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# **Role of the community matron in advance care planning and 'do not attempt CPR' decision-making: a qualitative study**

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## **Abstract**

The Community Matron (CM) is often the key worker in caring for patients with chronic life-limiting long term conditions (LTC) but these patients are not always recognised as palliative. The aim of this study was to explore CMs' experiences of advance care planning (ACP) and do not resuscitate (DNR) decision-making to understand whether and why they felt adequately prepared for this aspect of their role.

Qualitative data were generated from six CMs using a broad interpretive phenomenological approach. Face-to-face recorded interviews were analysed using template analysis. The study found that though participants were facing complex ethical situations around ACP and DNR almost on a daily basis none had received any formal training despite the emphasis on training within national and local guidelines. Participants often struggled to get their patients accepted onto the Gold Standards Framework. Variability and complexity were the main issues when trying to identify the palliative phase.

## Key Words

Community Matron, advance care planning, do not resuscitate decision making, long term conditions, palliative care

## Key Points

- Training for the CM role focused on advanced clinical skills, missing the opportunity to develop advanced practitioners equipped to care for patients who are often in the last few years of life.
- With appropriate training and support, CMs could help long term condition patients with palliative care needs to live well until they die by opening up discussions around their thoughts and wishes through ACP.
- Proactively opening up discussions around DNR would help to ensure that patients die with dignity and compassion avoiding unnecessary and often futile clinical interventions such as CPR
- The CM is often in a key position to identify those patients nearing end of life to ensure early intervention by the D/N and palliative care teams

## **Introduction**

The World Health Organisation (WHO) has predicted that the percentage of the world population who are over 60 is set to double and reach 2 billion by the year 2050 (2012). In the UK the past 25 years has seen an increase in the over 65's by one million (Bayliss & Sly 2010). This demographic change inevitably creates significant challenges for healthcare policymakers and practitioners – not least in the area of palliative care. More patients are living longer with complex long term conditions, and many will develop palliative care needs. A recent report by the Royal College of General Practitioners and Royal College of Nursing (RCN) highlights that 75% of UK deaths are from non-cancer conditions, and that these patients often experience at least three crisis admissions in their last year of life – with major cost implications for the health service and impact on patients' ability to "live well until they die" (2012, p.2). A particular difficulty is the unpredictability of dying trajectories for such patients, making it hard for practitioners to recognise when "really sick becomes dying" (WHO, European Region, 2011, p.3) and to have the confidence to make key decisions about end-of-life care. This need to improve palliative care for patients with long term conditions is now widely recognised in the UK and elsewhere, but much needs to be done to turn aspirations into reality (Scottish Government Health Department 2008, Clayton, Hancock, Butow, Tattersall & Currow, 2007)

## **The community matron role and palliative care**

In the UK, the type of long term condition patient described above will very often receive support in the community from a community matron (CM). The CM role was launched in 2005 as the key worker for patients with complex health and social care needs. Patients on the CM caseload would be the most

complex, often living with more than one co-morbidity and identified as high intensity users of primary or secondary care (DH, 2005,a). There remains ambiguity regarding the role and its impact on reducing hospital admissions (Ford, 2011). Lillyman, Saxon & Trembl (2009) evaluated the effectiveness of the role and identified variability in the implementation of the role and a lack of role clarity. One area where such lack of clarity is apparent is in relation to the CM role for patients with palliative care needs. A study by King, Melvin, Ashby and Firth (2010) found that there was wide variation in views of how CMs should be involved with patients who are recognised as being towards the end of life. Research in this area remains very limited.

### **Advance Care Planning and the Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) Form**

Advance Care Planning (ACP) is a voluntary process of discussion designed to help the individual and their family prepare for the future ensuring their wishes about their care and treatment are known in the event that they should lose capacity once their illness progresses (National End of Life care Programme, NEOFCP, p.6, 2011). ACP is widely recognised as good practice (e.g. Royal College of Physicians, 2009 and The Gold Standards Framework, Nd) and is step two of the key elements of the End of Life Care Pathway, which incorporates planning, assessing and establishing a patient's wishes as they approach the end of their life (National End of Life Care Strategy, NEOFCS, 2008).

ACP requires good communication between the health professional, patient and (in most cases) their family to be effective (Keri & Lobo 2011, Samanta &

Samanta 2010). Many professionals continue to find discussions about end of life issues difficult (Seymore, Almack & Kennedy 2010) for example, consideration of when to suspend or withhold treatment. Cardio-pulmonary resuscitation (CPR) is an important case in point. CPR has been a standard part of coronary care since the 1960's and an effective form of treatment to restart a heart that has stopped prematurely. It was never intended to restart a heart that was failing due to irreversible medical conditions. Identifying when a person reaches this phase can lead to differences of opinion, which is why a DNR decision is subject to policy and procedure with dedicated documentation. To support the clinician in the decision making process around DNR guidelines have been produced (Resuscitation Council, BMA, RCN, 2007) acknowledging the complexity and ethical dilemmas clinicians may face. The guidelines recognise that DNR decision-making needs to be set within the wider context of effective ACP.

The authors could find no research evidence directly examining CMs' experiences and understandings of ACP and DNR, and the first author's personal experience as a clinician suggested that these are topics that her fellow professionals often struggle with. This is therefore the focus of the study we describe in this article.

### **Aims and objectives**

The overall aim of the study was to explore the CM's experience of EOL decision-making for individuals with a life-limiting long term condition particularly focusing on advance care planning (ACP) and do not resuscitate (DNR) decision making.

We focused on three specific objectives:

1. To explore CMs education and training in palliative care.
2. The CMs role in providing palliative care.
3. The CMs personal experience using ACP and DNR forms.

The study did not seek to examine more broadly the CM role in EoLC or assess their conceptual knowledge of ACP and DNR decision-making. Rather it set out to explore participants' lived experience when working within this area of care.

## **Method**

This study used a qualitative approach, taking a broad interpretive phenomenological perspective focusing on participants' experiences of ACP and DNR within their practice. For the purpose of this study we focus on the generic CM managing a caseload of patients with LTCs and not those working as a disease specific specialist such as a heart failure specialist nurse.

## **Research setting**

The research was conducted within the NHS Yorkshire and the Humber region (NHS York & Humber). Participants' caseloads mostly covered urban and suburban areas, with some encompassing more rural locations. In 2010 NHS York & Humber developed and implemented across all care providers and the ambulance service a single patient-held DNR form. Version 13 was launched on the 1<sup>st</sup> April 2014 and it is hoped that eventually there will be a single national form (NHS York & Humber EoLC Work stream Legacy Paper, 2013).

## **Sample and recruitment**

Research in the phenomenological tradition typically employs small samples to enable personal experiences to be explored in depth (Smith, Flowers & Larkin, 2009). Purposive sampling was used with a brief overview of the research aims given at the CM's monthly team meeting. Interested CM's were then invited to take part. We sampled six CMs, three from each of two adjacent NHS Trusts. Five had been in post for at least three years and one just over a year. Four came to the role with a community background and two from an acute background. All had acquired advanced practitioner skills at Masters level (RCN, 2012). For coding purposes, and to maintain confidentiality/anonymity, pseudonyms were assigned at the transcribing phase.

## **Interview procedure**

We carried out semi-structured interviews with participants, using a topic guide that focused on: (i) education/training, (ii) experience using ACP forms, (iii) experience using DNR forms, and (iv) CM role in palliative care. In keeping with a semi-structured approach, the topic guide was used flexibly, allowing participants the opportunity to expand on issues of relevance to them. To obtain rich data that were focused on personal lived experience, participants were encouraged to think of particular patients and “walk” the researcher through their stories in relation to ACP and DNR. This proved very productive with lengthy episodes of narrative requiring little prompting from the interviewer. Interviews took place within the participant's locality to minimise disruption to their work schedule. They were audio-recorded with participant

consent, and transcribed verbatim in full. Participant details are summarised in table 1.

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INSERT TABLE 1 ABOUT HERE

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### **Data analysis**

Data were analysed using the Template Analysis (TA) style of thematic analysis (King, 2012), which is appropriate for use in phenomenological research (e.g. Rodriguez and King, 2014). In TA the analyst produces an initial template of hierarchically-organised themes on the basis of a sub-set of the data. This is then applied to further items of data, modified where necessary and the data re-coded. In the present study, author 1 developed the initial template on the basis of three of the transcripts. Author 2 carried out a blind coding of a sample of the data, to facilitate critical reflection on the emerging thematic structure. The full data set was then coded with several iterations of the template until a final version was defined (see figure 1).

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INSERT FIGURE 1 ABOUT HERE

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### **Ethics and Governance**

Local NHS Research and Development (R&D) Governance approval was obtained. Ethical approval was provided by the Research Ethics Panel, School of Human and Health Sciences, University of Huddersfield.

## **Findings and Discussion**

The participants all provided rich and detailed accounts of their experiences relating to ACP and DNR. Within the constraints of this article, we have chosen to highlight one or two key sub-themes from each of the five main themes that highlight issues of particular significance to the CMs' practice in relation to end of life decisions.

### **Practices and procedures around ACP and DNR**

#### *Experiences of training (or lack of it)*

In 2007 the Resuscitation Council guidelines clearly stated that DNR decision-making is complex and must be undertaken by experienced staff that have undergone training to maintain their knowledge and skills. One of the key competencies of the role of the CM is to support the patient and their family in planning for and making EoL decisions (DH, 2005, b. p, 9). Five of the participants had been in post for at least three years yet none of them had received any training in DNR decision-making. Despite all participants having undergone further training at Masters level the focus of that training was to gain competencies in advanced clinical skills (RCN, 2012) and none mentioned DNR decision-making as being part of that training.

Cath had only been out of the acute setting for less than a year yet she had not received any formal training around DNR decision-making either in her acute or CM role:

*'...being new to the role it's not something, that gets talked about but you don't get any training in how to approach it really...'*

Sue attended an advanced communication course because she felt her knowledge was limited coming from an acute background. Though she found

it useful she felt that it did not relate to caring for patients with a LTC especially the difficulty clinicians have when deciding the appropriate time to put in a DNR.

Within Trust B the District Nurses (D/Ns) had recently undergone extensive training around ACP DNR decision-making and there were plans in the future for CMs to receive it but when asked why the CM had not been included in this training, Bev replied:

*'Err thinking about where I work at the present which is (location of work and area) is that Community Matron's role in palliative care hasn't particularly been seen to be erm that important. It's been mainly District Nurses have very much taken the lead on palliative care erm and... Advance Care Planning'*

#### *Personal experience with ACP/DNR*

All participants expressed confidence with the concept of ACP and DNR, particularly when they knew the patient/family were in agreement with the decision-making process and/or they knew them well. However, when it came to actually signing the DNR form many participants were not confident completing the form and voiced insecurity. For example, although only one signature from a healthcare professional is required, many participants reported that they would prefer to also have a colleague sign the form, before they would feel confident in the process. This lack of confidence led to situations where the participants would avoid discussing ACP:

*'... I've not actually spoken to a lot of patients and like their families about do not resuscitate erm to be quite honest I've stayed clear of it really...'*

As the interviews progressed four of the participants (Debbie, Chris, Bev and Cath) began to think of the patients on their caseloads differently:

*'...to be honest on reflection of that I think most of my patients should really have some sort of Advance Care Plan from now.'*

This emphasised the need for more training in completing an ACP which can often lead on to the more complex advance directive.

### **Role in palliative care**

All the participants felt that the CM role was a palliative role. Debbie felt that she had more of a palliative role now than when she was a D/N:

*'...I think its just like being a palliative care nurse really that's what I truly feel...'*

Chris felt that the CM was in the best position to lead on palliative care with patients with a LTC, as their advanced clinical skills, knowledge of LTCs and case management were unique amongst professionals in the community. Working collaboratively with other professionals around LTCs, symptom management and ensuring that they know the patient's journey was seen as "enhancing the end of life care pathway for the patient"... [Bev].

Most participants experienced good working relationships with other professionals especially the D/N and Bev felt their knowledge and skills around LTC enhanced the palliative pathway for the patient. Some participants described difficulties letting go of the patient when they reached the end phase of their illness and the D/N team would take over. Though they felt this was right they described feelings of abandoning their patient. Other

professionals often bypassed them even when they had been involved for over a year referring the patient to the D/N on discharge if they were deemed palliative.

### **Long term conditions versus cancer**

Despite all the recent policy and strategy (NEoLCS, 2008, National Institute of Clinical Excellence, NICE, 2011) to ensure that patients receive good quality care towards EoL regardless of disease our evidence suggests there still remain inequalities in the care patients receive with a LTC compared to cancer. Participants continue to struggle to get patients on the Gold Standards Framework register in their practice because they were not deemed to be palliative:

‘...we only think of palliative as cancer. Every one of my COPD patients should be on that Gold Standards Framework but I can't get them on there, you know I can't, it's, there's still that thing of trying to get through to the GPs and I think until that's done the only people that are there is is the Community Matrons...’ [Cath]

Recognising the dying trajectory in patients whose condition is variable is difficult but early identification is paramount if patients are to receive planned proactive care to meet their needs, (GSF, Prognostic Indicator, 2011). The Scottish Government Action plan, ‘Living and Dying Well’, stressed the need to recognise triggers such as: ‘*critical events or significant deterioration during the disease trajectory indicating the need for a ‘change of gear’ in clinical management*’ (2008, p.9.). The CM is often best placed to recognize this though it seems to depend on the working relationship with their GP, which according to Mahmood-Yousuf, Munday, King, & Dale requires a non-

hierarchical structure in professional teams for effective decision-making to take place (2008).

Alongside variability in the dying trajectory a further challenge is the complexity of the patients; this is not surprising since the remit of a CM is to manage patients with complex conditions (DH, 2005, a). This complexity makes it difficult to know whether the person is living with or dying from one or more of these diseases (Lloyd, White, & Sutton, 2011).

'...I still think GP's struggle to, when to put it in, (DNR form) especially if they're long term conditions, cancer patients they're quite happy but for long term conditions there's still that, they don't know whether we are gonna actually make them better this time... [Sue]

Often, the patients were on the participant's caseloads for over two years.

Cath felt that the variability was the most difficult aspect compared to patients with cancer:

'...you never know, you know, which chest infection, which virus, which cold or which illness is going to be the one that makes them really really poorly, with can, you know with cancer they tend, I think they have more of an idea of how long's left.'

Developing predictive tools to identify patients approaching the end phase of their lives has become a more recent focus and though there is no definitive tool a recent report by NEEoLCP, (2013) recommends developing and building on existing data to try and identify patients approaching this phase of their lives. Given the difficulty it is not surprising that participants found this identification of patients nearing EoL extremely difficult to predict. Participants relied on their experiential knowledge that a good predictor of a patient

approaching EoL was a marked increase in their dependency and the level of care input that this necessitated.

## Relationships

### *Knowing patients well*

Participants felt that because they knew their patients really well, they were able to recognise clinical deterioration against the patient's norm rather than standard normal levels;

'...well because I mean she runs on saturations<sup>1</sup> around 82 most of the time but if you go in and they're 70 you know something's pretty wrong...' [Debbie]

The nature of CM involvement with patients and their families over time was seen by our participants as creating a 'unique' relationship that was potentially important to decision-making at EoL, as Bev describes:

*'Community Matron is in a very unique place, where they have, they have come along that patient journey er and know how that patient is, able to make informed decisions and the affect that the long-term condition has on them and the family as well. So we we are often in that unique role but I also see us being in a position where we are able to care co-ordinate and be a very valuable erm professional in the end of life care in helping other people understand the journey that they've come on and where they are erm from a diseased progression and symptom management and work alongside District Nurses, Macmillan Nurses, Specialist Nurses and the wishes of the patient in wherever they wish to end their life'...*

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<sup>1</sup> Oxygen saturation levels in a healthy patient are normally 95-100%. COPD patients can often run below this requiring an oxygen assessment if persistently below 92%. Many patients can have an Oxygen saturation level around 80-92% and is why CM's ensure the patients' normal baseline observations are on a Emergency Care Plan in the home to aid other professionals in their care.

## **Communication**

### *Transfer of care/lack of discussion*

All participants described scenarios – often traumatic - where patients had been transferred back into the community with a DNR in place but with no proper discussion with them and/or their families. This reflects the kind of poor practice in EoL communication and decision-making (Broadbent, 2013) that resulted in the controversy around the Liverpool Care Pathway (Boseley & Meikle, 2012). This was also highlighted more recently with the landmark decision that doctors acted unlawfully by placing a DNR decision on a patient without discussing it with her (Meikle, 2014). Often the CM would be the one who had to face distressed, angry patients and their relatives. Cath described a case where the patient had been very ill and placed on the Liverpool Care Pathway in hospital. He then made a recovery and was discharged home with no review of the DNR status:

*'...he was given a DNR form and when he came home the form was sent with him, which his son-in-law promptly waved in my face and said "what do you think of this?"'*

There appeared to be specific barriers when discussing ACP/DNR; in particular it was seen as negative by the patient and their carers. Debbie felt that the recent negative press had had an impact that more people were aware of DNR decision making but in a negative way. She perceived that if she broached it with patients they would think she was trying to “euthanise them”. Bev, when asked why she had not initiated DNR’s said it was because she went in with “a positive outlook in goal setting” implying that to discuss

ACP would be seen as negative by the patient. Sue felt that when trying to discuss ACP some of her patients felt that she was giving up on them and acknowledged that knowing the patient and their family so well created a personal barrier for her to start addressing EoLC issues. Notably, the NEEoLCS (2008) emphasises the need for clinicians **not** to view EoLC discussions as failing the patient.

## **Conclusion**

This research has given an insight into the lived experiences of the CM around ACP and DNR decision-making. The rich data obtained has highlighted the complexities around caring for patients living with and often dying from chronic LTCs, and the opportunities inherent in the nature of the CM role to effectively support patients and families up to the end of life. In this concluding section we will consider the limitations of the study and then highlight implications for practice and suggestions for future research.

## **Limitations**

A phenomenological study does not seek generalisability and small samples are inherent to the approach as noted above. Sample size is not therefore a limitation as such, but characteristics of the particular sample may limit the extent to which insights gained can be transferred to other settings. To enable a broad view of the CM's lived experience and to avoid researcher bias (Mehra, 2002), two CMs from three Local Health Care providers were to be interviewed. However, due to time constraints and time taken to obtain ethical approval within just one Trust, identifying gatekeepers within each Trust and

gaining R&D approval was not achievable. The interviewer (first author) was herself a CM and was known by some of the participants prior to the study. This kind of “insider” status can have some significant advantages in terms of enabling the building of trust and rapport, and the ability of the interviewer to understand nuances of the participants’ lifeworlds. However, it also has potential drawbacks (Dwyer & Buckle, 2007). It can also result in the avoidance of known locally sensitive issues. We cannot be sure that these problems did not occur in the present study, but we were at least aware of the danger of them in advance. Also, after the first interview, the second author looked closely and critically at the interview transcript to highlight any limitations in interview style and content. This served as a reflective aid for the interviewer in the remaining interviews.

### **Implications for practice**

The findings of this study underscore the importance of training for CMs in ACP and DNR – absence of such training for our participants contributed to their lack of confidence in incorporating these procedures into their practice. Given the types of patients CMs work with, and the growing recognition of the importance of palliative care for LTC and frail elderly patients, we would argue that such training should be a standard part of CM education.

CMs’ case management skills and knowledge of LTCs make them well-placed to play a significant – and sometimes leading – role for non-Cancer patients with palliative care needs. This relies on good collaborative working with other professionals, which in turn requires their acknowledgement of the legitimacy of the CM role in palliative care. The present study found there were

sometimes still problems in this area, in line with previous research (King, Melvin, Ashby & Firth, 2010).

A further challenge to good practice for CMs – and indeed other professionals – in this area is the nature of wider societal perspectives on decisions regarding the withdrawal of treatment at EoL. In the UK this has become more difficult as a result of the Liverpool Care Pathway controversy. Individual professionals cannot change such widescale suspicions about ACP/DNR, though they can ensure they do not reinforce taboos either by avoiding the subject or by handling conversations with patients and/or families badly. Again, training is likely to be important in ensuring confidence among healthcare professionals.

### **Suggestions for future research**

Further research is required to elucidate the factors that help or hinder CMs in taking a proactive role in ACP/DNR for patients with long term conditions. This needs to include both detailed examination of practice at the individual and team level, and wider investigation of the role played by organisational structures and leadership, and by health care policy.

Given the perceived importance of training in instilling skills and confidence regarding ACP/DNR, we need to see the publication of well-conducted evaluations of training to inform the design of future initiatives. Longitudinal studies that are able to assess sustained improvements in practice would be especially valuable, and should include the assessment of patient and family

outcomes such as levels of distress, satisfaction with service and post-bereavement well-being.

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Table 1. Participant details.

Participant (Pseudonyms)	Trust	Experience
Debbie	A	Experienced District Nurse (D/N) and CM with advanced skills
Chris	A	Experienced D/N and CM with advanced skills
Fran	A	Experienced D/N and CM with advanced skills
Bev	B	Experienced D/N and CM with advanced skills
Cath	B	Experienced acute nurse, new to the role with advanced clinical skills
Sue	B	Experienced acute nurse and CM with advanced clinical skills

Figure 1. Final coding template.

<p>1) Practices and procedures around ACP and DNR</p> <p>a) ACP b) DNR</p>	<p>1.1.Experiences of training (or lack of it)</p>	1.1.1 Practical sessions
		1.1.2 Legal implications
		1.1.3 Lack of documentation
		1.1.4. Lack of understanding
		1.1.5 What has helped/hindered
	<p>1.2. Personal experience with ACP/DNR</p>	1.2.1. Dying trajectory
		1.2.2. Confidence
		1.2.3. Avoidance
		1.2.4. Labelling of patient
		1.2.5. Perception of the term palliation
		1.2.6. Realisation on reflection
		1.2.7. Decision making
	<p>1.3. Barriers to communication</p>	1.3.1. Discussing ACP seen as negative/removing hope
1.3.2.Taboo word		
1.3.3. Family expectations		
1.3.4. Patient in denial		
<p>2) Role in palliative care</p>	<p>2.1.Perception of CM role care</p>	2.1.1. Previous role
		2.1.2. Personal experience of role
		2.1.3.Perception of colleagues

3) Long term conditions versus Cancer	3.1. Variability of disease	3.1.1. Longevity of disease
	3.2. Complexity of condition	
	3.3. Identification of palliative phase	
4) Relationships a) With patient b) With family c) With GP d) With other Professionals	4.1. Knowing patient well	
	4.2. Good collaborative working	4.2.1 Skill of D/N
	4.3.CMs being supported	4.3.1 Feeling well supported
4.3.2 Feeling unsupported		
5) Communication	5.1. Transfer of care	5.1. 1. Lack of discussion
		5.1. 2. Language used