qualitative expert interviews. Simultaneous data collection and analysis allow for occurring themes or categories and examples can be focused to thickly describe the phenomenon. Theoretical sampling guides data collection, while constant comparison and the usage of a coding paradigm are part of the analysing process. Data analysis merges a reflexive grounded theory approach with Goffman’s Framework Analysis.

**Results:** 30 POs in different settings and 15 expert interviews were conducted. The permanent occurrence of parallel strands is one central influencing factor described in the interviews and shown during the PO. These strands or lines of nurses’ actions are not only original nursing duties, but administrative and other tasks nurses additionally undertake. Depending on the institution and its organizational logic/culture, nurses’ central challenge seems to guide patient through the treatment process - not to care for them. This influences patient-side care and thereby the possibility to care for patients with severe breathlessness.

**Discussion:** The results on nurses’ DM give an indication to understand the influencing factors and their connection to different settings, knowledge, persons and circumstances. The focus on a highly relevant symptom shows the relevance to every day practice and the nurse-patient-interaction.

**Abstract number:** PO94

**Abstract type:** Print Only

**Specialist Palliative Care Advice for Advanced Oncological Patients in Acute Care Setting: The Experience of San Matteo Foundation, Pavia**

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**Introduction:** From the beginning the field of activity of the Medical Oncology Division (OD) in San Matteo Foundation was not purely cancer therapeutic, but has included the interdisciplinary cooperation with the Supportive and Palliative Care (PC) Unit, that was created inside the same structure. Specialists of PC Unit work closely and share in- and out-patients of the OD. From 2015 the PC Specialist is also available for advice at the bedside in Acute Care Setting. We present the experience of PC Team in Acute Care Setting in San Matteo Foundation.

**Methods:** A retrospective analysis of cases followed by the PC Team (advice) between 01/01/2015 and 30/09/2015 was conducted. Data were extracted from medical report and the reports of the multi-professional team.

**Results:** 32 patients (pts), 16 males, mean age 68 years (range 26-91) were evaluated. 18 pts in Internal Medicine, 7 pts in General Surgery, 4 pts in Hematology, 2 pts in Pulmonary, 1 in Orthopedics Surgery; 2 pts already in charge to our PC team. Main cancer diagnosis was gastrointestinal in 13, lung in 5 and haematological malignancies in 6. Main reason for admission in Acute Setting was delirium and/or neurological symptoms in 8, sepsis 7, dyspnoea 5. All pts were referred to our PC Unit to define the best care setting and manage difficult symptoms including fatigue (14 pts), pain (7 pts), dyspnoea (5 pts) and 2 for palliative sedation. After consultation, 24 pts were transferred to Hospice, 1 to Oncology, 6 pts were addressed to the Home Care Assistance, 1 pts died while still in the acute care ward.

**Conclusion:** In our experience the presence of the PC Specialist in Acute Care Setting help developing the plan for continuity of care so much desired by the patient and his family, thus ensuring a smooth transition, gradual and less traumatic by active therapy to palliative care, optimizing resources.

**Abstract number:** PO95

**Abstract type:** Print Only

**Integration and Relevance of Standard Operating Procedures for Palliative Care within the Network of German Comprehensive Cancer Centers**

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**Background:** Standard operating procedures (SOPs) are essential for quality management in hospitals and may ensure that processes are carried out following state of the art. The presence and relevance of SOPs for palliative care (PC) within the network of German Comprehensive Cancer Centers (CCC) is unknown.

**Methods:** In this descriptive study, 15 CCC were invited to name their internally available SOPs. All of them were grouped into

- (1) symptom-related,
- (2) clinical pathways and
- (3) measures and processes.

All CCC were then asked to classify all registered SOPs according to their relevance for PC. The results were evaluated in IBM SPSS Statistics.

**Results:** In the group of symptom-related SOPs pain management was most frequently available (n=11, 73%), followed by dyspnoea (n=7, 47%), care in the last days of life and nausea / vomiting (each n=6, 40%). The SOPs rated most relevant were delirium and other neuro-psychiatric diseases, pain management and care in the last days of life (each n=13, 87%), followed by bowel obstruction, dyspnoea and nausea / vomiting (each n=12, 80%). SOPs on integration of PC into clinical pathways of other medical disciplines was rarely available (n=1-3, 7-21%) though rated highly relevant (n=9, 60%). The most frequently available SOPs in the group of measures and processes were dealing with deceased patients (n=9, 60%) and standards for admission to the PC unit (n=8, 53%). The most relevant SOP was palliative sedation (n=12, 80%), followed by dealing with multi resistant pathogens, deceased patients and standards for admission to the PC unit (each n=9, 60%).

**Conclusions:** The availability of SOPs specifically for PC in the network of 15 German CCC is rather low. There are significant differences between the availability and the ratings of the relevance of certain SOPs. The development of a common set of relevant SOPs for PC in the CCC network may contribute considerably to quality assurance.

**Abstract number:** PO96

**Abstract type:** Print Only

### Single Point Palliative Care Bed Management Program for 6.3 Million Population Round the Clock: One Step Forward to Get the Highest Quality Care for our Patients

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**Background:** In December 2010, our 24hour service started giving round the clock Palliative Care and Support at the end of life. Continuity of care is our priority and it is essential to know where it takes place. From 2013 we formalized a system of centralized bed management. Total bed pool is 377 (192 in public units, 185 commissioned in private ones) available through 17 Palliative Care Home Support Teams, of which 6 are commissioned with the AECC (Spanish Association against Cancer), 12 Palliative Care Hospital Support Teams, 1 Pediatric Support Team, 7 public hospitals with recognized Referent professionals from other specialties and our 24/7 platform manned by specialists.

#### Aim:

- To identify which teams admit patients with complex palliative care needs to the 13 Palliative Care Units in the region.
- To establish the reasons for requesting admission.

**Methods:** Descriptive study and analysis of data collected in the Referral Document Protocol for adults within the Electronic PC Medical Records from 2011 to 2015.

**Results:** From a total of 8147 registered requests, 60.34% came from the acute sector Hospital Support Teams and Referent Teams; 35.68% from domiciliary care, both public and AECC teams; 3.44% by other Bedded Units; and 0.54% by PAL24.

Main reasons for referral were: symptom control 65%, family and social support 40%, care in the last days of life 10%.

**Conclusions:** The centralization and standardization of admission criteria to PC Units has contributed:

- To provide the resource that is more adequate according to patient and family need, most of the time improving professionals communication from different Care Settings
- To improve timely access of patients and their families to Palliative Care Resources

- To improve efficiency and make a better use of resources available with patients staying in their preferred place of care significantly longer
- Patient needs require earlier identification in the acute sector
- Reasons of referral are multicausal

**Abstract number:** PO97

**Abstract type:** Print Only

### The Construction of the Health Care Professional in Palliative Care Contexts: A Scoping Review on Caring for the Person in the End of Life

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**Background:** With the development and implementation of Palliative Care, health care professionals experience, more than ever, end-of-life caregiving. Caring in this particular context, where contact with suffering, end-of-life and death is experienced daily constitutes a professional and personal challenge. Understand the construction of this professionals will permitted to increase the professionals' welfare but also the patient care, since this will have an impact on their care. **Aim:** To analyse and describe the elements that contributes to the construction of the health care professional in the context of Palliative Care.

**Design:** Scoping Review, recommended to map the literature on a particular topic and to identify gaps in the research, based on the framework by Arksey and O'Malley.

**Data sources:** PubMed, Embase, CINAHL, Scopus databases, as well as grey literature, were searched for articles (2005-2015). Reference searching, hand searching, expert consultations complemented these Primary studies focus on different professionals working in Palliative Care Units or Hospice Centers were eligible for inclusion.

**Results:** In total, 22 articles (of 3632) were included, eighteen just about nurses. Six elements were defined: Construction and application of the concept of care; Psychosocial effects that the daily care produce; Meaning attributed to the process of end-of-life; Knowledge mobilized in the provision of care; Strategies adopted by health professionals in the process of building relationships; Factors that influence or affect the caregiving. Gaps identified in the publications were: relationships competencies and strategies adopted; the real needs from educational programs; the view of other professionals.

**Conclusions:** This review identifies elements that could be targeted for future interventions and gaps for future research.

**Keywords:** Palliative Care, End of Life Care, Review Literature, Staff Attitude, Health Care Professional

**Abstract number:** PO98

**Abstract type:** Print Only

### Development of a Palliative Care Clinical Pharmacist Service

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**Aims:** This research aims to describe the development of a clinical pharmacist service in a specialist palliative care unit in Ireland and to examine outcome measures of the service.

**Background:** Despite international evidence and recommendations in favour of pharmacist involvement in palliative care, a hospice service in Ireland receiving its medicine supply from a retail community pharmacy did not have a pharmacist on its multidisciplinary team (MDT).

**Methods:** A multidisciplinary steering group was formed to direct development of the service. The role of the clinical pharmacist was defined. The procedures for medicine prescribing, ordering and supply were determined. A pharmacist was recruited and received training in specialist palliative care practice. Pharmacy, nursing and medical staff were briefed or trained in new procedures. After one year of service provision, activity and costs of the service were reviewed. A literature review was conducted to inform future measurement of service outcomes.

**Results:** A clinical pharmacist service which facilitated pharmacist review of patients and their prescriptions and in-house dispensing of medicines was implemented. In the first year of service provision, the pharmacist conducted 939 reviews of patients and their prescriptions and attended 90 MDT meetings. Drug costs were reduced by 44%. Documenting pharmacist interventions in addition to staff and/or patient survey were two methods identified in the literature for further measurement of pharmacist service outcomes.

**Conclusion:** Initiation of a clinical pharmacist service in a specialist palliative care unit resulted in regular patient review by a pharmacist as part of the MDT. Quantitative data on the pharmacist's clinical activities and reductions

in drug spend were recorded. Future qualitative analysis of the service is recommended.

**Abstract number:** PO99

**Abstract type:** Print Only

### Inpatient Hospice Care in Czech Republic. Analysis of Data from National Health Registres

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Inpatient hospice care is being developed in the Czech Republic since 1996. In 2015, there are 17 hospices with total capacity of 450 beds (4,5 beds/100 000 inhabitants). All hospices are freestanding health institutions run by NGOs (64%), churches (29%) or local authorities (6%). Based on data from Death Certificate Register and National Register of Hospitalised Patients the following picture of inpatient hospice care arises:

- There is a large variability in the availability of hospice care in different administrative regions ranging from 0 to 8,5 hospice beds/100 000 inhabitants.
- Inpatient hospices are the place of death for 2,5% of all deceased and for 9,3% of cancer patients.
- The most common reason for hospice admission is advanced cancer (85,6%). Other diagnoses are much less common: post stroke states (7,1%), dementia (1%), heart disease (0,6%) and neurodegenerative disorders (0,4%).
- Patients are referred to hospice from acute care hospital in 47%, from their homes by their GPs in 29% and by other out-patient specialists in 20%.
- Average length of stay in hospice is 23,5 days (median 10 days), with 21% patients staying for more than 30 days.
- Patients terminate their stay in hospice by death, discharge home or to acute hospital in 89,4%, 7,4% and 2,1% respectively.

### Discussion:

- National Health Registres are a source of valuable information and data about the availability of hospice and palliative care services.
- Inpatient hospices have played an important role in promotion of the concept of palliative care in the

Czech Republic. Nevertheless they are the place of death only for 2,5% patients every year.

- Based on the distribution of patients with chronic diseases in need of palliative care in Czech health care system, other forms of palliative care delivery are critically needed.

**Abstract number:** PO100

**Abstract type:** Print Only

### Palliative Care at Home: A Literature Review

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**Introduction:** Palliative care promotes a holistic care, promoting a centered care to the patient and, thus contributing to the comfort and quality of life by addressing the problems associated with life-threatening diseases, preventing and relieving suffering.

**Aims:** Identify the evidence produced about home palliative care.

**Materials and methods:** A integrative review on the databases of ISI Web of Knowledge, CINHALL, MEDLINE and PubMed, B-on with the descriptors “palliative care”, “home care”, “nursing care”. Articles in the English language, existing in full text, with abstract and references available and analyzed by experts were included.

**Results:** A total of 69 articles were found and analyzed. The majority of the articles found are: original studies, literature reviews, editorials and commentaries. The most discussed topics were: home palliative care, family support, home care, symptom control and promoting quality of life. There is predominance in the last decade especially in 2009-2012 and the predominant language was English. The research reveals the increasing number of patients with progressive and incurable diseases and 68,2% of patients prefer die at home. It becomes essential to develop a network of care extended to cover the home assistance.

**Conclusion:** We observed that palliative care should improve social and innovative health policies, centered on the needs and preferences of patients, associating scientific knowledge, skills and attitudes in order to develop the excellence of care. According to the evidence found the development of a specialized care, implementing effective interventions which provide a dignified death, and supporting the family throughout the process including the stage of grief, contributes for an individualized approach

focused on the problems of patients and families, in symptom control and maximizing comfort.

**Abstract number:** PO101

**Abstract type:** Print Only

### Palliative Home Care, for a Holistic Approach to the Patient and Family

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**Introduction:** Palliative response to the needs of patients and families, and combine scientific knowledge and skills allied to humanism in order to promote the relief and prevention of suffering, enhance the quality of life, comfort.

**Aim:** Demonstrate the importance of palliative care at home, to the satisfaction of patients and families, and implementation of individualized care.

**Materials and methods:** A qualitative and comparative analysis of two cases. One patient with cancer without support of a palliative care team and another patient with neurological degenerative disease being accompanied by a palliative care team at home. Both males, aged between 69-77 years, have common co morbidities (depression, diabetes mellitus and hypertension). Data were collected through observation and resource a data collection instrument developed by the researcher with face and content validation by experts in the field of palliative care. Data were collected with informed consent of the participants and in their homes.

**Results:** We observed the high satisfaction of the patient and family that was under support of home palliative care team, with guidance and implement measures and care. The patient participated in all decisions and was aware of the progression of the disease as well as the possible consequences. In relation to the patient without palliative care, observed the anger and sadness face the situation, the difficulty in accessing individualized care, and targeted the patient and family needs, to access resources and support technical and financial, and the inability to manage the symptoms and the disease progression.

**Conclusions:** The analysis indicates that the accessibility of palliative care at home, using an approach that implements a systematic monitoring through the co-partnership between teams and patient/family, contribute to improving the quality of life and provide humanized and individualized care.

**Abstract number:** PO102

**Abstract type:** Print Only

**Palliative Care Costs in Canada: A Descriptive Comparison of Studies of Urban and Rural End-of-Life Patients**

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**Background:** Significant gaps in the evidence base on costs in rural communities in Canada and elsewhere are reported in the literature, particularly regarding costs to families. Because of limited access to health care services and other issues, rural end-of-life patients may show different consumption patterns of health care resources than their urban counterparts, and rural families may experience different financial burdens.

**Aim:** The study aimed to compare both the global picture of costs that occurred over six-months of participation in a palliative care program and the sharing of these costs in rural areas compared with those in urban areas.

**Methods:** Cohorts of palliative care patients and informal caregivers from urban and rural areas of Nova Scotia, Quebec and Manitoba, in Canada, were drawn from two prior studies employing a longitudinal, prospective design with repeated measures. A six-month follow-up was initially planned with participants. The questions targeted the goods and services used related to the patient's condition, including informal care, and the identification of who paid which costs.

**Results:** The mean total cost per patient reached was CAD\$26,652 in urban regions, while in rural areas it rose to CAD\$31,018. Rural families face expenses particularly related to prescription medication, out-of-pocket costs, and transportation. Urban families face expenses particularly related to private home care, followed by out-of-pocket costs, medical equipment/aids and prescription medication.

**Conclusion:** Despite the fact that families in both rural and urban areas faced a similar portion of overall costs, the distribution of these costs was somewhat different.

Results presented in this study were drawn from two studies funded by the Canadian Institutes for Health Research.

**Abstract number:** PO103

**Abstract type:** Print Only

**Understanding of and Barriers to the Provision of Palliative Care in the Emergency Department - A London View**

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**Background:** Faced with an ageing population, an increase in chronic illness and a rising number of patients attending the emergency department, Emergency Medicine staff are in a prime position to play a central role in the early implementation of palliative care. Much work has been done on moving palliative care upstream to the emergency department in America and Australia, but little data has been presented from the UK.

**Objective:** This study aimed to establish staff attitudes and barriers to palliative care within a busy central London emergency department.

**Design:** An anonymous paper survey comprising 10 questions incorporating multiple choice, single best, rating scale and free text was distributed among doctors and nurses within the emergency department. Quantitative and qualitative results were compiled and analysed using Microsoft Excel.

50 staff members (23 doctors, 27 nurses) responded to the questionnaire. This equates to 45% of the emergency department staff.

**Results:** 80% of respondents felt there was a training need in palliative care. Doctors and nurses both identified similar barriers to effective care. These included time constraints, the clinical environment and lack of ease of access to patient background information. The survey highlighted the areas of training to focus on, and the need to raise awareness of and integrate an electronic palliative care coordination system within the department and hospital.

**Conclusions:** This study offers a unique insight into a busy emergency department in London, and demonstrates a great need to increase training and awareness of palliative care within this setting to enhance patient, carer, and emergency department staff experience. We argue for moving palliative care provision upstream to the emergency department to cope with the increasing demands of an ageing population, and increasing use of the Emergency Department.

**Abstract number:** PO104

**Abstract type:** Print Only

**Relatives' Experiences with the Palliative Care Service (MPCS): Evaluating the Mobile Palliative Bridging Service**

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Dying people and their relatives prefer the home as the place where they want to die. Therefore, the need of at-home palliative care is rising constantly. Special care needs lead families to a multifaceted stress experience<sup>1,3</sup>. Professional mobile palliative care can sustain the possibility of staying at home in the terminal phase. MPCs is one of three consultation areas of the Cancer League Eastern Switzerland. The Bridging Service enables dying people to stay at home and supports family caregivers. This study evaluates former patients' experiences along with their supports, with the ten-year, existing MPCs. Moreover, the benefit of MPCs and the special needs of family caregivers were analyzed. Based on a literature research, a cross-sectional survey (n=224) was performed. The response rate was 47.3% (n=106). Descriptive and inferential statistics were used for analysis. The survey indicated that most of the patients (98.9%) were suffering from cancer. The average age of the family caregivers was 58.67 years. Among all patients, 62.5% were discharged from an institution to stay at home and were not symptom free. MPCs helped relatives to sustain the care at home. The younger the family members were, the more they felt encouraged through MPCs to care for the dying at home (p=0.034; n=90). Despite professional care of the patients in the hospital or in specialized palliative care wards before being discharged to the patient's home, there were still uncontrolled symptoms. In particular, pain and nutrition-related problems are most important to family members since they lead to a crisis at home. MPCs plays a fundamental role in empowering the families of patients to accomplish the tasks needed in a homecare situation. MPCs helps to support and protect family caregivers and patients from further crises. Unnecessary costs and hospital admission can thereby be avoided or delayed from the relatives' perspective.

**Abstract number:** PO105

**Abstract type:** Print Only

**Mixed Method Evaluation of Volunteers Work Satisfaction within a Tertiary Specialized Palliative Care Unit Team: Being Part Makes the Difference**

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The formalized work of volunteers is widely implemented in hospice settings. It is well-known that patients and family members profit from the practical and emotional support of volunteers. Not much is known about the benefits for the volunteers themselves. Under the auspice of the pastoral care and the University Palliative Care Center (PZI) together with the local Reformed Churches a one-year project was initiated in 11'2013 aiming at forming a team of volunteers supporting patients and families.

The aim of the study was to evaluate the satisfaction of volunteers within the project in regard of meeting their expectations and need for support to master complex patient and family situations.

To get insight into the process of implementing a volunteer service a questionnaire based on Pascuet et al (2012) was adapted to the adult situation and given at three time points (T1= start of the project; T2= after 6 months; T3= at the end) to the volunteers after their consent. In addition two focus group interviews with volunteers were performed to get a deeper insight.

All volunteers (N=10) participated in the evaluation. The overall satisfaction with their work was very high, especially the flexible work hours combined with high responsibilities was valued. Volunteers found it difficult that patients usually stay only two weeks on the unit which limits their possibility to closely connect with patients. Also, often not being there when a patient dies can be burdensome. Additional teaching sessions were organized to help them start conversations with patients or learn how to deal with suffering. Having the church involved in the project adds an important perspective because the volunteers can profit from their volunteer work experiences and attend specific courses.

The concept of volunteers in a tertiary hospital adds an important component to high quality care. The concerns of volunteers need to be taken serious and their involvement in the PZI is of high importance.

**Abstract number:** PO106

**Abstract type:** Print Only

**Cancer Support and Rehabilitation Programs - Characterization of Programs and Experiential Outcomes of Participation**

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**Aim:** The current body of knowledge is limited concerning the process of cancer rehabilitation. The aim was to identify types of cancer support and rehabilitation programs in Sweden and to investigate patients' experiential outcomes of participation in such programs.

**Methods:** A mixed-methods design was applied; a multiple case study for identification of existing programs and

focus groups interviews for generation of experiences of participation. Telephone interviews were completed with key representatives of nine programs and four focus groups with 19 men and women. An interview guide with 40 questions was used in the telephone interviews and one main question in the focus groups: Please describe your most significant experiences of participating in the programs. Analysis of the programs was descriptive followed by a cross-case analysis and the group interviews were interpreted with phenomenological hermeneutical method.

**Results:** Multimodal rehabilitation program provided a broad range of combined therapies, Comprehensive cancer support provided a combination of few therapies and Art therapy offering support by means of one specific therapy. The common objective was supporting self-help and providing time for reflection. It was of significance to receive support when most vulnerable and physical and psychological capabilities increased. All participants reported the value of the peer community and feeling of togetherness. Key representatives reported that participants returned to previous levels of occupational activities but the persons with cancer described that they struggled to find stability in a forever changed life situation.

**Conclusion:** Support and rehabilitation programs offer a variety of activities and therapies highly valuable for people with cancer when an unpredictable situation is turned into something meaningful. New insights were provided about characteristics and experiences of participating in support and rehabilitation programs.

**Abstract number:** PO107

**Abstract type:** Print Only

### Current Status and Palliative Medical Care Strategy Development in Russia

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In Russia like in many countries worldwide palliative medicine commenced in the end of the 1980-s. The setting up of a new type of medical care by the Federal Law on Public Health Protection was the imperative impulse for its further development. By the official data today there are about 600 palliative care units in Russia. Palliative medical care consulting outpatient offices and palliative care departments, hospices and nursing departments/hospitals are among them.

According to the official statistics 1,686,456 people die annually from diseases among them 291,775 from cancer and 1,394,681 from non-cancer illnesses. Preliminary

estimates show that from 260,000 to 520,000 incurable patients need palliative care. We may suppose that the actual number is significantly higher: about 1 mln. In Russia due to geographic, demographic, economical and ethnic variabilities in different regions it is not deemed possible to organize palliative care system by the uniform model. The current situation analysis suggests the two types of regional models: for the regions with up to 2 mln. (58 regions) and over 2 mln. population (27 regions).

The Russian Association for Palliative Care was established in 2012. Its mission is to promote the national palliative care concept development and support palliative medicine elaboration based on clinical guidelines and medical protocols implementation.

Palliative care strategy involves development and implementation of proposed regional palliative medical care models in each region of Russia; new treatment technologies and algorithms; palliative care clinical guidelines; up-to-date palliative care training programs for medical students, professionals and trainers in the existing system of medical education.

This approach allows to solve effectively the whole range of medical and social problems of incurable patients, provide opioids availability for adequate pain control and reduce social tension in the society.

**Abstract number:** PO108

**Abstract type:** Print Only

### Evaluation of the Partner Nursing System in a Palliative Care Ward

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**Background:** The Partner Nursing system (PNS) is a new system for nursing provision that originated at the Fukui University Hospital nursing department. Two nurses that form a partnership are responsible for several patients, resulting in a mutually complementary cooperative, while taking advantage of each other's characteristics and abilities. This PNS has recently been implemented in general ward Japanese hospitals.

**Aims:** To evaluate the significance of PNS in a palliative care ward.

**Methods:** In October 2014, the PNS was introduced to our palliative care ward, to improve the quality of nursing and also to establish a workplace in which it is easy to work systematically and maintain work-life balance. Twenty nurses discussed and evaluated the PNS after 1 year in September 2015.

**Results:** Through consultation and cooperation, the pairs of nurses were able to care and manage treatment, such as repositioning and drug administration, in a timely manner. By reducing the psychological burden of the primary nurse, the relationship between the patients and nurses was strengthened. Most of the nurses felt that the working environment became more comfortable because they shared the patients' information with the partner and were ensured a reliable break time. Approximately half of the nurses felt that the nursing system had become established for efficiency because the responsibility for patients had increased. When a lack of communication occurred between the partners, incidents often emerged.

**Conclusion:** Through introduction of the PNS, patients have been able to receive care and treatment in a timely manner. We were able to create a workplace where it is easy to enjoy a work-life balance. In the future, it will be important to recommend the PNS to target improvement of nursing quality and a partnership mindset in the palliative care ward.

**Abstract number:** PO109

**Abstract type:** Print Only

#### **Solving the Lack of Manpower in Palliative Care: Health Care Professionals' Beliefs and Solutions**

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**Background:** Although palliative care improves quality of life of terminal cancer patients and reduces medical expenditure during end of life, the lack of manpower in palliative care has become a critical issue along with its development in Taiwan.

**Objective:** The study investigated the puzzling factors and solutions of the lack of manpower in palliative care through a nationwide survey of health care professionals in Taiwan.

**Methods:** A nationwide survey in Taiwan during the period of 2011 to 2012. A semistructured questionnaire was designed, statistical analysis were performed using SPSS statistical software, including frequency distributions, mean values and standard deviation and canonical correlation analysis.

**Results:** Of 248 questionnaires sent to palliative workers at 11 hospices in Taiwan, 208 valid questionnaires (83.9%) were retrieved. Most of the respondents were nurses (61.5%) while only 80 respondents were physicians (38.5%). Canonical correlation analysis was used to examine the puzzling factors and solutions, which revealed that the value of the variates were 0.41 ( $p < 0.05$ ) for man power shortage. The puzzling factors of lack of manpower and canonical loading were: overtime working (0.78), burning out (0.77), feeling excessive pressure (0.77), and manpower distribution and job rotation (0.68). The best solutions correlated significantly with the above puzzling factors are ranked in the following order: recruiting more professionals (0.81), more education and promotion of palliative care to health professionals (0.79), and inviting volunteers (0.77).

**Conclusions:** The result suggests that there are solutions for the lack of manpower in palliative care. On the basis of it, it is essential to increase incentive for providing palliative care and to cultivate professionals who are competent for ethical decision making. While for countries striving for new palliative care programs, it is vital to setup a financially sustainable system at the very beginning.

**Abstract number:** PO110

**Abstract type:** Print Only

#### **Hospice Palliative Inpatients Benefit Therapeutically from Social Interventions Outside of Single Bedrooms**

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**Background:** Single patient rooms can positively impact on care delivery, working practices, safety and costs. However, isolation can negatively contribute to management of symptoms and sense of inclusivity. Engagement in meaningful activities can assist patients to improve their self-concept and decrease pain behaviours. A small study identified that hospice inpatients missed interactions with other people and that this also had an effect on their sense of psychological well-being and symptom control.

**Aim:** To understand if introducing social groups positively influence the palliation of symptoms and the sense of well-being of hospice inpatients.

**Methods:** Feedback was gained from hospice staff, patients and visitors regarding the proposal of social interventions outside of single rooms. Subsequently a weekly social group was developed, designed to encourage patient

interactions. Visual analogue and numerical rating scales of the management of pain, anxiety and stress experienced by patients were measured pre- and post- intervention. Qualitative data were also collected from people.

**Results:** There was agreement from staff that some patients would enjoy appropriate social activity but a concern at accomplishing these needs. Staff proposed both organised occasional events such as sharing national sporting occasions, attending music concerts, and regular groups involving traditional occupations such as games, gardening and discussion groups. Patients able to participate in social interactions reported improved symptom control and/or sense of well-being.

**Conclusions:** Hospice inpatient staff supported improving opportunities for patient social interaction outside of single rooms to improve their quality of life. Patients reported a benefit from attending social intervention groups. However it was also acknowledged that additional resources may need to be allocated to enable palliative patients to benefit from social groups and therapeutic activity.

**Abstract number:** PO111

**Abstract type:** Print Only

### **Planning for the Future: Seeking the Status of Health Services for Patients Eligible to Pediatric Palliative Care in a Italian Northern Region**

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**Aims:** Mapping services characteristics provided for patients in need for pediatric palliative care (PPC) is a fundamental point for launching the network for PPC provision. This research analyzes data from a survey launched in 2014 by the regional health authority and PPC group work. The region counts about 700.000 pediatric population (0-18). Research aims at highlighting the strength, weaknesses and development points as well as the understanding for professionals of specialist palliative care need.

**Methods:** The survey was addressed to PPC referrals for each local health authority (11). Patients and diagnosis (for the year 2013) were identified using the Association for Children's Palliative Care (ACT)/Royal College of Paediatrics and Child Health (RCPCH) categories. Topics were drafted upon the main key points of international guidelines and regional PPC law: cases numbers, type of services, home Care, hospital, organizational models.

**Results:** All the areas answered. Results outcomes: 322 children eligible to receive PPC divided in ACT/RCPCH Categories: Cat. 1: 56; Cat.2: 63; Cat.3: 70; Cat.4: 132. Patients prevalent place of assistance (282) and death is home.

Home care is provided by nurses and general practitioners. Hospital specialists provide training and supervise cases. Services lack of Psychologist and physiotherapists. 5 areas needed specialist PC intervention.

Hospital assistance provides a wide range of services including psychological support. Services are quite inhomogeneous through the regional units.

9 Local areas implemented a Unique access point (PUA) and 11 have a common system for managing patients: Individual Care Planning (ICP). Case manager is a different professional in each area; PC specialist is involved in ICP and PUA only in one area.

**Conclusions:** There is a good level of health services in the region as a starting point for PPC. Issues like homogeneity and needs of families will be further pursued appropriately.

**Abstract number:** PO112

**Abstract type:** Print Only

### **Reflective Debriefing Groups: Translating Findings on End of Life Care in Nursing Homes into Action**

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**Background/aims:** Nursing home residents have little access to palliative care and hospital admissions in the dying phase are common. A recent focus group study among nursing staff revealed a strong need for training on end of life issues, team building, ethical reflection, and emotional support. Here, a nurse-led approach to address these issues is presented.

**Methods:** Within an action research framework, staff and researchers established reflective debriefing group (RDBG) sessions. Each RDBG was held by the caregiving team within 5-10 days following the death of a resident. A session included 5 consecutive steps (resident's history - dying process - perception of end of life care by the team - areas for improvement - resulting changes). A palliative care expert was facilitating the RDBG and offered practical support in end of life care.

**Results:** Three RDBG sessions have been held starting in July 2015 with an attendance of 4-7 nursing staff members (both senior and junior), duration 30-45min each. The deceased were long-term residents (2-4 years) dying from non-malignant conditions. Issues discussed were physical symptoms, social isolation, and neuro-cognitive decline. Being able to give individualized care, an active role of nurses, appropriate drug therapy, and rituals after death was experienced positively. However, sudden crises, the failure to adequately manage cachexia, and terminal agitation

caused distress. RdBG participants defined specific areas for improvement: early discussion of goals of treatment and nutrition/hydration issues, standard symptom assessment, and team support.

**Conclusions:** RdBGs are a feasible tool to enhance team discussions, learning and empowerment among nursing staff caring for dying nursing home residents. Further sessions are scheduled. Action research methodology - as opposed to a conventional implementation process - encourages participants to set their own agenda and to define key areas for change.

**Abstract number:** PO113

**Abstract type:** Print Only

### **A Night Nursing Service for People with a Non-malignant Illness**

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**Aim:** In 2006, a national night nursing service that enables people with cancer to die at home was extended to people with non-malignant disease. The Irish Hospice Foundations (IHF) nurses for night care (NNC) service will be outlined in comparison to information available from the Minimum Data Set (MDS) and from the National Council for Palliative Care in the United Kingdom. This works aims to determine trends in access to specialist palliative care (SPC) by people with a non-malignant illness in Ireland.

**Method:** A comparative analysis was carried out with information from the NNC service, MDS and information available from the United Kingdom. Data was evaluated to determine trends, similarities and inconsistencies.

**Results:** There has been a consistent increase in demand for the NNC service since its commencement.

There are inconsistencies in access to the service nationally when compared to MDS information.

Non-malignant illnesses account for 16-17% of those that access SPC services in the UK and between 19-26% in Ireland.

**Conclusion:** The IHF NNC service should be available to all people with non-malignant life limiting diseases. These results suggest that there is variation in how the service is made available to people with non-malignant diseases who wish to die at home. As well as underutilisation, there may also be over use of the service in some areas across the country. The data also enables future projections on SPC service use in relation to non-malignant illnesses.

**Abstract number:** PO114

**Abstract type:** Print Only

### **Implementation of evidence-based Palliative Care in Acute Care Hospitals: Obstacles and Opportunities**

### **as Described by Politicians, Hospital Managers and Health Care Professionals**

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**Background:** In high income countries, such as Sweden, a large proportion of all deaths occur at hospitals which is commonly not consistent with the desire of the patient and next-of-kin. A common way to translate knowledge into clinical practice is to create practice guidelines for different levels of the health care organization. During the last years, national clinical guidelines for palliative care and guidance from the NBHW have been published for the first time in Sweden. Hence, the aim of this study was to identify perceptions of obstacles and opportunities for implementation of evidence-based palliative care in acute care hospitals, as described by local politicians, chief medical officers and health care professionals.

**Method:** Interviews were conducted with local politicians, chief medical officers and health care professionals and analysed through a directed qualitative content method, guided by The Consolidated Framework for Implementation Research.

**Results:** Palliative care was commonly mentioned as a comprehensive way for alleviation of patients' suffering with the overall goal for maintaining quality of life, especially in end of life care. Palliative care at the hospital was described by the staff as characterized by sudden disease, rapid changes back and forth between life and death and difficulties to predict the outcome. The environment, the culture, poor communication and poor cooperation in the work team were described as obstacles for implementation. The informants mentioned the newly published documents as important but the knowledge about the content varied a lot. A newly formed internal group with the assignment to develop the palliative care at the clinic was emphasized by all health care professionals as a good opportunity to get support and local guidelines.

**Conclusion:** An active process at different levels in the health care organization is important for a successful implementation of evidence-based palliative care in acute care hospitals.

**Abstract number:** PO115

**Abstract type:** Print Only

### Identifying Palliative and End of Life Research Priorities in Ireland: An Innovative Approach

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**Background:** Palliative and end of life care research is an underdeveloped research area. The importance of setting research priorities has been recognized internationally, however to date, this has largely been led by researchers and academics. James Lind Alliance advocate an approach to research priority setting whereby patients, carers and clinicians work together to agree the most important questions.

**Aim:** To identify and prioritise research questions for palliative and end of life care from the perspective of patients, carers and health care professionals in Ireland.

**Method:** Mixed methods four stage approach.

Stage 1: was part of a larger national study, which involved a survey focused on uncertainties of care, (n=1403 responses), subsequently categorized as interventional questions, into a list of questions (n=83).

Stage 2: An online survey asking user/carer organizations and professional groups in Ireland to rate these questions in terms of low to high priority (n=168 responses).

Stage 3: Involved a final prioritization workshop, using nominal group technique undertaken with user/carers (n=16), resulting in the identification of the top ten research priority for Ireland. Stage 4: Comprised a strategic workshop with academics, researchers and funders from the island of Ireland, to develop action plans for each of the areas.

**Results:** The top ten areas were identified and include aspects such as co-ordination of care; out of hours; care at home; pain and symptom management, palliative care and non-cancer and advanced care planning.

**Conclusions:** This process enables researchers to demonstrate that their research is relevant, targeted and valuable to the people who most need it. We will report preliminary findings on the process and types of questions proposed. Discussion with key stakeholders contributes to better co-ordination, seeking to address the highest priority areas together.

**Funded:** AIIHPC, larger study led by Marie Curie UK

**Abstract number:** PO116

**Abstract type:** Print Only

### User Involvement in Palliative Care: Evaluating the Process and Contribution of a User/Carer Forum Initiative

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**Background:** User involvement is widely promoted within health and social care policy as an effective means of developing patient-centred services. This has, however, particular challenges for palliative care, as patients are likely to be experiencing poor health, are psychologically vulnerable and socially isolated. Nevertheless this is an important agenda for palliative care to address. Voices-4Care is a user/carer Forum comprised of: patients service users, carers or former carers, and people from the wider community across the island of Ireland.

**Aim:** To evaluate the implementation process, contribution and lessons learnt from a Voices4Care initiative that have wider international relevance.

**Method:** A mixed methods approach comprised of four strands of work. Phase 1: Review of the literature on models of user involvement; Phase 2: secondary analysis and document review of user involvement activities and process; Phase 3: Two focus group with members of user/carer Forum (n= 14) and Phase 4: Key stakeholder telephone interviews with policy and hospice representatives (n=10) were conducted. Thematic analysis of verbatim transcripts was used to identify emergent themes.

**Results:** it was found that the Forum provided a supportive context in which the voices of users and carers could be heard, valued and contribute to mutual sharing of information and experiences. The impact of the forum was identified at personal, practice and policy levels. The personal level developed a sense of empowerment whilst the practice level challenged professional complacency and triggered discussions. The policy level was considered as more aspirational with potential for further development. Challenges were noted however with sustainability and building on progress to date.

**Conclusions:** Organisational cultures need to be supportive of user involvement and dedicated resources; leadership and openness are key factors for sustainability.

**Abstract number:** PO117

**Abstract type:** Print Only

### The Diagnostic Process of Suspected Lung Cancer Demystified

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**Aim:** This study aims to get insight into the timing and determinants of the timing of the diagnostic workup for lung cancer

**Background:** Guidelines recommend the diagnosis of lung cancer to be available in a 'timely' manner for

patients. However, it is not clear what 'timely' means nor how each process element contributes to the overall work up time and how health care providers and the patient themselves deal with this issue.

**Methods:** Qualitative semi-structured interviews were conducted with ten pulmonologists in Flanders to explore how the diagnosis of lung cancer is being made in the outpatient setting. Data were analysed using the Framework method.

**Results:** The diagnostic work up for lung cancer generally starts with the suspicion of malignancy based on imaging (Rx and/or CT). The way in which the diagnostic trajectory unfolds is the result of a combination of multiple elements and contextual factors. This may yield many different variations. The overall work up time is determined by biological disease factors (e.g. type and number of tests needed to get tumour diagnosis, staging and assessment of fitness for treatment), organisational factors (e.g. timely availability of test results) and factors related to patient and health care providers. Pulmonologists play a key role and may try to balance and spin the process to prepare the patient for the worst while keeping hope for the best.

**Conclusions:** This study reveals that the timing of test procedures and information provision do not solely depend on biological and organisational factors, but that patient and health care providers may also influence the work up process of lung cancer. These findings provide insight into care trajectories, which is relevant for the customization of care according to the patient's needs.

**Abstract number:** PO118

**Abstract type:** Print Only

**Admission to Intensive Care at the End of Life: Internal Medicine and Intensive Care Doctors' Expected Roles during Triage. A Qualitative Study**

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**Research aims:** The decision to admit a patient to intensive care (ICU) at the end of life is complex. Effective triage warrants good collaboration between the referring and the ICU doctor. Mutual acceptance of each other's roles and quality of interactions are determinants of collaboration. The aim is to explore referring and ICU doctors' perceptions of their roles during triage to intensive care.

**Study population:** ICU and internal medicine (MED) doctors, Geneva University Hospitals.

**Study design and methods:** 24 individual, in-depth interviews. Doctors reflected on their experiences of ICU admission decision making. Interviews were analysed using a thematic approach.

**Results:** Doctors report two types of roles: practical and identity roles. MED doctors' practical roles include recognizing clinical signs of severity, calling the ICU doctor at the right moment, collecting and imparting relevant information to the ICU doctor and life/death decision making. ICU doctors' practical roles include personally assessing the patient, making quick decisions, admitting the patient without delay, being a gatekeeper to the ICU and life/death decision making. Although ICU and MED doctors share common perceptions about each other's expected roles, they differ in their appreciation of how much each one actually fulfils his roles.

Regarding identity roles, MED doctors perceive themselves as leaders and partners of ICU doctors during triage, while ICU doctors see them mostly as partners and a help. ICU doctors perceive themselves as experienced, leader and helpful, while MED doctors see them mostly as senior and available.

**Conclusion:** MED and ICU doctors share common perceptions of their practical roles during triage. However different perceptions about fulfilment of expected roles and about identity roles influence the quality of interactions, and thus may impact quality of the collaboration between doctors.

**Funding:** Swiss National Science Foundation, NRP 67 "End-of-life".

**Abstract number:** PO119

**Abstract type:** Print Only

**Mapping Palliative Care Funding in Germany - A Scoping Review**

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**Background:** With the integration of palliative care (PC) in the German health care system there is an ongoing discussion whether current remuneration systems are adequate and comply with PC's concept of care.

**Aim:** To map information and evidence on PC funding in Germany.

**Methods:** For this scoping review, a bilingual (German/English) free text and MeshTerm based literature search in

the online databases Pubmed, Embase and Google Scholar was conducted. Timeframe was from 2001 onward. Inclusion criteria: scientific journal and book publications in German or English specifically dealing with costs and financing of PC in Germany.

**Results:** The search yielded 3568 references after deduplication. Only four of them (0.11%) met the inclusion criteria. Reasons for exclusion were: correct topic but referring to other country (6), PC but not financing (187), health care related but not PC (1,800), non-healthcare (1,308), other language (49), wrong publication format (214). The 4 included references were published in German (3 journal articles, 1 book chapter). Three publications deal with the remuneration of PC on PC units, one gives general information on PC funding in Germany. In the subsequent analysis, information from the publications will be mapped according to setting of care, remuneration system, remunerated resources (staff, drugs, medical equipment), patient type, disease, cost calculation model.

**Conclusions:** Despite the attention the topic receives in discussions, evidence in the literature is scarce. Remarkably, even though PC is provided in various settings, mainly data on the inpatient PC setting was found. Subsequent analysis will show which evidence is available, identify gaps of information and point out implications for future research.

Findings will be complemented by citation-tracking and results from a Google search describing PC funding in Germany.

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**Abstract number:** PO120

**Abstract type:** Print Only

**Patients' with Heart Failure and their Carers' Perspectives of Multidimensional Needs and How Care Can Be Improved in a Low Income Country: A Serial Interview Study**

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**Background:** Effective and accessible heart failure care should be informed by patients' and their family and health professionals' perspectives of needs. The literature from high-income countries reveal that multidimensional needs are often present. These needs have not been described in low income countries.

**Aims:** To identify the multidimensional needs of Ugandan heart failure patients from presentation to death and to identify patient-centred service improvements.

**Methods:** Patients were recruited at the Ugandan national referral hospital. A Ugandan palliative medicine doctor trained in qualitative research conducted serial qualitative interviews with patients and their carers at three time points over the course of their illness, firstly in the hospital and then at home for subsequent interviews. One-off interviews were conducted with health professionals. A grounded theory approach was used in data analysis which was assisted by the qualitative software package Nvivo.

**Findings:** 48 interviews were conducted with 21 patients and their carers and 8 interviews with their healthcare professionals. Physical needs, including severe and disabling breathlessness, abdominal swelling and fatigue were common and increased over time. Multidimensional needs included to have normal social functioning, to be able to work, to have control over their illness, and to cope and adapt to a changed life, and to find meaning in their suffering. Most health professionals acknowledged these needs except for spiritual distress. Information needs stood out as being largely unmet. Patients and health professionals suggested many improvements for training and service developments in different settings.

**Conclusion:** Heart failure management in Uganda requires an approach that identifies, assesses and meets multidimensional needs, embraces multidisciplinary care and strengthens health systems and staff training. These are all important tenets of palliative care.

**Abstract number:** PO121

**Abstract type:** Print Only

**Community Healthcare Involvement in Patients with Palliative Care Needs Prior to Emergency Department Presentation**

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**Background/aims:** Attendances at Emergency Departments (ED) at end of life are recognised as indicators of poor quality care. Enhanced community supports can reduce ED attendances. Our aim was to investigate how many patients referred to a hospital Palliative Medicine (PM) service who were admitted via the ED had been reviewed by a healthcare professional in the community prior to ED attendance.

**Methods:** All referrals to the hospital PM service of a large tertiary centre over a 2 month period were reviewed,

and those admitted via the ED were identified. ED notes were reviewed to identify which patients had been seen by a healthcare professional, i.e. General Practitioner (GP), Public Health Nurse (PHN) or Community Palliative Care Team (CPCT), prior to presentation to ED. Time of registration at ED was noted.

**Results:** 90 patients admitted through the ED who were subsequently referred to PM service over a two month period were included. 45 of the patients were seen by the PM service in the ED, the remainder were seen after admission to hospital from the ED.

The majority of patients,  $n=57$  (63.3%), were not seen by any healthcare professional in the community prior to attending the ED. More than half of these ( $n=31$ ) attended the ED outside normal working hours.

Only 33 patients (36.7%) had been reviewed in the community by a healthcare professional prior to presentation. Of those, 17 (51.5%) presented outside normal working hours. Almost all ( $n=29$ ) were seen by a GP, two by a PHN, and two by CPCT.

**Conclusions:** Our results suggest an under-utilisation of community services by palliative care patients prior to ED attendance. This raises the possibility that a proportion of the patients who attended the ED could have had their attendance and hospital admission avoided. Better education of patients in awareness of availability and utilisation of community services is required.

**Abstract number:** PO122

**Abstract type:** Print Only

### Utilisation of Hospital and A&E Services by the Elderly in the Last Three Months of Life: A Three-country Comparison

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**Background:** Healthcare utilisation can be a useful way to measure quality of care. However, analysis of healthcare utilisation is rare in palliative care due to challenges accessing and collecting good-quality data.

**Aims:** To determine hospital resource use in the last three months of life among elderly patients who accessed specialist palliative care in three countries.

**Methods:** A postal mortality follow-back survey among bereaved caregivers of patients including the Client Services Receipt Inventory, sent to bereaved caregivers of patients aged  $\geq 65$  who had accessed specialist palliative, plus analysis of patient record data. Participants were sampled through hospitals in 3 countries: UK (London), Ireland (Dublin), and the USA (New York City and San Francisco).

**Results:** 721 bereaved carers returned completed questionnaires (London  $n=245$ , Dublin  $n=236$ , NYC  $n=131$ , SF  $n=109$ ). Patients were: 53% women; mean age 79.9; and 46% with cancer. 70% had been hospital inpatients and average length of stay (LOS) was 23 days in London, 36 in Dublin, 15 in NYC and 14 in SF. The intensive care unit, which requires high resource use, was used by 34% (average LOS: 11 days in London, 18 in Dublin, 21 in NYC and 9 in SF). Outpatient clinic was visited, on average, 4 times in London and Dublin, 5 times in NYC and 7 in SF. Number of outpatient radiotherapy/outpatient chemotherapy appointments was 6/9 in London, 7/5 in Dublin, 10/8 in NY and 7/7 in SF. 64% of all patients visited ER or A&E twice. 61% in London used ambulance services, on average 3 times. 58%, 50% and 65% used ambulance services in Dublin, NYC and SF, on average twice.

**Conclusions:** Overall, older patients in this study relied heavily on hospital healthcare services during the last three months of life. The majority visited ER or A&E twice and used ambulance services multiple times. Our study highlights patterns of utilisation in older adults that are in conflict with the shift to provide more care in the community.

**Abstract number:** PO123

**Abstract type:** Print Only

### The Patient Experience of Advanced Cancer and Home Support: Qualitative Study

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**Background:** An effective humanised and interdisciplinary response to patients and families facing advanced illness relies on strong evidence. This is still developing in palliative care (PC). The provision of home care appears to be a priority as patients spend most of their last months of life at home. **Aim:** To explore the patient experience of advanced cancer with a focus on the existing and desired home support.

**Methods:** Exploratory qualitative study. We interviewed 10 adult cancer patients (6 female, mean age of 50, most

with breast cancer) recruited from a health centre in Portugal. Interviews were recorded, transcribed and analysed using the content analysis method proposed by Bardin (1977).

**Results:** Participants showed a good understanding of what PC entails, defined as care targeted to patients with advanced conditions (both cancer and non-cancer mentioned) and their families; with resources/means to maximise well-being, dignity and autonomy. Participants used various illness management strategies: positivism and denial (two opposites) were the most frequent. Two received some home support from charities but there was a general lack of information about the home care available in the region. Most considered a home PC team would be very useful, as it would allow them to remain at home, a preference shared by all. However, one patient said that at a later stage he would rather be in hospital, because his death at home could be negative for his children. The perceived utility of home PC for patients was more related to the support these teams could provide to their families than to benefits for themselves. More emphasis was given to the psychological care component than to the physical.

**Conclusion:** The results suggest that, from a patient perspective, the development of home-based PC is an adequate priority in a region where there is currently no such response. Psychological and family support are seen as key components of home care.

**Abstract number:** PO124

**Abstract type:** Print Only

### Drug Related Problems in Palliative Care Patients

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**Background:** “First, do no harm” is a fundamental principle in medicine emphasizing the need to critically evaluate possible side effects of medical treatment. Drug therapy is always associated with risks and special knowledge is needed regarding drug selection, administration, monitoring and transferring medications into another care sector.

**Aim:** This project aims to describe drug related problems on a palliative care unit, assess potential interventions and their outcomes by a clinical pharmacist.

**Methods:** Drug regimens of all patients admitted to a German palliative care unit were continuously screened during inpatients stay by a clinical pharmacist from January to December 2015 for potential drug related problems (DRP).

Identified DRP, subsequent recommendations and the associated outcome were classified based on the pharmaceutical care network Europe (PCNE) Classification scheme for Drug-Related Problems and evaluated.

**Results:** As the data collection process is still ongoing during preparation of this abstract, the final results will be presented at the conference. From January-September 2015 pharmacists identified and documented about 420 DRP. 60% of the identified DRP were manifest and ranged from a non-optimal treatment effect (37%), wrong treatment (10%) and untreated indications (8%). The causes were mainly inappropriate drug selection (9%) or combination (14%), inappropriate timing of administration (9%) or prescribing errors (i.e. necessary information missing; 25%). Pharmacists’ interventions lead to prescription modifications by doctors in two third of the cases. 7% of the suggested interventions were rejected by the prescribers. In 26% of DRP the outcome was unknown.

**Discussion:** Pharmacy intervention can identify and solve DRP and thus potentially help to improve the quality of palliative care pharmacotherapy.

**Abstract number:** PO125

**Abstract type:** Print Only

### Accessing Medicines for Palliative Care Patients

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**Background:** Medicines commonly used in Palliative Care are not always easily accessible to patients in the community setting. In particular, unlicensed medicines and non-prescription medicines may pose problems as they are not always paid for by the government medicines schemes and can be costly for the patient or their family members. This is a particular problem in Ireland where some medicines available in other European countries are unlicensed here.

**Aim:** The aim of this study was to gather data on the prevalence and impact of prescribing ‘non-reimbursable medicines’ for patients when they are discharged from specialist palliative care units into the community.

It also identifies the most commonly used ‘non-reimbursable medicines’.

### Method:

- This is a multicentre clinical study conducted over a two-week period from the 23/2/15 - 9/3/15.
- A data collection form was designed by the main investigator and trialled on 4 patients. Data collected included if the patient was prescribed a

'non-reimbursable medicine' and if so what it was. Data was collected on what hospice the patient had been discharged from.

- The data collection form was sent to all Pharmacists in specialist palliative care units throughout the Republic of Ireland.

- Each consecutive discharge prescription was reviewed by a pharmacist and data collected using the data collection form.
- The sample was determined as the number of consecutive discharges over a two week period. A total of 55 prescriptions were included.

**Table 1.** Top 4 Most Common Oral 'Non-reimbursable'.

	1.	2.	3.	4.
<b>Medicine</b>	Senna tablets	Sodium docusate	Chlorhexidine mouthwash	Bioextra mouthwash
<b>No. of patients</b>	32 (58%)	13 (24%)	6 (11%)	6 (11%)

**Results:** Only six prescriptions had no items that were non reimbursable

**Conclusion:** A significant number of palliative care patients are prescribed medicines on discharge from the inpatient setting that are not reimbursable on government medicines schemes despite these medicines being recommended by national guidelines.

**Abstract number:** PO126

**Abstract type:** Print Only

### Geriatric Palliative Care Integration through the Supportive Hospice and Aged Residential Care Exchange (SHARE) Programme

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**Background:** In New Zealand, 45% of people over 65 years old will live in residential aged care (RAC) at the time of their deaths. A collaborative model of geriatric palliative care is needed between hospice and RAC staff. The *Supportive Hospice and Aged Residential care Exchange* (SHARE) model was developed to integrate the palliative care expertise of hospice nurses with the gerontology expertise RAC nurses. This creates a unified and proactive approach to end of life needs of RAC residents. The model includes:

- (1) palliative care need registry,
- (2) systematic advanced care planning
- (3) on-site palliative care clinical coaching
- (4) debriefing of staff palliative care experiences.

**Methods:** The SHARE model was piloted in two RAC facilities (total 89 beds) in Auckland, New Zealand over a six month period. Refinement of the model design occurred in an iterative manner through regular feedback sessions

with SHARE staff. Semi-structured interviews were conducted with participating RAC nurses (2), Hospice nurses (2), RAC manager (1) and care assistants (3) to determine the new model's acceptability and sustainability. All interviews were recorded verbatim, and transcripts were double-coded to ensure consistency of themes.

**Results:** SHARE was positively viewed by RAC and hospice staff. The on-site clinical coaching and proactive approach to palliative care need identification and advanced care planning documentation were particularly beneficial to RAC staff. The hospice staff reported a greater appreciation of the palliative care burden in RAC. Relationships between hospice, RAC staff, and residents were key to the acceptability and sustainability of the model.

**Conclusion:** The pilot evaluation demonstrated that the SHARE model helps to integrate hospice and RAC expertise to anticipate the palliative care needs of older people in care. A larger trial across 20 RAC facilities will begin early in 2016.

**Abstract number:** PO127

**Abstract type:** Print Only

### The French Physiotherapists' Knowledge and Practices of Palliative Care

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In France, the subject of palliative care is not included in the physiotherapists' curriculum. Depending on the teaching staff, the theme is discussed for a few hours or not at all, while most physical therapists are bound to accompany some patients at the end of their lives.

In 2015, I conducted a quantitative study based on 618 physical therapists training or practicing in France. The questionnaire was about their knowledge, practices and desires with regards to training in palliative care.

The medium of dissemination selected was the internet (social networks). The data collected were subjected to statistical analysis with the software R.

The analysis shows that 86% of physiotherapists are involved in palliative care at least once per year, 42% at least once per month while 14% do not practice it at all. 94% of physiotherapists know that palliative care is a relief to the patient and 76% are aware that it reduces pain.

Nearly 25% of liberals have not heard of a law prohibiting unreasonable therapeutic intervention and 51% of physical therapists are not aware that palliative care is at odds with unreasonable obstinacy.

85% of qualified physiotherapists (and 83% of students) feel they have not had enough formation about palliative care. Physiotherapists actively seek it both during and after their studies, e.g. through continuous or on-line vocational training.

9% of respondents reported distress and isolation facing people taken into palliative care.

Due to a lack of knowledge or precision on the medical prescription, they are only 38% to act as it would be required.

A first positive sign in France is the reform of physiotherapy studies, which will take them from 3 to 4 years as of September 2016: palliative care will then be part and parcel of the curriculum.

Another avenue would be to make specialized training about palliative care more readily available for physiotherapists, maybe as online courses.

**Abstract number:** PO128

**Abstract type:** Print Only

### Palliative Care Outcomes for a Healthcare System

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**Background:** A recent trend in healthcare in the United States is for multiple hospitals to join to form a system. This calls for the case for Palliative Care (PC) to be made at both the hospital and system level.

**Methods:** The process and methodology of delivering outcomes data at a 12 hospital Healthcare System will be presented. Data from 7 hospitals on the same electronic medical record (EMR) will be shared. 5 studies were done to show the impact of PC.

### Results:

1. One year outcomes data of a newly established program.
  - Positive impact on LOS (5.08 days) in patients seen within 48 hours vs later.
  - The mortality of patients seen within the first 48 hours versus later: 1.01 vs 1.1
  - Drop in 30, 60 and 90 day readmissions: 61.5%, 47% and 42.1% respectively.
2. A 7 hospital modified matched pair study for patients with sepsis
  - Positive impact on LOS (1.67 days) in patients seen within 48 hours of admission vs those not seen by PC.
3. System financial impact: Patient/family directed care plan change methodology
  - Drop in cost of treatments for the hospitals showed an overall cost avoidance that was 1.5 times of the total cost of the programs to the system.
4. A four month ICU pilot with a full time physician in one of the hospitals.
  - Cost avoidance of more than \$600,000 and 315 saved ICU days .
5. System wide referrals to hospice.
  - 69.3% of referrals to hospice were by PC.

### Conclusions:

- Early PC has a positive impact on inpatient length of stay (LOS), readmission rate, mortality rate and cost of care.
- Savings at system level exceeds cost and PC improves quality of care.
- Evidence that a PC ICU model can reduce ICU LOS and reduce cost.
- PC increases referrals to hospice.

**Abstract number:** PO129

**Abstract type:** Print Only

### Specification of Palliative Care Day Services: A Three-centre Study

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**Background:** Palliative care day services (typically known as “day hospices”) are provided routinely across Europe. Due largely to the historically localised nature of development, there is wide variability in the organisation and content of services, which militates against strategic planning and development.

**Aims:** We aimed to address this knowledge deficit by identifying core service provision within one country by mapping three regional providers of palliative care day services.

**Methods:** A retrospective, observational study design, using the Donabedian quality framework, involved two components. Firstly, a review of local policy and operational documents at each site provided information on the structure of each service (how care is organised). This covered four key areas: service organisational structure; funding arrangements and expenditure; staffing and management structure, and; other information relevant to estimating the costs of service delivery. Secondly, a retrospective review of the clinical records of patients referred to the service at each site delivered information on the process of care (what is provided). Using reported attendance figures, cases were randomly selected according to a proportionate regime.

**Results:** The review covers key features of: the local-level patient populations, including socio-economic and diagnostic profile; referral, allocation and discharge; all interventions offered; service uptake, and; contextual information on patient circumstances, need and preferences for care. It delivers a comprehensive body of evidence concerning the structure and process of UK palliative care day services.

**Conclusions:** Our study makes a fundamental contribution to a previously limited evidence base on the organisation, content and mechanisms of delivery of palliative care day services.

**Abstract number:** PO130

**Abstract type:** Print Only

### Association of Timing of Palliative Care Consults on Quality Care Outcomes at a Community Based Hospital

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**Background:** Timing of palliative care (PC) consults in hospitalized patients can have an impact on outcomes. This secondary analysis was part of a larger initiative to measure the impact of palliative care for a healthcare system in the United States.

**Aim:** To study the impact of the timing of PC consults on length of stay (LOS) of PC patients in a community based hospital over a span of 1 year. Other outcomes include mortality and readmissions.

**Method:** We did a retrospective review of medical records of consecutive patients who were referred to PC during the time period (November 2012- October 2013). LOS of PC patients consulted within 48 hours of admission was compared to LOS of patients that were consulted after 48 hours. Based on the timing of consult we also calculated the mortality ratio of the two set of patients. In addition we calculated the 30, 60 and 90 day readmission rate pre and post PC consult.

**Results:** The difference in LOS of patients seen by PC after 48 hours (N=187) of admission (variance from expected) was 6.28 versus within 48 hours (N=353) of admission (variance from expected) was 1.20. The mean difference in LOS was 5.08 days. The mortality ratio of the two groups was 1.01 (within 48 hours) versus 1.10 (after 48 hours) ( $p = .131$ ). In addition the decrease in the 30, 60 and 90 day readmissions was 61.5%, 47% and 42.1% respectively.

**Conclusion:** Early PC consults was associated with a decrease in LOS and readmission rate with no increase in mortality rate. Further studies are needed to validate these findings.

**Abstract number:** PO131

**Abstract type:** Print Only

### Towards a Theory of the Volunteering Impact on Organisational Sustainability

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**Aims:** This paper aims to describe the:

- Approach to developing a theoretical model of the relationship between volunteering and the future

sustainability of voluntary hospice and palliative care organisations

- The relevance of the model to practice

**Methods:** The theory was developed using Dubin's key stages of theory development. The key components of the model were derived from a review of the literature exploring the role and influence of volunteering on hospices, how internal and external factors may affect this and to consider the relationship between volunteering and voluntary sector hospice sustainability. Using key words: hospice models, hospice development, hospice management, hospice structures, hospice organisation, volunteering and hospices, volunteer value, palliative care policy, volunteering policy and volunteering trends, the following databases were searched: CINHALL (EBSCO), British Nursing Index, Intute: Health and Life Sciences, ERIC, SCOPUS, ASSIA (CSA) Cochrane Library and Google Scholar.

**Results:**

- Six organisational sustainability factors were identified including demand for services, governance and leadership, income generation, responsive services, staff and volunteers, public support
- Volunteering significantly influences all areas of sustainability
- Volunteering and organisations are influenced by external factors at a national and local level including national policy, societal and demographic changes, economic situation, changing volunteer expectations and numbers of people volunteering.

**Conclusion:** The theoretical model has an important application for non-profit organisations. Used as part of the strategic review and planning process, it enables organisations to highlighting areas of weakness or risk to be addressed. This hypothesis has been tested in practice in 32 voluntary hospices across the UK and findings from the study support the model. Further testing of the model in other countries is planned.

**Abstract number:** PO132

**Abstract type:** Print Only

**Working with End Stage Diseases and Taking Care of Patients and Family Members in Palliative Care: Experience of Working with the ICU**

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Taking charge of pathologies End Stage in palliative care has increasingly new challenges for multidisciplinary teams that

are confronted with complex care; therefore, it must adapt and transform the tools to meet the needs of patients, families and health of the team. Professional experience From 2013 to date has been gained at the Hospice and ODCP (home care) has a pulmonary focus (oncological and non-oncological disorders), and for the first time on the territory of an experimental work in collaboration with the ICU.

**Aims:** Improving compliance and quality of end of life multi-professional integration and definition of operational and relational protocols.

**Methods:** Taking care of these patients resulted in: The acquisition of theoretical and technical skills related to the management of psychological problems related diseases End Stage with focus on disorders of adaptation and on the experiences of caregivers; Structuring an interview pre-admission; creating operational protocols through a continuous improvement of the quality of care; testing sessions integrated relaxation and guided visualization to work of psychologist and physiotherapist; the management of multi-professional talks to involve the patient and family in clear and shared definition of what they mean in these cases clinical appropriateness and ethical treatment.

**Results:** Patients situation in life-limiting / life-threatening maintain a state of high complexity care. The three dimensions considered, the clinical situation, relational autonomy of the person in need of early management of issues related to the transition, even cultural object by the departments of hospitalization to Hospice.

**Conclusions:** With respect to future projects definitely great importance has the consistency of institutional collaboration between multi professional team, the implementation and definition of operational protocols of simultaneous early care; collaboration with the network of palliative care planning.

**Abstract number:** PO133

**Abstract type:** Print Only

**Going Digital: Developing an Electronic Patient File from Scratch**

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**Background/aims:** Providing quality Palliative Care (PC) services at home in an extended area can be very

challenging when it comes to immediate, unhampered and precise data sharing within the interdisciplinary team. To meet these demands, we aimed to develop a tailor made, web based, patient centred, electronic patient file (e-file).

**Methods:** We first reviewed the bibliography concerning the e-files used in PC units worldwide, as well as the evidence-based symptom management guidelines relevant with PC. We also acquired a user's license from the Hellenic Data Protection Authority. The staff formed work groups according to their profession and presented their proposals in a work group consisting of a representative of each of the initial groups as well as of members of the Research Department of our unit. The consensus was presented to the whole of the interdisciplinary team and appropriate modifications were made. Finally, the software development company made the adjustments needed for the electronic form of the patient file.

**Results:** The main advantage of the e-file is real time input and access to the patient's data, by all health care professionals, from any place, at all times, something especially useful for the out-of-hours patient care. The software presents patient and carer data in a patient centred and not profession oriented fashion (physical, psychological, social, spiritual, practical issues, end of life care and bereavement). It allows for longitudinal follow up of each symptom, as well as for the holistic overview of the daily incident of care. Moreover, it provides useful print outs, follow up of organizational and clinical metrics and statistical data.

**Conclusions:** Creating a tailor made e-file for PC patients may be more time-consuming and strenuous than adopting an already existing one, but it is feasible and finally easier to be accepted by the professionals who will use it in every day practice.

The project was funded by European Funding Programmes.

**Abstract number:** PO134

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### **Resilience of Hospice Volunteers - The Silent Pillar of Hospice Work**

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**Introduction:** In the area of outpatient hospice care, volunteers are subjected to high psychological stresses. In contrast to professional hospice care staff, no research has been conducted about the resilience of volunteers. They seem to be a blind spot in that context so far.

**Aim:** The aim of my research is to identify the factors that resilience of hospice volunteers is composed of. Besides detecting the main factors at both personal and

organizational level, possibilities of gaining and promoting resilience shall be identified.

**Theoretical assumption / research questions:** Following a multi-level based comprehension of resilience the research questions are:

- (1) What are the main factors that composite resilience of volunteers?
- (2) When do volunteers characterize themselves as resilient and
- (3) which factors at the personal, team and organizational level do they consider necessary?

**Method / state of research:** A systematic literature review has been conducted and no studies have been found regarding volunteer resilience in the field of palliative and hospice care. Resilience has only been discussed for professional groups as hospice nurses and physicians. In the proposed contribution, I will present the main results of the literature review. Drawing on that literature I suggest considering a combination of two behaviors to be a major indicator for resilience of volunteers: continuous stay plus a high workload.

As next step in my research, about 20 Interviews with volunteers, supervisors and professional staff of outpatient hospice care will be conducted. During the literature review identified resilience factors are supposed to be validated and possibly extended or reduced. The aim is to develop a conceptual model/framework of resilience factors of volunteers in palliative care. This model can be used in order to develop a questionnaire for a quantitative survey that allows hospice service organizations to analyze the resilience status of their volunteer staff.

**Abstract number:** PO135

**Abstract type:** Print Only

### **To the Letter - Discharge Letters in the Irish Hospice Setting**

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**Background:** The Health Information and Quality Authority of Ireland published the National Standard for Patient Discharge Summary Information in 2013. It aimed to standardise the transmission of a comprehensive, accurate and timely discharge summary following discharge from a range of specialities.

**Aims:** To assess the time taken for discharge letters to be sent out, to establish whether these letters follow national recommendations and to begin the process of developing a discharge template in our institution.

**Methods:** The discharge letters for one ward in our specialist palliative care inpatient unit for a single calendar

month were included. Time to completion and compliance with national standards were noted. Included were letters for patients who died within the hospice and patients discharged home or to another place of care.

**Results:** 27 letters were included in the review. 63% (n=17) of these letters related to patients who died within the hospice. 37% (n=10) of the letters reviewed pertained to patients who were discharged home or to another place of care. For those patients who were discharged home, letters almost universally followed national guidelines. Only one of these letters was missing information relating to the date of discharge. The mean time to completion of discharge letters was 5 days (range 1 to 8 days). Whereas letters for patients discharged home were comprehensive, letters related to patients who had died, by their nature, omitted domains related to future care, were shorter and reflected more nuanced issues like bereavement risk, family insight and psychosocial support.

**Conclusions:** National recommendations are already visible in discharge letters from our institution however formal templates for patients who are being discharged and for patients who have died would be helpful. Potential delays in the completion of letters are hazardous and the development of formal templates in the Irish hospice setting may improve the process.

**Abstract number:** PO136

**Abstract type:** Print Only

**Feasibility of a Care Pathway Checklist (CPW-CL) to Address Patient Needs for Key Interventions Palliative Cancer Care (KI-PCCs) Identified by a Pragmatic Screening and Prioritization Tool in Routine Cancer Care**

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**Aim:** To test the feasibility of a CPW-CL to address patient needs for KI-PCCs identified by a pragmatic screening and prioritization tool in routine cancer care

**Method:** Patients are *screened* by r-ESAS, romanian validated version and six screening questions for KI-PCCs

(illness understanding, decision support, care networks, family care, end-of-life preparation, spirituality). Identified needs are *prioritized* by the assessing nurse and patients, then presented to the oncologists. For each KI-PCC a *CPW-CL* was developed until consensus of the 5 romanian centres. A training program was developed. The intervention is applied weekly for 3 weeks in incurable cancer patients from oncology units. Primary Outcome : feasibility (% assessment done, % interventions applied per protocol), secondary Outcomes : weekly change of rESAS score and KI-PCC screening question, IPOS scores at week 2 compared to reality map data, patient characteristics of feasible vs not, responders (ESAS change 2 points). Local teams discuss weekly in formalized meeting the feasibility of screening, of prioritization, of CPW-CL.

**Results:** Per centre 20 patients are included. Preliminary results (79 pts) suggest feasibility of the screening questions (5-15 minutes), prioritization challenges due to lack of time of oncologists and issues of patient trust in the assessor, practically helpful CPW-CL detailing concrete actions and referrals requiring 30-60 minutes per patient. Current challenges include the availability of home care, availability of HCPs to deliver family care, reimbursed time (by the house of insurance) to apply the interventions, coordination of symptom management, and discussing end-of-life issues. Patients welcome the intervention. Currently the CPW-CL is adapted to simplify the procedures.

**Conclusion:** Preliminary results suggest that a pragmatic screening is feasible, that practical CPW-CL can guide delivery of simple but important KI-PCC, and that new financing models are needed in Romania.

**Abstract number:** PO137

**Abstract type:** Print Only

**Promoting Free Exchange of Knowledge Across the Globe: The International Palliative Care Network Conference**

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**Aim:** To promote the free exchange of knowledge amongst palliative care professionals around the globe using a volunteer run internet based platform.

**Method:** Palliative Care Network (PCN) has annually hosted the International Palliative Care Network Conference (IPCNC) since 2011. Participation of palliative care professionals from all disciplines is free with

complimentary access to all materials. The lecture series includes invited and submitted lectures. In addition, there is an online poster exhibition. Invited lectures are presented by global palliative care experts using PowerPoint templates with audio embedded onto each slide. Posters are prepared on a PowerPoint template and displayed during the online conference. The 2015 conference is endorsed by 14 national, regional and international organizations and publications and is held under the auspices of the European Association for Palliative Care. Awards are sponsored for select posters by organizations and publications. Each participant receives an e-certificate.

**Participation:** The 2015 conference received abstracts from 18 countries across various disciplines.

**Impact:** Over the years, with increased awareness, participation has steadily increased. Select testimonials reflecting change in practice include:

“Better assessment of pain and symptom management; impact of uncontrolled pain on quality of life (USA)

“Better symptom management” (Kenya)

“I will be looking at ways to improve existing patient outcomes by adopting evidence based practices. (UK)

“It’s important to be exposed to a wide range experience from round the world; this will definitely affect our current practice.”(Iran)

“Consider some of the presentations/posters as I update hospital policy/procedures.” (Canada)

**Conclusion:** The IPCNC is an effective medium for enabling the free flow of knowledge with a positive impact on the relief of suffering globally.

Future studies are needed to determine effectiveness. Cost and time constraints feedback.

## Bereavement and family care givers

**Abstract number:** PO138

**Abstract type:** Print Only

### The Experiences of Caregivers of Patients with Delirium, and their Role in its Management in Palliative Care Settings

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**Background:** Delirium is a serious and distressing neuropsychiatric syndrome frequently experienced in palliative care settings. A need exists to better understand how caregivers of patients with delirium can be supported during delirium, and how they can help support the patient.

**Aims:** To explore the experiences of caregivers of terminally ill patients with delirium; to determine the potential

role of caregivers in the management of delirium; and to identify the type of support required to improve caregiver experience and to help the caregiver support the patient.

**Methods:** An integrative literature review was conducted. Four electronic databases were searched - PsychInfo, Medline, Cinahl and Scopus from January 2000 to July 2015 using the terms ‘delirium’, ‘terminal restlessness’, or ‘agitated restlessness’ combined with ‘carer’ or ‘caregiver’ or ‘family’ or ‘families’. Thirty-three papers met the inclusion criteria and remained in the final review.

**Results:** Papers focused on

- (i) caregiver experience - distress, deteriorating relationships, balancing the need to relieve suffering with desire to communicate, and helplessness versus control;
- ii) the caregiver role - detection and prevention, symptom monitoring, and acting as advocate, and
- iii) caregiver support - information needs, advice on responding to the patient, interventions to improve caregiver outcomes, and interventions delivered by caregivers to improve patient outcomes.

**Conclusion:** High levels of distress are experienced by caregivers of patients with delirium. Distress is heightened in palliative settings due to the potential irreversibility of delirium and uncertainty around whether the caregiver-patient relationship can be re-established before death. Caregivers can contribute to the management of patient delirium. Further intervention studies with informational, emotional and behavioural components are required. Reducing caregiver distress should be a goal of any future intervention.

**Abstract number:** PO139

**Abstract type:** Print Only

### The Relationship between Palliative Care and Bereavement Assistance in Italian Hospices

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The aim of this study is to analyse the influence of Bereavement Assistance on Palliative Care in Italian hospices.

The research stems from this observation: when the goal is to improve quality of life of a patient aware of his impending death, Bereavement Assistance is an integral part of Palliative Care and is provided also to the patients. When there is not awareness of death (frequent in Italian hospices), bereavement support covers only the family in the anticipatory mourning or after death.

In this regards, the first step of the research is a review of the international literature aimed to answer to this question: Bereavement Assistance is oriented only towards families or also towards patients?

The second step of the research is a quali-quantitative survey on bereavement support services of Italian hospices.

**Methodology:** ad hoc questionnaire administered by phone to the hospice psychologists in order to answer to the following questions:

- what is the percentage of Italian hospices in which Bereavement Assistance is delivered?
- what is the percentage of hospices where Bereavement Assistance covers only the family and not the patient?
- what are the major theories of mourning to which the bereavement support services of Italian hospices make reference? And what kind of assistance is provided (only for families or also for patients)?
- what are the main tools used to diagnose the mourning and to evaluate the assistance in comparison with international Bereavement Assistance?
- what is, in the Italian hospices, the degree of correlation between bereavement support provided only to families and the lack of patient awareness of death?

The outcomes of this study are under analysis and they may contribute to a considerable improvement of Palliative Care, all the times that improving the patient quality of life by controlling the symptoms is not enough because the awareness of the impending death make the quality of life worse.

**Abstract number:** PO140

**Abstract type:** Print Only

### **The Experience of Family Caregivers Caring for Terminally Ill Patients at Home: A Literature Approach**

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**Background:** Today, one of the relevant aspects in caring for a terminal stage patient is the care provided at home. While this process is directly related with the support provided by the healthcare services, family involvement is essential. Therefore, there is a need for awareness regarding the impact that this type of care has on the caregivers.

**Aim:** To learn the experience of the family caregivers who are caring for a terminally ill patient at home based on literature.

**Method:** A literature search was conducted using PubMed, CINHALL, Psycinfo, Cochrane Library and Scielo databases. Two of the researchers jointly carried out a qualitative content analysis on the 12 articles found. Four categories emerged from this analysis and they were consulted with the rest of the research team so as to assure reliability and validity of the results.

**Results:** The analysis classified the family caregiver experience into four categories:

- 1) Learning the diagnosis: the uncertainty of the future and of the prospects of death;
- 2) The impact of the care on a personal dimension
- 3) The personal relationship between the caregiver and the person being taken care of; and
- 4) The patient environment: informal/formal support.

**Conclusions:** This study has shown:

- 1) that caring for a loved one in terminal phase at home is important on a personal dimension and regarding the development of an interpersonal relationship;
- 2) the importance of the environment where this care is taking place and how this favors/hinders the role of the caregiver;
- 3) the main areas in which the “care and support of the caregiver” should be focused; and
- 4) the need to learn more about this phenomenon.

Adequate knowledge and awareness of this phenomenon, as well as the significance it has regarding the caretaker, and consequently, the person being cared for, will impact on the well-being of both individuals, in terms of support and resources needed and regarding the motivation for setting up different healthcare policies.

**Abstract number:** PO141

**Abstract type:** Print Only

### **Distance Caregivers in Palliative Care: A Hard-to-Reach Population with Specific Needs**

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**Background:** Palliative care guidelines worldwide emphasise the inclusion of family carers in the care of the

patient. While this takes place routinely with local carers, when carers live far from the patient they may sometimes go unnoticed or receive less support than local carers. Thanks in part to new technologies such as smart telephones and the internet, distance caregivers can now be actively involved in providing care.

**Aims:** To present the results from a study exploring the needs and experiences of distance caregivers in palliative care.

**Methods:** This study used mixed methods, including a quantitative survey and qualitative semi-structured interviews. Current and former carers were included in the sample. Distance caregivers were recruited using different strategies, including recruitment via seven hospices in South England, as well as social media (Twitter, Facebook).

**Results:** A total of 95 distance caregivers filled in the questionnaire, and 22 were interviewed. These distance caregivers were in a number of different countries including the UK, USA, China, and Australia. Most participants were female (82%), with a mean age of 49.7 years old, and were providing care to a parent (80%). 33% lived more than 100 miles within the same country as the patient, and 32% carers lived in a different country. Participants expressed in their interviews difficulties that are often linked to caregiving in palliative care, with the distance adding a degree of difficulty to this situation. Despite the distance, all participants expressed a deep connection to their relative. Some participants felt that the distance provided a “buffer zone”, and this generated feelings of guilt.

**Conclusion:** More research is needed in this area: including qualitative studies assessing the needs of these carers further, and quantitative studies exploring this population nationwide. Policy makers should be aware of the growing numbers of distance caregivers, and provide the appropriate resources.

**Abstract number:** PO142

**Abstract type:** Print Only

### Contextual Enablers and Barriers to the Implementation of Home-based Palliative Care Interventions

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**Research aim:** The effectiveness of home-based palliative care interventions (HBPC) is critically influenced by both context and implementation. In the context of the EU-funded INTEGRATE-HTA project and a demonstration HTA on HBPC services in Europe, we undertook a qualitative systematic review with the aim to identify enablers and barriers of context and implementation of HBPC services in Europe.

**Study design and methods:** We searched MEDLINE, EMBASE, PsycINFO and CINAHL for qualitative or mixed-method studies reporting barriers and facilitators of HBPC among adults. Screening, data extraction and quality appraisal followed standard procedures. Best fit framework synthesis as described by Carroll et al (2014) was applied as the method for analysis, using the Context and Implementation of Complex Interventions (CICI) framework as the a priori framework. This framework comprises eight domains of context (i.e. socio-cultural, ethical, legal, political, socio-economic, epidemiological, geographical and setting) and four domains of implementation (i.e. policy, funding, organization and structure and provider).

**Results and interpretation:** Of 2,988 records screened, 41 full-text articles met the inclusion criteria. HBPC interventions were observed to be very heterogeneous in terms of their design and delivery, and care settings also varied largely. Both ethical and socio-cultural context had significant impact on the successful implementation of HBPC, in particular the family context, as well as privacy, autonomy and conflicting interests of all individuals involved in HBPC. In terms of implementation barriers, continuity in terms of organization, information and staff as well as the individual characteristics of care providers were of major importance for the successful and satisfactory delivery of care. Numerous interactions between both context and implementation domains were observed.

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**Abstract number:** PO143

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### Methodological Considerations for Researching the Financial Costs of Family Caregiving within A Palliative Care Context

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**Background:** The financial impact of family caregiving in a palliative care context has been identified as an issue

which requires further research. However, little is known about how research should be conducted in this area.

**Aim:** The aim of this study was to explore the opinions of family caregivers in New Zealand regarding the need to conduct research relating to the financial costs of family caregiving and to explore their perspectives on acceptable and feasible methods of data collection.

**Methods:** A qualitative study design was adopted. Semi-structured interviews were conducted with 30 family caregivers who were either currently caring for a person with palliative care needs, or had done so in the past year.

**Results:** All participants felt that research relating to the costs of family caregiving within a palliative care context was important. There was little consensus regarding the most appropriate methods of data collection and administration. On-line methods were preferred by many participants, although face to face methods were particularly favoured by Māori participants. Both questionnaires and cost diaries were felt to have strengths and weaknesses. Prospective longitudinal designs are likely to be most appropriate for future research, in order to capture variations in costs over time.

**Conclusions:** The lack of consensus over a single preferred method makes it difficult to formulate specific recommendations regarding methods of data collection; providing participants with options for methods of completion may therefore be appropriate.

**Abstract number:** PO144

**Abstract type:** Print Only

### Systematic Risk Assessment for Family Caregivers in Palliative Home Care. A Feasibility Study

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**Objective:** Family caregivers of terminally ill patients are at risk of psychological distress during caregiving and complex grief disorder (CGD) after the loss. Early identification is crucial to ensure targeted support. A risk assessment tool was developed based on established risk factors e.g. previous loss and psychiatric disease. The aim was to test the feasibility of a systematic use of a risk assessment tool for caregivers to terminally ill patients in a palliative home care team (PCT) in Denmark.

**Methods:** All eligible caregivers to patients referred to the PCT from March 2015 were invited to join the study. PCT staff included caregivers in the study at the first home visit. Subsequently, the caregivers' needs for support were

discussed at an interdisciplinary conference based on the risk assessment. A support plan was documented in the patient's record. Feasibility was tested based on enrollment rates and perceived usefulness among healthcare professionals as well as documentation of support plan for the caregiver. Inclusion is ongoing and will end December 2015.

**Results:** Until October 2015, 113 caregivers were assessed for eligibility, and 82 (73%) met inclusion criteria and agreed to receive information about the study. Of these, 51 (62%) caregivers were included in the study. Participants consisted of 35 women (69%) and 16 men (31%). Mean age was 59 (range; 41-77). Preliminary analysis of feasibility showed that the systematic assessment was perceived as useful by PCT staff, but challenges were reported regarding the mentioning of the word "death" in the assessment tool. Findings will be presented, including descriptive statistics and measures of feasibility.

**Conclusions:** This study will provide valuable information on the feasibility of systematic use of a risk assessment tool for caregivers in palliative home care.

**Funding:** The Danish Cancer Society and TrygFonden.

**Abstract number:** PO145

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### Study of Resilience and its Relation with Quality of Life in Caregivers of Patients with Advanced Cancer Referred to Palliative Care Services

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**Background:** Caregiver wellbeing can influence family function and quality of life and physical health. Research has shown that resilience i.e. one's capacity to recover from extremes of trauma and stress is directly related to quality of life. There is a lack of studies in developing countries addressing resilience and its relationship with Quality of Life in care-givers of patients with advanced cancer.

**Aim:** To assess resilience and its relation with quality of life in adult caregivers of advanced cancer patients receiving palliative care.

**Methods:** A cross-sectional study was conducted in primary adult caregivers of patients with advanced cancer referred to Palliative Care clinic at a tertiary cancer care centre. Using convenience sampling, 30 caregivers were interviewed recording basic socio-demographic data, Connor-Davidson Resilience Scale (CD-RISC) questionnaire and WHO-QOL BREF questionnaire in their preferred languages. Data was analysed using SPSS v20 for descriptive statistics and tests for correlation between resilience and quality of life.

**Results:** Out of 30, 29 participants filled the questionnaires. There were 23 males (79%) of which 13 (44.8%) were sons. The mean age was 36.24 years (SD±9.9). The mean and SD for resilience score was 70.10±16.47 and Quality of life (QOL) score was 14.96±3.00. Pearson correlation coefficient between resilience and overall QOL was 0.46 ( $p=0.012$ ) and with social relation domain of QOL was 0.52 ( $p=0.004$ ). Males (71.70 vs 64.00) and graduates (76.25 vs 67.76) had higher resilience score, though it was not statistically significant.

**Conclusion:** The present study suggests that adult caregivers had good resilience. There was statistically significant correlation between resilience and social domains of QOL. Identification of resilience and appropriate psychosocial interventions to enhance resilience will be useful to improve caregivers' quality of life in a developing country context, both in clinical work and research.

**Abstract number:** PO146

**Abstract type:** Print Only

#### Top 5 Fears of Palliative Caregiver

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**Background:** On the one hand, we know that talking about death and dying can have a therapeutic effect on caregivers. However, on the other hand, some research suggests that both caregivers and terminally ill patients face considerable difficulties when discussing the disease and death.

**Aims:** To identify the five major fears of family caregivers of palliative patients at home and in palliative care units.

**Methods:** Cross-sectional descriptive and analytical study about family caregivers of palliative patients, combining quantitative and qualitative approaches. This abstract is part of an ongoing larger research on caregivers. The sample includes 130 family caregivers of palliative patients at home and in the Madeira's Regional Palliative Care Network.

Data collection has been conducted from April 2014 to April 2015, through a structured questionnaire with open and closed questions about the caregiver's fears.

Data analyses is being processed by the SPSS 20 and is going through content analysis. The study was approved by the ethics committee of the Madeira Health Service.

**Results:** This study is still under development therefore we will present at the conference the final results.

Preliminary data indicates that the major fears are: the fear of being present at the moment of death, the fear of being alone with the relative at the moment of death, the fear of not knowing what to do at the moment of death, the fear of finding the relative dead and the fear of not being able to provide the care needed in agony phase.

**Conclusions:** The data calls into question the presence of the family caregiver at the moment of death of the relative, leading us to wonder if this presence is always therapeutic. We should prepare the palliative professionals to deal and to communicate with caregivers about their fears and investigate new ways to intervene.

**Abstract number:** PO147

**Abstract type:** Print Only

#### Hospital Discharge in Advanced Disease: Can we Better Support Family Carers?

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**Background:** Family carers are crucial in making home care possible at end of life. Carer factors contribute to difficulties in achieving timely hospital discharge for patients and to potentially avoidable readmissions.

**Aim:** To investigate how carers' support needs are identified prior to patient discharge from acute care towards end of life (EOL) and suitability of using the evidence based Carer Support Needs Assessment Tool (CSNAT) in discharge planning.

**Method:** Qualitative design: focus groups (FGs) with practitioners supporting patient discharge from three acute hospital trusts in England. 39 participants: hospital specialist practitioners from palliative care and complex discharge plus community Macmillan nurses and district nurses. FGs explored discharge processes, challenges in supporting carers and potential value of the CSNAT. Thematic framework analysis.

**Results:** Palliative care discharges were complex: from different wards across hospitals involving many practitioners. Although carers were at times involved in discharge discussions, the focus was on patients' needs. Practitioners viewed the CSNAT as potentially valuable in the context of challenges faced in supporting carers. Practitioners regularly had to manage carers' (often unrealistic) expectations of their caregiving role at home and levels of support available, but without any guiding framework for identifying their needs.

The simple question format of the CSNAT was valued, allowing issues discussed to come from the carer's

perspective, rather than from the organisation. It was seen to permit anticipatory work with carers who had not yet thought through the extent of the caring role at home. Practitioners found carers not always able to express worries, but identified the CSNAT as enabling them to articulate concerns.

**Conclusion:** The CSNAT shows potential to enhance support for carers at hospital discharge and play a role in preventing readmissions towards the end of life.

**Funder:** Marie Curie Cancer Care.

**Abstract number:** PO148

**Abstract type:** Print Only

### Palliative Caregivers Difficulties in Madeira

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**Background:** Taking care of a family member who is dying is an intense and challenging experience. Family caregivers are faced simultaneously with increasing dependence, their own fears about death and the emotional impact of loss and grief. It is essential to identify the local difficulties of palliative caregivers in order to intervene preventively and to adapt resources.

**Aim:** To identify and analyze the main difficulties of informal caregivers of palliative outpatients in Madeira.

**Methods:** Cross sectional descriptive and analytical study about caregivers of palliative patients, with qualitative approaches. The sample includes 90 family caregivers of patients receiving palliative care at home. Data collection has been conducted from April 2014 to April 2015, through a structured interview put together by researchers and based on literature review and five clinical experts in palliative care. Data analyses is going through a content analysis. The study was approved by the ethics committee of the Madeira Health Service.

**Results:** This study is still under development. Therefore, we will present at the conference the final results. Preliminary results indicate that caregivers are faced with family difficulties related to the availability to care for the patient and increased family conflicts caused by the different opinions regarding their care. Most caregivers do not know how to precede if the patient dies at home, and some caregivers reported difficulties in overcoming the embarrassment related to their patients' hygiene care or dealing with malignant wounds odors.

**Conclusions:** These preliminary results can help us to intervene with caregivers in areas sometimes poorly explored.

### Education research

**Abstract number:** PO149

**Abstract type:** Print Only

### Advanced Practice Registered Nurses (APRN): Educating Present and Future Leaders in Palliative Care

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**Background/aims:** Advanced practice registered nurses (APRNs) play a vital role in accessing and managing care. While palliative care is growing in the United States, there continues to be a need for educating APRNs to participate and lead in this care. APRNs can respond to the complex needs of patients with serious and life-limiting illness and their families as outlined in the 2010 Institute of Medicine (IOM) report on the *Future of Nursing* and in the 2013 *National Consensus Project for Quality Care Clinical Practice Guidelines*.

**Methods:** The End-of-Life Nursing Education Consortium (ELNEC) - APRN curriculum, the first curriculum dedicated to APRN palliative care training, has been developed for APRNs working with children and adults. To date, over 340 APRNs have attended national courses. The majority of the participants work in acute care (51%), followed by 23% in rural or inner city clinics, and 19% in hospices.

**Results:** Pre-course data from the courses revealed that 44% of these APRNs are active members and 12% are leaders of their palliative care team. While the majority of participants stated they felt confident or very confident in pain assessment/management (81%/67%), symptom assessment/management (86%/68%), communication (88%), and ethical concerns (63%), they also reported less confidence in financial issues associated with palliative care (68%) and quality improvement concerns (42%). Twelve month post-course evaluation data demonstrated improved confidence in areas of practice with greatest improvement in clinical skills and that participants need more support in the financial aspects of practice and measuring outcomes.

**Conclusion:** With escalations in the aging population, increases in nursing and physician shortages, and reorganization of national healthcare, it is vital that APRNs be educated to promote and provide palliative care as never before.

**Funding:** The Cambia Foundation has provided grant support for ELNEC-APRN.

**Abstract number:** PO150

**Abstract type:** Print Only

### **An Audit of Physiotherapy Day Placements with Louth Specialist Palliative Care Team (SPCT)**

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Chartered Physiotherapists are required to undertake Continuous Professional Development (CPD). Placements are recognised as a valid form of CPD by the Irish Society of Chartered Physiotherapists.

Physiotherapy day placements in Specialist Palliative Care were developed aiming to enhance working relationships between Specialist and Generalist Palliative Care and develop Physiotherapists' confidence and skills working at Generalist Palliative Care level.

The SPCT Physiotherapy day placements were available to Community and Hospital Physiotherapists working with the author. Placements included attendance at Multidisciplinary Team Meeting (MDTM), patient visits, clinical discussion and reflection. On a standard form, attending Physiotherapists recorded positive points about the placement, suggested changes, learning needs identified, the anticipated clinical impact and scored the value of the MDTM, patient visits and clinical discussion. Completed forms were audited for 2010 to 2014 to ascertain if the placement aims were met.

Ten Physiotherapists attended and eight completed the evaluation. Evaluations of MDTM, patient visits and clinical discussion were scored very good or excellent. All participants identified learning needs and an anticipated impact on clinical practice resulting from the placement.

From feedback on placement structure and suggested changes, future placements will be individually tailored. Physiotherapists will identify their learning needs in advance using the National Palliative Care Programme competency document as a guide.

In conclusion, the aims of the placement are being achieved. It is an effective way to develop Physiotherapists' skills and confidence with Palliative Care patients and promote further learning while simultaneously developing links between Specialist and Generalist Palliative Care. Placements could be replicated by other SPC services.

**Abstract number:** PO151

**Abstract type:** Print Only

### **Pre-clinical Medical Students' Educational and Emotional Responses to an Early Hospice Experience**

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**Background/aims:** This study aims to describe pre-clinical medical students' educational and emotional responses to a required hospice experience.

**Methods:** In 2013-14, 202 MS2 accompanied hospice clinicians caring for patients followed by a debriefing. Students then entered free text responses to 2 emailed prompts:

1. Name 1-2 things you learned about hospice care you want to remember for future clinical work.
2. Briefly describe your emotional reactions to seeing a terminally ill patient at hospice.

Two authors read all responses to identify recurring themes, jointly devised a coding key, then independently coded all responses (1 or more codes). All authors discussed all coded responses to refine, finalize and tally codes.

#### **Results:**

**Table 1.**

Content themes of lessons learned about hospice care	Tally
Hospice eligibility, services, and options	33
Hospice care goals, philosophy, and outcomes	28
Provider attitudes, skills, and knowledge about hospice care	24
Hospice care for the family unit	21
Aspects of bedside practice	19
Diversity of patients' reactions/values/goals at end of life	18
End-of-life communication	14
Other themes each with tally <10	26
26 Total codes (for 175 responses from 92 students)	183

**Table 2.**

Emotional reactions to seeing terminally ill patients	Tally
No significant emotional reaction	26
Sad/depressed	17
Difficult/challenging	11
Heartened/encouraged	11
Mixed emotions (>1 emotion category expressed)	11
Moved/awed	10
Other themes each with tally <10	38
Total codes (for 86 responses from 86 students)	124

**Conclusions:** An early hospice experience is impactful as MS2 reported learning core aspects of US hospice care/philosophy. Students' emotional responses spanned a wide spectrum. These results may aide educators in anticipating

the spectrum of early student reactions to hospice and emphasizing key learning points.

**Abstract number:** PO152

**Abstract type:** Print Only

**The Difficulty of Having Meaningful Conference after Cancer Patients' Death: Analysis of Awareness Survey on Death Conference**

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**Aims:** The "death conference (DC)" has spread in Japan recently. The purposes of this multidisciplinary conference held after a cancer patient's death are to review the care, share the learnings, promote trustful relationship among professional staff, and enhance awareness of palliative care. Grief care for suffering staff will be possible by letting them express emotions.

In a 380-bed district general hospital, DC started first at Urology Ward (U-Ward) but discontinued because of not resulting in stress reduction. Therefore, before starting DC at Gastroenterological Surgery Ward (G-Ward), our palliative care team decided to focus on "healing" effect and conducted a survey to analyze the current situation and problems to achieve quality DC.

**Methods:** We conducted a questionnaire survey with 12 questions to select from 5-grade evaluation and 4 open questions (U-Ward: n=35, G-Ward: n=34) in Jan. 2015. As for G-ward, it was distributed before and after 5 DCs focusing on healing rather than criticizing.

**Results:** We obtained 85-91% response. The agree rate on the need of DC at G-Ward unexpectedly decreased to 62% after DCs from 83% before DCs ( $p=0.08$ ), in contrast to 91% of U-Ward ( $p=0.01$ ). After DCs at G-Ward, expectation for most components including "review the care" "opportunity to learn" and "share view of life and death" decreased. Many comments such as "talk the same matter every time" and "seem like a waste of time" showed the meaninglessness of DC. Although DC was given up at U-Ward, expectations for "information sharing" and "apply to future care" were higher than those at G-Ward. U-Ward staff are reaffirming the significance of DC through their care for the dying, even after feeling pain at previous DCs.

**Conclusion:** The results indicated DC has two aspects; healing and learning. It suggests enhancing the healing

effect after a distressed case and the learning aspect following a difficult case. Well-facilitated DC might lead to better practice in palliative care.

**Abstract number:** PO153

**Abstract type:** Print Only

**Sexual Health in Cancer and Palliative Care: Assessment of Need and Training Development**

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**Introduction:** It is known that sexual health concerns are rarely addressed by health care professionals (HCPs) working with cancer & palliative care patients. A Sexual Health & Wellbeing Group was convened with the aim of improving the sexual health literacy within one Welsh Health Board.

**Aim:**

1. To determine the current knowledge levels of HCPs working with cancer & palliative care patients regarding sexual health.
2. To determine the education requirements of these HCPs regarding management of such patients' sexuality concerns.
3. To develop sexual health training for cancer & palliative care settings.
4. To develop a sexual health care pathway to guide interventions with cancer & palliative care patients.

**Methods:** An anonymous online questionnaire was used to assess training, current practice, and education needs relating to the management of sexual health issues in cancer & palliative care. A literature review focusing on sexuality training & education was undertaken. Subsequently, both a training package & a sexual health pathway for cancer and palliative care were developed.

**Analysis:** Descriptive statistics and simple thematic analysis were used to analyse questionnaire data.

**Results:** There were 147 responses from Oncology, Palliative care, Primary care & district nursing. Overall response rate was 43% (100% response rate for both Oncology & Palliative care). Majority of respondents do not routinely assess sexual health issues or wait for the patient to raise the issue. Main reasons for non assessment were: not the presenting issue; not the focus of the consultation; wrong setting; or lack of training. Very few respondents used models to assess sexual health issues. Majority felt there was a need for further training & a care pathway.

**Outcome:** The results of the questionnaire have informed the need for & the type of sexual health education required

for HCPs working with cancer & palliative care patients. Next step: roll out the sexual health training programme.

**Abstract number:** PO154

**Abstract type:** Print Only

### **In the Presence of Death and Dying: How Do New Doctors Feel about Caring for Terminally Ill Patients?**

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**Background:** As medical students, new doctors may have had little exposure to dying patients (Gibbins J, 2011). Dying patients and their families report good communication and confidence in those caring for them as important (Virdun C, 2015). Thus, it is crucial that all doctors feel comfortable engaging with these patients.

**Aims:** The aim of our study was to evaluate whether new doctors had received teaching on end of life (EOL) care during medical school, and to discover if they felt comfortable around death and dying, and able to discuss these subjects with their patients.

**Methods:** The FATCOD scale, a questionnaire designed to assess attitudes of oncology nurses towards EOL care (Frommelt KH, 1991), was distributed to doctors, all in their first year of work in one teaching hospital. Following a pilot study, a subset of questions were chosen in the interest of time constraints. Ethical approval was granted to carry out this study.

**Results:** 36 responses (48%) were received. Respondents had trained in 5 different medical schools. 89% reported having had teaching on EOL care in medical school. Only 36% reported they had not yet cared for a dying patient. When asked whether they would be comfortable in the presence of a terminally ill patient who was crying, 25% agreed they would feel uncomfortable. 28% stated they would prefer if a patient they were caring for died while they were not present. Only 8% reported they would feel like running away when their patient actually died. However, 44% of respondents agreed they would feel uncomfortable talking about death with a dying person.

**Conclusions:** Our study found that a proportion of first year doctors do feel uncomfortable around death and, in particular, are uncomfortable speaking about death with dying patients. These findings may be used to structure teaching on end of life care at intern induction.

**Abstract number:** PO155

**Abstract type:** Print Only

### **A National Survey of Medical Physicians' and Trainees' Self-rated Competence Regarding Palliative Care for Adults with Life-limiting Conditions and their Families**

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**Background:** A national multidisciplinary Palliative Care Competence Framework (PCCF) was published in Ireland in 2014, describing competences for 14 disciplines at three levels (palliative care approach, generalist and specialist palliative care provision).

**Objective:** To examine self-perceived competence of doctors in palliative care using a novel instrument developed from the PCCF.

**Methods:** The PCCF was used to generate a questionnaire examining attitudes, behaviour and knowledge. The survey was distributed to a stratified random sample of Royal College of Physicians of Ireland members (n=587). 311 (53%) responses were analysed. The sample comprised basic specialist trainees (7.7%), higher specialist trainees (24.8%) and consultants (62.7%); 3.2% reported palliative medicine specialisation.

**Findings:** Analysis demonstrated the three subscales - attitudes (possible range 6-30), behaviour (possible range 11-55) and knowledge (possible range 10-50) - were reliable ( $\alpha > 0.85$ ) and normally distributed. Descriptive analyses highlighted variation, with scores in the upper range for attitudes (Mean=22.9, SD=5.1, Range: 6 - 30), but more moderate scores on behavioural ratings (Mean=38.6, SD=9.8, Range: 11-55) and knowledge of key competences (Mean=36.5, SD=8.2, Range: 10 - 50). Moderate to high significant positive correlations were found between the three scales, in particular between behaviour and knowledge ( $r = 0.859$ ,  $p < 0.01$ ). Comparison of trainees and consultants suggested that trainees have more positive attitudes towards responsibility for palliative care delivery ( $t=2.335$ ,  $p < 0.05$ ).

**Conclusions:** The WHA Resolution on Palliative Care (2014) points to the importance of a skilled workforce comprising specialist and generalist palliative care professionals. This national survey provides a point in time indication of Irish doctors' attitudes, behaviours and knowledge regarding palliative care and reveals the impact of education and training strategies to date.

**Abstract number:** PO156

**Abstract type:** Print Only

### Assessment of Palliative Care Training Needs among Hospital Doctors

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**Background:** Doctors in all specialties treat patients who have palliative care needs, yet many report difficulties managing communication around planning for end-of-life with patients & their families.

**Aim:** To elicit insight into Non Consultant Hospital Doctors' (NCHD) confidence in delivery of general (level 1) palliative care as outlined in the National Palliative Care Competency Framework 2014.

**Methodology:** Medical, Surgical & Anaesthetic NCHDs in a teaching model 3 Irish hospital were invited to participate. A survey instrument (employing Likert scales) was used to measure the 'self-assessment' data. We surveyed 38 competencies in the 6 domains. Participants were classified into 3 bands according to length of experience: those qualified less than 1 year; those qualified between 1 & 4 years; those qualified for more than 4 years.

**Results:** 125 NCHDs were invited to participate, 54 responses were received. Across all competencies, more experienced doctors felt more confident than those with less experience. All categories of doctor felt less confident in supporting families & patients in coping with loss, grief & bereavement, particularly when preparing families with children or vulnerable adults for the loss of a loved one. All categories of doctors expressed significantly less confidence in employing two specific competencies:

- Exploring psychological & spiritual dimensions;
- Applying the Irish Medical Council Ethical Guidelines.

**Conclusion:** This study provides a valuable insight into the confidence of hospital doctors at all levels in their delivery of general palliative care. The data provides a framework to guide the development of a tailored teaching programme to address training needs. The 2014 National Competency Framework has provided us with the opportunity to engage with our colleagues in a collaborative and meaningful way to support and enhance their skills and abilities in palliative care delivery.

**Abstract number:** PO157

**Abstract type:** Print Only

### The Development and Impact of a Training Programme for Volunteers Supporting People Living at Home with Advanced Life Limiting Illness: A Pilot Study

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**Background:** A public health approach to palliative care calls for the development of initiatives that empower the public to support people in their community who are living with advanced life-limiting illness. However, there is little evidence to inform the development and/or evaluation of training programmes to enable people to provide such support.

**Aims:** The aims of this study were to:

- 1) Describe the development of a 7 week (17.5hr) training programme for volunteers to enable them to deliver the Good Neighbour Partnership (GNP); an intervention designed to address the unmet needs of people living at home with life-limiting illness, in their last year of life;
- 2) To assess the impact of the programme on volunteers' knowledge, confidence, death self-efficacy and fear of death.

**Method:** A participatory action research approach, utilising quantitative methods to evaluate impact was employed. Data were collected using three questionnaires administered pre and post training.

**Results:** Twelve volunteers enrolled on and completed the training programme. There was a significant improvement in their self-reported knowledge of the GNP ( $z=-2.994$ ,  $p<0.000$ ,  $r=0.61$ ) and their confidence in using the skills associated with the intervention following the course ( $t(11)=-5.316$ ,  $p<0.000$ ). There was also a significant reduction in their own fear of death following programme completion ( $t(11) = 3.133$ ,  $p<0.01$ ) and an increase in their death self-efficacy ( $t(11) = -3.946$ ,  $p<0.002$ ).

**Conclusion:** The findings indicate that it is possible to design a training programme that provides volunteers with the necessary knowledge and skills to deliver this kind of intervention, whilst also impacting positively on their own fear of death and death self-efficacy. The results have informed the refinement of this new training programme which now comprises six modules, available online. Further studies are required to determine the impact of training on larger numbers of people over time.

**Abstract number:** PO158

**Abstract type:** Print Only

### Enhancing Learning for Health Care Assistants (HCA) through Constructive Alignment (CA)

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**Purpose:** Palliative care (PC) education should promote a meaningful learning experience for Health Care Assistants (HCA) that goes beyond the classroom to make significant change to the quality of care delivered.

**Background:** More often than not modules of learning are content driven and teacher centered as opposed to outcome driven and learner centered (Donnelly & Fitzmaurice 2005). The opportunity to redesign the module, Palliative Care Support for HCA arose using the principles of Constructive Alignment (CA).

**Method:** In CA meaning is not imposed or transmitted by the teacher, it is created by student activities, what the student does to achieve this understanding is important (Briggs 1999). There must be coherence between the learning outcomes (LO), teaching strategies and the assessment that encourages students to take responsibility for their own learning.

The LO and teaching strategies were discussed and reviewed. How the LO would be achieved through group work, role play, reflection and video was clarified. Each participant was encouraged to use their workbook for reflection on their portfolio. Ownership of the programme was supported through inclusion of a HCA from a nearby hospice to share her personal experience.

Group work was collated/displayed and the students were encouraged to photograph their work for their portfolios. Classroom Assessment Techniques such as the One Minute Paper were incorporated to check understanding and capture teachable moments.

**Results:** Twenty eight HCA participated in the programme and positively evaluated it. Some of their learning included:

‘The HCA has a very important role to play in the delivery of PC’

‘I found it helpful and I can bring back what I learned to my place of work’

**Conclusion/recommendations:** HCA’s felt valued and through the programme developed a new awareness of the importance of their role and place in the team in the delivery of quality PC.

**Abstract number:** PO159

**Abstract type:** Print Only

**Improving Attitudes and Stress Awareness in Palliative Care: An Educational Intervention with Healthcare Professionals**

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The aim of this study is to demonstrate that the measurement of attitudes toward care of dying and work related stress can be used to help educators to analyze the formative needs of healthcare professionals; to identify and assess psychological work related distress; to develop training programs focused on improving attitudes toward care of terminally ill patient and preventing stress; to ameliorate knowledge and beliefs on the death.

**Materials and methods:** We administered: the Frommelt Attitudes Toward Care Of Dying Scale - form B (FACTOD-B) that measures six specific dimensions: Fear/Malaise, The care of the Family, Communication, Family as Caring, Relationship and Active Care. They were asked to complete FATCOD- B included demographic information, age, years of experience in nursing and in palliative care, highest degree held, previous education on death and the Maugeri Stress Index (MSI) that provide five factors as Well-being, Adaptation, Support, Irritability and Avoidance. Data were collected from 15 healthcare professionals practicing in palliative care. An Educational Program was designed in the field of “Death and Dying” using the method of focused-group and role-playing and in the field of Stress management through the learning of a specific technique slow breath/heart-rate-based using the App named HeartRate Plus. FATCOD- form B-I and MSI were repeated three months later to measure the result of training program.

**Results:** Our intervention has increased the operators self-awareness about their emotional experience in caring dying patients and has encouraged to modify their attitudes. Moreover it has developed their expertise in the knowledge and management of stress signs related to their professional experience.

**Conclusion:** The measurement of formative needs and the improvement of nurses attitude toward care of dying patients together with the assessment of work-related distress, are fundamental to achieve the quality of care they provide.

**Abstract number:** PO160

**Abstract type:** Print Only

**Understanding of Palliative Care and Generalist Symptom Control among Healthcare Professionals in an Acute Hospital**

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**Background:** The majority of deaths in Ireland occur in hospitals or institutions. Furthermore the Palliative Care Programme has developed competencies in palliative care for health professionals. However there is little evidence regarding the pharmacological symptom control preferences of non-consultant hospital doctors (NCHDs) and staff nurses in Ireland or of their perception or concerns regarding specialist palliative care and symptom control.

**Objective:** To assess baseline understanding of palliative care and basic symptom control of non-palliative care medical and nursing staff in an acute general hospital. The aim is to aid evidence based medical and nursing education.

**Method:** A pilot study was carried out. Anonymous questionnaires were collected from NCHDs attending an introductory presentation on palliative care and symptom control in an acute hospital and also from staff nurses attending two separate induction syringe driver training sessions. Due to limited numbers, a descriptive analysis was done of the results.

**Results:** Completed questionnaires were received from 8 medical and 12 nursing staff. No participant had previously worked on a specialist palliative care team. 9 (45%) had previously worked in a general hospital with a specialist service.

14 (70%) cited prochlorperazine as first-line antiemetic of choice, among both medical and nursing staff. The most commonly favoured second line antiemetic was cyclizine, 7 (35%). Only 1 (5%) staff member was aware of the equivalence doses of morphine and tramadol and alfentanil. 6 (30%) identified concerns with using/prescribing opiates in syringe drivers, related to dosing, medications used and fear of overdose.

**Conclusion:** The small numbers involved is a limitation and generalisation of the results is not possible. Further large studies of generalist nursing and medical staff would be beneficial to aid evidence-based symptom control education.

**Abstract number:** PO161

**Abstract type:** Print Only

### **Palliative Care and End of Life Issue in Italian Undergraduate Nursing Programs**

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**Background:** Undergraduate nursing education should include palliative care as the European consensus suggest. Few country included palliative care education in undergraduate curriculum. In Italy, the Law 38/2010 and the Ministry Decrees of 2012 provided a framework for post-graduate education in Palliative Care for all healthcare professionals. However, in the current academic system there are no unique directions on nursing education in Palliative Care for undergraduate students and no data are available on the subject.

**Aim:** To evaluate the adherence of nursing undergraduate education in Palliative Care in Italy to the EAPC guide for nursing education, in particular to what extent their content match the EAPC recommendations.

**Method:** A descriptive study was conducted through the information provided on the universities official web pages.

**Results/conclusions:** 60% of the curricula includes palliative care content. However, they are heterogeneously distributed in different courses and provide few compulsory and mandatory teaching hours. The most frequent topics regards core values and definition of Palliative Care and a supportive care to dying person and family. Pain is the most frequently treated topic, with 70%. Data on clinical training suggest that education is essentially theoretical and thus theory and practice need more integration. The increasing needs for palliative care in different settings correspond to raising attention to nursing education in palliative care since undergraduate level. Academic undergraduate education in Palliative Care warrants implementation by national regulations, and definition of compulsory, mandatory, both theoretical and practical, teachings. The inclusion of Palliative Care teaching in University, for all levels of education, as well as research development, represent the two future challenge for this discipline.

**Abstract number:** PO162

**Abstract type:** Print Only

### **E-Learning - Time & Space in Palliative Care Education**

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**Background/aims:** An EAPC paper on core competencies in palliative care education (2013) supports the "use of

shared learning opportunities across countries and indicates that there is evidence that using digital learning tools enhances understanding of palliative care theory and its application to practice". The aim is to examine hospice educators perspective of utilising e-learning within palliative care education and to understand the challenges and how they could be overcome.

**Methods:** Data was collected from a purposeful sample of six hospice educators on the Island of Ireland using semi-structured interviews. The interviews were transcribed and the data was thematically analysed.

**Results:** Educators considered many factors when utilising E-Learning in palliative care education: aims of the programme, learner's experience of using computers and topic suitability as palliative care is by its nature very emotive. Time to prepare and develop expertise can prevent them from utilising E-Learning. Like all educational activities, does it have an impact? The challenge is "bringing it back to practice" and its application to clinical practice is key. They identified organisational factors such as specific policies, resources and support mechanisms (including technological, educational, learning technologist). Communication with staff to ensure "buy-in" about the role of e-learning in the organisation is essential. Having a support mechanism for hospice educators to share knowledge would be beneficial.

**Conclusions:** The views on the future of E-Learning in palliative care education were mixed. Some educators were passionate about E-Learning. All of the educators were keen to adopt a blended approach into their teaching. They acknowledged the challenges but felt that e-learning has a positive role in palliative care education.

"Knowing the benefits and the limitations and embracing that with the blended but my biggest, biggest thing is not to lose sight of the patient".

**Abstract number:** PO163

**Abstract type:** Print Only

### Educating Health Professionals when Time is Precious

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The presentation is about an intervention that aims to improve the level of basic knowledge amongst health professionals regarding treatment on the level of basic palliative care. A recent Danish government report [i] has shown that there is a great variation in basic level palliative care. Furthermore, the report also stated that there is a need to focus on the early stages of palliative care as well as on the palliative care of non-malignant conditions.

Palliative intervention takes place in all three health care sectors: Hospital, municipal care services and general practice. The intervention involves nurses, doctors and health care assistants.

Time is a precious commodity for patients, and health professionals often lack this vital commodity. This often creates a challenge when there is a need for building professional competences.

The intervention comprises short films and group based e-learning that can be executed locally; as opposed to teaching in a classroom. The methods chosen in the intervention are flexible:

The intervention has been tested over 10 workshops covering the palliative care of malignant, as well as non-malignant conditions. We would like to present the results and discuss some of the important aspects of the workshops. We would also like to address the subject of the education of health professionals whose primary focus and task is not necessarily palliative treatment. Our aim is, from the time of diagnosis, to facilitate coherence in the palliative care process across all sectors.

[i] Anbefalinger for den palliative indsats. The Danish Health Authority 2011

**Abstract number:** PO164

**Abstract type:** Print Only

### Educational Program on Death and Palliative Care

*Ascencio Huertas, Leticia*

Palliative Care, Instituto Nacional de Cancerologia, Mexico, Mexico

The relationship between health professionals and death, is a subject of interest not only by the daily contact with

**Table 1.**

Title	Product	Theme
Introduction to palliative care	Animation	Basic palliative care
Structured conversation about the patients' needs	Group based e-learning	Communication
Observation in the private home of the citizen	Group based e-learning	Communication
A case about symptoms and how to treat symptoms	Group based e-learning	Symptomatology
Instruction on how to treat symptoms	App	Symptomatology
Advance care planning	Film	Communication

death but by confrontation with his own death. This study was prospective, quasi-experimental, with pre-test and post-test. The goal was to generate knowledge, skills and appropriate health personnel in connection with the death through an educational program of death and palliative care, which consists of six thematic units. The instruments were: Scale of attitudes towards palliative care and Skills assessment questionnaire. The results shows that half of the subjects reported feeling competent to subsequent implementation of the educational program, with statistically significant differences in knowledge  $F(5, 126) = 8.5988, p > 0.05$ , and skills  $F(7, 124) = 6.1197, p = 0.05$ . Significant differences when considering the role of both curative and palliative care (75.8% pre-test and post-test 77.3%), consider the family in decisions about patient care (pre-test 37.9% and post-test 48.5%), and the expectations, desires, fears, suffering, social and cultural environment of the terminal patient and his family were relevant in the post-test (36.4% pre-test and post-test 62.1%) also develop active listening and encourage the participation of the patient and family in treatment decisions were significant in the post-test (pre-test 33.3 and post-test 60.6%). However, in the attitudinal skills not find significant changes pre-test and post-test,

$F(8, 123) = 0.76131, p = 0.63738$ .

**Abstract number:** PO165

**Abstract type:** Print Only

### E-learning in the Palliative Care in a Spanish University

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**Introduction:** El Virtual Classroom (VC) from Murcia University is the official e-learning where teachers and students have various online tools that facilitate the development of teaching and learning. The VC uses SAKAI platform (Apero Foundation).

**Objective:** To evaluate the use of VC in the Palliative Care subject of 2<sup>nd</sup> course of Grade of Nursing studies from Murcia University.

**Methods:** During the academic year 2014-2015 we used e-learning with a VC for Palliative Care subject. Interactive learning shifts the focus from a passive, teacher-centered model of the past years to one that is active and learner-centered, offering a stronger learning stimulus.

The tools in the VC were: Teaching guide, calendar, resources, announcements, private messages, chats, exercises, exams online, weblogs, message boards and teleconferencing.

**Results:** Of 205 official students in the Palliative Care subject, 99.5% visited VC. The total number of visit: 13673. In the months near to the final exam (1<sup>st</sup> July), the visits to the VC were of 3801 in May and 3951 in June. The tool more used was "Resources": the students can work with educational materials such as lessons, text, graphics, animation, audio, or video to produce engaging content. It contained 193 archives. Of them, 98.4% were downloaded.

The VC also has resolved student's doubts with the tool "Virtual tutorial" (100% were resolved).

The final satisfaction survey has shown higher levels of learner satisfaction (90%), understanding of concepts, achievement of course objectives, and changes in practice. Students explained that the VC allows learning to be individualized and transforming the role of the teacher (from disseminator to facilitator).

**Conclusion:** The integration of e-learning into education can catalyze the shift toward applying adult learning theory, where educators will no longer serve mainly as the distributors of content, but will become more involved as facilitators of learning and assessors of competency.

### End of life care and quality of dying

**Abstract number:** PO166

**Abstract type:** Print Only

### Functional Decline and Palliative Sedation in Geriatric Patients Attends by a Home Care Support Team

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**Background/aims:** Functional decline could be a indicator of the necessitate of sedation in terminal patients.

**Methods:** Descriptive prospective study.

**Results:** N: 199. Sedation in 41 patients (20% of total sample). Characteristics of the sedated patients: mean age 76 years, mean Barthel index previous 79 and in our first visit 38'5, Karnofsky 44, number of visit 3'7+/-2'5 in a mean chase time 43 days; presence of symptoms: pain 56%( mean EVA 5'8), dyspnea 32%(mean NYHA 2'9), anorexia 61%, anxiety 44%, depression 37%, insomnia 29%, psychomotorial agitation 14'6%, dementia 19'5%. Characteristics of the no sedated patients (N: 158): mean age 78 years, mean Barthel index previous 68'4 and in our

first visit 46'27, Karnofsky 50, number of visit 2'2+/-1'7 in a mean chase time 46 days; presence of symptoms: pain 45% (mean EVA 6'6), dyspnea 29% (mean NYHA 2'5), anorexia 54'5%, anxiety 26'6%, depression 32%, insomnia 36%, psychomotorial agitation 21'5%, dementia 26%.

#### Conclusions:

1. Patients sedated suffer most functional decline and poor quality of life in our first visit, and this characteristic could be a indicator of the necessitate of sedation in terminal patients.
2. Most presence of symptoms in sedated patients but lower perception of pain and dyspnea.
3. Lower chase time in sedated patients but most number of visits in this time.

**Abstract number:** PO167

**Abstract type:** Print Only

#### Shifting Gears: Family Experiences of 'Usual' and 'End-of-Life' Care in Residential Aged Care (ARC) - A New Zealand Example

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As populations age, increasing numbers of people will end their days in aged residential care (ARC). However, ARC staff often struggle identifying when a palliative care approach is appropriate (Gardiner 2011). There is little evidence describing family members' perceptions of ARC care during this transition.

**Aim:** The aim of this study was thus to explore bereaved family perceptions of the change in care direction from normal to end-of-life care for their relative.

**Methods:** Interviews were conducted with a convenience sample of 26 family members most involved in the residents' care (bereavement within the last 12 months). Topics included communication between staff and family, advance care planning, staffing issues, transitions in care (including the use of public hospital) and family support provided by the facility.

**Results** indicate that families often felt unprepared for the transition from normal to end-of-life care. Three emergent themes characterize the key aspects of the family views of this transition: lack of awareness, frustration with pain and symptom management and perceptions of exclusion from decision making.

**Conclusion:** Interventions are required to target staff palliative care education and communication skills in the provision of information to relatives during this transition period.

**Abstract number:** PO168

**Abstract type:** Print Only

#### Advance Care Planning and Place of Death in Paediatric Palliative Care

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**Objective:** In paediatric palliative care, a major question is how to help parents to understand that the life of their child is limited. A second question is to understand where they prefer to live the last days of life: referring university hospital, general hospital, or home?

In 2013-2014, our new regional paediatric palliative care team followed 12 children who presented with different oncological diseases (neuroblastoma, osteosarcoma, cerebral tumour, rhabdomyosarcoma). Because minors cannot write an "advance directive," we helped parents initiate advance care planning. All youth participated in the discussions.

**Results:** Since that time, all families have agreed to proceed with advance care planning. These children died where they wished, either in the hospital or at home nearby, so that any children and young adults who died in the oncology unit did so before the development of advance care planning.

During the presentation, we will describe how we gradually proposed advance care planning, and discuss four short scenarios to show our team's extreme flexibility to be as close as possible to their will.

We conclude that such care can more consistently and comprehensively provide appropriate end-of-life care for these patients and their families in keeping with their final preferences. Advance care planning helped parents and children to understand that professional caregivers will follow their wishes. Helped in this way, parents and children think about life each day rather than just wait for "the deadline".

**Abstract number:** PO169

**Abstract type:** Print Only

#### A Novel, Simple, Individualized Care Plan to Provide Excellent Care in the Last Days of Life: Successful Implementation of the Priorities for Care of the Dying Person for Hospital Inpatients

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Following the withdrawal of the Liverpool Care Pathway (LCP), the Leadership Alliance for Care of Dying People launched the National Priorities for Care of Dying People (PCDP) - five overarching principles to guide care in the terminal phase.

**Aims:** To develop a multidisciplinary individualised care-plan (ICP) for dying hospital inpatients that

1. incorporated the PCDPs including: ceilings of care, explicit plans regarding food & drink, symptom control & anticipatory prescribing, patient & carer involvement & communication
2. was simple & acceptable to all health care professionals (HCP) many of whom had distanced themselves from end of life care (EOLC) following the controversy around the LCP.

**Methods:** A focus group (Palliative Care & Care of the Elderly consultants, junior doctors & nurses) developed an ICP for dying patients, using

1. a single sheet proforma - Excellent Care in the Last Days of Life (used as part of each patient's medical notes)
2. usual observation chart
3. usual drug chart

Both charts were modified in line with plans set out in the Excellent Care proforma. After a two month pilot on two wards, the final version was launched hospital wide in April 2015. A retrospective case note review of inpatient deaths in May assessed the use of the ICP.

**Results:** 60 inpatients died in May 2015. 26/60 (43%) were cared for using the ICP. 55/60 (92%) casenotes were reviewed (Table 1).

PCDP based ICP improves the quality of EOLC for hospital inpatients, & is acceptable to HCPs.

**Table 1.**

Aspect of Care Plan	% Complete without ICP in place	% Complete with ICP in place
Explicit plan in notes re fluid	28	96
Explicit plan in notes re food	31	91
Drug chart rationalised	44	96
Anticipatory medications prescribed	58	96
Obs Chart modified	33	78
4hrly assessment pain, nausea, agitation and respiratory rate	31	78
Fluid offered 4hrly	28	96
Food offered 4hrly	31	91
Mouthcare given 4hrly	14	57

**Abstract number:** PO170

**Abstract type:** Print Only

### Measuring Geographical Accessibility to Palliative and End of Life Care Facilities: A Comparative Study in South London

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**Background:** Differing level of geographical accessibility to palliative and end of life care (PEoLC)-related services

may contribute to variation in place of death. Various measures for geographical accessibility have been proposed but not been compared in the context of PEoLC.

**Aim:** To compare different measures of geographical accessibility to PEoLC facilities in South London.

**Methods:** The following measures of geographical accessibility were calculated using ArcGIS® for individual death records in South London in 2012 (n=18,165). Location of usual residence and the nearest care home, hospital and hospice were used to derive the following distance measures:

- Straight line Euclidean distance to the nearest facility
- Manhattan distances to the nearest facility
- Buffer zones drawn around facilities at set distances; each death allocated a distance band
- Public Transport Accessibility Level score (PTALs)

These measures were visualised through geographical maps and compared using correlation analysis (Spearman's  $\rho$ ).

**Results:** Straight-line distances from usual residence to nearest facility range from 0-7860 metres (hospital), 0-3354m (care home) and 91-17,173m (hospice). Maps at borough level demonstrate similarities in patterns of geographical accessibility measures to care homes, hospitals and hospices. High correlations exist between, straight-line, Manhattan distances and distance bands to the nearest hospital ( $\rho=0.90-0.98$ ), care home ( $\rho=0.96-0.99$ ) and hospice ( $\rho=0.92-0.98$ ). PTALs was weakly and negatively correlated with straight-line distance measurements to nearest hospital, care home and hospice ( $\rho=-0.19$  to  $-0.16$ ).

**Conclusions:** Relatively simple and distance-based measures of geographical accessibility in South London are similar, suggesting the choice of these measures can be based on the ease of calculation. However, measures involving public transport information appears to represent different aspects of geographical accessibility, should be chosen on needs.

**Abstract number:** PO171

**Abstract type:** Print Only

### Excellent Care in the Last Days of Life, and Care and Respect in Death: A Step by Step Guide to Great End of Life Care (EOLC). Creation of a Multidisciplinary

**Table 1.**

SECTION	CLINICAL GUIDANCE	INFORMATION SUPPORT	ADMINISTRATIVE PROTOCOLS
<b>CARE FOR THE DYING PERSON</b>	How to create an Individualised Care Plan (ICP)* for Excellent Care at the End of Life, How to set up a syringe driver, Mini guidelines on symptom control	What to expect when someone is dying PIL, Tissue donation PIL, Chaplaincy Team contact details	How to complete ICP
<b>CARE AND RESPECT AFTER DEATH</b>	How to verify death, When to refer to a Coroner, Pictorial guide to undertaking Last Offices	Bereavement PIL, Chaplaincy team contact details	Mortuary Infection Control notification, Cancellation of future hospital appointments etc

\*inc recognition of dying, ceilings of care, explicit plans regarding food & drink, symptom control & anticipatory prescribing, patient & carer involvement & communication.

**Conclusion:** Following endorsement by Trust Medical and Nursing Directors, the guide was compiled into large, purple & white Resource Folders - clearly visible at each nursing station in each inpatient area. The front cover states the in & out of hours contact details for Specialist Palliative Care advice. It is the standard multidisciplinary

### Resource to Use in all Inpatient Settings in a Hospital Trust

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In a busy general hospital EOLC can be fragmented & of variable quality. Generic Healthcare Professionals need simple, accessible & practical advice regarding how to ensure best, comprehensive care.

**Aims:** To develop a step by step guide to giving best care from recognition that a patient is dying to transfer of a body to the mortuary. It would be the standard reference for all medical, nursing & administrative staff involved in any inpatient area: A&E, ward or ITU.

**Method:** A focus group (Palliative Care & Care of the Elderly (COTE) consultants, junior doctors, nurses, chaplaincy team & mortuary staff) reviewed recent national directives regarding gold standard care - One Chance To Get It Right<sup>1</sup>, Care After Death<sup>2</sup> and pre-existing Trust wide policies regarding EOLC & care after death. The group discussed the essential elements of care & guidance needed by staff until consensus was reached for each element to be included in the final resource.

**Results:** The essential building blocks to providing excellent care were agreed & distilled into Steps 1- 8 for Care of the Dying Person, and Steps 9 - 19 for Care and Respect After Death.

reference for care of all patients, & the focus of teaching on Trust Induction Training.

1. Leadership Alliance for Care of Dying People June 2014 PGR01509
2. Hospice UK April 2015

**Abstract number:** PO172

**Abstract type:** Print Only

### Autonomy in the Spotlight

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**Background:** The study was motivated by the researcher's experience as a nurse caring for people with terminal illness. An all-encompassing level of hospice inpatient care could diminish personal autonomy. A literature review revealed the significance of autonomy to those who were dying. There was no Irish and little international evidence exploring the concept.

**Aim:** The aim of the study was to explore and describe the effects on personal autonomy of admission to a specialist palliative care inpatient unit. Patients' expression of autonomy and evidence of its acknowledgement by the multidisciplinary team were both examined.

**Methodology:** Retrospective documentary analysis was utilised. The medical notes of six patients, all with cancer, were examined using a data extraction tool devised by the researcher. This tool was generated by the work of Vernooij-Dassen et al (2005) on patient autonomy in palliative care and a review of relevant literature. Directed content analysis of extracted data was guided by Lavoie et al's (2008) exploration of the dying person as an existential being.

**Findings:** Personal autonomy was expressed and experienced by all six patients. Five themes emerged. Autonomy was experienced by the existential 'Self' of the patients within four themes. These were 'Corporal Self', 'Becoming Self', 'Relational Self' and 'Free Self'. A fifth theme 'Empowering Care' emerged from the data reflecting the activities of the multidisciplinary team.

**Discussion:** The first four themes reflected how individuals expressed and maintained personal values within the boundaries of a hospice inpatient unit. The fifth theme reflected how the personal autonomy of the 'Self' was recognised, acknowledged and facilitated by the multidisciplinary team.

**Conclusion:** The significance and constituents of personal autonomy for patients receiving specialist palliative care were elucidated. Care ought to be multidimensional and fluctuate in line with the illness trajectory.

**Abstract number:** PO173

**Abstract type:** Print Only

### Everybody's Inevitable Circle of Life: Death Attitudes of Individuals Accompanying the Dying

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Professional health care workers and hospice volunteers are exposed to the experience of death and dying as they need to accompany patients through the dying process. The occupational confrontation with death demands examination of one's own meaning of death and the attitudes behind. At the same time this particular meaning seems to be distinguished by the lived experience of the death of others.

The review aims to bring out what death means to individuals who accompany dying persons and their family members until death and even after in a professional context.

Systematic Literature search in the databases Cinahl, Medline (Pubmed), PsycInfo and Psynex, including studies from 1970 to 2015. After a systematically thematic selection, all remaining studies were assessed methodologically. The articles were analysed thematically including a critical perspective to examine research gaps. All steps of literature selection and analysis were conducted by two reviewers, discussing different results in the research group to find a consensus.

Most of the 27 selected studies analysed the attitudes of professionals. Death is described in physiological, psychological and spiritual dimensions. These perspectives are important to integrate the lived experience one makes with the deaths of others into the own professional but also personal life. The perspectives vary through the emotional involvement of individuals who accompany dying persons. If there exists a close relationship, death could be distressing. Another aspect is the progress of illness and the suffering of the patient so that death is sometimes described as a salvation.

The review shows the meaning of death of the other for the remanent companion. It can have an impact on health professionals in their professional role and on the companions' private lives. Accepting death and one's own finiteness is often described as a requirement for their daily work and therefore a competence that needs institutional support.

**Abstract number:** PO174

**Abstract type:** Print Only

### Service Sculpting: A New Method for Hospice Service Evaluation

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**Background:** This collaborative (Hospice & University) project develops a tool to capture Hospice experiences

among users. Existing feedback left no room for improvement. Striving for excellence, the project reflects the Ambitions for Palliative and End of Life Care collaborations to find ways of delivering better care.

**Aim:** To develop a new technique that fully captures the Hospice experience and informs improvements to Hospice care.

**Methods:** Using Service Blueprinting (Bitner, 2007) as a starting point, we expanded this technique and designed a tool to capture every service element.

In-depth qualitative interviews with 38 in-patients, out-patients, visitors and bereaved families enabled a “deep-dive” to uncover perceptions of the whole service experience among these diverse users.

Interviews were recorded and transcribed.

**Results:** Thematic analysis of over 104,000 words of data revealed many excellent aspects of Hospice service. Staff frequently exceed people’s expectations. Striking comparisons to hospitals emerged. The Hospice makes people feel safe. Nevertheless, the new technique uncovered many areas for improvement, including serendipity of referrals processes, the need for better communications with external agencies, improvements amid the daunting arrival and admissions process, a desperate need for depression counselling among patients and carers, clarity of communication pertaining to actual end of life, and shortcomings in systems dealing with bereaved families.

**Conclusion:** The new service sculpting tool allows for every aspect of the service to be scrutinised from the user’s perspective. Unlike other tools, this in-depth examination reveals areas for improvement, many of which have already been implemented or form part of the Hospice’s planning process. The project’s success exceeded expectations and is to be repeated bi-annually. The new tool has potential to improve experiences of palliative and end of life care among patients and their families.

**Abstract number:** PO175

**Abstract type:** Print Only

**One Chance to Get it Right - Results from a Regional Quality Assurance for Care of the Dying Project, Using the Care of the Dying Evaluation (CODE™) Questionnaire for Bereaved Relatives**

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**Background:** Ensuring dying patients and their families receive high quality care and support wherever they die, is of paramount importance. Individual care planning, coordination of services (including symptom control), and sensitive and timely communication have been suggested to

promote improvements. Robust evaluation is required to assess the quality of care, one method being a survey of bereaved relatives: The CODE™ questionnaire was used in England in a recent national audit of care of the dying (NCDAH 2013/14) for this purpose.

**Aim:** Use CODE™ to assess the quality of care/support provided to people in the last days of life and their families in one region in England, in hospital, hospice and community settings.

**Method:** Participating organisations (7 hospitals, 7 hospices, 4 community settings) sent CODE™ questionnaires to bereaved relatives who met specific inclusion criteria, which was completed online or by hand.

**Results:** A total of 354 CODE™ questionnaires were included.

Key findings compare relatives’ perspectives in different care settings, including:

- Overall 63.5% relatives in the hospital setting would recommend the organisation compared to hospice 98.8%, community 96.0%
- Relatives from the hospital more likely to report ‘not at all’ that enough was done to control symptoms, particularly for ‘restlessness’ (15.2%) and ‘noisy rattle’ (18.3%)
- Overall a notable minority (17.1%) reported they were ‘not involved’ in discussions/decisions about the patients care - rising to 22.9% in the hospital
- 43/46 relatives who reported the patient did not die in the right place, were from the hospital setting

**Conclusion:** Variation exists across care settings, with perceptions in the hospital setting likely to be lower than in hospice or community, particularly for communication about the patient’s care (condition, treatment and place of care). Organisations were encouraged to create tailored action plans as part of ongoing quality improvement work to improve care provision.

**Abstract number:** PO176

**Abstract type:** Print Only

**The Role of Volunteers Working with People at the End of Life in their Own Homes**

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**Background:** Many organisations working with people at the end of life rely heavily on volunteers, who provide various roles in many different settings. It is important that volunteers practice in a safe and sustainable manner when in patients’ homes.

**Aims:** To ascertain current practice and use the literature to develop sustainable guidance that protects, strengthens and safeguards the roles of volunteers in patients' homes and the people with whom they work.

**Methods:**

- 1) information was requested from 14 British organisations, which work within end of life care regarding their work with volunteers,
- 2) a review of the literature using CINAHL, NICE and PubMed (Medline) was undertaken.

**Results:**

- 1) Eleven UK organisations, including hospices and national and local palliative care and end of life charities participated in telephone or email discussions. They utilised the services of volunteers in numerous ways; predominately within the organisation and rarely within the patient's home. The limited support provided in the home was carefully managed and volunteers were instructed that they were not allowed to undertake any manual handling or personal care. In these situations they sought support from employed colleagues.
- 2) Five studies met the inclusion criteria. These studies related to volunteers either based in specialist palliative care settings, including hospices (n=4) or with babies that are dying (n=1). They highlighted the roles volunteers typically undertake and the environments in which volunteering is undertaken.

**Conclusion:** Volunteers play an important role in providing supplementary support to palliative and end of life care providers. They are generally involved in day care and least commonly in home care. It is important that volunteers understand the boundaries of their remit and are supported to work within them, have regular supervision including time for reflective practice and have access to appropriate training.

**Funding:** Macmillan cancer support, UK.

**Abstract number:** PO177

**Abstract type:** Print Only

**Achieving Cost Effective Outcomes Based End of Life**

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**Background:** St Christopher's Hospice Care Home Project Team (CHPT) was established in 2008 after becoming a

Regional Training Centre for the Gold Standards Framework in Care Homes Programme (GSFCH). Commissioners across five Clinical Commissioning Groups (CCGs) were looking to support cost effective interventions through measurable outcomes including reduced hospital admissions. At the same time St Christopher's Hospice was seeking funding to help care home staff implement the programme through external facilitation. A system based approach offered the opportunity to achieve both objectives.

**Aims:** To establish a system that would fund facilitation in order to support and sustain the implementation of GSFCH programme.

**Method:** In 2009, the CHPT set up a cluster randomised controlled trial (CRCT) to determine how best to facilitate the GSFCH. Commissioners were interested and funded facilitator support for care home staff in return for data on the impact of the programme. Across all five CCGs, care home staff submitted data following the death of a resident.

**Results:** The percentage of residents dying in the nursing homes (NHs) increased from 57% (19 NHs) in 2008/09, to 79% (76 NHs) in 2014/15. Further data revealed an increase: in advance care plans (from 51% to 82%); last days of life documentation (from 25% to 49%); and, DNACPR documentation (from 52% to 87%).

**Meaning:** The CHPT has been funded through the same commissioning process for 8 years. From the trial we now know that on-going individual, organisational and systems based learning is essential to maintain cultural change. The role has expanded to incorporate a sustainability initiative, a clinical role and new audits.

**Conclusion:** Partnership working between practitioners, providers and commissioners offers a model to deliver cost effective appropriate outcome-based end-of-life care across systems. However, funding such initiatives in care homes is only worthwhile if a sustainability initiative is provided.

**Abstract number:** PO178

**Abstract type:** Print Only

**Achieving Symptom Control Not Medication Burden at the End of Life**

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**Background:** The population living in care homes in the UK is old, frail and has multi-morbidities. A consequence of living with multi-morbidities means that residents in care homes are prescribed multiple oral medications. Reviewing these throughout their admission is important.

**Aim:** To identify the prescribing practice for symptom control in the last month of life for residents dying in nursing homes.

**Method:** Thirty eight nursing homes implementing an end of life programme took part in a trial. In order to complete this programme the care home staff needed to evidence symptom control at the end of life. The data presented is from all items prescribed in the last month of life from all deceased residents' notes during the 2<sup>nd</sup> year of the GSFCH programme.

**Results:** The medical administration charts were available for 50% of the 638 residents who died in the nursing home during the data collection period. In the last month of life the mean number of oral medication prescribed for residents was 10 (range 0-27). The residents who died had been prescribed oral medication for symptom control in their last month of life. For example 84% of residents had been prescribed oral and/or transdermal analgesia.

In relation to recognising dying only 16% had all non-essential medication discontinued and 34% of residents were still prescribed antibiotics on the day of death. Only 37% residents had anticipatory PRN injectable medication prescribed.

**Meaning:** Symptom control at the end of life should incorporate a medication review. This was not the case for all residents within this study. It will only be achieved through care home staff and GPs working together. This should result in greater recognition of dying and the proactive planning of end of life care which must incorporate a medication review and anticipatory prescribing.

**Conclusion:** This study has highlighted medication burden in nursing homes and the inconsistent prescribing for symptom control at the end of life care.

**Abstract number:** PO179

**Abstract type:** Print Only

### Quality of Care during the Last Week of Older People's Lives in Swedish Nursing Homes. A Cross-sectional Retrospective Register-based Study

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**Table 1.** Symptom prevalence and relief.

Symptom	Prevalence (%)	Total symptom relief (%)
Pain	(66.0)	(81.4)
Respiratory tract secretion	(48.2)	(55.4)
Nausea	(10.1)	(50.2)
Anxiety	(34.3)	(70.3)
Shortness of breath	(14.1)	(46.2)
Confusion	(23.5)	(21.2)

**Study aim:** The aim was to examine the quality of care during the last week of life of older people who died in Swedish nursing homes.

**Methods:** The study used data from the Swedish palliative care register, of all registered individuals aged 60-95+, who died in nursing homes 2011-2012 (n=29,685). Variables related to symptoms, symptom relief, end-of-life-discussions and place of death preferences were explored with descriptive statistics.

**Results:** Most commonly deaths were caused by circulatory diseases (43.0%) and dementia (29.8%). The most prevalent symptom was pain whereas nausea was the least common (Table 1). Assessment of symptoms using a valid instrument was reported for pain in 14.2% of all cases and 9.1% for other symptoms. Of all individuals 90.0% had individual prescriptions for pain treatment, 76.9% for anxiety and 48.9% for nausea. End-of-life discussions were performed with 27.6% of the individuals, and with 63.1% of their relatives. The desired place of death was met for 54.5%.

**Conclusion:** More than half of all individuals had pain during their last week of life. However, pain seems to be a symptom for which the nursing homes have processes supporting a relatively positive outcome (i.e. symptom relief) compared to other symptoms, e.g. respiratory tract secretion and nausea. The majority of individuals died without having had an end of life discussion with health professionals. Whether or not this can be explained by communication difficulties, e.g. because of illness severity or being diagnosed with dementia remains to be further investigated.

**Funding:** Ersta Sköndal University College, Stockholm.

**Abstract number:** PO180

**Abstract type:** Print Only

### Communication Issues in the Palliative Care of Patients with End-stage Dementia - A Participatory Action Research Study

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Compassionate palliative care of high quality should be extended to all dying patients and not solely to cancer patients. Elderly patients suffering from end-stage dementia are especially vulnerable, as they have lost their ability to communicate their wishes for end-of-life care.

The purpose of this study is to gain a deeper understanding of the challenges in palliative care for the elderly, specifically in regards to elderly patients with dementia. The focus of the study is communication between doctors, nurses, family members, and patients. The aim is to develop and improve palliative care in a primary care bed ward for elderly patients.

The method used for the study is participatory action research. A group of experts were chosen for focus group interviews. The group consists of two RNs, one LPN, one doctor, two family members of dementia patients, and an expert in elderly care, crisis management, and grief therapy. The group members met in order to discuss specific challenges and create recommendations for how palliative care could be improved in the ward. Recommendations were implemented in the ward. After six months the result was evaluated and the focus group members reflected on the outcome in a second meeting. The data material consists of recordings from the two meetings. Recommendations were created on the municipal/district level as well.

The findings of the study show that information and communication is of utmost importance when striving to alleviate the suffering of dying dementia patients and their family members. A living will and advanced care planning (ACP) in the early phase of the disease will facilitate decision making for both family members and care personnel. The result implies that it is too late to start ACP when the patient has reached the end-stage of dementia and is admitted to the ward. Therefore, ACP needs to start early in the disease trajectory.

**Abstract number:** PO181

**Abstract type:** Print Only

**To Invest Time in Order to Save Time. Positive Aspects of PICC and Midline Adoption in Palliative Care: Results of a 4 Years Retrospective Observational Cross-sectional Study**

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**Introduction:** Peripherally Inserted Central Catheters (PICC) and Midline represent a consolidated alternative for fragile pts, but little is known on its use in palliative care. Ultrasound guidance and insertion at the pts' bed

limits pts' discomfort and is cost-effective. Nevertheless few information is available on pts' experience and on nurses opinion.

Aim of our 4 years retrospective observational study was to collect pros and cons of PICC/Midline management stemming from nurses experience and to describe pts' perceptions.

**Methods:** Pts' medical records of our Palliative Care Unit from Sept 2010 to Sept 2014 were retrospectively analyzed (192 devices/893 pts). Sex, age, KPS, PPI, Barthel Index, diagnosis, pts' opinion on PICC/Midline, average device duration, insertion procedure and device management complications were considered. Nurses compiled in Dec 2011 (n=8) and in April 2014 (n=6) an anonymous survey on pros and cons of the devices.

**Results:** Our population was mainly old (age 74.4±10.8, M 52.2%), with advanced cancer and reduced performance (KPS 27.4±9.7; PPI 6.3±2.5; Barthel Index 28.5±23.2; cancer diagnosis 82.3%). As to PICC/Midline, minor insertion complications were 23.4%, with no devices loss. 79.1% were removed due to pts' death, 8% due to erroneous management. Complications reduced through time while experience increased. In the first survey, training difficulties and time demanding for acquiring expertise were stressed by nurses, whereas in the second one management simplicity was emphasized. Devices were described as easing every day procedures and as aids saving time for usual care. Pts reported low anxiety and low distress during the insertion procedure and were overall satisfied with the device management.

**Conclusions:** PICC and Midline, even if requiring an initial demanding training, are often appreciated by nurses and pts in palliative care. To invest time and resources in training may help to save time to the team and suffering to the patients.

**Abstract number:** PO182

**Abstract type:** Print Only

**Survival after Out-of-Hospital CPR in Terminally and Chronically Ill Patients**

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**Background/aims:** There is good evidence both that patients (and staff) have unrealistic expectations about CPR survival, and that patients change their resuscitation preferences depending what outcomes they expect. A recent UK legal judgement suggests that consent should be as for a 'prudent patient'. To implement this approach for CPR we, ideally, need more pre-arrest and patient-specific information.

This study collates published evidence about patient-level prognostic factors for CPR survival. With the current

push for deaths at home, it concentrates on out-of-hospital cardiac arrests (OHCAs).

**Methods:** A literature review considered OHCA survival rates in terminally and chronically ill patients, with a special focus on high burden clinical conditions. The potential effects of patient age and functional status were also considered.

**Results:** Although there is relatively little published evidence, older, sicker and frailer patients have very low survival levels after CPR. OHCA survival is especially low for patients with advanced cancer, or advanced liver disease, or with dementia. Contradictory results for patients with multiple co-morbidities, or with other specific conditions, are partly explained by methodological issues. Importantly, the low CPR survival rates in the terminally and chronically ill are artificially inflated: resuscitation preferences change as clinical status worsens, and more of the sicker patients choose to avoid CPR.

**Conclusions:** Although the methodological issues make individual estimates impossible, patients and doctors need to know about the low survival rates following OHCA in patients with terminal and chronic illnesses. Discussions about resuscitation preferences may need to be revisited as patients get sicker, frailer and older. The forthcoming UK national approach considering decisions about CPR within overall goals of care and focusing on what treatments will be given rather than specifically on withholding CPR, may help here.

**Abstract number:** PO183

**Abstract type:** Print Only

### Changes in Place of Death of Patients who Die of Pelvic Cancers in England, a Population Based Study

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**Background:** Research says more than 70% of people would like to die at their residence. 28% of all deaths have an underlying cause of cancer (England, 2004 to 2013). Of all the cancer deaths, 18.6% of death is due to pelvic cancer. Pelvic (gynaecological, urological and colorectal) cancer accounts for 5% (n= 23,993) of all deaths in England. Patients who die of pelvic cancer have similar complications which may lead to multiple hospital admissions.

**Aim:** To find out what percentage of patients with pelvic cancer die in their preferred place of death and the changes made after implementation of end of life care strategy in 2008.

**Method:** A population based study using data extracted from Office of National Statistics (ONS) mortality database. The study is restricted to residents of England with

death registered from January 2004 to December 2013. Since the data is obtained in an anonymised format no individual patients can be traced back, hence ethical approval was not required. Two sided t test is used to determine difference in proportions.

**Data definition:** ONS data is coded using ICD version 10.

**Result:** The proportion of deaths from pelvic cancers (underlying) that occur in hospital has declined from 46% (2004) to 34% (2013); deaths occurring at home/care home have increased from 33% to 46%. Three quarters of studied deaths were more than 70 years of age. 71% of people who are resident of a care home died in a care home. Among those who lived at home about 26% died at home.

**Abstract number:** PO184

**Abstract type:** Print Only

### Defining Comfort: A Concept Analysis Research

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**Background:** Comfort is an important phenomenon to patients, relatives and healthcare practitioners. There is a need to clarify, to provide completeness and adequacy to the concept in order to provide indicators as an important outcome in quality of care and patients' well-being. Despite all the knowledge and research about comfort and comforting, it is still a very complex area, difficult to define, implement and evaluate, particularly in palliative care.

**Aim:** To provide a conceptually adequate definition of comfort.

**Methods:** Rodger's (2000) method of evolutionary concept analysis was used. A search with the terms comfort\* and concept, was conducted in electronic databases PubMed, EBSCO (all databases), SciELO, Bireme, PsycINFO, Cochrane Database of Systematic Reviews and JBI Library of Systematic Reviews. Portuguese, Spanish, French and English papers, published in peer-reviewed journals until December 31st 2014 were included.

**Results/discussion:** Forty studies were included. Antecedents include inward factors (imbalances, information, practitioner-client relationship, previous experiences) and outward factors (social support, skills/ beliefs of practitioners, institution's model of care, environment). Comfort is a desired state of satisfaction and happiness, expressed as a pleasant experience, as something positive/ good related to feeling strength and safe. It's a holistic experience related to satisfaction of needs and sensitive to individual's

perception and ability of adaptation. Comforting is a process which comprise consequences to both patients and carers (attributes). Quality of life, spirituality, suffering and happiness are related concepts. Pain relief and palliative/ supporting measures are surrogate terms.

**Conclusions:** The study provides a new proposal of a clear and evidence-based definition. Studies are needed to examine the use of this concept and to continue its refinement and effectiveness.

**Abstract number:** PO185

**Abstract type:** Print Only

### Do Not Wash your Dirty Linen in Public? Satisfaction Data and Quality of Volunteering in Hospice and Palliative Care

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**Aim:** Many aspects of volunteering have been discussed in literature, but not quality. No studies were found that address assessment methods for quality of volunteering in hospice and palliative care. This contribution presents data on satisfaction of hospice clients' family members. Step-wise we reflect on the value of such data to assess quality and share a (conceptual) search of how quality of volunteering in care focused roles in palliative care can be measured better.

**Methods/results:** Satisfaction data were gathered by VPTZ Nederland (national organisation). The inventory exists of 32 questions on 8 scales: information, communication, autonomy, competence, medical care, emotional and spiritual care, organisation. A pilot with this list resulted in 165 questionnaires, filled in by surviving relatives, found through 13 hospice organisations. Data show extreme satisfaction on psychosocial and spiritual care, privacy and communication. Medical care was scored a little lower.

**Reflection:** We reflect on the usability of satisfaction data to evaluate quality of volunteering in palliative care. To come to a specific set of instruments and a strategy for monitoring quality of volunteer contributions in hospice and palliative care, we continued with:

- a) literature research, performed to choose a theoretical perspective to grasp the essence of volunteering conceptually,
- b) development of a vision document with a clear operationalisation of quality of volunteering,
- c) feedback meetings in five different geographic areas of the Netherlands with audiences consisting of hospice coordinators and board members,

- d) feedback meetings with stakeholders like e.g. insurance companies, policy agents, patient organisations and professionals and their organisations,
- e) identification of criteria that evaluate volunteering and
- f) choosing instruments that measure and monitor quality in hospice and palliative care volunteering.

Funding comes from Stichting Roparun, The Netherlands.

**Abstract number:** PO186

**Abstract type:** Print Only

### “Palliative Sedation”? Use of Continuous Sedatives within the Last Seven Days of Life on a German Palliative Care Unit

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**Background:** Although guidelines for palliative sedation (PS) exist, it is still controversial when to call the use of sedatives “PS”. The lack of a common definition has been suggested as one of the reasons for the wide range of reported PS prevalence.

**Aims:** To describe frequency, indications, duration and dose of continuous sedatives (benzodiazepines, levomepromazin, haloperidol, propofol; given continuously or intermittently according to duration of action) and the use of the term “PS” in the last 7 days of life on a palliative care unit (PCU).

**Methods:** Retrospective analysis of medical records of patients who died on a German PCU between 8/2014 and 7/2015. Descriptive statistics with SPSS 23.

**Results:** 152/192 patients (79%) received continuous sedatives within the last 7 days of life. Midazolam (n=145/95%) was most frequently used, followed by haloperidol (n=25/16%) and levomepromazin (n=4/3%). For 21 patients (14%), the therapy was called “sedation”, for n=2 (1%) the term “PS” was documented.

Most frequent indications for continuous sedatives were agitation (n=51/34%) and anxiety (n=40/26%), median duration of use was 2.3 days (range 0.5 hours-16.2 days). For 85 patients (56%), continuous sedatives were started in the last 72 hours of life. Median midazolam doses increased towards death: The median total dose on the day of death was 14 (range 2-240) mg.

The maximum total daily midazolam doses of the 2 patients whose therapy was called “PS” were 135 and 58 mg. 11 other patients also had maximum total daily midazolam doses over 50 mg, for 3 of those the term “sedation” was documented. Depth of sedation was not consistently documented.

**Conclusions:** Most patients received continuous sedatives, mainly midazolam, within the last 7 days of life, with increasing doses towards death. Only for few patients this therapy was called “sedation” or “PS”. Qualitative studies may be helpful to explore the reasons for labelling comparable sedative actions with different terms.

**Abstract number:** PO187

**Abstract type:** Print Only

### Review of Specialist Palliative Care Referrals in the Intensive Care Unit

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**Introduction:** The Intensive Care Unit (I.C.U. ) is typically seen as an intensive lifesaving area, however 20% of all hospital deaths occur in the I.C.U.(Holcomb et al, 2004). International literature highlights concerns regarding the quality of palliative care that people in the I.C.U. receive. (Grossman,2013,Zomorodi,2010,Edghill,2009).

**Aim:** To review the role of the hospital Specialist Palliative Care Team in optimisation of symptom management and end of life care in the ICU setting.

**Methods:** A retrospective review of referrals to the palliative care service in 2012, with extraction of data pertaining to symptom control, palliative input and outcomes. Outcomes included time from referral to death and documentation of ultimate place of death.

**Results:** 160 patients were discharged from ICU in 2012. 116 people died in ICU in 2012. There were 33 referrals to the Palliative Care Service. All patients were seen on day of referral. 14 patients had a cancer diagnosis. The main reasons for referral were symptom control at end of life (14 patients); to facilitate transition of care out of ICU (7 patients); Pain management (8 patients); Symptom management (4 patients). 10 patients died in ICU; 16 patients were transferred to wards for end of life care and 1 patient was discharged home for end of life care.

**Conclusion:** The Specialist Palliative Care team have a valuable role to play in the ICU setting for relief of distressing symptoms, effective communication about goals of care and patient and family focused care and planning for transition to other settings. There are both positives and negatives to the ICU setting. The positives are one to one nursing, good communication, high level of medical input. The negatives are inability of patients to participate in EOL care, unrealistic expectations, difficult for family to participate in care, ethical issues, lack of privacy, intrusive technology, staffing patterns, education, skills and attitude of professionals.

**Abstract number:** PO188

**Abstract type:** Print Only

### Cognition and Existential Suffering in Patients with Advanced Cancer

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**Background:** Cognitive dysfunction is frequent among advanced cancer patients and can influence decision taking and self-perception, causing existential concerns.

**Aims:** To explore associations between cognitive dysfunction and existential concerns among patients with advanced cancer.

**Methods:** Out-patients with advanced cancer in palliative treatment were assessed from February 2013 to July 2015. Assessment was composed by objective and subjective measures. Objective assessment was performed using Continuous Reaction Time test (CRT) and Trail Making Test B (TMTB), which assess sustained attention and executive function respectively. Subjective assessment consisted of in-depth qualitative interview data 3 days after the tests and after 3 months. The semi-structured interviews covered personal background, experiences of cognitive dysfunction, existential needs and challenges encountered. A comparative thematic analysis was conducted to explore the nature of existential concerns and how cognitive dysfunction is related to existential suffering.

**Results:** 13 patients (11 female, mean age 58, mean years of school years 12,46% breast cancer, Karnofsky performance status mean 75,4%). Poor cognitive performance was observed in 12 patients (3 on CRT, 5 on TMTB, and 4 on both tests). Associations between the two measures showed that patients with poor attention struggled with maintaining previous activities, including work and leisure activities, which inflicted on self-perception and how to interact with significant others. Patients with poor executive function expressed difficulties with many impressions or demands. When involving significant others, this caused a rearrangement of their social life.

**Conclusion:** Associations between cognitive dysfunction and daily life interference were observed in almost all patients. The existential concerns stemming from these dysfunctions would turn into existential suffering, if no effective meaning-making strategies were established.

**Abstract number:** PO189

**Abstract type:** Print Only

### Parenteral Nutrition for Patients at the Palliative Phase of Advanced Cancer: What Are the Patients' Motivations to Accept or Refuse it?

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**Aims:** Eating is not just a biological need, it is also a symbolic activity. In end of life, the introduction of the Parenteral Nutrition (PN) in patients with advanced phase of cancer, malnourished is a recurring issue. The acceptance of the PN at this stage of the disease seem less guided by practical scientifically than justified by subjective reasons. Why a patient will accept or reject PN? Conducting randomized trials in end of life situations is challenging and qualitative approaches are necessary to understand better the patients' point of view.

**Method:** This qualitative study is ancillary to the "ALIM K"[1] trial (effectiveness of PN on quality of life). Data were collected through semi-structured interviews, in 12 French centers with patients who accept or reject PN and their relatives. For data analysis, we use the concepts of saturation method[2].

**Results:** Patients associate eating by mouth to a "normal function" that gives it a characteristic of "normal person". The PN will be perceived as a foreign element in the body causing a real anxiety. In addition, the acceptance or rejection of the PN often depends on the presence or absence of a relative: Most of patients who accepting PN have not relatives present in the care. The skin will then become a place of intersubjective meeting between the patient and the doctor.

**Conclusion:** Our results help to understand the acceptance or refusal reasons of PN of patients in order to ameliorate the communication around alimentation. Mealtimes stay for most patients and their relatives a special moment with each other that gives meaning to life.

Financed by PHRC 2011 from French Ministry of Health

- [1] Pazart, L., Cretin, E., Grodard, ... & Aubry, R. (2014). Parenteral nutrition at the palliative phase of advanced cancer: the ALIM-K study protocol for a randomized controlled trial. *Trials*, 15(1), 370.
- [2] Paillé, P., & Mucchielli, A. (2012). *L'analyse qualitative en sciences humaines et sociales*.

**Abstract number:** PO190  
**Abstract type:** Print Only

### Preliminary Evaluation of Nurses' Attitudes towards Death and Caring for Dying Patients

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**Background:** The quality of care provided by oncology nurses can be influenced by their attitude toward death and caring for dying patient. Until today we didn't have any information about these attitudes among nurses at our institution. This information can help us to plan and evaluate interventions, which could improve nurse's attitudes toward caring for dying patients.

**Methods:** We distributed 171 Frommelt Attitude Toward Care of the Dying Patient (FATCOD) and Death Attitude Profile Revised (DAP-R) questionnaires to nurses. In our preliminary evaluation we analysed some basic characteristics of participants and their attitudes towards caring for dying patients.

**Results:** We received 123 (70,3%) completed questionnaires. Eighty nine percent of participants were female, 82% had 6 or more years of working experiences, 19% more than 31 years. Frequency of caring for dying patients was 12% never, 13% annually, 27% monthly, 23% weekly, 24% daily. Forty two percent of nurses had some previous education in palliative care (PC).

Among the participants 58% felt nurses were capable of helping patients prepare for death, 33% were uncertain. If possible, 21% would prefer not to be assigned to care of a dying patient, 60% didn't have major concerns about that, 18% were uncertain. Thirty percent of nurses felt uncomfortable talking about impending death with a dying patient, 23% were uncertain, 46% did not have reservations. If a patient would ask »Nurse, am I dying?«, 21% believed redirection of the conversation was the right way to react. Eighty three percent felt caring for a dying patient was a worthwhile learning experience.

**Conclusion:** More than half of the participating nurses didn't have any PC education although most of them care for the dying patients. Probably that is the reason, why many of them feel uncertain being next to and talk to a dying patient.

We still need to complete further statistical analysis to discover possible correlation.

**Abstract number:** PO191  
**Abstract type:** Print Only

### Introducing a Physician Led Advance Care Planning Model into an Acute Care Clinical Environment

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**Background:** Implementation of a physician led Advance Care Planning (ACP) model into the acute care clinical environment commenced in 2014.

**Method:** An integral component of the project was the role of a Clinical Nurse Consultant (CNC) experienced in the implementation of an ACP program. The CNC attended post take ward rounds with two of the five attending physicians (intervention). The three remaining physicians continued to provide routine care (control group). The post take ward rounds were viewed as the ideal mechanism for identifying patients that would benefit from ACP conversations. The ACP physicians introduced the ACP concepts: the benefits of the ACP program to patients and families; linking this discussion to the patients current health status and the perceived health concerns for the future. The CNC receiving the referrals then continued the ACP processes by establishing a meaningful and sensitive relationship with the patient/families and facilitated a discussion on the patients values, life preferences and future health decisions including end of life (EOL) care choices.

**Results:** In total 713 consultations were conducted by the ACP CNC and 478 ACP documents were completed (Statement of Choices or Advance Health Directive and Enduring Power of Attorney documentation). The original project plan was abandoned due to the numerous requests by patients and physicians of the control group to also have ACP discussions and documents completed.

**Conclusions:** This pilot physician led ACP project has been found to be successful in introducing ACP within an acute medical environment and has now been introduced to 6 other hospitals within the Metro South Health Service.

**Abstract number:** PO192

**Abstract type:** Print Only

### First-year Nursing Students Attitude toward Care of Dying Patients - A Swedish Multicentre Study

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**Aim:** To describe Swedish first year undergraduate nursing students' attitudes toward care of dying patients. Possible affecting factors were investigated.

**Methods:** The Frommelt Attitude Toward Care of the Dying Scale (FATCOD) was used in six Universities. Descriptive statistics and regression analysis were used.

**Results:** 371 students (67.3%) reported overall positive attitude toward caring for dying patients (total mean FATCOD 119.5, SD 10.6) early in their first semester. Factors as age, earlier care experience and earlier education had impact and also, experience of meeting a dying person.

**Conclusion:** Nursing educators have to be aware of the impact that age, earlier care experience and education, experiences of meeting a dying person have on student's attitude toward care of the dying patients.

**Abstract number:** PO193

**Abstract type:** Print Only

### Intensified Symptom Management at the End of Life in Belgium: Trends in Medication Use

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**Background:** Palliative treatment has evolved over the years with regard to clinical guidelines and practice. We wanted to explore trends in medication use for intensified end-of-life symptom management in Belgium from 1998 to 2013 in relation to age, setting, and diagnosis.

**Methods:** A retrospective questionnaire survey of physicians certifying a large representative sample of Flemish death certificates in 1998, 2001, 2007 and 2013. We selected cases of symptom management intensified to the point that life-shortening effects had been taken into account. Medications were categorized into opioids, benzodiazepines, antipsychotics, anti-emetics, and others using the Anatomical Therapeutic Chemical classification.

**Results:** Response rates ranged from 49% (1998) to 61% (2013). Patients with intensified management accounted for 23.4%, 26.7%, 32.8% and 30.5% of all deaths in 1998 (n=450), 2001 (n=787), 2007 (n=1189), and 2013 (n=1144), respectively. Opioids remained the predominant medication class (used in more than 90% of cases), but was consistently less often the medication used in those 80 or older, with dementia and dying in the nursing home setting. Between 1998 and 2013, there was a significant increase of benzodiazepine use (11.9% to 32.4%,  $p < 0.001$ ), with the highest increase in deaths from cancer (12.5% to 43.7%,  $p < 0.001$ ). Also, the use of anesthetics increased significantly ( $p < 0.001$ ) from 0% in 1998 to 4.8% in 2013, with the highest increase in the hospital setting (0% to 7.1%,  $p < 0.001$ ).

**Conclusions:** Intensified symptom management at the end-of-life remains predominantly practiced through opioids with consistently high use over time. The increased

use of benzodiazepines and anesthetics probably reflects increased palliative sedation practices.

**Abstract number:** PO194

**Abstract type:** Print Only

### **Snoezelen Wards as a Therapeutic Alternative in the Treatment of Anxiety in Patients Palliative**

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**Background:** Snoezelen wards was born with the aim of creating physical spaces where you can work your way through sensations that are accessed from the sensory organs: ears, eyes, nose, mouth, skin. These spaces contain tools for visual, olfactory, auditory, vestibular and proprioceptive stimulation.

**Aim:** Analyze and evaluate the Snoezelen room as a therapeutic alternative to psycho-emotional disturbances and their application in palliative patients.

**Methods:** Literature review on electronic databases: CINAHL, Cochrane Library, CUIDEN, IBECs, MEDLINE, EMBASE.

**Result:** Lovarini study (2005) shows that palliative care patients with high levels of anxiety, after passing through the Snoezelen Room, experienced positive experiences and improve their level of well-being. No negative experiences are evident in relation to the levels of anxiety, being shown that Snoezelen sessions contribute to improving the welfare of the person, not having to resort to drug treatments to control the level of anxiety. From this publication various hospices in the UK were interested in the Snoezelen space.

According Cid (2010), the experience seems Snoezelen “chemistry decrease stress and increase relaxation chemistry”.

Moreover, the data provided by Codorniu et al. (2011) conclude that continuous technological and experienced scientists in the field of health advances have driven professionals to provide palliative care and alternative treatments as Snoezelen and evaluating their results according to criteria of efficacy, effectiveness, efficiency and satisfaction.

**Conclusions:** There are empirical evidence, through various publications of the effectiveness of the intervention, although some work groups lack of control does not allow definitive conclusions; therefore, it is necessary to continue scientific research to substantiate the Snoezelen effect.

**Abstract number:** PO195

**Abstract type:** Print Only

### **Bereaved Relatives - Their Experience of End of Life Care in Two Academic Adult Hospitals**

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Our two hospitals have over the past five years invested in programmes aimed at improving the quality of end of life care (EOLC). In collaboration our sites have undertaken research to

- 1) establish how we are meeting the needs of dying patients from the perspectives of relatives, and
- 2) test the feasibility of utilising post bereavement surveys in acute hospitals in Ireland.

This paper presents the qualitative data of the mixed methods study for both sites combined. Survey tool and methodology of VOICES<sup>1</sup>, established in the UK, was adapted for this study.

This post-bereavement study gathered data retrospectively from bereaved relatives between June - August 2015. A total of 860 deaths occurred in the period. 781 questionnaires were distributed to bereaved relatives 3-9 months after death of their relative with an information pack. Reminder letters were distributed 2 and 4 weeks later. A helpline was provided in each site during the data collection period. 356 questionnaires were returned giving an overall response rate of 45.6%. Qualitative survey component consisted of three open questions. Qualitative content data analysis was supported by NVivo, providing rigorous tools for coding, cross sectional analysis and structured and systematic presentation of the findings in themes.

Large amount of qualitative data was generated in both sites. Respondents appeared to welcome the opportunity to provide their perspective on care received. The main themes identified by the respondents range from gratitude, competent and compassionate care, communication enablers and barriers and systems failures.

The qualitative data confirms the need to further invest in end of life care in acute hospitals in Ireland. Asking

bereaved people for subjective descriptors of their experience of end of life care allows for powerful first hand statements and is a first step towards meaningful service user involvement. Findings will inform our hospitals' future EOLC quality improvement programmes.

**Abstract number:** PO196

**Abstract type:** Print Only

### Changing Trends in Medical Interventional Practices over a 17-year Period in a Hospice-based Specialist Palliative Care Unit (SPCU) in Ireland

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**Background:** Literature data suggests a temporal trend of increasing therapeutic interventions in patients with advanced cancer. Palliative and hospice care is associated with fewer interventions and prioritizing quality of life. A previous study in our hospice-based SPCU demonstrated substantive increases in laboratory and radiological investigations and therapeutic interventions from 1997 to 2007. **Aim:** To compare the prevalence, number and type of investigations and therapeutic interventions delivered to patients in our SPCU in 2007 and 2014.

**Methods:** Retrospective cohort data extracted from unified healthcare records of the first SPCU admission of all patients with a cancer diagnosis in the years 1997, 2007 and 2014. Data included demographics, frequency of laboratory tests, radiological imaging, electrocardiograms, out of hospice transfers for specialist consultations or investigations, and therapeutic interventions: cytotoxic or targeted chemotherapy, palliative radiotherapy, antibiotics, platelet or red cell transfusions, antifungals, antivirals and bisphosphonates. Descriptive data analysis using SPSS examined patient demographics and quantified and compared the frequency of investigations and interventions during the respective time periods.

**Results:** Chart data was available for 343 and 444 first admissions with a cancer diagnosis to the SPCU in 2007 and 2014, respectively. Preliminary results indicate that despite an increase in the prevalence of chemotherapy use from 1.2% to 7.6% between 1997 and 2007, this trend reversed to a prevalence of 3.4% in 2014. These data will be adjusted for length of stay, and the frequency of investigations will in turn be adjusted for length of stay and use of chemotherapy. There were no data available regarding a valid quality of life measure in these time periods.

**Conclusion:** The implication of these findings on SPCU service planning, delivery and on patient and family outcomes and experiences requires further research.

**Abstract number:** PO197

**Abstract type:** Print Only

### Short Terminal Admissions to a Specialist Palliative Care Inpatient Unit: A Retrospective Chart Review

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**Background/aims:** Specialist Palliative Care (SPC) inpatient admissions are associated with improved symptom control, psychological well-being and reduction of carer distress. To fully benefit from the multidisciplinary team input, early patient admission is advisable. Many patients however, are admitted in the last days of their lives. Late admissions can be a crisis in some situations or desirable in others. The aim was to examine the referral process and ascertain characteristics of patients who die within 48 hours of admission.

**Methods:** A retrospective chart review was conducted for all patients who died within 48 hours of admission at a 36-bedded SPC inpatient unit over a 2-year period. Demographic data, clinical information, reason for admission and preferred place of care were obtained.

**Results:** Of 1133 patients admitted during this period, 720 (63.5%) were terminal admissions with a mean length of stay of 21 days and median of 13 days. Fifty-six patients (7.7%) died within 48 hours of admission. Fifty-one patients (91%) had a malignant diagnosis with lung cancer being the most common. Terminal care was the reason for admission in 64% (36/56) of the patients.

Admission occurred within 1 day of referral in 95% of the patients. The preferred place of death was at home for 13 patients (23%), inpatient hospice for 7 patients (13%) and unknown/undocumented in the remainder (36 patients, 64%). Review of patients' charts however found that evidence of caregiver desire for hospice inpatient admission in the majority of cases (49 patients, 88%).

**Conclusion:** This review illustrates that the majority of patients in this group had advanced malignancies, poor performance status and were unwell at the time of admission. Most admissions occurred within 1 day of referral and although patients' preferred place of death was unknown or undocumented in almost two-thirds, there was evidence of care-giver desire for admission in most cases.

**Abstract number:** PO198

**Abstract type:** Print Only

### To Determine the Frequency and Nature of Benzodiazepine Prescribing in a Community Palliative Care Setting

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**Introduction:** Prescribing medications to alleviate distressing symptoms is a core aspect of palliative care. Benzodiazepines are a class of drugs extensively used in palliative care but few studies have attempted to study their use.

**Statement of aims/research questions:** To determine the frequency and nature of benzodiazepine prescribing in a community palliative care setting.

**Presentation of methods:** A retrospective review of all patients who were referred to the community palliative

care service over a 6 month period in 2014 was studied. The indication for use of benzodiazepines, choice of benzodiazepines, starting doses and dose titration and route were also recorded.

**Results:** 70 patients' notes were identified. 51% were on either a benzodiazepine or other psychotropic drug on referral to the palliative care team in the community. A further 22% were prescribed benzodiazepines. Age was not a strong indicator of starting a benzodiazepine. 33 patients were prescribed benzodiazepines in a continuous subcutaneous infusion (CSCI). Most of these were started between 24 hours and 3 days before they died for symptoms of end of life agitation or restlessness. No adverse effects were noted.

**Conclusion:** A high number of patients referred to the specialist palliative care service were prescribed benzodiazepines towards end of life. These drugs were well tolerated with no documented adverse effects. Use of benzodiazepines in palliative care merits further studies.

**Table 1.**

Name	Number of patients	Initial dose	Route of delivery	Average End Dose
Lorazepam	2	0.5-1mg bd/prn	PO	1mg
Alprazolam	5	0.25-0.5mg	PO	0.5mgs
Diazepam	3	2mgs bd/prn	PO	2mg
Nitrazepam	1	5mg nocte	PO	7.5mg
Temazepam	4	10mgs nocte	PO	10mgs
Zopiclone	11	3.75mgs nocte	PO	7.5mgs
Midazolam	38	2.5mg	TB/SC/CSCI	13.5mgs

**Table 2.**

Indication for use	Malignant Male	Non-Malignant Male	Malignant Female	Non-malignant Female
End of life agitation/ restlessness	9 (average age 65)	6 (average age 88)	15 (average age 70)	8 (average age 84)
SOB	2 (average age 65)	0	5 (average age 68)	1 (average age 70)
Seizure	1 (age 35)	1 (age 95)	2 (average age 63)	1 (age 91)
Other	1	1		

**Abstract number:** PO199

**Abstract type:** Print Only

### Descriptive Study of the Use Palliative Sedation at End of Life in a Palliative Care Unit

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**Aim:** The aim of this study was to describe the use of Palliative Sedation (PS), its indications and the differential characteristics between this patients who need PS and other patients followed up till death in a Palliative Care Unit.

**Methods:** This retrospective study reviewed clinical records of all patients followed up till death in a Palliative Care Unit from January to April 2014. Demographic and clinical data, prevalence, indications of PS and medications used were collected.

**Statistical Analysis:** Descriptive statistics for patient characteristics and non-parametric tests for group comparisons.

**Results:** A total of 125 patients died during the period studied and were included. The median age was 78 (P25:65,5-P75:85) years, and 68 (54%) were male, median length of stay was 14 (5-25) days, 84% were advanced cancer patients, and most common tumor was gastrointestinal 40 (32%). PS was used in 43 (34%) patients, the most common indications were delirium 25 cases (58%) and dyspnea in 13 (30%) patients. Midazolam was used in 37 (86%) PS, with a median daily final dose 36 (24-72) mg and levomepromazine in 6 (14%) PS. Length of sedation was 22,4 (10,7-36,5) hours. Patients with liver disease needed PS more often ( $p=0,03$ ). There were no other differences between patients that needed and not needed PS. Main indication were different between men and women, in women was delirium in 13 (81%) cases and in men was delirium 12 (50%) and dyspnea 11(45%), ( $p=0,08$ ). In cancer patients main indication was delirium 23 (72%) and dyspnea was the most common in non cancer patients 6 (75%) ( $p=0,16$ ).

**Conclusions:** PS was required in 34%. Patients with liver disease needed PS more often. Delirium and dyspnea were the most common indications. There were differences in most common indications between men (delirium and dyspnea) and women (delirium). Delirium was main indication in cancer patients and dyspnea in noncancer patients.

## Epidemiology and public health

**Abstract number:** PO200

**Abstract type:** Print Only

### Dementia Prevalence and Organization of Dementia Care in Disability Care Homes in Switzerland

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**Background:** With higher life expectancy an increasing number of people with intellectual disability (PWID) are at risk for developing dementia.

**Objective:** Since PWID are an often neglected patient population, the objective of this study was to investigate the prevalence of dementia in residential disability homes in Switzerland and to describe how residential homes organise dementia care.

**Methods:** All residential homes for adults with disabilities in Switzerland (N = 437) were invited to participate in a cross-sectional survey. A subset of questions covered the number of residents with diagnosed and suspected dementia and the organisation of dementia care. The response rate to the dementia-related questions was 32% (n = 140 care homes with 10403 residents).

**Results:** In residential homes specialised in PWID, 5.8% of the residents were reported to have a diagnosed or suspected dementia. In 140 deaths of PWID, 26% (n = 37) died with a diagnosed or suspected dementia. Residential homes for PWID mostly rely on internal resources (67.7%), general practitioners (61.3%) or psychiatrists (45.2%) for the care of residents with dementia, while specialised dementia nurses are rarely involved (16.1%).

**Conclusion:** This is the first study in Switzerland to assess the prevalence of dementia in PWID. The study indicates a diagnostic gap. Dementia care is provided in a heterogeneous way across Swiss residential homes for people with disability. Since the number of PWID requiring such care will likely increase in the future, best practice examples and guidelines are needed.

**Abstract number:** PO201

**Abstract type:** Print Only

### How Many People Need Palliative Care at the End of Life? A Nationwide Study Comparing Four Population-based Methods in France

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**Aims:** This study aimed to estimate the proportion of decedents who need palliative care across the different care settings in France by comparing four existing population-based methods, and to investigate the different illness trajectories at the end of life.

**Methods:** Death certificate data for all adults ( $\geq 18$ ) who died in France in 2008 were extracted. The underlying cause of death was used to apply four different estimation methods on the study population (n=536,158).

**Results:** Overall, depending on the estimation method used, between 40.7% (n=218,065) and 69.2% (n=371,231) of all decedents died from diseases that indicate a need for palliative care at the end of life. These percentages were higher for deaths in hospital (46.3-73.3%) than for those occurring at home (33.6-63.6%) or in a nursing home (35.9-71.6%). Among the people in need for palliative care, 48.2% followed a trajectory characterized by a short period of rapid functional decline (typically cancer), 39.8% followed a trajectory of long-term limitations punctuated by episodic acute exacerbation of their underlying chronic conditions (organ failure) and 12% followed a trajectory of frailty and prolonged dwindling typical of older people with dementia.

**Conclusion:** The proportion of people in need of palliative care, whether measured by the most conservative or

extensive estimating methods, is far from negligible and calls for appropriate health care system responses to address those needs: not only specialist palliative care services, but also programs and interventions to ensure the proper training and support of regular health care providers in the community, nursing home and hospital settings.

**Abstract number:** PO202

**Abstract type:** Print Only

**‘Death by Chocolate’: Engaging the Public in Discussion about End of Life through Community Café Conversation**

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**Background:** Illness, death and bereavement are difficult issues for most people to think about and discuss. A public health approach to palliative care advocates that specialist palliative care services adopt a whole population, participatory community based approach - working with people ‘upstream’ before they encounter illness or loss. This paper reflects on the adaptation of the World Café concept to engage people in Compassionate Communities Café Conversation (CCCC).

**Aim:** The overarching aim of the CCCC, was to create a safe, shared space to enable participants understand the importance of thinking and talking about death, loss and care. The specific objectives were:

- (1) to promote awareness and understanding of the Compassionate Communities Project;
- (2) to promote awareness and understanding of the importance of these issues;
- (3) to introduce the ‘language’ for conversations;
- (4) to share resources to help people engage in difficult conversations and advance planning;
- (5) to evaluate the impact and process.

**Methods:** The seven design principles of the World Café are central to the process of CCCC, together with the sharing of resources. Participants (n=74) were invited to complete pre and post-session questionnaires, designed to evaluate the impact of the CCCC.

**Results:** The response rate was 69%. Respondents were typically female (84%), mean age 56 years (SD = 12.6). The approach enabled people to share their wisdom, worries, and wishes over tea and cake. All participants would recommend the CCCC to a friend. A series of paired

samples t-tests indicated statistically significant post-Café improvements on all key domains of interest, with the exception of participants’ self-rating of difficulty discussing the issues of death, dying, loss, and care. One participant felt that they required follow-up support.

**Conclusion:** Our experience suggests that CCCC offers a potentially useful framework for inclusion in a health promoting palliative care toolkit.

**Abstract number:** PO203

**Abstract type:** Print Only

**Exploring the Impact of a New Public Health Approach to End-of-Life Care**

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**Background:** A new public health approach (NPHA) engages communities alongside professionals to meet the needs of those facing life-limiting illness and bereavement. It is increasingly recognized as complementing a clinical and health services approach to end-of-life care (EoLC) and interest in this approach is developing from funders, policy makers, researchers and practitioners.

**Aim:** To understand the range and nature of impacts from a NPHA to end-of-life care.

Study population - participants in a public health project led by a hospice in east London.

**Methods:** A mixed methods case study approach utilizing semi structured interviews, participant observation and documentary analysis. Interviews were recorded and transcribed verbatim and contemporaneous field notes were taken for participant observation of a range of events such as volunteer training and home visits. Documentary analysis included, for example, marketing materials and records of volunteer service. Ethical approval was granted.

**Analysis:** Modified Grounded Theory (Charmaz 2014) was used to analyse qualitative data and descriptive statistics used for quantitative data.

**Results:** Data collected from 10 interviews, 11 events and a 19 documents suggest themes including the legitimization of caring for volunteers in the community, the meaning and value of community, and the unique contribution of this role for recipients. Data also suggests this approach addresses social isolation for both volunteer and those who are sick, facilitates referrals to the hospice from previously hard to reach groups and develops links between local services.

**Conclusion:** This is the first study to explore and confirm the detail of the impact of a NPHA. It suggests that it could serve as a valuable approach in addressing social needs of people who are coming to the end of life- specifically

social isolation in a context characterized by increasingly limited health and social care resources.

**Abstract number:** PO204

**Abstract type:** Print Only

### Point Prevalence Survey on Infections and Antimicrobial Use in Irish Specialist Palliative Care Inpatient Units

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**Research aims:** To collect baseline data on the prevalence of infection and antimicrobial use in Specialist Palliative Care inpatient units in Ireland.

**Background:** Infection is among the leading causes of death in palliative care. Reasons include increased susceptibility a myriad of co-morbid conditions, suppressed immune and general functional decline

**Study population:** Five Irish SPC inpatient units representing 83% SPC inpatient beds.

**Methodology:** The study was designed as a national point prevalence survey based on the same methodology as the HALT PPS. Collection tools used, a ward list, a patient questionnaire and a facility questionnaire.

**Statistical analysis:** Data was analysed using SPSS Version 20 and Stata Ver. 9.2. The prevalence of infection, and antimicrobial use were calculated with 95% confidence intervals (CI). Univariate analysis using Fisher's exact test were conducted for categorical risk factors and statistical significance set as a level of 5% ( $P < 0.05$ ).

**Results & interpretation:** Respiratory tract infections 6.1%, oral candida, 4.4%, urinary tract infections, 3.5%. Total 26% of antimicrobials were prescribed prophylactically and 78% empirically.

Infections and antimicrobial treatment are common in Irish SPC inpatient units. Analysis showed no statistically significant relationships. High levels of empiric and prophylactic antimicrobial are in use in Irish SPC inpatient units.

**Abstract number:** PO205

**Abstract type:** Print Only

### How Can Palliative Care Be 'Framed' to Appeal to the Global Health Community?

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**Aim:** To consider how advocates can 'frame' palliative care to appeal to new global health actors?

**Methods:** Semi-structured interviews were conducted with 16 international palliative care experts from all world regions including a public-patient representative. Free coding and thematic analysis were performed. Codes were structured into 'frames' to consider the diverse arguments can be made to different global health actors based upon the benefits which it can offer to; patients, families and health systems. Informed by theories of global policy development and prioritisation from the Global Social Policy (GSP) school of thought, the relative likelihood of each frame to achieve policy change was assessed.

**Results:** Three clear ways of 'framing' palliative care were revealed 1) A human rights issue, with palliative care part of established rights; the right to health and the right to freedom from torture 2) An international development (economic) concern based upon the potential for reduced costs at the end of life for health systems and families, as well as how symptom management can facilitate longer working lives and reduce carer absence from work 3) As an ethical imperative, lack of access to services and consequent suffering is morally intolerable and needs a policy response.

GSP studies have shown economic arguments to be the most influential over policymakers. However, economic benefits are highly dependent upon the timing of palliative care, eg 'prolonged working lives' is inconsistent with late introduction of palliative care, whilst reduced 'health system expenditure' is reliant on care being delivered instead of curative efforts.

**Conclusion:** It is essential that palliative care has a clear message to deliver to the global health community. However, uncertainty regarding whether palliative care is a long term or end of life intervention limits the arguments which can be used to engage new global health actors.

**Abstract number:** PO206

**Abstract type:** Print Only

### Health Related Quality of Life of Lung Cancer People in Palliative Care

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**Background:** People with lung cancer may require constant palliative care for better control of pain and symptoms that affect their Health Related Quality of Life (HRQoL).

**Aims:** To analyze HRQoL of lung cancer people in palliative care.

**Methods:** A cross-sectional quantitative study. The sample consisted of 60 subjects with lung cancer in stage IIIb and IV. Instruments applied: Karnofsky Performance Scale (KPS), Economic Classification Criterion Brazil (CCEB) and European Organization for Research in the Treatment of Cancer (EORTC) QLQ-C30 and QLQ-LC13. Descriptive analyses and Mann-Whitney and Kruskal-Wallis tests were conducted.

**Results:** Sample is predominantly male (60%), aged between 50 and 69 years, married, retired, with low educational levels (elementary school) and economic status C. Regarding diagnosis, 78.33% were diagnosed with non-small cell lung cancer (NSCLC), stage IV and KPS between 100-80 (71.67%). Comparing groups with KPS between 100-80 and 70-50, it was identified statistical significance

( $p < 0.05$ ) for physical, cognitive, social and role functions, as well as fatigue, nausea and vomiting, pain, dyspnea, appetite loss, constipation and alopecia symptoms. Comparing HRQOL among subjects on IIIb and IV staging, submitted and not submitted to surgical treatment, being or not into effect of chemotherapy, only diarrhea and cough, global health and quality-of-life and pain in the arm or shoulder were significant respectively.

**Conclusion:** Subjects with advanced lung cancer have a high burden of symptoms and worst physical, emotional and roles functions performance along with functional decline imposed by disease evolution (lower KPS), limiting meaningful daily activities performance which had a major impact on most of HRQOL evaluated aspects regarding these population clinical characteristics, such as staging, conducted treatments and chemotherapy regimens.

**Financial support: CNPq - Brazil**

**Abstract number:** PO207

**Abstract type:** Print Only

### Quality of Life Related to Health of People with Head and Neck Cancer

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**Background:** The communication difficulties arising from the laryngectomy and treatment of head and neck cancer significantly interferes with quality of life specifically in emotional, functional and social aspects.

**Aims:** To evaluate the quality of life related to health of individuals living with head and neck cancer.

**Method:** An exploratory study using a quantitative methodology, cross-sectional. The data collection occurred from May to September 2015, with 100 people with head and neck cancer, which were divided in two groups: G1: laryngectomized patients, G2: not laryngectomized patients. For evaluation the following instruments were used: Functional Assessment Cancer Therapy-FACT H&N, Criteria of Economic Classification Brazil - CCEB and an alternative communication software for tablets. The statistical analysis was performed by the Fisher's exact test, Kruskal-Wallis test, ANCOVA and descriptive statistics.

**Results:** The prevalence of males (80%), aged between 59 and 74 years (58%), married (60%), not active retirees (76%), with low education (74%) and low socioeconomic status (40%). There was a statistical significance related to physical well-being when compared to schooling ( $p = 0.03$ ) and emotional well-being ( $p = 0.01$ ), the additional significant concerns were statistic related to subjects who had metastases ( $p = 0.02$ ) and those who have already been through radiotherapy treatments ( $p = 0.03$ ).

**Conclusion:** There are major concerns related to the treatment of head and neck cancer in patients who have not had surgical treatment versus those who have, showing a DECREASED emotional and well-being and poorer perception of quality of life related to health. The study suggests that early interventions should be made to better understand their diagnosis and treatment.

**Financial support: CAPES - Brazil**

**Abstract number:** PO208

**Abstract type:** Print Only

### Burden on Family Caregivers of the Elderly in Palliative Care

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**Background:** The illness of a family member brings many changes in family structure and caregivers may suffer burden in caring of elderly in Palliative Care.

**Aims:** To identify and analyze burden by/OF the family of caregivers of elderly people in Palliative Care.

**Methods:** An exploratory and cross-sectional study (May 2015-September 2015) in a Brazilian university hospital, using the protocols applications: Karnofsky Performance Status (KPS), Questionnaire clinical and sociodemographic, Brazil Economic Classification Criteria, and *Caregiver Burden Scale* (CBS), validated in Brazil. The sample was composed of 100 family caregivers separated according to KPS of the elderly in Palliative Care: Study Group 1 (SG1) with caregivers of elderly with KPS < 40, Study Group 2 (SG2) with KPS 70-80 and Control Group (CG) with KPS > 80. Analysis were performed using Fisher exact test and Regression Quantiles.

**Results:** The findings indicate that most caregivers are female (68%), with the age group of 56-71 years (37%), married (80%), catholic religion (66%), low educational level (48%), without paid work (58%), low economic class (64%), spending 24 hours per day in caring tasks (63%), not receiving any kind of help (63%). Most patients are not aided in proper palliative care services (88%). Caregivers burden are higher in SG1 than the CG, there are significant differences ( $p < 0,01$ ), mainly in those fields of the CBS: general strain ( $p < 0,01$ ); isolation ( $p < 0,01$ ); disappointment ( $p < 0,03$ ) and environment ( $p < 0,01$ ), also burden is higher in SG2 than CG ( $p = 0,02$ ) mainly in general strain ( $p = 0,01$ ) and isolation ( $p = 0,04$ ).

**Conclusion:** Burden in caregivers of elderly people in Palliative Care increases in response to progression of the patient's disease, decline of the functionality (< KPS) and impending death. Findings suggest the need of effective interventions and appropriate Palliative Care services to caregivers.

**Financial support:** CAPES - Brazil

**Abstract number:** PO209

**Abstract type:** Print Only

### Prevalence of Palliative Care (PC) Patients in a Mexican Cohort: A Latin-American Perspective

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**Introduction:** Evaluation of Mexico's current situation must be made to implement PC programs.

**Objectives:** Determine the prevalence of inpatients with advanced criteria in an internal medicine ward in a hospital in Mexico with 6 mo follow up to identify survival. Secondary objectives: PC needs, symptom burden, doctors opinion on PC referrals and therapy offered.

**Methods:** Until sample size completion, daily assessment of admissions to the ward was made to identify patients with any of the following: cancer, cardiac, renal or hepatic insufficiency, COPD, AIDS, stroke, fragility. After Chart review and interview with attending physician the following criteria were assessed:

- (A) Gold Standard Framework Surprise question to the physician: "Would it surprise you if patient died within the following 6 months?"
- (B) PPS of < 50%
- (C) Disease specific criteria of advanced phase. Patients were included as palliative if they fulfilled 1/3. Interviews were done to assess symptoms to patient; to attending physician to assess PC needs, attitude toward referral. After 6 mo follow up, death certificates were obtained to assess survival.

**Results:** After completion of 390 admissions, 139 (35%) patients had any of the diagnosis specified, 84 (60%) had at least 1 terminality criteria, and 59 (69%) died in the 6 month follow up, representing 15% of all the admissions to IM during the study period. 76 (90%) had a non oncological diagnosis (NO). PC was considered necessary by attending physician in 86% of Oncological and in 62% of NO; frequent reasons stated were symptoms and emotional aspects in both groups. The main symptoms in both groups were asthenia, pain and dyspnea. Most patients did not receive specific palliative symptom treatment (80-90%). Survival was significantly higher for NO (80 vs 33 days) vs oncological patients ( $p = 0.003$ ).

**Conclusion:** High prevalence of cancer and noncancer population in need of palliative care is clear. Specific programs should be established to attend the dying population in Mexico.

**Abstract number:** PO210

**Abstract type:** Print Only

### Cannabinoids and Medicinal Cannabis in Slovenia: Legislation, Science and Medical Practice

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**Background:** In 2014 tetrahydrocannabinol (THC) was reclassified in Slovenia, which led to the issuing of

the permission to use medicine based on cannabinoids. Generally, this change led to a lot of confusion and misinformation among Slovenian health workers. There were no instructions available concerning who can prescribe such medications, no official guidelines for their use. Presently, cannabinoids are almost exclusively prescribed and researched by oncologists, neurologists and pediatricians in tertiary institutions.

**Methodology:** For consideration and management of these issues, the Medical Chamber of Slovenia founded a workgroup. For this purpose the workgroup put together questionnaire for a survey about knowledge and opinions on cannabinoids in medicine. First round of surveys were answered by 97 Slovenian medical doctors.

**Results:** 48,3% would prescribe medicine containing cannabinoids

14,4% consider medicines with cannabinoids safe medicines, 60,9% think they are low-risk, and 17,5% think they are high-risk medications.

1% think cannabinoids never cause serious side effects, 28,9% think it is rare, while 60,8% think it is common. 44,3% judge their knowledge of medical indications for prescribing cannabinoids to be bad, while 46,4% judge it to be partial. 93,8% think they need more knowledge about medical use of cannabis.

**Conclusions:** Doctor's and other medical workers' knowledge about endocannabinoid system and cannabinoids is still lacking. There is no systematic education concerning this topic, additionally this topic is only superficially covered or even absent in medical and other healthcare-related faculties. To correct this, a workgroup is preparing a curriculum, based on related curriculums from abroad. We can expect the rise of general knowledge and lessening of misinformation about cannabis. With this we can count on scientifically supported use, aggregation of experience and creation of evidence-based guidelines for cannabinoid prescription.

## Ethics

**Abstract number:** PO211

**Abstract type:** Print Only

### Ethical Issues Experienced by Healthcare Workers Providing Palliative Care in Nursing Homes: A Qualitative Study

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The increasing medical complexity associated with an ageing population is resulting in increasing pressure on palliative care resources in nursing homes. Ethical issues experienced by care-providers are associated with detrimental

outcomes including burnout and moral distress, however, little is known about the nature of these issues within nursing homes.

The aim was to provide a comprehensive understanding of care-providers' experiences of ethical issues during palliative care provision within nursing homes in Northern Ireland (NI).

Qualitative, semi-structured interviews were conducted with a convenience sample of 13 registered nurses and 10 healthcare assistants working in nursing homes in NI. The interview guide was piloted prior to data collection and employed the critical incident technique to capture experiences of ethical issues during palliative care provision. Results were analysed by Thematic Analysis.

Three themes were found which grouped experiences of ethical issues; professional, relational, and organisational. Professional issues were found when participants felt conflicted between what they felt was right and their professional obligation. Relational issues mapped onto the "ethic of care" principles and resulted from disagreements and conflicts within the interdependent relationships between residents, families, or colleagues regarding best practice. Organisational issues resulted from the structure and quality of services available, including lacking resources, service organisation, service quality, and staff wellbeing.

These findings suggest ethical issues are commonplace within nursing homes in NI. Many of the core constituents of palliative care including dignity, relationships, and quality of life directly map onto the ethical issues reported, therefore, reducing ethical issues may directly improve the overall quality of palliative care provision. This research was funded by Queen's University Belfast.

**Abstract number:** PO212

**Abstract type:** Print Only

### An Humanist and Pragmatic Autonomy: The Konomie

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Who can make a serious health decision alone? In clinical situations, and especially in palliative care, a patient will make decisions that impact his or her relatives. For example, going home with many technical treatments or deciding to withdraw treatments will lead to repercussions on all family members, both social (a leave from work of a caregiver) and psychological (difficulty beginning the mourning process).

Realistically, nobody makes major decisions without taking relatives into account. For the rare who do, 35 years of clinical experience show us how difficult it is to help

relatives post-hoc, when they have not been able to participate in or give meaning to a previous decision. The answer is not to deny the patient decision-making capacity (autonomy) but to say that this autonomy must take relatives into account.

Our philosophical work has led us to propose the neologism “KONOMIE”, a word extracted from Greek, from the two words “*Koīné - nomos*”. This word describes a decision that can be made by one person, but made in terms that can be understood by everyone (consensus), and especially by his or her relatives. Distinct from both the former paternalistic model and the individualist autonomous model, this Konomie requires that care-givers be ever more attentive to what they communicate to the patient so the patient understands and makes the best decisions for him or herself, allowing discussion and even negotiation with relatives. This is a new challenge that can reduce the number of systemic misunderstandings between relatives and thus decrease the number of a family’s dramatic situations.

**Abstract number:** PO213

**Abstract type:** Print Only

### Qualitative Research about Euthanasia Concept, between Spanish Doctors

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The decriminalisation of euthanasia and assisted medical suicide has generated a continuous debate. The terminological confusion is one of the main difficulties in obtaining medical practice consensus. The objective of this study was to determine whether the terms of Euthanasia and physician assisted suicide are used with the same meaning by doctors in Extremadura (Spain).

**Material and method:** A qualitative study was conducted using two focus groups in which doctors from different specialties who attended a large number of terminal patients participated. No other focus group was required due to saturation. The sessions were tape recorded and transcribed by two experts in qualitative methodology. Atlas.ti software was used for the analysis. We were advised by the “Health Care at the end of life” Group of the Organizacion Médica Colegial of Spain.

**Results:** Terminological confusion was verified in:

- 1) The mixture of etymological, functional and social concepts,

- 2) the term Passive Euthanasia,
- 3) the association between euthanasia and physician assisted suicide,
- 4) the confusion with the equivalent “wish to hasten death”, and
- 5) the difficulty of differentiating sedation with Euthanasia.

There was consensus on some aspects:

- a) Full voluntariness,
- b) the condition of terminal illness, and
- c) the condition of unbearable symptoms.

**Conclusions:** Conceptual variability persists in relation to the concept of Euthanasia, and is particularly noticeable in the persistence of the concept of passive euthanasia. It would be desirable to achieve a common language to assign a precise meaning to these words to help doctors in their professional practice.

**Abstract number:** PO214

**Abstract type:** Print Only

### Dispensing Morphine at ‘End-of-Life’: A Prescription for Challenging Ethical Dilemmas in the Pharmacy

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**Background:** Morphine is the cornerstone of treatment for pain in end of life care. Legal restraints governing the supply of morphine in the Republic of Ireland require that a doctor’s prescription is presented to a community pharmacist before morphine may be legally dispensed. The nature of end of life however can mean that a patient’s symptoms deteriorate rapidly. Situations arise where a pharmacist may be called upon to dispense morphine to a patient before a legal prescription can be provided. While the pharmacist has a duty to ensure medicines are supplied lawfully, they may also be faced with conflicting ethical obligations to the patient.

**Aims:** To explore the legal and ethical considerations facing community pharmacists in such scenarios. Drawing from this review, suggest ways in which the incidence of such ethical/legal conflicts might be prevented.

**Method:** A literature review and summary of the relevant legislation precede the conceptualisation of Beauchamp and Childress’ four principle approach [Respect for patient autonomy, Beneficence, Non-Maleficence and Justice; in the context of ethical and legal dilemmas related to Morphine dispensing at end of life.

**Results:** Four means by which the ethical/legal conflict may be ameliorated are proposed:

- out of hours GP and pharmacy services
- anticipatory prescribing
- E-prescribing
- Pharmacist prescribing

**Conclusion:** Patient care at end of life depends on timely access to medicines. Increased understanding of the inevitable tensions that arise for pharmacists dispensing morphine, use of advancing technologies and communication tools, combined with research into pharmacist role development and the prospect of legislative change, present the potential for improved patient care and outcomes in an otherwise legally and ethically challenging scenario.

**Abstract number:** PO215

**Abstract type:** Print Only

### Practitioner Identified Ethical Challenges in Providing Palliative Care in Uganda

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**Background:** Very little empirical ethics literature exists to describe the ethical challenges faced by palliative care practitioners in a non-western setting. It is not well established whether the challenges are similar or substantially different in nature to those in a western setting. Without this literature base there is limited evidence to guide the structure of medical ethics modules within palliative care training programmes.

**Aims:** To ascertain major ethical challenges to palliative care practitioners in a Ugandan setting with a view to using the result to inform the design and support of ethics education modules at the Institute of Hospice and Palliative Care in Africa (IHPCA).

**Methodology:** A specifically designed questionnaire was offered for completion prior to a meeting of IHPCA faculty and clinical teams at Hospice Africa Uganda in Kampala. All respondents undertook clinical work as part of their roles. The aim of the questionnaire was to inform the design of teaching modules focusing on ethics.

**Results:** 14 completed questionnaires were collected. No formal analysis was conducted except for extraction of themes. Themes identified included challenges regarding respect for patient autonomy, involvement of family decision makers and confidentiality; access to care in health-care systems with limited resources; safety and intent of morphine use; specific challenges concerning the care of children.

**Discussion/conclusion:** These themes should provide the impetus for further research in this context of palliative care practice. Much more work is needed to more

rigorously explore these topics and their impact. This may allow developments around educational approaches, course design, clinical training and perhaps impact on broader philosophical debates such as the applicability, or not, of western medical ethics in a non-western setting and other debates in the developing field of global health ethics.

**Abstract number:** PO216

**Abstract type:** Print Only

### Person-centred Care Dialectics in Palliative Care - An Inquiry Informed by Ricœur's Hermeneutics

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In contemporary pluralistic societies, challenges have emerged in relation to the philosophical and ethical underpinnings of palliative care, in particular, regarding the person in need of palliation. Critical inquiry of the notion of person-centeredness, however, has not been characteristic of the field. With an attempt to bridge the competing agendas of individualization versus standardization and individuals versus populations as related to person-centred care, this theoretical inquiry aims to articulate and seek for dialectic integration.

A philosophical inquiry was applied using the hermeneutics of the self according to Paul Ricœur, which positions the capable and vulnerable self in constant interrelationships with others, in dialogues that will be contextualized in societal institutions. This framed the analysis for dialectic integration of competing agendas.

Person-centered care allows for an integration of the dialectics between suffering and capability, individualization and standardization, as well as, individual and population orientation. In this way, individualization and standardization, and orientation towards individuals and populations, do not need to be viewed as representing opposing perspectives.

Tensions between individualization and standardization, and between individuals and populations, were deconstructed and reconstructed as dialectics. Following this, person-centred care is not only about the individual as a person, but also about the interrelationships within

populations, including relevance and implications on the societal level for access to care and quality outcomes as well as palliative care as a human right. Further, explications of person-centred care are recommended for the development of philosophical underpinnings in palliative care.

**Abstract number:** PO217

**Abstract type:** Print Only

### Living Will: Do the Portuguese Know what it Is?

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**Introduction:** It has taken over three years since the law (25/2012) was passed and we still do not know about the Portuguese population's knowledge regarding the Living Will (LW), nor the law effects.

**Aim:** To identify the fraction of the full age Portuguese population that is aware of the meaning of Living Will; to classify and analyze the factors that might be related with this knowledge and, finally, recognize, among those who know what Living Will is, what was the information resource.

**Methods:** Stratified random sampling, in order to be representative of the Portuguese population over 18 years (n=1064); analytical, cross-sectional, observational study; It has been done through face-by-face interviews performed.

**Results:** Only 22% know what Living will is; this lack of knowledge is not influenced by gender, age or familiar conditions, but it appears to be influenced by the regional area along the country; the education seems to influence the knowledge about Living Will. The ones who have a high level education are those who know more: Degree course (48,8%); 12 years of school (27,7%); University students (26,2%); 7-11 years of school (17,8%); 4-6 years of school (11,3%); less than 4 years (3,1%). The salary income is related to the knowledge about the Living will. The ones who have a high salary know the Living will, especially those who earn between €3000 e €4999 (60,5%); those who earn between €1745 and €2999 (41,5%). Information resources: Social media-66,2%, family doctors-2,8%, Nurses-2,9%, others healthcare providers-4,3%, information

posted in the healthcare services-1%, other unidentified information resources-23,4%. From the 216 respondents who know what Living will is, only 194 answered to this question (do you know how to perform the LW?); From these 50,4% know how to do it or how to find someone to help.

**Conclusions:** More education strategies are needed to increase the knowledge about this citizen right.

**Abstract number:** PO218

**Abstract type:** Print Only

### Living Will: Do the Portuguese Think Do it?

*Capelas, Manuel<sup>1</sup>, Ferreira, Cátia<sup>2</sup>, Pereira, Cristina<sup>3</sup>, Alvarenga, Margarida<sup>3</sup>, Simões, Sandra Catarina<sup>4</sup>, Coelho, Silvia Patricia<sup>5</sup>, Freitas, Mara Sousa<sup>6</sup>*

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**Introduction:** It has taken over three years since the law (25/2012) was passed and we still do not know about the Portuguese population's knowledge regarding the Living Will (LW), nor the law effects.

**Aim:** To identify the fraction of the full age Portuguese population has done the LW and those who think to do or not, and to identify the reasons for that decision..

**Methods:** Stratified random sampling, in order to be representative of the Portuguese population over 18 years (n=1064); analytical, cross-sectional, observational study; It has been done through face-by-face interviews performed.

**Results:** Only 1,4 % of the respondents have done the Living will. None of them is registered in RENTEV (national database do LW); All of them provided specific instructions to healthcare providers and 2/3 pointed an healthcare proxy; From the ones who did not do the living will (n=213), only 207 answered this question: 32,8% have the intention to do it and 41,1% not, at all; 26,1% do not know yet. The age, marital status, education level and the salary income influence the decision "to do or not to do". For those who not want to do, the main reasons for that are "Not thought properly about it" (63,5%), "accept the life at every moment" (22,4%), "lack of trust in the health professionals" (2,4%), "lack of trust in the health system" (2,4%).

**Conclusions:** More reflexion about these questions are needed to increase the quality of the care and the trust in the health system and professionals.

**Abstract number:** PO219

**Abstract type:** Print Only

**Differences and Similarities in Ethical Decisions and Workplace Experiences in Palliative and Intensive Care Units: A Mixed-methods Study**

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**Background:** Professionals working both in palliative and intensive care units (PCUs/ICUs) care for patients with life-threatening diseases or conditions, provide end-of-life care, make ethical decisions, face human vulnerability, suffering, dying and death. However, while in ICUs the major goal is to save lives, in PCUs it is the one of promoting quality of life, minimize suffering and provide a peaceful death.

**Aims:** To identify and compare workplace experiences and ethical decisions in PCUs and ICUs.

**Methods:** A mixed-methods study including: (I) A survey with (i) a questionnaire of socio-demographic and professional characteristics and (ii) a questionnaire of workplace experiences and ethical decisions in the day and week prior to completion. (II) Interviews with physicians and nurses from both settings.

**Participants:** 9 PCUs and 10 ICUs in Portugal. 392 professionals completed the survey; 39 were interviewed.

**Results:** In the week prior to survey completion, more professionals working in ICUs reported a patient's death; this was not statistically significant. Conflicts with patients and families and communication on diagnosis/prognosis happened more often in PCUs ( $p=.026$ ;  $p=.003$ ;  $p=.005$  respectively). In the day of survey completion, more professionals were caring for a dying patient ( $p=.039$ ) and more deaths ( $p=.038$ ) occurred in PCUs. Palliative sedation was more often in ICUs ( $p=.004$ ). In the day of survey completion, the only significant differences referred to communication issues; this was more common in PCUs ( $p=.026$ ). Interviews showed that the most frequent experience was caring for a dying patient. While intra-team conflicts were mostly mentioned by professionals working in ICUs, communication on diagnosis/prognosis were referred mainly by those working in PCUs. Palliative sedation was the most mentioned ethical decision.

**Conclusions:** Workplace experiences varied between PCUs and ICUs. Similarities refer to caring for a dying patient and palliative sedation.

**Abstract number:** PO220

**Abstract type:** Print Only

**'Just Because it Feels Good': Moral Considerations in the Palliative Care for People with Intellectual Disabilities**

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In the palliative care for people with intellectual disabilities (ID) the same moral issues are present as in the normal population. The particular nature of this care form causes the usual protocols and guidelines for these issues to be virtually unusable and usual care to be highly unpredictable. Especially the position of the client is ill-represented. This means that caregivers are required to use their personal moral judgments. Often the answer to the question why they make choices in care is "just because it feels good". Using three case studies, the process of forming daily moral considerations is shown.

The study is designed from an ethics of care perspective that offers the possibility to focus on the interrelational character of the care, attention for the context of care and the possibility to ask the question to what good living in a palliative care phase entails. Three cases were selected from patients admitted to a hospice for people with ID in The Netherlands, and analysed retrospectively.

The first case is of a homeless man of 67 with a mild ID, who's lifestyle was incompatible with the institutional boundaries of the hospice. The second case is of a 50-year-old man with severe intellectual and physical disabilities, showing extremely problematic behaviour. The last case is of a 33-year-old woman with a mild ID, who confronted the hospice staff with her personal wishes that caused moral conflicts within the staff members.

Development of moral sensitivity of staff members of palliative care facilities for people with ID deserves attention. This will form an important source of moral wealth in the development of excellent palliative care for people with ID.

**Abstract number:** PO221

**Abstract type:** Print Only

**Decision Making Capacity in Children Regarding Life and Death Decisions - Contrasting Views Internationally and Contextually on Age of Responsibility**

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**Background/aims:** In 2014 Belgium was the first country to remove age restrictions on euthanasia for terminally ill children. In the Netherlands voluntary euthanasia is legal

for people aged 12 and over but illegal under 12. However, Prosecutors will not press charges if the “Groningen Protocol” is followed. **Aims:** To compare and contrast legislation and policy on children’s age of maturity in health, life and death decision making.

**Methods:** A Literature Review of Policy and Legislative Frameworks regarding children’s decision making on health in UK and international comparisons.

**Results:** The UN Convention on the Rights of the Child defines a child as everyone under 18 unless, “under the law applicable to the child, majority is attained earlier”. The latter refers, for example to age of criminal responsibility. Article 12 of the UNCRC grants a child who is capable of forming a view the right to express that view freely in all matters affecting him or her; and these views should be given due weight in accordance with the age and maturity of the child. Age of criminal responsibility (including homicide): England and Wales 10, Scotland 8 (12), Germany 14, Iceland 15. Brazil & Chile 18, Morocco 12 Bahrain 15, Lebanon 7. The age of consent (the legal age to have sex) in the UK is 16 but the law says anyone under 13 can never legally give consent. It is illegal under 18 years old to buy alcohol or cigarettes. The UK, General Medical Council ‘Good Medical Practice’ states that doctors must safeguard and protect the health and well-being of children and young people. Well-being includes respecting their views. Children can make their own decisions at 16. Under 16, ‘Gillick Competency’ and ‘Fraser Guidelines’ are used to balance rights and wishes with protecting from harm.

**Conclusions:** Children’s involvement in treatment decision making regarding end of life is located in a complex and conflicting value, policy and legislative framework.

## Psychosocial care and spirituality

**Abstract number:** PO222

**Abstract type:** Print Only

### Did Japan’s Cancer Control Act Drive the Spread of Psychosocial Care Nationwide?

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**Aim:** The effects of psychosocial care for cancer patients on improvement of QOL have been reported outside Japan (e.g., Spiegel et al., 1989; Fawzy et al., 1990). Although similar results have been seen in Japan (e.g., Fukui et al., 2001; Hosaka, 2001; and Yoshida et al. 2004), it did not spread nationwide as a standardized care until the Cancer Control Act of 2007 came into force. It was accompanied by the

Basic Plan to Promote Cancer Control Programs, which required designated cancer care hospitals in each prefecture to provide peer support programs. This study investigates whether this led to enhanced psychosocial care and a larger number of them.

**Methods:** New information from the Internet and other material was added to a list we created in 2006 to survey groups that were providing psychosocial support for cancer patients. A questionnaire was sent to 1,061 organizations with published addresses. The responses collected totaled 461 (recovery rate: 43.4%). The questionnaire asked about location of activity, founder, target cancer sites, group meetings, and management type.

**Results:** Of the 1,061 organizations on the list in 2013 (triple compared with 2006), 238 groups targeted all types of cancer (51.5%), 107 targeted breast cancer (23.2%), 27 laryngectomy (5.8%), 26 blood cancer (5.6%), and others. The number of groups holding group meetings for psychosocial support was 418 (90.7%). Cross tabulation analysis of founders and group types proved: ( $\chi^2(25) = 190.7, p = .00$ ). Cases that showed significantly higher numbers than expected were 145 self-help groups managed by patient groups (31.5%), 72 support groups run by professionals in hospitals (15.6%), and 43 jointly-run groups operated by professionals alongside patients (9.3%).

**Conclusion:** Opportunities for psychosocial support increased after the Cancer Control Act was enacted. Nationwide psychosocial care is still in its early stages, so we need to support operators and expand to cover refractory and rare cancers.

**Abstract number:** PO223

**Abstract type:** Print Only

### Palliative Care Needs at Different Phases in the Illness Trajectory: A Survey Study in Patients with Cancer

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**Background:** Despite the growing consensus on the benefits of initiating palliative care early in the disease trajectory it remains unclear at what point palliative care needs emerge.

**Aim:** This study investigates quality of life and unmet palliative care needs at three phases in the cancer trajectory,

curative, life-prolonging and most advanced (prognosis < six months/no further disease-modifying treatment).

**Method:** We collected self-reported data from 620 patients with cancer in the University Hospital of Ghent, Belgium. They completed a questionnaire on quality of life (using the EORTC QLQ-C30) and unmet care needs within the domains of palliative care. We used European reference values of the EORTC QLQ-C30 to compare the mean scores with a norm group.

**Results:** The groups further on in the cancer trajectory reported statistically and clinically significantly poorer functioning compared with earlier phases, also when controlled for the effects of sex, age or type of cancer. Higher symptom burdens for fatigue, pain, dyspnea and appetite loss were found in groups further into the trajectory,  $p < .001$ . Patients in the curative phase experienced physical symptoms and had clinically significantly worse functioning than a European reference group.

**Conclusion:** This paper demonstrates the ongoing need for oncologists to address the broader palliative care needs of patients from diagnosis onwards. A palliative care approach needs to be initiated in standard oncological care early in the care trajectory, possibly together with curative treatment, and palliative needs will gradually become more severe as the illness progresses.

**Abstract number:** PO224

**Abstract type:** Print Only

### What Activities Do EAPC Members Consider to Be Spiritual Care? Results from a Survey on Behalf of the EAPC Spiritual Care Taskforce

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**Background:** Palliative care seeks to attend to patients' spiritual needs, and several national or international guidelines for spiritual care (SC) have been written. However, little is known about how care providers actually implement SC guidelines in practice, nor about which specific activities practitioners understand to be SC. The implementation subgroup of the EAPC Spiritual Care Taskforce (SCTF) explored this via a scoping exercise investigating EAPC members' understandings of which activities they consider to be SC.

**Methods:** We piloted a survey tool with an opportunistic sample of members of the SCTF and other EAPC conference delegates. Following analysis of pilot responses, the

tool was revised slightly and then made available through the EAPC website, with EAPC members emailed to request their participation. Data for the wider survey is currently being collected, and a further content analysis including all responses will be conducted in early 2016.

**Results:** The initial pilot-test involved 30 people: 3 Belgian, 10 Danish, 3 Dutch, 3 English, 3 Romanian, 7 Spanish, 1 Swedish, aged 37-57, with 22 women, and from a range of professions, including chaplains, nurses, psychologists, and physicians. Their experience in palliative care ranged from 0.5 to 15 years. A few respondents said they did not provide SC nor know what it comprised. Others identified a wide variety of activities as SC, ranging from personal conversations with priests or other professionals, through religious services or prayer (individually or in groups), to art therapy, acupuncture and other complementary therapies.

**Conclusions:** Although SC is a key element of palliative care, and national and international SC guidelines have been produced, even members of the EAPC have widely varying understandings of which activities comprise SC. In turn this may mean that its provision varies and/or is inconsistent. Greater conceptual clarity might assist practitioners to support patients in this area.

**Abstract number:** PO225

**Abstract type:** Print Only

### Experiences with the Collaboration of Pastoral Care and Outpatient Palliative Care Teams: A Qualitative Interview Study

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**Background:** Caring for spiritual and religious needs of patients is part of the holistic concept of palliative care (PC). Most inpatient PC teams already integrate chaplains - however, in the outpatient PC setting there is only sporadic collaboration with pastoral care.

**Aim:** To explore ways to integrate pastoral care in the ambulant PC setting and which benefits derive from a cooperation.

**Method:** Semi-structured qualitative interviews with PC professionals working in specialist palliative home care services in Germany. In half of the included PC services, a chaplain was member of the team. Interviews were audio-taped, transcribed and analysed using content analysis method.

**Result:** 35 interviews were conducted with 12 nurses, 12 physicians, 5 social workers and 6 chaplains from 12 home care teams. According to the interviewed professionals a chaplain in the team supports the spiritual competence. Religious/spiritual care gains increasing impact within the team. Chaplains are advisors for the team and for individual team members. They stimulate reflections on a meta-level with the perspective of an outsider. Collaborations with chaplains were rated mostly positive by the teams. Members of teams without pastoral care expressed the need for support in spiritual and religious matters and for training of team members. Critical voices regarding the inclusion of chaplains were: Doubts whether patient's trust an unknown clergy, felt competition between the chaplain and other team members, potential negative impact on the perception of PC service as being influenced by the churches.

**Conclusion:** The inclusion of pastoral care in PC home care teams increases the spiritual competence of the team, by supporting both, the patient and the team. Requirements for a successful integration and collaboration are the chaplain's qualification and openness within the team.

**Abstract number:** PO226

**Abstract type:** Print Only

### The Nuts and Bolts of Compassion: A Patient-informed Conceptual Model of Compassionate Care at the End of Life

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**Background:** Compassion is considered a central indicator of quality palliative care, is increasingly regarded as a patient right and practice competency, and is consistently identified as an important but unmet need among patients facing the end of life. But what is compassion—really? How might an evidence based approach to compassion inform clinical practice?

**Methods:** Qualitative interviews with palliative cancer inpatients at a large urban teaching hospital were conducted to address a significant gap in the literature—the lack of

patient perspectives on the topic of compassion. Interviews were recorded, transcribed and analyzed in accordance with Grounded Theory methodology.

**Results:** 53 patients identified the key categories and themes associated with compassion, generating the first conceptual model of compassion within healthcare. Patients came from diverse spiritual backgrounds with 53% identifying as spiritual and religious, 37% as spiritual but not religious, 4% religious but not spiritual, and 6% having no spiritual or religious background. Patient exemplars on the motivators, facilitators, inhibitors and impact of compassion produced seven categories of compassion: virtues, relational space, virtuous response, seeking to understand, relational communicating, attending to needs and patient reported outcomes. Patient data also generated the first empirical definition of compassion—*a virtuous response that seeks to address the suffering and needs of a person through relational understanding and action.*

**Conclusions:** While patients, policymakers and researchers increasingly identify compassion as a standard of practice—compassion seems to be increasingly considered an ‘optional extra’ within healthcare systems that are primarily focused on economics and efficiency. Patient descriptions and experiences of compassion provide an empirical foundation to examine and enhance this essential ingredient within palliative care research, practice, and education.

**Abstract number:** PO227

**Abstract type:** Print Only

### For God's and Goodness Sake: A Constructivist Grounded Theory of Palliative Care Patients' Spiritual Needs

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**Background:** Palliative care staff are obliged to provide spiritual care according to patients' needs but difficulties exist in recognising and responding to spiritual needs as little research exists from patients' perspectives. The EAPC survey on spiritual care identified understanding spirituality as a research priority.

**Aim:** To understand palliative care patients' spiritual needs based on their perceptions of spirituality and experience of spiritual care.

**Sample:** Clinicians recruited adults with life limiting conditions attending an Irish hospice's palliative care inpatient or day hospice services.

**Methods:** Using Charmaz's constructivist grounded theory methodology, theoretical sampling directed data collection that was transcribed verbatim and analysed concurrently. Aided by ATLAS.ti software, line-by-line coding led to initial and focused codes and eventual theoretical categories until data was considered saturated and a theory constructed.

**Results:** 9 men and 9 women (N=18) aged between 55-90 years and predominantly of Roman Catholic affiliation (n=14) participated in interviews averaging 60 minutes. Experiencing God and eternalising family connections are core spiritual experiences rooted in cultural and religious upbringing and expressed through serving others through God or moral goodness. As patients do not expect staff to address their spiritual needs, mystical or God experiences are hidden to avoid offending or burdening others. Where tension exists in expressing spiritual experiences, unspoken hidden truths can trigger transient attacks of spiritual struggle. Although patients tend not to identify with spiritual care's professional discourse, its attributes are recognised as manifestations of good integrated care.

**Conclusion:** Despite declining religious practices in Ireland, addressing palliative care patients' spiritual needs requires tapping into spiritual experiences rooted in Christian values of serving others through God or moral goodness.

**Abstract number:** PO228

**Abstract type:** Print Only

*'There's a Spring in her Step that Just Wasn't there before'* **The Experience of Volunteers Delivering an Intervention to Meet the Social and Practical Needs of People with Advanced Illness**

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**Background:** Recent years have seen a growing policy impetus internationally towards the provision of community-led interventions to address the social and practical needs of people at the end of life. Such interventions are at the heart of a Compassionate Communities model of health promoting palliative care. This study explores the feasibility of a new community-based intervention in Ireland and adds to a small pool of evidence.

**Aim:** The pre-pilot study aimed to:

- 1) Implement a pilot Good Neighbour Partnership (GNP) intervention using volunteers to offer free

social and practical support to people living with palliative care needs in their last year of life;

- 2) Evaluate its feasibility from the perspective of Compassionate Communities Volunteers (CCVs).

**Design:** An interpretative research design using qualitative methods of data collection and analysis was employed; one-to-one interviews were conducted eight weeks post-intervention; these were recorded, transcribed and analysed using standard thematic analysis.

**Participants:** Interviews were conducted with three CCVs who delivered the GNP intervention during the pre-pilot phase.

**Results:** Six main themes were identified, including:

- 1) the overall experience of the GNP;
- 2) the logistics of intervention delivery;
- 3) the profile and characteristics of people supported;
- 4) the experience of working with Good Neighbours;
- 5) the perceived impact of the intervention;
- 6) emerging issues for consideration.

**Conclusion:** The pre-pilot experience of the CCVs was extremely positive. Several perceived benefits were noted for the person receiving support as well as for family members and other volunteers. Emerging issues included the need for a screening tool to ensure appropriate referral and a plan to support post-intervention visits. These will be addressed prior to testing the intervention as part of an exploratory randomised controlled trial.

**Abstract number:** PO229

**Abstract type:** Print Only

**Resilience, a Construct to Discover**

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Resilience (RS) is defined as the ability to overcome adversity, and there is no major adversity that overcomes our own death. Thus, we would like to know if this coping style has an influence over Spiritual needs (SN) in Palliative Care (PC). To describe how coping style RS develops in patients in the last stage of life on a PC unit at hospice. To study the relationship between RS and subscales of Psychological Well-being (PWB): Autonomy, Self-Acceptance (SA), Environmental mastery, Personal Growth (PG), Positive Relationships (PR) and Purpose in Life

(PL). To explore if there is a relationship between RS and SN. To research if RS increases or decreases according to variable Perception of near death (PND). Descriptive-correlational study with patients hospitalized on a palliative unit. Analyzed variables: Relationships status, PND, RS (BRCS), PWB (Ryff's Scales) and SN (GES).

A sample of 57 patients. Average age = 64,61, 56,1% are men, 50,9 % have a perception of near death and 64,9% are not in a relationship. 49,1 % have high and medium levels of RS and 50,9 % low levels. RS has a significant correlation with PG, SA and PL. Related to SN, there is a relationship between RS and all assessed SN, with the exception of "Still expecting positive events despite of my disease" (EPE),  $p = 0,086$  and "Connection to a Higher Reality"(CHR),  $p = 00115$ . The group of patients with low levels of RS as much as the one with higher levels have a positive correlation with Intrapersonal SN.

Half of the patients included in this study have high levels of RS. It is related to PG, SA and PL, consequently to variable PWB. Intrapersonal SN, especially Meaningful Life, are also statically related to this construct.

However, RS is not acting as intermediary for EPE and CHG. Both variables are not moderate by copyng, but instead by personality and information about the process. The variable CHG can be a copyng strategy itself.

**Abstract number:** PO230

**Abstract type:** Print Only

### What Is the Effect of Spiritual Care Training on the Attitudes and Competencies of Hospital Staff? (SPIRIT-NL)

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**Background:** In the Netherlands palliative care (PC) is not a medical specialization and non academic teaching hospitals do not have PC units. In these hospitals palliative care is delivered by healthcare professionals in curative departments, supported by PC consultation teams. A national multidisciplinary guideline (2010) on spiritual care (SC) recommends SC delivered by all healthcare professionals in any setting where palliative patients are treated, supported by specialists in this field: healthcare chaplains.

**Aims:** Improving staff basic competencies for multidisciplinary spiritual care: recognising, referring, self reflectiveness and open attitude towards patient spirituality and

measuring the effect of training SC in PC on attitudes and competencies of clinical teams.

**Methods:** Explorative multicentre trial: healthcare chaplains of 7 non academic teaching hospitals implemented a pilot training SC in PC to 9 clinical teams. Participants received digital questionnaires before the training about their perceived barriers for spiritual care, their personal spiritual attitudes and involvement (SAIL) and spiritual care competencies (SCCS). Perceived barriers to competencies of the caregivers were also measured twice (1 and 6 months) after the training. All participants received a digital Learning Style Inventory (Kolb 3.1). Qualitative and quantitative methods were used to analyse the effects of the intervention.

**Results:** 268 clinicians are included in this study, significant effect reducing lack of knowledge, no significant effect on other barriers for spiritual care, significant effect on competencies for multidisciplinary spiritual care on 2 out of 6 subscales of the SCCS.

**Conclusion:** Healthcare professionals score high on spiritual themes and involvement. The SCCS was developed for nursing education but seems also feasible for multidisciplinary groups of clinicians. Further research should focus on quality indicators for spiritual care training.

**Abstract number:** PO231

**Abstract type:** Print Only

### Prevalence and Sources of Distress in Hospice Day Therapy Services

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**Research aims:** Psychological distress in patients receiving palliative care is under-reported and under-treated. In specialist palliative care day services, the number of patients presenting with clinical levels of anxiety or depression is largely unknown. The current aim is to assess the levels and sources of distress in this clinical population, including levels of likely psychological morbidity, using standardised assessment tools.

**Study population:** Patients attending specialist palliative care day services at a hospice. All patients admitted to day services were eligible for screening, with exclusion criteria including communication difficulties and cognitive impairment.

**Study design and methods:** Patients attending specialist palliative care day services and meeting the eligibility criteria were screened using the Hospital Anxiety and Depression Scale (HADS) and the Distress Thermometer and Problem List (DT), in addition to recording demographic and medical detail.

**Method of statistical analysis:** Descriptive data analysis was undertaken.

**Results and interpretation:** 51 patients were approached and successfully screened. 61% of patients were female, 86% with a cancer diagnosis, 78% referred for supportive care, all community dwelling. The majority of the patients reported normal levels of generalised anxiety (52%) or depression (49%) on the HADS, with a subgroup of patients reporting levels indicating probable anxiety (26%) or depressive (28%) disorder. Most patients (63%) indicated levels of distress on the DT which would recommend formal intervention. Patients reported a variety of problems, with a high level of reporting for emotional problems.

Prevalence of anxiety and depression is high in this population, alongside patient recognition of emotional problems. The DT may serve as a useful starting point for identifying broader sources of distress which may benefit from intervention.

**Abstract number:** PO232

**Abstract type:** Print Only

**Psychological Distress in a Hospice In-patient Population: Levels of Psychological Morbidity and Meeting Patient Need**

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**Research aims:** Psychological distress in patients receiving palliative care is under-reported and under-treated. The current aim is to assess levels and sources of distress in patients admitted to a hospice in-patient unit (IPU), and staff perception of current resources in meeting the identified need.

**Study population:** All patients were eligible for screening, exclusion criteria including communication/cognitive difficulties. Purposive sampling was used to recruit hospice staff from a range of disciplines to focus groups.

**Study design and methods:** Patients on admission to the IPU and meeting the inclusion criteria were screened using the Distress Thermometer (DT) and Problem List (PL), and the Hospital Anxiety and Depression Scale (HADS). A series of 5 focus groups were also conducted with 21 members of hospice staff, with a semi-structured interview schedule focused on expectation of patient need, meeting patient need and further support needed.

**Method of statistical analysis:** Descriptive data analysis was undertaken on the patient data. Semantic thematic analysis was undertaken on the staff focus group transcripts, with 5 superordinate themes emerging.

**Results and interpretation:** 76 patients successfully completed the DT & HADS, 59% female, 93% with malignant disease and 4% primarily for terminal care. 43% of

patients reported probable levels of anxiety disorder and 42% reported probable levels of depressive disorder, with 74% of patients indicated a level of distress on the DT suggesting formal intervention is needed. Superordinate themes from staff data included anticipation of high level of patient distress, insight gained from utilising psychological screening tools, over-stretching professional role boundaries, the need for a structured referral pathway and need for clinical psychology input.

Prevalence of anxiety and depression is high in this population. Identified challenges to successful management may be useful for service planning.

**Abstract number:** PO233

**Abstract type:** Print Only

**Patient Dignity Question in Palliative Care: A Systematic Review of the Literature**

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**Background:** People receiving palliative care (PC) may have particularly sensitive needs so is especially important applying a patient-centred care. A novel intervention to this regard is the Patient Dignity Question (PDQ) which elicits information regarding patient personhood. It can have an effect on health professionals' perceptions toward the patient, influencing the "care tenor" which is important in maintaining the patient's dignity.

**Objective:** To conduct a systematic review about PDQ.

**Methods:** Systematic search of the literature from 2015 in PubMed, CINAHL, E-journals and PsycInfo. Papers focused on PDQ with palliative care patients were selected. A content analysis of the results was conducted.

**Results:** Four studies were identified. They have been conducted in Canada and Scotland with PC patients. The findings can be grouped in 3 areas:

Patient and family positive perceptions on PDQ. They consider the information transmitted was important for health care providers as could affect the way they care for the patient. It helped them to feel valued as individual. They recommend the intervention to other patients. Professionals' positive perceptions indicate that they learn something new about the patients and that it has a positive impact in their attitude, care tenor, empathy, respect and job satisfaction. It also increases the connection and the ability to communicate better with the patient. PDQ acceptability, which is adequate as there is a high percentage of participants and most patients and families informed that the summary was accurate and they gave the permission to place it in the chart. Professionals consider the intervention easy and quick to complete.

**Conclusion:** PDQ offers the opportunity to promote patient-centred and dignified care. It is well received by patients, families and health professionals. Further evidence is needed regarding the PDQ in other contexts.

**Abstract number:** PO234

**Abstract type:** Print Only

### Psychosocial Health Care Needs in a Group of Women Newly Diagnosed with Breast Cancer

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**Background:** Psychosocial implications for patients in the recovery phase after breast cancer treatment has been intensively investigated in recent years, however, little is known about the psychosocial and physical needs of Danish breast cancer patients during the phase of transition from diagnosis to early treatment.

**Aim:** The aim of the study was to provide detailed insights into the physic and psychosocial health care needs in a group of women newly diagnosed with breast cancer and in the midst of their primary treatment phase.

**Study design and methods:** This study had a descriptive design with data collection including 12 semi-structured interviews with 6 women undergoing radiation therapy and 6 women undergoing chemotherapy. Three experienced researchers analyzed the transcribed interviews independently according to five steps (Kvale, 1997). The analyses resulted in four themes.

#### Results:

Uncertainty was experienced in the period from point of diagnosis to treatment begins. The women experienced a kind of rootlessness and inability to cope with shifting departments in charge of their different parts of their treatment.

Powerlessness in the sense of losing control of almost every part of their lives. "I want my hair and my life back," they said, illustrating a normal life putt on "hold" because the cancer came "as a thief in the night".

Employment situation was a big issue for the women and interpreted as a manifestation of the important feeling of normality, cohesion, networking and obtaining self-efficacy.

Ruminations regarding the future included worries about "time left to live in" and self-contradictions as "I am fully recovered - right?". The ruminations also led to acts and decisions without the women's usual thoughtfulness and logic.

**Conclusion:** Understanding the above mentioned needs in a transition process from early treatment to recovery is

important in order to assist health care professionals predict signs of early rehabilitation needs.

**Abstract number:** PO235

**Abstract type:** Print Only

### Behavioural Changes in People with Intellectual Disabilities and Autism in the Palliative Care Phase: Breaking Behavioural Patterns

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The increasing longevity in people with an intellectual disability (ID) stresses the importance of excellent palliative care. Recognising the palliative care phase is difficult in people with autism spectrum disorder (ASD) and intellectual disabilities (ID). Behaviour change in autistic people with ID (who normally have stable behaviour patterns) may be indicative of the palliative care phase. The aim of this study is to investigate the prevalence of changes in the autistic behaviour pattern in people with autism and ID in the palliative care phase.

Data are collected within a cohort of 12 men with all levels of ID, in a care organisation in The Netherlands, who also had a diagnosis for ASD or presented autistic behaviour related to a syndrome and for whom palliative care was indicated.

A retrospective cohort study design is used in which behavioural change data are extracted from the patient records between November 2012 and October 2015. The behavioural changes seen in the palliative stage are presented.

For all patients changes in autistic behavior patterns were observed. For five patients a decrease was observed in the severity of persistent deficits in social communication and social interaction (domain 1 in DSM 5). Mostly seen was an increase in the quantity of taking initiative to make contact and an increase in the quality of the interaction. For nine patients there was reported that there was a decrease in the severity of restricted, repetitive patterns of behavior, interests or activities (domain 2 in DSM 5). Eight patients started to allow help of social workers, nurses and physicians--which they never did before.

The results indicate that in patients with autism, cognitive or emotional awareness of the approaching end of life occurs. Caregivers should consider unexplained behaviour change as possible signs of life limiting conditions.

**Abstract number:** PO236

**Abstract type:** Print Only

### The Feeling of Gratitude in Palliative Care Patients: A Pilot Study

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**Background:** Although the psychological sphere is recognized as a major component of quality of life in palliative care, the majority of research mainly concerns a better understanding and improvement of negative factors, e.g., anxiety, depression or hopelessness. We postulate that positive psychology may represent an additional point of interest for palliative care practice. This pilot study aims to assess the relationship between

- (i) gratitude and quality of life (QOL) and
- (ii) gratitude and psychological distress (anxiety and depression) in palliative patients.

**Method:** We performed a cross-sectional study involving face-to-face interviews with palliative patients in a Swiss university hospital. QOL was assessed by the *McGill-Quality of Life questionnaire* (MQOL, physical subscale, psychological subscale, existential subscale, relationship subscale, total score), gratitude by the *Gratitude Questionnaire* (GQ-6), and psychological distress by the *Hospital Anxiety and Depression Scale* (HADS, anxiety and depression subscales, total score).

**Results:** Between March and September 2015, 20 patients completed the protocol (30% recruitment rate; 60% female, mean age  $66.5 \pm 13.4$ ). The results show a significant positive relationship between the total gratitude score and

- (i) the existential subscale ( $r=.76, p=.000$ ),
- (ii) the relational subscale ( $r=.55, p=.018$ ), and
- (iii) the total score of the MQOL ( $r=.67, p=.003$ ).

In addition, we found a significant negative relationship between the total gratitude score and the depression subscale ( $r=-.64, p=.005$ ) as well as the total score of the HADS ( $r=-.75, p=.000$ ).

**Conclusion:** These data suggest a significant relationship between gratitude and QOL. Gratitude may represent a protective factor against psychological distress in palliative care patients. These preliminary results require confirmation in a larger study.

**Abstract number:** PO237

**Abstract type:** Print Only

### Spiritual Needs Documentation by SPC Teams Habitually: Getting the Picture of How

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**Background:** Spirituality is one of the dimensions inherent to the person, thus an individual's health and well-being benefit when it is addressed; thus, providing measurable outcomes is fundamental to adequate Palliative Care provision.

**Aim:** To measure documented concern regarding Spiritual Care by specific PC teams. Establish quantity, quality and processes to give account of Spiritual Care provision.

**Methods:** Retrospective analysis of Spirituality fields in the Protocols of Electronic PC Medical Records for 1 year, for a reference population of 6.3 million and 560 professionals working in specific PC teams. A random sample of 302 cases was selected from a total of 9125 patients in PC Register of which 4134 were in PC Program.

**Results:** An average of 6 protocols was completed for each case. Of all the protocols that include spirituality dominium items (Multidisciplinary Action Plan, Subcutaneous route, Adult referral protocol, Last hours/days, Pain and Assessment) the more often used protocols were: the Assessment Protocol (mainly used by domiciliary teams), the Referral Protocol (similar use of domiciliary and hospital teams). Spirituality items were completed under 50% in all protocols. By far, the protocol more frequently completed is the Multidisciplinary Action Plan. Home Care Teams registered the most (58, 78%). Preferred place of Care is starting to pick up but there is little completion on communication issues re decision making.

**Conclusions:** Documentation of all Spiritual Care activity is key to obtaining robust outcomes measurements and contributes to improve its provision and ensures Continuity of Care providing a good flow of clinical information. Rate of spirituality fields completion remains low within the electronic patient records: the level of awareness on spirituality documentation must be heightened. Thorough

assessment of spiritual needs attending end of life patients and families needs to be reinforced amongst professionals.

**Abstract number:** PO238

**Abstract type:** Print Only

### Professional's Views on the Factors that Intervene in Provision of Spiritual Care at the End of Life in Spain

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**Background:** Spirituality is one of the dimensions inherent to the person, thus an individual's health and well-being benefit when it is addressed. In spite of this we have observed looking at electronic patients records, that the rate of spirituality fields completion remains low. There are multiple reasons that can hinder the provision of Spiritual Care activity to patients by PC professionals.

**Aim:** To determine what are the elements that professionals feel either as facilitators or barriers when addressing the Spirituality Dimension in Palliative Care.

**Methods:** Analysis of the results of a survey undertaken during a Regional Advanced/Expert Spirituality Training day, offered to professionals Specialists in PC from all care settings. The tool was an adaptation of C. Pulchaski's Consensus Conference and included five free text questions. Answers from participants were analyzed thematically.

**Results:** 50 places were offered for the Regional Advanced/Expert Spirituality Training Day. 40 professionals assisted, 28 were registered palliative care professionals. 29 professionals replied to the survey. Regarding needs when addressing Spiritual Care, participants highlighted the following as important: Training, Knowledge, Time, Respect, Knowing how to identify spiritual needs, knowing how to identify family needs and the need to have experienced professionals. Regarding Resources participants highlighted: Training, Knowledge, Time, Professionals themselves, other professionals, other patient family, strategy, protocols and guidelines. Regarding Competencies key points were

identified as Training Knowledge, skills-abilities and Motivation-attitudes.

**Conclusions:** Spiritual Care implementation must have a strong cultural background, combined with accredited activities and criteria.

In our setting, professionals identify resources, "full teams", clear criteria to differentiate from other aspects of care and more general public awareness is called for.

### Communication and information

**Abstract number:** PO239

**Abstract type:** Print Only

### Integrating Oncology and Palliative Care: Communication Training Needs for Oncology Nurses

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Integrating palliative care into oncology requires sensitive communication about diagnosis, discussing factors influencing treatment decision-making, mediating family communication, and psychosocial counseling about difficult topics. Oncology nurses are expected to initiate shared decision-making with the patient and family, however there is little instruction available for nurses on how to communicate in a way that accomplishes this approach. To assist oncology nurses with discussions about palliative care topics, we received funding to provide a two-day communication training course offered annually for four years to a cohort of 100 competitively selected oncology nurses. Participants in our first course ( $n=82$ ) completed a pre-course survey to report educational offerings at their institution, the perceived effectiveness of communication with patients at their institution across the cancer trajectory, and their own degree of difficulty with communication topics. More than 75% of teams reported that their organization had not provided training on how to break bad news, talk about goals of care and care transitions, or talk about recurrence. Nurses rated communication with patients about survivorship (4.36), end of life (4.64), during bereavement (3.92) and time of death (4.72) as least effective at their institution (on a scale of 0=not effective to 10=very effective), reporting that their own communication about hospice and palliative (5.18), conflicts with patient/family (5.18), conflict with team members (4.87), and financial topics (4.08) as most difficult (on a scale of 0=not difficult to 10=very difficult). More than 50% of nurses surveyed are present when bad news or prognosis information is provided to the patient. Palliative care

communication training for oncology nurses is needed, especially given their strong impact on quality patient care and family support. This project was funded by the National Cancer Institute, United States.

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**How Are Mobile Phones Being Utilised in Palliative Care Services in Sub-Saharan Africa? A Systematic Review and Visual Framework for Research Development**

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**Background/aims:** Current coverage of palliative care (PC) services in sub-Saharan Africa (SSA) remains woefully inadequate, but harnessing mobile phone technology could be one approach to facilitating greater service coverage and engaging with patients with life-limiting progressive disease. A systematic literature review was conducted to identify the development and use of mobile phone interventions in PC services in SSA.

**Methods:** 13 electronic databases from 1990 to 2015 were searched with handsearching of journals and citation searching from included article reference lists. Articles were assessed against inclusion and exclusion criteria and study details extracted and tabulated by two researchers. Included articles underwent descriptive analysis and were mapped to a visual framework. The framework depicts 13 common approaches to mobile phone use in health services plotted against SSA palliative care delivery models.

**Results:** Of 1110 identified articles, a total of 5 were included. All interventions were at an early, piloting stage, with most designed to facilitate direct patient/caregiver-to-provider contact. Interventions were reported in PC services from Nigeria, Uganda, Kenya and Malawi. The application of mobile phone interventions is limited to the palliative treatment, guidance and coordination stages of services. No interventions are currently reported that support diagnosis and referral, or terminal and bereavement care.

**Conclusions:** Mobile phone interventions for PC in SSA are small in number and development is at an early stage. The visual framework identifies gaps in research and development of mobile phone approaches that respond to known health system constraints. Mobile phone network coverage continues to increase in SSA with extensive use of mobile phones by PC patients and their families. This is an opportune time to devise a structured, evidence-based approach to explore how mobile phones can enhance existing PC services in the region.

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**Utility of Mobile Phones for Better Management of Terminal Cancer Patients in Rural Bengal - An NGO Based Approach**

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**Purpose:** Due to financial incapability and absence of manpower poor families often fail to carry their advanced cancer patients to the nodal centres. This pilot study will explore whether communication by mobile phone can lessen this burden.

**Methodology:** Initially a plan was generated regarding management of an advanced cancer patient in a nodal centre at District Head Quarter. Subsequently every two week a trained social worker attached to nodal centre will follow up and give necessary advice and emotional support to the patients and their families through their registered mobile phone number. Patient's family were also encouraged to communicate with the team by phone in case of fresh complain and urgency in between.

**Results:** Since initiation in, 143 cancer patients were contacted by mobile phone every two weeks to enquire about their difficulties. In 76% of the situation trained social workers could give necessary advice by phone regarding management of their physical symptoms. Moreover patient's family were really overwhelmed by the emotional support offered by the team over phone. Only 24% of cancer patients has to attend the nodal centre for expert advice from Palliative Care specialists.

**Conclusion:** This novel approach helped

- In providing regular physical and emotional support to the patients and their families.
- In significantly reducing the financial and manpower problems of carrying patients to the nodal units.
- In improve the quality of life of patients by continuous guidance.

More and more team members can take help of this new strategy for better communication and uninterrupted care.

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**"Dying in YouTube." How People Share their Experience of Terminal Illness Online: A Systematic Review of YouTube Videos**

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**Background:** During the last decade, the use of social media has become mainstream in many areas, including health care. A number of individuals facing a terminal prognosis have posted videos in YouTube, in which they share their experiences of advanced illness and death. These videos usually stay publicly available online for years and can be watched freely, becoming a source of both information and misinformation for patients and their families. This might be a concern for clinicians, who may lack the training on how to manage this phenomenon.

**Aims:** To describe how individuals share their experience of terminal illness in YouTube videos.

**Methods:** A search strategy was designed to search YouTube content. Search results were screened by two independent researchers based on inclusion and exclusion criteria. Descriptive data (sociodemographic characteristics of author, length of videos, number of views) was extracted, and included videos were analysed using qualitative content analysis.

**Results:** A total of 33 videos were included in this review. The majority of the individuals in the videos were females (60.6%), middle aged (48.8%), and North-American (90.9%). All but one had advanced cancer. Themes identified were around symptoms, treatment options (including complementary and alternative medicine), family support and emotional difficulties.

**Discussion:** International studies predict an increased use of social media in the future. It is reasonable to expect that more patients and carers may watch and create videos in the coming years. This may affect future palliative care patients and their families, and also the general population's views on dying. We present a number of implications for clinicians, policy makers and researchers, and suggest strategies for clinicians who may be faced with their patients watching these videos.

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**Twitter-Only Poster #EAPC2016TOP: #EAPC versus #ESMO - Comparative 2 Year Quantitative and Sentiment Analysis of Twitter Activity at EAPC and European Cancer Conferences**

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**Background:** We collected public Twitter data from EAPC congresses in 2014 and 2015 and compared this with similar size European Oncology events (ESMO/ECC). This poster can only be accessed through Twitter on #EAPC2016TOP

**Aims:** To analyse, quantify and benchmark use of #EAPC2014, #ESMO14, #EAPC2015, #ECC2015 hashtags on Twitter.

**Methods:** An advanced Twitter search using the hashtags described in Aims was conducted by four reviewers independently. Data were collated manually, counted, compared and verified with a third party Twitter analysis tool, *Symplur*. A timeline was agreed: 7 days prior to start of first day of respective conference, and 7 days after last day of conference. Organizers were approached to ensure that no other hashtags had been circulated, to avoid missing data.

**Results:** The results are displayed in table 1 below.

**Table 1.**

Official Hashtag for EAPC and European Cancer Conference for 2014/2015	Original Tweets	Total Tweets (includes original Tweets and Re-Tweets)	Individual Twitter accounts generating total tweets
#EAPC2014	445	2,789	621
#ESMO14	1,582	13,169	3,119
#EAPC2015	1,417	8,947	1,740
#ECC2015	2,199	13,555	4,779

Sentiment analysis on Twitter showed that conference attendees made mainly positive comments about events and talks. We further sub-categorized Tweets into 'Status update', 'Slide/Poster Photo upload', 'Other Photo' content, to further define how users were interacting.

**Conclusions:** For EAPC alone between 2014 and 2015, this represents a year on year increase of 218% for original Tweets and 221% for Total Tweets. Compared to a similar size European cancer conference event, there is potential for an increase in numbers. Photo uploads were research slides and posters, publishing these to a vast audience and thus making data freely available to interested non-attendees worldwide. Pharmaceutical companies' and charities' Twitter accounts had some of the highest audience reach.

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### **Helping Families Find a Way through the Fog: The Development of a Family Information Leaflet on Delirium for a Palliative Care Unit**

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**Background:** Witnessing delirium can cause severe distress. Family members report a need for more informational support.

**Aims:** To perform a scoping review for information provision to informal caregivers (IC) regarding adult patients with delirium in a palliative care (PC) setting.

**Methods:** A systematic literature search for information provision to IC regarding delirium in adults was conducted in multiple databases (Ovid MEDLINE® In-Process & Other Non-Indexed Citations, Ovid MEDLINE®, Embase, PsycINFO, CINAHL, and ERIC) for the years 1990-2015. Alcohol or substance withdrawal delirium, post-operative delirium and articles not in English or French were excluded. Similarly, the SCOPUS database was searched for impact of delirium on families in PC. The grey literature search to source delirium IC brochures and education resources included websites of professional delirium associations. Hand searching supplemented all searches and included delirium clinical practice guidelines. Level 1 screening of titles and abstracts derived from the database searches was followed by a Level 2 screen of full-text review of included papers.

**Results:** The systematic 'information provision' search found 322 citations with a final 17 full-text articles included. The 'impact' search returned 15 citations. After

reviewing an additional 15 hand-searched papers, a final 17 full-text articles were included. Nineteen website links were included after reviewing 247 website hits. Data was collated onto extraction templates. Themes from all sources were used to create a MindMap, which formed the foundation for drafting a local family information leaflet on delirium. The four major domains for IC informational needs were: Education, Management, Experience and Self-Care.

**Conclusion:** The scoping review confirmed the domains of desired information provision identified by IC. These results should be incorporated into information provided to families as part of delirium quality improvement initiatives.

**Abstract number:** PO245

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### **MRSA and Other Multi-drug Resistant Pathogens in German Print Media - A Media Analysis**

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**Background:** During interviews about methicillin-resistant staphylococcus aureus (MRSA) and other multidrug-resistant pathogens (MDROs) in end of life situations it became obvious that most patients and informal caregivers do at least have some previous ideas about MRSA/MDRO. That knowledge may often be influenced by articles in print media, where the topic of MRSA/MDRO has become popular over the last years.

**Aim:** This study aims to describe reporting of MRSA and other MDRO in end-of-life care in print media to show which associations and information influence patients and informal caregivers at the time MRSA/MDRO is diagnosed.

**Methods:** A media analysis was conducted for a set of articles using content analysis to gather information about MRSA/MDRO-reporting in widespread print media (national and local daily and weekly newspapers and magazines).

**Results:** For content analyzes 357 articles reporting about MRSA/MDRO in health care were included. The results show three content categories of reported themes: case reports, general information about MRSA/MDRO and factors influencing MRSA/MDRO occurrence. Many of the reports construct a picture of dangerous and life threatening pathogens and at times they do not correctly differentiate patient groups, pathogens or circumstances of occurrence. No articles about MRSA/MDRO with particular focus on end-of-life care were found.

**Conclusions:** Professional caregivers and stakeholders should pay closer attention to media associated ideas about MRSA which could cause anxiety and uncertainty for patients and their families. The findings of this study could have consequences for the manner of giving written or verbal information.

**Abstract number:** PO246

**Abstract type:** Print Only

### **Empowerment of Patients in the Process of a Structured Advance Care Planning According to the SENS Framework**

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A structured advance care planning (ACP) in Palliative Care according to the **SENS**-Framework (Symptoms, End-of-life decisions, Network, Support) supports patients in keeping complex situation under control as much as possible. To help patients to be prepared for the ACP conversation with professionals according to SENS a brochure and a prompt sheet was developed according to the principles of patient- and family education in collaboration with an expert in communication sciences.

The aim of the project was to pilot test the brochure / prompt sheet among patients and family members for its comprehensibility and workability.

Feedback from patients and family members (n=20) was obtained using a semi-structured questionnaire. Their response and suggestions were used to design the final version of the brochure.

Patients perceived the layout of the brochure as appealing, the illustrations supported the explanations to 'SENS'. The content was comprehensible except for a few words needing more details or lay language. The SENS-topics were of great relevance to patients and families and supported the preparation of the areas to be discussed in the ACP with professionals. It enabled patients to prioritize topics of concern. Patients and family members felt more confident and empowered in raising their concerns or fears and discuss them with the interprofessional team.

To prepare the ACP conversations a brochure which explains and structures the topics according to SENS seems to meet communication needs of patients, families and professionals. Patients and family members feel better prepared for family conferences and round table discussions. The SENS topics provide a common structure for active participation of patients and family. The right moment of the conversation, the way how the brochure is presented to patients and the oral explanation given with the brochure have to be clearly defined within the

interprofessional team to maximize the benefit for patients and families.

**Abstract number:** PO247

**Abstract type:** Print Only

### **Rendering the Ungraspable Graspable - The Use of Metaphors in Swedish Palliative Cancer Care**

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Good communication is of utmost importance in all forms of cancer care and especially so in the palliative context. To render the ungraspable graspable, metaphors are frequently used drawing on their capacity to capture the intangible in terms of more familiar experiences. For instance, to die from cancer can be described as 'coming to the end of a life journey' or 'losing a battle'. Metaphors are largely language and culture specific. Today's increasingly multicultural societies require particular awareness in order to achieve dignified, individualized palliative cancer care. This project aims to strengthen the scientific foundation for the use of metaphors in Swedish palliative cancer care. A secondary aim is to compare the use of metaphors in Sweden and the UK in order to reveal differences and similarities. Textual data are collected from

- a) internet-based blogs, where patients write about their illness-related emotions and experiences while being in palliative care, and from
- b) interviews with patients, family and health care professionals, where the focus is to investigate what it means to live a dignified life in palliative care.

The two sets of data are analyzed using both qualitative and quantitative linguistic methods. First, the Praggeljaz procedure, a well-established linguistic method for metaphor identification, is used in order to manually identify metaphorical expressions in the material, develop analytic categories adapted to the Swedish language data and ensure inter-rater reliability. Second, the material is approached by means of corpus linguistic methods. The combination of research methods is inspired by the UK-based MELC project. The data are currently being processed and the first results will be presented at the conference. The project is funded by The Kamprad Family Foundation, Sweden.

**Abstract number:** PO248

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### Community Nurses' Perceptions of Inter-professional Collaboration in Palliative Home Care

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**Background:** In palliative home care, general practitioners (GPs) collaborate closely with community nurses (CNs). Additional assistance of a specialised nurse of the palliative home care team (PHCT) may be required. As such, every member of this care team has his own responsibilities. This trio of health care providers is an "ad-hoc" team, which means that the composition may change with every patient.

**Aim:** To investigate the community nurses' own role perception in this team.

To investigate how the CN perceives the collaboration within this 'ad-hoc' team and the factors influencing the collaboration.

**Methods:** Semi-structured interviews with 20 CNs. Data analysis is based on a grounded theory approach.

**Results:** CNs perceive to be GP's 'eyes and ears' and to be coordinators of care if patient's needs change, whereas the GP is final responsible. CNs perceive PHCT nurses as equal, although they are seen as palliative care experts. CNs have mixed experiences of collaboration within the 'ad-hoc' team. Factors influencing the collaboration may be external (e.g. GP's lack of time to answer CNs' questions), intra-personal (e.g. CNs not daring to express their objections regarding GP's treatment decisions) or inter-personal (e.g. hierarchy or e.g. arising tensions if less experienced GPs are not open to discuss palliative treatment options with CNs). PHCT nurses are always willing to answer questions. Furthermore, being nurses too, CNs feel more relaxed to discuss patient's situation with PHCT nurses. Moreover both CN and PHCT nurse will start a coalition if they perceive a need to convince the GP of treatment decisions.

**Conclusion:** CNs' position and role execution is determined by several factors, which influence the inter-professional collaboration. They may have an impact on the efficiency and as a result on the quality of patient care. Improving inter-professional communication may enhance inter-professional collaboration.

**Abstract number:** PO249

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### Clinical Handover from Hospital Teams Reviewing Hospice Inpatients: An Audit

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**Introduction:** Patients are being admitted to hospices at earlier stages in their disease trajectory than previously. As

a result, there are frequent transfers between hospice and acute hospital for various outpatient appointments and procedures. Effective clinical handover is an important patient safety mechanism.

**Aims:** To examine the handover process between hospital and hospice following outpatient review or procedure

**Standard:** No national standard was available. Therefore it was agreed locally that all off-site clinic reviews should provide written handover to the hospice team within 48 hours of appointment.

**Methods:** The notes of ten patients who attended hospital appointments over a 4 week period were reviewed retrospectively. Data collected included demographics, details of clinic appointment, evidence of handover (written and verbal) between hospital and hospice, time delays in receiving handover, and information contained.

**Results:** Handovers were received by the hospice for only 3/10 patients (2 verbal only, 1 written and verbal). In each case the handover was received within 12 hours of appointment and contact details for further information was available. No handover was received for the remaining 7 patients.

**Intervention:** A Clinical Handover Form was designed and introduced. It requests free text comments under the following headings: discussions / plans / outcomes; treatments given or investigations performed; follow up arrangements; follow up action required by hospice team; name, role and contact details of person completing.

**Reaudit:** Since the introduction of the form, 6 patients have attended outpatient appointments. Handover has been received for 4/6 (66%) - 3 written, 1 both written and verbal, and all received within 48 hours of appointment.

**Conclusion:** A handover proforma appears to have increased the likelihood of the hospice receiving key clinical information post hospital appointments, thus enhancing patient safety.

**Abstract number:** PO250

**Abstract type:** Print Only

### The Feasibility of Discussing Advance Care Planning as a Part of a Support Service Provided by Palliative Care Nurses for Patients Newly Diagnosed with Advanced Lung Cancer

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**Background:** The aim of advance care planning (ACP) is to allow patients to take active part in decision making, increase the quality of care and minimize the risk of providing treatment that is either futile or not wanted. Whilst it is well recognized that an ACP discussion is an important part of palliative care, there is still a need to explore how it can become part of routine practice, ensuring a timely and person-centred discussion.

**Aim:** This study focuses on the feasibility of incorporating an ACP discussion, aided by an ACP booklet, into a palliative care support service for patients newly diagnosed with advanced lung cancer attending an outpatient clinic.

**Methods:** Semi structured interviews with patients and family members were used to assess whether opening a discussion on ACP as part of a palliative care service is acceptable and helpful. Special focus was on the experience of the booklet, the timing of the discussion and the role of the palliative care nurse in initiating and leading the ACP discussion. Reflective field notes were written by the palliative care nurse after each ACP discussion session. Interviews were transcribed verbatim, field notes typed up and the data analysed using thematic analysis.

**Results:** Seven interviews and field notes were analysed. Key findings from the study indicate that an ACP discussion as part of a palliative care service for this patient group and done by a palliative care nurse is acceptable, important and helpful even though uncomfortable.

The ACP discussion was a process aided by the booklet and even though the patients did not write in the booklet it prompted a discussion and supported the nurse in initiating and having the discussion.

**Conclusion:** This study highlights that an ACP discussion, offered to patients newly diagnosed with lung cancer, is supportive if structured as a part of a palliative care service. Palliative care nurses can be in a good position to open up the discussion with patients in outpatient clinics.

**Abstract number:** PO251

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### All Aboard! - A Collaborative Approach to the Implementation of a National Palliative Care Needs Assessment Education Programme: Doing Things Right and Doing the Right Things

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**Purpose:** Collaboration is vital to the successful implementation of a National Palliative Care Needs Assessment (PCNA) Education programme.

**Background:** The National Clinical Programme for Palliative Care and the Health Service Executive launched the PCNA guidance document followed by a train the facilitator programme to deliver a two day educational programme to support its implementation. Thirteen facilitators were trained and formed the PCNA Working Group.

**Method:** The Plan-Do- Study- Act (PDSA) provided the framework that maximised the available resources, and skills while also enabling us to incorporate a 360 degree evaluation and reflection to our programmes.

**Findings:** To create effective working environment and maximise meeting effectiveness, we appointed a chair, vice chair and secretary and agreed Terms of Reference. The PCNA incorporates emancipatory practice development (EPD); two observers were required at each programme to gain confidence and competence in EPD facilitation.

A robust and comprehensive communication strategy advertising/highlighting the programme was crucial.

**Learning:** The key to our success included:

- The communication strategy
- Rotating meeting venues and using teleconferencing
- Supporting facilitator's in gaining confidence
- Using the RCNME to coordinate the administration of the programme
- Reciprocal learning from facilitators utilising the 360 degree feedback for programme improvement

### Challenges:

- Geographical spread
- Acknowledging each person's contribution and debating the best way forward inclusively
- Balancing excising workloads
- Facilitation and the EPD approach

**Conclusion:** Our approach to the implementation of this national programme demonstrates the importance of collaboration and developing an effective communication strategy. This PDSA model enabled us do things right and to do the right things. Our next step is to actively look at ways to measure the impact of this programme on palliative care patients/significant others in a meaningful way.

**Abstract number:** PO252

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### The Five-finger-Rule for End-of-Life Care - A Substitute for LCP?

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**Background/aims:** The Liverpool care pathway (LCP) has been criticized in the public. It may be dangerous to follow the LCP as guideline without using clinical judgement and repeated if the patient is dying. Prior consent and communication are most important around the LCP and end-of-life care (Riley 2013). The aim of the present work was to find a simple substitute for using the LCP in order to make the approach more simple and to avoid unnecessary paperwork.

**Methods:** Based on the main content and categories of the LCP a simple five-finger-rule was created as mnemonic to aid communication and decision-making in end-of-life care.

**Results:** A simple mnemonic called the five-finger-rule of end-of-life care can help to remember important measures and guide the decision-making process in end-of-life care for health-care personal with limited contact to dying people.

The five-finger-rule of end-of-life care:

- Check the patients medication and remove unnecessary medication
- Plan medication that might be needed on demand to relieve distressing symptoms
- Unnecessary medical treatment / measures should be stopped
- Information and discussion of further treatment with the patient (and relatives)
- Take care of spiritual or religious wishes and needs

**Conclusions:** A simple mnemonic might have the potential to reduce paperwork and misuse connected to the LCP. Together with education in basic palliative care it may have the potential to improve end-of-life care for patients in hospitals, nursing homes or at home. Further research on the practicability of the five-finger-rule is needed.

**Abstract number:** PO253

**Abstract type:** Print Only

### Usefulness of a Reception's Protocol on Nurses' Part when a Patient Is Admitted on a Palliative Care Unit

*Ibáñez del Prado, Celia<sup>1</sup>, Redondo Elvira, Tamara<sup>2</sup>, Romero Fernández, María Isabel<sup>2</sup>, García Raya, Sonia<sup>2</sup>, Jiménez Domené, Paula<sup>2</sup>, Collar Rodríguez, Elena<sup>2</sup>, Barbas Abad, Sara<sup>3</sup>, Guerra Cordero, Laura<sup>2</sup>, Martínez*

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We would like to assess the level of satisfaction with nurses' reception on a Palliative Care unit. Analyzed variables are sociodemographic, understanding of palliative unit's aims, waiting time, evaluation of reception and contrast to other services.

**Methodology:** Descriptive study. Ad hoc hetero-applied survey where it is measured variables of the study once reception's protocol has been carried out.

**Results:** A sample of 47 caregivers. Average age= 52, 22. Kinship: 49, 6% are sons/daughters; 24, 4 % are spouses, 24, 4% are other members of the family and 2, 2 % are friends or neighbours.

85, 7 were assisted before 10 minutes from their arrival with the exception of 2 people, who were assisted after 10 minutes. The aims were clear for 100% of them and they also felt they were well received. Global evaluation= 9, 7 over 10. 81, 8% said they did not get the same attention on other units.

**Conclusion:** Reception's protocol is effective to clarify objectives with caregivers and involve them in the management program. Besides, caregivers felt they were assisted properly. This protocol should be applied to other units at most of the hospitals, specially units for the chronically ill, in order to improve their satisfaction and to adjust aims of intervention. It is good for caregivers just like for care team.

**Abstract number:** PO254

**Abstract type:** Print Only

### Improving Communication between a Specialist Palliative Care Service and a Long-stay Care Unit

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Waterford Hospice, Waterford, Ireland

In 2015 The Irish Hospice Foundation set up a one-day workshop 'What matters to me'. It set out to improve communication skills, confidence and competence for all staff dealing with residents of long-stay settings at the end of life. The information gleaned from the workshop in our geographical area clearly showed there was a gap in communication between the staff and their residents and families, but also between us, the Specialist palliative care team and the staff working in the long-stay unit.

We consulted the CNM3 of the unit to establish how best we could do this. We then designed a 2 page communication sheet that would be completed by ourselves for each resident under our care who entered the long-stay unit.

This contained a variety of information from simple demographics, such as next of kin details, to more complex information such as patients understanding of their disease and wishes regarding ceilings of treatment. This was then piloted on the first 20 residents entering the unit and lasted for 3.5 months.

We then designed an audit tool to ascertain if the communication sheet had been of any benefit to the staff and if there was any information missing that could be of further help to them. All responders were assured of their anonymity.

The participants in the audit were 10 Staff nurses and 6 HCA's. We had 6 completed responses making a 37.5% response rate.

Of the responses we received there was no negative feedback. All responders felt they were much better equipped to begin caring for the residents and felt it enabled them to feel more confident in approaching and beginning difficult conversations with residents and their carers.

In conclusion, the addition of this communication sheet has been received by the staff as an extremely valuable tool to enable them to communicate more effectively and more confidently with their residents and families.

**Abstract number:** PO255

**Abstract type:** Print Only

### Digital Advance Planning Beyond your Day of Death

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**Background:** How we deal with death has significantly changed with the advent of social media. Many private thoughts, photos and diary entries, in some cases directly from a hospital bed, are now published to microblogs and will remain there for future generations to access. Furthermore, it is now possible to create digital messages beyond death way into the future.

**Aim:** We discuss the novel concept of *Digital Advance Planning (DAP)* and what implications this will have on those people nearing the end of life. We summarise what advice can be given on managing digital content into posterity. DAP tools like DeadSocial allow users to programme and plan their digital afterlife in advance, even extending to being able to pre-programme blogs to appear after death, and convey video messages to loved-ones in the future.

**Methods:** This session will provide attendees with information on how to advise those affected by palliative and life-limiting illness with information and resources to plan

their digital legacy in advance of death or significant deterioration. Details around what organizations like the Digital Legacy Association can offer will be explored. In a similar way in which we should plan for the destiny of our physical possessions and what happens to them after our deaths, those facing the last years of their lives may also wish to consider what happens to passwords, online appliances, subscriptions, photo albums, videos and social media channels after they die. We also discuss some of the legal and ethical conundrums this can create.

**Results:** We examine how social media are breaking down taboos around the topic of death. Professionals will be encouraged to research online activities in relation to end of life digital planning, on sites like [www.DigitalLegacyAssociation.org](http://www.DigitalLegacyAssociation.org), [www.DeadSocial.org](http://www.DeadSocial.org) and [@deadsocial](https://twitter.com/deadsocial)

**Conclusions:** Digital Advance Planning is a concept that many healthcare professionals may not yet be aware of, but it is likely to become commonplace in future.

### Palliative care in specific groups

**Abstract number:** PO256

**Abstract type:** Print Only

#### End of Life Care Documentation in Residential Care of Older People: A Chart Analysis

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**Background:** Many older people who enter residential care either die there or are transferred somewhere else to die (O'Shea et al, 2008). Consequently, excellent care delivery in such settings demands comprehensive attention to individualised end of life care (EOLC), which integrates palliative care principles and person centred care. This paper represents a phase of a larger action research study and examines documented care practices in the last 48 hours of life for older people in residential care.

**Methods:** A time limited retrospective chart review was carried out using a modified version of the TENO (Teno, 1999) "End of life chart audit tool" in two large residential care facilities. The audit focused on care received in the last 48 hours of life, identifying planning for EOLC or palliative care references.

**Presentation of results:** A total of 53 charts were reviewed. Charts reflected 24 males and 29 females with an age range between 69-96 years. Ethical approval was sought and obtained from each site. The average length of stay was 1015 days. Most commonly documented cause of death was aspirate pneumonia. Pain was the most commonly assessed symptom in the last 48 hours of life, yet, the efficacy of the outcomes of interventions was only

documented in 15 residents charts. 28 residents had a syringe driver in place and the most common drug used was Morphine.

The term palliative care was only specifically mentioned in 7 charts, however, an end of life care plan was present in 50% of the charts reviewed. 44 residents had a DNR order and 86% of these orders were in discussion with family members and not the residents. The emotional support of family around the time of dying and death was only mentioned in 5 charts.

**Conclusion:** Documenting care is an essential component of care delivery in EOLC. This study demonstrates deficits in chart documentation and EOLC practice which has consequences on both practice delivery and staff understandings.

**Abstract number:** PO257

**Abstract type:** Print Only

### **Palliative Care or End of Life Care?: Using Death Reviews to Improve Care for Older People Living in Nursing Homes**

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**Background:** With more people dying in the context of old age with advanced chronic illness, it can be difficult to develop consensus when palliative care (PC) should commence. Nowhere is this confusion more apparent than in nursing homes as it is not always clear which nursing home residents are close to death (Bern-Klug 2009). Consequently, this study examines how precisely the interface of older person care and palliative care is managed in nursing homes.

**Methodology:** Using action research, staff in 2 residential care units for older people joined co-operative inquiry groups. The goal was to facilitate participants to use their own experience of PC in order to understand their world and practice and inductively develop new and creative ways of looking at things through learning how to change things they might want to change and finding out how to improve care delivery. Through the use of death reviews, the group reflected on their own experience of caring for dying residents.

**Results:** Over an 8 month period, 35 death reviews took place. Groups used a reflective process on each resident's death to understand and reflect on care, in particular, to reflect on the resident's final days. Many challenges were identified, including recognising when a resident is dying and being able to provide the most appropriate care.

**Conclusion:** Healthcare providers are challenged to evaluate care being given and put in place resources to ensure that a PC approach is delivered with appropriate consultation from specialist PC providers, if required.

Consequently, this research identifies the complex nature of a palliative care approach in older person residential care and the challenges staff experience in caring for older people as they approach the end of life. Language and understandings are important. Staff valued care, and using an action research process facilitated staffs' insight into PC as a continuum, describing a merging of person centred care and palliative care.

**Abstract number:** PO258

**Abstract type:** Print Only

### **Palliative Care Service Provision for Veterans with Non-malignant Respiratory Disease and their Carers, in Rural America**

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**Background/aims:** It is recognised that the majority of patients diagnosed with a malignant disease will have access to palliative care. It is less clear if the same standards of palliative care are available to those with non-malignant respiratory disease and their carers living in rural areas of America. This study aimed to explore palliative care provision for veterans with non-malignant respiratory disease and their carers living in remote areas of America.

**Methods:** An explorative study consisting of 4 focus groups with 16 healthcare professionals from a large rural veteran hospital in America. Purposive sampling was employed to recruit participants who were involved in the care of patients with bronchiectasis, chronic obstructive pulmonary disease and interstitial lung disease. Focus groups were transcribed verbatim and the data was analysed using thematic analysis.

**Results:** Findings highlighted several perceptions of what hindered the delivery of optimal palliative care to these patients and their carers, such as the prognostic uncertainty aligned with a diagnosis of non-malignant respiratory disease and a lack of availability of local palliative service provision. Participants' experiences also highlighted the influence a patient's cultural background and the misconceptions held by the veteran population, and the healthcare professionals themselves, had on their willingness to accept palliative care.

**Conclusions:** The management of patients with non-malignant respiratory disease is complex and challenging with a clear need for a stronger and more integrative model

of practice, incorporating palliative care in a responsive and dynamic way. Misconceptions regarding the role of palliative care can impact on services received. Inequalities in palliative service provision can also be caused by the rurality of patients geographical location.

**Funding:** Department of Health Social Services and Public Safety Northern Ireland through the Florence Nightingale Foundation.

**Abstract number:** PO259

**Abstract type:** Print Only

### Contributes for a Model of Supervision of Family Caregivers of Terminal Ill at Home: A Qualitative Study

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**Background:** Family caregivers play an important role in the support of terminal ill at home. However, there are few models of clinic supervision that help to make decisions according the clinical situation of the terminally ill and needs of family caregiver. Bringing international classification for nursing practice (ICNP<sup>®</sup>) and systematic clinic supervision, we could improve the quality of care provided.

**Aim:** To explore self-care needs and risks of terminal ill and met/unmet needs of family caregiver at home to understanding decision-making processes.

**Design:** Data were collected from December 2013 to July of 2014, using a qualitative interviews, observations and notes based on ethnographic approach. Data were codified using ICNP<sup>®</sup>, triangulated with literature. Flowcharts were validated by experts.

**Results:** 10 family caregivers and 10 terminals ill (8 had dementia as principal diagnostic). Data were categorised into diagnostic criteria that conducted to deficit in self-care and risks. Family caregivers reported the need of improvement of skills and knowledge. Unmet needs appear especially on prevention of complications or absences of awareness for some of these complications. All family caregivers need of formal/ informal support, especially after assessing their physic, emotional and relational capacity so as availability of time to provide care.

**Conclusion:** This study identifies diagnostic criteria's for deficit in self-care and ricks of terminal ill. Also evidence the importance of assessment of the family caregiver's capacity, time and type of support/device specific for each deficit or risk of terminal ill using decisional flowcharts. This research provides a strategy, that if it is used systematic way, can help to conceptualize care of quickly and correctly.

**Implications:** Models that use encoded data may help to improve care quality. Also, it can provided information for obtaining health indicators, special if the documentation is done in electronic systems.

**Abstract number:** PO260

**Abstract type:** Print Only

### Perspectives of Parents Caring for their Child with a Non-malignant Life-limiting Condition: The Role of Children's Palliative Care Services

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The aim of this study was to explore perspectives of parents caring for their child with a non-malignant life-limiting condition (NMLLC) on the island of Ireland.

#### Specific objective:

- Provide an understanding of the unique perspectives of parents caring for their child with a NMLLC including their experiences of Children's Palliative Care (CPC) service provision.

This study utilised a mixed methods research design. Purposive sampling was used to recruit parents in five research sites in Ireland (both north and south). Clinical gatekeepers identified and made initial contact with potential participants at each research site. A total of 22 one-to-one semi-structured interviews were conducted with parents (17 mothers and 5 fathers) over an eight month period. The parents spoke about the life of twenty children with a variety of conditions aged between one and seventeen years. The parents interviewed were from a wide socio-demographic spread. Topic areas pertaining to experiences of caring for their child on a daily basis, including access and experiences of services were explored during the interview. Thematic analysis was conducted. Themes pertaining to parental exhaustion, parental physical and social isolation, sibling concerns, spousal relationship issues, difficulties in securing respite services and challenges associated with hospitalisation emerged.

These findings highlight the impact that caring for a child with a NMLLC has on the family and provide a foundation from which to consider optimal palliative care provision for children.

**Abstract number:** PO261

**Abstract type:** Print Only

### Elderly that Care Other Elderly: This Group Needs Palliative Care?

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**Introduction:** The chronic situations associated to changes in family contributed to increasing numbers of older people who cares for another elder. In this sense, it would be relevant to know the characteristics of these caregivers to measure the need of palliative care.

**Aim:** To identify the profile of elderly caregiver who cares another elderly at home.

**Materials and methods:** Cross-sectional study with elderly caregivers who care for an elderly at home. Data were collected by questionnaire that includes Barthel Scale, Lawton and Brody Scale, Index of complexity of pharmacotherapy, Geriatric Depression Scale and Mini Mental State Examination. Data were analyzed with SPSS version 22 for Windows.

**Results:** Participated 30 elderly caregivers with 74±6.9years. The most are female, married and with low education. All are independent in daily living activities while in instrumental activities 10 have partial dependency and 3 severe. They refer, on average, 3 diseases and taking 6 drugs/day. Twelve have depression and 3 have cognitive deficit. The difficulties are physical requirement, absence of support and reduced reporting to manage critical events. The strategy adopted is question the social worker but when occurs the intensification of symptoms most caregivers use the emergency. As for community resources, they highlight the home support service.

**Conclusion:** Characteristics of caregiver difficults the effective exercise of the role and promoting health problems. It is important expand the research but also develop tools of evaluation/monitoring and intervention centered on long-term care and palliative care philosophy.

**Abstract number:** PO262

**Abstract type:** Print Only

### US & UK Patient Perceptions of Living with Idiopathic Pulmonary Fibrosis [IPF]: Impact, Survival, & Symptom Burden

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**Introduction:** IPF is a progressive lung condition associated with high symptom burden, survival of 2-5 years post diagnosis & follows an unpredictable trajectory. Palliation of symptoms may be initiated at diagnosis. This work aims to gain patient perspective of adaptation, treatment & survival in IPF in order to enhance clinical management & patient-physician interactions.

**Methods:** 26 patients were recruited at 3 academic referral centres in US & UK. English-speaking adults diagnosed with IPF UK (n=12) & US (n=14) & stratified for disease severity participated in 1 of 4 focus groups. A safe environment was created to enable free flow discussion. Prompts were used as necessary for clarification & expansion of patient-presented concepts. Discussions were audio-recorded, transcribed & underwent independent analysis using inductive methodology.

Each transcript was deconstructed to basic concepts by at least 4 of 6 independent analysts, including a carer & clinical psychologist with special interest in IPF. A Patient & Public involvement officer attended UK groups. An iterative process including independent reading & re-reading, individual thematic analysis & group discussion identified core themes & sub-themes therein.

**Results:** Participants discussed their experiences of living with IPF from their own perspective. By this method concepts were identified that characterise both intrinsic & extrinsic factors that impact living with IPF. See table:

SYMPTOM BURDEN  
CONDITION MANAGEMENT  
PSYCHOSOCIAL MANAGEMENT  
SYMPTOM MANAGEMENT  
UNCERTAINTY  
LIFE CHANGES  
COMMUNICATION  
KNOWLEDGE  
PHYSICAL ENVIRONMENT  
ADVANCED PREPAREDNESS

More detailed sub-themes were also identified.

**Discussion:** Patients reported that focus group participation was a positive & supportive experience & expressed an interest in meeting again. Our conceptual framework will inform & enhance clinical service provision in line with National guidance. The feasibility of supportive group work in IPF populations is being explored.

**Abstract number:** PO263

**Abstract type:** Print Only

### Integrating Medical, Psychological and Palliative Care in an Intensive Care Setting; Insights Gained from

### a Critical Care Staff Support & Reflective Practice Group Series Using Inductive Content Analysis

*Doyle, Anne-Marie<sup>1</sup>, Naldrett, Ian<sup>2</sup>, Price, Susanna<sup>2</sup>, Cordingley, Jeremy<sup>2</sup>, Ross, Joy<sup>3</sup>*

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**Background:** There is a growing awareness of the psychological challenges faced by patients & families during critical illness & recovery. It is recognised too, that staff face challenges related to the use of increasingly advanced technology & routine exposure to patient/family distress in relation to illness/surgery, acquired disability, cognitive impairment & death; up to 30% of patients admitted to intensive care die during their stay or within a month. It is recognised that positive staff well-being contributes to the delivery of high quality care.

**Aims:** The study evaluated the introduction of a group programme with 4 objectives:

1. To provide an opportunity for staff to reflect on the challenges of working in critical care;
2. To promote a sense of positive staff support;
3. To input perspectives from Psychology & Palliative Care Specialities;
4. To generate insights to inform quality improvement.

**Method:** Two series of 10 weekly sessions were offered to staff; the groups were facilitated by a consultant clinical psychologist and a consultant in palliative care medicine. Detailed notes of discussions were taken contemporaneously and were analysed using inductive content analysis.

**Results:** Identified key themes included: high levels of professionalism, high work satisfaction & high work motivation; other key themes indicated challenges related to: maintaining high standards of healthcare, interdisciplinary communication, team-working, decision-making, prolonged active medical treatment & traumatic incidents for staff.

**Conclusions:** Critical care staff face a variety of challenges in their roles and benefited from an opportunity to discuss stressors & concerns in a supportive, reflective learning environment; insights gained informed quality improvements & further opportunities for staff support & training. An integrated model of medical, psychological & palliative care offers promising benefits & new possibilities in relation to increasing quality of healthcare.

**Abstract number:** PO264

**Abstract type:** Print Only

### Loss and Grief in Dementia

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**Background:** A range of losses occur throughout a person's journey with dementia. Losses occur for the person and for their families as the disease progresses. Healthcare staff also experience losses throughout their time caring for a person with dementia. Grief as a result of these losses is under-recognised and under-reported by people with dementia and their families.

**Aim:** To develop a guidance document and factsheet to support healthcare staff to recognise, acknowledge and respond to loss and grief in dementia.

**Methods:** An Expert Advisory Group (EAG) was convened. The group followed the National Clinical Effectiveness Committee approach to developing guidelines which included literature reviews, consensus building and consultation with key stakeholders.

**Results:** The guidance document and factsheets will be available in March 2015 to support healthcare staff in working with loss and grief in dementia. Key considerations for good practice will be listed. The guidance will focus on 3 key areas: loss and grief for the person with dementia, loss and grief for families and loss and grief for staff. Resources will be listed for each of these areas.

**Conclusion:** Recognising loss and grief as part of the experience of having dementia is a core part of good dementia care. Provision of supports to people with dementia and their families at transition points is essential.

**Abstract number:** PO265

**Abstract type:** Print Only

### Dying to Talk: Facilitating Discussions on Future and End-of-Life Care with People with Dementia

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**Background:** People dying with dementia are a vulnerable group at risk of not being involved in end-of-life care (EOLC) discussions. Discussions with a person with dementia about future and end-of-life care should take place as early as possible. Within healthcare, many staff are reluctant to initiate

EOLC discussions with people with dementia due to fears of causing distress, role uncertainty and a lack of confidence in delivering bad news. There has been an absence in the literature to support staff to initiate EOLC discussions.

**Aim:** To develop a guidance document and factsheet to support healthcare staff to facilitate discussions on future and end-of-life care with people with dementia.

**Methods:** An Expert Advisory Group (EAG) was convened. The group followed the National Clinical Effectiveness Committee (NCEC) approach to developing guidelines which included literature reviews, consensus building and consultation with key stakeholders.

**Results:** The guidance document and factsheet is available to support healthcare staff to initiate and facilitate EOLC discussions with people who have dementia. The document lists 5 key considerations to inform good practice in communicating with a person with dementia and lists guidance and resources for staff.

These are:

1. Recognise that communication with a person with dementia is always possible
2. Develop knowledge about the progression of dementia and key triggers for end-of-life discussions
3. Plan future care to optimise comfort
4. Promote personhood throughout the person's journey
5. Record future wishes when they are expressed.

**Conclusion:** Communicating with a person with dementia requires staff to be flexible and skilled in their approach. Further supports and training are required to support healthcare staff to communicate with people who have dementia about their future and end-of-life care.

**Abstract number:** PO266

**Abstract type:** Print Only

#### **Creating our Vision for End-of-Life Care in Residential Care**

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**Background:** As part of our engagement with the Irish Hospice Foundation's "A Journey of Change" programme, we developed our unique Vision for end-of-life care. The development of our Vision was the first in a number of initiatives within the programme, which provides support and training for staff to provide the best possible care for residents at the end of their lives.

**Methods:** Members of our Compassionate End of Life Group (CEOL Group) attended a highly personal, reflective workshop to begin to develop our Vision. Based on the Irish Hospice Foundation's Framework on what good end-of-life care looks like (I.H.F., 2014), the workshop provided opportunities to reflect on culture and attitudes to end of life and death in our centre. In small groups we utilised tools to examine and assess our values, with regard to Person Centred Care, Ethical Care, Care Planning/Discussions now and for the future, Family & Bereavement Care and Staff Support. The CEOL group then elicited the thoughts, attitudes and values of the organisation as a whole in relation to end-of-life care. Several strategies were employed to glean such information. The cornerstone of the initiative was the STOP START CONTINUE CHANGE exercise (Morrison, 2008). We asked staff what they would stop, start, continue, change in relation to identified elements of end-of-life care in our organisation, "if it was you" and "if it was someone close to you".

**Results:** Several themes emerged. These included the importance of private room & space, family, named carers, pain relief, comfort, hospice involvement, communication and documenting wishes. These underpinned the formation of Our Vision for End-of-Life Care.

**Conclusion:** Through a structured supported process we were able to reflect and consider our attitudes and culture with regard to end-of-life and death. We led the organisation to do likewise thus ensuring that our Vision is unique and held by all staff.

**Abstract number:** PO267

**Abstract type:** Print Only

#### **The Development of a Tool to Identify People with Intellectual Disabilities (ID) in Need of Palliative Care**

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**Background:** Professionals caring for people with ID are in need of support in identifying their patients in need of palliative care.

**Research aims:** We aimed to develop a valid and applicable tool that helps professionals to identify people with ID who are in need of palliative care.

**Study design and methods:** We used a mixed-method design. First, physicians completed a retrospective survey about their last patient with ID with a non-sudden death. Second, we performed interviews with physicians and

caregivers regarding identification of patients in need of palliative care. These steps generated relevant items for the tool, which were subsequently prioritized in focus groups. The resulting preliminary tool was tested for validity and applicability in a prospective follow-up study among 190 Dutch people with ID with an elevated risk of dying within 12 months. At 0, 5 and 10 months, physicians and caregivers completed the tool and provided information on applicability and relevant parameters of health and functioning: illness burden, comorbid conditions, symptoms, activities of daily living, mobility and medication use.

**Method of statistical analyses:** We examined the content validity by triangulating; views obtained from literature, retrospective survey and in-depth interviews with experts. Construct validity was studied by examining independent associations between the tool on the one hand and the parameters on the other hand using multiple linear and logistic regression analyses. In addition, we assessed the sensitivity and specificity of the checklist in predicting survival. Responsiveness is assessed by associating baseline data of the tool with follow-up parameter data, controlling for baseline parameter data, in generalized linear models with random effects.

**Results and interpretation:** The analyses are now in progress and the results and the final tool will be presented at the conference.

**Source of funding:** *ZonMw* (project number: 1151.0033).

**Abstract number:** PO268

**Abstract type:** Print Only

### Access to Respite and Social Care for Young Adults in Wales: Please Mind the Gap

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**Background:** Young people with life-limiting conditions (LLC) constitute a new and growing population with distinct palliative care needs. As well as complex physical needs, these young adults and their families have particular needs for respite and social care.

**Aim:** To describe provision of respite and social care for young people with LLC across Wales.

**Method:** All health boards and councils in Wales were contacted with a request for information about respite and social care services provided to 18-30 year olds with LLC. Care homes were also contacted about their services, registration, availability of nursing care and activities.

**Results:** All 7 Health Boards and 22 Councils responded. Response rate from care homes was very low. 2 care homes replied in full; 1 was registered to care for adults under age 40. Most health boards reported that only usual adult services are available. Just 1 health board reported providing respite for this group. 2 councils reported access to respite services with 24 hour nursing.

**Discussion:** Although essential for many young people with LLC, respite with 24 hour nursing care is frequently not available. Many respite and social services are targeted at people with learning disabilities and, in many cases, no distinction was made between services for people with learning disabilities and those without.

**Conclusion:** This national survey demonstrates that respite and social care services for young adults with LLC in Wales are variable, limited and difficult to identify. There appears to be little awareness of this group's unique needs.

No funding was received for this study.

**Abstract number:** PO269

**Abstract type:** Print Only

### Parents' Priorities in Caring for Children with Life Limiting Conditions Nearing End of Life at Home, a Retrospective Qualitative Analysis

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Paediatric palliative care needs a flexible coordinated and collaborative team approach that can respond to the changing needs of the child and family, particularly at end-of-life. As a service development initiative, a steering group of senior professionals identified bereaved parents' experiences as essential in developing an integrated and progressive children's palliative care service for end-of-life care at home.

**Aims:** The study sought to identify elements of current service availability, delivery and coordination valued by parents when their child was nearing end-of-life at home.

**Methods:** A retrospective qualitative study with purposeful sampling of bereaved parents was conducted. All parents were bereaved at least 6 months to a maximum of 36 months. Semi structured interviews were carried out with an interview guide. Interviews were digitally recorded and transcribed verbatim. Transcript data was entered into

Nvivo for analysis. Data was analysed using a thematic approach by two researchers.

**Results:** 8 bereaved parents of 5 children who died at home were interviewed

Priorities identified

- Availability of skilled professionals familiar with their child
- Communication between key worker, parents and professionals
- Key worker with links to acute paediatric services
- Out of hours support
- Hands on care by skilled nurses at end of life
- Bereavement support starting prior to the death of the child was helpful

Independent of the individual circumstances, these priorities were universal and recurrently referenced by parents.

**Conclusion:** This study identifies parents' priorities for service provision in caring for children at end-of-life at home. Key areas for service development are highlighted to establish integrated, flexible and coordinated care to maintain parental resilience in caring for children at home.

**Abstract number:** PO270

**Abstract type:** Print Only

### Quality of Life in Patients with Severe Multiple Sclerosis (MS): Comparing Individualized Tools and Standard Questionnaires

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**Background:** individualized measures of quality of life (QoL) differ from standard patient reported outcome measures (PROMS) because the explored domains are elicited directly by the participants and not listed in preformed questionnaires.

**Aim:** To evaluate the feasibility and usefulness of the Schedule for the evaluation of individual QoL -Direct Weighting (SEIQoL-DW) in patients severely affected by MS, and compare the results with standard PROMS.

**Methods:** SEIQoL-DW and other PROMS, such as POS-S-MS, CORE-POS, EQ-5D, HADS, were used in the basal

evaluation of the PeNSAMI trial (ISRCTN73082124), a randomized, multi center, double blind, Italian trial which aims at evaluating the impact of a palliative care approach in people with advanced MS.

**Results:** 59 patients with advanced MS were assessed at baseline. 48 completed the SEIQoL-DW (mean age 60, 58% women, mean EDSS 8.5). The remaining 11 patients could not complete the measure due to cognitive impairment or severe communication issues. In no cases the SEIQoL-DW was considered invalid by the research team. Most elicited cue was "family"(94%), followed by "relationships" and "leisure activities" (both 65%). Mean SEIQoL-DW index score was 59.1 (SD 25.5, range 3-100); very low correlation with the other PROMS was found, 20% of the elicited cues in the SEIQoL-DW were not listed in POS-S-MS nor in POS-CORE.

**Conclusions:** SEIQoL-DW is an interesting tool to evaluate QoL in advanced MS patients. Most participants, even very ill persons, can complete it. It provides information that could be missed using standard PROMS only.

**Abstract number:** PO271

**Abstract type:** Print Only

### Changing Referral Patterns to an Evolving Children's Palliative Care Service

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**Background:** Paediatric palliative care is an evolving speciality. The first consultant paediatrician with a special interest in paediatric palliative medicine was appointed to a national tertiary paediatric centre in May 2011. Prior to this, the children's palliative care service had been led by 2 visiting part time adult palliative medicine physicians. Having a full time palliative medicine paediatrician on site has resulted in an increase in the number of referrals to the service. This study undertakes to compare referral patterns before and after the appointment of the palliative medicine paediatrician.

**Methods:** The medical records of all children referred to the palliative care service from 01/01/2010 to 30/16/2010

and from 01/01/2015 to 30/06/2015 were reviewed retrospectively. Data collected included the number of referrals, diagnoses, referral sources and reasons for referral.

**Results:** There were 38 referrals to the children's palliative care service during the first half of 2010 and 56 referrals during the same period in 2015. The most common source of referrals for both periods was medical oncology (27% in both years). In 2015, referrals were received from teams who had not referred in 2010, namely Obstetrics (referred 3 patients), intensive care (4 patients) and general paediatrics (12 patients). In 2010, 66% of referrals were for symptom control and 9% for terminal care whereas in 2015, 43% of referrals were for symptom control, 52% were for terminal care and 5% were antenatal reviews.

**Conclusions:** Referrals to the children's palliative care service have increased by 68% since the appointment of the palliative medicine paediatrician. The pattern of referral sources has changed outside of the medical oncology cohort. The number of referrals for terminal care has increased. This information highlights the need to further develop the service with an emphasis on increased staffing.

**Abstract number:** PO272

**Abstract type:** Print Only

**Perinatal Palliative Care in the Case Of Severe, Life-limiting and Incurable Conditions: A Qualitative Study with Professionals from Pregnancy Counselling Services**

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**Background and aim:** Prenatally diagnosed life-limiting disease of the child (LLD) is often associated with great uncertainty and fear, because parents do not know what to expect. In the US, UK and Australia, frameworks for perinatal palliative care (PPC) have been developed, aiming at accompanying families and children during pregnancy, delivery and after birth. In Germany no structured PPC programs exist, however according to existing law families can make demand on counselling by a specialized pregnancy counselling service if termination of pregnancy in LLD is considered. Thus our aim was to analyze the experiences of pregnancy counselling services as well as their needs and concerns in this context.

**Methods:** We conducted semi-structured interviews with 9 senior professionals (8 female, 1 male) from three different pregnancy counselling services in varied areas (6 city, 3 urban). Participants were chosen by selective sampling. The interviews were evaluated by descriptive and evaluation coding according to Saldana.

**Results:** The participants reported difficulties associated with insufficient cooperation between the different disciplines involved. They experienced that psychosocial and emotional aspects are underestimated in medical counselling. The interviewees would appreciate a framework of a multidisciplinary approach providing comprehensive PPC for the families. Moreover some presumed families might better cope with bereavement with the support of PPC after they decided to continue the pregnancy.

**Conclusion and perspective:** A PPC framework could coordinate the multidisciplinary approach and offer additional support for families who decided to carry the pregnancy to term and to take care for the child. Further studies with other professionals involved and with couples who have already experienced the dilemma of decision-making in perinatal LLD are needed. The results of our study substantiate the necessity of developing PPC programs in Germany.

**Abstract number:** PO273

**Abstract type:** Print Only

**Integrating Key-interventions Palliative Cancer Care (KI-PCC) in Routine Oncology: Development of a Clinical Practice Tool Applicable for Oncology and Specialist Palliative Care Health Care Professionals (HcP) in Various Settings**

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**Aim:** To develop a clinical practice tool for in- and outpatient care to monitor patient needs for KI-PCCs and their delivery by HcPs in variable settings

**Study design and methods:** Focus groups (FG) with HcPs explored the perceived relevance of KI-PCCs in daily routine, patient characteristics in need of KI-PCCs, and practice settings. Ad verbatim transcripts were sequentially analysed starting with predefined main categories (patient and hcp characteristics, assessment, trigger, time and structural aspects), followed by inductive content analysis (codes, subcategories, comparison FGs, reordering) until consensus.

**Results:** From 3 FG (9 nurses, 17 doctors, 1 psychologist) all hcp agreed that all seven KIPCCs are important in routine oncology care from diagnosis to death, but are scarcely documented. KI-PCC monitoring requires HCP competencies (awareness of patients vulnerability: Illness understanding, patients' hope, anxiety, decision making capacity; responding to verbal or non-verbal hints: situational reactions or expressions of patients during interactions), working single, joint, sequential, or in multiprofessional clinics (influenced

by attitude). Both settings (emergency room, out-/inpatient, oncology/ palliative) and triggers (progressive disease, toxicity, unplanned hospitalisation, severe symptoms, end-of-life) can mandate KIPCC monitoring. But KIPCC shall be applied individualized, voluntary, highly embedded in routine work flows and steered, HCPs discouraged patient reported outcomes. Our data support the importance of attitude and competences in communication - namely to access hints - and multiprofessional collaboration.

**Conclusion:** KIPCC are important in oncologic routine care and shall be documented in a longitudinal way. Effective training of hcp for KIPCC documentation seems to be essential. Whether KIPCC documentation can be supported by a checklist for hcp and/or a booklet for patients about existing offers shall be examined in further research.

## Non-cancer

**Abstract number:** PO274

**Abstract type:** Print Only

### The Dementia Patients Journey in a Specialist Palliative Care (SPC) Service - From a Carers Perspective

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**Aim:** The aim of this study was to evaluate the dementia patients journey in a SPC service from a carers perspective.

#### Methodology:

- A literature search was completed
- A retrospective case note review was carried out of referrals of patients with a diagnosis of dementia in 2012 to a Specialist Palliative Care Service. A structured questionnaire was completed.
- 6 carers of dementia patients were interviewed to determine their experiences.

#### Results of case note review:

- 409 referrals were received in 2012
- 15% (61) of patients were included in the study as they were referred with a primary diagnosis of dementia or had a co-morbidity of dementia.
- 51% of patients were located in the general hospital setting
- 36% of patients did not have a geriatrician or the psychiatry of old age service involved at the time of the referral.
- The main indication for referral was for symptom control of pain and confusion.

- 50% of the patients referred were involved in the service for 8-14 days

#### Results of interviews:

3 main themes emerged from the interviews

1. The Challenge of Caring
2. Experience of SPC Service
3. Management of Care

13 key recommendations emerged from the study which would ensure better co-ordination of services, continuity of care for dementia patients and support for carers in their role.

**Conclusion:** Specialist palliative care for people with dementia is under researched. This project aimed to bridge the gap by illustrating the dementia palliative care patient's journey in a specialist palliative care service in Ireland. Carers discussed that at a point in their relatives dementia illness they began to struggle and reached a point where they needed 'something else'. Carers described the SPC service as been that 'something else' and they fulfilled their role through their support, specialist symptom control knowledge and expertise in communication.

**Abstract number:** PO275

**Abstract type:** Print Only

### Peculiarities of Geriatric Patients with Dementia Included in Palliative Program

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**Background/aims:** More and more research studies that focus on non-cancer patient with irreversible disease.

**Methods:** observational, prospective and analytical study.

**Results:** N=638. Dementia 30.7% (N=195). Men 42.6% (N=83), women 57.4% (N=112), mean age 83'88+/-7. Vascular dementia 40.4% (N=74), Alzheimer 31.7% (N=58), mixed 12% (N=22), Parkinson-dementia 8.7% (N=16), Lewy body dementia 0.5% (N=1), other 6.6% (N=12). Mean Reisberg GDS 6+/-1.05. Mean Pfeiffer 8.87 errors, Mean Pfeiffer without dementia 1.48 (p < 0.001). Mean Barthel previous 19'73 +/-31'8 and 11'9 +/-23 in first visit. Mean Barthel previous patients without dementia 85 +/- 30.3 and 52'34+/-38 in first visit (p< 0.001). Die 31.8% (N=62) compared to 53'1% without dementia (N=234) and are hospitalized 6.7% (N=13) and 17.5% without dementia (N=77). Pressure ulcer 19.6% (N=38), compared to 3'9% (N=17) in non-demented. Clinical in dementia: psychomotor agitation 38.5%

(N=75), anorexia 31.3% (N=61), pain 27.2% (N=53), mean VAS 1.8+/-6.43, insomnia 15.9% (N=31), dyspnea 7.2% (N=14) mean NYHA 0.8+/-3'43, anxiety 5.6% (N=11), 2.1% nausea (N=4) and depression 1.5% (N=3). patients without dementia: psychomotor agitation 10% (N=44), anorexia 53'3% (N=235), pain 50'6% (N=223) mean VAS 6.54+/-1.8, insomnia 25'4% (N=112), dyspnea 28.3% (N=125) mean NYHA 0.84+/-2'59, anxiety 31'1% (N=137), 16.8% nausea (N=74) and depression 29.9% (N=132) (p< 0.001 all symptoms). Sedation dementia 8'2% (N=16) and 20.4% without dementia (N=90) (p < 0.001).

#### Conclusions:

1. less functional decline in patients with dementia, although prior overall situation worse.
2. More frequent presence of symptoms in patients without dementia, except psychomotor agitation.
3. Dementia is not a factor that predisposes sedation.

**Abstract number:** PO276

**Abstract type:** Print Only

#### Identifying and Responding to Health Care Professional Barriers and Facilitators to Meeting the Needs of Patients with Advanced COPD and their Informal Carers

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**Background:** Management of advanced chronic obstructive pulmonary disease (COPD) should relieve symptoms, optimise daily functioning and reduce carer burden. Health care professional (HCP) barriers and facilitators to meeting patient and carer needs exist but our understanding of them is limited, and we don't know stakeholder views of actionable responses to them.

**Aim:** To identify barriers and facilitators to HCPs' ability to meet patient and carer needs in advanced COPD, and stakeholder views of actionable responses to them.

**Method:** HCPs were nominated by a population-based cohort of patients participating in the multiple-perspective mixed-method Living with Breathlessness Study. We purposively sampled 45 HCPs for topic-guided interviews: medical and nursing specialists and generalists from primary and secondary care. Verbatim transcripts analysed with framework approach. National stakeholder workshop (October 2015) will review actionable responses.

**Results:** Barriers and facilitators to meeting needs exist at operational, professional and patient levels, varying by professional group and setting. Barriers included: the drive of organisational and medical agenda, focus on prognostication and patient categorisation, time constraints, lack of confidence and skills in psychological support and end of life conversations, lack of patient support needs assessment, lack of referable services, service location, managing expectations (commissioners and patients), and non-compliance. Facilitators included: longevity of patient-HCP relationships, listening skills, accessibility and patient expertise. Some HCPs described the facilitative effect of the study interviews for reflection on their clinical practice. Stakeholder views of actionable-responses will be reported. **Conclusion:** Actioning stakeholder-endorsed responses to HCP barriers and facilitators to meeting needs could improve care and support of patients and carers living with advanced COPD.

**Funders:** Marie Curie & NIHR CDF.

**Abstract number:** PO277

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#### A Re-audit of the Provision of Specialist Palliative Care to a Cohort of Patients Attending a Dedicated Motor Neuron Disease Clinic

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**Background:** The European Federation of Neurological Societies (EFNS) Task Force on Amyotrophic Lateral Sclerosis (ALS) 2012 recommended that palliative care should be part of the multidisciplinary clinic & a palliative care approach should be incorporated at time of diagnosis. Following this, the provision to specialist palliative care (SPC) to an acute hospital ALS MDT was audited against this standard. SPC did not form part of the dedicated MDT. SPC were involved with 48% of patients, but only 14% of patients were referred within a year following diagnosis. To implement change in line with international standards set out by the 2012 EFNS task force, a SPC physician was formally incorporated into the ALS MDT in July 2014.

**Aim:** To determine the input of the SPC Service at a dedicated ALS clinic at Cork University Hospital following the incorporation of a SPC physician to the MDT.

**Method:** Data was collected retrospectively from separate ALS and SPC patient databases, and the records of all patients attending the ALS clinic from July 2014 to January 2015 were reviewed.

**Results:** 28 pts attended the clinic during the 6 month period. 79% were reviewed by a SPC physician. Of those reviewed at the clinic 23% were referred to SPC services. 27% of patients reviewed were already known to the SPC services. 50% of patients did not require referral to SPC services. In total, 6 patients (21.4%) died during the study period; 2 at home and 4 in hospice. For patients already known to SPC services prior to the introduction of SPC to the clinic, 62.5% were referred by their GP, 25% neurology, and 12.2% geriatric medicine. Since the introduction of SPC to the MDT all new referrals to SPC services were generated by the MDT.

**Conclusion:** With increasing demands on the palliative care services it was interesting to see that 50% of patients reviewed by SPC at the clinic were managed alone by SPC input at the MDT clinic.

**Abstract number:** PO278

**Abstract type:** Print Only

#### **Retrospective Comparative Cohort Study of Patients With COPD and Lung Cancer Receiving Specialist Palliative Care: Referral Pathways and Patterns of Service Utilisation**

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**Background:** Specialist Palliative Care (SPC) is of proven benefit for cancer patients. The expansion of SPC for patients with Chronic Obstructive Pulmonary Disease (COPD) has been recommended. At present our service provides SPC for patients with COPD and has tailored its response. The pattern of service utilization of these patients and the effectiveness of the SPC response has not previously been reported.

**Aims:** To identify referral pathways, and patterns of service utilization, of patients with COPD and lung cancer receiving SPC.

**Methods:** A retrospective cohort comparative study was undertaken. A retrospective electronic data base and chart review was performed. A specifically designed proforma was used to collect information regarding patient's demographics, symptoms, comorbidities and medications, and to examine each documented interaction for key words or concepts. Data was entered onto SPSS.

**Results:** Here we present a section of data from the larger study. Forty-seven patients with COPD were identified. A random sample of patients with lung cancer under the care of the service was generated. Patients with COPD were less likely to have been referred by a hospital based

Specialist Palliative Care team. The primary reason for referral in the COPD cohort was symptom management. Patients with COPD were more likely to have their initial assessment in the outpatient clinic or Day Hospice setting. The COPD cohort was more likely to be discharged from SPC but their length of care was significantly longer.

**Conclusion:** The Specialist Palliative Care response to patients with COPD has evolved and become more tailored. This study will inform further development of service provision. Further research is required to evaluate the effectiveness of the response.

**Abstract number:** PO279

**Abstract type:** Print Only

#### **Feasibility and Acceptability of a Patient-Reported Outcome Intervention in Advanced Heart Failure**

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**Background:** Patients with advanced chronic heart failure (CHF) have symptoms and other concerns which are inadequately addressed. Patient-reported outcome measures (PROMs) can potentially improve the identification and management of palliative symptoms and other concerns. This has not been demonstrated in advanced CHF.

**Aim:** To examine the feasibility and acceptability of using a PROM - the Integrated Palliative care Outcome Scale (IPOS) - together with heart failure nurse (HFN) education and training, to improve the identification and management of symptoms and concerns in advanced CHF patients.

**Methods:** A sequential mixed-methods design was used to determine the feasibility of; recruitment, retention, intervention adherence/compliance and follow-up assessment completion (symptom burden, quality of life, psychological well-being). Patient and HFN qualitative semi-structured interviews explored intervention and study design acceptability.

**Results:** Conversion to consent was 46.9% (372 screened, 81 approached, 38 recruited). 66% of participants completed the IPOS intervention with minimal missing items (6%). 60% of participants completed all follow-up assessments (1-2 days, 1-2 weeks and 4-6 weeks post IPOS completion) with no missing data. Patients and HFNs found

the study design and intervention acceptable with the latter described as non-burdensome, relevant to advanced CHF symptoms and concerns, patient-centred and with easy readability.

**Conclusion:** This study shows that a palliative-specific PROM-based intervention investigated using a pre-post uncontrolled longitudinal study design is feasible and acceptable to both advanced CHF patients and HFNs in nurse-led disease management clinics. A future cluster randomised control trial - informed by these recruitment and retention data - is needed to test the effectiveness of the intervention.

**Abstract number:** PO280

**Abstract type:** Print Only

### The View of Lung Specialists on Palliative Care for Patients with COPD: A Survey Study

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**Objective:** Palliative care (PC) for patients with COPD is not yet common practice. Since lung specialists have a key role in providing good quality PC for patients with COPD their view on this subject was explored to guide future research and develop services.

**Methods:** A survey study was performed by members of the Netherlands Association of Physicians for Lung Diseases and Tuberculosis. (NVALT).

**Results/discussion:** The 256 of 804 respondents (32%) covered 85.9% of the hospital organizations in the Netherlands. Most lung specialists (92.2%) indicated to distinguish a palliative phase in the COPD trajectory. To identify patients for PC all formulated criteria were to a greater or lesser extend mentioned to be used. Aspects of PC in COPD considered important were: Advance Care Planning conversation (82%), communication between lung specialist and GP (77%) and identification of patients for PC (75.8%), while the latter was considered the most important aspect for improvement (67.6%). Lung specialist indicated to prefer organizing PC for hospitalized patients with COPD themselves (55.5%), while 30.9% indicated to prefer a cooperation with a Specialized Palliative Care Team (SPCT). In the ambulatory setting a multi disciplinary cooperation between lungs specialist, GP and a respiratory nurse specialist was preferred (71.1%).

**Conclusions:** To encourage lung specialists to initiate PC in patients with COPD we recommend to conduct further research into more specific criteria to identify patients with COPD for PC. Furthermore, lung specialists should improve their skills of PC and members of the SPCT

should be better informed about the management of COPD to improve care during hospitalization. Communication between lung specialist and GP should be emphasized in training to improve PC for patients with COPD in the ambulatory setting.

**Abstract number:** PO281

**Abstract type:** Print Only

### Feasibility of the Use of a Set of Indicators for Proactive Palliative Care in Patients with COPD: A Pilot Study

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**Objectives:** To identify patients hospitalized for an acute exacerbation COPD who have a poor prognosis and might benefit from proactive palliative care, a set of indicators had been developed from the literature. A patient is considered eligible for proactive palliative care when meeting  $\geq 2$  criteria of the proposed set of eleven indicators. In order to develop a doctor-friendly and patient-convenient tool our primary objective was to examine whether these indicators are documented consistently in the medical records. Besides, percentage of patients with a poor prognosis and prognostic value were explored.

**Methods:** We conducted a retrospective medical record review of 33 patients.

**Results:** Five indicators; NIV, comorbidity, BMI, previous admissions for AECOPD, and age were always documented. Three indicators, hypoxaemia and/or hypercapnia, professional home care, and actual FEV1% were documented in more than half of the records, while CCQ, MRC dyspnea, and the surprise question were never registered. Besides, 78.8% of the patients met  $\geq 2$  criteria and there was a significant association between meeting  $\geq 2$  criteria and mortality within 1 year (one-sided Fisher's Exact Test,  $p = .04$ ).

**Conclusions:** The set of indicators for proactive palliative care in patients with COPD appeared to be user-friendly and feasible.

**Abstract number:** PO282

**Abstract type:** Print Only

### Why is Parallel Planning for: Saving Lives with High Technology Intervention, Secondary Prevention of Risk Factors and Preparing for the Worst, all at the Same Time, so Important for Patients with Advanced Liver Disease?

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**Background/aims:** UK deaths from Liver Disease(LD) rose >300% over 40 years. 3/4 patients with cirrhosis are first diagnosed during hospital admission. 80% men and 70% females die of LD < 75 years and final complications: encephalopathy, ascites, variceal bleeding are often sudden and frightening. Aims to use mixed methods: literature review and data analysis to demonstrate the need for a parallel approach: treatment of life threatening acute complications, secondary prevention, and palliative/supportive care to prepare for the worst.

**Methods:** Literature review -combined search terms: parallel planning, end of life care, palliative care, death and liver disease. 2 National Confidential Enquiries into avoidable deaths (NCEPOD): 'Measuring the Units' and 'Time to Get Control' evaluated. Evidence on effectiveness of secondary prevention in advanced LD was sought and on prognostic indicators. Data from National End of Life Care Intelligence Network (NEoLCIN) linked Mortality Data/Hospital Episode Statistics Data for England analysed.

**Results:** Parallel Planning for LD cited twice in literature. NCEPOD Reports identify missed opportunities to save lives in decompensated LD. Good effectiveness of brief interventions for alcohol cessation and treatment of Hepatitis C even in decompensated disease. Liver Transplant is 'curative' option but < 10% eligible and patients die on waiting list. Predictive indicators of death e.g. UKELD useful. NEoLCIN data show significant outlier geographical areas comparing hospital admissions and mortality, 1 in 10 patients dying in hospital die in A&E, 25% of patients admitted once in last year of life and die in admission. Few LD patients die in hospices or access palliative care.

**Conclusions:** Liver specialists and patients are reluctant to consider palliative care while there is hope. Parallel planning and care improvements need to be implemented so more liver patients receive optimal life-saving AND supportive and palliative care.

**Abstract number:** PO283

**Abstract type:** Print Only

### To Assess the Effectiveness of Specialist Palliative Care Consultation for Hospital In-patients with Chronic Obstructive Pulmonary Disease (COPD)

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**Background:** Advanced Chronic Obstructive Pulmonary Disease (COPD) carries a significant symptom burden and poor prognosis. However, such patients are more likely to undergo invasive procedures, die in Intensive Care Units, and less likely to attend hospice care, compared to those with lung cancer.<sup>1</sup>

**Aim:** We aim in our study to capture the symptom burden carried by in-patients, in an acute hospital, with a diagnosis of COPD, referred to specialist palliative care (SPC) services and to assess the effectiveness of SPC involvement in their management.

**Methods/results:** Following ethical approval by the Irish Health Service Executive North East Area Research Ethics Committee, a prospective longitudinal study will be carried out in an acute Irish Hospital over a 4 month period (December 2015 to April 2016), assessing all in-patients with COPD referred to a SPC hospital team. They will be assessed by a member of SPC hospital team for symptom burden, at time of initial consultation and again 72 hours later, using four assessment tools: COPD Assessment Test (CAT), Edmonton Symptom Assessment System (ESAS), Modified Borg Dyspnoea Scale and St George's Respiratory Questionnaire (SGRQ). We will compare the results of all questionnaires at both time-points to determine how SPC consultation impacts on their symptom burden. The following information will also be recorded at 72 hours and 6 weeks later: survived/not survived; discharged/remains inpatient; and length of hospital stay. We aim to recruit 15 patients. Primary outcome will be the CAT score. Secondary outcomes will include: Modified Borg Dyspnoea Scale score; SGRQ score; ESAS domains scores; length of hospital stay; and survival.

**Conclusion:** We hope to show how SPC consultation can impact on the symptom burden, length of hospital stay, and survival of hospital in-patients with COPD.

1. Chou WC et al. Comparing End-Of-Life care for hospitalised patients with COPD and lung cancer in Taiwan. *J Palliative Care* 2013;29(1):29-35.

**Abstract number:** PO284

**Abstract type:** Print Only

### COPD-IPF Palliative Care Study: An Assessment of the Palliative Care Needs in Advanced Chronic Obstructive Pulmonary Disease (COPD) and Idiopathic Pulmonary Fibrosis (IPF)

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Palliative care services can play a role in the advanced stages of COPD and IPF. To tailor efficient services for this population their peculiar palliative care needs of are to be explored. Family caregivers, and professionals point of view help to model new services.

**Aims:** To assess the palliative care needs in patients with advanced COPD and IPF, in their informal carers and the experience of lung specialists about this topic.

**Methods:** IPOS- Integrated Palliative Outcome Score and ZBI7-Zarit Burden Interview 7 items were used during semi structured interviews with patient-informal carer dyads. In a focus group lung specialists were asked to fill the staff version of IPOS and to discuss the palliative care issues of their patients.

**Results:** 8 COPD, 1 IPF patients and 7 family carers were interviewed (2 more IPF patients will be interviewed shortly). 1 focus group involving 4 lung specialist that work in COPD and IPF tertiary clinics was conducted. Patients' IPOS highlight that dyspnoea at rest, and poor mobility are the most severe physical symptoms, weakness, pain and dry mouth are reported as moderate. Psychological issues like anxiety and depression are severe as well as existential dimensions. Information and practical problems were less reported. Professionals recognise the high burden of problems: only pain is less thought to be a problem compared with patients' results. Although morphine is considered a mainstream to treat shortness of breath, only 1 patient was using it. Lung specialist declare that if palliative care was involved it would have been easier for them to prescribe opioids. Family carers report stress, time used for caregiving and bad impact on their own health status as the main issues.

**Conclusions:** Preliminary results indicate a high burden of unmet palliative care needs in patients and their carers and a need to collaborate with pulmonary clinics in order to model efficient palliative care services tailored on the unmet needs.

**Abstract number:** PO285

**Abstract type:** Print Only

### Registering Needs, Accessing PC Program, Evaluating the Twilight Zone between Supportive and Palliative Care

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**Background:** Current Palliative Care is developing towards adequate response to patient and family's needs. Complexity of care, rather than diagnosis and prognosis or level of care, guide the design of Specialist Palliative Care Programs based on multidisciplinary consensus.

#### Aim:

- To establish the percentage of patients with non-malignant disease those have been entered in a Regional Palliative Care program and the evolution in numbers across all Care Settings in the last 5 years.
- To appraise the guiding trigger points included in the Single Referral Protocol part of the electronic patient records as a tool to support decision making.

	Domiciliary PC Teams		Hospital PC Teams		Inpatient Units		PAL 24 Contacts	
	Malignant	Non Malignant	Malignant	Non Malignant	Malignant	Non Malignant	Malignant	Non Malignant
Year 2012	4425	974	4925	965	2826	479	11640	1211
Year 2013	4518	1127	4651	1117	3459	618	12670	1985
Year 2014	4654	1202	4914	1138	3166	477	13117	2081
1st Semester of 2015	3350	1066	2878	795	2096	392	8125	1611
TOTAL number of patients	16497	4369	17368	4015	11547	1966	45552	6888

[Distribution of malignant/non malignant]

**Methods:** Descriptive study of the distribution of people with malignant and non-malignant pathologies across all settings. Analysis of the degree of digital completion of the trigger points fields from a sample of 79 patients of people with non-malignant disease included in the PC program.

**Results:**

In the sample, 19% patients had non malignant disease and 81% malignant disease. Pathology distribution showed that 54% had Dementia, 13 % Heart Failure, 13 % Chronic Respiratory Disease, 13% Other Neurologic Conditions and 7% Kidney Failure. Trigger point fields had been completed in 66,6% of cases.

**Conclusions:**

- Our Regional Program includes an increased number of patients with non malignant disease.
- Homogeneous criteria across the board are important.
- Guiding clinical trigger points might be helpful.
- Further research into complexity levels is needed.

**Abstract number:** PO286

**Abstract type:** Print Only

**The Unit of Care of Parkinsonian Patients Holds up Best Supportive Care and Refuses Palliative Care**

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**Aims:** Relatives of patients with Parkinsonian diseases often care in a very exclusive way for the patients and want to have life-prolonging therapies at a time when the patient has already entered the last phase of the disease. Often it is not possible to evaluate whether it is in accordance with advance directives and the wishes of patients since different types of dementia are part of the last phases of these diseases.

**Methods:** We have systematically evaluated relatives and patients with Parkinsonian diseases whom we have followed for at least 3 years. With all patients and relatives we had end of life and advance directive discussions and all have followed by an palliative care expert. Patients and relatives came at regular visits either to our outpatient department or to the hospital. In the last phase of the disease we frequently have cared for them.

**Results:** We have so far identified 11 pairs of patients and relatives whom we have followed until the last phase. Although all had advanced directives and had refused life prolonging therapies at an early time they and especially their relatives demanded to have life-prolonging therapies in the advanced phase. This included eventh feeding tube placement in 7 cases in the very late phase when we have only minimally been able to get in contact with the patient.

**Conclusions:** The unit of care in Parkinsonian diseases often wants to have life-prolonging therapies without respecting prior decision on advance directives. Since dying it these diseases often is a waiver decision, the relatives might not be able to cope with it.

**Abstract number:** PO287

**Abstract type:** Print Only

**Unpaid Care Costs: Value of Informal Care for Advanced Dementia Care Home Residents**

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**Aims:** To provide estimates and explore the economic implications associated with informal care and indirect financial costs borne by carers of advanced dementia care home residents.

**Methods:** From a prospective cohort study of 85 participants with advanced dementia residing in care homes, 35 informal carers completed RUD-Lite questionnaire. For estimation, we used all available information about carer characteristics and circumstances, applying replacement cost method for retired carers and opportunity cost approach for those employed at least part-time. We tested the sensitivity of estimates based on national minimum wage and the national average wage.

**Results:** The median age of informal carers is 62 (IQR 54-69), 69% female, 20% are a spouse to the care home resident, while 70% are a son or daughter. 40% are the sole informal carers, without any help from family or friends. Most are married, retired, with an average 1.27 children still residing at home. 38% were employed for pay, working on average 20 hours/week and 23% had to stop work or take early retirement in order to provide care. Informal carers on average provide 1.43 (IQR 0-1.75) hours per day and 10.3 days per month (IQR 0-16) of care. Cost estimates of informal care provided range between £450 and £2100 per month, at an average of £27/hour. Only 1 carer received social security benefit in recognition of her caring role.

**Conclusion:** Most health economic studies assess the costs at the end of life from the provider perspective, usually focussing exclusively on acute care costs, while wider social care system costs, such as costs borne by carers are

typically not included. Dementia cost-of-illness studies consistently show that the largest single cost element is borne by unpaid carers, in our study of advanced dementia participants residing in care homes rather than at their own homes, quantified costs of informal care provision are still substantial.

## Translational research

**Abstract number:** PO288

**Abstract type:** Print Only

### **Recurrent Aspiration Pneumonia: Can this Life threatening Condition Be Safely Reversed?**

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Aspiration pneumonia is a life-threatening problem facing many patients with upper Gastrointestinal (GI) malignancies, and non-malignant reasons. In our service, since 2000, we have looked at a novel approach to managing this very distressing, symptomatic and life threatening condition.

**Methods:** Patients are commenced on octreotide, starting dose 1000 mcgs sub-cutaneously (s/c) in 24 hours and Metaclopramide s/c at starting dose of 30mgs s/c in 24

hours. Metaclopramide is used to 'wake up' the bowel from ongoing ileus and octreotide used to reduce GI secretions at source. Dose escalation in octreotide to a maximum dose of 3000 mcgs s/c in 24 hours. For patients with dramatic responses, these patients are commenced onto long acting somatuline, at a dose equivalent to octreotide that we have worked out over the last 15 years of using this regime. Metaclopramide is converted to oral/fastmelts of domperidone to avoid long term extrapyramidal side effects of metoclopramide.

**Results:** Four cases, three patients with upper GI malignancies and one with a non-malignant cause for recurrent aspiration pneumonia are explored. All four had a prognosis of weeks to months at referral and all four had repeated hospital admissions for aspiration pneumonia. All four patients survived safely for years with monthly somatuline and domperidone. Hospital admissions were minimal to none with further aspirations. One patient did have one hospital admission after her somatuline was inadvertently stopped for a period of months, back on somatuline and she has remained free of further aspirations since.

**Conclusion:** This safe long-term solution for aspiration pneumonia by replacing the missing and/or dysfunctional upper GI valves with a pharmacological solution deserves further research. It has now become 'normal practice' in our busy Cancer Centre hospital that all appropriate patients are referred to our service to get this protocol!.

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