"Everyone was like flies around a jam pot": A phenomenological study exploring the experiences of people affected by advanced disease in relation to the involvement of multiple health care services

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Copyright statement

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Abstract

People living with advanced disease face challenges to their being-in-the-world; these are attributable to both the nature and progression of their illness and the level and variability of their care needs. Recent policy initiatives and literature promote community care for patients with advanced disease, and there are a plethora of different health services that may be involved in care provision for people in the last year of their lives. The current research takes a phenomenological approach, informed primarily by the work of van Manen, to explore the lived experiences of patients and their spousal-carers in relation to the multiple services that are involved in their care.

In-depth, semi-structured interviews with twelve patients with advanced disease, and eight spousal-carers were conducted. These interviews employed the Pictor technique to support people in reflecting on, and communicating, their experiences of care situations. Pictor is an innovative technique that is used with lay-participants for the first time in this research. The technique encourages people to reflect on relationships and personal experiences, and then to communicate these through the creation and discussion of a visual chart. The digitally recorded data were transcribed verbatim and analysed using interpretive phenomenological methods, supported by Template Analysis, which allowed the hierarchical coding of themes.

The research findings indicate that advanced disease affects people in many different ways; participants' perceived meaning of illness is instrumental in how they view and engage with health care services. The lived experience of this phenomenon is discussed as an 'unhomelike-being-in-the-world', and 'striving for poise'. The varied experiences of participants are illuminated and further explored with a focus on key relationships with health care providers. Here, it is argued that consideration of 'authentic relationships' is a valuable resource in supporting people affected by advanced disease.

Disseminated findings

Publications

Hardy, B. (2011) Palliative care in the community: The complexity of service provision. *British Journal of Community Nursing*, 16, (11) p. 522.

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Hardy, B., King, N. & Firth, J. (2012) Applying the Pictor technique to research interviews with people affected by advanced disease. *Nurse Researcher,* 21, (1) pp. 6-10.

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Hardy, B. June (2012) *Challenging self-theory: The unforeseen outcomes of conducting research within one's own area of clinical practice.* World Research Congress of the European Association for Palliative Care, Trondheim, Norway.

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Supplementary materials
1. A4 copies of the participant's Pictor charts
2. Copies of publications

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Abbreviations

AD	Advanced Disease
BMA	British Medical Association
CHD	Coronary Heart Disease
COPD	Chronic Obstructive Pulmonary Disease
DN	District Nurse
EoL	End of Life
EORTC	European Organization for Research and Treatment of Cancer
GP	General Practitioner
GSF	Gold Standards Framework
IPA	Interpretive Phenomenological Analysis
LCP	Liverpool Care Pathway
MDT	Multi-Disciplinary Team
MND	Motor Neurone Disease
NEoLCP	National End of Life Care Programme
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NYHA	New York Heart Association
PCP	Personal Construct Psychology
PCT	Primary Care Trust
PHCT	Primary Health Care Team
PIG	Prognostic Indicator Guidance
PPC	Preferred Priorities for Care
QoL	Quality of Life
RCGP	Royal College of General Practitioners
RCN	Royal College of Nurses
SEIQoL	Schedule for the Evaluation of Individual Quality of Life
TA	Template Analysis
UK	United Kingdom
WHO	World Health Organization

Preface

The purpose of this thesis is to explore and describe the lived experiences of people affected by advanced disease in relation to the multiple health services involved in their care.

The research takes an interpretative approach, and in line with this methodological standpoint I will take the opportunity at the outset of this thesis to describe my own orientation towards the research being conducted, considering what has driven my commitment to, and interest in, this phenomenon (van Manen, 1990). As van Manen discusses (1990, p. 43), research does not occur in a disembodied fashion, and is:

> always a project of someone: a real person, who, in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence.

By highlighting my personal circumstances in relation to this investigation, I aim to bring to light factors which impact upon my view of the world, and influence my interpretation of phenomena. This is termed reflexivity, and is a dynamic process in which I continually strive to recognise my subjective responses to phenomena, and the influence of these on the research process (Finlay, 2002).

My awareness of advanced disease has developed predominantly through my clinical work as a District Nurse (DN). Prior to commencing this research I worked full time as a DN Sister, managing a busy urban community nursing team. I have worked in community nursing since 2002, holding posts in Newcastle, Wakefield and Doncaster. Community nursing is a generalist service providing nursing care to people in clinics and their own homes. The nursing care that is delivered is wide-ranging, and specific service delivery varies in different health authorities. However, the care of people with

advanced disease, and those at the end of life, forms a central component of these services, as these people receive substantial amounts of care within the community and particularly within the home environment. As a community nurse, and latterly a DN, I have been involved in the home nursing care of people affected by AD at various stages of their illness. As my career developed I became increasingly aware of the complexity of the services available to support this population, and subsequently developed an interest in patient and carer experiences of this situation.

My personal experiences are also significant in regard to my understanding of the world. I grew up in the small rural Derbyshire village of Edale, which has a strong community focus, and I am very aware of the influence of this community on my perceptions of collaborative working. As a child I knew the name of every person living in the village, who at times took on the roles of extended family. Growing up in this environment taught me what it means to care about others. People took an interest in each other's lives, were there for each other in times of crisis and celebration, and looked after each other in times of sickness. In many senses it was an idyllic childhood (although as a querulous teenager I would have described it in very different terms!). Thinking back upon this time, I am particularly struck by the generosity of this community in sharing not only their time, but also their aspiration of a bright future for the children who lived there. This community demonstrates what can be achieved when people work together and care about each other, and these are principles that have been very influential throughout my nursing career.

I have also witnessed the implications of illness upon family members, particularly my Nanna, who was the main carer for my Grandfather who had been significantly disabled by a series of strokes. I have observed some of the many challenges and frustrations that she faced as a consequence of her change from independent wife to a depended upon carer, and marvelled at her ability to organise and manage their lives around his disability.

These factors form part of my interest and orientation to this research. Throughout this thesis I will continue to reflect on the influence of my personal perspective of the world on the development of this work.

Chapter 1: Introduction

People approaching the end of their lives, and living with advanced disease, face extraordinary challenges and changes in their lived experience of the world. Advanced Disease (AD) may be diagnosed suddenly, an unexpected cancer diagnosis or recurrence. Equally, people may have lived with malignant or non-malignant conditions for many years before their disease gets to the advanced stages.

In the United Kingdom (UK), there is now a range of health care services available to support people with AD. People will often receive care from several different health care teams, containing many different services, simultaneously. These services can span the primary and secondary care environments (Munday and Shipman, 2007). In the community, services may be under a number of different guises, such as; specialist palliative care, including hospice teams and Macmillan nurses; community nursing, including district nursing, Community Matrons, and rapid response teams; general practice, including general practitioners (GPs), practice nurses and support staff; allied health care professionals, such as physiotherapy, occupational therapy, and dieticians; and disease, or symptom specific health care providers, such as nurse specialists. Sometimes these teams will incorporate people from other professional groups, such as social work. These varied services are not necessarily coterminous, may not have developed in a coordinated fashion, may have different geographic boundaries, may not have clearly defined roles, and can be responsible to different administrative authorities. This can lead to challenges in providing continuity, and in coordinating care for people with AD (Victor, 2000).

This research sets out to explore the experiences of people affected by AD, who have many different services involved in their care whilst the patient is in the community setting. This chapter will set the context for later exploration of the experiences of people with AD by exploring the historical development of

health care services for this population, and describing the current context of care provision. In chapter two I will consider theoretical and research literature in relation to the phenomenon, before detailing my specific research question and aims of this project.

1.1 Definitional complexities

Before I can address the literature around AD and associated service provision, it is important to consider the lack of consensus about the definitions used in both primary care and palliative care (Fallon and Smyth, 2008; Shipman et al, 2008; Riley and Ross, 2005). Terminology used by academics and health care professionals when describing people affected by AD, and the care that they receive, can be diverse with the same terms used to describe different stages of illness and care delivery (Pastrana et al, 2008). An example of this is the term 'End of Life' (EoL). The EoL Care Strategy (DH, 2008a) defines EoL care as that which:

> Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.
>
> National Council for Palliative Care, 2006. Cited from DH, 2008a, p. 47.

This clearly relates EoL care to all people who have advanced, progressive and incurable illness, and the strategy clarifies that this stage may commence for some people at diagnosis or for others when prognosis is measured in months, or in a year or so. However, it has been shown that there is a lack of consensus between academics, clinical staff and service users as to what 'end of life' refers to, varying from a few days to a year or more (Shipman et al, 2008). The diversity in the use of the same term can lead to miscommunication and confusion amongst service users and providers, who

may use and interpret the meanings of these terms differently (Billings, 1998; Bliss et al, 2000), and can have implications for services being utilised (O'Connor, 2005).

An example of different professional and lay interpretations of terminology is also evident in the word 'terminal'. The Gold Standards Framework (GSF) relates the terminal phase of an illness to the dying phase – whereby someone has probably only days to live (GSF, 2011). However, this term was used extensively in the media to describe the health of Jane Tomlinson, 'Terminal Cancer Sufferer' (BBC News, 2007), a woman diagnosed with advanced metastatic breast cancer in 2000, who went on to raise nearly two million pounds for charity and be awarded a CBE before her death in 2007 (Jane Tomlinson appeal website, 2010). The first example of this term is relating it to a phase in a disease, the second example is referring to a disease that is incurable and will ultimately result in death. Although the use of this term in both contexts shares the same underlying principle, that the illness will result in death, the time frame being referred to is very different.

As a research population, people who are moving towards the end of their lives are described and defined in a number of ways. They may be classified according to their specific diagnosis (e.g. lung cancer or Parkinson's disease), by the care that they receive (e.g. palliative care, supportive care, terminal care, community care) by the location of that care (e.g. primary or secondary care, hospice, home) the stage in their disease trajectory (e.g. advanced disease, end of life, terminal, dying), or by their expected prognosis (years, months, weeks or days). The lack of consistency and consensus in utilized terminology has implications for research. Inconsistencies in terminology contribute to difficulties in collating research findings (Riley and Ross, 2005), and have implications for the dissemination of findings, which may be overlooked if key terms are not identified.

Choice of terminology is also important for recruitment strategies, for example if I consider the term 'palliative' there may be several presenting issues for

research design. The World Health Organization (WHO) defines palliative care as:

> an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
>
> WHO, 2008, p. 84.

Palliative care is advocated as an approach that is suitable for all people living with life threatening illness. Interestingly, the WHO also states that:

> Palliative care meets the needs of all patients requiring relief from symptoms, and the needs of patients and their families for psychosocial and supportive care. This is particularly true when patients are in advanced stages and have a very low chance of being cured, or when they are facing the terminal phase of the disease. Because of the emotional, spiritual, social and economic consequences of cancer and its management, palliative care services addressing the needs of patients and their families, from the time of diagnosis, can improve quality of life and the ability to cope effectively.
>
> WHO, 2007, p. V.

According to these definitions, palliative care is clearly related to the care of people with AD and has a focus on holistic care. Interestingly, the second description of palliative care suggests that palliative care as an approach is suitable from diagnosis of life-threatening illness for those with cancer, and may run alongside treatments given with curative intent (even though there may be a low chance of success). However, it is uncertain as to whether all services understand the term 'palliative' to mean the same thing as the term has been used inconsistently by service providers (Fallon and Smyth, 2008). Additionally, service users may not self-identify with the 'palliative' label - one

that is emotive and can be distressing to patients and families (Filbert, 2008) who may misunderstand the intention of this term and relate it only to terminal care (Wenrich et al, 2001).

Because of the disparity and common misconceptions of the terms used for this population, careful consideration has been given to this issue. Consequently, I have chosen to describe the focus of this thesis as 'people affected by Advanced Disease' (AD). This term is taken from the GSF Prognostic Indicator Guidance (PIG), which has been developed as a clinical tool to support the identification of people who are approaching the end of life, likely to die within the next twelve months, and have increased need for intervention from clinical services (GSF, 2008; GSF, 2011). Within the PIG, clinical guidelines are given to identify patients who meet these criteria. As well as being clinically helpful, this is a useful tool in the research setting and can be applied to identify a population of people approaching the end of life. A copy of the PIG can be found in Appendix 1.

This research is also interested in the lay-carers of people affected by AD. Lay-carers are described as a person in a close supporting role to the patient, who shares the illness experience, and who undertakes care work and emotional management (NICE, 2004). For simplicity, I will refer to these people as 'carers' in the text.

1.2 The context of care provision for people with AD

In this section, I will provide an overview to living with AD in the 20th and 21st century, exploring how patient and family experiences may have changed, and how the services that provide care to these people have developed. I will then move on to consider the current context of primary care provision for people with AD in the UK, and discuss policy that has influenced the development of these systems of care. The purpose of this overview of care provision is to set the scene for understanding people's experiences of service involvement in AD.

1.2.1 Historical overview

Attitudes to, and causes of illness, dying and death have changed considerably over the last one-hundred or so years. At the beginning of the 20th Century, dying was predominantly managed by family, within the home environment (Dickenson et al, 2000). The majority of deaths were quite sudden, and caused by accidents, infections and childbirth (Murray et al, 2005). Diseases such as diphtheria, pneumonia and TB were common and there were extremely limited treatment options for those affected. People were expected to endure their pain and suffering, and poverty was widespread (Rivett, 1998). Some health services and support did exist for people with disease. General practitioners would provide medical care to those who could afford their services, and hospitals managed through the voluntary sector were available to people who had paid into private insurance or contributory schemes. The poor who were sick and infirm may have gone to a workhouse infirmary although this was not an attractive option as these institutions were notorious for terrible living conditions and the people using them were stigmatized (Crowther, 1983).

In London, cancer wards had been available from as early as 1792, and in the latter half of the nineteenth century several hospitals specifically for cancer were established, which sometimes also provided specific facilities for terminally ill people. For example, in 1887 a small unit was built in the grounds of the London Cancer Hospital for 'incurables' (Lewis, 2007, p. 91). In the late nineteenth and early twentieth century several hospices were created to provide a place for the respectable poor who had been diagnosed as 'dying'. These hospices were run by religious orders; care of the physical body was important, but of higher priority was spiritual care and curing the soul (Humphreys, 2001).

The need for home nursing had been identified in the middle of the nineteenth century. In 1859, William Rathbone, a philanthropist based in Liverpool, employed a nurse to care for his wife during her final illness. He realised the

benefit that this could have for the poor, and retained the nurse to continue to work in the Liverpool area (Cohen, 2010). Rathbone hoped to extend this project, but found a lack of suitable, experienced, nurses so established a training institute in 1863 that later became the Queens Institute for District Nursing (District Nursing 150, 2012). District nursing services quickly expanded and by 1938 there were 2182 local district nursing associations in England and Wales, providing nursing services to the sick in their own homes and community clinics (Pountney, 2009). However, these services were generally still only available to those people who paid into the provident schemes that funded them, although the very poor and elderly were often nursed for free (District Nursing 150, 2012).

The introduction of the National Health Service (NHS) in 1948 heralded a new era in health care in the UK. The NHS had an initial goal of converting the haphazard organisation of health care provision in the UK into a modern system (Clark, 1999), and had a focus on rehabilitation and cure (Lewis, 2007). Clark (2007) suggests that in the early days of the NHS, death was seen as a failure of medicine, and often people dying from cancer were either overlooked by health professionals or abandoned entirely. The 'chronically sick' who required hospital care were often treated in units separated from the acute hospitals, and Rivett (1998) proposes that care was often poor for this population due to the large numbers of patients, and limited numbers of staff.

With the introduction of the NHS, GP services had become available to the entire population. However, GP services were also often extremely stretched and a single GP could have in excess of 3000 patients on their list. They would often work as a single-handed practice and quality of provision varied enormously (Rivett, 1998). From 1948, the responsibility for community nursing services had fallen to local health authorities, along with the development of social support and preventative health services. Initially, many utilised the voluntary organisations that had existed prior to the NHS, but soon brought these services in-house. Community nursing services worked beyond their capacity as an increasing number of early discharges from hospital impacted upon their workload and revealed shortages of nursing

staff (Rivett, 1998). In 1951, Marie Curie and the Queens Institute of District Nursing undertook a national survey of cancer patients living in the home. The survey revealed that psychological suffering and failure to seek treatment was common, and recommendations were made to increase the availability of residential homes, domestic aids and night nurses (Lewis, 2007).

The late 1950's and early 1960's saw an expansion of interest in the care of the dying, demonstrated through the beginning of research in this area, and recognition of the interdependence of physical and mental suffering (Clark, 2007). In 1967, Cicely Saunders founded St Christopher's hospice, which is widely credited as being the first modern hospice. The modern hospice movement had emerged partially in response to the perceived neglect of people who were dying under the care of the biomedical approach that was dominant in health care (Rosenberg, 2011). Saunders had a vision of care that encompassed physical, social, and spiritual spheres, and her work has significantly influenced the development of the modern hospice movement and the palliative approach to care. The phrase 'palliative care' care did not get used regularly until the 1970's, when it was used to describe a new model of hospital based care for the dying, based upon the same principles as the hospice movement (Mount, 1976).

Other charitable organisations had also identified the need for care to be available to those with cancer and the dying. Macmillan Cancer Support was founded in 1911 by Douglas Macmillan as 'the society for the prevention and relief of cancer', which provided information on recognising, treating and preventing cancer to both the public and doctors. This organisation had developed slowly until the 1970's when rapid expansion took place: the charity began to employ its own 'Macmillan' nurses, develop cancer inpatient units, and contribute considerable funding to the education of doctors, nurses and students in pain control and cancer care. Macmillan Cancer Support now employs over 3500 health professionals, runs telephone help lines and an interactive website for people affected by cancer and they continue to run education programmes for the public and health professionals (Macmillan Cancer Support, 2012). The Marie Curie Memorial Foundation was

established in 1948 and was dedicated to alleviating suffering from cancer. In 1950, the foundation became a charity that provided specialist homes and home nursing for people affected by cancer, and education to the public on symptoms and treatments (Marie Curie Cancer Care, 2012). These nursing homes further transitioned in the 1980's to specialist palliative care centres, alongside considerable expansion in hospice bed availability throughout the country (Clark, 2007).

As the principles of palliative care became increasingly recognised, Palliative Medicine was established as a sub-specialism of general medicine in 1987, and then as a specialism in its own right in 1995 (Clark, 2007). Although similar in orientation, 'palliative medicine' generally describes the care that is delivered by medical specialists, as opposed to 'palliative care', which refers to an approach to care that can be delivered by various health care teams (Charlton, 2002). Between the 1970s and 1990s there was considerable growth in the provision of palliative care services (Lewis, 2007). Hospital palliative care teams developed across the country from only five in 1982 to 275 by 1996, and in the 1980s around ten new hospices were being built per year (Clark, 2007). The Calman-Hine Report (DH, 1995), the result of an expert advisory group convened to provide guidance on the development of cancer services, is credited with having a significant impact on the integration of palliative care services into the mainstream NHS, and developing palliative care into a NHS specialty in its own right (Finlay, 2001). The report suggested that palliative care should be available to patients early on in their disease, and that they should have access to multi-disciplinary palliative care teams. The report acknowledged that the majority of palliative care is delivered by generalist primary care teams, advocated that DNs were key to the provision of primary palliative care services, and suggested that training and education were vital to improve care provision (Lewis, 2007). The care of people dying from cancer was now firmly established as being of relevance to medicine and health care. Interestingly, between 1974 and 2003 the number of people dying at home nearly halved (Gomes et al, 2012), this could be in part due to the expansion of hospice bed availability. However, people who were living with AD as a result of conditions other than cancer generally did

not have access to specialist palliative care services (those whose sole remit is the provision of palliative care) or palliative medicine, and there was limited recognition of the changing needs of people with non-malignant conditions as their disease became advanced (Wasson, 2000).

Towards the end of the twentieth century there was an increasing policy emphasis on the care needs of people living with AD regardless of their diagnosis, and of the value of commencing the principles of palliative care early on in an individual's disease trajectory (Clark, 2002). Changes in the care of people affected by AD were taking place amongst rapid developments in the NHS. The New Labour government, elected in 1997, had bought renewed political focus on the NHS in general. One of New Labour's manifesto pledges was that the NHS would be at the centre of their drive to modernise public sector services (Dowling and Glendinning, 2003). New Labour aimed to introduce national standards that would eliminate the geographical variations experienced in community care, and to reduce unplanned hospital admissions (Leathard, 2000). The white paper 'The New NHS: modern, dependable' (DH, 1997) laid out the structure of future primary care developments and announced the introduction of significant service changes alongside a new perspective of the role of the patient, from passive recipient to active participant in their own health. There was to be an increased emphasis on partnership working between services, patients were to be empowered and there was a far greater emphasis on preventative measures to ill health. National Service Frameworks were introduced and were key publications in the drive to reduce inequalities and increase standards. National Service Frameworks were developed for several disease groups, including cancer, chronic obstructive pulmonary disease (COPD), coronary heart disease (CHD), renal disease, older people and long-term (neurological) conditions. Within all of these frameworks there is some acknowledgement and discussion of end of life care, and an expectation that all people at the end of life should have access to holistic palliative care delivered by appropriately skilled professionals.

The NHS Cancer Plan (DH, 2000) promised extra funding for hospice and specialist palliative care services to improve equitable access across the country, as well as financial investment in training for generalist palliative providers in order to increase access to skilled palliative care support in the community. The push for patient empowerment led to the notion of patient choice rising up the political agenda at this time. As Downie and Randall (2008) describe, choice has for a long time been a pivotal component of health care and is the foundation of the principle of consent – the doctor (or other health care professional) chooses an appropriate treatment and the patient chooses whether or not to consent to that treatment. However, choice as a political concept derives more from the notions of consumerism, and 'patient as consumer' is the model of health care that the UK government has been promoting (Kite and Tate, 2005). This consumerist model is not symbiotic with the traditional foundations of the NHS (although has become increasingly prevalent in todays NHS). In a consumerist model, competition is an essential component as a means to attract customers; a tension exists between the consumer who wants a great deal, and the supplier who wants to make a profit (Downie and Randall, 2008). The consumer purchases their product on the basis of its availability, the price and their knowledge of the product. They then take responsibility for the decision made to purchase that product (Kite and Tate, 2005). However, 'choice' in health care is constrained by availability of services and interventions, an individual's ability to understand the choices available to them, and their confidence to express their choices to those people who may be able to facilitate the choices. In palliative care, the ideal became that patients should have choice over place of care and place of death, whether this be a hospital, at home, in a hospice, or a care home (DH, 2003). However, whether this choice actually exists for most people with AD is debatable. Equitable access to service provision does not exist; there are geographic variations in what is available and to whom (Cooley, 2007). For example, not everyone can choose to be under specialist palliative care services, and not everyone can die in a hospice bed. Additionally, when people are ill the choices that they may have made when healthy may no longer be desirable, appropriate or available in their individual circumstances. For example, a patient may be able to evaluate which

hospital offers the best treatment for their condition, but be unable to travel there because of their health. This can lead to inequitable access to health care (Downie and Randall, 2008) with the healthy and educated having increased choices about their care.

In 2003 it was pledged that all adult patients would have access to quality palliative care provision, regardless of their diagnosis (DH, 2003). The role of service users in service development, and a commitment to patient and family choice was further demonstrated in the National Institute of Clinical Excellence (NICE) guidance on palliative and supportive care (2004). This guidance again focuses specifically on cancer services, however it is significant in its emphasis on both supportive and palliative care. Supportive care is described as care that should be provided at all stages of the cancer pathway from pre-diagnosis onwards (NICE, 2004), and has a focus on quality of life and symptom management (National Council for Hospice and Specialist Palliative Care Services, 2002). Supportive care takes the principles of palliative care but delivers it to people from a very early stage in the disease process. The NICE guidance again highlighted the importance of primary care and generalist community services in the provision of palliative and supportive care. Care provision is no longer solely the domain of a single GP (Munday, 2002), and primary health care is now based around the notion of a group of people providing care, which is sometimes referred to as the primary health care team (PHCT) team, or a multidisciplinary team (MDT). These primary care teams were perceived to be in a good position to consider patients who would benefit from a palliative approach due to their potential long-term relationships with their patients and families (Murray et al, 2004).

1.2.2 The National End of Life Care Programme

The NHS National End of Life Care Programme (NEoLCP) commenced in 2004. The programme had the initial aims of enabling more people to have choice about their place of care and place of death, to decrease emergency admissions for palliative patients, to decrease the number of care home residents being transferred to hospital in the last weeks of life, and to increase the skills of generalists in end of life care (NEoLCP, 2008). In relation to care processes, the NEoLCP initially proposed that these outcomes could be achieved by the use of three tools, the Gold Standards Framework (GSF), the Liverpool Care Pathway (LCP) and the Preferred Priorities of Care (PPC) plan.

The GSF was designed to *'...support, encourage and enable primary health care teams to develop improvements in the supportive care of patients in the last stages of life*' (Thomas, 2003, p.176), and has been particularly influential in the development of modern care for people affected by AD. Initially developed with cancer patients in mind, it was later proposed that the GSF be rolled out to all patients with end stage illness. It was suggested that use of the framework in practice facilitates improved communication, coordination, symptom control, carer support, and care of the dying, or the Seven Cs (Thomas, 2003). Practitioners predominantly received the GSF positively (Thomas and Noble, 2007). Teams using the GSF reported increased use of practice based registers, and therefore improved identification of patients in need of palliative and supportive care, earlier referral to district nurse teams, increased team meetings and subsequent improved communication amongst the team (Mahmood-Yousuf et al, 2008). However, Mahmood-Yousuf et al also found that problems still persisted despite GSF usage. These included district nurses and GPs wanting different styles of communication, with nurses preferring meetings to be more formal, and hierarchical relationships between doctors and nurses persisting. Research by King et al (2005) also demonstrated some concern from practitioners about increased workload on GSF co-ordinators within their teams. Munday et al (2007) found that those

GP practices that already had effective organisational structures, and good relationships between staff, were more likely to achieve success in delivering quality services. They suggested that a real commitment to palliative care is required by teams to achieve high standards, and that simply going through the motions of implementing the GSF would not significantly improve care.

The LCP and PPC are specific tools that are designed to support care for people with AD. The LCP is a tool utilised in the last hours or days of life. Initially developed for use in hospices, the pathway aims to ensure that needs are met at the very end of life and provides a framework to ensure that busy staff can provide comprehensive care (National Audit Office, 2005). The tool can be used in any care environment and has been adapted for use in hospitals, the community, and in care homes. The LCP also provides a basis under which care can be audited, and therefore does not just contribute to hands on care but also makes this care measurable, and possibly provides a method of monitoring improvements in palliative care. The PPC is an advance care planning tool and was originally designed by Lancashire and South Cumbria network as a five-page booklet to identify the wishes of patients and their main carers (NEoLCP, 2008). Initial evaluations of this tool found that patients found it empowering as it provided them back-up to argue their care preferences. It also reduced collusion from staff and carers as patient wishes were fully documented and using the PPC document could facilitate difficult conversations with patients and carers (Pemberton et al, 2003). Uptake of these tools has been varied, for example NHS Yorkshire and the Humber (2008) reported that in the Yorkshire and the Humber Strategic Health Authority only 40% of GP practices were using the full GSF, only 21% using the LCP and only 11% using PPC. However, the average across England was reported to be 70% of GP practices using one or more tool (NHS Yorkshire and the Humber, 2008). Research by Hughes et al (2010) found that in a survey of UK GP practices, 61% reported using the GSF, but only 24.4% were using the LCP, 12.3% using PPC. These figures also need to be considered in the context of the response rate of 60%, as it is possible that those practices that did not respond were not engaging with these end of life care initiatives.

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In 2008 the End of Life Care Strategy (DH, 2008a) was launched, and the NEoLCP now works to support the implementation of this strategy (NEoLCP, 2008). The strategy has been significant in recent developments in care provision for people affected by AD, and is specifically devoted to end of life care regardless of diagnosis. Many elements of the End of Life Care Strategy have featured in previous guidance, for example, central to implementing good practice remained the continued roll out of the GSF, LCP and PPC. What is new in this strategy is the drive to improve the profile of palliative care across health and social care in general, and to increase familiarity with death and dying in society. The role of informal carers is also acknowledged within the strategy, including the assertion that they should have their own communication and information needs assessed, and that they should be acknowledged as co-workers within the palliative care team.

These policies seem to have been influential in changing the culture of care for the dying. A review of location of death showed that home deaths had increased from 18.3% of total deaths to 20.8% of totals deaths between 2004 and 2010, which appears to demonstrate a reversal in the trend for institutional deaths in the UK (Gomes et al, 2012). However, it is widely reported that a majority of people would choose to die at home (Gomes and Higginson, 2004), and these figures continue to fall well below that goal.

Alongside the development of these initiatives aiming to improve end of life care, there has also been an increase in specific services available for people with a plethora of conditions, particularly nursing services. Disease specific nurse specialists, and Community Matrons (CMs), a case-management service intended to focus on the care of people with complex long-term conditions (Lillyman et al, 2009), are two of the roles that now have a regular presence within the primary care team and may have involvement in the care of people with AD. New forms of specialist palliative care have also developed with services such as hospice day care, and hospice at home becoming commonly available. However, the majority of specialist palliative care services remain orientated to people with cancer, with around 90% of

inpatient beds, and 85-90% of specialist palliative home care being used by cancer patients (National Council for Palliative Care, 2011). Andrews and Seymour (2011) explored why there was limited referral to specialist palliative care for non-cancer patients. They found that both health care staff and patients did not always consider the non-cancer patient as 'palliative', that other specialist roles may be involved already with the care of these patients, and that there was a perception that specialist palliative care was for cancer patients only.

Summary

Over the past century, health care provision for people affected by AD has changed enormously. Prior to the NHS, care was provided by families, or for a small number of people within specific facilities for terminally ill people. It was recognised that improvements could be made to the care of people with AD, and a number of charities developed to address these issues. However, access to this type of support and intervention was not universal or guaranteed. The NHS heralded a new era of health care, and GP and community nursing services were available to the entire population. However, initially the focus of NHS care was on cure and rehabilitation, and care of the dying was often neglected. Community services were stretched and people did not always seek help with their needs. Around the middle of the twentieth century interest began to develop in the care of the dying, hospices became established, and the concept of hospice care that encompassed physical, spiritual and social domains was developed. Alongside the hospice movement was the developing concept of palliative care, and gradually the development and expansion of services specifically for people who were identified as having palliative care needs. These services were predominantly targeted at cancer patients and it wasn't until the end of the twentieth century that the value of palliative care for all people regardless of diagnosis was recognised on a large scale.

Since the turn of the twenty-first century there has been an accelerating interest in palliative, supportive and end of life care. The NEoLCP has developed to support the implementation of specific national guidance and interventions that have been designed to improve the care of people with AD, and those at the end of their lives.

1.2.3 The current context of care provision

Currently, people affected by AD and those towards the end of their lives may receive care that is delivered by a wide range of individuals and organisations (NEoLCP, 2011) and it seems likely that this situation will continue. As described by Burt et al (2005, p. 3):

> Palliative care patients often have complex needs and may have contact with many organisations and individuals during their final months of life, all providing different aspects of treatment, care and support at home, at hospital and in other locations. Additionally, each patient's 'journey' through care takes place within the wider context of local and national priorities and policies that influence the care they receive.

The range and extent of the services that people affected by AD may have contact with is demonstrated in Figure 1. Care is being delivered by numerous different services that span primary and secondary care. Much of this care occurs in the primary care setting, provided by the PHCT. Although described as a 'team', the PHCT consists of several potential MDTs, including; community specialist palliative care; out-of-hours health care; the general practice team; community nursing teams; and emergency response teams.

1 PROVIDING PALLIATIVE CARE: A COMPLEX 'WHOLE SYSTEM'

Home | Residential home | Nursing home | Hospital inpatient | Hospital outpatient | Hospice inpatient | Hospice day care | Continuing care unit

Primary healthcare team
Specialist palliative care team – hospice
Specialist palliative care team – community
Specialist palliative care team – hospital

Patient and family

National policy, targets and strategy
Local policy, targets and strategy
Commissioners

GP | District nurse | Specialist palliative care nurse | Palliative care consultant | Hospital team: – specialist – oncology – palliative – specialist nurses
Marie Curie nurse | Ambulance service | Social worker | Care assistant
Pharmacist | Complementary therapist | Dietician | Occupational therapist | Voluntary: – Night sitting – Taxi service – Carer respite
Physiotherapist | Speech therapist | Psychologist | Rapid response team
Bereavement service | Chaplain/ religious leader

Figure 1. The system of palliative care provision. Reproduced from Burt et al, 2005, p. 4.

Collaborative health care

There are a number of terms used in the policy and academic literature in relation to the need for the various individuals, and teams, involved in care provision to work together for patient care. 'Teamwork', 'multi-disciplinary working', 'interprofessional working' and 'collaborative working' often get used interchangeably, and there are other over-lapping care concepts such as

coordination of care and shared care that also relate to this notion (King et al, 2012; Zwarenstein et al, 2009). Zwarenstein et al (2009) describe interprofessional collaboration as the process by which people from different professional groups work together to achieve positive patient outcomes. King et al (2012) argue that a collaborative working perspective recognises that it is not just within team behaviours that are influential in the provision of care, but also what happens between teams, and that how health professionals work together in practice is likely to have an impact upon the patient and carer experience of health care. The notion of interprofessional collaborative working (for simplicity I will now refer to this only as collaborative working) considers the various specialist, multi-disciplinary, and generalist teams who are involved in care provision, in addition to professionals who might not consider themselves part of these teams.

The importance of collaborative working is recognised in health care policy (For example NICE, 2004; DH, 2005; DH, 2007), and in practice and educational initiatives such as multi-disciplinary team meetings (DH, 2008), and undergraduate interprofessional education (Sundari et al, 2012). Related aspects to collaborative working, such as good communication and coordination of care are mentioned frequently in health services policy, indeed these principles have become so ingrained in the language of health services that it is hard to imagine them not being present. Although good collaborative working is an aspiration of health care, there are many challenges to this being realised in practice. Downing (2012) suggests that effective collaborations between services can be challenging to develop and it takes time to build the required relationships, trust and respect. The various components of the health care team are often not located together at one base point, may use different systems of documentation, may be employed by different organisations and be working towards different care agendas (Victor, 2000). They may have poor understanding of one another's role (Auty, 2005; McDonald and McCallin, 2011) and be concerned about role erosion from newly developed services (King et al, 2010). Burt et al (2005) explored primary palliative care provision in London. They found that there were wide ranging differences in the way that services were provided between different

boroughs, and that key members of the team (GPs, DNs and clinical nurse specialists) had varying perceptions of each other's role in palliative care provision. This finding is echoed by King et al (2010), who investigated community nurses experiences of collaborative working in palliative care and found that there were often conflicting views between DNs and Community Matrons as to who should have the central role in palliative care. These factors can contribute to conflict and misunderstanding amongst health care services that will potentially influence the patient experience of care provision.

1.2.4 Future developments in care provision for people with AD

As Hockley (2008) describes, policy is continually changing and developing. This is certainly the case in health care at the moment, and recent policy and service initiatives highlight this. The coalition government, elected in 2010, have proposed radical and highly controversial changes to the structure and organisation of the NHS. These proposals have far-reaching implications for the care of people affected by AD. Andrew Lansley, Secretary of State for Health, had promised to end the cycle of NHS re-organisation (RCN, 2010), however the 2010 white paper 'Equity and Excellence: Liberating the NHS' announced ambitious and far-reaching reform within the NHS (Kings Fund, 2010). The white paper proposals include the abolition of Primary Care Trusts (PCTs), to be replaced by Clinical Commissioning Groups, led by GPs. These groups will be responsible for managing health care resources and commissioning services for local populations (Addicott and Hiley, 2011). The British Medical Association (BMA) (2010) describe how further proposals include increased competition between service providers, new and increasingly localised pay agreements, greater possibilities for social enterprises, and public health to become the responsibility of local health authorities. The white paper has received very mixed reactions; concerns have been raised about many aspects of the paper including the need for such radical reform, the difficulties in making these changes at a time of increasing financial pressures, and the assumption that greater competition

will deliver increasing value for money has been challenged (BMA, 2010; Kings Fund, 2010; RCN, 2010). GPs themselves echoed the concerns highlighted above, and have discussed the potential detrimental impact on the GP role, including the effect on the doctor/patient relationship of them becoming budget holders (Royal College of General Practitioners, 2010).

In January 2011 the Health and Social Care Bill was presented to parliament, setting out the legislation required to implement the government's reforms (BMA 2011a). However, many aspects of the Health and Social Care Bill continued to be challenged by leading professional groups, and in May 2011 the government halted the passage of the bill and commenced a 'listening exercise' (BMA, 2011b), following which a number of changes were made to the reforms. However, these changes were not perceived to be adequate in ensuring that the bill delivered on its promises. Both the BMA (2011c) and the Royal College of Nurses (RCN) (2012) called for the bill to be withdrawn, and the Royal College of General Practitioners (RCGP) asked for further clarity on a number of issues within the Bill with which it continued to have serious concerns (2011). These are clearly turbulent times for the NHS and its staff, and the changes proposed by the Bill risk causing additional bureaucracy and confusion within the Health Service (Kings Fund, 2011). Despite widespread resistance, the Health and Social Care Bill finished its passage through Parliament and received Royal Assent in March 2012. The ongoing changes within the NHS will continue, and these will undoubtedly impact on service design and delivery, which will affect care provision for people with AD and their experiences of service provision.

Summary

There are now many different services and health care professionals involved in the provision of care for people affected by AD. Collaborative working is an aspiration of health care, but these varied services face many challenges to engage effectively in working together. Services are rapidly evolving, and are currently subject to significant changes in terms of organisation and funding.

These ongoing changes are likely to affect the structure and delivery of care to people affected by AD in the near future.

1.3 The academic orientation of the thesis

As this thesis has developed I have often been asked *'what is your PhD in Beth? Is it nursing? Is it health psychology? Is it palliative care?'* This seemingly simple question left me in a quandary – does this thesis sit within one academic discipline?

Having considered this issue, I feel that the complex nature of the phenomenon in question is reflected in the academic orientation of this thesis. The phenomenon to be explored is one that I became aware of as a nurse, and is relevant to practicing nurses who have contact with this population. The investigation of this issue is informed by nursing theory and I acknowledge the influence of my nursing career and education upon the development of my ideas. However, this thesis is also influenced by psychological theory under the guidance of my supervisors Nigel King and Alison Rodriguez. The population under investigation is one to which palliative and supportive care services are involved, and theory and literature is again drawn from this discipline. However, not all members of this population may be receiving specialist palliative care services, and generalist service providers also have a considerable stake in care provision for these people.

In conclusion to this issue, I believe that this thesis falls across these preordained academic and professional boundaries. In this way, it reflects both the complexity of the phenomenon under investigation and my own generalist background. In line with this foundation, I hope the findings of this research will be of interest to people from a variety of academic and clinical disciplines.

1.4 The structure of the thesis

This research will utilise van Manen's (1990; 1997a) phenomenological approach to illuminate the lived experience of people who are affected by AD and have multiple services involved in their care. Van Manen's hermeneutic phenomenology is offered as both research methodology and research method, and his ideas have informed all stages of the research process.

The thesis is structured into nine chapters:

Chapter two will set the context for the research, exploring the conceptual and theoretical literature in relation to patients and carers lived experience of AD. I will then report on the process and findings of a systematic literature search in relation to the experience of multiple service involvement. The chapter concludes by considering why the current research is needed, and detailing the aims of this research.

In Chapter three, I consider the philosophical basis of this research and offer a rationale for why phenomenology has been chosen as a methodological framework. I will outline various phenomenological research approaches before exploring van Manen's Human Science Research, which is chosen as the dominant approach to inform this research.

Chapter four commences with a discussion of the ethical issues inherent in research with people affected by people with AD. The methods used in this research are described, considering the empirical methods that were used to collect the lived experience examples, and the reflective methods that were used to explore, analyse and interpret the data. As part of this I will introduce the innovative research technique 'Pictor' that was utilised as part of the research interview to support participant reflection and communication of their experiences.

Because of the complexity of the phenomenon under investigation, four chapters are devoted to unravelling the lived experience of this phenomenon. Chapter five is spilt into two parts: the first part will introduce the findings sections of the thesis, offering a rationale for the structure of the findings chapters. The second part will introduce the participants who took part in this research, and explore aspects of the research interviews that contributed to my understanding of their individual experiences. Each of the following findings chapters is structured on the template that was developed as part of the data analysis. Chapter six focuses on unique elements of the patient experience, chapter seven focuses on unique elements of the carer experience, and in chapter eight I focus upon perceptions of key relationships between patients, carers, and members of the health care team.

In chapter nine, I will present the essential themes relating to this phenomenon, exploring the implications of these for practice. I will also take the opportunity to critique the methodology employed in this research, including deliberation of the strengths and weaknesses of the approach taken. Finally, I will personally reflect on the transformational nature of the research process.

Chapter 2: Literature review

Everything changes when one is living with dying. The world changes sociologically, economically, physically, emotionally, and spiritually. Life centres around physicians, lab technicians, test results, and others who are dealing with illness. Just as the nuclear medicine units are all underground, the "community" of people who live with ongoing encounters with the medical world is like a secret society, out of view of the healthy and well-defended. Thousands of people pass through AIDS clinics and cancer centres daily, some looking ill, some in wheelchairs, some wearing face masks, many wearing funny little hats like the one I wear. Some look frightened, as though they don't yet know whether they will be forced to join the ranks of patients. Some obvious patients look as socialized into the surroundings as the medicine men and women who are in charge. Unless one's work involves medicine, or unless one has someone close who is ill, it is initially a strange and terrifying world, full of space-age equipment and Star Trekian procedures. In order to avoid losing one's way in an impersonal system full of black holes and misinformation, it is necessary to learn how to ask questions, to advocate on behalf of oneself-often when one's energy and compelling needs make it practically impossible to do so.

Wood, 2001, pp. 98-99.

Nancy Carolyn Wood, an American psychotherapist, died from lung cancer in 1999. She wrote the above extract about her own experiences of living with dying. This extract vividly demonstrates the change that illness brings, the experience of entering a new and unfamiliar medical world, the isolation of illness that can distance the sufferer from others who are healthy, and of learning how to be within, and navigate the health care system.

In chapter one I outlined the focus of this research on patient and carer experiences of service involvement whilst they are in the community setting. I have identified that primary care services for people with AD are continually

changing, with the current model of care provision being based around the notion of a primary health care team. Patients will often also be continuing under the care of secondary care specialists. I will now build upon this contextual perspective to explore the theoretical and research literature in relation to living with AD, and use of the health care services. Throughout this discussion I will argue that in order to understand the experience of people affected by AD we need to attend to the meanings that are attached to phenomena. I will subsequently argue that a phenomenological approach to exploring the experience of service involvement is a valuable contribution to the existing evidence base.

2.1 Living with advanced disease

The lived experience of AD involves many potentially significant components; getting a diagnosis; telling family and friends; noticing deteriorating physical health and losing the ability to function as before; living with symptoms; discussing the possibility of death with a child. These are just a few possible aspects to lived experience, and the possibilities for research in this area are seemingly endless. The broad focus of this research is experiences of health care services. This is not a phenomenon that happens in isolation of other factors relating to having AD, or caring for someone with AD. In the following discussion I will draw upon some key concepts within the health literature that help to explore and explain the lived experiences of people affected by AD. This discussion will form the contextual background from which to consider the experience of service use.

2.1.1 Quality of life

Quality of life (QoL) is a broad umbrella concept that generally refers to having a 'good life', but incorporates other theoretical notions such as well-being, happiness, meaning in life, fulfilling needs, living with dignity and achieving life potential (Ventegodt et al, 2003). The concept of QoL is

significant within discussions of care for people with AD. Promotion of QoL is often used as a rationale for palliative care provision (Payne, 2006), and a frequent goal of care interventions for people with AD (Tassinari and Maltoni, 2009). It has been suggested that measurement of QoL in palliative care is one way that the discipline can create a stronger evidence base on which to implement it's interventions (Baumrucker, 2004), and subsequently, affect on QoL is often used as an outcome measure in relation to health care interventions for people with AD (Kaasa and Loge, 2002).

Quality of life is a culturally and historically bound concept (Ventergodt, 2003). The concept has its origins in the political and social sciences, and was seen to be a method of measuring the social change that was promised by health and welfare programmes in the second half of the 20th century, such as new housing, and increased educational attainment (Armstrong and Caldwell, 2004). Subsequently, much of the early empirical work into QoL was undertaken in the fields of sociology and psychology with the aim of estimating satisfaction, happiness, and well-being (Morgan, 2000).

Quality of life is subjective and multidimensional (Cella, 1994; Morgan, 2000). In relation to health, QoL incorporates physical, emotional, social and spiritual factors. There have been numerous attempts to define QOL to make it measurable, but Barofsky (2012) highlights that these all have limitations. Measurement approaches can be context specific which limits their generalizability, and content-based definitions such as individual assessment and consensus on specific domains, can be biased towards individual and investigator preference. To compound this problem, QoL is an inherently abstract concept and thus it will never be possible to completely define QoL based on content. Despite this, there are numerous tools that purport to measure QoL, for example the McGill Quality of Life Questionnaire (Cohen et al, 1995), the European Organization for Research and Treatment of Cancer (EORTC) measures including specific tools for palliative care and for evaluating services, and the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (Payne, 2006). These tools vary in the populations they are

directed at, and the length and complexity of the tool, but they all ask a number of questions that aim to elicit the QoL of the respondent.

Morgan (2000) suggests that one of the reasons why there are so many QoL measures is that it is extremely hard to capture the hidden spiritual dimensions of people who are facing their own mortality. Crang and Muncey (2008) used the SEIQoL in combination with unstructured interviews to explore the notion of QoL in hospice patients. They found that the SEIQoL did give a window into the participants QoL, but it did not capture spiritual and existential issues, despite these being more important to the participants than physical symptoms. Quality of life is subjective, and a further difficulty in using these measures with people affected by AD is that a significant proportion of people may be too unwell to complete the questionnaires themselves, and therefore a proxy may be relied upon and may not give a true indication of the persons QoL (Jones et al, 2011). Equally, the questionnaires can be unwieldy, lengthy and time consuming, and may be too generic to address the factors of importance to the specific person who is competing them (Dunderdale et al, 2005).

There is disagreement in how QoL is defined and how it can be best assessed. However, if we consider Ventegodt et al's (2003) very generic description of QoL as a 'good life' then it is evident that people affected by AD face many challenges to their QoL. For example, AD is generally characterized by progressive physical decline, and people will almost always be experiencing a number of physical symptoms that impact upon all areas of life (Boyd et al, 2004; Brännström et al, 2006; Hasson et al, 2008; Higginson and Costantini, 2008; Kuhl, 2011), which can be very disturbing to normal functioning (Boyd et al, 2004; Higginson and Costantini, 2008). People will often experience multiple symptoms over the progression of their illness, and sometimes be living with many symptoms at the same time. But it is not just the physical effects of disease that threaten quality of life. Existential concerns may come to the fore, and there may be fear about the future, and about death (Appelin et al, 2005). Indeed, Farber et al (2003) describe how one of the overwhelming impacts of living with serious illness is that the

knowledge of impending death permeates every moment of people's lives, and is an inescapable presence. Ultimately, it is what these various disease related factors mean to individuals, as to how they impact upon an individual's QoL.

2.1.2 The good death

I have established that QoL is an important concept in the care of people with AD. In parallel to this concept is the notion of a quality death, referred to in the literature as a good death. The concept of a good death is also neither straightforward, nor universally agreed upon (Kehl, 2006), but can be seen as a priority both at political and societal levels (Ellershaw et al, 2010). Within palliative care, a good death is an ideal associated with the goal of achieving positive outcomes for those who are dying, and is a primary outcome for services delivering care for those at the end of their lives (Kehl, 2006). From the 1980's onwards, the term also was used as a synonym for euthanasia, and more recently issues of a good death have become caught up with the right-to-die movement (Walters, 2004). Although these are important issues, this discussion will focus on the more general notions of this concept as used within the health literature.

In the early years of the palliative care movement, a good death was understood as one that was free of unpleasant symptoms, which included physical pain and psychological social and spiritual suffering (Walters, 2004). Since this time, a massive volume of literature has been produced relating to the concept of a good death. Kehl (2006) undertook a concept analysis of the term based on literature drawn from the past 50 years and found that there is considerable agreement in the literature as to the attributes of a good death, but variation in the importance given to the different attributes. Important aspects of a good death included being in control and having choice, being comfortable, having a sense of closure, being recognised as an individual with value, and having trust in care providers who know the patients and their family. Conversely, 'bad death' deaths are characterised as those in which

there is a lack of acceptance of death in patients and families, or there is a failure to actively pursue the fulfilment of living up until the final stages of dying (Hart et al, 1998). Jones and Willis (2003) argue that although these may be the good and bad deaths for some people, it is important not to lose sight of personal wishes. Some people will die in circumstances that seem unfair, untimely and will never be accepted. Some may choose to be actively treated, to pursue cure, do not accept a peaceful or pain eliminated death, and choose not to engage in conversations about death and dying. Heath (2008) also makes this argument by suggesting that although pain can be very destructive, it can also be reassuring – reminding people that they are alive, still have sensation and a physical presence. Thus, the elimination of pain as a universal goal will not ensure a good death for everyone. Indeed, it can be argued that if factors relating to personal choice are honoured, even when they challenge the popular perceptions of a good death, then they are actually contributing to the good death of that particular patient.

The concept of a good death is socially constructed, and shaped by historical, cultural and personal narratives (Koraromy, 2008; Watts, 2012). Goldsteen et al (2006) took a hermeneutic approach to exploring the concept of a good death from the perspectives of people with a short life expectancy (three months or less). Their findings indicate that people's understanding of factors relating to a good death conform to normative expectations, and people may see themselves as negatively or positively dealing with these expectations. Thus, they suggest that people refer to the social narratives that are available to them and organise their own life stories within these narratives (Goldsteen et al, 2006). Hart et al (1998) argue that there is a risk that the lives of dying people are shaped to fit the good death ideology, which influences the behaviour of caregivers and the goals of patient care. Although referring specifically to hospice care, it is an interesting assertion that the ideal of a good death, which on the surface appears to be choice promoting, may actually challenge the notions of autonomy that it proposes to support.

The notion of a good death has been influential in current policy; for example, discussion of advance care planning, preferred place of care, and the

Liverpool Care Pathway are key elements of the Gold Standards Framework and end of life care policy. These elements all clearly contribute to aspects of the 'good death' in their promotion of choice, control, and the eradication of unpleasant symptoms. It is often suggested that care pathways benefit patients and health professionals, and implied that they improve the quality of dying, although Watts (2012) suggests that there is little evidence to support this claim. It can also be argued that the notion of a good death can foster unrealistic expectations of what can be achieved relating to dying and death, and that many of the components so dominant within health care policy may not be factors which are actually of importance to individuals. For example, home as place of death is a frequently cited goal of current policy, and a desire of patients (Higginson and Sen-Gupta, 2000), however, some research has suggested that this is not a goal shared by everyone (Steinhauser et al, 2000), and that decisions related to place of death may fluctuate as people's health and circumstances change (Munday et al, 2009). These factors highlight the individualistic and evolving nature of a good death.

Despite the lack of consensus as to exactly what constitutes a good death, there is consensus as to the value of a quality dying as an aspiration of health care. Of particular interest for this study is the role of effective interprofesional relationships in the creation of a quality dying scenario. However, there are numerous problems with the concept of a good death as an outcome measure. Families, patients and health professional's may have different opinions on what makes a good death and thus when exploring this notion it has to be considered whose perception of a good death is being evaluated. Equally, although this concept is of known interest within the professional literature, it is less evident how important it is to patients and families themselves (Munday et al, 2009). Finally, I have alluded to the individualistic nature of a quality dying – however this may be lost if evaluation is of a 'good death' per sae.

2.1.3 Transitions

'Transition' refers to people's responses during a period of change, and their ability to adjust and adapt to new life circumstances in order to incorporate the change into their lives (Kralik et al, 2006). The phrase is sometimes used to exclusively refer to transitions between care settings – for example hospital and hospice, and between care types – for example on referral to palliative care (Abarshi et al, 2009). For people affected by AD there are many potential points where transition can occur, for example this might include the point of diagnosis, as disease progresses and disabling symptoms develop, or having new services involved in care. Various terms are used in the health literature to describe the notion of transition, including illness trajectory, which is particularly used in progressive illness to depict the successive potential transitions experienced (Kralik et al, 2006).

Disease and illness trajectories

Trajectories are one way of considering health and illness over a period of time and involve longitudinal investigation of the health and illness of specific populations (Henly et al, 2011). They highlight potential transitions as illnesses fluctuate or progress, and visually and theoretically demonstrate the different types of decline experienced. An understanding of trajectories can help to identify patterns of changing care need, and highlight appropriate points for particular aspects of care, such as advance care planning (Murtagh et al, 2011). Additionally, the theoretical framing of illness and dying as a complex longitudinal experience with distinct phases of increased need can provide a tool for the planning of service delivery (Penrod et al, 2011). Glaser and Strauss first proposed the concept of disease trajectories in their seminal work during the 1960's (Gott et al, 2007). More recently, several illness trajectory models have been developed that relate specifically to AD, focusing on different disease populations. These trajectories depict potential points of transition for patients and carers affected by AD. For example, Murray et al (2005) describe the three most commonly used conceptual trajectories of declining health: a progressive chronic illness trajectory in which people

experience a steady deterioration with a clear terminal phase of illness (mainly cancer); a gradual decline trajectory which is interrupted with periods of acute deterioration with some recovery, and a seemingly sudden, possibly unexpected death (mainly non-malignant conditions such as heart failure); and a trajectory of prolonged decline (mainly elderly and dementia) (Murray et al, 2005). These can be diagrammatically presented and are shown in Figure 2.
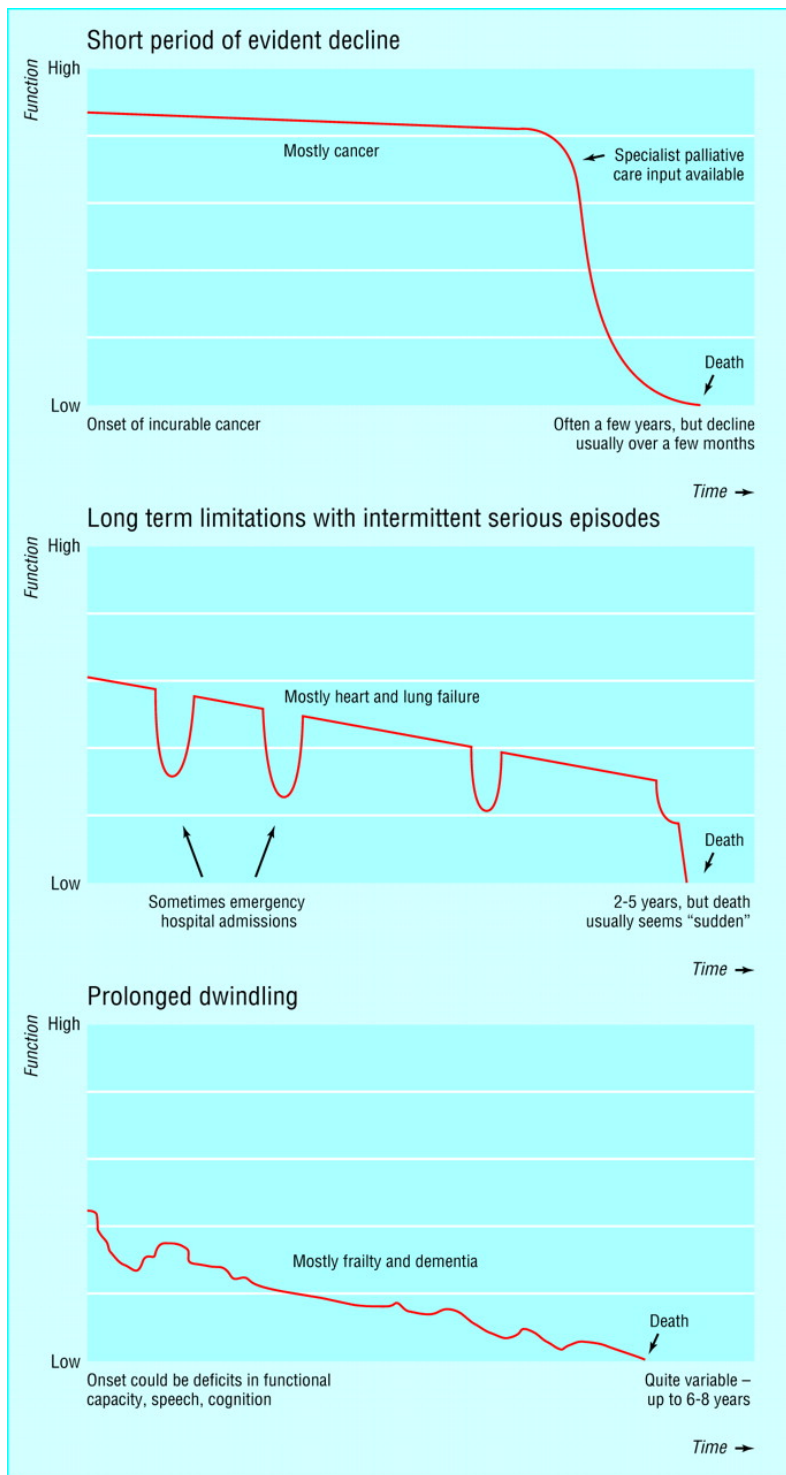
Figure 2. Illness trajectories. Cited from Murray et al, 2005, p. 1008.

The trajectories indicate the different patterns of declining function that are experienced by people with different diagnoses, the troughs in the diagram representing rapid decline in people's health and functioning. These trajectories have become widely accepted, however there is some research to suggest that these trajectories are not universal. Murtagh et al (2011) investigated the functional decline in people with conservatively managed end-stage renal disease who were in the last year of life. They used the Karnofsky Performance Scale as a measure of functional status and reassessed this monthly over the last twelve months of the patient's life. The functional trajectory that they discovered is closer to trajectory one as described by Murray et al, rather than the organ failure trajectory. Gott et al (2007) looked at the trajectories of people with heart failure in the last two years of life, using two separate questionnaires that were completed by patients every three months. Interestingly, Gott et al found no specific pattern to the trajectories that people experienced, and challenge the evidence base relating to trajectories as a tool for functional prognostication and service planning in relation to heart failure.

The trajectories described so far have been based on measures of functional decline. Penrod et al (2011; 2012) propose a conceptual trajectory of caregiving at the end of life based on the findings of a grounded theory study involving 46 spousal-carers. They describe five phases of the caregiving trajectory; sensing a disruption, challenging normal, building a new normal, and reinventing normal (following the death of the care recipient). They suggest that these five phases occur in all caregiving trajectories, but when, and how often they occur will depend on the illness trajectory of their partner (based around the three general trajectories as suggested by Murray et al (2005) and shown on p.51). This conceptualisation of caregiving demonstrates the interdependency of carers and patients experience, and also highlights the numerous adjustments that caregivers are having to make as they reinvent their 'sense of normal'. These trajectory conceptualisations are informed by a sample of american spousal-carers whose partners were receiving care through palliative or hospital programmes. They might look

very different if other contextual variables were considered such as different family relationships, treatment pathways and cultural factors (Ersek, 2011).

Time is a fundamental component of disease trajectories, as it is the course of illness over a passage of time that is measured and visualised. However, although a seemingly simple concept, measurement of time can be challenging and has numerous aspects, for example time as measured by a clock, and perceived time, are potentially very different (Henly et al, 2011). Although these trajectory diagrams are a useful way to broadly conceptualise the experience of disease, they do not provide insight into how these trajectories are experienced by people themselves, or what the peaks and troughs of decline mean to people. Equally, these trajectories could be taken to indicate that all people with a certain condition follow the same patterns of decline, and although patterns across populations are a valuable tool, it remains important to remember that they are only broad generalisations about experience, and not necessarily indicative of an individual's disease pathway.

Becoming a carer

I have touched upon the impact of AD on carers in relation to the model of transition proposed by Penrod et al (2011; 2012). Carers are a heterogeneous group (Ugalde et al, 2011) and are foremost wives, husbands, partners, children, family members or friends of people who need help with their day-to-day living (Carers UK, 2011). The carer's life has been forever changed by the presence of AD and they live with the uncertainty about the future that also affects their loved[1] one (Farber et al, 2003; Funk et al, 2010). Carers take on many roles: these include the provision of physical care, household management, organisation of financial affairs, and the adoption of roles which were been previously undertaken by the ill person (Ugalde et al, 2011; Stajduhar et al, 2010). Lay-carers have an ambiguous role in relation to health services. They are both a provider of care, and indeed essential in enabling people to live, and die at home (Funk et al, 2010), but also receivers

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[1] I have used the term 'loved one' to describe the person that the carer is providing care towards. However, I acknowledge that in some caring situations, care may be provided to someone who may not be considered by the carer to be a 'loved one'.

of care, as they are supported to fulfil their role (Brobäck and Berterö, 2003; Payne et al, 2010; Stajduhar et al, 2010) and deal with their own health issues.

Becoming a carer is generally not a 'choice' that is made (Cavaye, 2006), and the person who has become a carer may feel that there was no option about them undertaking this role (Boyd et al, 2004; Perreault et al, 2004), as they strive to support their loved one in their decision to remain at home (Stajduhar, 2003; Wennman-Larsen and Tishelman, 2002). Caregiving is often seen as an extension of family relationships (Jo et al, 2007), and spousal-carers may perceive the role to be part of their marriage commitment (Appelin et al, 2005). Where people have not had a good relationship with the person who requires care, the acceptance of the caregiving role may be made with reluctance and born out of a sense of duty and obligation, rather than affection (Cavaye, 2006). How people become a carer in part depends on how the needs of the person they care for have changed. When AD has developed from a long-standing condition, carers may have had a gradual adjustment to the caregiving role, for example in Parkinson's disease (Hasson et al, 2010). However, when disease has been diagnosed at the advanced stages, and health has deteriorated quickly, people find themselves rapidly having to adapt to their new role (Brobäck and Berterö, 2003).

There is consensus in the research literature that being a carer for someone with AD has many implications. Carers experience both physical and emotional strain associated with their caregiving role (Andershed, 2006; Farber et al, 2003; Funk et al, 2010; Hasson et al, 2010; Jo et al, 2007; Proot et al, 2003; Stajduhar, 2003). Combined with this, carers and their families may be coping with financial hardship (Farber et al, 2003; Funk et al, 2010; Jo et al, 2007; Proot et al, 2003); their own ability to undertake paid employment being compromised by their caring responsibilities, and additional loss of earnings caused by their loved one being unable to work. This problem can be further exacerbated by an increase in expenses as specific equipment and adaptations may be required to enable their loved one in the home.

Carer's levels of distress are sometimes documented as being as high, or higher than that of the patient, with a variety of factors contributing to the impact of AD upon the carer, including age and gender, the quality of the relationship with the patient, levels of the patients distress and the personal meanings attached to specific situations (Carlson et al, 2000; Harding et al, 2003; Galfin and Watkins, 2011).

2.1.4 Grief and loss

Grief is described as an individual response to loss (Buglass, 2010). For people affected by AD there are many losses to grieve for. The most obvious loss for people with AD is the impending loss of life, and loss of a perceived future. In AD, the future has become unpredictable and uncertain, and is no longer taken for granted (Brännström et al, 2006, Hopp et al, 2010). However, these are not the only losses. As disease progresses, and dependence on others increases, people may experience a shrinking social world (Seamark et al, 2004; Boyd et al, 2004), because of poor mobility and the burden of symptoms (Aldred et al, 2005; Hopp et al, 2010). People may have to give up hobbies and social activities. Previously taken for granted social interactions, such as mealtimes, may become compromised due to the effect of symptoms (Farber et al, 2003) and treatments. Furthermore, time with family that was once a pleasure may become a strain as the ability to engage in social interaction changes (Aldred et al, 2005). These factors can contribute to social isolation (Brännström et al, 2006; Hasson et al, 2008; Hopp et al, 2010), and are part of the progressive losses that are an essential theme of the experience of AD.

Carers also experience a number of losses. Primarily they are faced with the loss of their loved one. Matt Seaton, the husband of Ruth Picardie, a journalist for the Observer who died from breast cancer in 1997, vividly describes this:

You always imagine death as a sudden event, a clean break between being and non-being, possession and loss – and for some, facing perhaps the dreadful trauma of losing a loved one killed suddenly in an accident, that is how it must be. But with a progressive disease like cancer, dying is a relentlessly attritional process of estrangement. You want so much to do and say the right thing, but you are doomed to frustration, failure and regret. The only really 'right thing' would be to make that person you love well again, and that is the one great godlike task you cannot perform.

I know I was wrong in many important ways: our relationship is an irreducible historical fact – for eleven years, before the cancer, it was what it was, and nothing can alter that. And it lives on, too, in the most real possible way in our children; there is no greater saving grace.

I know also that regret and guilt are the classic symptoms of bereavement. In a sense, I'm aware that what I feel is almost a cliché. None of that, though, alters the angrily chafing, subjective truth of the feeling. I just wish – how I wish – I could have somehow got round it: loved Ruth, or made her feel loved, in the old way, to the very end.

But the truth is that it was no longer possible. The cancer had interpolated itself, sending out its rogue cells to multiply madly and lay waste like an army of termites. Cancer changed everything: it put us on different tracks, stretching our grasp of one another to the limit and eventually forcing us apart. In the end, I could not reach her, and it felt like a failure in me. And then she was gone.

Picardie et al, 1998, pp. 103-104.

In addition to facing the death of a loved one, carers experience many other losses. The time devoted to caregiving compromises the time available for other activities including time to oneself (Hasson et al, 2010; Proot et al, 2003) and time for the continuation of other roles such as spouse or child

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(Stajduhar, 2003). Carers are often very committed to the care they provide, feel constantly responsible for the care that is received by their loved one (Brännström et al, 2007) and may feel unable to take a break (Ugalde et al, 2011).

This commitment impacts on the carers social life. Previous leisure activities may be discontinued due to the desire to be available to the ill person 24 hours per day, leading to a loss of personal freedom (Munck et al, 2008), social isolation (Brännström et al, 2007; Hasson et al, 2010) and loneliness (Proot et al, 2003). Indeed, carers may experience feelings of guilt if they desire or need a break from their role as caregiver (Brobäck and Berterö, 2003). This can lead to boredom (Seamark et al, 2004) and frustration. However, it is suggested that continuation of previous activities may provide distraction (Proot et al, 2003) and enhance coping (Funk et al, 2010). Carers have to find new ways to maintain social contacts, for example Seamark et al (2004) found that carers of people affected by COPD increasingly interacted with social networks through telephone contacts, to compensate for their reduced ability to engage in face-to-face contact. Not only does the carer experience the multiple changes to their lives that have already been described, but when they live with the person for whom they are providing care, they also have to adapt to a changed home environment. As the health of their loved one deteriorates, increasing amounts of medical equipment may be required, and increasing numbers of health and social care professionals may be visiting the house. The carer may experience a loss of privacy as the personal space of 'home' is changed into a medicalised environment, and may feel pushed aside in a space that was theirs (Appelin et al, 2005; Stajduhar, 2003).

There are many theories about grief as a process, which sometime describe grief in terms of stages that a person has to work through. These theories suggest that a person goes through a period of adjustment before accepting their loss, and often consider loss in terms of death or separation. Kübler-Ross proposed a model of grief to describe the response in terminally-ill patients to the awareness of their approaching death; denial and dissociation,

anger, bargaining, depression and acceptance (Kübler-Ross, 1970). This model is often presented as a process, so it is important to note that Kübler-Ross did not intend her theory as a strict linear process, although subsequent theorists have often presented it that way (Kübler-Ross Foundation, 2012). Other grief theories have followed a process model and depict grief as developing from initial shock through to adjustment and recovery (Bowlby, 1973; Parkes, 1998). Inherent within these explanations of grief is the assumption that grief is a normal response to intense loss, and is characterised by universal stages of adaption and response to the experience (Neimeyer, 2002). These stage theories have many limitations in explaining the lived experience of grief. Stage theories indicate that all people grieve in similar ways and do not account for the uniqueness of loss and bereavement. People are perceived as passive in the grief process, seen as going through stages, rather than active participants in an evolving emotional experience. They do not tell us how people cope with their losses (Bonanno, 2007).

Neimeyer et al (2002) argue that the meaning of any loss is significant in how a person adapts and integrates that loss into their lives. This constructivist approach suggests that humans seek meaning in their mourning and attempt to create an account of their experience that provides continuity between the person who they were, and the person who they are now. These meanings are informed by personal and cultural factors. Furthermore, people who experience significant losses can find positive meaning through their loss, and can experience personal growth through subsequent meaning reconstruction. For example, despite the many challenging aspects of undertaking their role, carers often describe many positive elements of their experience (Hudson, 2004). Caregiving can be seen as a time when profound meaning is present (Farber et al, 2003), and described as life enriching, enabling valuable time to be spent with the loved one (Stajduhar, 2003; Jo et al, 2007). Other valuable aspects of caregiving include feelings of satisfaction, pleasure and thankfulness (Andershed, 2006), and comfort in knowing that the care wishes of the loved one are being accommodated (Brännström et al, 2007). People who have a diagnosis of AD and are approaching their own deaths may also find this a time for life-review and reflection (Hopp et al, 2010). Kuhl (2011)

used phenomenology as an approach to explore the lived experience of terminal illness in cancer and AIDS. He found that the illness had provided the opportunity for people to appraise their lives, which could lead to feelings of accomplishment and pride. This finding is echoed in other studies, for example Nakashima and Canda (2005) interviewed sixteen older adults who were diagnosed as being terminally ill. These adults described how they used their internal and external resources, and their sense of resilience to develop new skills, engage in activities to support future generations, and fortify relationships with loved ones. Through this, they developed a sense of spiritualness that created existential meaning in life. Although people affected by AD will experience many loses, how these loses are interpreted, and the meaning ascribed to them, is significant in how the loss will be experienced.

2.2 Experiences of service provision

The principle focus of this research is patient and carer experiences of receiving services from multiple providers, and to ensure that I have thoroughly considered the existing literature base before specifying my own research question I decided to utilise a systematic search strategy for this part of the literature review. Systematic literature reviews have become an important research method in health and social care, contributing towards the evidence base by presenting analysis of the available literature on any one topic (Aveyard, 2010). Equally, the process of literature searching is important when wanting to consider the existing knowledge base before designing and undertaking research. The Cochrane Library, launched in 1993, has become a renowned source of systematic review, promoting a systematic approach to reviewing primary research in health care and health policy (The Cochrane Collaboration, 2012). The reviews undertaken by The Cochrane Collaboration are orientated towards evaluating the effectiveness of interventions, predominantly measured by clinical trials (Green et al, 2011). The Cochrane Qualitative Research Methods Group has developed guidance for the systematic review of qualitative research. However, this extensive full type of systematic review method is not appropriate for this study, as I am not

aiming to make clinical recommendations based on the result of the findings of current literature, and I do not have the resources to utilise other researchers in the process of identifying, appraising and synthesising the literature. However, a systematic approach to literature searching, combined with the principles of critical appraisal, can still be undertaken. As I am not undertaking a full systematic literature review, I will refer to this process as a systematic literature search.

There is some debate as to whether findings from qualitative studies, using different methodological approaches, can be compared (Jones, 2004). For the purpose of this systematic literature search, I believe it is entirely appropriate to explore research from different methodologies, as these varying perspectives will add depth to the understanding of the phenomenon. To support the process I have utilised the ideas of Hawker et al (2002) who describe a method of systematic literature searching that is suited to exploring research from disparate methodologies.

2.2.1 Systematic literature search method

Aims

In the previous chapter, I discussed the context of service provision for people with AD, and established that there are often multiple services involved in the care of this population. The aim of this systematic literature search is to identify and appraise existing research that explores patient and carer experiences of multiple service provision when they are in the community setting, in the UK. I decided to locate only UK studies because of the variation in models of service provision around the world.

Locating and accessing the literature

The process of undertaking a systematic literature search as described by Hawker et al (2002) incorporates several stages, the first of which is to locate the literature. As I identified in the introduction to this thesis, the terminology

used to describe the population of patients with AD can be diverse. In order to make sure that all of the relevant literature was identified, I developed a search strategy that incorporated the various terms used to define the population, and the services they might be receiving. To help ensure that I had considered all possible terms, I utilised a modified version of the acronym PICO, which stands for Population, Intervention, Comparison and Outcome. This acronym is widely used as a method of structuring answerable clinical review questions, although the comparator may not always be evident (Stone, 2002). Indeed, the comparator is not necessary for this review, as I am not evaluating a clinical intervention. However, I have also considered an additional element, environment, as this is a central component of my review objectives. Table 1 identifies the key terms utilised as part of the search strategy. These key terms were applied as part of electronic database searches on the Cochrane Library, CINAHL and PsychINFO databases, making use of appropriate Boolean operators, wildcards and truncations to maximise the search results. Some of the databases that were searched have functionality that enables searching of papers that have cited the selected paper. Where this was the case, this option was utilised to broaden the search.

Despite having developed a systematic approach to searching, I still found that papers were sometimes hard to identify. Creative titles are often used in journal articles discussing qualitative research, and title review alone was often not adequate to identify whether the research was of relevance. I also found that terminology issues contributed to difficulty identifying appropriate papers: some titles identified would initially appear to be about peoples experiences of 'palliative care' but on closer examination it became apparent that the research was focused on the stage of the illness, rather than the care that was being received. Additionally, because service use is one part of people's experience of AD, I found that some papers included findings of relevance to this review, despite the main focus of the paper being on experience in general.

Table 1. Key terms used in search strategy

Line no.	Population		Intervention		Outcome	Environment
1	People affected by AD	End of life Terminal	Receiving intervention from multiple care providers		Experiences of...	Primary care
2	Patient (s)	Service user(s)	Support	Contact	Relationships with...	Home
3	Carer(s).	Lay-carer(s) Spousal-carer(s) Partner(s) Husband Wife Family member	Palliative care services End of life care services Interdisciplinary Collaborative Continuity			Community
4			Supportive care services			
5			Generalist services			

Inclusion criteria

Articles that had been 'hit' through the above search strategy were screened for relevance by applying inclusion and exclusion criteria. Articles were included if they were of relevance to the specific research question, reported original research (i.e. not comment or discussion papers), were undertaken in the UK, were available in English, reported research undertaken since the year 1995[2], and included adult participants diagnosed with AD[3]. Additionally, articles were excluded if they were unavailable through the British Library.

Articles were screened initially on their title and key words, and then on their abstract. A total of 74 papers were identified as a result if this process. The

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[2] 1995 was chosen as the cut of date for this literature review as this was the year the Calman Hine report was published which is credited with having a significant impact on the integration of palliative care services into the mainstream NHS, and developing palliative care into a NHS speciality in its own right (Finlay 2001).

[3] AD as defined in the GSF and discussed on p.21.

full text of these papers were retrieved and read to ascertain their suitability for this search. A considerable number of the papers were rejected as they described research that had been undertaken outside of the UK. Other papers were rejected because they were focusing on a specific care service, they looked generically at the experience of being a patient or carer but did not discuss involvement of services, or they were evaluating a specific primary care intervention. Finally, eighteen papers were identified as being relevant to this literature search.

The specific search results are documented in appendix 2, and summarised below.

Total number of references identified N=4665	Papers included in final review N=18
References rejected based on title, keywords and abstract N=4591	Additional papers identified through reference lists N=1
Number of full papers examined N=74	rejected papers N=57
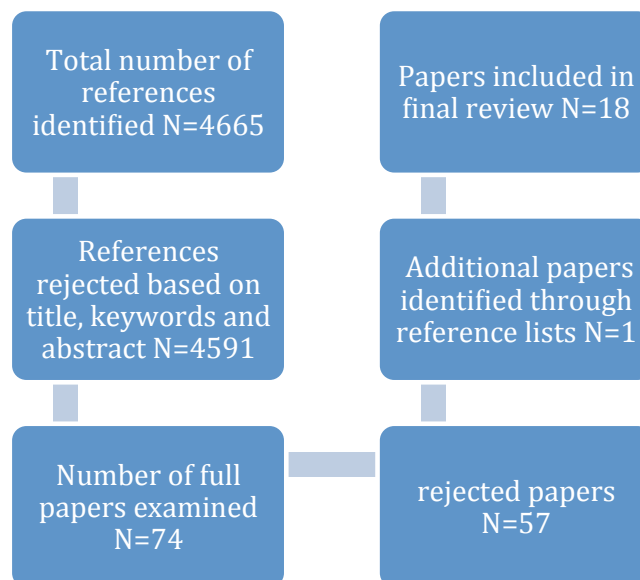
Figure 3. Summary of search strategy

A summary of the included studies is found in appendix 3. Analysis of the included papers revealed five broad themes (Aveyard, 2007) relating to the experience of service involvement. The following sections discuss methodological issues related to the included papers, and the findings of this analysis.

2.2.2 Methodological issues

The eighteen studies identified have employed a variety of methodologies and have focused on different populations. Of these studies, five have focused exclusively on the carer perspective (Grande et al, 2004; Hasson et al, 2010; King et al, 2004; Koffman and Higginson, 2001; Newbury, 2011), and four are retrospective, (Grande et al, 2004; Hasson et al, 2010; King et al, 2004; Koffman and Higginson, 2001). The studies focus on different diagnostic groups: two studies exclusively focus on cancer patients (Richards et al, 2011; Worth et al, 2006), three on heart failure (Aldred et al, 2005; Boyd et al, 2004; Boyd et al, 2009), one on COPD (Seamark et al, 2004), and one on Parkinson's disease (Hasson et al, 2010). A further nine studies have mixed diagnostic populations; however, in only one of these (Murray et al, 2002) is the number of participants with non-malignant disease equal to the participants with a cancer diagnosis. In two of the studies the diagnosis is not specified (Conner et al, 2008; Grande et al, 2004) although the participants were all known to specialist palliative care teams and thus it can be presumed likely to be predominantly people affected by cancer. The experiences of people affected by cancer are disproportionately represented in the research. In part, this may be related to historical perspectives and the lack of awareness of the end of life and palliative needs of people affected by non-malignant conditions. Despite this, the chronology of the papers reviewed suggests that end of life care research is increasingly being undertaken with populations who have a non-malignant diagnosis.

All of the studies have documented the approval of the appropriate ethics committees. However, it is apparent that ethical and practical issues can be complicated to manage in research with these populations. There are well-documented difficulties in undertaking research with populations affected by AD (which I will discuss further in chapter four). These incorporate ethical concerns about including people with AD in research, and the problem of retaining participants in studies when health is likely to deteriorate, and life expectancy may be short. Retrospective research has often been used as a

method to overcome some of these difficulties; however, this does not avoid all ethical issues as bereaved carers remain vulnerable (Addington-Hall, 2002), and carer's perceptions can be different to the patient's experience (Beaver et al, 2000). Thus findings are only indicative of carer's perceptions, not patient experiences. Equally, carer perceptions may have changed since the care contacts took place – affected by events surrounding the patient's death, and the opportunity for reflection that the passage of time provides. Prospective studies offer opportunity to access participants whilst events are occurring, however they also have their limitations, as the protection of participants in prospective studies is potentially problematic. For example, Conner et al (2008 p. 548) describe how as part of their protocol *'it was agreed that if the participants showed signs of distress or fatigue the interview would be abandoned and the researcher would assist the patient'*. Although appearing to be protecting participants, this attitude could also be interpreted as restricting the participant's choice about whether to continue with the interview or not, and it is not clear whether the intention of Conner et al was to finish the interview, or to pause and deal with presenting issues and then give participants the choice as to whether to continue or not.

The findings of the literature review will be now discussed in relation to the five broad themes. 1. The range of services involved. 2. Service utilisation. 3. Coordination and communication. 4. Relationships. 5. Factors unique to the carer's experience.

2.2.3 The range of services involved in care

As anticipated, all of the studies identified that there were numerous agencies and individuals involved in the care provision for people with AD. People's experiences of these services varied enormously, and both favourable and poor examples are given in the literature (Boyd et al, 2004; Boyd et al, 2009; Conner et al, 2008; Exley et al, 2005; Hasson et al, 2010; Koffman and Higginson, 2001). Koffman and Higginson (2001) identified ethnic differences in care experience in their research exploring satisfaction with care in the last

twelve months of life. They interviewed bereaved carers of black Caribbean and white British people with AD and found differences in care experiences. For example, the carers of the black Caribbean participants were less likely to be satisfied with GP services, and they perceived that nursing staff spent less time with them than their white British counterparts did. Although this research used interviews, they were structured based on questions that the participants were asked to rate on a 1-4 point scale and this was supported by a few more qualitative type questions. Thus, although the findings of this study do reveal apparent differences in care experience according to ethnicity, there is limited information as to what this meant to the participants. Additionally, the carers of both populations self-identified as the main carer, and for the black Caribbean population the greater proportion of these were the children of the deceased person, as opposed to the spouse as was the case in the white British sample. Koffman and Higginson suggest that this different relationship with the deceased person may further affect the interpretation of the participants on their experiences, and thus differences cannot be attributed to ethnicity alone.

Difference in care experience was also evident between people who had a different diagnoses. Two studies specifically compared service use amongst different diagnostic groups. Exley et al (2005) aimed to identify the challenges of meeting the needs of people dying from malignant and non-malignant disease in primary care. They interviewed people affected by cancer and cardiorespiratory disease, who they had recruited from GP practices thought be delivering high quality care (chosen as the research focus was 'challenges', not 'deficits' in care provision). They found that even in practices where there was a commitment to the end of life care of people with non-malignant disease, there was clear disparity between the experiences of these diagnostic populations. Those affected with cancer were more likely to understand their diagnosis, their prognosis and to be accessing more services for their supportive care needs. Those with cardiorespiratory disease were more likely to have their health care managed by secondary care, and were often confused about the care they were receiving – citing episodic episodes of care intervention over a long period of

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time. These episodic care encounters can be partly explained by the disease trajectory of cardiorespiratory disease which can be described as following a path of long term increasing limitations, accompanied by exacerbations in illness which often require hospital admission (Murray et al, 2005. See diagram on p.51 for further details). However, the illness trajectory alone does not account for the confusion that existed in this population about the care that they received. Murray et al (2002) also compared service use of people living with different diagnoses, using people with lung cancer and with cardiac failure as comparison groups. They utilised a longitudinal research design and undertook three-monthly interviews with their participants, as well as a focus group with health professionals. Their findings also demonstrated the increased service availability in primary care for those living with cancer, and that those with cardiac failure had little planned support and were more likely to have their care managed by secondary care professionals.

As well as difference in the access to services, some studies identified other factors in relation to the number of services involved in patient care. Seamark et al (2004) undertook interpretative phenomenological analysis (IPA) to explore the lived experience of people affected by severe COPD. One of their findings was, like in the previous studies cited, that care was often provided to this population in secondary care clinics. However, care that could be given at home was highly valued as the effort of attending secondary care settings was hard in light of progressive health losses. They also report that people were ambivalent to the idea of having a respiratory nurse specialist involved in their care, commenting that this would be another person involved, and they were unsure what they could add that other members of the PHCT were not already providing. Participants also felt that they possessed a good knowledge of their own condition and did not need further self-care education. Although this study cites the nurse specialist role that people were being resistant to, it is interesting that it is the idea of an extra person being involved in care that seems to have been what was objected to, suggesting a sense of the health care team being already extensive in its presence. Equally, the notion that patients perceive themselves as already having expert knowledge

about their own conditions provides an insight into how the support needs of those with long term (as in this instance), and new diagnoses may vary.

Beaver et al (1999) and Beaver et al (2000) report on the same study, which explored the views of terminally ill people and their carers on primary care services. Although they use the phrase 'terminal', they recruited patients with an expected twelve-month prognosis or less. They interviewed fifteen patients, ten current carers, and nineteen bereaved carers, and used a combination of open and closed questioning to collect their data, which were then subjected to thematic content analysis. They report fragmented services and the impact of unpredictable home visits from the PHCT. The implications of this were that it was hard for carers to plan care and to organise their lives, however the services themselves were appreciated. Bereaved carers who participated in this research report how the number of services involved in primary care increased as the patient moved towards the end of their lives. Although these two papers describe several positive and negative aspects of primary care provision for patients and carers affected by terminal illness, the papers do not extend this analysis to consider what these factors mean to the people involved.

2.2.4 Factors that impact upon service utilisation

Service users were sometimes confused about the roles of the different individuals and agencies involved in care provision. This had an impact upon service utilisation (Murray et al, 2002) and could lead to uncertainty as to who to contact for assistance (Conner et al, 2008), confusion as to how to access services (Exley et al, 2005), and reluctance to access services where they are associated with care for the dying, or those with cancer (Boyd et al, 2009; Hasson et al, 2010). Sometimes people were uncertain as to who had provided a service, or the job titles of the people who they had contact with (Jarrett et al, 1999; King et al, 2004). Furthermore, the language used by service providers could also be confusing, with a range of unfamiliar and unusual terms being used that were not understood by service users (Aldred

et al, 2005; Beaver et al, 2000) and could cause fear when they were associated with death – for example the term 'hospice' (Cotterell, 2008).

A number of other factors affected service utilisation. Exley et al (2005) discuss how participants who perceived that there was nothing that could be done for their condition were deterred from requesting assistance from health professionals, as they did not want to be 'a bother' to them. A similar issue is identified by two studies exploring experiences of accessing out-of-hours care. Richards et al (2011) undertook interviews with 28 people affected by cancer (patients and carers) about their experiences of accessing out-of-hours services, and Worth et al (2006) undertook interviews with 32 patients and 19 carers (including 15 dyadic interviews) about their perceptions of out-of-hours care. The findings from these studies suggest that people find it hard to assess the legitimacy of their own problems and have difficulty in deciding when to ask for help from health care services. This problem was compounded in the out-of-hours period when people were not sure of the response they would receive from unfamiliar health professionals, and feared being labelled as difficult or demanding.

When people have had a negative experience of a health care service, then there can be reluctance to utilise the service in the future (Aldred et al, 2005; Exley et al, 2005; Worth et al, 2006; Richards et al, 2011). This is demonstrated by Aldred et al (2005) who investigated the impact of heart failure on the lives of older people. They found that participants were reluctant to access their GP. They wanted time to spend with their doctor to talk about how they were feeling. However, previous experience of GP contacts made them wary of requesting intervention as they felt that they would be admitted to hospital, an intervention felt to be unwanted and inappropriate. Aldred et al interviewed ten patients and their carers, and their inclusion criteria stated that heart failure was to be at New York Heart

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Association (NYHA) scale 2-5[4]. However, they found that often people with the most advanced disease declined to take part, and acknowledge that has an impact upon the data collected as it was overrepresented by people in the earlier stages of heart failure.

2.2.5 Coordination and communication

Amongst the plethora of services that participants had received across these studies, it is perhaps unsurprising that coordination and communication were frequently identified as themes. Communication amongst the PHCT and between primary and secondary care is seen as being an important factor for continuity of care (Boyd et al, 2004; Jarret et al, 1999). Cotterell (2008) explored the experiences and needs of 25 people affected by AD (just under half affected by non-malignant conditions) in relation to health and social care services. One of Cotterell's findings was that people were concerned about the lack of communication between the various health and social care providers, and the subsequent impact that this would have on the care that they received. Lack of communication between primary and secondary care contributes to uncertainty as to where to seek help when problems are experienced. For example, in Aldred et al's (2005) research they give an example of a patient being advised by secondary care that a treatment could only be initiated by primary care, and by primary care, that secondary care needed to be contacted regarding the issue – leading to the patient feeling caught between the two and uncertain of how to proceed. Problems with communication can also be blamed for treatments not being given appropriately within the primary care setting because hospital staff failed to pass information on in a timely manner, and to contradictory advice being received from the various different health care providers (Exley et al, 2005; Beaver et al, 2000).

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[4] 4 The NYHA functional classification system was developed to support doctors in assessing the impact of cardiac symptoms on patient's activities of daily living, but is also used frequently as a research tool to measure the effectiveness of interventions and for identifying a research population (Bennett et al, 2002).

2.2.6 Relationships

Although there were negative aspects of having a range of services involved in care provision, positive aspects are also identified within the research. For example, knowing that there were services available when they were needed was reassuring and highly valued (Beaver et al, 2000; King et al, 2004; Richards et al, 2011).

Many of the studies reviewed reported on perceptions of individual relationships with members of the PHCT. Continuity of care provider is described as being highly valued and desired (Beaver et al, 2000; Newbury, 2011; Richards et al, 2011), seen as a positive experience (Seamark et al, 2004) and perceived as enabling the development of positive and supportive relationships (Boyd et al, 2009; Jarrett et al, 1999). This could contribute to the sense of being known as an individual to the people providing care (Conner et al, 2008; Worth et al, 2006). Having personal style relationships with health care professionals is discussed as being important (Exley et al, 2005) and is described in a number of ways in the literature, including having a sense of familiarity (Hasson et al, 2011) and being like 'a buddy' (King et al, 2004, p. 80). Feeling cared for was also important to individuals in their relationships with health care professionals. This is demonstrated in several ways. The time that health professionals spent with patients and carers was associated with increased satisfaction with services (Koffman and Higginsion, 2001), and mourned when not available (Aldred et al, 2005; Newbury, 2011). Positive associations were held when individual health professionals were perceived as going beyond their professional obligation (Grande et al, 2004) for example, when usual services were contactable during the out-of-hours period (King et al, 2004) visited at home and showed empathy (Hasson et al, 2010), or seemed to show a genuine interest in the service user and take their problems seriously (Boyd et al, 2004; Cotterell, 2008; Exley et al, 2005; Jarrett et al, 1999). When service users perceived that health providers did not take their problems seriously then this could be very distressing (Richards et al, 2011).

2.2.7 Factors unique to the carer experience

Some of the papers reviewed report specifically on carers' perspectives of their own experiences of service provision. Newbury (2011) explored carers' views of services at the end of life for people who were dying at home. She found that carers felt they played a pivotal role in care provision, but desired health professionals to guide them through the dying process, as this was a new and unknown experience. This grounded theory study is interesting in the presentation of its findings as parts of a 'play' in which carers take on a role, participate in a 'performance', have 'directors' who are the professional help, and are surrounded by a 'supporting cast' which includes family members, and paid carers. However, this research is reported in a nursing journal that, although peer reviewed, is designed to be in plain English, and lacks detail about the research process or how the findings were generated. Beaver et al (2000) report that carers perceive a lack of specific support for themselves, as well as not being provided with effective information to enable them to successfully fulfil their role as carer. This problem was further exacerbated, as they were not always present when health professionals were with the 'patient', and as such were removed from this form of information exchange. Grande et al (2004) also found that carers rarely identified that the services involved provided any support specifically for themselves. Hasson et al (2010) explored the palliative and end of life experiences of former carers of people with Parkinson's disease. The carers had been bereaved for between six and twenty four months, and were all family members of the deceased. Their research also found that carers were undertaking their role predominantly without any guidance from health professionals. Interestingly their research highlighted that the carers were undertaking a proactive information and service searching function to enable their 'patient' to get the best available care, as well as having to act as a go between for the various services involved to compensate for a lack of perceived communication between these services.

2.3 Chapter summary and my research question

The literature reviewed here has demonstrated that living with AD is a complex human experience in which people are attempting to accommodate awareness of their own mortality, cope with the demands of living with illness, whilst adjusting to altered relationships and developing new ones with the health professionals involved in their care.

Research has explored the experience of receiving care from the perspectives of people affected by AD. However, the existing evidence based has not attended to the lived experience of this phenomenon. Explorations of lived experience occur within the interpretative research paradigm and employ phenomenological methodology. This approach generates knowledge that is important in developing understanding related to the experiences of people affected by AD for a number of reasons:

- Phenomenology argues that lived experience always occurs in relation to the physical body, and as such it is important to attend to embodied experience in research. People with AD undergo many changes in their physical being due to the presence of disease. Phenomenological research facilitates exploration of these embodied issues in relation to the phenomenon of interest.

- Temporality (the experience of time), spatiality (the experience of space) and relationality (the experience of relationships) are key interlinked themes within the phenomenological approach (van Manen, 1990). These key themes are considered to be applicable to the lived experience of all people. However, I argue that in research with people affected by AD these themes are particularly powerful due to the impact that AD can have on all parts of the sufferer's life.

- Rather than evaluating experience, for example considering what is good or bad, interpretive phenomenological research considers the

meaning of phenomena. Qualitative research techniques are employed but there is no fixed method. Therefore methods can be designed for the particular investigation to be conducted. This ensures that methods are sensitive to the needs of the population to be studied, an important consideration in research with people affected by AD.

Although all of the research that has been considered in relation to service involvement has used qualitative methods, only one has used phenomenology (Seamark et al, 2004), and that explored the lived experience of advanced COPD, and reported on service related experiences as part of this. The findings of phenomenological research are valuable to the health sciences and can offer a powerful insight into the experiences of service users. These insights can be used to influence health professionals and health policy. Thus, I propose to utilise phenomenological methodology to explore the experience of patients and carers in regard to the involvement of numerous services in primary care.

My research question is therefore:

What is the lived experience of people affected by advanced disease, in relation to their contacts with multiple services?

In the following chapter I will discuss phenomenology as both philosophy and research methodology. Defining why it is a suitable approach for deeper understanding of this phenomenon, and further discussing the value of phenomenological studies as a health care research approach.

Chapter 3: Methodology

There are various methodological frameworks that can be used to address research questions. The choice of which framework to use will affect all stages of the research process; from question development, choice of methods, presentation of findings and ultimately what the research can claim to have found and how the findings can be utilized. Research methodologies are grounded in philosophical assumptions about the nature of knowledge and what can be known. For example, quantitative research is generally perceived to lean towards a positivist basis with the premise being that there is a 'truth' out there that is waiting to be discovered (Murphy et al, 1998). The goal of such research is statistical certainty, and results that can be generalised to a larger population. Qualitative research exists within the interpretive paradigm, which asserts that perceptions and experiences are socially, culturally, historically, and linguistically produced. The aim of qualitative research is to produce detailed descriptions and in-depth understanding of experience, or phenomena (Finlay, 2006a).

The methodological framework chosen for this research is phenomenology, a qualitative human science methodology with a strong philosophical basis (van Manen, 1990). In this chapter I will provide a rationale for why I have chosen this methodological approach. I will discuss the historical development of phenomenology and how this has informed the philosophical assumptions inherent when undertaking this type of enquiry. Although phenomenology provides the framework for this research, I have also used a method that has developed from Personal Construct Psychology (PCP), an approach that has many similarities with phenomenology (Butt, 2008). I will briefly describe PCP, highlighting it as a congruent research approach with phenomenology. Finally, I will describe some established phenomenological research approaches, before focusing on van Manen's (1990) Human Science Research as a method of enquiry. I will go on to discuss why this has been

chosen as the specific framework to guide me in designing this research and addressing my research question:

What is the lived experience of people with advanced disease, and their carers, in relation to their contacts with multiple services?

3.1 Rationale for taking a phenomenological approach in this research

Phenomenology is a philosophical movement that arose around the beginning of the twentieth century and which has more recently been applied as a research methodology. Although there are similarities between phenomenology and other qualitative methodologies, it is a distinct and separate methodological approach to research (Starks and Brown Trinidad, 2007). Phenomenology has been chosen as the methodology for this research because:

a) Phenomenology helps us to understand other's lived experience of the world. In the first half of the literature review I explored concepts and theories that are used in the literature to describe some elements of the experience of AD. The literature drawn upon for that discussion highlighted that a person with AD faces many changes. Not only has the physical body altered, but illness also affects the experience of time, personal and health care relationships, and changes the physical and social spaces a person a person uses. Phenomenological methodology considers these factors in an attempt to understand experience as it is 'lived' (van Manen, 1990).

I argue that the knowledge generated from phenomenological research has particular value in the health sciences. Most people who work in the health professions will not have personally experienced AD as either a person with a diagnosis, or their carer. Phenomenological research offers the opportunity to gain a better understanding of another's experience of the world. One outcome of phenomenological research is the creation of phenomenological

descriptions that aim to overcome the tension that exists between retaining the richness and depth of individual lived experience, whilst also still emphasizing what can be applied generally (Todres, 2011). These descriptions may include anecdotes and examples of participants' words, and they attempt to lay open the essential themes of a phenomenon to create 'thoughtfulness' in the reader, and thus encourage personal reflection on the phenomenon (van Manen, 1990). In this way the reader is encouraged to have their own conversation with the text, questioning the nature of the phenomenon under investigation, considering their own relation to it, and reflecting upon the significance of the phenomenon. By doing this they may develop both embodied and discursive understanding of the phenomenon through their personal engagement with the text (van Manen, 2011). The body is the vehicle of our being-in-the-world: when the body changes due to disease, the embodied relationship with the world also changes affecting all aspects of experience (Walton and Madjar, 1999). Understanding this changed embodied relationship supports health professionals in delivering care with tact and empathy.

Van Manen (2002; 2011) asserts that phenomenology provides knowledge that can inform and animate our action, and as such can contribute towards practice improvement by challenging everyday thinking and ways of behaving. Van der Zalm and Bergum (2000, p. 218) suggest that if this can be achieved, and if the lived experience of patients and carers is made visible, it may be possible to *'enlighten practice'*. As van Manen (2001, p. 472) describes:

> Professional practice needs to be, not only pragmatic and effective, but also
> philosophic and reflective so that one can act and interact with competence
> and tact, and with human understanding.

b) Phenomenological research exposes ordinary and everyday aspects of health care, and encourages the challenging of assumption. Phenomenological research processes facilitate the exposure of the researchers assumptions about the world, and the way people experience it.

These processes encourage the researcher to continually consider how their beliefs are impacting upon the findings of the study. In doing so, the researcher is striving for an increasingly adequate account of others' lived experience. As a health care professional myself I have preformed opinions and ideas about patient and carer experiences of service involvement, and thus these processes are particularly important.

The researcher attempts to consider the experience without assuming what the most significant aspects of the experience are, and in this way the meanings people ascribe to everyday elements of health care can be revealed (Madjar and Walton, 1999). For example; this could relate to the environments of care and the experience of having health professionals in your own home; the language of care and how health professionals discuss issues of health and illness; or the embodied experience of care, such as what it feels like to be touched or looked upon by a health professional. Phenomenological research can reveal aspects of care which occur many times everyday and are often largely overlooked because of their ordinariness, but can hold great significance to the people who experience them (van der Zalm and Bergum, 2000).

c) Phenomenological research methods can be flexible to the specific research question and population. People affected by AD are potentially vulnerable because of their health, personal circumstances, and their dependence on health care services. Research methods need to be sensitive to this vulnerability. Seymour and Clark (1998) suggest that phenomenology is particularly suited as a methodology in the human sciences as it enables '*subjective experiences to be elicited with compassion, whilst at the same time conforming to expectations and principles of scientific rigour*' (p.127). Phenomenology has developed from philosophical practice, rather than originally as a research methodology and there is considerable flexibility around choice of research methods. This flexibility offers the opportunity for researchers to utilize creative approaches to data collection, analysis, and presentation of findings (van Manen, 1990). Methods can be specifically

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designed to overcome the challenges inherent in dealing with people affected by AD as a research population.

d) Phenomenological research processes impact upon researchers themselves, having particular benefits for researchers who also work within clinical practice. Van Manen (1990; 2011) asserts that phenomenological research can have a transformative affect upon researchers. The researcher will increase their personal knowledge of the phenomenon, but also develop a greater awareness of 'being' through enhanced understanding of their own and others experience (van Manen, 1999). This transformative effect can be both a challenging and positive experience for the researcher (Hardy, 2012). The process of challenging prior assumption may reveal aspects of the researcher's belief system that were previously hidden from them. Although this may be an uncomfortable process, it potentially has positive implications for researchers who also work in clinical practice as the increased self-awareness, combined with improved understanding of human experience, can lead to direct benefits for clinical care (Coyle, 2003).

The combination of these factors not only makes phenomenology a valuable methodology for the health sciences, but also particularly suited to the current research question. I have already stated that phenomenology is a philosophically driven methodology, and in the above rationale I have alluded to some of this philosophy. I will now move on to consider this philosophy in more depth, which will ground my later discussions of phenomenology as a research methodology.

3.2 Phenomenology

As Spinelli (2005) describes, philosophy uses the term 'phenomena' to refer to the 'appearances of things', as opposed to 'the things themselves', and accordingly, we experience a phenomenal world. Phenomenologicaly speaking, our everyday experience of the world is a continual interpretational

process. We perceive objects within the world, and it is the meanings that we attach to these objects that create the existence and the reality of them for us. As humans we ascribe meaning to all things, and these meanings are influenced by a variety of factors including our social and cultural environment, our place in history, and our physical and mental state. Therefore, although there exists an objective reality that is independent of our interpretations of it, we can never know that reality because we only have access to it through our conscious awareness of it. 'Reality' is therefore open to a number of possible alternative interpretations. Broadly speaking, the aim of phenomenology is to explore phenomena as they appear to the consciousness of the person experiencing them, whilst avoiding prejudice about what the phenomena might be (Moran, 2000).

Although there is broad consensus that phenomenology is interested in phenomena, there is not a single agreed method or theoretical perspective as to how to conduct phenomenological enquiry. Rather, phenomenology has a range of proponents who have diverse interests, practices and interpretations as to what the central issues of phenomenology are (Moran, 2000). This can make phenomenology a challenge to the novice researcher. Added to this, phenomenology is linguistically (Ihde, 1986) and philosophically complex. However, appreciation of the terminology and of the associated theories is important, as these are inherent within the methodology as it is applied to research. Consideration of the historical development of phenomenology is also significant as there are a variety of established approaches to applying phenomenology as a research methodology (see p.95). These different approaches vary in their assumptions, in line with the thinking of the different phenomenological philosophers who have informed their work. Therefore an awareness of the origins of these ideas aids in the appropriate application of phenomenology as a research methodology.

Brentano first used the phrase 'descriptive phenomenology' (Dowling, 2007), however it is Husserl who is generally credited with being the founder of phenomenological thought. Phenomenology has been continually reinterpreted, but has evolved from two related but distinct approaches:

Husserl's transcendental phenomenology, or descriptive phenomenology, and Heidegger's existential phenomenology and hermeneutics, or interpretive phenomenology (Mackay, 2005). I will consider each of these in turn, illuminating the key concepts within each that have informed subsequent phenomenological research methods.

3.2.1 Descriptive phenomenology

The central notion of Husserl's phenomenology is that all consciousness is of something, indeed, that consciousness constitutes the world but in such a way that is hard to describe or define (Moran, 2000). Thus, as humans we are always conscious of something, and there is always a direction, or object for this consciousness. This concept is termed 'intentionality': all experience is experience of something (van Manen, 1990). Intentionality is a correlation of the experiencing of something, and how it is experienced, which are termed 'Noesis' and 'Noema'. This is diagrammatically presented by Ihde (1986) p. 44:

Noesis (Experiencing) → Noema (Experienced)
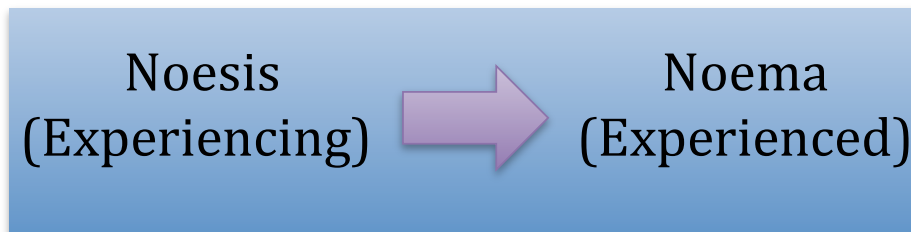
Figure 4. Noesis and Noema

This diagram demonstrates that we have all been through 'experiencing' of something before we have 'experienced' something. Our experiencing is pre-reflective. I will put this intentional correlation into context: a person who has experienced pain (Noema) has experienced this pain in a certain way – for example intensely or intermittently (Noesis). The person describing the pain is describing something that has already happened to them. We can only describe the Noema, as all description is reflection on something that has happened already, even when it appears immediate. If I am listening to a

patient discussing their pain with me they might describe it as shooting, sharp or stabbing. I might ask how intense the pain is and they may describe it on a pain scale of seven out of ten, or very severe. From a phenomenological perspective, the patient is describing a pain that they have experienced and reflected upon in order to be able to verbalize their experience of the phenomenon of pain. It is only through assessment of non-verbal indications of pain that I get closer to witnessing their experiencing of pain. However, this is of course then my interpretation of their experiencing of pain, and the actual phenomenon, their actual experiencing of pain, eludes me. Additionally, as Ihde (1986) points out, the Noesis of experience is often happening without our conscious awareness of it. An alternative example highlights this well; it was not until I began to think about typing on the keyboard in front of me that I became aware of the patterns of my fingers or the feel of the keys. Before I began to reflect upon this phenomenon I was largely oblivious to it. The significance of this becomes more obvious if I refer back to my previous pain example; the patient is taking analgesia and their pain appears to have resolved, they are doing the washing up and getting on with everyday activities. However, the nurse asks the patient about their pain – which they then consider and reflect upon. The pain had become almost invisible to them, but as they become aware of the noetic aspect of their pain the noematic aspects increase. Their pain suddenly appears to them again. The effectiveness of distraction techniques for pain management can be explained in these terms.

Husserl was interested in discovering the 'things themselves', the actual way that phenomena appear to consciousness. He suggested that it is possible to transcend bias and presupposition to obtain a state of pre-reflective awareness in which to describe phenomena as they present themselves to us, and thus rediscover the 'life-world' (Giorgi and Giorgi, 2008). It is suggested that this is achieved by stepping outside of the intentional correlation described above, in order to obtain a 'god's eye view' of phenomena, and thus transcend everyday experience (Ihde, 1986). Husserl's interest was not confined to physical objects, but extended to experiences such as emotions, concepts, sensations, and feelings. Husserl suggested

that anything that *'presented itself to consciousness'* could be understood through phenomenological processes (Rapport, 2005, p. 126), namely the phenomenological reduction. These processes were rigorous, and aimed to overcome subjective opinions and pre-existing theories in order to achieve an essential understanding of phenomena (Dowling, 2007).

The Phenomenological Reduction

For Husserl, the transcendental-phenomenological reduction was the method of accessing pre-reflective experience, the immediate experience of life before it has been interpreted. However, Husserl described a number of different reductions, which has led to some confusion in the literature as to the nature of the reduction (Langdridge, 2007; Moran, 2000). The reduction that I describe here is based upon Schmitt's (1959) interpretation. Undertaking the reduction enables the phenomenologist to move beyond their 'natural attitude', the pre-analytic attitude from which we perceive the world and generally accept its reality. Movement beyond this attitude enables the researcher to get closer to 'the things themselves', and enables identification of the essential features, or essences, of phenomena. The reduction begins with a process of reflection in which things that were previously taken for granted, and perceived as self-evident or certain, are questioned. What was once certainty has now become simply a claim, the questioner has detached themselves from their previous reality and perceives those previously taken for granted objects as phenomena to be explored. In this way, the questioner has 'bracketed' their prior knowledge in order to consider phenomena anew. Once this has been achieved, the questioner is said to be in the 'epoché', or to be in the phenomenological attitude (Ihde, 1986).

The search for essence

Once the phenomenon has been reduced, and the questioner is in the epoché, then search for the phenomenon's essence can begin. The term essence is one that I initially misunderstood in my first readings of phenomenology, associating it with some kind of mystical, spiritual or invisible 'sense' of an object. However, the Husserlian approach to essence was not

enigmatic (Dahlberg, 2006). When used within philosophy, 'essence' is a term that refers to the nature of something, to those aspects that constitute the reality of something rather than the appearance of that thing (Grieder, 1999). Husserl proposed that consideration of a singular experience could ultimately reveal this universal truth, or essence (Moran, 2000), and suggested that the essence is revealed through eidetic seeing which could be intuited through a process of fantasy, or imaginative variation (Ihde, 1986). In this mode, the phenomenologist systematically considers all possible examples of the phenomenon, varying aspects of the phenomenon, to identify the structural, or essential, features of that phenomenon.

To demonstrate the application of the eidetic reduction I will again consider the concept of 'pain'. I could think of an example in a palliative care setting of pain being an unpleasant sensory experience that indicates the deterioration of the physical body. However, if we are to imaginatively vary the setting of that pain to the experience of receiving a massage on very tight muscles following the completion of a marathon, then the pain may have pleasurable aspects, indicating the hard work done. The pain remains a sensation within the body, however the experience of the pain is different: thus we might begin to consider whether sensation is an essence of pain. We could test this further by asking the negative question (Giorgi, 2008b), can pain exist without sensation? According to Husserl, if we were to continue with these variations, we would get closer to discovering the essence of pain.

It is important to remember that the initial phenomenological method proposed by Husserl was intended as a philosophical method, as opposed to a psychological method of understanding others' experience of the world (Giorgi, 2008a). Many philosophers have rejected some of Husserl's phenomenology, particularly the notion of the transcendental ego, the ability to step outside of everyday experience in order to obtain a gods eye view of phenomena. These philosophers have approached phenomenology from an existential standpoint, suggesting that it is not possible to step outside of experience because we are always 'in-the-world', and inseparable from it.

3.2.2 Interpretive phenomenology and being-in-the-world

Heidegger, and the existentialists who followed his work, had an ontological focus to their philosophy, and were orientated towards the nature of existence and the notion of Dasein (man), or being-in-the-world (Todres, 2011). The work that has followed these ideas is often referred to as interpretive phenomenology. Heidegger challenged the Cartesian notion of mind-body dualism in which it was supposed that people were subjects that exist independently from the objects of the world, and the accompanying notion that objects could be separated into distinct units and generalized (Plager, 1994). Heidegger's assertion was that Dasein is always already a being-in-the-world. Dasein has context, environment, and personal references within which meaning is created (Moran, 2000). As such, phenomena cannot be understood without considering the world from within which they are experienced. Additionally, Heidegger rejected the notion of a complete phenomenological reduction. Instead he asserted that human existence is always the existence of someone – it has '*mineness*' (Moran, 2000, p. 197). Thus any investigation and interpretation of human existence cannot be entirely neutral, and the questioner must always also consider the influence of himself or herself on the findings.

I have described how the existentialists asserted that humans are beings-in-the-world, and how any investigation requires consideration of the investigators viewpoint. Furthermore, they suggested that all people are meaning makers, and as such investigation is orientated towards human interpretation of phenomena, and the way that people attach meaning to experience (Rapport, 2005). The existentialist approach advocates that as humans we have freedom to make choices and define our course in life (Hatab, 1999). These choices are not limited to material choices, as these will always occur within the restraints of our physical, social, and historical circumstance, but extend to the meaning that is attached to all experience. Thus, although we are not free to choose our circumstance, we are free to

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choose what this circumstance means to us, and potentially alter our interpretation of it. In this way the existentialist approach is very liberating, and also has similarities with Personal Construct Psychology, which is discussed on p.92. Additionally, Heidegger proposed that we are not isolated individuals in our meaning making, but that we are social beings who participate in the world through a shared community of understanding (Plager, 1994). This shared understanding forms a background to our everyday existence and is what makes life understandable; it can form the basis for further understanding, but can also restrict further understanding, as this is lost in the acceptance of everyday interpretation (Plager, 1994). Despite the presence of a shared community and culture, as a being-in-the-world we ultimately experience the world in a unique way and cannot directly experience the world through another's perception (Spinelli, 2005).

Existentialist philosophy is complex and expansive and I do not have the scope to explore it in depth within this thesis. However, there are central components relating to being-in-the-world that are important to consider as these directly impact upon how the philosophy translates into research methodology. I will briefly explore some of these here, drawing upon those that have influenced my understanding of the philosophy, and have impacted upon my delivery and interpretation of this research.

Embodied experience: The phenomenological notion of embodiment is of particular relevance to research in the health sciences, whose interest is so closely linked with people's experience of an altered embodied relationship with the world. We are all in-the-world in a certain, bodily, way. Our access to the world is through our physical body, and all experience is mediated through our physical being (Finlay, 2006b; van Manen, 1990). We look upon the world through our eyes, we smell the world, hear the world, and feel the world upon our skin. Furthermore, our embodied experience affects our understanding of the world. When we feel ill, when our body does not feel 'normal' or is uncomfortable, our relationship with the world changes. My experience of writing this chapter is embodied; the sensation of the keys under my fingers, the noise of the rain at the window, the bright light of the

computer screen causing me to slightly squint, the warmth of the room I am sitting in. However, my embodied experience of this changes when I start to get some back ache; no longer do the words flow so easily, I am distracted and irritable, the noise of the rain is no longer a pleasant background noise, but a reminder that I am trapped inside until the thesis is finished. My discomfort has changed my lived experience of the situation. Embodiment is a central phenomenological notion and has particular relevance in this research as people with AD experience momentous changes in their embodied experience of the world.

Language: Language is central to our being-in-the-world and it is through language we create our understanding of the world. Heidegger famously said that:

> It is not so much that we see the objects and things but rather that we first talk about them. To put it more precisely: we do not say what we see, but rather the reverse, we see what one says about the matter.
>
> Heidegger, 1992, p. 56.

When we think of anything we put this into language. The pain I experience is stinging, throbbing, sore, nagging: these terms make the pain into something that I can communicate with others. Equally, language helps us to shape our reality - as Heidegger says in the quote above, we see what we have language to enable us to see. It is very hard for us to describe something that we do not have a word for. This attention to language extends to considering the etymology of words. The historical origins of language can offer insight into the meaning of the words, which connect us with the source of that language and the world from which the words arouse (van Manen, 1990). For example, the etymology of the word 'hospice' gives us insight into the meaning of hospice care. The word is thought to have developed from the Latin 'hospitum' meaning guesthouse, and related to being a guest. In the early nineteenth century a hospice was a resting place for weary travellers, and later became a place for the destitute or sick. It was not until the mid-

twentieth century that the term had its more familiar usage as an environment for care of terminally ill people (Barnhart and Steinmetz, 1998). The history of this term gives us insight into what 'hospice' means; it is a place of rest for the weary, people who have struggled with illness symptoms and a deteriorating physical being. It is also a resting place for those that care about them, and hospices are often described as places of calm. The hospice movement is also known for how well it treats its patients and their families, and is associated with high quality holistic care. The hospice in a sense is a host to its guests, attending to their needs and making them comfortable and welcome. Discourse Analysis, an alternative research methodology, also places the examination of language at the heart of its approach. However, Discourse Analysis is different from phenomenology in that it aims to explore how knowledge and meaning are created through discourse, rather on the language as way of understanding lived experience (Starks and Brown Trinidad, 2007).

Temporality: Temporality is related to the lived experience of time: that which changes length and meaning depending on what we are doing or how we are feeling (Fuchs, 2005). Ten minutes waiting for the results of an investigation that might indicate you have cancer is a very different embodied experience than ten minutes driving on a routine journey to work. In the former, the experience of time might be that it feels never ending; the clock drags, seeming to move forward much slower than you would hope. In the latter example you may be entirely unaware of time passing; the experience being almost inaccessible in its mundaneness, passing in a flash. Heidegger suggested that temporality is an essential component of existence, and that Dasein is always moving towards the future (Langdridge, 2007). Furthermore, lived experience also contains the temporal dimensions of past, present and future. These aspects of temporal experience inform each other – the experience of past situations inform our interpretation of them in the present, and we carry our past with us in the language and expressions we use, in the ideas we have about the world. Equally, we have a sense of our future. We plan and prepare for events of that future; what we are to eat over the coming week, paying the mortgage for a house we can live in, planning for retirement.

The interwoven perceptions of past and future create a meaningful present that is a person's life story (Guignon, 2012). We also reconsider our past in the light of our present, reinterpreting who we once were and who we are now (van Manen, 1990). By considering AD in these terms, the profound impact of serious illness can be explained. The sense of future has been altered and distorted, and the sense of past reconsidered in light of an interrupted life story that may be no longer coherent or satisfying. Issues relating to temporality can therefore be particularly pertinent in research relating to AD.

Being-toward-death: The limit of our future, of the existence of Dasein, is death, and as humans we have a finite life. All experience occurs against the knowledge of this finitude, although generally Dasein is oblivious of our being-toward-death. However, certain life events will bring our sense of being-toward-death to the fore, for example being diagnosed with AD. Although we have no choice about this, we do have choice (because we are 'free') about how we face this, and other experiences. An awareness of our being-toward-death can cause anxiety, and this anxiety is further exacerbated with the realization that life is essentially meaningless unless we ascribe meaning to it, loss of meaning itself being a cause of anxiety and anguish (Cerbone, 2006). If we consider this in relation to the experience of people facing the end of their lives, one of the comments that I have frequently heard from people facing death is *'why me? What have I done to deserve this? I want to be cured; surely there is something you can do? I am not going to give up, I will fight this'*. The person experiences a loss of meaning, they cannot make sense of their situation, cannot rationalize their suffering and they experience acute anxiety associated with this. Equally however, some people may conceptualise their circumstances in very different terms. In this way the individual might think *'why not me? People die and now is my time'* embracing the freedom to reconsider their circumstance, accepting the presence and inevitability of death.

I have considered the existential perspective of phenomenology and some key elements of the philosophy that inform research. I will now move on to consider the method suggested by Heidegger that takes the investigator from

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their naive seeing of the world, towards discovering the meaning of phenomena (Zichi Cohen and Omery, 1994).

3.2.3 Hermeneutics

The hermeneutic turn in phenomenology emphasizes the need for interpretation of data (or 'text'). The researcher has to move beyond what is directly given in the text: they interpret the text. Heidegger argued that as humans we are always in the process of some form of interpretation whether this is obvious or not (Todres and Wheeler, 2001). Gadamer, whose work followed Heidegger, developed the idea of a philosophical hermeneutic (Wright, 2000) and suggested that if we can focus on our pre-understandings of phenomena, then increasingly adequate understandings can emerge. (Todres and Wheeler, 2001). Gadamer suggested that we exist in a certain point in history, and that to understand a text it is important to consider the 'horizon' of the person who created the text.

> If we fail to transpose ourselves into the historical horizon from which the traditionary text speaks, we will misunderstand the significance of what it has to say to us.
>
> Gadamer, 2004, p. 301.

In research in the human sciences, the text that is analysed is generally created by a research participant; the person whose experiences are being collected to gain a better understanding of a phenomenon. To understand the meaning in their text we must consider this in the light of their horizon, their historical circumstance, endeavouring to understand this perspective.

The researcher also has their own horizon, and as Vessey (2009) describes, a horizon is not a fixed point: it expands as we consider it differently, or change our standpoint. Each new insight into the meaning of phenomena has created a new horizon from which to question the data, continually asking what meaning the researcher themselves has brought to the emerging

findings. Thus, in the hermeneutic approach the method attempts to merge horizons of the researcher with the person who has created the text, and continually questions the emerging interpretation in light of the researchers new horizon of meaning.

Interpretation is a circular process in which the fore-structures of understanding, those pre-understandings which are known in advance of formal interpretation, are brought to conscious awareness and are considered in terms of a partial understanding of phenomena, and a more complete whole (Mackay, 2005). This is called the hermeneutic circle of understanding (Figure 5) and is a back and forth process in which we set out with a general sense of what things mean, use this knowledge as a background to interpret phenomena, and on the basis of emerging insights we revise the initial perception of what things meant (Guignon, 2012). In this way, the hermeneutic cycle continues, getting closer to increasingly adequate accounts of experience.

Questioning prior knowledge

New horizon of meaning

New pre-understanding
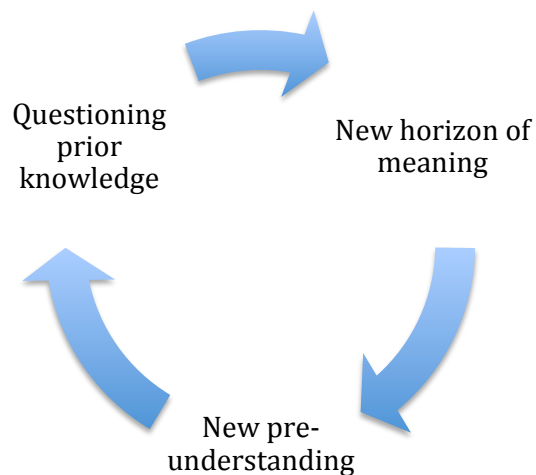
Figure 5. The hermeneutic circle

However, as this is a cyclical process it is always acknowledged that there are multiple possible interpretations of a text, and no single reading will ever reveal a final truth.

3.3 Personal Construct Psychology

Personal Construct Psychology (PCP) is a personality theory that was developed by George Kelly, a psychotherapist working in America during the early and mid-twentieth century (Butt, 2004) and which has similarities with the phenomenological approach (Butt, 2005). I discuss PCP here, as a method used in this research has developed from a PCP setting. Personal Construct Psychology particularly focuses on how people give meaning and definition to the things in their lives (Epting and Paris, 2006). Kelly suggested that people build their reality on the basis of their experience and act accordingly; it is their interpretation of experience that is significant to them, not the experiencing itself. People are like scientists who have their own theories about both themselves and others, and it is these theories that form the background to their behaviour (Butt, 2004). Kelly proposed that it is futile to consider what is the correct version of reality, or correct theory or description of the world, and that instead we should consider how alternative constructions of reality might be useful in different circumstances, a notion that he termed constructive alternativism (Butt, 2008). Thus, like the existential phenomenological approach, PCP advocates that people are meaning makers who are trying to make sense of their experience, and it is the meaning that is ascribed to experience that is significant. PCP also recognizes that people live within a physical world which constrains the possible options that are available to them, but that despite an individual's circumstances, there will always be alternative possible constructions to explain these circumstances, people are free to determine their meaning making.

Despite these apparent similarities between PCP and phenomenology, Kelly did not recognize PCP as a form of phenomenology. Butt (2008) suggests

that this was due to his lack of awareness of what was happening in the work of the European phenomenological philosophers of the time, as their work had not been translated into English at that point. Additionally, the phenomenology that was being introduced into America in the 1950's had little in common with the ideas of the European philosophers, and was more aligned to drive based deterministic theories in which people have internal drives and motivations which create their behaviour (Butt, 2005). It is also important to remember that Kelly was not creating a philosophy in order to study the world; rather he was approaching the issue of personality from the perspective of a therapist.

There are numerous PCP techniques designed to help elicit peoples meaning systems and interpretations in a therapy setting (Butt and Burr, 2004). Creative techniques are used within a therapy environment to assist people to reflect on elements of their lives that may be difficult to articulate, and hidden within the everyday way of seeing the world. This is also something that we want research participants to do in order to share their experiences of phenomena with a researcher. The use of such methods can be used in a supplementary way in research interviews to help people share their experiences, and in recent years, the value of some of these techniques within a research environment has been recognized. One of these techniques, 'Pictor', is used in this research, and I will discuss this further in the next chapter.

3.4 Phenomenology as research method

So far in this chapter I have explored some of the foundational ideas that form the basis of phenomenology as a philosophy, and a research methodology. I will now consider how this philosophy has been applied to research methods. There are numerous published approaches to phenomenological research methods, and these can be conceptualized as being on a spectrum between the descriptive and interpretive paradigms. At the descriptive end of the spectrum, following the work of Husserl, is the descriptive phenomenological

method which has been particularly championed by the Duquesne University under Amedeo Giorgi (Giorgi, 2008b), and more recently the Sheffield School of phenomenological psychology. Both of these proponents of the descriptive method also recognize the ideas of later philosophers: Giorgi (2008b) acknowledges the influence of Merleau-Ponty in the development of his ideas, and Ashworth (2003a) (The Sheffield School) describes his area of interest as existential phenomenology, incorporating the lifeworld as a fundamental concept. Towards the interpretive end of the spectrum is van Manen's Human Science approach (which also draws upon Husserlian elements) and Interpretative Phenomenological Analysis (IPA) developed by Jonathon Smith. There are also methods such as Template Analysis (King, 2004) that can be incorporated into a phenomenological approach. These approaches vary in the methods they advocate as a way of accessing and interpreting lived experience and are summarized in Table 2. Giorgi (2008a) suggests that because of the variations in the phenomenological approaches it is important for researchers to choose one methodology on which to base their approach. I have chosen the work of Max van Manen (1990; 1997a) to inform this research and will now discuss his work, highlighting why his hermeneutic approach is suitable for this research.

Table 2. Phenomenological research approaches

Name	Main features	Methods
Descriptive phenomenology (The Duquesne University)	Championed by Giorgi at the Dusquesne University. Developed from Husserlian philosophy. There is a focus upon the lifeworld and 'the things themselves', with an aim of describing experience rather than interpreting it. Analysis searches for essential structure and essence of experience. (Langdridge, 2007)	1. The researcher must formulate a phenomenological question to be addressed. This involves finding a phenomenon of interest, and may include considering the existing literature, or observation of phenomenon within the lifeworld. 2. Data are collected through rich descriptions of experience. A number of descriptions are obtained to understand the phenomena, however the exact number is dependent upon the quality of the descriptions and thus a purposive sampling strategy is utilised to gather descriptions that contain richness and depth. 3. If the data have been collected by interviews then these are transcribed and the text explored by; considering a sense of the experience as a whole, always bearing in mind the context of the experience; breaking the text into smaller 'meaning units'; transforming these meaning units into a more general expression of their sense; formulating the essential general structure(s) of the experience by considering what is typical of the phenomenon. This involves considering the parts and the whole of the experience – that is the emerging general structure and the individual experiences to see if the emerging explanation helps to better explain the individual experience. 4. Finally, this is communicated to a reader in a written form that aids understanding. (Todres, 2005).
The Sheffield School	Peter Ashworth at Sheffield University has developed this approach to phenomenological psychology that has a focus upon the lifeworld, but does not presuppose that there is an essence to experience. Rather, the lifeworld itself is seen as a having essential	1. The ideographic nature of the method will mean that a small sample will generally be used, possibly focusing on only one case. 2. The method will follow a similar approach to the other descriptive methods with the researcher obtaining first person accounts of experience, and then exploring these in terms of meaning units. 3. Once meaning units have been identified, these are analysed using the seven factions (essential features) of the lifeworld as a guide. These seven factions are: selfhood, sociality, embodiment, temporality, spatiality, project and

Name	Main features	Methods
	features. There are seven 'fractions' of the lifeworld which can be used as a heuristic to provide detailed description of the lifeworld. The approach is idiographic with any findings that suggest generality to experience being seen as a bonus. (Ashworth, 2003b)	discourse. These fractions can be used individually or in combination to explore different elements of the lifeworld. 4. No attempt is made to identify invariant essences of a phenomenon, the emphasis is on looking for individual variability of experience, but it is acknowledged that common structures may be present. 5. The writing up of studies based on this method will often involve presenting an individual case, or account of experience, followed by a discussion structured around the lifeworld fractions. (Ashworth, 2003b)
Van Manen's Human Science Research	Hermeneutic phenomenology, with an emphasis upon the role of writing as part of method. The approach aims to explore meaning that people give to their lives (Rapport, 2005). Van Manen suggests a method to guide the research process. This method is heuristic rather than prescriptive, and he suggests that the specific method needs to be suitable to the phenomena under investigation.	1. Turning to a phenomenon that seriously interests us and commits us to the world 2. Investigating experience as we live it rather than as we conceptualise it. 3. Reflecting on the essential themes which characterise the phenomenon 4. Describing the phenomenon through the art of writing and rewriting. 5. Maintaining a strong and orientated pedagogical relation to the phenomenon. 6. Balancing the research context by considering parts and whole. (Van Manen, 1990)
Interpretative Phenomenological Analysis (IPA)	Developed by Jonathon Smith. IPA is interested in the meanings that particular events and circumstances have for participants. The researcher has an active meaning-making role in the research process, and the researchers view of the world, as well as their interaction with the	1. Data are generally collected by semi-structured interviews. The interview is then transcribed verbatim. 2. Data are thematically analysed. Initially the left hand margin of the transcript is used to annotate interesting or significant things the participants has said, the right hand margin is then used to document themes that emerge. 3. Once this has been done all emergent themes are written in a list, connections are looked for and themes are clustered. Analysis is iterative, and moves between researcher and text. Themes are then placed in a table. 4. Analysis of further transcripts can either use the first table of themes to help

Name	Main features	Methods
	research participant, are acknowledged to have an impact on research findings (Willig, 2008).	the researcher orientate themselves to the text, or can be commenced again from scratch. 5. Ultimately a master table of themes is compiled which are translated into a narrative account. (Smith and Osborn, 2008)
Template Analysis	An approach to data analysis, developed by Nigel King at the University of Huddersfield, which complements phenomenological methodologies. It can also be used to analyse any form of textual data from various methodological positions. The method is particularly useful for larger data sets due to the possible inclusion of *a priori* themes, and through the development of a thematic template. This template can be based on a subsection of transcripts that are then applied to the remaining transcripts, modifying the template in an iterative fashion as required.	1. Define *a priori* themes if appropriate 2. Commence initial coding on a subset of transcripts. Identify elements that are relevant to your research question. If a relevant *a priori* theme exists than attach it to the relevant section of text, if not then modify an existing theme or develop a new one. 3. Once all data on the subset have been coded, then an initial template is produced. Similar themes are grouped together into more general higher order codes that describe broader themes in the data. 4. The initial template is then applied to the all of the data. Revisions are made to the template in an iterative fashion. New codes may be inserted, old ones revised, codes deleted that are no longer useful, and amended into higher or lower order codes as an increasingly adequate interpretation of the data is achieved. 5. The final template is used to assist interpretation and writing of findings. (King, 2004)

3.5 Van Manen's Human Science Research

I have chosen van Manen's (1990; 1997a) human science research method to guide and structure this phenomenological research. Van Manen proposes a hermeneutic phenomenological approach to understanding (Rapport, 2005; Rodriguez and King, 2009), but also draws on elements of the descriptive phenomenological approach (Plager, 1994). Human science research is phenomenological, in that it turns to lived experience, it is hermeneutic in that it interprets the 'texts' of life, and semiotic in that there is a focus on the language of these texts (van Manen, 1990). To be a researcher undertaking human science research is to question the way in which we experience the world. Van Manen describes this as a caring act in which the researcher wants to discover what is essential to being, and to truly understand a person's experience. Van Manen's work is focused towards understanding pedagogy, but his ideas are transferable to other situations and I feel are particularly suited to understanding the lived world of patients and carers. Van Manen's phenomenological method has a further advantage in that it is particularly approachable to a novice phenomenological researcher such as myself. He has also published work that intentionally aims to make phenomenology accessible to researchers who are not professional philosophers, and do not have extensive experience in the tradition (van Manen, 2001).

Van Manen describes two methodological dimensions to phenomenological research: the reduction and the vocative dimension (van Manen, 2011). To become a phenomenological researcher, to undertake phenomenological research, is to learn to take up the phenomenological attitude. This attitude is one in which there is a heightened awareness to the things in the world as we live them, rather than as they are already theorized and conceptualized (van Manen, 2001) and this is achieved by the 'reduction'. Van Manen (1990) claims the reduction is necessary to come to an understanding of the essential structure of something, in order to be able to return to the '*world as lived in an enriched and deepened fashion*' (p.185). For van Manen, the

reduction is not a defined or predetermined procedure, rather, it is the practicing of a thoughtful attentiveness that enables the researcher to come to understand the unique meaning and significance of a phenomenon (van Manen, 2002). This involves the researcher *'awakening a profound sense of wonder and amazement at the mysteriousness of the belief in the* world' (van Manen, 1990, p. 185), which in turn animates a sense of questioning of the meaning of the experience. The researcher needs to overcome *'subjective, or private preference, inclinations or expectations'* and to *'strip away'* (p. 185) theories and scientific ideas that may prevent them from coming to terms with experience as lived.

My interest in, and orientation to, the phenomenon under investigation originated in clinical practice, born out of personal observations. I had predetermined ideas about what this lived experience was like. I also had some knowledge of the literature base in relation to the experience of AD. To truly undertake phenomenological research meant that I needed to find a way to become aware of my own perceptions and fore-understandings, so that I could consider these in relation to the emerging findings. As a researcher, my aim was to move beyond these personal perceptions to truly be able to see the phenomenon, not to adopt a god's eye view as in transcendental phenomenology, but in order to get to an increasingly adequate account of lived experience. To do this involves having a hermeneutic conversation with the text (see Figure 5), asking myself, what meanings am I attaching to this experience? In what way has my prior understanding impacted upon this finding? If I reconsider this, what else does this tell me about this phenomenon?

The second key component of van Manen's methodology is the vocative dimension. In this aspect of his methodology there is an emphasis on the role of language in the analysis of text, and in the creation of phenomenological descriptions. Poetic meaning, language, metaphor, anecdote and imagery are encouraged as they contribute to the creation of a vocative text that has the power to 'speak' to the reader, and communicate the meaning embedded within it (van Manen, 2011). Indeed, 'writing' and the process of 'seeing' that

can be obtained through writing and re-writing of these phenomenological descriptions are a key element of the phenomenological method.

These two key methodological principles underpin van Manen's phenomenological method. This method, and its application in this research will be discussed in the next chapter.

3.6 Chapter summary

Phenomenology is a complex philosophy that has been applied in a research context with the aim of increasing understanding of lived experience. In this chapter I have explored the phenomenological philosophy that forms the basis of phenomenological research approaches. Having considered various possible methods with which to explore the phenomenon of multiple service involvement in primary care, I have chosen to utilize the ideas of Max van Manen (1990; 1997a) to structure my research method. Van Manen (1990) suggests a heuristic method that can support and guide the hermeneutic researcher. This method, and its application, is discussed in the following chapter where I will demonstrate how van Manen's ideas have been employed in this research to help illuminate this phenomenon.

Chapter 4: Methods

Lived experience is both the starting point and the end point of phenomenological research. The aim of phenomenology is to transform lived experience into a textual expression of its essence – in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which the reader is powerfully animated in his or her own lived experience.

<div align="right">van Manen, 1990, p. 36.</div>

In the previous chapter I discussed phenomenology as both philosophy and research methodology, and described how van Manen's hermeneutic approach is particularly suited to exploring patient and carer experience. This chapter will focus on how I have employed this methodological framework to the research methods used in this study.

4.1 van Manen's phenomenological method

As I explained in the previous chapter, to undertake human science research is to study lived experience, not with the desire to generate theory with which to explain that experience, but rather to offer plausible insights into lived experience. Van Manen (1990) suggests an '*elemental methodical structure*' (p. 30), which contains six research activities that form the core of phenomenological inquiry:

1. Turning to a phenomenon which seriously interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualise it.
3. Reflecting on the essential themes which characterize the phenomenon.
4. Describing the phenomenon through the art of writing and rewriting.

5. Maintaining a strong and orientated ...[5] relation to the phenomenon.

6. Balancing the research context by considering the parts and whole.

Although presented as a process, this method is non-linear and these activities are interconnected. These research activities are demonstrated at various points throughout this thesis. For example, in the preface I have described my interest in this phenomenon, and the context from which I identified the need for the research, which forms part of my orientation towards this subject. In this chapter I will describe how I have accessed descriptions of lived experience, and how these descriptions will be explored and reflected upon. In the findings and discussion chapters I will consider the themes that characterise this phenomenon, and I have endeavoured to transform the lived experience of the participants into text – utilising the process of writing, and re-writing.

This methodical structure has provided me with a guide in considering the various stages of the research process; within each of these activities further specific methods have been considered. Van Manen (2011) suggests two categories of specific research method; empirical and reflective methods. Empirical methods are used to access actual examples of lived experience. Reflective methods are used to explore these lived experience examples. These two forms of methods will be considered separately. However, I will commence with a discussion of ethical issues, as consideration of these has underpinned the total design of the research.

4.2 Ethical considerations

Ethical issues are inherent in the research process and research should demonstrate that it has applied ethical principles and standards in written work and reports (British Psychological Society, 2004; RCN, 2005; RCN, 2009). Ethical obstacles can be prominent in research with people affected

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[5] Van Manen's original text included the word 'pedagogical' here. This has been removed, as is not my orientation towards the phenomenon.

by AD (Kaasa and De Conno, 2001). Research involving this population is the subject of much discussion regarding the specific ethical dilemmas faced, indeed the ethical issues seem to be heightened relating to the short life expectancy of participants and the potential for harm outweighing possible benefit for research participants (Hopkinson et al, 2005). The ethical issues are numerous and far reaching. For example, there are issues relating to research participants such as difficulties around obtaining informed consent (Dean and McClement, 2002), the potential emotional burden on patient and family (Gysels et al, 2008), the rapidly changing nature of an individual's health and circumstances which may impact upon their ability to make informed decisions about research participation, and the likelihood that research findings will be of no benefit to participants whose life expectancy is short (Addington-Hall, 2002). There are also issues surrounding research processes; such as the problems of recruitment by health professionals and subsequent risks of coercion, the challenge of gate-keeping by recruiters (Ewing et al, 2004; Kaasa and De Conno, 2001), and the transformative effect of the research process on both participants and researchers (van Manen, 1990).

When considering ethical issues in research it is important to remember what actual risks the research participant is being exposed to. Health related research often involves people being recruited to randomised control trials that test new medications, or interventions, that aim to help cure or palliate symptoms, and improve QoL. This type of research has possible physical risks to the participants who take part. Qualitative research has an entirely different focus and the risks involved are less obvious, but still present. Participants are giving their time and energy – precious commodities for people affected by AD. They are also often being asked to discuss and reflect on sensitive and personal issues. This carries with it the risk of emotional upset, and in very extreme cases psychological harm. Seymour and Clark (1998) highlight how phenomenology is particularly suited as a qualitative approach for research with people affected by AD, as the flexibility of the method allows research to be designed sensitively accommodating issues pertinent to the participants involved.

As I describe the specific methods employed in this research, I will also explore how ethical issues have been considered, and methods designed accordingly. The proposed study received ethical approval from the NHS Research Ethics Service on the 08.09.09, and gained Research Governance Management Authorisation on the 24.09.09.

4.3 Empirical methods

Empirical research methods are those that aim to gather a range of lived experience accounts of the phenomenon under investigation (van Manen, 2011). Empirical research methods can utilise a variety of techniques and processes, however they must consider the implications of an individual's health status and social situation, and how this may impact upon their ability to contribute towards research. People with AD have, by definition, complex health problems that may affect their functional ability. As I described in chapter two, common physical symptoms such as pain, breathlessness and fatigue may be present alongside psychosocial issues such as stress, anxiety and uncertainty (McKechnie et al, 2007). The impact of AD on carers should not be underestimated, and research consistently shows that there are physical and psychosocial impacts here too (Covinsky et al, 1994; Aoun et al, 2005; Cain et al, 2004; Stajduhar et al, 2008), and of course, carers may also have their own health problems. As I describe the empirical methods utilised in this study I will highlight how these potential physical, psychosocial and ethical issues have been attended to as part the practical design of this research.

4.3.1 Identifying the research population and inclusion criteria

The aim of this research is to explore the experiences of people who are in the advanced stages of disease, with a life expectancy of around twelve

months, in relation to the involvement of multiple care services. Identifying people with a short life expectancy can be a challenge as prognostication in AD can be challenging. Throughout this thesis I have used the term 'advanced disease', based on the GSF (2008) guidance, to define my area of interest (see p.22 for further discussion of this). The Prognostic Indicator Guidance (PIG) (GSF, 2011; Thomas, 2010) is included within the GSF as a guide to help health workers identify individuals with varying diagnoses, who may be in the last year or so of their lives. The PIG includes diagnostic guides that contain pathological indicators and 'the surprise question', a question that recognises intuitive understanding in health professionals, and asks them to consider whether they would be 'surprised' if the individual were still alive in six to twelve months. This guide has been utilised to define my research population, and a detailed guide to the PIG can be found in appendix 1.

People affected by any AD could find themselves receiving multiple health care services. I have chosen four diagnostic groups on which to focus. These are: heart failure, COPD, Parkinson's disease, and cancer. These disease groups have been chosen for several reasons. Firstly, these diseases all have different trajectories, presentations and clinical features, however the people living with them will all spend the majority of their time receiving care in the community setting. Secondly, these diagnoses are all included within the PIG, and as such, a guide is available for identifying people who are around the same stages of their life span. Thirdly, these groups will all have access to similar generalist health services for support, but may be accessing unique specialist services. The aim of looking at experiences of people across varied diagnostic categories is to be able to draw some conclusions about this experience that are relevant to people living with AD, as opposed to being exclusively relevant to a single diagnostic group. In this way, these findings may be of particular interest to generalist service providers who are targeting their service provision to people affected by a wide range of diseases.

Further specific inclusion criteria, and their rationale, are outlined in table 3:

Table 3. Inclusion criteria

Inclusion criteria	Rationale
Patients have a progressive disease in the advanced stages (based on the PIG and identified by health professionals). This could be a cancer, heart disease, COPD, or Parkinson's disease.	1. These diseases all have different trajectories, presentations and clinical features; however the people living with them will all spend the majority of their time within the community setting. 2. These diagnoses are all included within the PIG, and as such a guide is available for identifying people who are around the same stages of their life span. 3. These groups will all have access to similar generalist health services for support, but may be accessing unique specialist services.
Carers must self identify with the 'carer' role, and believe themselves to be the main carer for a patient with the above diagnosis. Patients are able to participate without their lay-carer and vice versa.	The focus of the research is on the experiences of patients and carers, not expressly on the experiences of patient/carer dyads, and as such it is not a requirement for both to participate together.
Both patient and carer should to be aware of the diagnosis, and that the disease is progressive and in the advanced stages. This is to be confirmed by the health professional who refers them for inclusion.	This should ensure that the participant will not be surprised by the request to be included in this study, and that the interviewer will not cause distress by mentioning something of which the participant has been previously unaware.
In addition to their GP, patients must be receiving support from two or more services in the community.	The research aims to explore the experience of people with multiple services involved in their care.
Patients and carers must be over eighteen years old.	This study is focussing on adult experiences.
The referring clinician must confirm that there are no known lone worker risks to a researcher interviewing the participant in their own home.	This is for researcher safety.
All participants must speak English.	There is no budget for translation services within this project.

4.3.2 Sample, access to participants and recruitment

Texts on phenomenological research methodology and methods rarely discuss sampling procedures, although it is generally accepted that sample size is likely to be small and should be informed by theoretical demands and practical constraints (Norlyk and Harder, 2010). In order to accommodate the mixture of diagnoses, and to ensure good variation within the sample, a purposive sampling technique has been utilised.

In principle, once research has been granted ethical and local approval, all people who meet the inclusion criteria should be offered the choice to participate; indeed it could be seen as unethical if people are not offered this choice as this removes opportunity for individual autonomy (Ewing et al, 2004). However, in practice this does not always happen in qualitative studies, and recruiting patient and carer participants is often reported as challenging (Addington-Hall, 2002; Ewing et al, 2004; Hopkinson et al, 2005). Due to data protection restrictions, UK health research often utilises NHS staff, or processes, as part of research recruitment strategies (Redsell and Cheater, 2001). This approach is not problem-free, and 'gatekeeping' by NHS staff is often documented as a reason for poor recruitment to both clinical trials and qualitative research, particularly in palliative care (Addington-Hall, 2002; Ewing et al, 2004; Flemming et al, 2008). Ewing et al (2004) had difficulties recruiting in their own research. Based on an evaluation of the challenges they faced, they suggest that both primary and secondary care practitioners may be caught in a dilemma, realising that there is a need to co-operate with, and be supportive of research, but at the same time feeling that they should be protecting their patients from anxiety and upset. Terminology may be a further issue, for example the term 'palliative care' may be misunderstood by staff who associate it with the terminal stages of illness, and thus by the time participants are considered for inclusion they may be too physically ill to participate. Staff may also be concerned about revealing the 'terminal' nature of the disease to potential participants (Seymour et al, 2005), and thus again exclude them as a means of protection. Workload pressures,

time constraints and local and organisational change are also obstacles when using NHS staff, as they have many competing demands on their time, and may have to prioritise between clinical work and other activities, including assisting with research (Ewing et al, 2004). It is also suggested that some health service staff may be simply uninterested in research and therefore not perceive it to be a priority (Lundström and Strang, 2004).

Despite these known difficulties, recruiting through NHS staff is sometimes the only option for researchers. Participants for this study were indeed recruited in primary care, through the clinicians with whom they had contact. Recruiters included specialist heart failure, COPD, and Parkinson's disease nursing teams, four district nursing teams and a Macmillan nurse team. All of these teams were operating in one primary care trust, covering a 224 square mile radius incorporating both urban and rural settings. The decision to recruit through these teams was pragmatic. I believed that this group of nurses would have an excellent insight into their patient group, and whether people met the inclusion criteria. I also had good connections with health staff in these areas. Although I was aware of the pressures that these teams were under, I anticipated that my prior relationship with them might increase my access to participants, and potentially reduce the problem of gatekeeping. I met with the recruiting teams to inform them about the research, discuss their involvement, and give them information about what their role would be. All teams were also given written information that reiterated this, and clearly outlined the inclusion criteria. The health professional's role was purposefully left simple, and involved them identifying, and then giving potential participants an information pack about the research, with a freepost reply slip that was to be returned directly to me by the participant if they were interested in receiving further information. Examples of the documentation that was given to recruiters and participants can be found in appendix 4.

As a result of this strategy, twenty participants (N=20) were recruited across the diagnostic groups. This included people with COPD (N=4) and their carers (N=2), cancer (N=4) and their carers (N=2), Parkinson's disease (N=2) and their carers (N=2) and heart failure (N=2) and their carers (N=2). This

was a good sample size for this phenomenological study, enabling depth within the analysis whilst allowing for a range of diagnosis and circumstance. In chapter nine (p.301) I will reflect on the challenges I faced in recruiting for this study and the effectiveness of my recruitment strategy.

4.3.3 The preliminary meeting and informed consent

When the participant returned the reply slip to me I contacted them by telephone to introduce myself, and to arrange a convenient time to meet and discuss the research. The aims of this first meeting were twofold. Firstly, participants had the opportunity to discuss the written information they had received from their health professional prior to deciding whether to participate in the study (based on the RCN (2005) guidelines for obtaining informed consent). This meeting also meant that the participant could meet me before deciding whether or not to participate in the research. I anticipated that this would reduce some of their concerns about participating in a research interview, and I believe assisted in the development of a rapport between the participant and myself (Dickson-Swift et al, 2007). If both the patient and the carer had requested information about the study then they were seen together at this stage. If the patient and/or carer decided that they wanted to participate in the research, then consent forms were signed and an appointment made for the research interview.

The consent form was structured based on advice from the NHS ethics service and the University of Huddersfield ethics panel, and can be found in appendix 5. Informed ongoing consent can be hard to achieve in qualitative research due to the unpredictable nature of interviews, which can reveal information that is unanticipated by either the researcher or the participant. Because of this issue a 'process informed consent' (Speziale and Carpenter, 2007) strategy was adopted. Process informed consent involves re-evaluating a participant's consent to be involved at various stages in the research process. This approach was particularly suited to this research, as the participant's capacity and personal circumstances could potentially

change throughout the course of the research. It was made clear to participants that they could withdraw their consent at any time without repercussion, and consent to participate was reassessed verbally at various stages throughout their involvement in the research, including during the interview itself.

The interview was arranged for not sooner than seven days after the initial meeting, which gave the participant further time to consider their inclusion. Furthermore, all participants were contacted the day prior to the interview to confirm it remained convenient, and that they still wanted to be involved in the research.

4.3.4 The research interview

Research interviews gather and explore narrative accounts of lived experience (van Manen, 1990) and are the predominant method of data collection in qualitative research in general (DiCicco-Bloom and Crabtree, 2006; King and Horrocks, 2010), and phenomenological research in particular. Hermeneutic interviewing is a *'means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon* (van Manen, 1990, p. 66) and requires the interviewer to retain a reflective openness to the phenomenon under investigation, by engaging in active listening (Sorrell and Redmond, 1995), considering the embodied experience of participants and self (King and Horrocks, 2010; Finlay, 2006a) whilst remaining orientated to the focus of the interview (van Manen, 1990). There is some debate in the literature surrounding the role of semi–structured interview schedules in phenomenological studies (Wimpenny and Gass, 2000) as a structured approach is not congruent with the methodology. However, it is a requirement of NHS ethics committees to submit an interview schedule with qualitative applications. Rather than containing exact questions, an interview guide can contain themes that may be explored with the participant (Kvale, 1983). The interview guide was created (appendix 5) and used as a prompt throughout

the interview to help ensure that areas of interest were discussed with the participant.

All interviews were recorded and transcribed verbatim. Around half of this transcription was undertaken by myself, and half by a colleague. Transcription of research interviews may arouse a strong emotional response in transcribers (Clark et al, 2000). Bearing this in mind, support was given to the colleague doing the transcribing in the form of regular conversations about what she was doing and how she was feeling about it. In-order to adhere to the principles of anonymity and confidentiality, all names, places and identifying details were altered in the transcribed data. It is, however, very hard to completely disguise the identity of research participants, and deductive disclosure can occur when the traits of groups or individuals make them identifiable in research reports (Kaiser, 2009). As part of the consent process, I discussed this with participants, although interestingly this did not seem to be a concern to any of them.

As van Manen (1990) states, research methods may have an effect on research participants, and it is acknowledged that research interviews, which encourage people to discuss, consider and reflect upon their situation, will potentially impact upon participants in some way (Chapple, 2006; Colbourne and Sque, 2005). However, these effects may not necessarily be negative. Murray (2003) suggests that research interviews may have therapeutic benefits for participants, who have the opportunity to discuss and share their experiences. However, it remains essential that support is available to participants both during and following the period of research. Thus, all participants were given contact details for PALS - the NHS Patient Advice and Liaison Service, and with the individual's permission, their GP and the referring clinician were also informed of their inclusion. This was to ensure that the participant could easily follow up issues raised during the interview with local health professionals, if they chose to do so.

There are further factors to consider when designing interviews for this population. People affected by AD may have complex physical and

psychosocial difficulties that may affect their ability to contribute to conventional research interviews (Hopkinson et al, 2005). For example; breathlessness affects the ability to talk for extended periods of time; pain and associated drug treatments can affect concentration. Equally, there may be emotional barriers to participation: people are speaking about their individual experiences at potentially traumatic periods of their lives, which can lead to participants becoming upset or distressed (Harris et al, 2008). Participants may also find it hard to articulate their experiences and thoughts, and to reflect upon their experiences, which may be complex with many factors involved. In addition to this, recent research (QNI, 2011) into community home nursing has highlighted that some people do not know who it is that is delivering their care. This was a particular issue in this research where people were being asked to discuss the people and services who were providing their care.

Although face-to-face interviews are frequently used in qualitative research, methods have been slow to evolve to include complementary techniques that may enhance the interview itself. A study by Kendall et al (2007) exploring challenges in end of life care research, found that despite some researchers perceiving there to be advantages to using innovative methods, few had utilised non-mainstream qualitative techniques. Harris et al (2008) suggest that researchers need to '*step outside their methodological comfort zones*' (p. 385) in order to consider and develop new techniques for research, a notion which is supported by van Manen who suggests that the researcher '*needs to be creative in finding approaches and procedures uniquely suited to this particular project and this individual researcher*' (1990, p. 163).

One of the anticipated challenges in this research was the complexity of the phenomenon under investigation. I was unsure whether participants would be able to describe the complex array of services involved in their care, or would be able to remember the names of the different services involved. Equally, it was uncertain as to whether they would be able to conceptualise and reflect on their experiences of this situation at a time when they were experiencing multiple and rapid changes in their embodied experience of the world.

Because of these uncertainties, I felt that the complex nature of this research question required an innovative approach to support the research participants in sharing their experiences.

There is an increasing recognition of the value of visual methods as accepted ways of gathering data in qualitative research (Woodhouse, 2012), and several research studies have used some form of 'mapping' to help the exchange of information in research situations about service related issues, particularly in the field of social work. These include; Genograms, which are a graphical representation of the structure of an individual's family; Ecomaps, which are a graphical portrayal of family and social relationships (Rempel et al, 2007); and Pictor, a technique that helps participants explore and discuss roles and relationships (King et al, 2010). The Ecomapping, and Pictor techniques share many similarities as both use a visual technique to support participant reflection on relationships (King et al, in press). Ecomaps encourage people to map their support networks, and provide a visual means of promoting discussions about the structure of networks and their supportive functions. The technique has been used in research with carers of people affected by motor neurone disease (Ray and Street, 2005) and is used as a social work tool to consider the clients social resources, and how these resources may affect the achievement of personal goals (Lieberman, 2011). Creating the 'map' involves the participant drawing themself, and their family, in a genogram circle in the centre of the map, surrounded by other circles representing the elements of their social network. The strength of the different relationships is then demonstrated by either the thickness, or number of lines, drawn between the outer and inner circle, and other aspects can be demonstrated by using dashed or wiggly lines, for example to indicate a broken or problematic relationship (Ray and Street, 2005). An example Ecomap is shown in Figure 6.
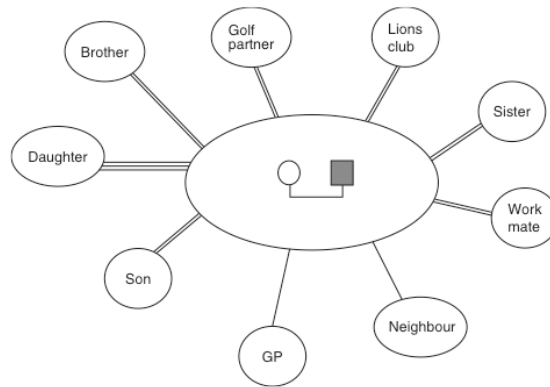
Figure 6. Ecomap. Reproduced from Ray and Street, 2005, p. 547.

The Pictor technique involves the creation of a 'chart', which encourages people to reflect on roles and relationships, and has been used to explore issues around collaborative working in health care (King et al, 2010). The chart is developed by using simple arrow shaped 'post-it' notes, which the participant is asked to arrange in a way that helps them to share their experiences of the situation (King et al, 2010). An example Pictor chart is shown in Figure 7.

Although these techniques both aim to elicit information about relationships and interactions, Pictor is felt to be the most appropriate technique for this research as it facilitates exploration of role perception, and relationship dynamics across networks of care (King et al, in press). It was also felt to be a relatively simple technique to use with people who may have complex problems.
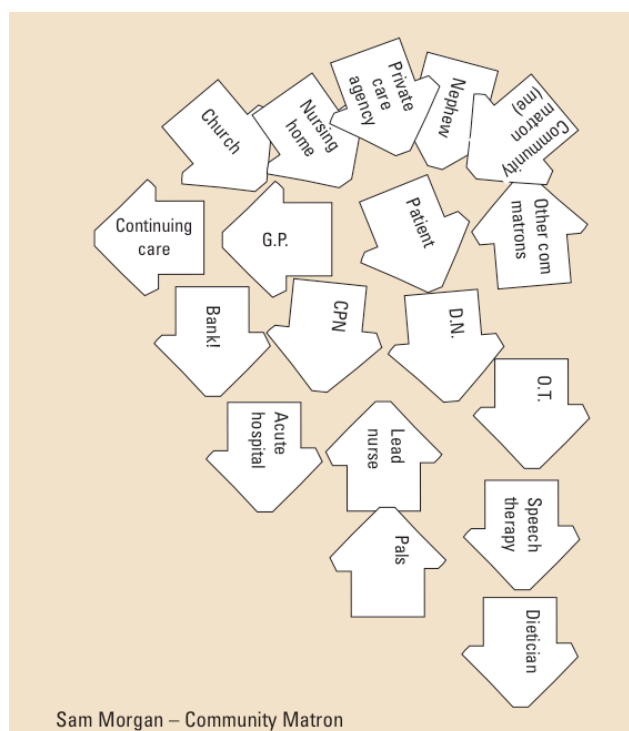
Figure 7. Pictor chart. Reproduced from King et al, 2010, p.94.

4.3.5 The Pictor technique

The Pictor technique is used as part of a research interview to help elucidate the lived experience of the participant. It achieves this by helping to reveal the meanings and interpretations that people attach to their experiences, as well as facilitating participants in visually articulating their experiences with regard to roles and relationships.   The technique has developed from Hargreaves' (1979) Social Network Method (a family therapy tool), which Ross et al (2005) applied in research exploring inter-professional relationships and collaborative working in health and social care. The technique has since been used, and named, by King et al (2010) who explored district nurses' and community matrons' understanding of their own and others' roles in palliative care settings, and is currently being used in a number of other, as yet unpublished, studies.

Pictor is based on the principles of interpretive phenomenology and Personal Construct Psychology. Both of these approaches propose that people are engaged with trying to make sense of the world, and this sense making impacts on how the world is experienced. They both also recognise that this meaning is not easily accessible to conscious reflection. Much of experience is pre-reflective, but by helping people to reflect on their experiences, and to visually articulate their roles and relationships, the researcher can develop a picture of how the world is experienced by the participant (King and Horrocks, 2010). The Pictor technique was developed to overcome some of the methodological challenges of researching collaborative working; such as participants recounting their experiences according to practiced, or conventional descriptions (Ross et al, 2005); or only being able to think of the obvious people involved in a case, neglecting those who are less obvious, but whose presence still offers the researcher valuable insights into their experience (King et al, 2007). Although the current study is not exploring collaborative working from a health professional perspective, it was felt that these benefits of the Pictor technique could also overcome some of the perceived challenges associated with exploring patients' and carers' experiences of multiple service involvement.

The Pictor technique involves the creation of a chart that forms the basis of the research interview. The chart is a graphical representation of the participant's world in relation to service involvement, and facilitates a detailed exploration of the participant's experience with regard to roles and relationships. The creation of the chart encourages participants to reflect on, and communicate, their experiences with the researcher. King et al (2010) describe the process of the Pictor technique as used with health professionals:

- The participant is provided with a stack of sticky, arrow shaped, post it notes, an A1 sheet of paper, and a pen.
- They are asked to bring to mind a case of collaborative working that they clearly remember.

- They are requested to write the name, initials or role title of every person that they can think of who was involved in the case on a arrow shaped post it note. They must also create a note for themselves, and the patient who the case revolves around. These arrows are then arranged on the A1 paper. The participant is advised that there is no fixed way to do this, but they might want to consider using the direction and proximity of the arrows to indicate features of the different relationships.
- To remove the danger of influencing the participant, the researcher leaves the room while the chart is created.
- Once the chart is created, it is used as the basis of discussion of the case.

This is the first time the technique has been used with lay-participants. To explore the potential of its use, two trial interviews were undertaken. One involved the mother of a boy with profound learning difficulties, and the other a women in her late 70's, who was a carer for her elderly mother. Based on these two interviews some slight modifications were made to the technique described by King et al (2010), with the aim of simplifying the process for lay-participants. These changes were to break the process into smaller stages, so that the participant did not have to retain so much information about what was expected of them, and to rethink the size of the paper required to create the chart on. This second change was a pragmatic one. Because the interviews happened in private homes, there was no guarantee that a large workspace would be available on which to create the chart. Equally, because of the health of some participants, they might be unable to sit at a table, and the use of a smaller piece of paper meant that the chart could be created on a mobile hard surface, such as a tray. A further change was to show the participant a demonstration Pictor chart if they were unsure what was being asked of them. This change was introduced as it became apparent that some people struggled with the concept until they could see the type of image they were being asked to create. The chart they were shown was developed from a fictional case of a first year university student. A fictional case, from a

different type of scenario, was used to avoid influencing participants about who to include on their own charts. Thus, the Pictor technique that has been used in this research involved the following process:

- The participant was encouraged to think about their current situation with regard to the various different people/services involved. They were provided with a large blank sheet of paper (A1 if possible, but as large as the space could accommodate) and a stack of arrow-shaped 'Post-It' notes. The participant was asked to write on the arrows the initials, role title or name of every person they could think of who was involved with their care. They were advised that this could include health services, and other people or factors that were significant to them in their illness experience. They also wrote their own name, and if relevant the name of their partner, on an arrow. If the participant was unable to write, I did this for them, under their direction.

- For the second stage, the participant was asked to arrange the arrows on the large sheet of paper. There were advised that there are no fixed rules as to how they should do this, but it was suggested that they might use aspects such as the direction of the arrows and the proximity to other arrows to indicate features of their different relationships.

- If the participant was unclear about what they were being asked to do, they were shown an example Pictor chart from a fictional case.

- For most interviews it was not possible for me to leave the room, so I sat in silence whilst the chart was being created. However, audio recording was left on whilst this was happening in case the participant wanted to talk about their chart as they created it.

- Once the layout (or 'chart') was completed, it was used as the basis of the discussion about the participant's situation and experiences.

- The charts were retained following the interview. The 'Post-it' notes were drawn around and names replaced with pseudonyms to protect anonymity. The charts were photographed and reduced to A4 size. This made it easier to refer to the chart alongside the transcript to help illuminate the text and aid the analysis (King and Horrocks, 2010).

Care was taken during the analysis to avoid positivistic assumptions by drawing conclusions from the charts directly (in isolation from the interview 'text'), for example by assuming that an individual who only placed a small number of services on a chart only had only these services involved in their care. The chart is not an objective and complete measure, rather it is one way of perceiving the participant's experience, and the creation of the chart captures the thinking of the participant and allows them to verbalise these thoughts. However, it is suggested that patterns across several charts may well be worthy of close attention as part of the thematic analysis (King and Horrocks, 2010) as these may be indicative of similar experiences and understandings across the research population.

4.4 Reflective methods

Phenomenological reflection is the process by which we attempt to understand the meaning of phenomena, by using various 'reflective' methods that enable us to get closer to experience as it is lived. This 'meaning' is multidimensional and communicated through text (van Manen, 1990; 2002). Reflective methods are those that contribute to the analysis of the data that has been collected by the empirical methods.

The phenomenological reduction is a key component of van Manen's method, and is central to being able to undertake reflective methods effectively. It is through the processes of the phenomenological reduction that data is looked at in a fresh light, as pre-understandings are identified and previously taken

for granted assumptions are challenged. These pre-understandings and personal assumptions occur on many levels, and the identification of these can be surprising. As a researcher, the way I view the world has been informed by many factors, including my place in history, my social and cultural environment, my education, and my own embodied experience of the world. Assumptions are sometimes easy to identify, for example my nurse training having an impact on the way I might perceive 'patients'. However, assumption is often more deeply concealed, for example, it was not until I encountered the work of Iona Heath (2008) that I began to question my assumption that palliative care, in particular the obliteration of symptoms of pain, was automatically the most appropriate treatment for people living with AD. As I developed my thematic framework for this research, I have entered into a hermeneutic conversation with the data, and continued to challenge and question how my pre-understandings and assumptions have impacted on the emerging findings.

To support the process of identifying my personal assumptions about the data, and maintaining a reflective openness to developing insights into the research, I have kept a research journal from the commencement of this PhD. Research diaries are advocated as a tool in qualitative research with the varied objectives of documenting process, facilitating transparency, developing critical thinking, aiding reflection, contributing to learning and assisting with analysis (Clarke, 2009; Wall et al, 2004). I have used my diary to record developing research ideas, details of my meetings with participants, my feelings and reactions to these contacts, as well as documenting emerging insights into the phenomenon under investigation. These notes were used alongside participant transcripts and Pictor charts in the analysis and interpretation of data.

These personal reflective processes have been ongoing throughout the research. Specific methods have also been used to support the analysis and interpretation of the data.

4.4.1 Data analysis and theme development

Thematic analysis is perhaps the most familiar approach to exploring qualitative data. Van Manen (1990, p. 90) describes themes as:

> The stars that make up the universes of meaning we live through. By the light of these themes we can navigate and explore such universes. Themes have phenomenological power when they allow us to proceed with phenomenological descriptions.

A phenomenological theme helps to give control and order to phenomenological writing, and themes can be understood as *'structures of experience'* (van Manen, 1990, p. 79). A theme is an interpretative product that helps to make sense of a notion, gets to the core of the notion that is trying to be understood, but is always acknowledged to be a reduction of that notion (van Manen, 1990, p.92). Van Manen (1990) suggests three possible methods of identifying thematic aspects of a text. 1. A wholistic (sic) approach, where the whole text is considered in relation to an individual theme. 2. Selective or highlighting approach, where sections of text are considered in relation to theme development. 3. Detailed, or line-by-line approach in which every line is considered, questioning what the line, or sentence is saying about the phenomenon under investigation.

To explore the lived experience accounts collected from participants, I have predominantly used the selective approach to thematic analysis, considering sections of text and questioning what they tell me about the lived experience of multiple service involvement. Additionally, Van Manen (1990; 2011) proposed that there are certain universal aspects to lived experience that he described as lifeworld existentials, and he suggested that using these as a thematic guide could be particularly illuminating. There are four fundamental existential themes that are probably applicable to all humans regardless of their social, cultural or historical circumstance. These are spatiality (lived space), temporality (lived time) corporeality (lived body) and relationality (lived

human relation). Rather than use these existentials as *a priori* themes, they have been considered alongside the thematic analysis, directing me to aspects of the participant's narrative that illuminated their lived experience in these areas.

A limitation of this approach to analysis was that it generated a vast amount of thematic data, and I quickly realised that I needed a more structured method to assist me in the analysis, and a way to manage the thematic detail that emerged. For this reason, I turned to a technique called Template Analysis to support the analytic process.

Template Analysis

Template Analysis (TA) is a flexible technique that is suited to a wide variety of methodological approaches, including phenomenology (King, 2012). Template Analysis involves the development of a thematic, hierarchical template, which is then used to support the interpretation and writing up of findings (King, 2007). The process of creating the template begins by thematically coding a subset of transcripts, using *a priori* themes as appropriate. From this initial coding, the first template is created by grouping together themes that emerge from the initial analysis. This template is applied to the remaining transcripts, making modifications in an iterative fashion by adding to, or modifying the template as new themes are developed (King, 2012). Despite the template being 'hierarchical', the hierarchy does not necessarily indicate a hierarchy of importance; rather, it is a way of organising the data that allows the researcher access into the participants experience so that they can then explore the meanings within the text. This is important as the principles of the phenomenological reduction (particularly horizonatilsation) can still be applied. A further advantage of TA is that it allows the researcher to create an audit trail of the analysis stage of the research, and document how themes were identified and thinking evolved (King, 2012). Thus the process of revelation and decision trail is documented (Rapport, 2005), an important component of trustworthiness (Whitehead, 2004).

Two colleagues helped me to develop the initial template; one who is an experienced qualitative researcher with limited knowledge of health care provision, the other who is an experienced palliative care nurse and educator. The first colleague was involved in the very early stages of the template development. We both independently coded four of the transcripts, and through a process of discussion of the transcripts, use of *a priori* codes, and consideration of the emerging coded data, developed an initial template. I then took this initial template, and began to apply it to the other transcripts, making modifications as required. As the template became increasingly developed, I utilised the second colleague to support me in justifying the application and arrangement of codes within the template. Although the collaboration with these colleagues constituted a small part of the analysis, it was a valuable hermeneutic process and encouraged me to challenge my assumptions about the data.

The process of template development is discussed further in chapter 5a, and the evolving template structure can be found in appendix 7.

4.4.2 Interpretation and the role of writing

The coding and interpretation of texts is presented here as a linear process, however this is not strictly the case. The thematic codes applied in a TA template are acknowledged to be already a source of interpretation, but this is only the starting point of the interpretation of the text.

Further interpretation involves the researcher developing a conversation with the text, melding personal knowledge with emergent understanding to reveal new meaning underlying the text (Rapport, 2005). This was achieved by a lengthy process of moving between the developing template, the original participant narratives, the created Pictor charts, and my interpretations of the phenomenon, whilst trying never to lose sight of the individual accounts and contexts (Crist and Tanner, 2003). In this way I have continually explored the

'parts' of this phenomenon, in relation to the 'whole'. This is an example of hermeneutic understanding, utilising the hermeneutic circle. In Figure 8, this research process is demonstrated in comparison to the hermeneutic circle described in chapter three. This ongoing cyclical process leads to an increasingly adequate interpretation.
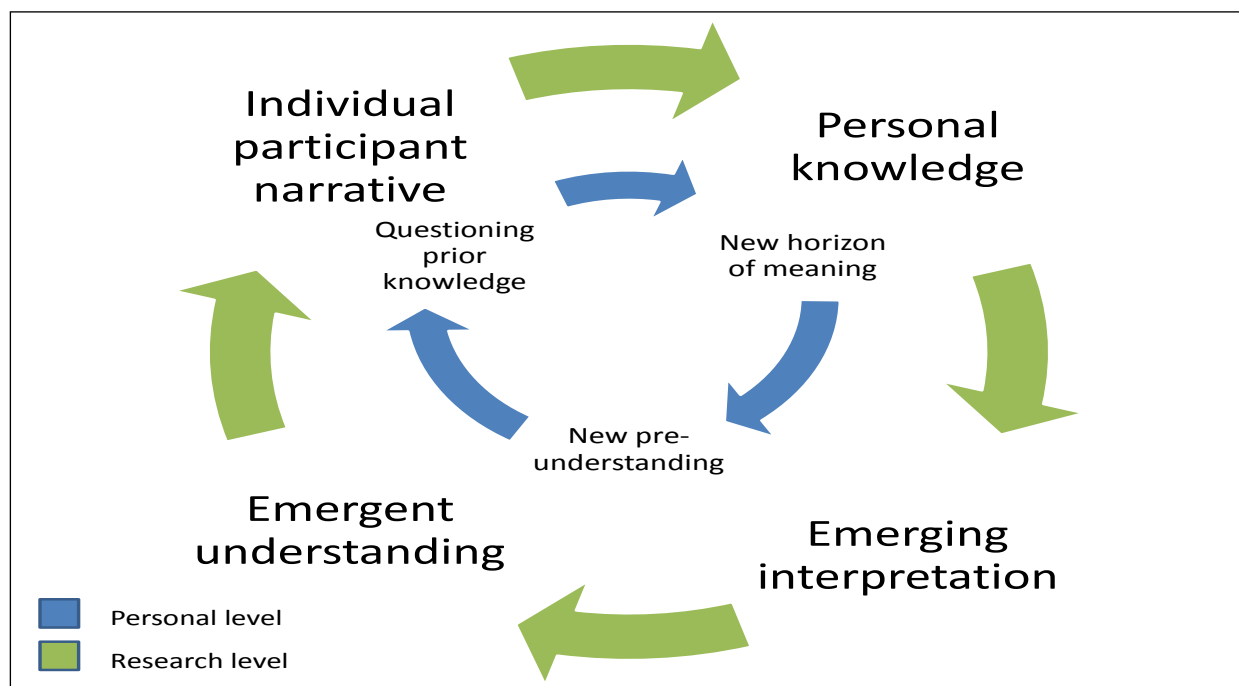
Figure 8. Hermeneutic circle related to research method

Writing was central to this interpretive process, and it is argued that writing is an integral part of research interpretation (Holloway, 2005; King, 2012). Writing is much more than simply externalising one's thoughts on a subject, or of creating the final research report: writing is at the heart of the phenomenological research process (van Manen, 2011). My research insights depended on me being able to find *'the rights words and phrases, on styles and traditions, on metaphor and figures of speech, on argument and poetic image'* (van Manen, 2002, online), as described by van Manen (2002 online) this is an artistic process:

just as a painter draws the world so the phenomenologist tries to use

words to evoke some aspect of human existence in a linguistic image.

In many ways the creation of a phenomenological description is the search for the impossible, as hermeneutic phenomenology strives for a full written interpretive account of an element of the lifeworld, whilst also acknowledging that life is always more complex than any text can reveal (van Manen, 1990). The created phenomenological text in this research aims to orientate the reader reflectively to the lived experience of multiple service involvement, and contains anecdotes and examples of participant's words to support my attempts to lay open the structures of this experience. Todres (2011) argues that there is a need to balance the structural dimensions of writing, such as thematic presentation, with textural and aesthetic dimensions that communicate the richness of experience. The design of this research has been based upon these principles: structural dimensions are supported by the use of TA, and textual and aesthetic dimensions are supported by the use of participant's words, descriptions of participant's experience in relation to specific themes, use of metaphor, and consideration of van Manen's existential themes. Through this balance, the reader is encouraged to personally reflect on the phenomena and engage in a 'conversational relation' (van Manen, 1990, p.77) with the text through their own questioning of the meaning of the experience, in an attempt to understand the phenomenon.

4.4.3 Participant involvement in analysis and collaborative reflection

In some qualitative approaches the use of participants to validate research findings is commonly used. However, there is contention about the potential collaborative role of research participants in the interpretation and validation of findings. Sometimes seen as a mark of credibility, participant involvement in analysis, or member checking as it is sometimes referred, is a complex issue. Bradbury-Jones et al (2010) argue that the process of involving participants to validate findings encourages the negotiation of meaning between participants and researchers. They assert that it is the participants' experience, and the researcher only has access to this experience through

them, and as such involving participants creates a convergence of perspectives. Giorgi (2008a) criticises this view, claiming that participants are describing their view from the everyday perspective of the natural attitude: he suggests that once phenomenological analysis has been undertaken then it is only possible to verify these interpretations by phenomenological procedures. Additionally, interpretations may have a strong disciplinary orientation, and as such some expertise may be required to understand the interpretation (Giorgi, 2008a). Pragmatic factors also need to be considered: there is a potential power disparity between research participants and researchers, particularly for lay-participants. Participants may feel intellectually intimidated and unable to express their opinions on the data. They may want to please researchers who they feel are working to raise awareness of their situation, and as such agree with a researchers interpretations. Participants may also not recognise themselves in interpreted data, or remember what they said during initial interviews. Holloway (2005) gives the example of presenting a participant with a summary of their interview, to which the participant confirmed that his experiences had been captured. Holloway later realised that the participant had been given the wrong summary. This is described as a helpful process as it clarified that there were similarities between the different participants' experiences, but does highlight that the participant role in interpretation is not straightforward.

Other factors also need to be considered with my research population. Patients' short life expectancy makes their involvement in analysis potentially unachievable, and carers may be bereaved and have a new perspective on their lived experience, and new personal interpretations of what the situation was like.

Van Manen (1990; 2002) suggests a process of 'collaborative reflection' that can involve research participants, but can also utilise research groups or seminars to generate discussion that may facilitate deeper insights into the phenomenon. This is the approach that I have taken. I have obtained clinical and research advice through-out the research process from members of MacPacc, the Macmillan Palliative and Cancer Care collaborative. Discussion

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of this project with professional and lay-members of MacPacc has facilitated the development of ideas, provided suggestions for the troubleshooting of difficulties, and has enabled me to share emerging findings. Details of membership of this group can be found in appendix 6. As I described earlier in this chapter, I have also utilised other researchers at various stages in the research to share ideas with, and to assist with analysis and interpretation of findings.

The research method that has been used in this research is summarised in Figure 9.

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┌─────────────────────────────────────────────────────────────────────────────┐
│ Health professionals identify patients and carers on their caseloads who    │
│ meet the inclusion criteria and give them an information pack, including a   │
│ reply slip for further information.                                          │
└─────────────────────────────────────────────────────────────────────────────┘
                    │
                    ▼
┌──────────────────────────┐   ┌──────┐        ┌──────┐      ┌──────────────────┐
│ Patient and/or carer     │   │ Yes  │        │ No   │ ───▶ │ No further       │
│ return reply slip.       │   └──────┘        └──────┘      │ intervention.    │
└──────────────────────────┘        │                        └──────────────────┘
                                    ▼
┌─────────────────────────────────────────────────────────────────────────────┐
│ Potential participant contacted to arrange an initial meeting with the       │
│ researcher where they will have time to ask questions and be given           │
│ information about the research.                                              │
└─────────────────────────────────────────────────────────────────────────────┘

┌──────────────────────────┐   ┌──────┐   ┌──────┐           ┌──────────────────┐
│ Decide to participate?    │   │ Yes  │   │ No   │ ───▶      │ No further       │
└──────────────────────────┘   └──────┘   └──────┘           │ intervention.    │
                                    │                         └──────────────────┘
                                    ▼
┌─────────────────────────────────────────────────────────────────────────────┐
│ Letter sent to participant's GP and health professional informing them of    │
│ inclusion.                                                                   │
└─────────────────────────────────────────────────────────────────────────────┘
                    │
                    ▼
┌─────────────────────────────────────────────────────────────────────────────┐
│  • Interview to happen not sooner than seven days after the initial meeting. │
│  • Interview to be held at participant's house (unless other venue           │
│    requested).                                                               │
│  • Written consent obtained prior to interview commencing.                   │
│  • Patients and carers to be interviewed separately.                         │
│  • Pictor technique used in interviews.                                      │
└─────────────────────────────────────────────────────────────────────────────┘
            │                                              │
            ▼                                              ▼
┌──────────────────────────┐              ┌──────────────────────────────────┐
│ Data analysed using      │              │ Participants sent letter thanking │
│ Template Analysis, and   │              │ them for their participation.    │
│ hermeneutic procedures.  │              └──────────────────────────────────┘
└──────────────────────────┘
            │
            ▼
┌─────────────────────────────────────────────────────────────────────────────┐
│ Findings disseminated through academic journals and conference presentations.│
└─────────────────────────────────────────────────────────────────────────────┘
                                                            │
                                                            ▼
                              ┌──────────────────────────────────────────┐
                              │ Recommendations made for clinical        │
                              │ practice and further research            │
                              └──────────────────────────────────────────┘
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Figure 9. Summary of research method

4.5 The challenge of having a dual role

Throughout the majority of this research I have continued to practice as a District Nursing Sister in the community health care trust from which participants have been recruited. This has presented several challenges in terms of both ethical and practical design of the research method. My clinical role is based within an out-of-hours district nursing service, and I also previously managed a DN team providing care during normal working hours in the same geographic locality. There was the potential that some of my previous long-term conditions patients may still be active on the caseloads, and that some of my current patients could be eligible to participate.

The dilemma this presented was multifaceted. If I previously knew the participant then I might have had preconceived ideas about their history, circumstance and situation. If I was to see participants in both capacities, as nurse and researcher, then there were several potential issues. I could have broken confidentially by sharing information I had been given in the research situation with staff from the clinical situation; participants might 'edit' their story so as to not affect clinical care; and the clinical care that I delivered could have changed due to knowing the participant in a different way. Additionally, whilst interviewing participants I might encounter a situation where unresolved clinical issues were present, and I needed to consider whether I would stay in researcher role or should act as a nurse (Wilkes and Beale, 2005). There were also risks of coercion if the potential participant already had a relationship with me as a nurse.

To manage this situation I did not recruit directly from the DN team that I had previously managed. I had a local agreement with my clinical colleagues that I would not be involved in the clinical care of individuals who were taking part in the research, except in unavoidable circumstances. I also informed all participants that I held a dual role, and that there was a chance they might see me in my clinical capacity. It was emphasised to participants that the

research was not being undertaken for the local trust, and that the information that they gave me would not be shared directly with their clinical teams.

However, my having known a participant previously, or having a role in their current clinical care, was not an exclusion criteria for this research. I felt that in considering these issues I had become aware of the risks, and had therefore made them more manageable. My understanding of the potential impact of my dual role on the research findings enabled me to consider this in relation to the participant contacts, interview, and subsequent data analysis.

I had planned that if participants had clinical questions then these would be addressed at the end of the interview by signposting them on to the appropriate person/team to deal with these. This situation only occurred in three of the interviews where I felt that carers would benefit from extra support, and I provided them with information of local services that they could access if they required.

4.6 Chapter summary

Research methods are the key to accessing lived experience, and sharing these insights with others. Innovative methods are sometimes required to enable the sharing of lived experience, and this method has embraced an innovative technique called 'Pictor' to facilitate information sharing in interviews, and exploration of roles and relationships. In the following chapters I will present the findings of this research, before finally reflecting on the methods utilised in this research, and their effectiveness in exploring this aspect of human experience.

Chapter 5(a): Introduction to the findings

Twelve patients with various medical conditions and eight carers were interviewed for this study. The focus of these interviews was individuals' lived experiences of having multiple services involved in their care. Although my interest was their contacts and relationships with these services, for the participants this formed just one part of their illness experience that they wanted to share with me. Participants spoke in detail about living with AD, including the physical and psychosocial impacts of their illness. Narratives were complex and interwoven with the many different aspects of their lives (visually demonstrated in Figure 10). Although much of these data are not specifically related to the research question, they form the background from which the phenomena can be understood, and as such constitute a valuable component to understanding the participant's experience.

Figure 10. The interwoven nature of individual experience

I had initially anticipated that the patient and carer data would be explored separately, as I perceived that these two groups would be fundamentally different in their lived experience. The patient lives with the physical effects of AD and the services they discuss are involved because of their own health issues. The carer is closely involved with the patient; they watch the physical and psychosocial effects of AD. Their relationship with services is as a secondary individual, and the services discussed are not generally involved for their own specific needs, but because of the patient that they are attached to (Beaver et al, 2000; Grande et al, 2004; Hasson et al, 2010). However, as the analysis progressed I realised that by applying the separate categories of patient and carer to these two groups of people I was restricting my deeper interpretation of this experience as one lived by people. Reid et al (2005) suggest that there is a need to balance emic and etic perspectives. The emic position refers to the insider's perspective and therefore hearing the participant's story and placing this at the core of an account. The etic position is where the researcher is aiming to make interpretative sense of this account by applying categories (such as patient and carer) to the data. Whilst exploring the text, I began to realise that the etic categories of patient and carer were confining my interpretation by restricting my thinking within these preordained parameters. By looking beyond these boundaries it became apparent that there were also many interesting elements of this experience as lived by 'people' in this situation. This enabled my analysis to further illuminate key relationships, their complex nature and impact on the lived experience of having multiple services involved in care.

Although patients and carers were interviewed separately, when they had participated as a couple their narratives often overlapped and intertwined. Both people were living with AD, and they often described contacts with the same people, and discussed the same events. They also frequently described how each other were central within their lives. The experience of AD and the involvement of multiple agencies was one that was closely linked and lived together, and therefore separating experience was difficult for the purpose of reporting the findings.

Bearing these difficulties in mind, I have conceptualised three aspects to structure my exploration of the lived experiences of patients and carers. The first aspect proposes that the very nature of this lived experience is interconnected and shared between patient and carer. This aspect can be seen as an integrative theme that occurs throughout the data. The second aspect proposes that there are some unique and inevitable differences in patients' and carers' experiences because of their different ways of being-in-the-world and the discrete nature of their 'category'. The third aspect proposes that there are some elements of this phenomenon that are experienced similarly regardless of the 'patient' or 'carer' categories that people are placed in. These three aspects are portrayed in Figure 11. These similarities and differences are conveyed throughout the findings chapters, in which I have tried to remain *'thoughtfully aware of the consequential in the inconsequential, the significant in the taken for granted'* (Van Manen, 1990, p.8).

5(a).1 A change in terminology – 'spousal-carers'

Throughout this research I have used the term 'lay-carer/carer' to describe the non-patient participants in the research, but as I commenced interviews with my 'carer' participants many of my previously hidden assumptions about this role were revealed to me. Lay-carer/carer is predominantly a title that is given to this population by services, and along with the title can be presumptions about the willingness of individuals to undertake the caring role, and the skills that the carer possesses to enable this. In some senses I believe the use of the term makes the family member more invisible to services, as it formalises their role within the ill persons life but potentially detracts from their position as wife, husband, child, family member or friend. I began to find it extremely uncomfortable to continue to use this term, which was so alien to my participants. Although not part of my original inclusion criteria, all of the carer participants in this study were part of a married couple, the husband or wife to the 'patient' affected by AD. People did not generally identify with the word 'carer' to formalise their role. They were wives and husbands, involved in a

situation that affected them both. All of the participants in this research are both spouses and carers. To acknowledge both aspects of the role that people were discussing with me I will now refer to this group of people as 'spousal-carers', a term that I feel recognises the dual aspect to their experience and incorporating both the 'emic' and 'etic' perspectives.

5(a).2 The thematic template

As discussed on p.122, Template Analysis was utilised as a technique to support the analysis of the data. This involved an iterative process of developing the thematic template, or structure to the experience. Initial versions of the template can be found in appendix 7. The final thematic template that was developed to support the exploration of these findings is in Figure 12.
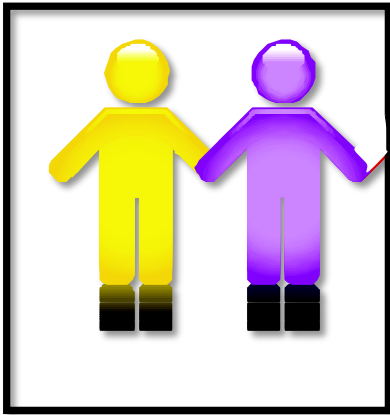
Aspect one: the lived experience of advanced disease is shared and interconnected between patient and spousal-carer.
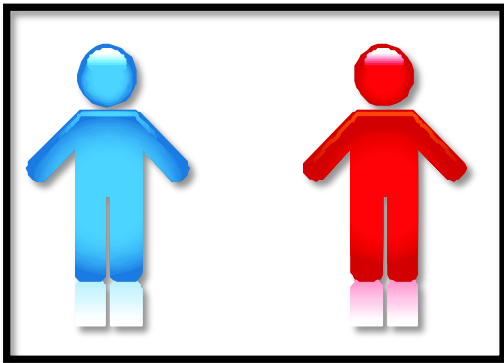
Aspect two: there are unique and inevitable difference in the experience of patients and spousal-carers because of their different ways of being-in-the-world.
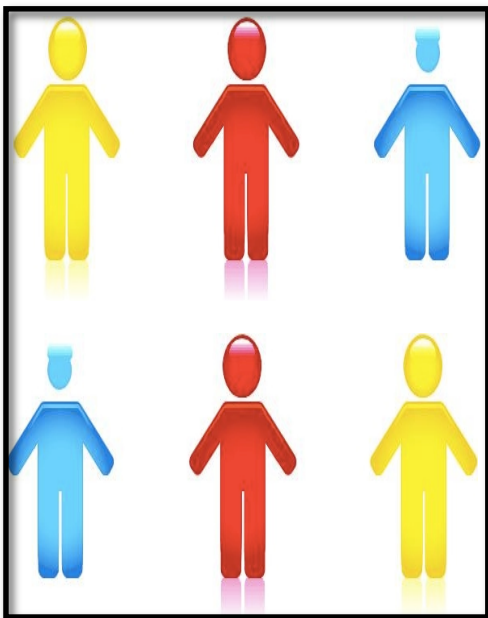
Aspect three: some elements of experience regarding multiple service involvement are shared between people, regardless of their specific category or label.

Figure 11. Three aspects of the experience of advanced disease and multiple service involvement

Chapter 6: Patient experiences

1. Recognising illness: recognising services
    1.1 They do things to me: we do things together
    1.2 Helping me face my illness: the comforting presence of services
        1.2.1 Previous invisibility of services
    1.2 Services reducing the isolation of illness
        1.2.1 Being different
        1.2.2 Being understood
        1.2.3 Acceptance of death and dying

Chapter 7: Spousal-carer experiences

2.   A partner who is ill: being a spouse, being a carer
    2.1 The patient focus
        2.1.1 *'There's no support for me'...*
        2.1.2 *'I don't want to cry in front of him':* Partners presence restricting the spousal-carer's opportunity for discussion with health services
    2.2 Declining service involvement
        2.2.1 *'And of course I said I am fine'*
    2.3 *'My strength'*: support from friends and family
    2.4 Always watching: a unique insight
        2.4.1 Specialist knowledge: contribution to, and rejection from the care team

Chapter 8: Key relationships with services

3.   My care team: using a team that works for me
    3.1 Coordinating and managing the team
    3.2 Significant health service relationships
        3.2.1 Individuals, not role
        3.2.2 *'like'* a friendship
        3.2.3 Knowing them, knowing me
        3.2.4 Listening to me
        3.2.5 Not solving the unsolvable
    3.3 *'My Doctor':* GP involvement
        3.3.1 Desire for holistic and supportive involvement
        3.3.2 Secondary to other services
        3.3.3 In acute illness

Integrative theme: the interconnectedness of patient and spousal-carer experience

Figure 12. The final template

5a.2.1 Integrative theme: the interconnectedness of patient and spousal-carer experience

Running throughout the structure of this experience is the integrative theme 'interconnectedness of patient and spousal-carer experience'. This theme has been located as integrative as it permeates all other themes on the template (King, 2004).

On many of the Pictor charts people placed their partner very close to themselves, and people repeatedly discussed how their experiences were shared, and the importance of their partners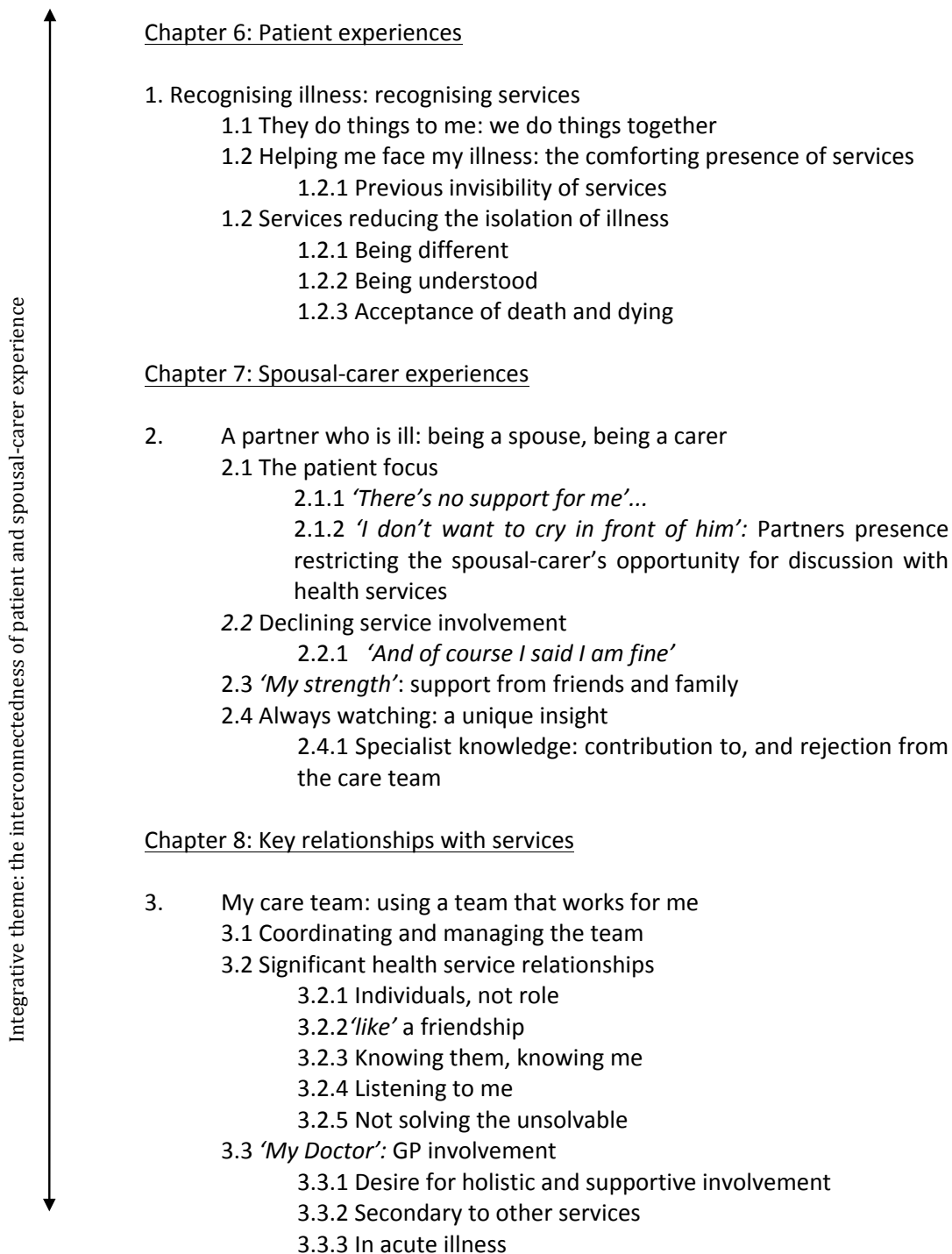 in living with illness. Patients' realised that their illness had impacted upon their partner and acknowledged that they would be unable to manage without them. Spousal-carers' talked about how their lives had changed and how their partners' needs took precedence over their own at this stage in their lives.

For example, Paul and Sarah placed their arrows adjacent to each other on their respective charts (p.146 and p.148). Paul explained that this was because *'Sarah does everything'*, and Sarah put Paul at the bottom of the chart, explaining that she saw her role as to protect him. Michael and Amy placed themselves opposite each other with the tip of the arrow pointing towards the other on their Pictor charts (p.151 and p.152). Michael described Amy as *'the main help'*, and Amy stated that *'they are the two main ones'* which is why they had to be in the centre of the chart. Tracey rationalised the placement of her husband on the Pictor chart (p.173) as *'Norman has got to go next to me 'cos we're a team'*, and, although Norman did not place Tracey closest to himself on his chart (p.172) he described her as *'fitting in with everything'*. Nearly all of the charts that include a spousal-carer follow a similar pattern, with either adjacent arrows or the point of the arrows touching. Notable exceptions were Kevin's and Edward's charts (p. 165 and p.178); they had used the arrows to show how their experience was orientated towards their wife - looking after them and supporting them. Lucy's chart (p.179) also followed a different pattern, and she is slightly separate from her

husband, Charlie, however she went on to describe her placing of him on the Pictor chart:

> Charlie is the first person, er, who would, because he's here all the time, and he's with me.

Ken, George and Aggie also placed their partners near themselves (p. 143, p.166 and p. 155) – despite them not participating in the research. Ken stated that '*certainly I couldn't manage without my family*', George placed his wife pointing into him because '*She's always there*', and Aggie described her placement of her partner '*he's got to be on the top, 'cos he's number one*'. Of all the people involved in this experience, it was partners who were depended on most, who were available, and who provided support at all times.

This theme presented a dilemma in the writing up of these findings. Its infiltration in all structures of the experience made the inclusion of the theme as a discrete discussion unsatisfactory. Rather, I have chosen to outline this theme here, and allude to it where appropriate throughout the findings chapters. Thus, the structuring of the findings in this manner has enabled me to stay focused upon the main aims of the research, and avoids over complication that would affect the unravelling of the essential structure of the experience of people who have multiple services involved in their care.

5a.3 Structure of the findings chapters

In order to explicate my interpretation of this phenomenon, its intricacies and complexities, the findings are presented over four chapters.

Chapter 5b. Introducing the Participants

This chapter will introduce the people who participated in the research. The purpose of this chapter is to give background context to ease the understanding of the interpretation of this experience for the reader. I will discuss each patient's health issues and reasons for inclusion in this research, as well as exploring other aspects of their and their spousal-carers

lives which contributed to my understanding of their lived experience. As part of this exploration, my personal observations at the time of their interview are considered/reflected upon: this includes such things as my response to their physical environment, bodily expressions, interactions with others, and any interview disruptions.   Reflecting on these characteristics further aided my interpretation and understanding of their experiences. Finally, each summary will close with comments on how successfully the Pictor technique was utilised within the individual interviews.

Chapter 6. Patient experiences

In this chapter I will consider the unique aspects of this phenomenon considering the 'etic' category and perspective of patient. This chapter is based upon a discrete analysis of the patient related data, which facilitated exploration of the experience through the patient's narrative.

Chapter 7. Spousal-carer experiences

Chapter seven will explore the unique aspects of this phenomenon considering the 'etic' category and perspective of 'spousal-carer'. Like the previous chapter, the template upon which this chapter is structured has been created from a discrete analysis of the spousal-carer data.

Chapter 8. Key relationships with services

The findings presented in this chapter developed from analysis across both patient and spousal-carer data. They relate to aspects of the experience that were evident in both the patients and spousal-carer data, and I present them here rather than in the previous two chapters to avoid repetitive discussion. This chapter will explore the notion that people develop key relationships, which are central and dominant within their experience and within the team of people that are involved. I will explore aspects of these relationships that made them important to participants as well as looking at how people felt in relation to this 'team' of people at different points in their illness, and their utilisation of this team to meet their needs.

5.4 Final note

Throughout these chapters I will use direct quotes from the interviews to illustrate my findings. These quotes have intentionally not been 'tidied up' – I have included the pauses from participants, as well as leaving in the 'umms' and 'errs' within the text. I have chosen to do this to help illustrate that participant's narratives were sometimes not smooth or flowing, and to situate my phenomenological analysis as close as possible to participants' reported experience. It was hard and often emotional for participants to speak about their illness and share their experiences with me. These were not practiced narratives and participants were often speaking about events for the first time.

Data within these chapters are anonymised as far as possible and all names for people and places are pseudonyms.

Chapter 5b:
Introducing the participants

Twenty people affected by AD participated in this research, and I introduce these participants in this chapter with the aim of providing contextual detail to aid understanding in the following findings chapters. Table 4 provides an overview of the people who participated, showing their pseudonyms, their ages and diagnoses. I will then move on to provide a more detailed summary of the individual participants, describing their background and perception of their diagnosis. Where possible, I borrow participants' own words to aid the illumination of these people's experience. I will also take the opportunity to discuss aspects of their interview that were striking or pertinent to the analysis. The Pictor charts that participants created are also presented here, and I will explore how they individually utilised the Pictor technique. I have also provided A4 versions of the Pictor charts so that the reader can refer to these with ease. When creating their Pictor charts I asked participants to bring to mind health care services, and other people or factors that had been significant as part of their experience. Although the main focus of this research is their experience of multiple service involvement, these other people or factors have been considered where it helps to illuminate their experiences with health care services. Where patients and spousal-carers participated as a couple their summaries are presented together. All summaries are based on the individual's own version of events. Because of this, it is sometimes apparent that partners have a different understanding of the diagnosis and what illness means, as well as conflicting descriptions of their life story. Additionally, because these summaries are based on the participant's own interpretation and description of their illness, sometimes the descriptions of illness do not tally with general medical logic or procedures.

Table 4. Brief summary of the participants

Patient pseudonym	Age	Diagnosis (patient's perspective)	Spousal-carer pseudonym	Age
Ken	66	Bowel cancer with metastatic disease	Unable to arrange interview with Ken's wife.	-
Paul	67	Prostate cancer and 'growth' on spine	Sarah	68
Michael	63	Lung cancer with metastatic disease	Amy	62
Aggie	57	Breast cancer with metastatic disease	No carer nominated	-
Eric	70	Emphysema	Sue	62
Elsie	80	COPD and diabetes	No carer identified.	-
Laura	64	COPD and diabetes	Kevin	65
George	61	COPD and rheumatoid arthritis	He didn't think his partner would want to participate	-
Roger	65	Heart failure and diabetes	Tricia	64
Norman	76	Heart failure and kidney failure	Tracey	?[6]
Annie	60	Parkinson's disease	Edward	63
Lucy	68	Parkinson's disease	Charlie	68

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[6] Tracey did not provide her age. My estimate would be that she was slightly younger than her husband, in her late 60's.
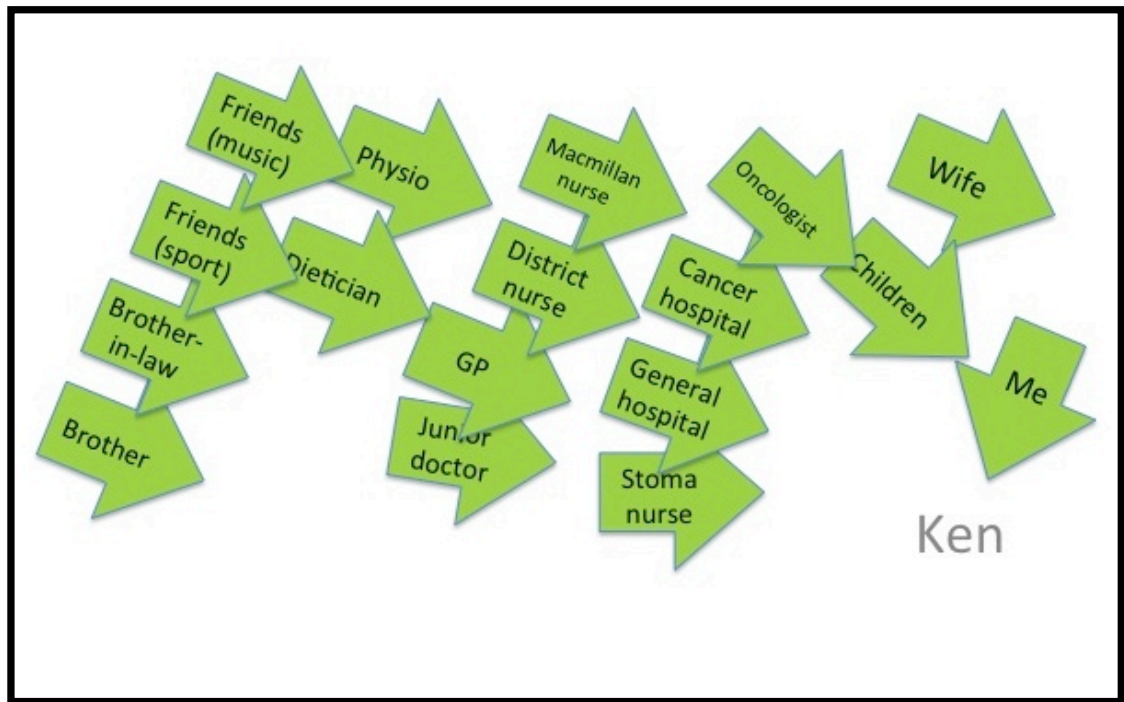
Figure 13. Ken's Pictor chart

Ken is married with two grown up children and several grandchildren. He recently retired and had looked forward to his retirement, anticipating many happy years free from the stress that his job caused.

Eight months before the interview, Ken had become constipated. He contacted his GP who gave him some medication to help him *'go'*. This didn't work so Ken returned on several occasions and each time saw a different GP. After ten days Ken had had enough. He demanded that his GP take further action and subsequently Ken was admitted to hospital for further investigations.

From there everything accelerated, they[7] did scans and immediately told Ken that he had a tumour in his bowel which they operated on the next day. They were not able to remove the tumour as this would have been too dangerous, and to Ken's horror, they formed a stoma. This was extremely difficult for him to come to terms with, as he had never encountered anything like it before.

Ken described his diagnosis as bowel cancer with metastatic disease. He had chosen not to be told a prognosis but knew it to be very poor.

Interview observations: Ken informed me at his initial meeting that he had a history of depression, and for me not to worry if he got upset. Ken did cry, but more markedly only made eye contact with me on a couple of occasions throughout the interview. This left me feeling as though I had not really engaged with Ken and it was not until I began analysing Ken's transcript that I appreciated the richness of our conversation

At the time of the interview Ken was receiving a course of palliative chemotherapy. I interviewed him on a Monday morning. As I arrived for the interview he told me that he had been in hospital over the weekend because his temperature had been elevated and he had required intravenous antibiotics[8]. Ken sat with his pyjamas on in the living room and was obviously tired. I asked him if he would like to postpone the interview, but he was adamant that he wanted it to happen that day, making it very clear that he saw this as an opportunity to *'give something back for all the fabulous care I have received'*.

Ken's narrative was littered with statements regarding the *'brilliant'* care that he had received, but he struggled to give examples of where it had been brilliant. When I asked Ken if he had had any negative experiences he

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[7] Several of the participants described some of their health contacts as 'They'. I have borrowed this phrase where appropriate to situate these summaries as close as possible to the participant's own description of their experience.

[8] I had contacted Ken the evening before the interview to confirm that it was still convenient for me to see him. He had informed me he was fine, did not mention his illness over the weekend, and stated he wanted the interview to go ahead as planned.

became busy with his stoma bag as though evading the issue. I got the sense that Ken did not want to consider his situation in these terms:

> BH: You've told me about lots of good experiences with all these people, very positive. Has there been any negative experiences?
>
> Ken: I don't think so, I don't think so, I can't say – just excuse me a little bit (checks stoma bag) I'm getting to the sort of stage... just checking my bag at the moment (talks to tape) I'm ok, I might have to curtail in a moment.

It is possible that Ken's attitude stemmed from his awareness of my dual role as a nurse and researcher. However, I did not feel this was the case, and believe that Ken had spoken frankly about his lived experiences and perceptions of his care

Spousal-carer details: Ken's wife had initially returned the reply slip registering her interest in participating in the research, and my initial meeting was arranged to be convenient for both Ken and his wife. However, only Ken was in the house on my arrival, and he explained that his wife had to change her plans at the last minute. I arranged the interview with Ken, and explained that if she liked I could discuss the research with her at that point. Ken's wife was in the house on the day that I interviewed Ken, but was too busy to talk to me. I left her my contact details but she never got in touch. I was given no indication for her reasons for declining involvement, but I got the impression that she might not share Ken's seemingly positive outlook on the services that had been involved.

Pictor observations: Ken took to the concept of the Pictor technique with ease, rapidly thinking of the people involved, and arranging the arrows predominantly in silence. His main concern about creating the chart seemed to be the risk that he might leave somebody out, and that this could be interpreted as a lack of gratitude for the care and support that he had been

receiving. Ken had lost most of the sensation in his fingers because of his chemotherapy treatment and struggled to write, so I wrote the Pictor arrows under his direction.

5b.2 Paul (67) and Sarah (68)
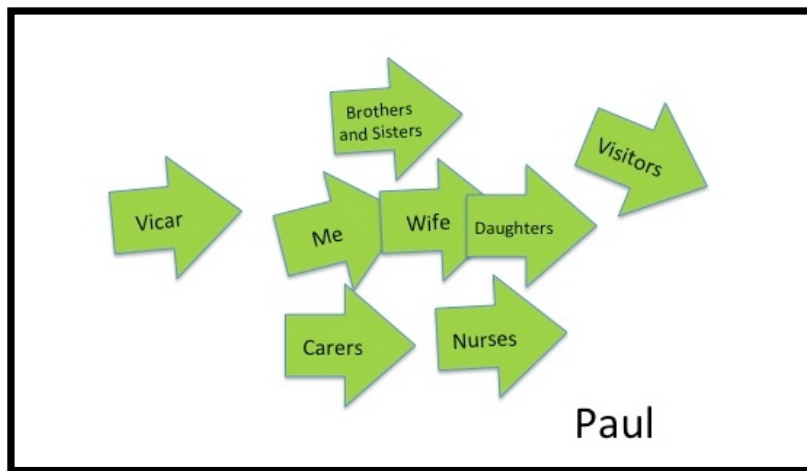
Figure 14. Paul's Pictor chart

Paul: Paul was diagnosed with prostate cancer two and a half years ago. Paul had been '*well'* up until recently when he started being sick, disorientated and couldn't walk properly.   Paul was sent into hospital and he had radiotherapy to his groin, shoulders, chest and ribs. Following this he had severe problems with nausea and vomiting which required a syringe driver for symptom control. He also had a large pressure sore on his sacrum and during this time he had daily DN visits. These problems have since improved and Paul now takes his medication orally and the wound is only dressed twice a week. Paul has been mostly in bed since his discharge from hospital due to a problem with his back.

Paul described his diagnosis as prostate cancer, and said that he also had a disfigurement to his spine.

Interview observations: At my first meeting with Paul and Sarah, I was met at the garden gate by Sarah: *'are you Beth?'* she hurriedly blurted at me. I explained that I was, and she immediately went on *'we are very pleased to take part in your research but we do not discuss that Paul has a terminal illness, we do not discuss that he is not going to get better and he might not know this, we describe it as a chronic condition, is that OK?[9]'* I explained that it was, and that I had no details about Paul's illness apart from what they chose to tell me.

I entered the house with some trepidation – there were obviously some differences in understanding about this family's situation, and I was aware that in my role as researcher I could possibly upset this state of affairs, with the potential to significantly impact on their lives.

Paul was quiet at that initial meeting, and during the interview itself he appeared to find it very hard to consider his situation, becoming tearful when discussing how his impaired physical health meant he could no longer undertake the household maintenance, and how this was now all on Sarah's shoulders. Paul would often look bemused at my questions, answering *'ask Sarah, she knows everything'*.

The interview took place in Paul's bedroom. The room was small and crowded and Paul was lying in a hospital bed, with an overhead hoist. I sat in a large armchair that was next to the bed. There was a hospital style table over the bed, a wheelchair in the corner, several bookcases crammed with books and I could see boxes of dressings and catheter supplies. Paul's bed faced towards the door to the room and faced out onto the main corridor of the house. I asked him if he would like me to shut the door while we were talking, he replied *'no'*, explaining how he always left it open because it was his connection with the *'outside world'*.

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[9] These details were not audio recorded but were documented in my research diary following the meeting.

Pictor Observations: Paul appeared to find it very hard to do the Pictor chart, struggling both with the concept and identifying people who were currently involved with him for anything other than social reasons.
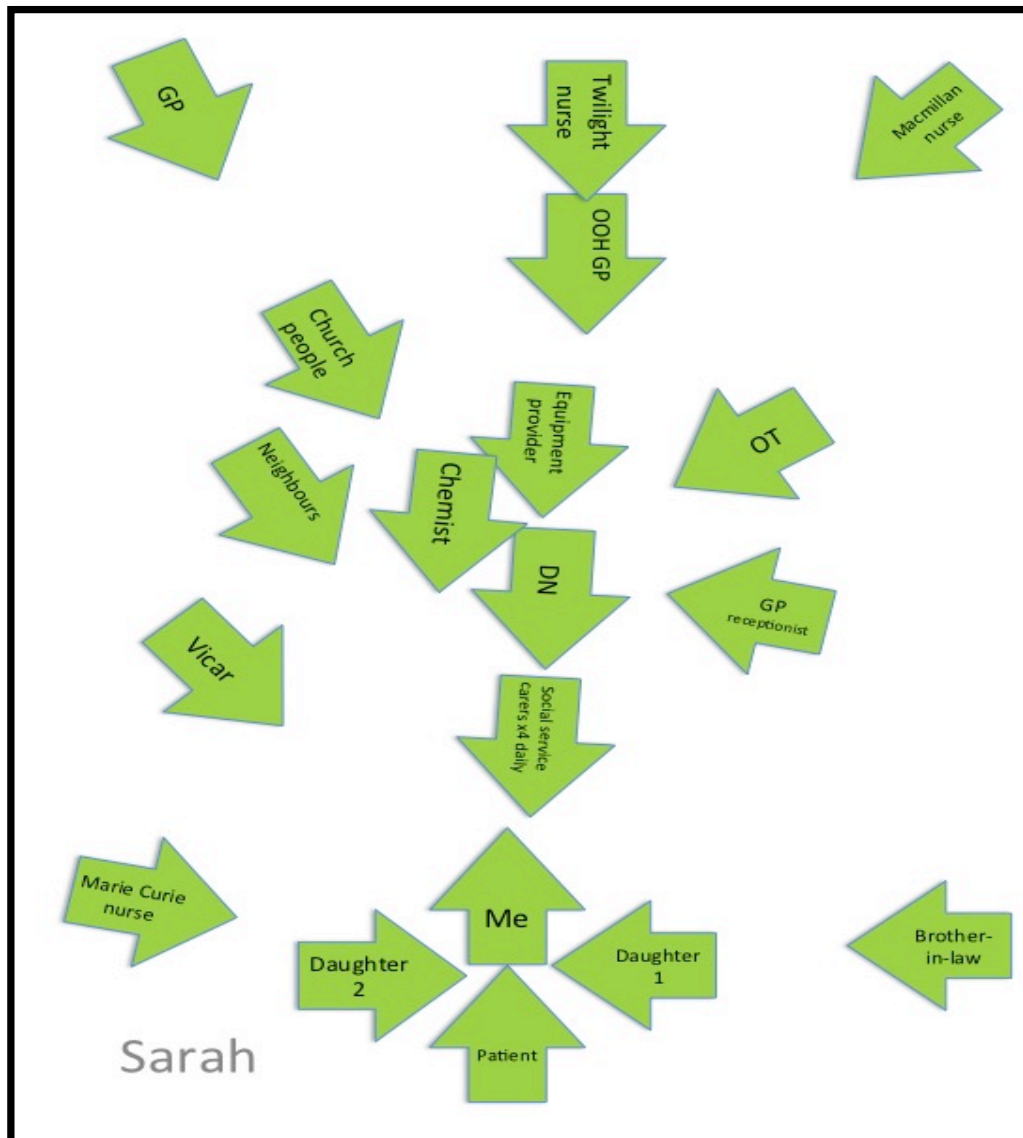

Figure 15. Sarah's Pictor chart

Sarah: Sarah had been married to Paul for 45 years. She described Paul's condition in much more detail than Paul himself. Paul had experienced some back pain four years ago following an injury at work, this back pain could not

be resolved and a year later Paul was diagnosed with prostate cancer. Unfortunately this had already spread to his bones, which Sarah believed was due to the delay in diagnosis. Following this Paul and Sarah had a good couple of years where they were able to live as normal. However, eight months prior to the interview Paul had begun to experience pain, and they returned to the hospital where Sarah was informed that the disease had progressed. Paul had some chemotherapy treatment, but a couple of months later Paul could not pass urine, was unable to walk and started vomiting. He was admitted to hospital and received radiotherapy treatment. Sarah was told that Paul had spinal cord compression. A large case conference took place around Paul's bed where they planned what was to happen. Sarah was very pleased by the number of people involved at this time. They arranged for equipment to be put into the house, and for carers to come so that Paul could return home. Whilst in hospital a Macmillan nurse told Sarah that Paul did not have long to live. It surprised Sarah that this information had been given by a nurse and not a doctor. Sarah had a friend who had a similar condition to Paul, and who also developed spinal cord compression but who has sadly since died. Paul had been home from hospital for four months at the time of the interview, and Sarah believed his longevity was to do with their attitude to his illness, and to not acknowledging that Paul had a terminal disease and thus maintaining hope.

Sarah and Paul had lived in the same village their entire lives, and had strong relationships with the local population, and many people enquired about Paul whenever Sarah was out in the village. Sarah enjoyed this attention, and felt that this demonstrated care and respect from their community. Sarah felt it was important that she maintained an active role in village life, as through this she brought local news and stories of the village back home to Paul, thus continuing to include him as part of village life too.

Sarah and Paul had two daughters who were both in their thirties. One of them was blind and still lived locally.

Sarah described Paul's diagnosis as prostate cancer with spinal cord compression and multiple metastases.

Interview observations: I sat at the dining room table with Sarah for the interview. There were several interruptions throughout the interview, including a door-to-door salesman who she chatted to for about ten minutes.

Pictor observations: The Pictor chart was introduced to Sarah about ten minutes into the interview. The technique was very facilitative in this interview. Sarah quickly grasped the concept, she wrote the names on the arrows and explained to me who the person/ service was and their role, and arranged the chart as she went along. In this way the creation of the chart lasted for most of the interview. Sarah used the spaces and direction of arrows on the chart to show different aspects of her relationships, which she then explained as we carried on with the interview: for example putting the twilight nurses towards the edge of the chart because she didn't use them very much, and putting the GPs and Macmillan nurses towards the edge because she was angry with them and they didn't have much involvement. Sarah described the layout of her chart as *'how I see it at the moment'*.

5b. 3 Michael (63) and Amy (62)
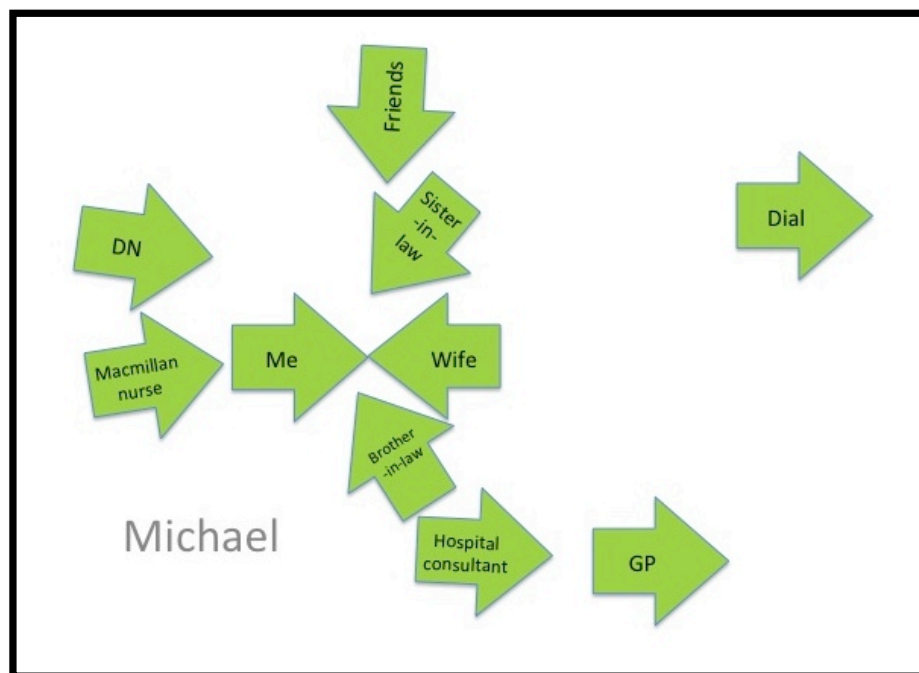
Figure 16. Michael's Pictor chart

Michael: Michael had always been fit, active and independent. He had enjoyed being practical and helping his friends and family with DIY tasks. A year before the interview Michael had developed a chest infection, for which he saw his GP and was given antibiotics. This happened three times in the space of two months before he was sent to the hospital chest clinic for investigations, where they confirmed he had an infection. Michael had become worried though, and did not believe the doctor's diagnosis. On the fourth occasion he saw a new doctor at the hospital who took the situation into his own hands and demanded scans and investigations. This doctor told Michael that he had inoperable cancer in both of his lungs, and he had since had radiotherapy treatment. Michael believed that this treatment went terribly wrong though because they burnt his back, chest and throat which had led him to have ongoing problems, particularly with eating and drinking.

Interview observations: Michael was visibly distressed at several points during the interview, and cried openly whenever he mentioned the cancer. However, he was very keen to participate in the research, *'as long as it did not involve any injections',* stating his motivation as a desire to improve care for other people.

Pictor observations: Michael initially seemed confused by the Pictor exercise. He explained that it was Amy who was good with words and he was better with practical things. After he started to create his chart he seemed to relax and appeared to enjoy the process.
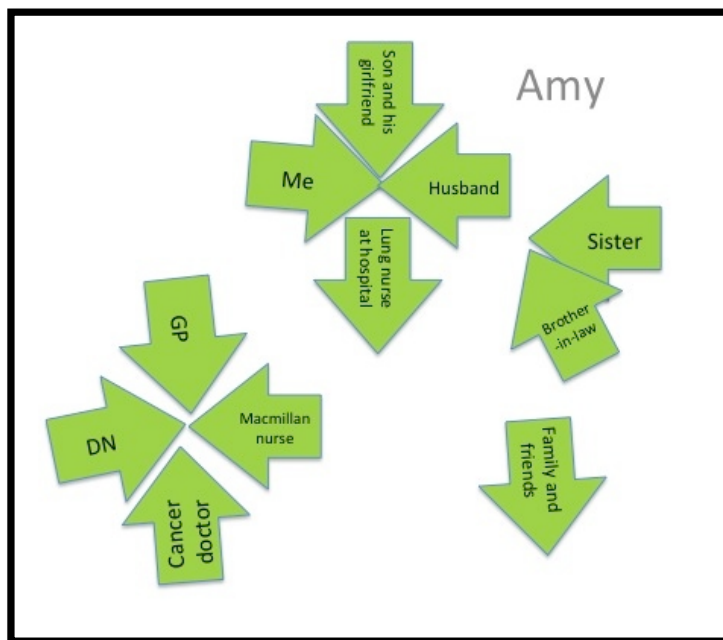
Figure 17. Amy's Pictor chart

Amy: Amy retired from work some years ago due to a back injury. She described how she missed the companionship of work, as she had good friends there, a bit like a family. She was particularly close to one group of women who she still met up with every few weeks.

Michael and Amy had been married for a long time, but Amy found it hard now they were both at home all the time. She enjoyed her own space, but Michael

liked to be in her company all of the time, even when her friends visited. Amy explained that he wouldn't even let her catch a bus alone, and insisted on driving her everywhere. This meant it was extremely hard for Amy to get a 'break', both from Michael, and from the situation.

Michael's diagnosis had been very hard for Amy to accept and understand. She was extremely angry about the delay in diagnosis, and thought the doctors should have done something earlier. However she was aware that nothing could be proved, and that it would not change anything about Michael's situation anyway.

Amy's own health had been suffering, and she had lost a considerable amount of weight. Amy blamed this partly on the anti-depressants her doctor had put her on. Amy subsequently stopped taking the tablets, and told the doctor she would not be taking anything else. One of the nurses advised that she eat lots of bread and jam to help her put the weight on, but nothing seemed to help. This is a major concern for Amy, as she was very aware that Michael's health was going to deteriorate, and that there was much worse to come. She was scared that because she had already reacted this badly to the stress, and felt that she would not be able to cope in the future. She also described that if she could not cope, then both her and Michael's world would disintegrate, as her strength was needed to support them both.

Interview observations: On several occasions during the interview Amy became very upset, particularly around her concerns for the future. Her distress was palpable, and I asked Amy at different points during the interview if she wanted to continue. Amy was adamant that she did and I got the sense that by contributing to the research Amy was taking a positive action in a situation where opportunities for this were extremely limited. At the end of the interview I asked Amy if she would like contact numbers for people she could access to discuss some of her concerns. This was politely refused and she explained to me that she chose not to discuss her fears as this would make them real, and by acknowledging them she would have admitted defeat, and the illness would have beaten them:

Amy:	Yea, I know I am, but, yea I'm scared about what's in front, erm, but I can't change it. I've got to deal with it anyway. And I just, you see, I don't like getting like this (upset). I can't let go, I can't let go. Because if I do. I can't drag myself back again, and I think, *INAUDIBLE*, because I think I, ok I'm upset now…
BH:	And we've been talking about lots of things…
Amy:	and this is just the tip of the ice berg, I think if I spoke to anybody in more detail then the flood gates would go and I'll not, I know me, and it'll take me a long time to get myself back to where I want to be, and I can't afford to let myself get that. You know what I mean? So, I know a friend of mine kept saying, *'you need to talk to someone you need to talk to someone*...' what did she say... I says to Jane, *'I can't'* because its as if I'm admitting defeat. And I'm not defeated yet. We've got some fighting to do. I know what the end result is, don't know when, and won't want to know when. We don't want a prognosis because we don't want that time limit, that there because as it got closer you think, today, is it today...

I left this interview feeling very sad for Amy, and frustrated about the seemingly inadequate support she was receiving through formal channels.

Pictor observations: Amy completed the Pictor chart whilst I waited in a separate room. She seemed a little uncomfortable doing this initially, concerned that she might do it incorrectly. I reassured her that this was not the case, and she completed the chart in about ten minutes. The process of creating the chart highlighted a significant issue for Amy: she had two sons, but was estranged from one of them and had not seen him, or his three children for a number of years. Amy started talking about this son because she felt she could not include him on the chart. Amy also became emotional

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about this subject during the interview, stating that she did not normally discuss her estranged son with anyone.

5b.4 Aggie (57)
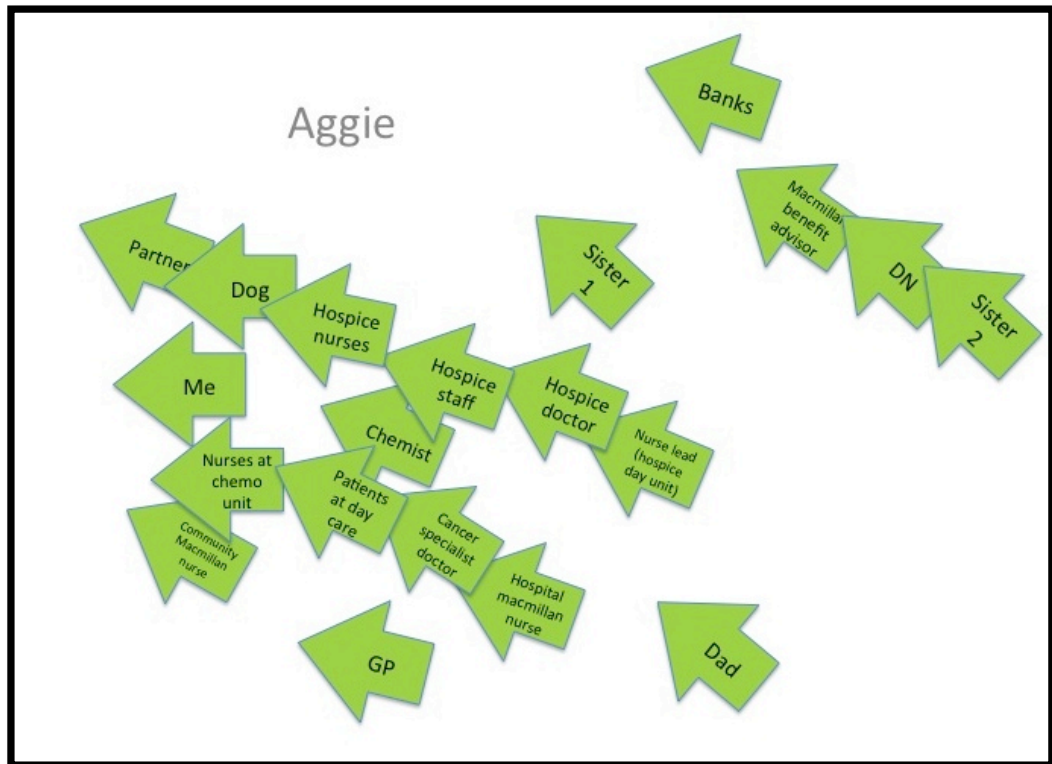
Figure 18. Aggie's Pictor chart

Aggies's son had died suddenly of a heart attack eight months before her breast cancer diagnosis. Aggie described the cancer as taking everything: it not only stole her future, it also stole her time to grieve for her son. After two years of treatment Aggie was told that she was cancer free, and was guaranteed it would be at least 15 years before it came back. However, one year later Aggie developed pain in her back, and after further investigations was told that the cancer had returned.

Aggie had cancer in her spine, liver, lung and leg, and had recent radiotherapy treatment to assist in managing her pain. The pain was a significant problem for Aggie as it affected her mobility, and meant she could not walk her dog. This was very important to her, as the dog had belonged to her son.

Aggie lived alone in a terrace house, in a small ex-coalfields town. Financial issues had been a significant component of Aggie's illness experience. Aggie was very angry at the banks and insurance companies with whom she previously held health insurance policies. These companies had refused to pay her what she felt she was owed, and the financial consequences of this were massive for Aggie.

Carer details: Aggie had a partner who was unable to live with her because this would affect her benefits, and she could not afford to lose them. She did not think he would want to participate in this research.

Interview observations: Aggie's interview took place at her kitchen table. She was extremely friendly and open about her illness, and how she felt about her situation. Aggie seemed to want to share every aspect of her experiences with me, at one point showing me the scars from her mastectomy. She also shared with me an idea she had for a hospice 'cancer girls' calendar, in the style of the famous 'alternative' WI calendar. She showed me some photographs she had taken of herself semi-naked which she planned to show to the lead nurse at the hospice to enthuse her about the idea. Aggie got obvious pleasure from our conversation, and said she enjoyed having the opportunity to talk about her experiences. I followed this up by discussing some attitudes to research:

BH: Yeah. Erm, it's interesting you were saying that you've enjoyed this afternoon, 'cos there's some people that think that we shouldn't do research on people who are poorly and got various conditions...

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Aggie:	Why?
BH:	Because it might upset them or, erm, or they might be too poorly and got better things to do really, erm...
Aggie:	Ooh.
BH:	but...
Aggie:	Miserable sods!

Pictor observations: Aggie needed some prompting to think of different people involved with her. However, once she had put some initial names down onto the arrows she quickly started coming up with others. Aggie created the chart whilst she explained it, and I was sitting next to her throughout the process. Aggie was surprised by the amount of people she identified – which is pertinent as much of her story was about the isolation she felt.

> I did, to look at, when I look at all these people here, I don't rea' I didn't realise that, I didn't realise that, that, that a' all these people are involved in, I' involved in my life. There's a lot in't there. There is a lot.
>
> Aggie

Aggie also commented on how the creation of the chart had made her reflect on the different people in her life, and what they meant to her:

Aggie:	It's, it's made me think, it's taking perspective all the different people that's round me and all the people that's important to me, and all the people that's not important to me, people that, that are there just 'cos they have to be, not that they don't, not that they want to be, if you know what I mean. And it make... that's what it makes me think. People are there 'cos they want to be there, not 'cos they have to.
BH:	It's interesting...

5b.5 Eric (70) and Sue (62)
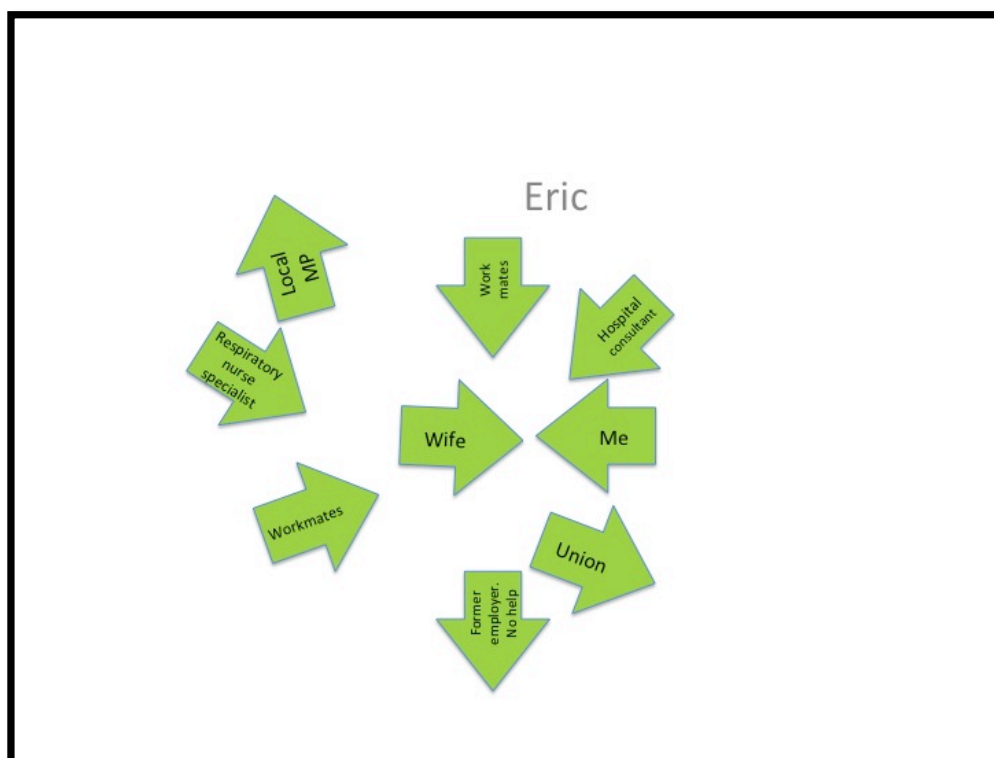
Figure 19. Eric's Pictor chart

Eric: Eric had worked for a power station prior to his diagnosis of asbestosis sixteen years ago. Over the last few years he had embarked on a campaign to raise awareness of the risk of asbestos, and he asked me to watch a recent local TV news bulletin that he had featured in. He also asked me to look at a folder of newspaper cuttings, and letters he had written to his local MP.

Eric had not left the house, except for medical appointments, for the previous three years. He became breathless whilst talking, struggled to use his upper body, and walking to his bathroom left him exhausted.

Interview observations: At my initial meeting with Eric and Sue, Eric did most of the talking. He was a small man who was sat in an upright chair, with a movable table in front of him. Eric had oxygen delivered via a nasal cannula, piped from an oxygen concentrator[10] that was at the back of the room. I was offered a seat on the sofa opposite Eric, but once he started creating the Pictor chart I moved so that I was knelt opposite him so that Eric did not have to turn his head to talk to me. During the interview Eric was eager to direct the conversation, wanting to talk about his former employer and his campaign to raise awareness of asbestosis, and it was a challenge to keep Eric focussed on the research questions.

Towards the end of Eric's interview Sue came and sat at the back of the room. From this point onwards Eric tended to check his answers with Sue, and I felt that he worried that Sue might think he was giving the wrong answer.

Pictor observations: I wrote the Pictor arrows under Eric's direction, as his breathlessness was exacerbated by the use of his arms. He created his chart predominantly in silence and we then discussed the chart, using it as a springboard to other aspects of his experience of illness and service involvement.

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[10] An oxygen concentrator is a device that can deliver oxygen therapy in the home environment.
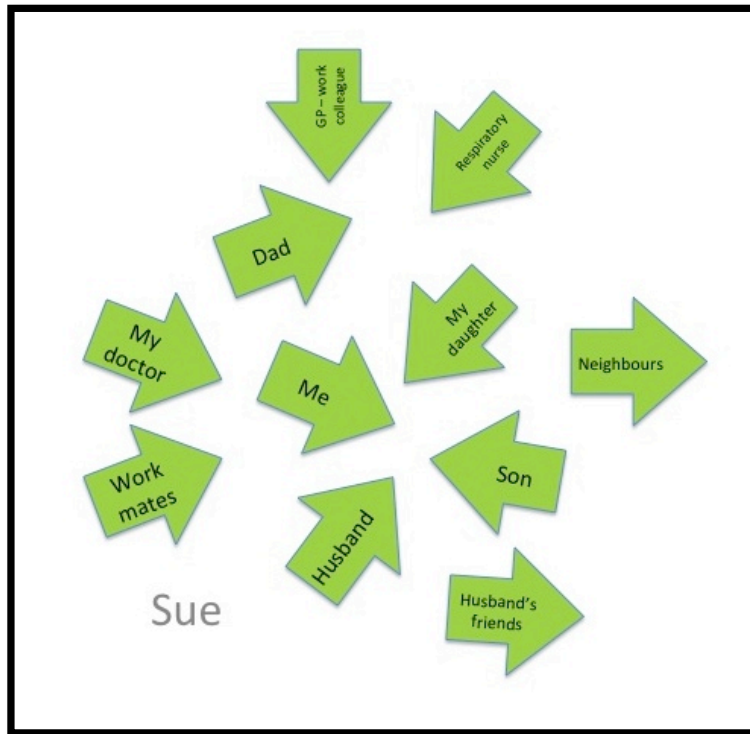
Figure 20. Sue's Pictor chart

Sue: Sue had lived in the same mining community all of her life. She had been married to Eric for around thirty years, and they both had children from previous relationships. Sue worked part-time as a receptionist in a local doctor's surgery, a job, which she enjoyed as it gave her a sense of normality in her life. Despite this, Sue was planning to take a break from work the month after I interviewed her, she felt that she was becoming overloaded with her other responsibilities. Sue described her employer and her colleagues as being amazingly supportive and flexible around her needs.

Eric was diagnosed with asbestosis in his early 50s, and initially they managed to continue normal lives, taking as many holidays as they could, as they were always aware that Eric's health would one day deteriorate. Over the last few years Eric's health had dominated their existence. Sue's lifestyle and daily routine was carefully managed to ensure that Eric still managed to do as much for himself as possible. Increasingly, these activities were restricted as Eric's breathing deteriorated; simple tasks such as getting ready

for bed, which had taken a couple of minutes, were now time consuming activities. Sue helped Eric to wash and dress, and they were waiting for a wheeled commode to be delivered so that Sue could push Eric into the bathroom. Sue also looked after her 88-year-old father who lived near-by. He needed assistance with shopping, general household maintenance and with transport to any appointments.

Sue had been unwell herself, and has had breast cancer and a mastectomy. She has since been given the *'all clear'*. The Macmillan nurse had advised Sue that it was not good for her to get stressed. Sue felt that this advice was unachievable in her current situation and she worried about what might happen with her own health.

Interview observations: The interview took place in Sue's kitchen. She spoke very freely about her experiences and I felt that we both enjoyed the conversation.

Pictor observations: I stayed in the room whilst Sue created her Pictor chart. She undertook this task mainly in silence and we then discussed her chart for the rest of the interview.

5b.6 Elsie (80)
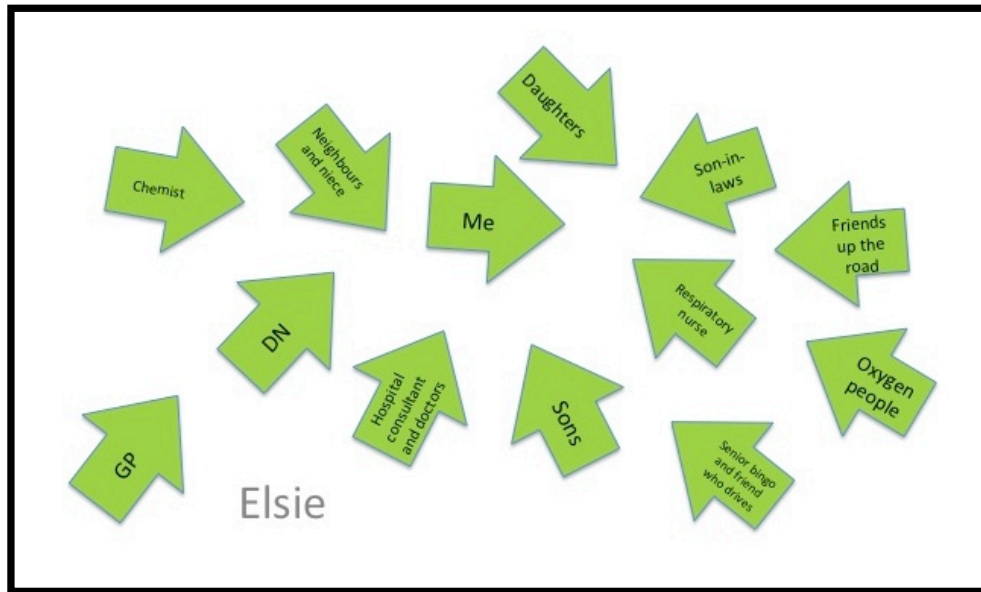
Figure 21. Elsie's Pictor chart

Elsie lived alone in a bungalow on a large housing estate surrounded by similar properties. She had four children, and several grandchildren who are all very important to her. Twenty-two years ago Elsie had started to notice some chest problems. The doctors could not agree what was wrong with her, referring to her as the *'special lady'*, however ultimately they decided that she had COPD. Elsie had also recently been diagnosed with diabetes.

In the summer Elsie described how she was able to get out of the house on a scooter taking portable oxygen with her, but during the winter she was dependent on others for her shopping, and her daughters to take her to the supermarket when needed.

Interview observations: During the interview, Elsie remained sitting in a large armchair with oxygen tubing surrounding her. Two oxygen concentrators were in the corner of her room and Elsie informed me that she had to have two because she needed more oxygen than one machine could supply her. I

initially sat on a sofa that was at right angles to Elsie, but once we had commenced the Pictor exercise (which was done on a padded footstool that was in front of Elsie) I moved and knelt on the floor in front of this. By doing this I was facing Elsie, and also able to see the chart, so that I could make reference to this without moving from my seat. At the end of the interview Elsie stated that she had enjoyed her afternoon, and having someone to talk to about her experiences.

Carer details: Elsie prided herself on her independence; she was very clear that she did not identify anyone as a 'carer', as she looked after herself.

Pictor observations: Elsie created her Pictor chart extremely quickly. I felt that Elsie really just wanted to talk; she struggled to listen to my Pictor directions, as well as to some of my questions. There did not seem to be much thought that went into the arrangement of the arrows on the chart, although the chart still provided a basis for our discussion.

5b.7 Laura (64) and Kevin (65)
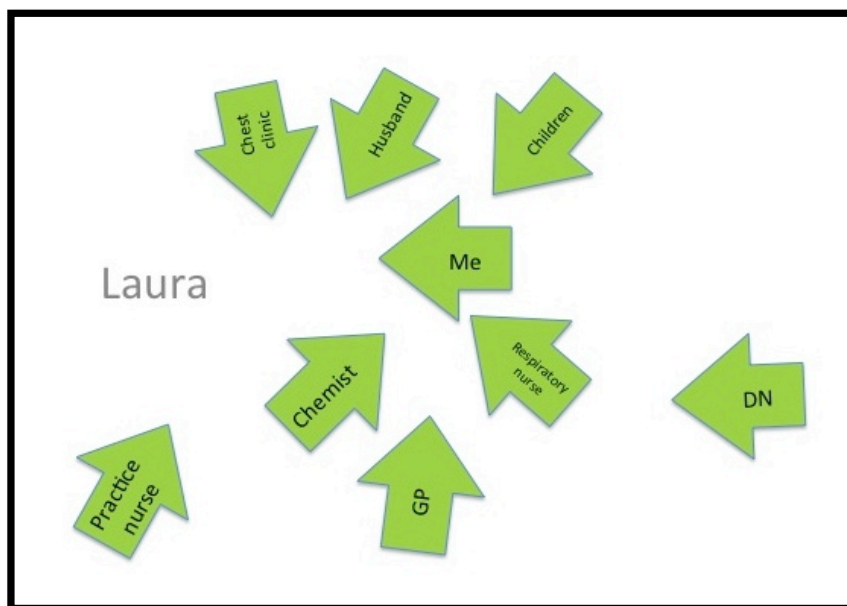
Figure 22. Laura's Pictor chart

Laura: Laura had 'spots' on her lungs, which cause breathing problems and the doctor had told her she had COPD. She was also a diabetic, and five years ago had her leg amputated because of a clot, and had to stay in hospital for nearly a year. Laura used oxygen most of the day, and struggled to walk short distances. She rarely went out because when she did Kevin, her husband, had to push her in the wheelchair, and she worried about him doing this. Her daughters bought her clothes, or she ordered them through catalogues. Kevin did the food shopping and other errands.

Interview observations: Laura was in her wheelchair when she answered the door, and there was a false leg propped against the wall. Her oxygen bottle was at the side of the room but she did not use it during the interview. We sat at the dining room table for the interview.

Pictor observations: Laura took to the idea of the Pictor technique quickly. She created her chart in silence and we then used the chart as the basis of discussing her experiences.
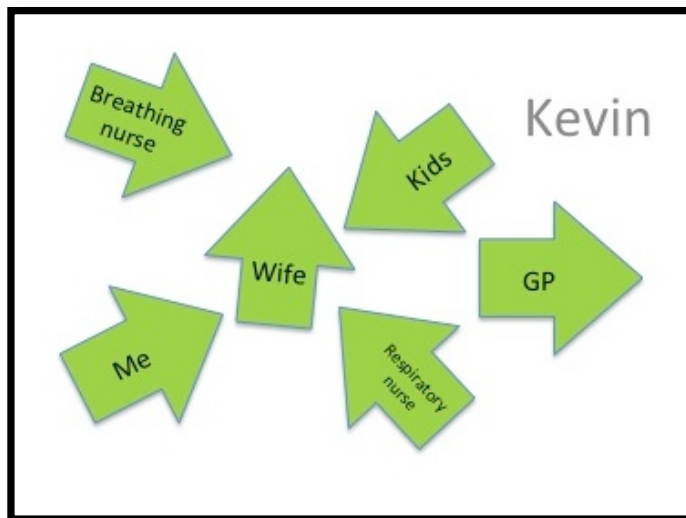
Figure 23. Kevin's Pictor chart

Kevin: Kevin and Laura have three children, the last of whom had recently left home. When Laura first became ill and was admitted to hospital, Kevin also became ill. He was so upset by the situation he stopped looking after himself, and ended up in a diabetic coma. Both he and Laura were in the Intensive care unit together. Kevin can remember very little from this time. He had to take a year off work because of his health, and was then made redundant twelve months after his return.

Kevin did everything he could to help Laura. He did all the shopping and errands, and helped her with things like washing her hair.

Interview observations: The interview with Kevin was the shortest that I undertook, and he appeared very uncomfortable discussing his experiences or emotionally engaging with his situation. Following this interview I wrote in my research diary: *'very un-talkative – like pulling teeth!'* my personal frustrations at this challenging interview evident.

Pictor observations: Kevin struggled with the idea of the Pictor chart and identifying anybody involved, especially people to meet his needs, a concept that appeared to bemuse him. Kevin did create a chart, and despite my initial frustrations at its lack of detail, demonstrates his lack of connection with health services relating to his and Laura's situation.

5b.8 George (61)
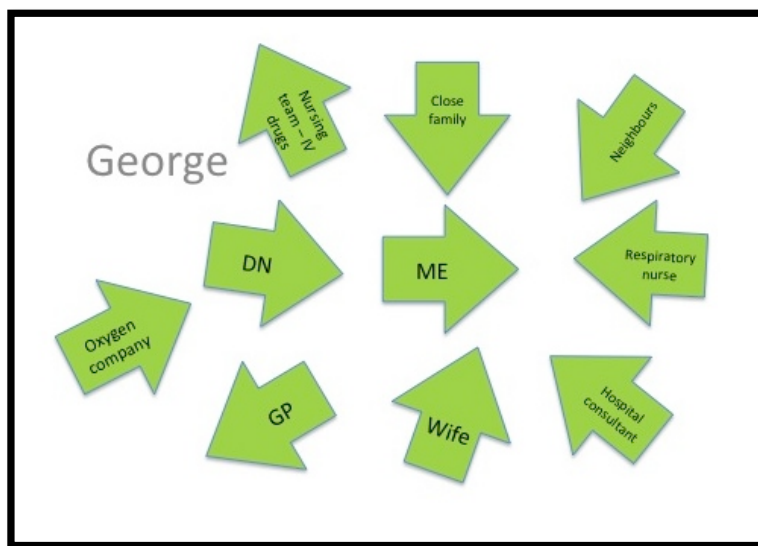
Figure 24. George's Pictor chart

George, an ex-miner, lived with his wife, and had family who lived close by. George described his health problems as rheumatoid arthritis and COPD.

George's life was very restricted because of his breathing. He was able to get to the back door, but struggled to get to his workshop, which was at the end of the garden. George did not see many people except his family, and he did not go out. George's condition was extremely variable, and he had been admitted to hospital numerous times in the twelve months prior to the

interview because of exacerbations of his condition. When at home, George monitored his own condition, checking the colour of his sputum and his temperature. If he started to notice signs of infection he did not like to tell anybody. He knew it would not go away on its own, and that he would be admitted to hospital, but he tried to postpone this for as long as he could.

Interview observations: George's interview took place in his living room and he sat in a large chair by the window. His oxygen tubing ran the length of the room from a concentrator that was elsewhere. George was very welcoming when I arrived, chatty, and jokey, but he quickly became extremely breathless and started coughing. It took about fifteen minutes for George to regain his breath enough for him to be able to restart talking, and his embarrassment regarding this was palpable. There were several interruptions during this interview. Just after we had started the Pictor technique, George's respiratory nurse specialist arrived. I observed her knocking on the front door and walking straight into his living room. George explained that he had expected her earlier, and she apologised for being late. I offered to leave the room whilst they were talking, but the nurse said '*I don't mind as long as George doesn't*' – he agreed it was fine and insisted I stayed. I was extremely uncomfortable with this, feeling as though he had not really been given a choice about my presence in his clinical consultation. George's daughter arrived about three quarters of the way through the interview. She sat in a chair at the other end of the room, and frustratingly started answering some of the questions for George, or they answered between them. This interview particularly highlights some of the challenges of undertaking research interviews in participant's own homes.

Pictor observations: I assisted George to write the arrows, as writing caused him to become breathless. Having the creation of the Pictor chart interrupted seemed to affect George's focus on the task. Initially he was concentrating hard on this, but following the respiratory nurse visit he seemed to find it difficult to regain this concentration.

Spousal-carer details: George did not want his wife to be asked to participate in the research. She worked during the day, and he described how her evenings were precious time off, and he did not want this to be interrupted.

5b.9 Roger (65) and Tricia (64)
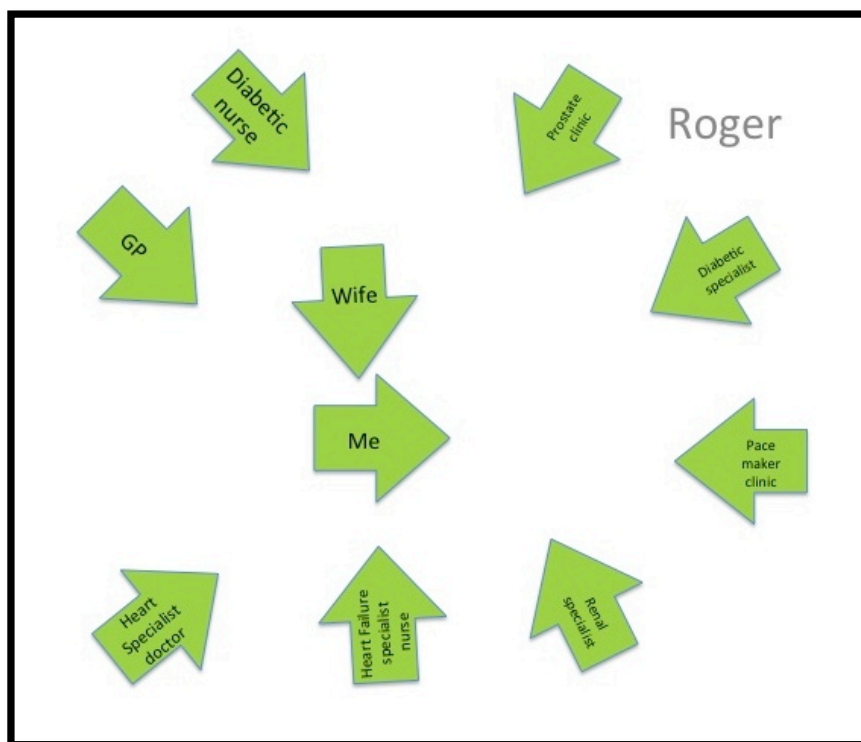
Figure 25. Roger's Pictor chart

Roger: Roger had a stressful job working in a children's home. When he was 59, he suddenly developed breathing problems. He went to his GP and saw a locum doctor who informed him that he was suffering with anxiety. A week later, still feeling ill, he returned to his GP surgery and saw one of the regular doctors who immediately did an investigation and informed him he had suffered a heart attack. Roger has not worked since.

Roger was not suitable for a heart transplant but had a pacemaker fitted which he asked me to feel in his chest. He commented on how obtrusive he

found it because it caught on his clothes, and he described how he was always aware of its presence. The heart problems had progressed slowly, and his health had gradually deteriorated. Roger was told he had heart failure after a second operation. He had since developed kidney and prostate problems in addition to his long-standing diabetes. Roger knew that there was a chance that he may not wake up one day, or may just drop dead at any point. He did not plan for a long-term future, and would not look beyond the end of a year because he did not want to *'push his luck'*.

Roger described having *'good days and bad days'*, and he got breathless on minimal exertion. Tricia, his wife, had to help him get washed and dressed, as well as doing most of the household maintenance. This is a concern for Roger as she also has her own health problems.

Interview observations: Roger's interview went smoothly. He talked freely about his experiences and required little prompting to share these.

Pictor observations: Pictor worked well within Roger's interview and he quickly grasped the concept of the technique.
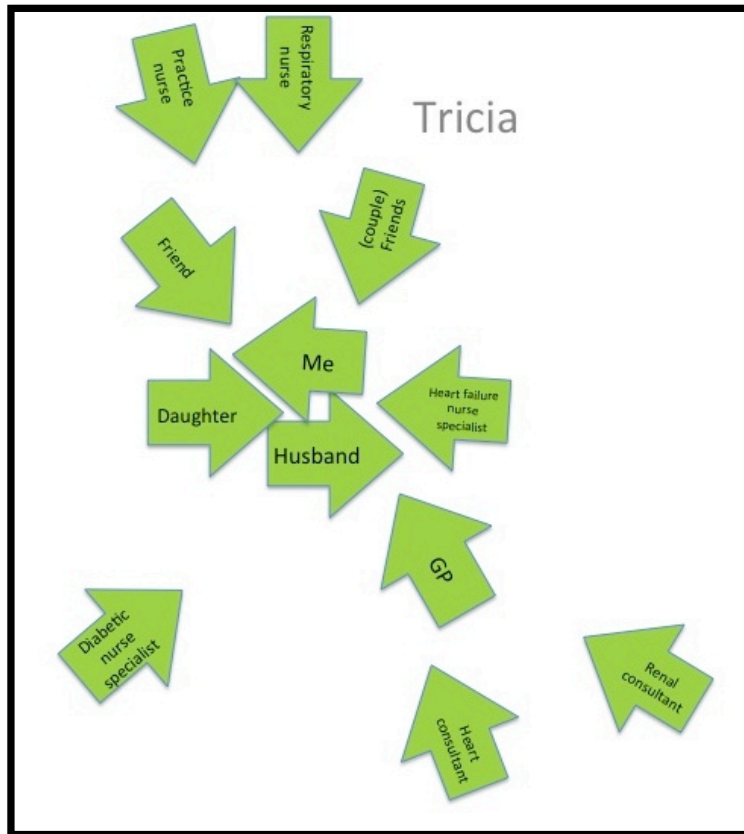
Figure 26. Tricia's Pictor chart

Tricia: Tricia had been in a caring role for many years. Her mother had COPD, and Tricia was her main carer for the last ten years of her life. Two years after her mother's death, her father developed dementia. Tricia managed to look after him at home for four years, but eventually his behaviour became too complex and he moved permanently into residential care. Tricia used to visit him every day, but since Roger's health had deteriorated, she only managed to go a couple of times a week.

Tricia has COPD herself. Tricia told me how she did not like seeing doctors or hospitals about her own health, as all they did was comment about her weight, and how her symptoms would improve if she was thinner.

Tricia described her close relationship with Roger, explaining that; *'I think we've grown closer together actually, we always have been close but I think*

we are closer now, probably, well because we're near the end (of life) *and we don't know do we?'* They had two adopted children, and two grandchildren, one of whom was severely disabled.

Interview observations: Tricia was very chatty throughout her interview, appearing to enjoy the opportunity to discuss how she felt about Roger's illness and her own situation. About half way through the interview, Roger came into the room where I was interviewing Tricia, explaining he was just going to be on the sofa and have a nap. He did not interrupt our conversation, and I felt that Tricia spoke openly despite his presence.

Pictor observations: Tricia seemed to find the process of creating, and discussing the Pictor chart particularly facilitative of sharing her experiences; using the chart to show various factors about her relationships, including the focus of her life upon Roger's health, and the frustrations she felt towards her own health providers. At the end of Tricia's interview, Roger walked over and they spontaneously shared their charts with each other, discussing the people that were involved and who had been placed where.

5b.10 Norman (76) and Tracey (68)
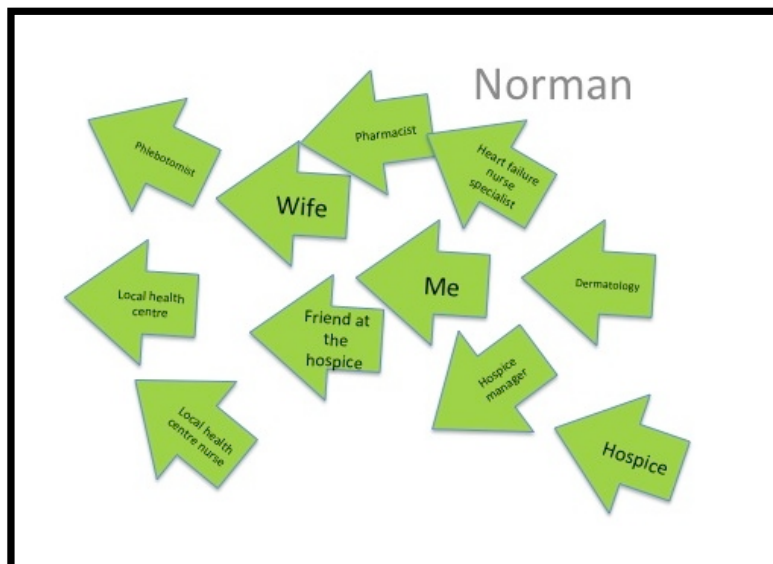
Figure 27. Norman's Pictor chart

N*orman:* Norman was working as an engineer when he found out that he had a '*dickey heart'* and he subsequently retired. He had since had four operations on his heart, including a triple bypass, and had a pacemaker fitted. Norman had lots of *'sores'* on his legs that kept breaking down. Initially, these were dressed by the DNs, but Tracey had taken over the dressing of these wounds. Norman became breathless when he walked short distances. He went to a day centre once a week, but apart from that liked to sit in his chair and do jigsaws.

Interview observations: Norman actively participated in the interview but sometimes got muddled with details. On a couple of occasions Tracey (who was pottering in the garden and kitchen next to the room we were in) would shout out the answer to one of my questions, seemingly frustrated that Norman was getting the answers to my questions wrong.

Pictor observations: Norman completed a Pictor chart. This technique was very useful in this interview. Norman did become muddled at times, and having the arrows written meant I could draw Norman back to the chart when he got confused. Norman also mentioned several other services that he did not put on his chart.
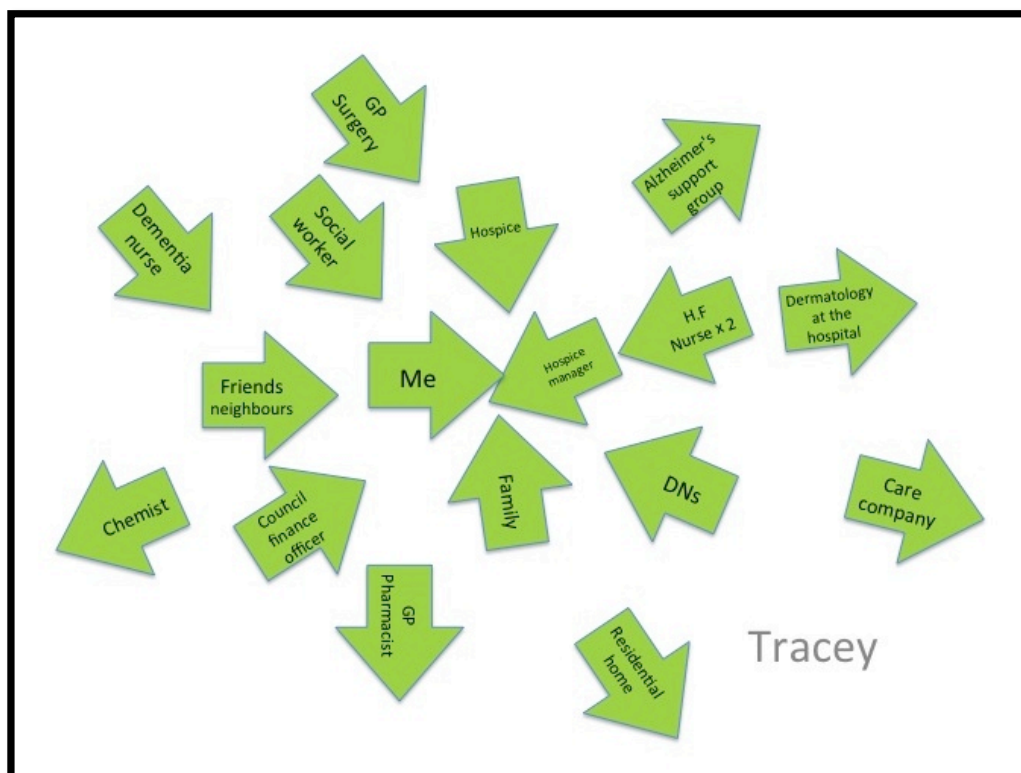
Figure 28. Tracey's Pictor chart

Tracey: Tracey placed great emphasis on getting the details of her own, and Norman's experience 'correct'. She had listened in on much of Norman's interview, and apologised profusely about Norman getting so many details wrong. Tracey went on to discuss Norman's health: They were told in 2007 that Norman did not have long to live – his heart and kidneys were failing and he was suffering with severe oedema. It was at this point that DNs and the heart failure nurse specialist became involved. At this time Tracey had to give full personal care to Norman. Norman was then admitted to the hospice for symptom management and they all anticipated that he would die. During his

time in the hospice Norman's medications were altered and one of his tablets was discontinued. From this point onwards Norman's health began to improve, and Tracey was informed that one of the medications that Norman was taking could have been poisoning him.

Since this time, and until very recently, Norman had been attending hospice day care on a weekly basis. The day care nurse at the hospice noticed that Norman was having *'absent episodes'*. This was investigated by the hospital who diagnosed early stage Alzheimer's disease. The hospital had decided not to do any further investigations or treatments regarding this, as Norman's heart was so enlarged that they told Tracey he would die before the Alzheimer's would go *'full term'*.

Tracey had noticed Norman becoming quieter, and he did not engage with her as much, which she attributed to the dementia. She no longer allowed him to answer the telephone, because he said the wrong thing to people, and she described getting very frustrated when he moved things around the house because she couldn't then find them. She gave him colouring to do because he seemed to enjoy this.

Tracey did not discuss her own background in any detail. They have two daughters and they had a son who was killed in a car crash when he was a teenager. Tracey had heart problems herself, and also had a pacemaker fitted.

Tracey was only providing minimal physical care to Norman at the time of the interview, and this was only when he had an *'accident'* (continence related). Otherwise, Norman managed independently although everything took him a very long time.

Pictor observations: Tracy initially did not think she would be able to identify many people involved to put onto her Pictor chart:

> BH: You may end up with loads (of arrows), but that's fine...

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Tracey: I shouldn't think so, we don't see many people, I'll fetch
            something to for it to rest on....

However, once she had completed her chart, Tracey was surprised by how many people she had identified.   The process of creating the chart had encouraged her to move beyond her initial perspective, and enabled her to consider in more depth the range of people involved, as well as facilitating her to reflect on her relationships with these people.

I can't think of anybody else, I didn't realise I got so much contact!

Tracey

I knew Norman and Tracey prior to their involvement in this research as Norman had been under the care of the DN team I managed. I gave careful consideration about the impact of my prior knowledge of them and their situation, both during the interview and during analysis, to minimise the impact that my prior understanding could have on influencing the analysis.

5b.11 Annie (60) and Edward (63)
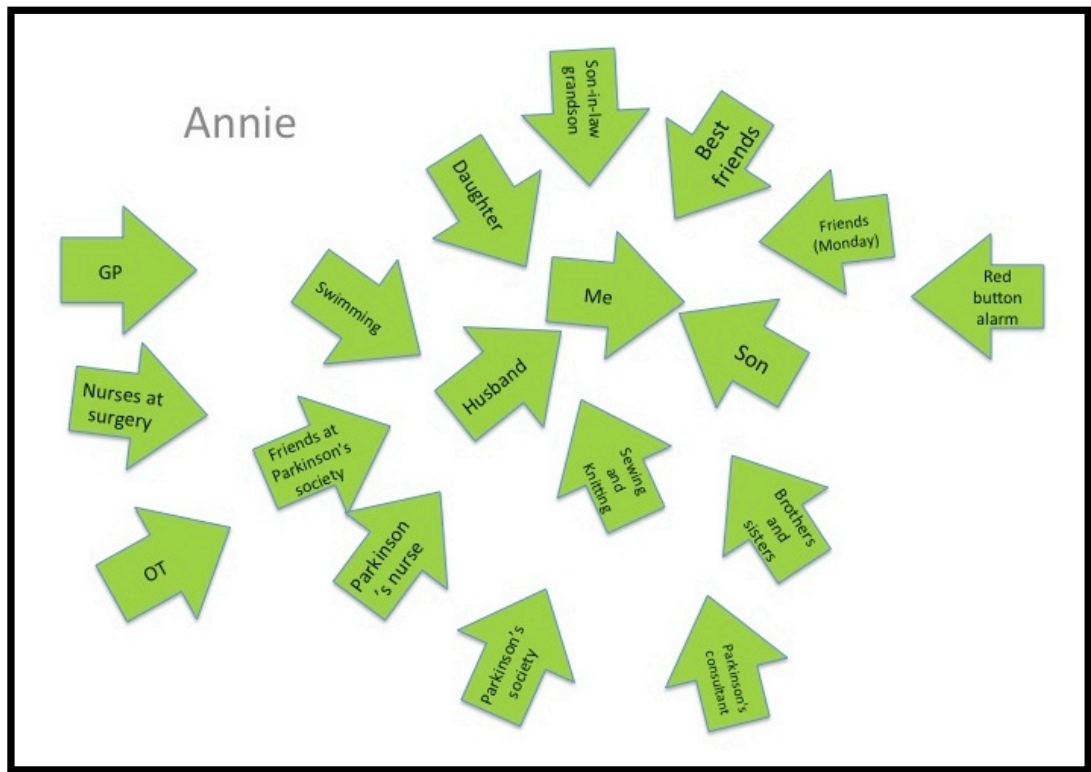
Figure 29. Annie's Pictor chart

Annie: 25 years ago, Annie was on holiday and noticed that she couldn't keep her fingers still to hold the tapestry that she was working on. Annie was in her late thirties with two teenage children. Two years later Annie was diagnosed with Parkinson's disease.

Annie likes to give a positive impression of her outlook on life. At our initial meeting she explained to me that: *'as long as I can put one foot in-front of the other I am OK'.*

Annie had a close group of friends, and had recently started learning to swim so that she could go to the pool with her grandson. Both Annie and her husband Edward were previously involved with the local Parkinson's support

group, but this had closed due to a local dispute. However, they continued to organise events and meetings with their friends from this group.

Interview observations: During the interview Annie was sitting in an upright chair with a table in front of her. It was impossible for Annie to stay still, her whole upper body violently moving for the entirety of the time we were talking. At our initial meeting, Annie explained that the dyskinesia[11] was due to the medications, without which she would be locked solid and completely unable to move; a situation that had occurred eighteen months previously when her medications had been altered and she had to have an extended spell in hospital.

Annie and Edward had participated in several research studies before. Edward had been involved with a questionnaire study about carers, and Annie had been involved with at least ten studies – mainly drug trials. They were both committed to research and improving the care and treatment of people affected by Parkinson's disease.

Pictor observations: Annie asked me to write the Pictor arrows for her as her dyskinesia made writing difficult. She arranged these for herself.

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[11] Dyskinesia is a movement disorder characterised by impairment of voluntary movement (Weller, 1999), which includes uncontrolled movements that are sometimes seen in Parkinson's disease after long-term treatment with Levadopa (Parkinson's UK, 2010).
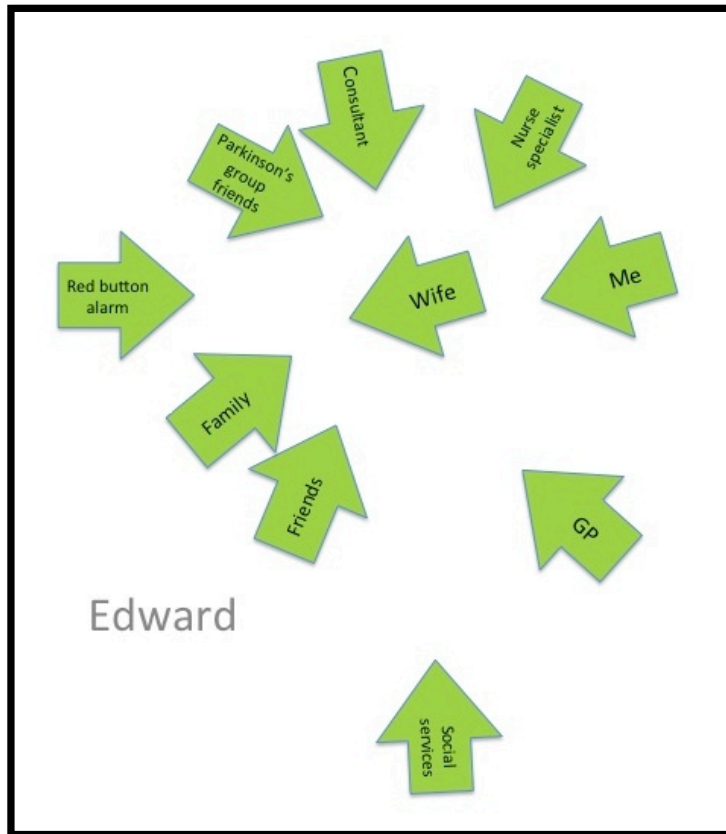
Figure 30. Edward's Pictor chart

Edward: Edward gave up his job as a welder fitter 13 years ago to look after Annie. This was a hard decision to make as Edward's work had consumed his life. At first it was exceedingly hard adjusting to this transition. Edward and Annie had not previously spent long periods of time with each other and found that they were tripping over each other. Just under a year after leaving his job, Edward was admitted to hospital with exceptionally high blood pressure, which caused him to go blind for three months, and he was diagnosed with diabetes. During this time Annie had to look after Edward and the roles were reversed. Edward described how this meant they now had a more even footing.

Interview observations: Edward seemed to enjoy the interview and appeared to engage openly in the conversation.

Pictor observations: Edward was unable to reflect on his own relationships with the various services involved and created the Pictor chart showing how he thought of these services and people in relation to Annie. This however very much reflected his perception of his role being to maximise Annie's independence, supporting her to get the most out of her life.

> Yeah, but I don't know if I can do it because, my world revolves around her, so I would put her int' middle... every time.
>
> Edward

5b.12 Lucy (68) and Charlie (68)
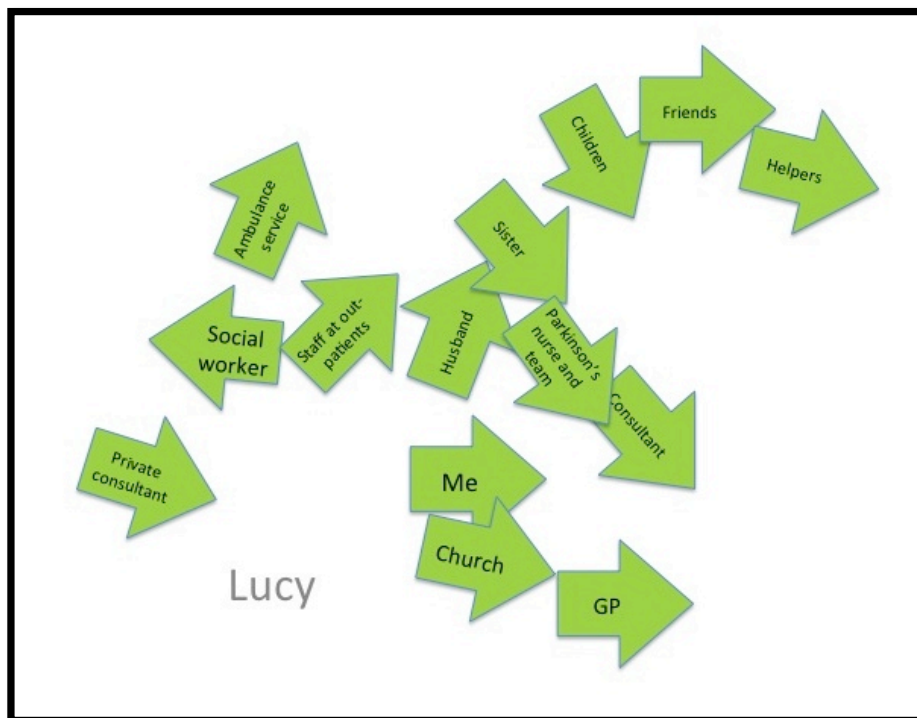
Figure 31. Lucy's Pictor chart

Lucy: Lucy and her husband Charlie were living in a small rural community, and despite having been there for 35 years, Lucy described how they were *'newcomers'* to this village where some families had lived for generations. Despite this, Lucy felt at home here, and over the years had been very

involved with the local church, particularly with the Sunday school. They had two children, neither of whom lived locally, and several grandchildren.

Other people noticed Lucy's symptoms before she did. A cousin was concerned that Lucy appeared *'out-of-sorts'*, and once when she was out shopping, a stranger offered her a chair and asked if she was all right. This made Lucy start to question herself about whether she was unwell. It was while on holiday that Charlie pointed out to Lucy that she was walking slower than usual, and on their return home she went to her GP. It was going to take several months for her to be able to see a specialist so they paid to see a private consultant. After a set of seemingly very simple tests the consultant diagnosed Parkinson's disease.

That was five years ago, and Lucy discussed how her health changed quite quickly after this. She described *'good days and bad days'*, and was determined to continue as normal. At my initial meeting Lucy was struggling to walk, and visibly experienced a lot of uncontrolled movement all over her body. Charlie also informed me that she had been hallucinating, and had recently had some falls that required her to be admitted to hospital.

Interview observations: When I interviewed Lucy she offered me a coffee, which I accepted. I observed how Lucy was struggling. She could not get the coffee granules in the cup, whilst pouring the kettle she spilt boiling water over the work surfaces, and then whilst carrying the coffee she spilt it on the floor, narrowly missing her legs. I offered to help make the coffee, but this was politely refused, and I found it extremely hard to watch Lucy struggle. These observations gave me a small insight into the frustrations that Charlie described, as he watched his wife struggle to maintain a '*normal'* existence.

Pictor observations: I wrote the arrows for Lucy because she struggled to hold a pen. She arranged them herself, and appeared to enjoy the creative aspect of the Pictor technique.
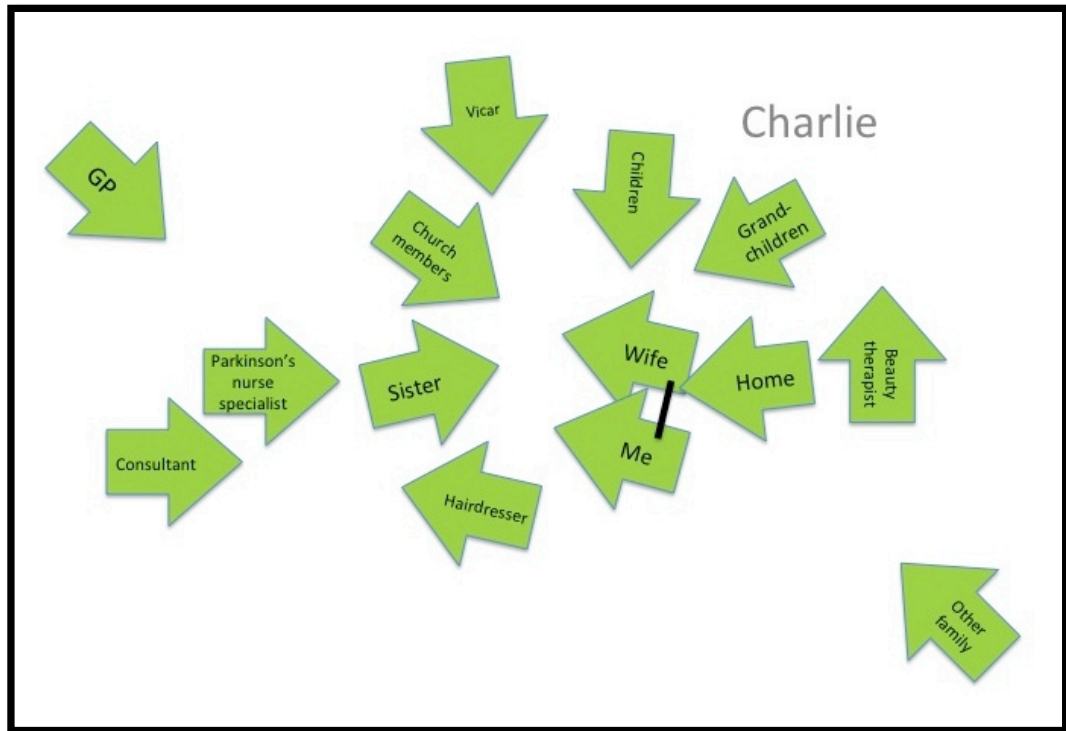
Figure 32. Charlie's Pictor chart

Charlie: Charlie retired nine years ago; he had lots of plans for his retirement and mourns the loss of these dreams. Charlie used to enjoy golf but had given this up, as he did not like to be away from Lucy for long as she was becoming increasingly unsteady on her feet. They used to enjoy going out with friends and family for meals and social evenings, but this had also stopped, as Lucy was messy when she ate and this embarrassed Charlie. Lucy could no longer drive, and was unable to walk anywhere on her own. She had also lost her confidence and Charlie described how he tried to support her with anything that she needed and *'is at her beck and call'*. Charlie got very frustrated with Lucy. He did not mean to, and he tried not to interfere but found this very hard. If he witnessed a potential accident he wanted to stop this before it happened. However, he also acknowledged that he sometimes intervened too early, which annoyed Lucy.

Charlie had very little help. Friends and neighbours offered but this was refused. Charlie did not think it was good for Lucy to see them accepting help, as this might make her feel worse than she did already.

Interview observations: I was slightly intimidated by Charlie at the beginning of his interview. He appeared to be a very intelligent man with strong opinions and I was unsure if he would be prepared to discuss his experiences regarding his wife's illness. However, as the interview progressed I feel that I developed a good rapport with Charlie, who relaxed into the conversation.

Pictor observations: Charlie was initially sceptical about the Pictor chart*:*

> I'm not sure how helpful I shall find it... but we'll, we'll, we'll see.
>
> Charlie

However he quickly became engaged with the task, and produced a detailed chart. Charlie used a pen to mark a line between him and Lucy. This was to indicate their *'joint relationship'* and how they were *'hand in hand'* in this situation.

5b.13 Chapter summary

In phenomenological research it is important to consider the setting in which a phenomenon occurs. These participant summaries demonstrate the wide-ranging physical and social circumstances that form the background context to the participant's experiences of multiple service involvement. Despite this breadth, the sample does not represent anyone of an ethnically diverse background, and is dominated by people over the age of 60. I will discuss the implications of this in chapter nine, exploring how this affects the transferability of the findings, and the opportunities that this could present for further research with these populations.

Chapter 6: Patient experiences

The phenomenological analysis of the patient transcripts revealed that the patient experience of multiple service involvement was extremely complex and varied; taking on different meanings depending on the individual's perception of illness, diagnosis, circumstance and their embodied awareness. Indeed, even on an individual basis people described how the experience of having many services involved was continually changing over the course of their illness.

6.1 Presentation of the findings

The following sections will present the findings of the discrete analysis of the patient related data. These sections are structured based on the template that was created to facilitate the analysis, which is shown in Table 5. I will commence each of the sections with a summary of the theme, before moving on to explore that theme in more detail, drawing directly on participant narratives to illuminate the findings. At the end of the chapter I will discuss this experience utilising literature that further helps to illuminate the phenomenon.

Table 5. Template for patient experiences

'Patient' analysis		
Theme	**Texts the theme was evident within:**	**Theme illuminated with examples from:**
1. Recognising illness: recognising services	All	Paul, Aggie, Annie, Michael and Norman
1.1 They do things to me: we do things together	George, Michael, Eric, Paul, Laura, Ken and Elsie	George, Eric, Michael Laura, Ken and Elsie
1.2 Helping me face my illness: the comforting presence of services 1.2.1 Previous invisibility of services	Ken, Lucy, Aggie, Elsie, George, Roger, Lucy, Annie and Norman	Ken, Lucy
1.3 Services reducing the isolation of illness 1.3.1 Being different 1.3.2 Being understood 1.3.3 Acceptance of death and dying	Aggie, Elsie, George, Michael, Eric, Laura, Ken, Lucy, Norman and Roger	Aggie, George, Ken, Norman and Roger

T1. Recognising illness: recognising services

Theme summary: The meaning and experience of illness has implications for an individual's awareness of services, and how they are subsequently utilised. Where illness is a very significant part of an individual's lifeworld, forming a substantial background to their experience, there is a strong connection to the services involved with them. For example, Ken, Aggie and Lucy all experienced their illness very keenly within their daily functioning, it was a dominant part of their existence at this time and health services were important in living with, and managing their situation. Where illness is less dominant within daily experience, the connection with services is less obvious. This might occur when illness is unacknowledged or where wellness takes precedence over illness. For example, Annie's life is focussed towards her

health and the things that she can achieve, rather than the implications of her disease, and Paul, who does not publicly acknowledge the implications of his disease. Furthermore, awareness of services may change throughout the illness trajectory. Michael describes how their presence around the time of his diagnosis was quite overwhelming, but Norman, who has lived with illness for many years, is fairly ambivalent about service involvement.

This is illustrated in Figure 33, which highlights the relationship between individual's perceptions of their health problems in relation to their perception of service involvement. For example, where health loss and illness issues were very dominant within the individual's life, there was greater dependency on, and identification of services.

Perceived service involvement when health loss and illness is dominant in daily experience

Perceived service involvement when health is dominant in daily experience

Individual's experience as a whole

Individual's experience - services

Individual's experience – illness
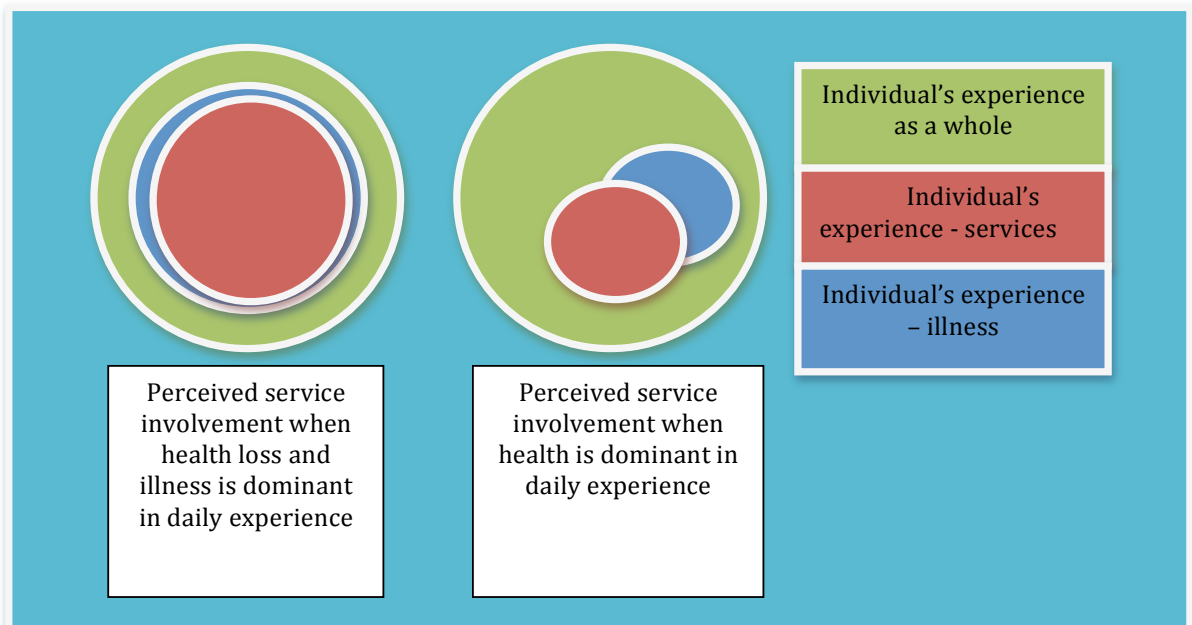
Figure 33. Perceived levels of service involvement in relation to perception of illness.

Aggie provides a good example of this theme, she was keenly aware of her illness and how it impacted upon her life, and she depended greatly upon the services involved in her care. Aggie spoke vividly about the people/services who had helped her, and how they had impacted on her ability to cope with

her cancer. The experience of illness formed a large portion of the background to her daily existence, and services (both those that helped and those that did not) were a significant component of her life.

Conversely, Paul was oblivious to service involvement and found it extremely hard to identify people involved in his situation beyond very generically discussing 'nurses' and 'carers'. This was reflected in his Pictor chart, on which he was only able to identify a few people. He talked briefly about the people involved at the hospital, but could not name specific teams or people who saw him at home - although he discussed his vicar who visited regularly and made him laugh, and his family who visited regularly. I had been informed by Paul's wife, Sarah, that Paul did not know his diagnosis or prognosis, and that this was not something they discussed amongst themselves. Despite this, I got the sense from Paul that he was very aware of his situation, but that he acknowledged that it was a taboo subject and should not be discussed. Paul seemed bemused that I was asking him about 'his' experiences of the people involved in his care, he frequently replied to questions regarding his specific experiences with:

> The thing is, Sarah could tell you more about it than I can.
>
> Paul

Paul repeated this phrase almost identically five times during the interview, indeed he appeared to have devolved responsibility for many aspects his life to Sarah, accepting that he was no longer in control of what was happening to him and showing little interest in, or knowledge of, the services involved. The notion that Paul's illness was not dominant within his daily existence seems contradictory. The physical effects of the cancer were extremely evident within his home environment; the hospital bed, hoist, regular visits from health staff and carers, combined with Paul's decreased social world due to his immobility. These things did effect Paul, his unnamed illness was significant for him, but in terms of his inability to contribute equally to his partnership with Sarah rather than the effect of the illness upon his own physical life. Sarah

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was Paul's network, and through her, he had unquestioning faith that everything would be taken care of.

Annie discussed her diagnosis and explained that she knew her condition would affect her life expectancy, and that her health would continue to deteriorate. However, her focus was towards living, acquiring new skills, enjoying her family, and being as active and self-caring as her physical difficulties allowed. The illness was only one small part of the background of her experience. Annie identified six health related services involved in her care but only discussed one as being significant at the time of the interview – the Parkinson's disease nurse specialist. This nurse was significant because he was the link for any medical assistance, but she only spoke with him every few months. If her condition changed and she required help, she would contact services. She knew they were available to her if she required them, and that they would respond to her requests for assistance. Annie did not see the need for involvement of other people, she had all the help she required through her husband and friends, and enjoyed her life of which Parkinson's disease was just one part.

Annie found that the availability of services allowed her independence from them. Knowing that they are there for her, available to her whenever she felt it was necessary, enabled her to be free of them when she did not need them. This gave Annie a feeling of control over the management of her life, and her illness.

At certain times in the illness trajectory, people were aware to a greater extent of the presence of services. For some people this was particularly evident at diagnosis, and when diagnosis had occurred recently, the arrival and involvement of services was experienced as sudden and surprising. This was Michael's experience. He had struggled to find out what was wrong with him, why he was feeling ill and what was causing his infections. He felt that nobody was really interested in his problem, and nobody would give him a name for why he was feeling so ill. However, as soon as Michael received the cancer diagnosis he was aware that people were interested in his illness:

'everyone was like flies around a jam pot'. Along with the naming of his condition came a sudden influx of people. This metaphor helped to open up Michael's experience for me. From his description, you get a sense of how this felt to Michael, a swarm of people buzzing around him, people who wanted something from him. Flies approach the jam pot because they smell something sweet, something they want. But they have a passing interest, moving away when they spot something else of interest to them. Their interest is temporary –the fly does not stay still for long. This initial rush of services had faded for Michael. He was still aware of their presence, but the overwhelming nature of their involvement had receded.

Norman described the contrasting emotions he felt at the involvement of health care services. He placed himself at the centre of his Pictor chart and wrote arrows for several of the services that were involved – he also discussed district nurses, and a GP, whom he did not include on his chart. I asked him about the range of people that he saw:

> BH: OK, what's it's like having all these different people involved?
>
> Norman: Sometimes it's nice, and sometimes it's monotonous. But I mean (pause), I think...
>
> BH: What, what makes it nice?
>
> Norman: Well, the nice.. that they're thinking and knowing I've got somebody there as a back u' you know, to to, to see check on me. I mean, Tracey keeps a check on me, if I overdo things I'm in trouble. But er....
>
> BH: And what makes it monotonous?
>
> Norman: Well, they only come, at wrong time (laughs), but er, I mean 'cos sometimes you get a warning they're coming, they say "*Oh we're coming so and so*", but sometimes they don't bother and, err... catch you.

Norman had lived with his illness for a long time, and had experienced significant exacerbations over the years when he was aware that he might die

imminently. Norman was aware of various services involved in his care, but was fairly ambivalent about them. These services were an erratic presence, and it was his wife, Tracey, who was the permanent presence in his life providing all the care that he needed. This included managing his chronic leg wounds, providing personal care, dispensing his tablets and liaising with outside agencies as required. Despite this, he gained reassurance from having a range of health services involved. This reassurance was tempered with the unpredictability of their involvement that limited his own ability to plan his life.

T1.1 They do things to me: we do things together.

Theme summary: The patient may feel like an active and inclusive member of their care team and that care is happening with them rather than to them. When this occurs, and patients feel connected with the people providing their care, they may be discussed in the context of 'we'. However, sometimes situations happen 'to' the patient; they are not in control of what is happening and do not feel included in decision making, or active as part of the care team. 'They' are an anonymous group of people; 'They' is a group with no name or gender. In this situation, the individual may feel a sense of powerlessness.

Elsie was passionate about remaining in control of her situation and maintaining her independence. Her health had deteriorated rapidly a couple of years ago and she had been admitted to hospital:

> And I knew my breathing was getting worse because I kept sitting down, and my doctor made an appointment with the specialist at the hospital, Dr Smith. And I'd been to town the day before. And I went on a Tuesday. And they insisted on getting a wheelchair.
>
> Elsie

Elsie highlights in this extract that only the day before her hospital admission she was mobile enough to be shopping in the local city, but as soon as she arrived at the hospital 'they' made her immobile by placing her in a chair. Elsie felt her autonomy being threatened by the removal of her independent mobility.

Like Elsie, when people felt they had no choice and control in their own situation there was a sense that health services became anonymous and distanced from individuals:

> They put me in (hospital)... I think it was in November
>
> > George
>
> They, (sighs) they sent me to the hospital
>
> > Eric

In these two examples both George and Eric had experienced exacerbations of their COPD. Neither wanted to be admitted to hospital and both had resisted telling a health professional about their exacerbation until they had become very unwell. Based on their previous experiences, both men described how they felt their admission was inevitable once others knew how unwell they were. The admission challenged their sense of freedom; this was another aspect of their lives that was compromised by their disease.

Michael was very disillusioned with the involvement of some of the health services he discussed, particularly when they did not share his perception of what his main problems were. Michael described some of his contacts as a one-way exchange, he has something of interest to them – his illness, but they had little of interest to him as they did not listen, or address his perception of the problem. This was highlighted with regard to his radiotherapy treatment and the subsequent burns that he experienced to his throat and chest causing him severe difficulties swallowing both fluid and food:

They burnt my back, my chest, they burnt my throat.

<div align="right">Michael</div>

The burns Michael suffered were delivered by an anonymous 'They'. He was angry about this, but not at a specific person or at the treatment itself. Rather, Michael was angry with the whole of the system that had allowed this to happen to him, that had let him down by causing him more damage and problems than he started with.

This was a significant concern for Michael, as he believed that appropriate nutrition and the strength he would gain from this was essential for him to be able to fight the cancer, and thus without this, the cancer would win and he would die:

> So it's the throat really that is the biggest worry that I've got. Because if I get rid of that then I can eat and drink and hopefully and put some weight on... I'm a bloody skeleton.

<div align="right">Michael</div>

Michael had tried to initiate conversations with the people who were involved with him about this, but they were not concerned about his throat, they were only interested in his chest and lungs (the location of the cancer) and dismissed Michael's own concerns. Subsequently Michael doubted his own interpretation of his situation, and questioned the legitimacy of his own perception of his problems:

> Michael: Nobody's said anything, nobody has said anything about my throat. I think their main concern is my chest, they're not bothered about my throat, that's how it seems.
>
> BH: Who do you discuss your throat with?
>
> Michael: Everybody, honestly, everybody. Dr Ward, the nurses, everybody. Dr Ward doesn't seem bothered by it, they don't

seem that bothered about it up at the clinic. So, I dunno, it can't be anything particular, I mean. So...

BH: What happens when you mention your throat to them...?

Michael: *'Oh, right, OK'*... that's it, you know... as I said they just don't seem over concerned.   And it's only through the radiotherapy and that is what's caused it.

Michael did not feel that health services shared his understanding of his health problems.   This lack of shared understanding effected Michael's relationship with health services and he was extremely frustrated that no one seemed to be helping him with this.   Michael also felt a sense of powerlessness in regard to his situation, he did not know how to make it better, and his attempts to get assistance and advice were dismissed.   He was overwhelmed by the people who were involved but felt terribly alone living with his disease because of a lack of shared recognition of his problems.

This sense of health professionals being an anonymous nameless group, who do things to individuals, is contrasted with a sense of inclusion that individuals felt when decisions were made together with the people involved in their care. When Ken spoke about his early experiences of his illness there was often a sense of his being out of control, of things happening to him that were unanticipated and unexpected:

Ken: June this year I went into hospital cos I thought, we thought, I was constipated I couldn't pass any faeces and anything. And I, this was after ten days after doing anything, eventually I had to say to the doctor you have to do something. Went in, they whipped me in there. And they kept me in the same night and operated the next day.

BH: In the hospital?

Ken: Yes, they found that I had a tumour.

In the above extract, there is a progression in the language Ken uses. He had an initial diagnosis of constipation which was agreed between himself and the doctors *'we'*. As he started to question the legitimacy of this diagnosis and challenged the doctors decision this changes to *'I',* however once this was re-evaluated by the medical team and the situation rapidly escalated beyond his control, he became passive in the situation with no choice about what *'they'* were doing to him.

People experience service involvement in a number of ways, sometimes this is inclusive and decisions are felt to be shared and there is an element of ownership over events. However, at other times care happens to people, they are passive recipients in situations beyond their control.

T1.2 Helping me face my illness: the comforting presence of services

Theme summary: The network of services provides a supportive framework that the patient stands within, buffering them from the horror of their situation, and preparing them for the future. These services may have been previously invisible and non-existent within the individual's field of experience. 'Knowing' that health services are 'there' cushions someone from the anxiety of a changing physicality and the feeling of living within an unknown body.

Ken, like Michael, had received his diagnosis of incurable cancer completely unexpectedly; his understanding of his symptoms moving from them being insignificant, to constipation, to cancer and stoma formation within just a few days. Following his surgery he very quickly had access to a plethora of health services of which he had been previously unaware. The sudden involvement of multiple health service staff was amazing for Ken, and he felt indebted to these people for the support that he had received. Ken had previously had little involvement with health services beyond routine primary care contacts. The unexpected involvement of many previously invisible health professionals

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left Ken feeling humbled, and surprised by his previous naivety about their existence:

> I've been supported very very well. It's unbelievable that there is so many people doing this sort of thing I had no idea at all.

> And it's rather humbling at times to think what these people do. And there's me wafting through my life oblivious to all the amazing things that are available.

> Whatever I want they do their best, I get what I want. It absolutely amazes me. There's me going through life my head in the clouds almost.
>
> <div align="right">Ken</div>

Prior to Ken's diagnosis he describes himself as *'wafting'*, and with his '*head in the clouds'*, evoking the image of him floating through life, as though his previous non-cancer existence was somehow less substantial than his new world, and he looks back on this time as though it is dreamlike. Ken's new world is dominated by health and illness, and the people that surround him are a powerful force that enables him to cope with this:

> if it wasn't for these people (referring to the chart) I would probably have collapsed in a heap by now
>
> <div align="right">Ken</div>

Ken felt that these people were physically supporting him, both enabling him to come to terms with his diagnosis and to live his life, as well as helping him to stand tall and face his fears. This image is echoed in Ken's Pictor chart. There is the sense that Ken felt he was physically leaning into the people that are around him, drawing on their strength to fuel his own. Whilst considering Ken's experiences of his network, I realised that this could be graphically represented by simply replacing the arrows on Ken's Pictor chart with images

<div align="center">194</div>

of people with their arms outstretched, pushing him on, whilst being there to catch him if he were to fall (Figure 34). If he turned around they would be there for him, and he was aware of their presence. Despite this, he was alone with his illness, slightly separate from these people, although his family, with whom his lived experience was much more closely shared, were as close to him as they could be.
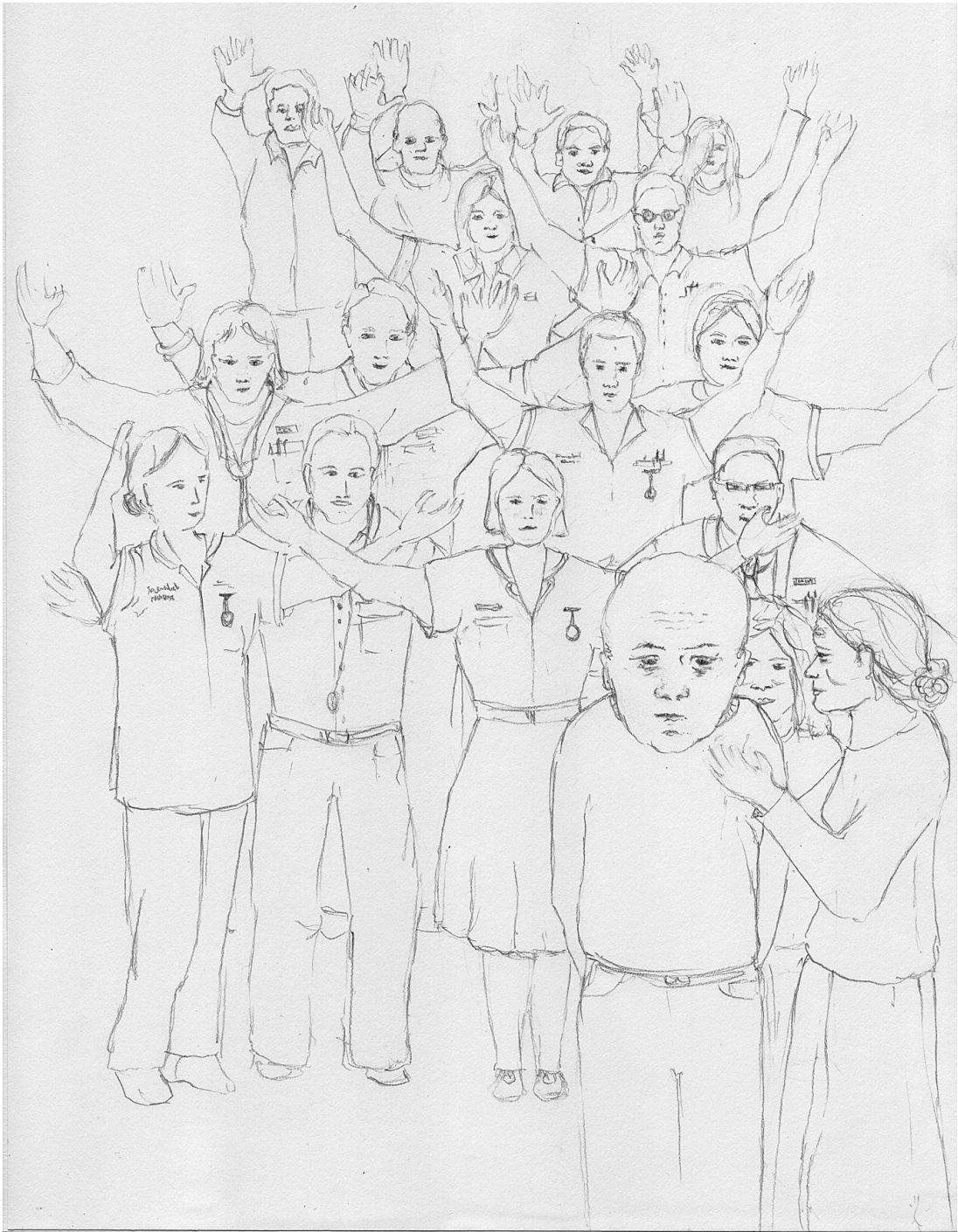
Figure 34. A visual interpretation of Ken's Pictor chart. Illustration by Emma
Hardy.

The supportive nature of the network of services also helps to cosset an individual from the apprehension of a changed physicality and an uncertain future. Lucy, whose Parkinson's symptoms had accelerated rapidly since her diagnosis, felt extremely lucky to be receiving such a good service that made her feel safe. This is particularly highlighted when she discussed the future. Lucy was aware that her husband would like to move from the village where they currently lived, in order to be closer to their children and grandchildren. Lucy was extremely reluctant for this to happen, speaking about this in terms of both her sense of home and belonging within the village, but also her fear that she would not receive as good medical care elsewhere:

> Lucy: But that does concern me (moving away) because I think I've got such a good sy' we've got such a good system here, I mean I don't know, erm, about the other systems round the country, with Parkinson's 'nd, etcetera, erm, but it's a, a good system I've been quite happy being there, so I'm concerned that if I move away, what happens? I mean, do they have these sorts of clinics and things?
>
> BH: I'm not sure, but I'm sure Joseph (Parkinsons's nurse specialist) would be able to tell you.
>
> Lucy: Mm. Because that's one thing that's really, sort of holding me back in a way.

In this instance, the system she is referring to is the Parkinson's consultants, clinics and specialist nursing team who work closely together and to whom she has regular access. The sense of security she felt in relation to this system gave her confidence that someone was always available to her if she felt she needed it.

Lucy's fear of being without this system was exacerbated by her contacts with health professionals who she perceived as being outside of her circle of supporters. Medication timing is extremely important in managing the

symptoms of Parkinson's disease, with only small errors having a large impact on the symptoms of the sufferer. Lucy was waiting for cataract surgery, which she was eager to undertake, feeling that her current poor vision disabled her significantly, and that this was a problem that could be remedied (unlike her other physical difficulties). However, her desire to have the treatment was tempered with her fear about being a patient at the hospital, being under the care of people who she did not know or trust to manage her condition appropriately:

> BH: When you, yeah, when you have contacts with kind of, other, health environments, so with your cataracts with your eyes, do they understand the, the Parkinson's?
>
> Lucy: No. I don't think so. You know it's something that, *"Oh yes"* and they write it on a bit of paper. Er, no. That's why I must make sure, that's why I rung Joseph (Parkinson's nurse specialist) really and he'll, er ring back later today, hopefully, erm. And then perhaps we can have a little chat about it. Yeah. I don't think there's er too many people do know about it really.

Having confidence in the services closet to her, also gave her confidence that the services that she did not trust so explicitly would have the information and support available to them to ensure that she would be looked after appropriately. Knowing that these people were there for her, comfort her and reduce her anxiety. Lucy trusted that the Parkinson's team would oversee, and take responsibility for her situation while she was in hospital, and would be available to her during this time. She felt known to them, and trusted that they would honour this relationship by making sure she was safe. The involvement of her health care system gave her confidence to face the uncertainty of her symptoms, condition and the future.

T1.3 Services reducing the isolation of illness

Theme summary: Advanced disease changes the way that individuals interact with the world. Pain may be present, lifestyle may change as fatigue sets in, social spaces decrease as breathlessness or dyskinesia affect mobility, and medical equipment changes the home environment. Fear of the future and altered priorities further distance someone from their previous existence. Friends, family and communities have not felt this change in the same way. Similarities in experience have been lost, shared understanding has gone and subsequently the relationship has changed leaving the 'patient' feeling isolated from the people to whom they had previously been closest. Health professionals create a haven for patients when they accept this new world, which helps to re-address the isolation experienced by the patient.

Aggie had two sisters who she had been very close to before her illness, and several friends who she used to see regularly. These contacts with friends and family had become an increasing strain for Aggie. Aggie had accepted that she had a terminal illness, and that was going to die, however her friends and family had not. When meeting with these people they showed concern for Aggie's health, but within this concern was a focus upon an ultimate extension of life, and of a cure for her cancer. They avoided conversations about Aggie's actual experiences of illness, pain, fear and her eventual death. Aggie's sisters caused her particular distress, often cutting out magazine articles about new cancer treatments and cures, insisting that she present these to the health professionals involved, so that these new options could be explored:

> Aggie: Paula (Sister) yeah. She bought me two books off o't internet about foods what help cure cancer. She's given me all sorts. She reads them' things in magazines and rings me up. She rang me up last week about erm, a, a magazine, an article in the magazine where erm, this woman had cancer and, it's like an experimental job, it's a hormone. And they feed it to people with cancer 'cos it

kills apparently, the hormone, this type of hormone, eats the cancer away, so it cures you. So, I tell Dr Ram (consultant) about it he just laughs at me.

BH: Does he? What does he say?

Aggie: *"Your sister been reading magazines again?"*   Yeah. And she does. She does, she's a nightmare with it. She's looking, she'll know she's doing it for me, bless her, but, she's trying to find a cure for me and she's not going to. She isn't, she's not going to and I don't know why she just won't let it, just, you know, just leave it at that. But, she don't' mean, she'll get there I don't know, in the end I suppose.

BH: Why do you think she keeps looking for stuff?

Aggie: I don't know (pause), But... 'cos she wants to cure me! She wants to cure me and it's not... it's not gonna work is it.

The lack of acceptance and understanding of these friends and family had left Aggie feeling extremely alone, they did not understand or share in the world that Aggie was living in.

Aggie had many health professionals now involved in her care, and had developed particularly strong connections with the hospice and Macmillan staff. Aggie felt that these people understood that cancer is much more than an illness to be endured, and a problem to be fixed. For Aggie, cancer was something that permeated all areas of her life. Her contacts with people who understood this provided her with a space in-which she feet she could exist as herself, and through this she could experience the healing she needed to '*feel better'*. This is something that she knew could not be achieved medically:

Aggie: I've spoken to my sister about stuff and and, and she's turned round and said *"Oh, d'you know, "Get your'sen sorted"* you know, *"get your life back together"* you know*, "Stop being such a fool*

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and, you know, sort your sen' out". And they don't understand.
They don't understand. I don't think any of them do.

BH: Any? Who do you mean by any of them?

Aggie: I mean, I think more, mainly about my family. Bess (Macmillan
Nurse) knows. She knows what I'm going through. Dr Gotson
(Hospice doctor) she, she does as well. And, and Angela (Hospice
day care nurse). They all know that, I mean they're the... They are
the only one's that know what I'm actually going through at the
minute. They (family) think cancer's an... it is an illness. Cancer is
an illness but, a' at the moment, they're (health staff) the only
ones that could talk to me, and make me feel better in meself.
The others don't.

Norman's health had fluctuated significantly over the years, and several years
ago he thought that he had entered the final phase of his illness and was
going to die. At this time Norman started attending hospice day care.
Norman really enjoyed his time at day care, and he had made friends there:

But you know er, same as going to' hospice, that were all right because,
with all me friends there now and, I made friends wi' 'em all and, I knew
'em all an...

Norman

He also found solace there in the company of others who were dealing with
the turbulence of uncertain existence. He felt like he had got to know the staff
personally and enjoyed what had become his only social outing during the
week, and his only time away from Tracey, his wife. Norman felt that by
attending the hospice his heart problems were monitored and he had access
to people who understood his condition, who could help him if he needed:

BH: What about, do you see anybody specifically for your heart
problems?

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Norman: Well they usually keep a check on me at 'hospice because,

the... they are nurses, er, they've all been ont' ward.

Unusually, Norman had attended the hospice day care for a number of years but shortly before I interviewed Norman he had been informed that he could no longer attend as funding was no longer available – instead he had been offered a place at a day care centre run by social services. Norman was pragmatic about this, discussing the cuts that were being faced by public services, but was clearly sad that he would no longer have contact with the people who had become close to him and understood his condition.

George described to me how the effects of his illness had reduced his physical world. He was previously a sociable man who had enjoyed being an active member of the local club and spending time with family and friends. George had stopped his social activities a number of years ago, not as I first presumed because of difficulties accessing the club due to his breathlessness, but because of his embarrassment about his sputum production:

But, even ye' you can't , you haven't got a social life. 'Cos yer', if you go out, I've not been out for god, I can' don't remember many times, a while now, you'd be sitting 'n, this is what I'm thinking like, you start coughing and you fetch stuff up, and you sit in company, and I'll say you go somewhere for a dinner, with your family, ye' you can't do it. Y' know what I mean, so, my life's in here (the house). It's changed completely.

George

George no longer felt like the person that his friends used to know. He was not the strong man who worked in the pit; he barely recognised himself and had slowly declined contact with his old friends. George had several services coming to see him at home including district nurses, a team to administer intravenous antibiotics when he needed them, and the respiratory nurse specialist. George is comfortable in the company of these people; they

understand that he needs his oxygen, that he gets breathless when he talks, and that he coughs and produces phlegm. He is not embarrassed with these people. They are now his only company apart from his family.

I asked Roger if he talked about his heart condition with his wife, or with friends:

> I tend not to because, not because I…. I think it's something, (its) my problem
> and my problem alone.

> Roger

Despite feeling that the heart failure was his own problem to deal with, he confidently engaged with Rachel, the nurse specialist, to address any problems that he was having. He described her as *'more like a friend that anything… because we see her that much'*, he felt able to use this relationship to support him to live with his illness.

6.2 Discussion

One major theme with three sub-themes, have been used to explore the lived experience of patients with regard to their multiple health care contacts. The findings echo the existing evidence base and many similarities are evident. For example, there are difference in care experience according to diagnosis (Exley et al, 2005), people can be overwhelmed by the number of services involved in care (Seamark et al, 2004), and people can find unpredictable involvement of health services disruptive to planning their lives (Beaver et al, 1999). These themes constitute the 'parts' of the experience of AD in relation to service involvement. In this discussion, I will draw upon literature that helps to illuminate these participants being-in-the world in relation to their AD and subsequent experiences of service involvement, in this way I am extending my phenomenological analysis of this phenomenon.

Illness is not only physiological and pathological deviation; in a fundamental way the person's sense of being is challenged and threatened by illness.

Tyreman, 2011, p. 288.

An altered embodied and temporal experience, and a *'changed physiognomy of the world'* (van Manen, 1998 p. 5), underpins the experiences of the patient participants in this study. This phenomenological perspective of illness, as an alteration in the interaction between a person and the world, is the starting point for the consideration of the experience of AD and service involvement. An initial awareness of change within the body signals the need for service involvement; the body feels and behaves differently than it used to, and there is a search with services for a diagnostic label to explain these changes.

Hayne (2002) writes about the phenomenology of diagnosis, of receiving a name for a set of symptoms. She describes how diagnosis may come as a shock but also may have crept up on a person through the slow awareness of a changing physical body. The body is no longer taken for granted but has become a permanent reminder of the named illness, having a profound impact on individual's lives. Partly, this diagnostic impact is related to prognostic consequences, and a new bodily awareness in which there is an increasing attentiveness to embodied experience, and a sense of separateness from the body that can now be objectified and discussed, as happens with health service contacts. This is dramatically demonstrated in Ken's situation; his diagnostic label changing from constipation to terminal bowel cancer in a few short hours, his body feeling the same, but these feelings taking on new meaning. The fullness in his abdomen no longer signalling a routine health inconvenience, but a sign that he has a terminal illness, that he has cancer and that he is going to die. Leder (1990, p.1) describes the paradox of bodily presence, on one hand being an inescapable presence within our lives, but on the other being *'essentially characterised by absence'*. When we feel healthy, we are largely unaware of our body, it is an instrument through which we perceive our world, but in illness there is a change in bodily self-awareness that may alter our relationship with our world,

and the body becomes present to us (Hockey, 2008). For all of these participants it was awareness of changes within their body that had signalled the need for an assessment of their health, and ultimately led to diagnosis. Further changes often continued to be a signal for the need for additional assessment and intervention of services.

For some of these participants, diagnosis was not a recent occurrence and some of the most striking differences between participants in the different diagnostic groups was how they interpreted the meaning of the physical manifestations of their illness, and the impact this had on their embodied experience, their sense of time and of the imminence of their death and the role of services within their lives. It was generally the case that those who had a diagnosis of one of the non-malignant conditions had received this diagnosis many years previously, in comparison to the people with a diagnosis of cancer who had received their diagnosis much more recently. The participants with a non-malignant diagnosis had often experienced their illness changing slowly over the years. Services had become involved gradually, and although their disease was now categorised as advanced, and they were aware of a limited future, this did not generally dominate their daily life; there was a steady plod to the rhythm of their experience. Amongst the cancer participants their disease had often progressed rapidly, a plethora of services became involved over a short space of time and their sense of future was often starkly short. The pace of change was rapid, and their experience flurried.

People's experience of their illness, and their subsequent relationship with services was affected by their meaning making in relation to their illness. Indeed, having a diagnosis of AD did not necessarily mean that someone saw themselves as being 'ill'. I discussed in chapter two how quality of life (QoL) is often used in relation to the goals and outcomes of care for people with AD. On a simple level, the differences in people's understanding of health and illness could be explained in terms of their QoL: people who perceive themselves to have a better QoL potentially have less desire or need for service involvement. Equally, the notion of wellness, or well-being is

frequently used as a synonym for health, incorporating physical, social and psychological factors, and also seen as a contributory factor for QoL (Ventegodt et al, 2003). However, these concepts do little to explicate the complex relationship between physical disease, embodied experience of the world and subsequent health care connections. Svenaeus (2000; 2011) presents a conceptualisation of illness that I believe does help to illuminate some of the variation seen amongst these participants' experiences in relation to their involvement with health services. He suggests that the phenomenology of illness can be explained through the concept of 'otherness', which is *'a foreignness that permeates the ill life when the lived body takes on alien qualities'* and incorporates an *'unhomelike being-in-the-world'* (p. 333). To consider this metaphor, it is important to explore what is meant by 'homelike'. Home is not used to indicate that someone is happy, for indeed it is possible not to like or be happy in the 'home' that is lived in, but rather to capture the normal and unapparent way of everyday life (Svenaeus 2011). Home is somewhere familiar, it is a space that is known and does not require much conscious effort to move around or be within (Ahlzén, 2011). Svenaeus (2011) proposes that illness interrupts the life story, rendering both the past and the future as alien in the sense that they are your own but have a strange new quality that is unfamiliar and unknown. The world of illness is unhomelike, in that it is not like the previous lifeworld experienced (the normal, homelike world); identity and sense of self is challenged as the relationship with the world is altered, leading to a disturbance in the meaning process of everyday life. There is an alienation of embodied experience that is inescapable as the otherness of the body becomes dominant, permeating the whole of the being-in-the-world for the person experiencing illness.

To put this into context I will use the contrasting examples of Aggie and Annie. Aggie felt a great 'unhomelikeness' to her experience, her body was continually changing and her whole sense of being-in-the-world was altered as she struggled with the physical implications of the cancer, such as chronic pain and reduced mobility. Personal relationships had also changed as others failed to recognise her altered sense of self. She felt marked out and different from the people who had been part of her previous normality, she

had become *'alone in a separate world'* (Boston, 2000, p.66). The isolation that Aggie felt in this unhomelike state was tempered by her contact with health professionals who provided her relief from this feeling; they relieved her pain, and provided her with understanding companionship, they normalised her otherwise abnormal world. The involvement of health professionals who recognised Aggie's new world created a homelike space to 'be' within, as well as offering solutions to some of her physical difficulties that meant her embodied experience was less present to her.

Annie also knew she had disease – however, she did not consider herself to be an ill person. She had a 'homelike' being-in-the-world; she understood her body, and despite the pronounced dyskinesia, her physical symptoms were not dominant within her everyday life. She lived in a certain way because of the presence of the disease but did not align this with being ill, seeing herself as healthy because she had an active and meaningful life. Annie described times when this homelike experience was threatened, for example, when her medications were changed and her physical symptoms altered so that they were no longer familiar or predictable; they became alien to her and her body no longer felt like her own. It was not just her embodied experience that was altered, and she lost her sense of purpose, as she could not participate in the active life that gave her existence meaning. The familiarity of the condition that had become her 'normal' was interrupted. It is when Annie's sense of homelikeness is disturbed that she feels the need for support from services; this is when they are helpful to her.

I have used this metaphor to help describe the varied experiences of these participants, but it has also been applied to the possible goal of health services. Sveneaus (2000) suggests that the role of health care services is to help people return to a homelike state. He uses the example of a person who has had a stroke, and describes the multiple services who are involved in trying to return the patient to their homelike being-in-the-world, including medics who attend to the biological problems, and therapists and nurses who attend to other aspects of the patients functioning. The goal of these services is to bring back a homelike state, however, as Sveneaus points out, this will

not be achieved unless the patient's meaning patterns, their way of making sense of the world, also change. In common with the stroke patient described by Sveneaus (2000), people affected by AD experience a permanent change in their embodied relationship with the world because of their illness. However, unlike the stroke patient who, once the initial effects of their stroke have receded may expect functionality to stay the same or improve, people with AD are more likely to experience a deteriorating functionality, with possible periods of stability (as seen in the functional trajectory diagram on p.51). Dekkers (1999) questions whether it is still adequate to use the metaphor of homelikeness in relation to people who are seriously ill. Certainly, cure, and return to the lived experience of the world before the presence of disease, is an unobtainable goal for people with AD. Dekkers (2009) suggests that a more appropriate metaphor in relation to the goals of palliative care might be 'to bring the patient home'. This sense of coming home has spatial (literally the space of ones own home), corporeal (referring to the space of ones body) psychosocial (recreating home through positive relationships with others) and spiritual (home as a religious or spiritual space) dimensions. This is an interesting way to consider the different aspects of the metaphor of home, and reiterates many of the fundamental principles of palliative care such as addressing physical, social and spiritual issues. However, there is danger that Dekker's conceptualisation of the role of services being 'to bring the patent home' could be misused in practice. As Dekkers (2009) himself highlight's, 'home' in his conceptualisation has inherently positive associations. For people whose home does not represent a positive space, the use of this metaphor to describe the role of services in AD may be ineffective.

The notions of a homelike and unhomelike being-in-the-world have illuminated these participants' lived experience, and their dependence on, and independence of, health care services. It has contributed to this description of their different ways of being-in-the-world in relation to their illness, and their understanding of the need for, and desire for interventions from health care professionals. Despite this, it may have limitations if applied to the function of services for people with AD in practice, particularly around the metaphor of

'homelike', as has been seen to some extent in Dekkers (2009) paper. 'Home' is a well-used notion in the care for people with AD. Policy suggests that many people want to die at home and be cared for at home (DH, 2008a) and these aims have become central in much of end of life care policy and practice. There is a risk that those who are unfamiliar with philosophical and metaphorical thinking could rely on the everyday understanding of 'home', and use the metaphor as strengthening the argument for place of care and death, thus missing the deeper insights that this metaphor offers for understanding illness experience (Ahlzén, 2011).

6.3 Chapter summary

People living with AD are facing a continual alteration in their embodied experience of the world, which impacts upon their interpretation of the meaning of their experiences. The metaphor of an 'unhomelike and homelike being-in-the-world' has been used to illuminate how the meaning of illness impacts upon the awareness of, and desire for interventions from health care services.

Chapter 7: Spousal-carer experiences

Spousal-carers face multiple changes in their own being-in-the-world as a result of their partner's illness. They are the wife or husband to someone affected by AD, and their experience of this situation is in many ways inextricably related to their partner's experience. Despite this connection, the spousal-carer experience is also inevitably separate and disparate from that of their partner. This chapter will initially present the findings of the discrete analysis of the spousal-carer data. I will then discuss these findings in relation to the extant literature, and consider my conceptualisation of the spousal-carer experience in relation to service involvement as one that is a 'striving for poise'.

7.1 Presentation of the findings

The section of the template that has structured the presentation of the spousal-carer findings is presented in table 6. As in the previous chapter, I will explore these themes in turn. Each theme will start with a summary, before moving on to explore the theme in detail.

Table 6. Template for the spousal-carer experience

'Spousal-carer' analysis		
Theme	Texts the theme was evident within:	Theme illuminated with examples from:
2 A partner who is ill: being a spouse, being a carer	All	Sue, Tricia, Tracey
2.1 The patient focus 2.1.1 'There's no support for me'... 2.1.2 'I don't want to cry in front of him': partners presence restricting the spousal-carer's opportunity for discussion with health services	All	Amy and Tricia, Kevin, Sue
2.2 Declining service involvement 2.2.1 'And of course I said I am fine'	Charlie, Edward, Amy, Tricia	Charlie, Edward, Amy
2.3 'My strength': support from friends and family	All	Tricia, Edward, Sarah, Charlie
2.4 Always watching: a unique insight 2.4.1 Specialist knowledge: contribution to, and rejection from the care team	All	All

T2. A partner who is ill: being a spouse, being a carer

Theme summary: Being a spousal-carer means to be personally involved with someone who is affected by illness. However, the term and role 'carer', may not be one with which individuals identify; rather, they may see the caring role as an intrinsic part of their relationship with their partner.

This theme is not directly related to the spousal experience of service involvement. However, this is the 'ground' upon which the experience of services occurs, and as such it constitutes a valuable part of understanding the experience of spousal-carers in relation to service involvement.

Having the title of 'carer' implies that there is something about this function that is in addition to being a partner, spouse, family member or friend;

suggesting that being involved with someone who needs 'care' is an extended role to someone in a relationship where this is not required. This title is not so much taken by an individual as given to them by their contacts with health and social services. I wonder if it is possible to be the partner of someone in this situation and not to be a spousal-carer? Or whether being a carer is automatically assumed through the terminology of the formal support services that become involved?

Caring for someone with AD is a diverse role as these participants demonstrate. It may include providing physical care and practical support, which promotes normal functioning and compensates for the decreasing ability of the ill person. However, in many of the examples given by these participants the 'care' that they were providing was a continuation of their previous relationship, of nurturing and loving their partner:

BH: What would you say your role is in all of this then?

Tricia: I'm his wife, primarily. And I want to be his wife for as long as I can. So that's (laughs).

BH: role's a funny word int' it, I hate that word, sorry.

Tricia: I do care for him, I am his main carer, but I would be anyway as his wife wouldn't I? But, we're a married couple, we're equals, he's no more important than I am, and we always come to a compromise don't we...

Tricia was both wife and carer, and these roles are inseparable as part of her relationship with her husband. It was important to Tricia that she remained as a wife to Roger, and that their relationship did not become fundamentally altered by Roger's illness meaning that she would become solely a carer.

Sue also used the term 'carer' when discussing her role in relation to her husband, but contrasted this 'loving caring' that she provided for her husband, and the daughterly caring that she was obliged to provide for her father. The

former role being a continuation of her marriage and relationship, the latter being born out of duty and for which she gained no sense of satisfaction:

> For Eric I'm his carer, his loving carer. For my dad I'm his daughter that cares for him, and he makes me feel like I should do it, that's what I'm here for.
>
> Sue

Gaining the title of 'carer' entitles the individual to various other resources; this could be in the form of carer support groups, carer assessments of their needs, and financial support from the government who formally acknowledge the added burden of the caring role. Interestingly, none of the spousal-carers who participated in this research were accessing any type of formal service that may be available to them in their caring capacity and none of them were aware of having had an assessment of their needs. It is impossible to tell from this research whether assessments had happened and people were unaware, and whether services had been offered, declined and forgotten. Only Tracey discussed receiving any financial assistance in relation to her caring role and this was provided to pay for respite and day-care for Norman. This had recently been cancelled however:

> I've cancelled, I've suspended the money because, we've got over a thousand there, and they kept sending it in and I kept saying, well I mean I couldn't, I can't get him out, and they paid for the chair, which I didn't want them to do. I mean we're independent Beth, we don't… it, to, to Norman it's charity. You know we're from that generation.
>
> Tracey

The financial support offered to Tracey compromised her sense of autonomy and was declined, as she preferred to retain her financial self-sufficiency as this reinforced her feeling of ability to cope. It is also possible that the receipt of financial reward in returning for her 'caring' role was felt as a betrayal towards Norman. Caring for him was something that she did because she was his wife; the money was not something that she was entitled to:

We don't believe in... to me that's taking somebody else's money.

Tracey

These extracts also demonstrate how Tracey's experiences are closely connected to her husband's, she starts by talking about the care she is providing, and the aspects of the experience which are hers alone - managing the finances, and arranging for Norman to leave the house, but moves on to talk about 'their' shared philosophy and ideals - to be independent and resilient. Although she is the 'carer' they are managing the situation in a way that is honest to their shared principles, and by abiding to this philosophy they remain authentic to their personal way of living.

For these participants, being a spousal-carer was an extension of their marital relationship. The disease that had affected their partner also affected them in an intrinsic and connected way. The spousal-carers often saw themselves as having a role in physical care provision, but also as acting as an advocate for their partner. This involved protecting them, promoting normality, and attempting to ensure that their needs and wishes were accommodated. This led to a complex relationship with the services involved in care provision, which I will now consider.

T2.1. The patient focus

Theme summary: There is a web of services that surround the 'patient'. The spousal-carer watches and monitors these, looking out for the best interests of their partner. Services are interested in the needs of the 'patient': the person with AD. Support is orientated towards the patient, and spousal-carers are a secondary person to this focus of attention. Spousal-carers may not identify that they are receiving support in their own right, or perceive that they have any reason for intervention for their own needs. The spousal-carer will often accompany their partner to medical appointments, or be present at

home visits by health care professionals, for example a District nurse or Macmillan nurse. The spousal-carer rarely has contact with health professionals when they are on their own; this limits opportunity for the spousal-carer to converse with these people independently.

Amy and Michael had numerous health professionals involved in their lives. Michael was under the care of a hospital consultant, he had seen hospital Macmillan nurse specialists, regularly visited his GP, and saw various district nurses and a Macmillan nurse at home. Amy had attended all of these appointments and been present during all of the home visits. I asked Amy about the conversations that she had with the various services:

> BH: When these health professionals are involved, what kind of things do you discuss with them when they see you?
>
> Amy: Just how he is, if he needs anything.
>
> BH: Who chooses what to talk about?
>
> Amy: Well, I suppose in a way they do.

The contacts with these services were entirely about Michael problems, and the conversations directed by the health professional. Amy described what happened when the nurses visited Michael at home:

> I suppose first and foremost they ask how he is, and then from there either he, well, he'll tell them how he feels, and if there's anything gone on that he's forgotten about I'll chip in and I'll tell them and they take his blood which is what they're doing at the moment and they write the report and that's it off they go.
>
> Amy

The nurse who leads the conversation sets the agenda of the visit. Amy listened to Michael telling them how he is, if he forgets anything Amy would contribute, giving them the fullest picture of Michael's situation. It is not only

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the visiting nurses who see Michael as the focus of care, but also Amy herself; it is about them as a couple telling the nurses about Michael's illness. The 'patient' is the focus of the contact, and Amy is an ancillary support person who is also present. Interestingly, this extract also shows Amy ensuring that the nurses are fully informed. She feels it is important that she makes certain that all information is conveyed correctly, realising that she may have a better overview and memory of what has been happening than her husband. By doing this she is contributing to ensuring that he gets the best help that he can. I will discuss this concept further in theme 2.4, p.227.

Roger and Tricia also had an array of people involved for Roger's health issues. Whilst explaining the arrangement of her Pictor chart, Tricia discussed how the services that were placed closest to her and Roger were all about Roger's health issues, and her own services were peripheral and secondary to this:

> Well, I mean, that's within our family group look, Rachel is as important so... Rogers's heart failure's the most, thing that I worry about obviously, because he's got renal failure, prostrate, insulin based diabetes, and that's the thing I worry about, int' it. I just think he's greedy! And like I'm on the edge aren't I. I don't matter, my things are out there...
>
> Tricia

The focus of care was Roger; his health needs took priority over Tricia's own in both her eyes and, in her perception, the eyes of the people who were involved in Roger's care. Tricia tried to utilise some of the specialist services involved to explore and discuss her own concerns about Roger's illness. She described how the heart failure nurse specialist had been placed on the chart between herself and Roger, and explained that she had done this because this nurse was there for both of them:

Tricia: She's the main person in the equation.

BH: Who's that?

Tricia: Rachel Baker, the heart failure nurse, Both to Roger and to me because I can ring her up and speak to her when he's not in or he's in bed or...

Tricia describes Rachel as *'the crutch on the medical side'*, someone who is important to her because she will attend to Roger's health problems and understands the complexities of his condition. Tricia was able to talk to Rachel about Roger's health, and she knew that if she had problems with Roger she could contact Rachel and help would be provided. However, when it came to Tricia discussing her own concerns about the future, and what would happen when Roger's disease progressed, Tricia did not get such a satisfactory response. Tricia felt that Rachel knew she had anxieties about the situation. Tricia had tried to discuss her concerns with Rachel and with Roger's heart failure consultant. But when she did, *'she'll say "Oh don't worry we're on top of it*". Tricia did worry though, and lived with her fears of what was going to happen to Roger. This lack of recognition of Tricia's experience of the illness situation exacerbates her concerns, as it is the unknown that she fears most. Despite a very positive relationship with these two services, Tricia's own concerns and issues are felt to be unrecognised and unimportant, leaving Tricia feeling isolated.

The patient focus is sometimes so dominant that it had not occurred to people that carer support might be a role of health care services. This was the case for Kevin. As Laura's condition has deteriorated, Kevin had found that she needed him more and more. He helped increasingly around the house, helped to wash her hair, did all the shopping, watched to make sure she was safe getting up and down stairs, and did anything he could to make their lives run as smoothly as possible. I asked Kevin about support that was available for him:

> What support that I got, apart from my odd trips to the doctors I don't get, there's no support for me. It's Laura that gets all the support, the, I don't get any.
>
> Kevin

For Kevin, the focus of services was Laura. He was peripheral to these services and of no interest to them. Kevin struggled to create a Pictor chart. He could not identify people who were involved with him, and his chart shows the few people who were involved all being directed towards Laura, including himself. The suggestion that he might access services to support him in his caring capacity was an alien concept.

The patient focus of care also had practical implications, and meant that the spousal-carer rarely saw any of the health professionals involved when they were on their own. Amy had only once seen a health professional regarding Michael's illness when he wasn't present. Amy knew that Michael worried about her, about how she was feeling, and about what was going to happen to her after his death. Amy did not want to add to Michael's concerns and anxiety by showing him how much she was also suffering by discussing her own fears in his presence. Spousal-carers often attended appointments with their partners, and were present when services visited their partner at home. The spousal-carers all discussed how they desired to protect their partner in one-way or another. This included protecting them from witnessing the impact that the illness has had upon them, including hiding their own emotional response to the situation. Tricia, and Sue described how they chose not to discuss sensitive issues, or their own concerns in the presence of their partner. This meant that they had to find other ways to have these conversations, or that these conversations did not occur.

Sue described her sense of frustration and distress at Eric's illness, and how she did not want him to see her like this:

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I don't want to cry in front of Eric. You know, when you see him struggling, you sit there and I think, I feel so useless. Because you can't do owt for them. Somebody got a backache and stuff like that, you'd say why don't you lie down and that and I'll get you a couple of painkillers, have an hour. But you can't do that with this.

<div align="right">Sue</div>

Sue felt the futility of their situation, and for Eric to see her crying would only add to his struggles and to his own problems. Sue rarely saw anybody who she could discuss Eric's health and her own concerns about this, when he was not present. She has a good relationship with the nurse specialist who was involved (Jane), and I asked her if she got to see Jane on her own at all:

Not unless I ring her at work. If I have to ring her for anything I normally leave it until I'm at work. And then she'll say *'I'll tell you what darling I'll pop in'* and then I'll come home and tell Eric that I've spoken to Jane, and she's going to come through and see us for whatever reason.

<div align="right">Sue</div>

Sue tried to have a private conversation away from Eric, but Jane then offers to come and visit and see Eric, the private conversation is thwarted (although the home visit is still appreciated). The visit is about dealing with Eric's issues and does not give Sue opportunity to discuss specific problems and concerns that she is having. Sue did not feel like her own experience of Eric's health problems was recognised. This was frustrating to her and at times she felt very alone and isolated despite the involvement of services she saw as being supportive to Eric.

Tricia described how she would contact her friends to discuss her own experience of the situation, but that she only did this out of earshot of Roger:

I can ring her up and speak to her when he's not in or he's in bed or....

<div align="right">Tricia</div>

Tricia did not handle situations in the same way as Roger; he liked to live in the present moment, dealing with problems as they arose, taking the weeks as they came. Tricia would rather plan for the future; she wanted to know what was going happen and to have considered all eventualities. Roger refused to discuss these things, and Tricia knew that he did not like her to discuss them either. She had to find ways to have these conversations when he was not able to hear her; thus protecting him, but also trying to manage her own response to the situation.

T2.2 Declining service involvement

Theme summary: Sometimes services, and opportunities for discussion of their own issues, were declined by the spousal-carer. This occurred when they saw themselves in the supporting capacity, rather than as needing any support themselves, and when talking about personal feelings was felt to be to distressing, and could compromise the fragile emotional stability of their partner.

I have described how Kevin seemed bemused by the notion that services might have a role in supporting him in the situation. The other male participants demonstrated similar attitudes towards the potential involvement of outside agencies, or assistance from members of their community. Edward's chart shows himself on the periphery pointing in towards his wife, who is surrounded by formal and informal support. Edward did not identify himself as needing support, rather he was the provider of it. This support was primarily for Annie, but he also saw himself as having a role in also the wider Parkinson's community, and he was actively involved with the local support group.

Accepting support could be seen as a sign of neediness, and of not coping. Charlie demonstrates this:

Do you have any involvement with any, kind of erm, support groups like the Parkinson's groups or?

Charlie: No, no. Erm, (pause), I've, always been slightly reluctant to get involved with those, 'cos I, I feel in some ways that it… it does sends another message you see.

Charlie's dismissal of 'support' included any intervention from others into his and Lucy's world, including physical assistance with care, respite care so that he could have a break, and any kind of psychosocial interventions. Charlie explained that he felt that if he accepted support in his role as Lucy's husband, as her carer, that this would be an indication to both Lucy and the wider community that they were being beaten by the illness.

Charlie identified several people on his chart as being important to him because they were important to Lucy, for example the hairdresser that Lucy attended weekly and who made her feel better about herself. Charlie felt better when Lucy felt better, whether this was her Parkinson's symptoms being managed effectively, or interventions that improved her general sense of well-being. Although I have identified a lack of specific support for spousal-carers, it seems as though support given to the patient is also support in some way to the spousal-carer. This indirect support included physical interventions which reduced the need for intervention by the spousal-carer, the spousal-carer knowing that the 'patient' was getting effective care thus reducing their own worry and concern, and witnessing interventions which positively affected their partners sense of comfort and security in living with their illness. Because so much of the focus of the spousal-carer was on improving and maintaining their spouses well-being, any action from services to help them with this was valuable to them as well. In this way, it could be considered that the provision of good patient care has direct implications for spousal-carers lived experience.

Amy had been feeling unwell for some time, she was losing weight and had many questions about what was to happen in the future, but she did not raise

these issues when the opportunity presented. The Macmillan nurse contacted Michael and Amy regularly by phone:

> BH: Do any of the, you've got the Macmillan nurses and the DNs involved here. Do they give you chance to see them on your own away from Michael
>
> Amy: No, no, they always ask how I am, errm, and when Pauline rings me obviously her primary... (laughs), I don't know the word. But first and foremost she asks about Michael put it that way. But she does always ask how I am, and of course, I'll say I'm fine. And I am most of the time, I am most of the time, I have my moments… myself away. But more often than not... because I don't want to upset Michael. And as I say, this is the easy bit, so...

'*I am fine*' is the automatic response for Amy to enquiries about her own feelings and situation. This response is given without thought, and rolls off her tongue without consideration to the question that she is answering. She is responding to the social greeting, rather than to the enquiry about her own issues. Although she had been asked how she was, there was no consideration given to her reply. Amy was not 'fine' when I met her, and appeared to be coping poorly with Michael's diagnosis and prognosis. At the end of my conversation with Amy, I explained that I thought she was important within the care situation and asked if she would consider talking to someone about some of the issues that we had been discussing:

> Amy: Yea, I know I am, but, yea I'm scared about what's in front, erm, but I can't change it. I've got to deal with it anyway. And I just, you see, I don't like getting like this. I can't let go, I can't let go. Because if I do. I can't drag myself back again. And I think *INAUDIBLE* because I think I, ok I'm upset now..
>
> BH: and we've been talking about lots of things

Amy: and this is just the tip of the iceberg, I think if I spoke to anybody in more detail then the flood gates would go and I'll not, I know me, and it'll take me a long time to get myself back to where I want to be, and I can't afford to let myself get that. You know what I mean, so, I know a friend of mine kept saying you need to talk to someone you need to talk to someone… what did she say… I says to Jane, *'I can't because it's as if I'm admitting defeat'*. And I'm not defeated yet. We've got some fighting to do. I know what the end result is, don't know when, and won't want to know when. We don't want a prognosis because we don't want that time limit that there because as it got closer you think, today, is it today?

The thought of talking scared Amy. To talk about her fears would make them real, to discuss the future might bring it closer to the present and Amy was not ready to face this yet. Amy became very upset during the interview, but described this as '*the tip of the iceberg'*, she felt that there was a mountain of emotion buried within her. Amy was retaining some control of her situation by not talking about it. By responding *'I am fine…'* she was ultimately protecting herself and Michael from the danger of her uncontrolled emotional distress, which would impact upon them both.

For these people, primary care services were not seen as having a role in supporting them, or being utilised to support them in their role. However, this does not mean that spousal-carers did not discuss the difficulties that were associated with their role, and participants discussed how friends and family were vitally important in helping them to support their partner.

T2.3 'My strength': support from friends and family

Theme summary: Health services were not seen as having a role in directly supporting the spousal-carers. However friends and/or extended family

members were sources of personal support. These people offered the spousal-carer a space away from their partner to be able to cry, share frustrations and discuss their concerns about their partner before taking them to formal services. Friends and family would also provide practical support, either through spending time with the person who is unwell, or through assisting with practical tasks that the spousal-carer may be unable to manage on their own.

Sue talked to friends about her situation, and she relied on her daughter, Kate, to talk to about how she was feeling. Kate understood some of what Sue was going through, and allowed Sue to cry, something she felt unable to do at home. Having this space to go to, and knowing that it was there, helped Sue to feel that she could cope with the present and prepare for the future:

> Now Kate, she's my strength her, because I go to her sometimes for a coffee, and I walk in, and she'll go *'aye up mam'* and I'll go *'bad day'* and I'll walk in and that means I want to cry. And she'll make coffee, and by the time she's got the coffee I'll be all right.
>
> Sue

Referring to Tricia's chart, she placed the various medical services who were involved surrounding Roger, they were his services, and placed two friends surrounding her, these people were the significant support for herself. One of these friends, Sally, she utilised to discuss her concerns:

> And I spoke to Sally about it, I said *'He's not as well as he was and I'm worried about him'* and so her and Damien came for coffee one night and they saw how tired he got, and how breathless he gets, and then she rang me when he weren't in to have a conversation, I mean he can't hear you if you're on the phone can he, and she says *'You're right, there's a big change Tricia'*.
>
> Tricia

These conversations allow Tricia to share her observations of Roger's health;

her friends validate these observations, and give her confidence to then take them to Roger's nurse specialist. She also identified other friends on her Pictor chart, however Tricia saw these people as helping her in a much more practical way:

> They'll, they see to our cases and everything and, if we're shopping George carries it for me, he comes up every Tuesday night to put my bins out and boxes, yeah. On a Thursday they ring me and say *'We're going to town and we're going to the Tesco, is there anything you'd like'*. And other times they'll say *'Would you like to go to Retford on Tuesday, we'll all go we'll have some lunch'* and, there's like Edinburgh Wool Mill and, Ponds Forge and all that you know so I can get some bedding and some tops and things and George carries it for me and she'll say *'George take these back to car 'cos Tricia wants some more stuff'* you know. And they're really good aren't they?
>
> <div align="right">Tricia</div>

This relationship is important to Tricia for several reasons. The practical support is invaluable, and they offer some respite and access to the outside world, which has become increasingly rare since Roger's health had deteriorated. More importantly though, they understood that Tricia's world has changed, and they allowed her some normality, facilitating this through practical intervention such as carrying shopping and taking bins out, tasks that are hard for Tricia because of her own health problems.

Making friends with people who were in a similar situation was valuable as it meant that experiences could be shared, problems solved together, as well as learning from others about different ways to manage the condition:

> BH: How do you, what do you get out of the friends from the Parkinson's group?
>
> Edward: Well it's a different set of people, it's, but it's people who've got, they've all got a, a common illness if you know what I

mean, a common cond' it's not an illness it's a condition is Parkinson's, I mean it's, disease is wrong it's just a condition, but, they've all got themselves, not all of them, half of them have got themselves same thing as Annie's got. The other half have got there self same thing as me; they're looking after them. Well, what can we do to make it better, *'Well I do this and it helps'*, so we sort of swap ideas about. They swap ideas about people with Parkinson's, a different way of looking at things, a different way of doing things.

It is interesting here that Edward refers to Parkinson's as a condition rather than an illness. Annie is not 'ill', rather she lives with a condition that affects their lives but which is Annie's normal state of health. The friends that Edward has made through the Parkinson's group share a similar perspective and there is a strong focus on them 'living', and having a nice time together. In this group there is a shared understanding, a connection because of shared experience. This creates a space of mutual support, which is empowering to Edward.

Sarah and Charlie found support from friends and family in a practical way. Sarah described how family members were helping her to do the household jobs that she struggled with:

His brothers been really good to me as well. Digging bits of the garden for me, I keep it hoed but Grant will do that. Err, and when I had this new boiler Grant came and took the wood out that was on the wall and has re-done the top so that it's boxed in and I've only got to wallpaper it. So he'll do jobs like that for me. He cleared the garage, he cleared the loft out when we did the installation, and he cleared the garage for me. Stuff like that. So I've got someone I can call on for what I call heavy jobs if I need to.

Sarah

This help relieves Sarah of the worry of these jobs, which she knows Paul is now unable to do. It also means that Paul will not be worrying about these jobs. Sarah knows that Paul worries about the household maintenance, and relieving Paul of this concern helps Sarah.

Charlie also has practical help from family:

> BH: In what way do they, help?
>
> Charlie: Er, well they come up, they, I mean my, my daughter will, er, certainly take over cooking and stuff, like they come up to see us, so, I mean they, they will give some, some practical help, some practical help. And funnily enough, the grandchildren who are getting older, they're w' they're very good family, they're, they will, for example my, er, my daughters youngest son is, is very helpful when she comes up 'cos he, he'll walk alongside her and, and help her walking along the street, and that type of thing.

Like Sarah, this practical help is appreciated for its own end, but it also helps him to see Lucy being supported by her family, by them continuing to get on as a family, and by treating Lucy normally. Again, it is the support to Lucy that Charlie finds most beneficial to himself.

T2.4 Always watching: a unique insight

Theme summary: The spousal-carer has a unique awareness of the changing health of their partner. They knew the person before their illness, and have watched the affects of illness upon their partner. Family, friends, and services have a transitory insight into the world of illness. These people can be deceived, and deceive themselves as to the 'realities' of AD, a privilege that is not afforded to the spousal-carer. The spousal-carer may want others to see

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this reality, to comprehend the world that they are living within, and thus understand their experiences better. Watching their partner, their response to treatment and their experience of living with illness has given the spousal-carer a comprehensive insight into the 'patient's' life. The spousal-carer may also have developed a detailed knowledge of their partner's medical condition and its management. This knowledge can be fed back to health services to help improve the care given to their partner. This contribution is received in different ways. A positive reaction makes the spousal-carer feel included and in control of their situation. A negative response can leave the spousal-carer feeling undermined and their contribution undervalued and overlooked. This emphasises the spousal-carer's subordinate position in care provision.

Sue had seen Eric change from a strong, active person who was a leader amongst his colleagues, to a man who struggled to get to the bathroom independently. Eric had some good friends who visited him frequently. When these friends were present Eric changed, and acted as though things were like they always were, advising his friends, laughing and joking:

> That's why people say when they come in to see him, they say *'well, you were all right today'*, or they've see him a couple of days and they're surprised *'weren't Eric all right'* and I think, you don't know what I see. But, well yea, *'he were fine weren't he and you had a right, a good chat didn't you'*, but don't forget he isn't fine, don't forget that, he isn't, he's not going to get… the thing that's… they think he's going to get this marvellous pill that all of a sudden is just going to do something for him, but it don't work like that apparently.
>
> Sue

People commenting about Eric's 'health' adds to Sue's frustrations, she wanted them to be able to see how he really was, as she had to do. Sue wanted to be able to think the same way as these people, to believe in a magic cure, or to go away and forget the illness that has ravaged her husband's body. However, Sue could see what was really happening, she

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was present with her husband in his experience, and there was no escaping this reality. She wanted others to be able to see this too, to share her understanding, and to share the burden that this inescapable knowledge had given her, but Sue was alone in this understanding of her husband and his illness.

Watching the experiences of their partner could be an emotional experience:

> Well, I, I mean as a (inaudible) living with Parkinson's it's… it's a… it's emotionally draining in many respects, 'cos, you can, you can be close to tears, at times, er, I mean when you see somebody that's… that… that's been a companion and a, a friend over many years, that is not coping very well, then it's, it's a major problem.
>
> Edward

The spousal-carer is watching their partner change, looking out for new signs or symptoms of the disease progressing:

> I suppose I'm sort of looking all' time, that's the problem int' it. 'Cos you live on the edge, really. You know, I'm just watching him for changes…
>
> Tricia

Tricia watched Roger all the time, she was aware of every aspect of his physicality, watching his breathing, his movement around the house, and changes to his stance that might indicate pain. Tricia felt that she knew Roger better than anybody else. She also knew that he would not generally self-report any problems that he was having. Tricia was constantly assessing Roger for signs of his illness deteriorating or for an indication that he was hiding something from her, something that she felt that she should know about, so that she can get help him with this. The spousal-carer's sense of being-in-the-world is a continually shifting in response to the observations of their partner. Watching the change in their partner's body brings increasing attention to their own embodied experience, and an awareness of the terminal

nature of their partner's illness raising existential questions about the spousal-carers own mortality. Tricia described to me how she watched Roger sleep and continually checked he was breathing. She described Roger's initial heart attack as 'silent', they had no signs of it happening. She worried that this would reoccur and he would die during the night. Her reason for vigilance in her observations was not as simple as being able to prevent Roger's death; rather, she hoped to be present at his death if it did occur, and she felt that by being asleep she would be absent from him. Tricia also described fears around her own death, not at fear of dying or being dead, but that she might die before her husband. She was worried that her family would not keep her ashes safe until her husband's death, so that they could be buried together. As far as I am aware, Tricia's wish to be with her husband in death had not been discussed with anyone except myself[12], despite this being a significant concern for her.

The spousal-carer accumulates knowledge from their observations, and this insight into their partner's illness can then be fed back to the health services who are involved in their partner's care:

> Charlie:　For example I can see the effects of the pills and I've, the one
> problem I do have is a bit out', I can be a bit outspoken at times,
> and I don't think the, erm, consultant welcomed me when I
> challenged him on the, on what he was doing.
>
> BH:　Right. What happened there?
>
> Charlie:　Er, well I just, I just felt that they weren't getting to grips with the
> real problem, 'cos the real problem that we have is, is twofold,
> one it was, that, that clearly there's a stiffness in, in movement
> and joints, which they loosen up with pills, but then if they loosed
> up too much then we get, huge amount of dyskinesia. And I said
> *'I don't like that I don't want that, so what pill's causing it'"*,erm,
> they don't appear to want tell you these things, possible 'cos they

don't always know. But I know what caused it, 'cos I can see the effects after the pills

BH: So what happened with doctor, er the consultant, when you kind of said?

Charlie: you could just, you could just detect an irritation, that *'I've allowed you to sit in here, just be quiet cos I know best'*. Well he knows best about the condition and all that sort of thing, but he doesn't know best necessarily about what's going on in my life.

Charlie felt excluded from this care team, and deeply frustrated at the lack of recognition of his perception of the problem. He felt that he had a superior knowledge about his wife, and how she lived with her disease, but that her medical team do not acknowledge this perspective, asserting their authority by belittling his own insight:

I think you've got to understand in the, in these relationships is that we're not stupid.

Charlie

To Charlie, the health care team is only interested in their own understanding of how best to live with Parkinson's symptoms, It is not important to them how Lucy and Charlie actually live with this disease. Charlie used the arrows on his Pictor chart to show this; by placing the health services (GP, Parkinson's nurse specialist and Consultant) at the periphery of the chart, he demonstrated and then discussed his frustrations at the health services' attitude to his involvement in his wife's care.

Amy also described a situation in-which health professionals ignored her own assessment of a situation.   Michael had been ill for several days and developed persistent hiccups.   His problems had occurred over a bank holiday weekend, and Amy had made dozens of phone calls to nurses and doctors from the out-of-hours service but had difficulty getting through to the right person, and when she did, she felt as though they did not take her

concerns seriously. By the Monday morning, Amy was getting desperate and a doctor visited at home:

> Michael hadn't eaten or drunk anything since the Friday and he was hallucinating, so we knew he were dehydrated but he (the doctor) insisted he weren't.
>
> <div align="right">Amy</div>

This doctor disagreed with Amy's interpretation of what was wrong with her husband, and offered no explanation or intervention to help him. This left Amy with nowhere to turn. She strongly felt that Michael needed urgent help; she knew he needed to eat and drink, and his hallucinations were extremely distressing to witness. The following day Amy managed to speak to Michael's Macmillan nurse and he was admitted to hospital. But this incident, where Amy's own judgement was ignored made her decide to bypass primary care services in the future, stating that if a similar incident occurred she would just dial 999 for an emergency ambulance.

Norman had had his legs bandaged for many years by the district nurses, as he often suffered with leaking oedema. Tracey had started doing this because the bandages would often become soaked before the nurse was due to visit. Norman had developed some ulceration on his legs, and now had compression bandaging. Tracey was taught to do this by the wound care specialist nurse at the hospital who was happy for Tracey to take on this role, advising Tracey to liaise with the community nurses if she felt there were any problems. One day, a nurse came to do Norman's blood test and dress his legs:

> Tracey: there was the one that Norman was on about, he goes on about, this old one that came, sh', she got it wrong (the bandages) but er, we, we had to alter it all but, by the time she was finished, she was quite nasty, you know.
>
> BH: In what way was she nasty?

Tracey: Er, well, I was trying to tell her, what we did, and she said *'I'm the nurse here! I'm not interested in what you think'*. So I said *'Right, that's it'* you know... I said *'But I'm trying to tell you'* she said *'I'm not interested, I'm the nurse, and I say what we do!'*. So I said *'Oh well, that's it'* you know, I thought, please yourself madam.

This nurse did not recognise Tracey's skills and understanding of her husband's treatments. Tracey was confident in her own competence however, she had been taught by someone whose judgement she trusted, and subsequently she re-did Norman's compression after the nurse had left, thus ensuring that he got the appropriate treatment.

In contrast to these examples, Sarah works closely with the health care professionals who are involved. She knows what they are doing at all times, and they liaise with her about any problems with Paul. For example, if the home carers thought that Sarah should be aware of something, they would bring it to her attention:

They come first thing in the morning and they bed bath Paul. They cream, they watch out for little pressure points. They point out to me if they think there is something I should see. By trial and error we found out that Paul is allergic to the catheters, the stuff that it is made out of, and now we have a tube.

Sarah

Sarah works with the carers, and liaises with the district nurses to ensure that Paul gets the most appropriate care. She felt part of this team that was looking after her husband. She was the constant in her husband's care and this meant that she in a good position to oversee what was happening at all times. The acceptance of this role by others meant that Sarah felt that she was in control of what is happening to them both.

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Being a spousal-carer amongst multiple service involvement means different things to different people. Spousal-carers were aware to varying extents of a network of people around them. Spousal-carers discussed how the focus of their lives was on their partner and their illness, and how health care services were predominantly orientated towards their partner's situation. Opportunities to discuss their own needs with formal care providers were infrequent, and spouses depended more upon personal networks for emotional and physical support with the situation. Spousal-carers often experienced conflicting emotions regarding their role with regard to the care situation. They played a part in providing physical care, and had concern for their partner throughout the day and night. This ongoing involvement meant that the spousal-carer often felt that they were very knowledgeable about their partner's illness, and took ownership for monitoring all aspects of their situation. This could lead to conflict with health care professionals who did not acknowledge this unique insight, or their knowledge and skills.

7.2 Discussion

One main theme with four subthemes, have been utilised to illuminate the unique elements of this experience for spousal-carers. These findings indicate the profound impact of AD upon spousal-carers that is well documented in the literature (Andershed, 2006; Farber et al, 2003; Funk et al, 2010; Hasson et al, 2010; Jo et al 2007; Proot et al, 2003). These findings also support those of Beaver et al (2000), Grande et al (2004) and Hasson et al (2010) who suggest that carers rarely identify that health services provide any support specifically for themselves. To further explore the lived experience of spousal-carers I will discuss two aspects to this phenomenon that are seen to be key within the experience. Firstly, I will explore these findings in relation to the lack of support the spousal-carers experienced directly for themselves. Secondly, I will draw out a number of tensions that these people experienced in their role as spousal-carer in relation to the involvement of health care services, and discuss how these can be conceptualised as 'striving for poise'.

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Although the term 'carer' is not one which all people may identify with (Smith, 2009), taking on the role of carer was a natural progression for these participants once their partner became ill, a continuation of their previous relationship with their spouse. This view has been highlighted in other work exploring the nature of caring; for example, that the caring role may come out of a sense of duty and responsibility to their family member (Perreault et al, 2004), or as an extension to familial relationships which have altered over time as illness progresses (Jo et al, 2007).

As van Manen (1990) describes, lived experience is relational, and thus the illness experience of the biologically ill patient will have an impact upon the experiences of those that are closest to them. The physical and psychosocial implications of a partner's illness, and of undertaking a caring role are well documented (Aoun et al, 2005; Stajduhar et al, 2008). Despite the *'rhetoric of concern for the whole family'* (Smith and Skilbeck, 2008, p. 337) that pervades the philosophy of palliative care, carer's needs are not always attended to. This research study, like many others over the last decade, identified that spousal-carers do not always feel proactively supported by health services who appear not to acknowledge the impact of another's disease upon them (Hudson, 2004; Cain et al, 2004; Linderholm and Friedrichsen, 2010). It is the patient's needs that determine what support is received rather than the specific needs of the carer (Kristjanson and Aoun, 2004), and the patient is the focus of care delivery (Brobäck and Berterö, 2003). This has lead some authors to use the term 'hidden patient' (Hill, 2003; Kristjanson and Aoun, 2004) or 'hidden client' (Bergs, 2001) to describe carers. This term is used to indicate that that the impact of disease is not upon a patient as a singular autonomous individual, but that the carer may suffer with a variety of stress related ill-health, and psychosocial issues as a consequence of their situation. Several reasons have been identified in this research as to why spousal-carers may not access or utilise services. This included services not offering support, carers not identifying that they have any personal support needs, declining support as acceptance could challenge the notion that they are

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coping-well, and lack of opportunity to discuss personal needs in private, away from their partner.

Although these spousal-carers did not identify specific support given to themselves by health services, it was apparent that when their partner received support and effective health care, this was experienced as support and comfort to the spousal-carer. Cain et al (2004) used focus groups to explore the influence of palliative care services on caregivers. One of their findings was that although caregivers identified that more support for themselves would have been helpful, their primary concern was getting better care for the person they were caring for, a factor also highlighted by Funk et al (2009). Spousal-carers in this research utilised other sources for their own emotional support, especially family and friends. It is suggested that informal sources of support are particularly important to carers in light of the lack of support from formal health care services (Perreault et al, 2004). Jo et al (2007) however noted that despite the importance of informal support networks, they could also come with their own challenges and some friends and family members were not prepared to deal with terminal disease, and as such had difficulty interacting with carers and care recipients. These spousal-carers predominantly discussed positive support from their informal networks, however I feel the heavy utilisation of these networks raises some interesting opportunities for service provision and how these networks themselves are supported.

A number of tensions underpin the lived experience of these spousal-carers. These tensions are prevalent throughout the experience of being a spousal-carer in relation to health care services, and many others were evident in the contextual, background, data I obtained about the spousal-caring experience. In the context of the spousal-carer experience in relation to service involvement, the following tensions are evident:

- People wanted to remain as a wife or husband, but also to do their best in the altered role as a carer (theme 2).

- People wanted their partner to be the focus of attention, but also wanted their own role to be recognised (theme 2.1).

- People felt unsupported, but couldn't identify their own support needs (theme 2.1).

- People wanted to support their partners but might decline service help in doing this (theme 2.2).

- People wanted to talk about their own issues, but declined opportunities to do this in order to protect their partners (themes 2.1, 2.2).

- People felt that they had a unique knowledge of their own and partner situation, but did not always feel this was recognised or acted upon (theme 2.4)

Other research into the experiences of carers has identified and conceptualised this tension. For example, Harding and Higginson (2001) suggest the notion of 'ambivalence' to encompass carers' attitudes to their own needs. The notion of ambivalence is used to describe the conflict that was felt by carers, the 'push and pull' that they may feel in their everyday choices, for example the desire for recreation and time away from a ill partner may be tempered with anxiety felt at being away from them. Brobäck and Berterö (2003) describe a feeling of 'insufficiency' that permeates the phenomena of family caregivers in palliative care. In relation to service involvement the feeling of insufficiency related to their relationship within the care team. Caregivers wanted to be recognised and included as part of the care team and when this occurred they had a feeling of participation, which was a positive experience. However, when this did not occur, relatives felt like an outsider. They described the loneliness of their situation in which they desired to be seen as a person in their own right, but felt like the focus of attention was the patient. This feeling of insufficiency extended to feeling insulted where people did not value their insight into the patient's problems. Relatives perceived that they knew their loved one best, and lack of acknowledgement of this excluded them further from health care services.

In many ways, the spousal-carer experience is also unhomelike, as described in chapter six. The world of AD is strange and unfamiliar, their relationship with their partner has changed because of the illness, and they have had to undertake a new role. The space of home, which may contain medical equipment, and their relationships within the community are also changed. However, the spousal-carers' lived experience also contained the aforementioned tensions. I have conceptualised that these tensions can be described as 'striving for poise', and these tensions directly underpin the unique aspects of the spousal-carer experience in relation to service involvement. 'Poise' has several meanings that can all be used to help illuminate this phenomenon:

- Poise relates to being calm, having composure, and behaving with dignity in social situations. We see this in the spousal-carer experience where people want to be seen as coping, to not be a burden to the people they care about, and to be respectful and grateful towards the people who are providing care to their partner.

- Poise relates to a control of bodily movement and bodily posture, to a graceful manner of engaging in action. The spousal-carer wants to be seen to be holding their head high, and to be able to manage the physical demands of their partners care needs. The spousal-carer strives to ensure that the people involved in care delivery are fully informed of what is happening with their partner. They want to be respected by the care team and be seen in a positive manor in relation to their partners care delivery.

- Poise is about equilibrium, about having a stable state of balance. The spousal-carer attempts to maintain balance in in all aspects of their lives with their partner. Balancing their old and new roles, balancing their own emotional response to the situation with how they want to be seen as coping with the situation, balancing their partner's needs and their own needs.

- Poise is also about having a suspended state, of hovering or hanging. The spousal-carer feels this state of suspension. They are trying to live in the present but are aware that the future may bring untold challenges and the loss of their partner. The experience of time is altered by the knowledge that it is precious and limited. In some ways this experience is akin to being on a roller coaster, the carriage teeters at the top of a downward spiral, but for a few moments there is nothing, as though time is standing still. There is no way back from this place, to the solid ground on which you would rather stand. For those few moments there is time to get your breath, to look around, to take stock of what is to come. However this place in time is only suspended, it cannot be halted, and although there may be further moments of respite this roller coaster will continue.

The spousal-carer experience is underpinned by these factors; they are striving for balance, composure, control and space within the experience of their partners AD. By considering the spousal-carer experience in these terms, we can see how their lived experience can be seen as a striving for poise, in which their embodied experience of the world is changed in many ways.

7.3 Chapter summary

The spousal-carer has a complex relationship with health care services because of the many conflicting aspects of their everyday lived experience, as they try and protect their partner and promote normality, whilst also attempting to ensure their partner receives the best possible care. The spousal-carer's experience is littered with tensions. For example, provider and receiver of care, observer of illness who desires to be seen and heard in their own right, having feelings of being unsupported but being unsure of own support needs, believing the best way to help their partner is to decline help. In balancing these tensions, the spousal-carer can be conceptualised as 'striving for poise'.

Key relationships have been found to be a significant part of both the spousal-carers and the patients experience with regard to having multiple services involved in their care. The following chapter will explore the findings from this research pertaining to these key relationships.

Chapter 8: Key relationships with services

People affected by advanced disease have many different services involved with their care, which can be seen on the Pictor charts created by the participants. In chapter five (a), I proposed a structure to exploring the lived experience of multiple service involvement that contained three aspects. Firstly, that the experience is interconnected and shared between the patient and spousal-carer, and this has been an integrative theme across the findings. The second aspect proposed that there are unique elements, and inevitable differences in the lived experience of patients and spousal-carers because of their different ways of being-in-the-world. The findings of this analysis have been presented in chapters six and seven, where I have used the conceptualisations of an 'unhomelike being-in-the-world' and 'striving for poise' to describe the patient and spousal-carer experience. In this chapter I will build upon this analysis, and present the findings relating to aspect three of my structure of the experience. This aspect proposed that there are many elements of the experience of multiple service involvement that are experienced similarly by people, regardless of their 'patient' or 'carer' category. This analysis was developed from reflection on the experience across the patient and carer data, and through consideration of the patient and carer dyads.

8.1 Presentation of the findings

The focus of this chapter is on the participants key relationships with health services. I will consider aspects of these relationships that were meaningful, looking at the reasons for participants finding different relationships to be important within their care. The implications of these different relationships for the utilisation of health care services by patients and spousal-carers are explored. At the end of this chapter, I will consider the conceptualisation of

'authentic' relationships to describe this experience. The template pertaining to the findings presented in this chapter is presented in Table 7.

Table 7. Key relationships template

Key relationships template			
	Theme	Texts that the theme was evident in:	Theme illuminated with examples from:
3.	My care team: using a team that works for me	Sarah, Laura, Aggie, Ken, Michael, Amy, Eric, Sue, George, Elsie, Roger, Tricia, Tracey, Lucy, Charlie, Annie and Edward	Tricia, Lucy, Laura
3.1	Coordinating and managing the team	Sarah, Elsie, Amy, Michael, Tracey, Norman Charlie, Lucy, and Sue and Eric, Edward and Annie, Sarah and Paul	Elsie, Amy and Michael, Norman, Lucy and Eric
3.2 3.2.1 3.2.2 3.2.3 3.2.4 3.2.5	Significant health service relationships Individuals, not role 'Like' a friendship Knowing them, knowing me Listening to me Not solving the unsolvable	Sarah, Michael, Aggie, Eric, Sue, Elsie, Laura, George, Roger, Tricia, Norman, Tracey, Lucy, Charlie	Aggie, Tricia, Roger, Sarah, Norman, Tracy, Lucy, George, Paul and Michael
3.3 3.3.1 3.3.2 3.3.3	'My Doctor': GP involvement Desire for holistic and supportive involvement Secondary to other services In acute illness	All	Norman, Tracey, Roger, Lucy, Michael, George, Sue, Elsie, Michael, Laura, Sarah, Paul

T3. My care team: using a team that works for me

Theme summary: Patients and spousal-carers identified many people and services who are involved in their care; some of whom were more closely involved than others. Who is involved may be partly the patient or spousal-carer's choice, and the findings from this research indicate that the patient and their spousal-carer utilise the people who they find most useful to meet their needs. This may be people they feel a personal relationship with, people who they feel have the best knowledge of their condition, or people who are easily accessible to them. The use of these individuals may be to the exclusion of other services that may also be available, or may involve bypassing services that would be the 'correct' ones to use.

This is an overarching theme. In this section I will give explicit examples of where individuals have chosen to use, or not use certain health professionals for their care. The following subthemes will expand further on the notion that service users have different relationships with the professionals involved in their care, and choose to use different people to meet their needs. In this way, the patient and spousal-carer are using a team of people that works best for them.

When Roger's health had started to deteriorate he had been offered various different sources of help; one of which was the involvement of a Community Matron. This was around the time that Community Matrons were introduced into primary care, and Tricia had some insight into this role:

> Tricia: So like I think he could've been passed on to that... (Community Matron service) and I sort of said to Rachel (heart failure nurse specialist) '*Oh*', 'cos I think we would have lost Rachel. It would've become a, because they're an umbrella of, knowing something about everything aren't they? A matron? It's heart and respiratory and diabetes and, you know all sorts... They're not a, like Rachel's a specialist, and Lara

> (Diabetes nurse) is a specialist. I think they're (community matron) more of an umbrella… and they can go to the specialist to get more information. So, it should work, and it probably does, you see the two heart failure nurses went to be matrons because it were twice as much money, and they weren't working any longer.

BH: Mm, so did you not want the matron, well Ivy, is it Ivy?

Tricia: No, Ivy, yeah no. Well I think we were better with Rachel. Because Ivy wasn't a specialist in heart or kidneys

Tricia and Roger had refused the involvement of the Community Matron, as they felt that they would lose their heart failure nurse specialist with whom they had a very good relationship. As the interview progressed, Tricia went on to to talk about the individual who was in the Community Matron role, a woman who she had known for some years, and had been a local district nursing sister. Tricia knew her from the local community, but did not like her very much. She was also aware of many of the tensions amongst community nurses that had surrounded the introduction of this role, and did not want to compromise her relationship with the other nurses involved in Roger's care. Tricia and Roger's reasons for declining the Community Matron were multifaceted, but ultimately Tricia perceived this as their choice.

Laura also chose to use her nurse specialist over other nursing roles. In the following extract she is discussing the practice nurse at the doctor's surgery:

> Y' yes, she er (pause). I'm supposed to ring her, and it's supposed, they're supposed to be all involved but I find I get on easier ringing Lucy…. (respiratory nurse specialist). Oh to be honest, I don't like the practice nurse

> Laura

Laura was supposed to visit her practice nurse for medication reviews and management of her other health issues, and she felt that the practice nurse

was supposed to be her first port of call at the surgery if she had any problems. Laura discussed several reasons why she chose not to involve the practice nurse. She started by discussing the nurse's lack of availability, and that she did not seem to have up-to-date knowledge about her treatment from the chest clinic. Laura then went further to talk about the practice nurse in a more personal context; she had been a nurse at the surgery for many years and when Laura's children were little she had taken them to see this nurse. Laura did not like the attitude that she had taken to her children at that time, she also did not trust that one person could have knowledge about so many different health issues, or be a specialist in so many areas:

BH: What is it about her that, she doesn't get to hear this by the way, but what is it about her that you don't like?

Laura: She wears too many different hats I think. She does the Asthma Clinic, the Well-Woman Clinic, now she's doing the chest liaison thing or whatever it is, erm. I don't know (laughs).

BH: OK. What is it about having her having different roles?

Laura: I feel she's got too many hats to concentrate on one, you know.

Laura disliked the practice nurse as an individual, as well as lacking confidence in the breadth of her clinical knowledge. She also found that the nurse specialist who was now involved in her care met all her needs, not just her respiratory problems, and consequently no longer visited the practice nurse, despite feeling that she was using the system incorrectly in this regard.

Having confidence in a health professional's clinical knowledge, as well as being able to have a personal connection with them, was one reason for choosing to utilise certain individuals:

BH: Has he (the GP) got any involvement at the moment, now?

Lucy: No he's retired, yeah (laughs).

BH: Have you got another GP that you...?

Lucy:	Ah yes I mean there's, well there's several people, they, but I think there's about twelve of them, erm, yes and you, you do tend to pick, erm, those people…
BH:	Right, which er, people sorry?
Lucy:	The people who you can talk to and get on with who you feel know perhaps a little bit about you the er, the disease.

Lucy and her family had seen the same GP for many years and had considered him to be their family doctor. After his retirement, nobody had replaced him as her named doctor, and she had the option of seeing one of several doctors but did not identify with one being specifically for her. Lucy assessed which doctors best understood Parkinson's disease and its implications, and chose to see these people when she could, feeling that she was more likely to get assistance with her issues when this was the case.

Services were utilised where they were felt to be most likely to respond to the problem, even where they were felt to be an inappropriate person to contact:

> I did ring Mae - I shouldn't have done really.
>
> Tricia

Mae was the 'heart attack' nurse who Roger and Tricia had first had contact with in hospital. Tricia liked this nurse, who had reassured her after Roger's initial heart attack. She had rung Mae several times after Roger was initially discharged from hospital, when she had questions and concerns about Roger's condition. Tricia knew that Mae was the wrong person to contact, and knew that it was no longer Mae's responsibility to be helping her, but despite this Tricia continued to utilise her as she found Mae to be the most useful person available to her at this time.

The notion of contacting the people that are most useful, and whose company is more enjoyable seems common sense. However, as these examples demonstrate, this sometimes meant that people felt they were using the

system inappropriately. In the following subthemes I will further explore factors that have contributed to the health care relationships experienced by these participants.

T3.1 Coordinating and managing the team

Theme summary: This theme explores the idea that patients and spousal-carers may feel they have a role in arranging services, communicating between them, and coordinating the situation. Either the patient or the spousal-carer may take on this function and act as keeper for information that can be relayed between people and services as required to facilitate effective care. The patient may leave this to their partner, trusting in their skill to monitor and manage the situation for them. Sometimes health systems are complex and it becomes hard to organise the interventions required. This has implications for care, takes valuable time and may have financial repercussions.

People identified various practical aspects to their care including personal care, managing medications, attending appointments, wound care, arranging equipment, organising respite, and communicating amongst the various different services involved. Different participants took ownership for organising and coordinating different elements of this. For example, Elsie needed her oxygen with her at all times and described to me the process of arranging transport for hospital appointments:

> Because if I ring an ambulance I have to make sure its got oxygen in. Because they won't take my oxygen on there – they have to have oxygen on themselves. So if I ring an ambulance I've got to tell them I want an ambulance with oxygen on, and that I've got to have two tanks.
>
> Elsie

Elsie took charge of organising all aspects of her care, and felt that it was imperative that she knew how to organise things that she needed in relation to

her health and illness, because otherwise she would not be able to access the services as she needed. Other examples of how Elsie managed her own situation included maintaining a phone book of the names of people who she needed to speak to in connection with her care, and at all times knowing what was happening with regard to getting the interventions she needed. This ranged from ordering prescriptions and arranging through the local pharmacy for them to be delivered; to contacting a consultant's secretary directly to arrange a visit if she felt she needed it (something that she had not done but discussed that the she would do if she felt it was necessary).

Many of the participants' Pictor charts show a plethora of services involved, and during my conversation with Amy I asked her how the different services knew what was happening, what each other were doing and how they communicated with each other:

> Through us. I mean, Dr Korish (GP)... Michael hasn't actually seen him for a few weeks but we did make a point of making an appointment to go and see him to keep him in the loop, cos a couple of times, early on after the diagnosis, we had to go and see him and he hadn't had a report through from the hospital yet, so, so we were sort of keeping him up to date. Whether or not he got anything through after we'd seen him I don't know, but we were keeping him in the loop and err, I don't know if they liaise between Macmillan nurses and district nurses. I don't know how it works.
>
> Amy

Michael commented on how he felt that it was his responsibility to keep the GP informed of what was happening to him:

> I do keep him informed, I go and see him, shall we say once a month, just to keep him in the loop if you like, tell him what's happening and everything else.
>
> Michael

Both Amy and Michael use the same expression, *'in the loop'*. I don't know if this was something they had discussed together, or was just a phrase that they both used, but it gave me the sense of their communication with the team being essential to the flow of information around the team. They envisaged processes that happened elsewhere, for example the nurses and GP communicating, and hospital letters being sent to GPs. Amy felt that it was their responsibility to ensure that the health care professionals knew what was happening when they visited. Partly she did this through maintaining files of information about what people had said at various health care contacts, so that she could ensure she relayed this information correctly. Amy and Michael perceived that they were the hub for activity, and if they communicated with the team then the information would be shared. They were the constant presence in the care team, and they saw everyone involved. By sharing information amongst the health care team, Michael and Amy were ensuring that everyone is in *'the loop'*, they all know what was happening in all areas of Michaels care and treatment. This is diagrammatically presented in Figure 35:
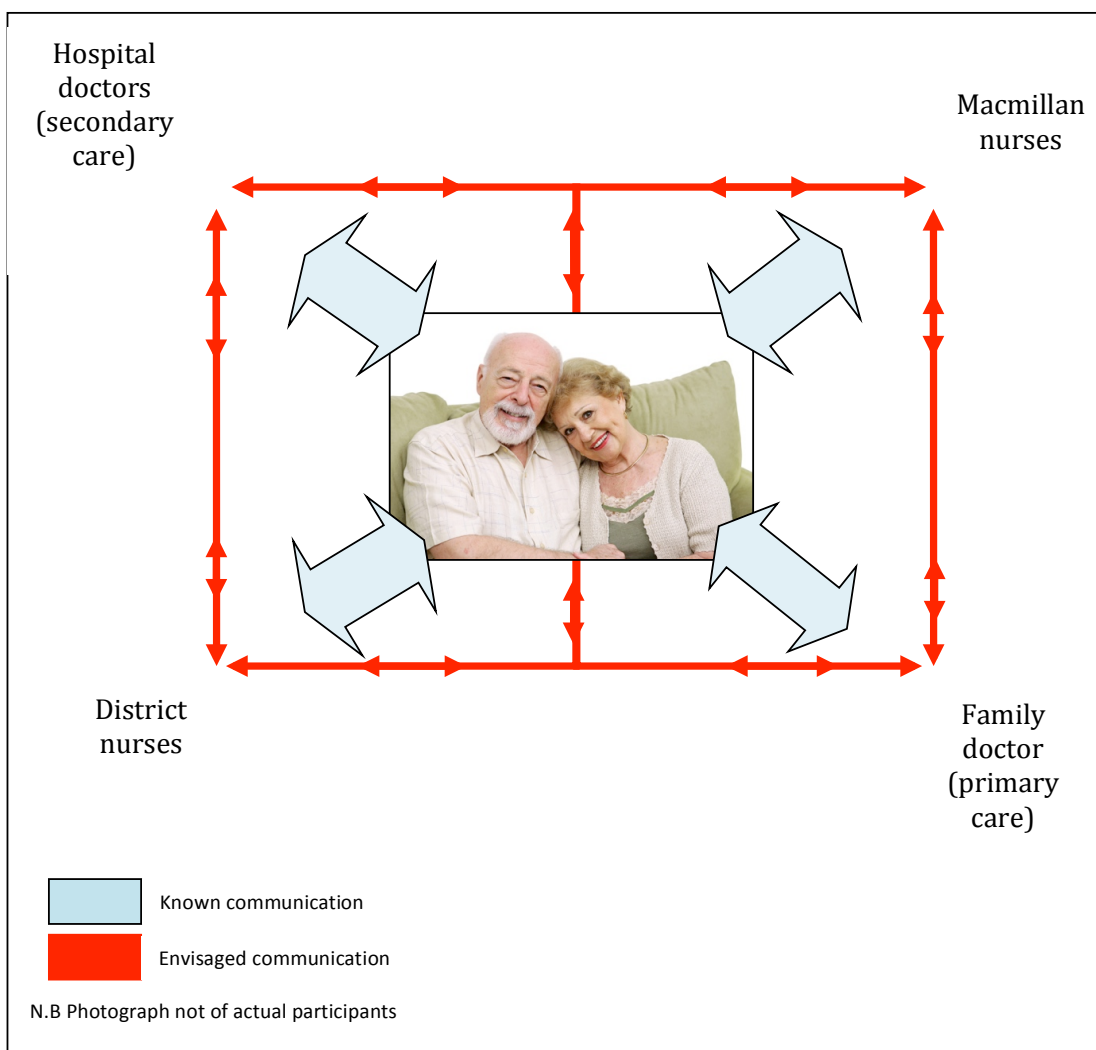
Figure 35. Communication – imagined and known processes (Michael and Amy's experience).

Michael found it hard to keep track of what was happening with his care. He did not know who was visiting when, or which information he should share with the different teams. However, he was confident that Amy had this knowledge and would manage these people, letting him know where he should be and what he should do, as well as monitoring his health and liaising with health care services when this was required:

BH: Does Amy, does she keep an eye on...

Michael: Everything, and I mean everything, I mean... if I cough its 'are

you all right', things like that. She's got her eye on the ball, no doubt about that.

Despite these actions, and feeling like she had a good knowledge of health systems and processes, Amy had not always had satisfactory contacts with health services. She highlighted one incident where she had been unable to obtain health care assistance in the out-of-hours period (explored on p.232) On this occasion she was unable to use a team of people that worked effectively for them, this left them with unresolved care issues, and a deeply unsatisfactory care situation. The outcome of this was that Amy had decided she would not use these services again, and would bypass them in an attempt to get the care she felt Michael needed. In this way, she was trying to use the best team, to get the best care for Michael.

Others also saw themselves as taking on a coordinating role. Tracey saw herself as being pivotal in monitoring and organising Norman's care. I asked her about this:

> BH: How do you keep track of, all these things going on?
>
> Tracey: With difficulty! (Both laugh) It isn't so bad actually because er, I phone most of them, and they… fortunately, what I decided to do was, I was on a 'light user' phone (tariff), and then er, there was an offer, to erm… you could have as many phone calls as you like, you just paid £50, and that was it. Well that's been a godsend to me because, er up to now I've made two hundred and twenty calls, and I'd've never afforded to pay it. So, 'cos I have to keep ringing you know.

This role was not optional for Tracey, it was part and parcel of her daily care for Norman, and ensured that she knew that everything was happening as it should be, but it has had financial implications to which she has had to adapt. Norman knew that Tracey undertook this, that she was in touch with the

various services and that because of this he did not need to concern himself with these matters:

> But Tracey's in touch with the clinic, er the, hos' at th doct' the doctors 'cos, there's erm, pharmacy, and she's, she keeps a check on me like medication and everything...
>
> Norman

Lucy, Eric and Paul all described how their partners (Charlie, Sue and Sarah) also kept an overview of what was happening with their care, and in organising various elements of this care:

> Charlie was terrific as well, he was, he, he can keep his head (laughs), erm. Yeah, he kept his head and arranged all these things.
>
> Lucy

> But that's Sue, its Sue does that. Because she works in' system so she's knows when I'll want them.
>
> Eric

> Ask Sarah, she knows everything.
>
> Paul

Lucy saw Charlie as being more capable than she was, and was proud of his ability to organise these things, and felt safe because of his ability to cope in a crisis and take control where she was no longer able. Eric also saw Sue as managing much of what was happening to him, he attributed her ability to do this to her knowledge of health systems, knowledge that he didn't have. Paul entirely trusted Sarah with organising all elements of his care. For these patients, there was a sense of relief and total trust that their partners had the skills to be able to ensure that they got the care that they needed. The responsibility for arranging care, and ensuring their needs were met had been given to the spousal-carer, who was heavily depended upon.

T3.2 Significant health service relationships

Theme summary: Not all relationships with health care professionals were the same. Relationships were often based on individual characteristics, rather than the role that the person was in. Relationships in which the patient or spousal-carer felt known, were perceived to be reciprocal, were timely and friendly, and in which the problems pertinent to the patient or spousal-carer were addressed, were often those with whom participants identified most keenly, and used the most.

When participants spoke about the people closely involved with their care they spoke about them as individuals. The relationships that they had formed with these individuals were based on personal characteristics rather than the professional role that the individual was in. This is particularly well demonstrated by Tracey who discussed how there had been three different heart failure nurse specialists involved in Norman's care:

> Jenna's (heart failure nurse specialist) took over from Denise Archer (heart failure nurse specialist). Er, now, she doesn't do the same as Denise did. Denise used to ring the infirmary and that, she really was er, she used to ring me, two, three times a week if she hadn't been, er, and she always made sure she came. Well Jenna doesn't. Jenna'll come, she'll ring every now and again and I'll speak, I mean I had Jess (heart failure nurse specialist) for a while, er, and Jess took a while a bi, of getting used to because when she talks, she's a bit abrupt, er well you know that, she's rather brusque. So er, but when we got to know her, you know, er but then it changed to Jenna, who's very good, but erm, she keeps changing his pills. She's, she's so, she wants him to be well, and this is why I see the pharmacist, I mean the pharmacist (laughs) so often! You know, she keeps changing his pills, so she's seeing him, now, she doesn't come to the house now, with him at the day centre, she's there (her base point is in the same place as the day centre). So she's seeing him tomorrow. And I weigh him and take his blood pressure every day, if there's

any fluctuation, or if he's i'll, I ring her.

<div align="right">*Tracey*</div>

Tracey missed the input that Denise had in Norman's care. She was someone whom Tracey had trusted, liked, and felt understood Norman's illness and their personal goals for his 'health'. Tracey had not developed such a personal relationship with Jenna, and Tracey rarely met with Jenna as she now visited Norman when he was at the day centre. Tracey went on to sum up the difference between the care given by Jenna and Denise:

> She's not the same as Denise you see. The... it's a different kind of nursing, I mean we d'... we don't need her.

<div align="right">*Tracey*</div>

Tracey needed care in a relationship that she trusted, from someone who understood her husband's condition and that he could not be made *'well'*. This was not something she felt that she received from Jenna, although she made it clear that she had no specific complaints about the service that was received from Jenna.

Tricia had also experienced different people involved from the same role, and had different nurse specialists involved because of both her own, and her husband's multiple health problems. She discussed many of these individuals and then summed up:

> In them jobs you get some good pe' (whispers) good people and bad people don't you, you get some better at it than others.

<div align="right">*Tricia*</div>

Several participants spoke of 'liking' the people they utilised for their care, and their feelings of friendship towards them. The feel of being cared for and cared about went beyond a clinical relationship, and there was a sense that these people were trusted to do their best:

I think me and her's (Macmillan nurse) got really close, she she's, she feels more like a sister to me than she does, and a friend, more like a best friend, than a Macmillan nurse. I know she's a Macmillan nurse but she feels like a best friend who you can just ring up and talk to any time.

<div align="right">Aggie</div>

For Aggie, the Macmillan nurse had filled a void in her life that had been left by her friends no longer having much contact with her. This was someone she felt safe with, who she felt understood her situation. Aggie was comfortable in the company of this person to whom she felt very close:

She, I mean, Bess (Macmillan nurse), a' I haven't, I don't I haven't known her for a for a long time, but for the time I have known her I feel, I feel that I've got re' I feel that I have got really close to Bess. Cos she... she's sorted a lot of my medication out and, when... when it's been late or it's not arrived at the chemist, she's been on the phone and rollocked 'em and, do you know what I mean? and said *'You best get this now'*, and *'you best...'* and... and ever since then the, soon as I say it's me, do you know they (chemist) can't do enough for me.

<div align="right">`   Aggie</div>

Bess had acted as an advocate for Aggie, had arranged things that Aggie was unable to do for herself and had smoothed Aggie's experience of her illness. She had co-ordinated some of the care that she needed, and compensated for Aggie's inability to do this for herself. The Macmillan nurse was placed very close to Aggie on her Pictor chart, and was someone that she felt was essential to her ability to cope at the time of the interview.

Roger and Tracey both described a very close relationship with the respiratory nurse specialist, Rachel:

Rachel's more like a friend than anything if you know what... because we see

her that much.

<div align="right">Roger</div>

In this quote Roger had attributed this friendship to the amount of time they had spent with Rachel, she had been a consistent presence as Roger's illness had developed. Roger and Tricia were obviously very grateful to Rachel for everything that she did. Rachel had become a familiar person in their lives, she knew about them and they felt that they had a personal connection with her. This was contrasted with the relationships that they had with Roger's consultants:

> We see the consultants as well but you don't get on a familiar footing with them do you.

<div align="right">Tricia</div>

This sense of familiarity was complemented by Rachel's availability. Roger felt that she was 'there' for him: In the extract below I think this was probably meant in a physical sense, but I felt that this 'being there' was more than being physically with Roger and Tricia. Rachel was with Roger and Tricia as part of their experience, she knew them, and her involvement made them feel less alone in living with AD:

Roger: But I can pretty well, pretty easily get hol' h' hold of her or leave a message for her so, she's on hand, I wouldn't go twenty-four hours, if I'd left a message I wouldn't go twenty-four hours without being able to, speak to her. Whereas er, Dr Craite (GP) you know you can't get I' I' if I phoned up now I'd probably not get an appointment 'til, lucky to get one at end ot' week you know.

BH: Is that your GP Dr Craite?

Roger: Yeah, yeah. But Rachel, she's always there.

Being 'known' to, and 'knowing' the person involved with care was often discussed as being important. This was sometimes simply being known by name, sometimes having a voice recognised on the end of a telephone but sometimes a deeper sense of somebody understanding the lived experience of another. Sarah described how she had become known to the reception staff at the GP surgery:

> But they know me by name. I suppose because the earlier things, when I was upset and I needed doctor, and they were so good.
>
> Sarah

Sarah found the reception staff to be particularly helpful. She felt that they took her seriously because they knew the kind of person that she was:

> The doctors receptionists have been great. I think they know I don't panic so they always take on board everything that I ask them to do.
>
> Sarah

The receptionists would arrange prescriptions for Sarah, chase up DNs when Paul had catheter problems, and would ensure that she got to speak to a doctor when she needed to. Sarah cultivated this relationship, taking opportunities to publicly express her thanks for their assistance. This relationship made it easier for her to obtain the care she needed for her husband.

Lucy had attended the Parkinson's out-patients clinic on numerous occasions. She described the warmth that she felt from the staff there and the familiarity that they had with her:

> ...and they, they greet you *'Oh hello Lucy, come on in, do you want a cup of tea?'* And you know… that's something that's really quite nice.
>
> Lucy

Lucy felt she was made welcome by the staff in the clinic and she was at ease when she was there. The use of her name contributed to her sense of being welcome, she felt recognised and seen for the person she was, rather than being defined by her illness.

Tracey had been particularly close to her district nurse team with whom she had regular contact to arrange visits for their blood tests, Norman's wound dressings, as well as regular support visits. Recently, their old district nursing team had amalgamated with another, and they less frequently saw the nurses with whom they were familiar:

> Tracey: They were in a team, and we got to know them, and I used to
>   ring and er tell them, I mean they were very good, they never
>   got it wrong, and er, I used to ring and, they'd talked to me, it
>   depended who it was, I mean er, I think they're at the, the
>   woman at your place they called her Marg, I think, and...
>
> BH: I think, yeah.
>
> Tracey: I never met her but I used to talk to her, but all the, all of
>   them got to know us very well, you know and er, when the er,
>   baby was born (grandchild), the last one, you know they were
>   interested and everything. Er, they knew all about the family,
>   and we knew about them, they used to talk about themselves,
>   and we got, we called them friends you know.

Tracey described how she would ring up and her voice would be recognised by the nurse who answered the phone, giving this as an example of how well the team knew her. She described another instance where a staff nurse who they knew well visited one day and Norman was unexpectedly unwell. The staff nurse insisted on getting the doctor and staying until he arrived, from which point he was admitted to hospital. This nurse knew Norman well, and knew there was something wrong. She cared enough to stay and ensure that Norman was looked after, and because they trusted this nurse, Tracey did not

mind her taking control of the situation. I asked Tracey about the new team and what impact it had had on them:

> Tracey: it's, disjointed, you don't know who's coming.
>
> BH: How does that make you feel?
>
> Tracey: Well I don't like it personally because, I have to stand there, and I mean they've no idea how ill Norman was, they come, they've no idea what his leg looked like before.

This new team did not know Tracey and Norman in the same way; they did not understand the severity or history of his illness. The continuity was also gone, as well as the friendship, which Tracey misses - *'the rapports gone'* she stated, *'they knew us'*.

Feeling an affinity towards the individual who was providing care helped individuals feel comfortable with their involvement:

> I like Jane, I like her coming. Its like, she's just somebody from down your road coming, and you can say really what you want, you know.
>
> Sue

Jane was Eric's nurse specialist and had been involved for a number of years. She was the only health professional who Eric accepted care from, and they had declined regular DN, and home care input. Sue also identified particularly well with Jane, not only did she have expert knowledge about Eric's condition, but she also understood Eric's way of dealing with his health problems and his dry sense of humour. Sue felt able to relate to Jane, trusted that she would do her best for Eric, and was not concerned about being judged by her for Eric's occasional belligerent behaviour. Despite this, Sue did not discuss her own concerns and issues with Jane, who she saw as being Eric's nurse. Sue did talk about her own issues during the interview, particularly her sense of isolation in dealing with Eric's illness. Sue wanted to talk to someone, without being given advice or platitude about Eric's health, and without them trying to

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resolve the problem. Sue knew Eric could not be cured, and that the approach to care was managing his symptoms, and Sue found it very hard when this did not seem to be recognised by other services:

> And I think that's the main thing, when they just listen to you. You know, when they're not butting in and saying well you know, *'take him to hospital, take him to...'*- he doesn't want to go to hospital, he's frightened he's not going to come out. *'Well there nothing I can do'*, but she listens to me (GP work colleague). She lets me moan on about it, *'well there I am again doctor, a barrel of laughs as usual'* (laughs), she just, (laughs) she just laughs with me.
>
> Sue

In this extract Sue was referring to one of the GPs that she worked with. This was one of the few people with whom Sue had been able to actually talk about how she was feeling, and the challenges she faced. These conversations made Sue feel better within herself, and she was comforted by the thought that she was really understood.

Having a positive relationship with a health professional was extremely valuable to these participants. Despite the numbers of people involved, most participants discussed one or two people who were particularly helpful to them. These relationships all varied in the length of time that they had existed for, but had similarities, particularly where the person felt that the health professional related to them as a person, and recognised their illness experience.

T3.3 *'My Doctor'*: GP involvement

Theme summary: This theme explores the notion that service users anticipate GPs having an integral role in their care. Participants often described their GP as 'My Doctor': a person who may have known the individual for many years, and had looked after family members. 'My Doctor' is someone who can be accessed based on individual interpretation of need. Some

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participants wanted their GP be involved in their care in a holistic and supportive way, and felt that regular contact would be reassuring. People described their GPs active involvement at times of acute illness. GPs were sometimes seen as a secondary service now there were lots of services involved in care provision. When GPs had little involvement, or did not seem to understand the difficulties inherent in living with AD, this could be interpreted as a lack of respect and of care.

GPs are the only specific role I have focussed on. There are two reasons for this. All participants had a GP, and consequently it has been possible to look at perspectives of this specific role across participants. Secondly, discussion of GPs, and their role, raised some strong reactions in the participants regarding their anticipated and actual involvement.

GPs are often identified in the literature as being a key primary care resource for patients with AD, therefore I was surprised by how GPs were represented on the Pictor charts. Paul, Eric, and Norman did not include a GP on their charts. Sarah, Michael, Aggie, Elsie, Annie, and Charlie placed the GP on the periphery of the chart away from other services. George, Tracey, Michael, Kevin and Lucy placed the GP pointing away from themselves.   When GPs had been excluded entirely I would ask participants if they had a GP involved in their care:

> BH: I see you haven't put a GP on your chart, do you see a local
>   doctor?
>
> Norman: Now who's them?
>
> BH: Your Doctor.
>
> Norman: I know, that's what I've said!

Norman had not seen his GP for several years. This was something of a joke for Norman, he felt that in some way his GP should be more central to his experience but could not pin point why or for what. He wanted the GP involved in his care, but could not identify a specific role for him within this.

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His physical and care needs were being met, but there was a sense that the GP should be more present in his illness experience. However, Norman was not dissatisfied with the service, or his relationship with the GP who he was confident would visit if it were ever requested. Norman, and his wife Tracey felt a connection with the GP, and Tracey described a situation when Norman and been very ill and the GP had visited:

> Tracey: Dr Sobel, who, our GP, he came in to say goodbye he says *'I'm sorry old son but, er, this is the last time I'll see you'*, (laughing), shook hands with him.
>
> BH: Dr Sobel did?
>
> Tracey: Dr Sobel, Oh yeah.
>
> BH: What did…
>
> Tracey: Norman said *'Oh, its all right, thank-you for everything'* (laughing). But, Dr Sobel once told both of us, we, he said *'if you were horses you'd have been shot by now'*. I mean, that's our sense of humour you know!

Although told in a jovial fashion, this anecdote was very revealing about Tracey's feelings about the GP. She felt that they were respected by the GP who had visited them to acknowledge that Norman was extremely ill. She also felt that the GP knew them well enough to make a joke that many would find crass. As described earlier, feeling known to a service was very important for Tracey, and although the GP was rarely involved in their care himself, she was confident he would be if they needed him.

It was striking that amongst all of the participants there was a feeling that the GP is your own doctor, in a fashion that other doctors were generally not. People discussed *'my doctor'* when referring to their GP, and had expectations of the role that *'my doctor'* should be fulfilling. There was a sense of ownership associated with the GP. This ownership was focussed on a particular GP rather than the surgery team. The sense of 'my doctor'

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extended to feeling that the doctor also identified you as 'theirs', and thus had a responsibility towards the patient:

> But he claims to be my doctor if you know what I mean, but I can never get in to see him.
>
> <div align="right">Roger</div>

I will return to an extract I utilised earlier. Lucy had spoken about '*my doctor*' and his involvement in her diagnosis a few years previously, I asked her about his current involvement:

> BH: Has he (the GP) got any involvement at the moment, now?
>
> Lucy: No he's retired, yeah (laughs).
>
> BH: Have you got another GP that you....?
>
> Lucy: Ah yes I mean there's, well there's several people, they, but I think there's about twelve of them…

Lucy had known her family doctor the whole time she had lived in the village. Her doctor had followed the family through their lives, looked after her children when they had childhood illnesses and was known to Lucy and her family. Lucy's doctor had retired and she no longer identified with any one particular doctor being hers, and rarely used the GPs. Being known to the GP had been an important part of the relationship for Lucy.

> When I say doctors, that is my own doctor.
>
> <div align="right">Michael</div>

The GP is Michael's own doctor. This is in comparison to the hospital doctors, the other doctors involved in his care. They are different to his own doctor. Michael does not feel the same connection with the hospital doctors. His own doctor is associated with him personally and Michael felt a sense of belonging to this doctor.

Others also spoke about the sense of belonging to a particular doctor:

> He's my GP
>
> > George

> I think that my doctor, my doctor that particular day...
>
> > Sue

> To have your own doctor interested...
>
> > Elsie

There was a perception that the GP was a doctor to whom there was some ownership, and who should be having an important role in the care of people with AD. Despite George, Sue and Elsie all speaking about their 'own' doctor, none were very happy with the actual role that their GP was having in their care. Their perception of the GP role, and desire for holistic and supportive care, did not match with their experience of the care that was being provided. For example, George tried to avoid contacting his GP, he felt that if he did then he would be admitted to hospital *'every time I see him he sends me to hospital! That's why I stopped going down....'*, Sue felt her own GP had no insight into her problems, and Elsie was frustrated at the lack of interest shown towards her by her own GP.

Elsie was angry about the lack of GP involvement in her care. She did not originally place a GP on her Pictor chart, and when I asked her about this she became much more animated than during the rest of the interview. Elsie felt a great sense of injustice about the GPs involvement in older people's health, not just her own.

> Elsie: Well, I haven't seen him (the GP) once in two years. And I do think he should take time out from his surgery duties to see them that can't get to the surgery. I think there should be a time that he sets aside, even if it were only about 20 minutes

that he goes round and sees these patients that's not been to see him and just have a little chat with them. If they can chat like I can. I mean, I don't, I mean even people with Alzheimer's would, I think he should take time out once every two or three months to see them.

BH: Would you find that helpful?

Elsie: No, I wouldn't find it helpful but I would find it rather nice I think, to have your doctor interested enough to come and see you every two or three months to see how you're getting on and that. Because I'm on his panel you know. It doesn't mean to say because I don't make appointments to go and see him that there's nothing wrong with me. Because there is something wrong with me and he knows all this.

For Elsie, having regular GP involvement was not about having particular health needs that needed attending to, it was about being acknowledged by her GP, and about him making a small amount of time for her and noticing that she is living with severe illness. Elsie felt that her GP had some responsibility for overseeing her health, but that he failed in this responsibility towards her. Interestingly, Elsie never requested a GP visit, and did express confidence that if she asked he would visit. Elsie's frustrations seemed to lie in a more deep-rooted belief in how the GP should behaviour towards her, and other 'elderly' people. The potential visit from the doctor would represent much more than a medical need, it would show respect and value towards her, and others in her situation.

All patient participants were continuing under the care of some form of secondary service for their AD, ranging from disease specific consultants, to palliative medicine specialists. Roger saw several different consultants for his various conditions (diabetes, heart failure and prostate problems), and these visits had superseded his contacts with his GP.

He's involved, but er, I've not seen him for ages, yeh, I used to see him pretty

regular but... (pause) Er, ss I'm, been to hospital I don't see much of him (GP) now.

<div align="right">Roger</div>

Roger partly attributed this lack of involvement to practical matters, his principal issues were being addressed somewhere else. Roger was rather scornful of the GPs, and the GP surgery staff, he described them as '*airy fairy*', not taking his problems very seriously or dealing with them in an effective manner. They did not understand the difficulties his illness caused him, demonstrated through their reluctance to do a home visit:

> I don't think doctors are that much involved anyway nowadays. It's like them not coming out and visiting and that sort of stuff. I mean, it's off days... I ... I struggle to get to the end of the drive. I mean it's not as if... but they won't come and see you.

<div align="right">Roger</div>

Roger did however identify that the GP was still a central person in his care provision. He described how he would contact his GP for any new problems rather than speaking with Rachel (the heart failure nurse specialist, his preferred health care worker). Roger's reasons for this were two-fold. Firstly, he *'did not want to stand on too many toes'*, knowing that there had been previous conflict between Rachel and the GP about medication issues. The GP had overruled Rachel's advice, and Roger was aware that *'Rachel can't say anything because, she's the GP int' she, she's the one who's in charge sort of thing',* perceiving that there is a hierarchy of authority which he should not challenge. Secondly, Roger felt that by seeing his GP he was reducing Rachel's workload, he knew how busy she was and did not want to place extra work on her by directing all his queries towards her. In this way Roger was protecting Rachel, and helping her in her work.

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Others also described how GPs had become less involved in care now other services were part of the care team. There was awareness that the GPs involvement was ongoing, despite not seeing them in person.

> Now Tara (respiratory nurse specialist), Tara n' the doctors in hospital have took over properly, mm, well. They've took over really, I'm still under Dr Talbot (GP) for (inaudible), but they've, they're the ones that look after me.
>
> George

> I don't know where I would but the doctors (GP) on that particular thing (Pictor chart). He's sort of down here we'll say. As a secondary…
>
> Michael

Laura described her relief at the fact that her involvement with secondary care services meant that she could use the GP less. It is very hard for her to access the doctor's surgery. The surgery had no car park, there was a steep ramp to access the building, and she was afraid that Kevin would hurt himself by pushing her up this slope. Then there were two separate doors to navigate through before the waiting area was reached. Before she got access to the chest clinic and the nurse specialist, she used to try and contact the GP to get help with her chest problems, but her doctor only worked part time and was *'reluctant to come out'* so she would generally be spoken to by a nurse on the telephone who would arrange antibiotics. Laura compared the care she received from the chest clinic whose care she was now under, and that which she had received from the GP:

> I think they (chest clinic) are more aware, well, they probably see more peop', obviously they'll see more people than just me but, they seem more aware of my problems and the struggle I've got with it.
>
> Laura

She went on to describe:

...and the chest clinic, erm, you know, I'm not just a 'patient'

<div align="right">Laura</div>

The access issues and the GP's reluctance to visit contributed to Laura's sense that the GP did not understand how it was to live with COPD. She saw their role now as being to provide her medications, and chose to utilise other services, particularly her nurse specialist, for any issues other than this. At the chest clinic, Laura was more than someone who needed medications, more than someone who had an illness and needed help. She felt like a person in these contacts, someone of value.

Sarah did not initially include a GP on her chart:

> BH: Now, you've not included the GP on here?
>
> Sarah: Well I haven't seen him since Paul was ill. Right, not seen the doctor at all. I mean I'll put him on, but right on the periphery. Yea. That doesn't mean to say he wouldn't come if I asked him. But, I think that I thought he might just come you know, and call in just to see how things were going. But I do know that I would get one if I asked for one.

Again, Sarah was confident that the GP would come if ever she requested it, and she had no concerns about the quality of the medical care that was provided and described the GP as *'helpful'*. She also described how the GP had been very good when Paul had developed spinal cord compression, a view that was shared by her husband:

> The doctors were really good because they came, they must have come everyday, sometimes twice a day, and he called in on the way home to see how things were.

<div align="right">Sarah</div>

I've not seen him at all since last time I went to hospital... I think first time I

need a doctor he'll come. Because he used to say, before, '*I'll go, because I'm*

involved', and he was, he did all he could to stop me being sick before he sent

me in hospital, before they got me to hospital.

<div align="right">Paul</div>

However, Sarah was '*a bit surprised*' that the doctors had never been to see Paul since this time; she had anticipated that they would visit to see her husband because of his health issues, and this expectation had not been fulfilled. Sarah felt that a regular visit would be comforting and give her confidence, rather than meeting a particular medical need:

I think, I think I've put him down there because I feel that it wouldn't hurt

just once a month for somebody to do a visit. I think you'd feel slightly more

reassured.

<div align="right">Sarah</div>

Most people expressed confidence that if they ever requested a GP visit for a medical problem then someone would come. It struck me that what some people desired was not the eradication of ill health, or a particular medical intervention, but rather they wanted recognition from their doctor, a person who possibly knew them before the presence of AD. They knew that their, or their partner's illness, was incurable and that little could be done, but they wanted their doctor to hear their story and acknowledge their experience.

8.2 Discussion

This chapter has explored key relationships within the network of services involved in care provision. The overarching theme 'my care team: using a team that works for me', has considered how people utilised services and individuals within their care network. I have explored the notion that certain members of the care team were more significant than others, based upon the

relationships that were developed, and the anticipated role of the service. Research has frequently demonstrated that the type of relationship held with a care provider is an important component of the care experience. For example, the feeling of being known by a care provider (Conner et al, 2008; Worth et al, 2006), having a personal style relationship (Exley et al, 2005; Hasson et al, 2011; King et al, 2004), and feeling cared about (Koffman and Higginson, 2001: Grande et al, 2004) are all aspects associated with positive health care relationships. Where services are associated with not taking problems seriously, this can be a distressing care experience (Richards et al, 2011). The findings of this research suggest that the different relationships held with health care professionals impact on how people use and respond to health care services. I have also suggested that patients and carers sometimes take an active information sharing, and coordinating function as part of their care team. In this discussion I will consider the conceptualisation of 'authentic relationships' to draw together this experience, exploring how this notion can help to describe the different relationships that people discussed. I will also consider the specific coordinating element of patients and spousal-carers experience, and their reaction to the perceived and actual GP involvement in their care.

Relationships are a fundamental part of human experience, through which humans attach meaning and purpose to life (Hawthorne and Yurkovich, 2003). Much of health care is a fundamentally interpersonal experience (Thorne and Robinson, 1998). Patients and their families enter into a relationship with health care workers that can have a significant impact upon the experience of health care, and their lives:

> The characteristics and actions of health care services and staff, and the ways they relate to patients, have implications for patients' experiences of being enabled (or not) to feel, be and do what they value feeling, being and doing – in the course of their health care contacts and beyond. Experiences of health

care delivery matter because they shape and represent capabilities that are key to how well people's lives can go.

<div align="right">Entwistle et al, 2012, p.73.</div>

This chapter has dealt with a variety of relationships, all meaningful to those within them, and some of which have eased the experience of AD. I propose that the concept of 'authentic relationships' is useful in describing the lived experience of relationships with care providers.

Authenticity as a concept has developed from existentialist philosophy. Spinelli (2005) suggests that 'authenticity', as used by Heidegger, refers to *'the capacity that each of us has to embrace Being as it presents itself to us as ours.'* and 'inauthenticity' emerges when people interpret themselves as '*reactive victims of experience'* (p. 110). Heidegger proposed that Daesin lives predominantly in an inauthentic mode of being. In this mode we are moving along in the everyday world of existence and have unquestioning acceptance of our circumstance, thus denying responsibility for life's choices and hiding from the possibilities of freedom (Flynn, 1999), therefore avoiding the reality of our limited, mortal existence. However, the authentic mode of being has the characteristics of truth and responsibility. In this mode, Daesin owns the choices that he makes, and embraces the freedom that is his. Existence is no longer taken for granted and there is acceptance of the inevitable reality that is being-towards-death. It can appear that there is a moral judgment associated with these two ways of being, however Moran (2000) suggests that Heidegger did not intend any moral association with either, and he considered both to be 'normal' elements of being-in-the-world.

When I refer to authenticity in relation to the relationships described in this research, I am not referring to a relationship in which authenticity is promoted, for example through an interaction in which the goal is an increased authentic being in the patient, or a relationship in which the health professional perceives themselves to be behaving in an authentic way by 'being real' as their normal self (Aranda and Street, 1999, p. 77). Rather, I am referring to

the perceived way of being of the health professional within the encounter that engenders a sense of acceptance, comfort and security in the patient or spousal-carer, who feel a connection with the person providing care. In the authentic relationship, the patient and spousal-carer can relate to the health care professional who is available and approachable, this person is present with them as part of their illness experience, and subsequently the patient and spousal-carer feel known to them. In this relationship, the patient and spousal carer are able to live with the illness in a way that is true to themselves.

Authenticity is a concept that has been applied in the literature around health care relationships. Authenticity is seen as an important component of therapeutic (Starr, 2008) and trusting relationships (Falk-Rafael, 2001). It involves openness from the health-professional to the lived experience of the person who is the focus of the contact (Starr, 2008). The authentic health care relationship makes the patient feel like their actual lived experience is witnessed, and that they are seen as a person within the health care encounter, allowing the patient freedom to be themself, and expose their vulnerabilities (Radwin, 2000). Paulson (2004) writes of the *'mutual presence of being'* (p. 347) that can exist in a shared encounter between a terminally ill patient and a care professional. In these encounters, an authentic connection is made in which both parties accept that it may be uncomfortable experience (for example talking about issues of death, dying, loss and grief) as it is a new situation, but it is one that can be faced together. Daniel (1998) suggests that achieving an authentic relationship may involve the nurse recognising their own vulnerabilities, so that they can enter into an inter-subjective (as opposed to hierarchical) relationship with the patient through which both parties can benefit.

As a result of their research exploring the relationship between patients with breast cancer and their surgeons, Salmon et al (2011) define authentic caring as *'practitioners' conscientious execution of their role'* (p. 448). They found that despite consultants disregarding patient cues about emotional and personal difficulties, both parties felt that their was a personal connection, this was because of the perception that surgeons were being 'themselves' and

acting with sincerity, which was then interpreted by the patient as showing them value and treating them in a genuine manner. Interestingly, they also describe how both patients and surgeons were aware of the limits of this relationship, and that the personal relationship did not extend beyond the surgeons role. Authentic relationships are also demonstrated by Carlsson et al (2006), who explored violent encounters between patients and formal carers within a psychiatric care setting. They identified two essential themes pertaining to the situation: 'authentic personal' and 'detached impersonal' encounters. Authentic encounters were characterised by a sense of 'presence' from the staff member who appeared to allow themselves to be affected by the suffering of the person that they were dealing with. These encounters were experienced as straightforward, sincere, and respectful. In these encounters, the patient felt that the formal carer was willing to listen to their story, and that there was room for a two-way dialogue; feelings of security and confidence were engendered. Contrary to this, the consequence of detached impersonal encounters was that the patient had feelings of insignificance and worthlessness that made them feel helpless.

Seno (2010) describes authenticity in end of life health care encounters from a provider perspective. She undertook interpretative phenomenological research with six experienced nurses, with the aim of discovering what the nurses felt happened when they helped the dying and their families to cope better with their situation. Seno's work focuses on people at the end of life, but this is defined as encompassing sudden death, imminent dying, having a prognosis of weeks or months, or having no set prognosis but an anticipated life expectancy of less than twelve months. Seno found that these nurses behaved in such a way towards their patients that it enabled the patients' *'to be themselves, the way they are'* (p. 383). Authentic behaviour incorporates a *'full sustained presence that facilitates rapport'* (p. 379), this is a step beyond momentary empathy, and facilitates a balance between individualisation and the sense of being-with others. Seno describes five interwoven patterns from the nurses narratives which illuminate authentic being-with others in end of life encounters; being comfortable with, and accepting of death; personal experience with death and dying that enabled them to connect with, and

engage and attune to patients, families and other healthcare providers; being possessed of an optimum (authentic) state of mind, a condition of authentic being-toward-death; being able to call forth what another knows; and situating and regulating interpersonal space, organisational and system circumstances on behalf of the family and dying member.

Seno's patterns were expressly developed from an exploration of how the nurses could promote good death experiences, and as such the original application of the patterns is orientated towards the very end of the illness trajectory as the patient is nearing death, and families are bereaved. However, within these patterns are behaviours from the nurses that they perceived helped the patient and their families in their experience. Building on the work of Seno, I have conceptualised that what the participants in this research describe when they discuss the important relationships in their care, is their own sense of being-with-others in their AD experience, their own authentic and non-authentic relationships. In Table 8, I have applied Seno's five patterns to extracts from the participant's narrative, which demonstrates how the patterns can be applied to authentic and non-authentic encounters for these participants. Seno's original pattern is described along with the associated nursing behaviours, alongside this are extracts of the participants' narratives that demonstrate or contradict these behaviours. The development of this table, and application of Seno's framework, formed a secondary layer to the interpretation of these participant's experiences, and it is included here to demonstrate how the conceptualisation of the importance of authentic relationships was developed. The authentic relationships described contain the feeling of being understood, acknowledgement of person, trust, familiarity, interest, care, being-there, and being given time. The non-authentic relationships do not acknowledge the autonomy, knowledge, or expertise of the person affected by AD, or recognise the effects of illness upon the person.

Table 8. Authentic and non-authentic relationships. Based on the work of Seno (2010)

The five patterns of being-with in end of life care (interwoven and interconnected)	Patterns applied to patient and carer experiences in advanced disease: authentic	Patterns applied to patient and carer experiences in advanced disease: non-authentic
Pattern one: being comfortable with and accepting of death Knowing that death is as much a part of life as is living.	They (family) think cancer's an... it is an illness. Cancer is an illness but, a' at the moment, they're (health staff) the only ones that could talk to me, and make me feel better in meself. (Aggie) I like to hear the truth, I don't like people humming and arring about me. I just want people to say what they mean, and let me know what it is. (Elsie) We talked it through (with Macmillan nurse), I've prepared myself, and I've got a booklet, you know. For when things deteriorate. I know what to expect in a way. (Ken)	I never sent for a doctor because if a doctor comes all he says is go to hospital. And I know what to expect in hospital and I'm not going to hospital. (Eric) But, 'cos she wants to cure me! (Sister) She wants to cure me and it's not... it's not gonna work is it. (Aggie)
Pattern two: personal experience with death and dying that enabled them to connect with, engage and attune to	I know she's a Macmillan nurse but she feels like a best friend who you can just ring up and talk to any time. (Aggie)	I mean we see the consultants as well but you don't get on a familiar footing with them do you. (Tricia)

The five patterns of being-with in end of life care (interwoven and interconnected)	Patterns applied to patient and carer experiences in advanced disease: authentic	Patterns applied to patient and carer experiences in advanced disease: non-authentic
patients, families and other health care providers.	She listens to me (pause) she listen's to a lot of stuff, and she don't interfere, she don't interfere. (Aggie about Macmillan nurse)	You could just, you could just detect an irritation, that 'I've allowed you to sit in here, just be quiet cos I know best'. (Charlie talking about discussing treatment with a consultant)
Attuned to and sharing emotions – prerequisite to understanding another's inner world.	Rachel's (nurse specialist) more like a friend than anything. (Roger)	Nobody's said anything, nobody has said anything about my throat. I think their main concern is my
Having a full and sustained presence.	They knew all about the family, and we knew about them, they used to talk about themselves, and we got, we called them friends you know. (Tracey)	chest, they're not bothered about my throat, that's how it seems. (Michael. Services not listening to his perception of the problem)
Enabled by experience.		
Being present – listening.	And I think that's the main thing, when they just listen to you. (Sue)	
	…and the chest clinic, erm, you know, I'm not just a 'patient'. (Laura)	
Pattern three: possessed of an optimum	And er, but she's (heart failure nurse specialist), she's	She said 'I'm not interested, I'm the nurse, and I say

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The five patterns of being-with in end of life care (interwoven and interconnected)	Patterns applied to patient and carer experiences in advanced disease: authentic	Patterns applied to patient and carer experiences in advanced disease: non-authentic
(authentic) state of mind.	got time for you, you know you go in and she'll sp' sit and speak to you, ask how you're going, ask how Tricia	what we do!'. (Tracey)
State of mind that is clear, calm, open and unknowing.	is all all that sort of stuff. (Roger)	Amy did tell them about the clinical history but they didn't seem to know what they were doing, and that was the worrying part. (Michael)
Pattern four: they were able to call forth what another knows	Rachel, she's always there. (Roger)	So we knew he were dehydrated but he (Doctor) insisted he weren't. (Amy)
Being with physically (touch) and mindfully (presence).	We built up a rapport with them. (Tracey discussing DNs)	
Letting people be, how they need to be at that time.	The doctors were really good because hey came, they must have come everyday, sometimes twice a day and he called in on the way home to see how things were (Sarah)	
Identifying needs.	I just tell him if I want to see him if I'm not feeling to good and if I can't get out to see him he's promised	

The five patterns of being-with in end of life care (interwoven and interconnected)	Patterns applied to patient and carer experiences in advanced disease: authentic	Patterns applied to patient and carer experiences in advanced disease: non-authentic
	he'd come here to see me. (Elsie)	
	But she does take my (oxygen sats), and she talks about it, you know. And she talks about the disease and that, and err, yea, we have a laugh, shes' alright	
	Claire (nurse specialist), I like her. (Elsie).	
Pattern five: they situated and regulated interpersonal space and organisational and system circumstances on behalf of the family and dying member.	But the staff there are all very nice, they, they work there all the time, er and they're not sort of, dashing around from, or doing shift work and things and you, you don't see different people at different times you don't because they're all the same. (Lucy)	I don't think doctors are that much involved anyway nowadays. It's like them not coming out and visiting and that sort of stuff. (Roger)
		Don't get me wrong I suppose they do know what they were doing but they gave the impression that they had no idea and all they wanted to do was get in and get out as quick as they can. (Michael)
Making comfortable through changing the environment.	I wouldn't go 24hours if I left a message, I wouldn't go 24 hours without being able to speak to her (nurse specialist). Roger	There is a ramp up to the surgery doors, and the doors are only really wide enough to get the wheelchair in,
	If we've wanted anything, what did I want, something	

The five patterns of being-with in end of life care (interwoven and interconnected)	Patterns applied to patient and carer experiences in advanced disease: authentic	Patterns applied to patient and carer experiences in advanced disease: non-authentic
	I could only get from Sheffield, and the next day it was here. That's how good they are. (Michael talking about the Macmillan Nurse)	so I have to drop her off at the kerb, and then go and park the car and them Ill come back and take her in. Then she's shattered when she goes in to see the doctor. (Kevin)
	What I do find, which is very helpful, they have this contact with the GP practice (Ken, discussing how DNs can arrange things through the surgery for him).	You try and get a home visit and they won't come. (Kevin)
		On the Saturday I rang the emergency doctors, because of course all the surgeries are closed, and they sent a nurse out and gave an injection, which didn't do any good and I rang again. And all Saturday night I must have spoken to 13 or 14 different people on the phone. And at a certain point you get away from the emergency doctors to NHS direct. Horrendous. Absolutely horrendous. (Amy)

The application of Seno's framework highlights the authentic and non-authentic aspects of the care experience for these participants. Linderholm and Friedrickson (2010) describe how building and maintaining authentic relationships between professionals and carers (the focus of their research) is vitally important, and involves recognition of carer's expertise by health professionals. Other research supports the idea of authenticity in health care relationships, although it does not always expressly use the term. For example, showing a genuine interest in the wellbeing of the individual (Boyd et al, 2004) being aware of an individual's suffering (Mok and Chiu, 2004), having rapport (Funk et al, 2010) and being like a friend (Mok and Chiu, 2004; Holtslander et al, 2005) are all suggested as contributing to the development of trusting relationships.

Dissatisfaction is often present when non-authentic behaviours are experienced, such as individual needs and preference not being given credence, perception of own health problems not being taken seriously, and when contacts are felt to be dehumanising (Rogers et al, 2000). Hawthorne and Yurkovich (2003) highlight that relationships in palliative and supportive care are paramount within its ethos, and where patients, their families, and formal services are brought together because of AD a *'human relationship unfolds in unique and mysterious ways'* (p. 261). They suggest that this human relationship can be overlooked in the giving of care where the focus may be orientated towards problem solving through the 'science' of palliative care, factors such as managing pain by administering analgesia and particular emphasis given to medical investigations and procedures. Attention to these aspects can negate the importance of the patient/family relationship with a health professional, and its contribution to quality of life (Hawthorne and Yurkovich, 2003), factors which have been very important to the participant's in this research.

Amongst these different types of relationship between receivers and providers of care, these findings suggest that people actively utilise individuals and services that they think will best meet their needs. This may not necessarily be the people with whom the most authentic relationships were developed;

indeed at times there was a desire to protect those people from added workload. The findings of this research indicate that people assess their own needs, and contact the person who they feel is most able to help them with that problem. Further to this, having numerous people involved can lead to patients and carers finding themselves in a position of co-ordinator between the various health and social care professionals involved, a finding also demonstrated by Smith (2009), and Funk (2009). When this happened people felt that they had some control over what was happening in their lives, although, as Smith (2009) suggests, when carers take on increasing responsibility for these activities it may further distance them from identifying their own support needs. It is perhaps not surprising that some people take on a management role in their own care, as people who have spent a lifetime managing their own lives, coordinating families, managing budgets and resources do not suddenly lose these skills because disease has entered their lives (Kellehear, 2007).

Participants spoke animatedly (although not always in a positive context) about their GP. This role was one that was important to participants, although not because of the characteristics of the individual relationship they had with a specific GP, but rather the importance placed on the GP role. This was a role in which a consistent authentic relationship was desired but not always received. There was a sense that the GP was a role with which they identified, and had a concrete understanding of the care that the person in that role should be providing. In many ways, the desired role could be seen as being a slightly romantic understanding of how GPs are involved in their patients' lives. Someone to visit them at home and who can just 'pop in', who knows them and their family, who has an overview of what is happening with their care, and who is a consistent presence in their experience. This very strong perception of the GP role was in sharp contrast to some of the other health professional roles that were discussed, where frequently there was ambiguity about what was expected from the professional delivering the care.

The Royal College of General Practitioners suggests that GPs have a central role in the care for people with AD:

Caring for people nearing the end of their lives is part of the core business of General Practice. The GP and the primary care team occupy a central role in the delivery of end of life care in the community. This role is greatly valued by patients and remains pivotal to the effective provision of all other care.

Thomas, 2009, p.2.

Burt et al (2006) suggest that the majority of GPs see palliative care as central within their role, thus the lack of involvement or seeming interest in some of these patients may be a local issue, relating to the health authority in which the research took place. Furthermore, it could be due to the specific participants recruited into this study who all had multiple service involvement, and as such could be seen to be having their health needs met by agencies other than the GP. Despite these factors, people still desired the GP to be part of their care team, but could not identify specifically why beyond intervention for acute illness episodes, or the prescribing of medicines and did not generally contact them for intervention beyond this. The GPs seemingly have a role that other services were not, or could not, fulfil. There is a desire for a relationship with the GP that acknowledges the effects of disease, and recognises and witnesses an individual's illness experience. Iona Heath (2008) argues that one of the key roles of the GP in the care of the dying is to witness the human experience of illness and disease, a role that she suggests should be shared with other colleagues. She writes very persuasively of the value of this role, which is in part related to the value placed upon ordinary human life. Heath argues that amongst so much change within primary care (and she was writing before the 2010 white paper) there is a risk of losing these elements to care. These findings suggest that although many members of the health care team were providing this role, there remained a strong desire for GPs to also be involved.

I have discussed the concept of authentic relationships in the care of people affected by AD, and the implications of non-authentic relationships. I recognise that in the current context of health care provision in the UK, the

type of relationship I have described may be hard to achieve in clinical practice, and in the following chapter I will explore the implications of this research for the practice setting.

8.3 Chapter summary

This chapter has presented the findings of the data looking across the patient and spousal-carer experiences. I have identified that a variety of relationships exist between the service user and the services involved in their care, and that service users may chose who to use for their care provision based upon their previous experiences, and personal preferences. I have used the conceptualisation of 'authentic' and 'non-authentic' relationships to help describe the experience of these relationships.

In the following discussion chapter, I will draw together the analysis from the finings presented across the four findings chapters. I will also evaluate the effectiveness of the Pictor technique, exploring its value as a research tool when used with people affected by AD.

Chapter 9: Discussion

This research set out to explore the everyday lived experience of people affected by AD in relation to the multiple services involved in their care. Throughout the previous four chapters, I have laid out the structure of this experience by using phenomenological writing as method, supported by Template Analysis to help organise the findings. I have explored the 'parts' of this phenomenon and attempted to explicate and make recognisable the meanings that were implicit in the lived experiences of the participants (van Manen, 1997b). In this chapter, I will draw together this structure by taking a wholistic approach (van Manen, 1990, p.92) and identifying essential themes in order to express the possible overall meaning of the phenomenon. These essential themes will be used as a basis for discussing the implications of these findings for further research and practice. I will also take the opportunity to critique the research methodology employed in this research and consider the strengths and weaknesses of the approach taken. Finally, I will personally reflect upon the transformational nature of the research process.

9.1 Essential themes

Chapters five to eight thematically presented the findings of this research. In this section, I progress beyond the particularities of the experience of multiple service involvement (the incidental themes) in a move towards the essence, or essential themes of the experience. There is some debate in the phenomenological literature as to what constitutes 'essence', and how the notion is be applied in phenomenological research (this was explored in chapter three). Descriptive approaches to phenomenology are most often positively associated with the notion of essence. The interpretative approaches suggest that it is not possible to obtain universal essence, as it is not possible to transcend our understanding of the world, because we exist in the world and cannot separate ourselves from it (Rapport, 2005).

The influence of both descriptive and interpretive phenomenology is evident in van Manen's approach to essence. Although he acknowledges that it is impossible to transcend experience, he maintains that there are essential aspects to phenomena that can be ascertained by considering '*aspects or qualities that make a phenomenon what it is, and without which the phenomenon could not be what it is*' (van Manen, 1990, p. 107). These essential aspects should not be confused with generalisations about human nature or human life. Rather, they are concerned with *possible* human experience, and it is acknowledged that the determining of meaning will always be incomplete and tentative (van Manen, 2011).

9.1.1 The process of identifying essential themes

In attempting to identify essential themes, I undertook the method of free imaginative variation. This involves asking of the theme '*is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon*' (van Manen, 1990, p. 107). In searching for essential themes, I spent a considerable amount of time mulling over the lived experiences of these participants, considering their words and questioning my analysis. I was struggling to bring into language what I was seeing within the texts of these participants' experiences. As van Manen (2006, p, 718) states:

> The problem of writing is that one must bring into presence this phenomenon that can be represented only in words—and yet escapes all representation. The writer who aims to bring the object of his or her gaze into presence is always involved in a tensional relation between presentation (immediate "seeing" and understanding) and representation (understanding mediated by words).

Sometimes moments of insight appeared as if from nowhere, for example during the time I was grappling with the initial analysis of the data, I took a few days off for a camping trip with a friend. As I was driving to the campsite the following words came to me:

Be here with me, let me be your friend

So that you can be mine

And I can trust you, until my future ends.

This crude poem captured something that I was seeing in the text but was struggling to describe in words. It incorporates the notions of being there, reciprocity, desire for friendship and a personal-style relationship, trust, ownership, time, and awareness of the finitude of life. From this initial insight, and through the writing and rewriting of the incidental themes pertaining to the structure of this phenomenon, I finally felt able to create a sententious phrase[13] (van Manen, 1999) that captures what I perceive to be part of the essential meaning in this experience.

> Advanced disease and multiple service involvement affects a person with illness and those who care about them. It is characterised by a desire for balance on the shifting sands of an alien embodied experience. Health care services, and authentic relationships, are important when people experience an unhomelike being-in-the-world, or are striving for poise. The multiple services involved in an individual's care create a unique health care team.

There are four essential themes within this sententious phrase, which I will consider in turn. I will also explore implications of each theme for practice and further research. A tension exists for phenomenological researchers working in the health sciences. On the one hand, phenomenological research aims to produce rich descriptions of experience that attend to everyday aspects of lived experience. It aims to create empathic understanding of the phenomenon under investigation, whilst encouraging thoughtfulness and personal reflection on the phenomenon in the reader (van Manen, 2001). The findings of phenomenological research do not aim to be generalizable, and do not lend themselves to specific recommendations for the clinical environment.

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[13] Van Manen describes the sententious phrase as one that may capture the fundamental meaning, or main significance of the text as a whole.

Having said this, the creation of phenomenological descriptions and the process of identifying essential themes that characterise the phenomenon does highlight issues of relevance to the practice setting. In the following discussions I will raise some of these issues that directly relate to practice. However, I do this with the caveat that practice changes should not be made solely in the light of these findings, and that these findings should be used in combination with other research, and specific evaluation of interventions, to explore the effectiveness of changes in practice.

9.1.2 Advanced disease and multiple service involvement affects a person with illness and those who care about them

It is clear that although disease affects only the body that contains it, illness affects the patient and those that 'care' about them. I have used the integrative theme *'the interconnectedness of patient and spousal-carer experience'* to encompass the notion that this phenomenon is not experienced in isolation, but affects the diseased person and their partner. Further to this, based upon my own lived experience as a practitioner and a researcher, and my reading of the literature, I propose that the effect of AD extends beyond the spouse of a person experiencing illness, and continues to other family members, friends, community and indeed those formal health providers who have contact with them.

Illness affects all those who have contact with it, although the meaning of that illness will be different across individuals and contexts. This different meaning can be demonstrated by an example from clinical practice. It is Friday afternoon and the busy primary health care team have just received another hospital discharge that is going to stretch resources, and compromise the care of others in the locality as they strive to provide optimum care to all. For the patient it is also Friday afternoon, you are being discharged from hospital because there is nothing more that medicine can do for you, and you are coming home to die. You and your family are uncertain of how the immediate

future is going to develop, or who is available to help support you with these rapidly unfolding events.

Implications for practice and further research

It is apparent from this research that a lack of recognition of the effect of illness upon spouses, and a lack of acknowledgment of their intrinsic role in the life of their partner has a significant impact on the being-in-the-world of the spousal-carer. This finding is reported elsewhere in the research literature (Higginson et al, 1990; Payne and Hudson, 2009; Soothill et al, 2001; Payne et al, 1999), and despite decades of research in this area, carer related issues are still not being met. There are many potential reasons as to why carer issues remain unresolved. One possible reason is suggested by Foster (2005) who proposes that the term 'carer' acts as a technical way for health and social care services to relate to a role that is common to many people at some point in their lives. The use of this term places a formalised label to something that the participants in this study undertook through commitment and love to their partner, rather than as a choice. I am certainly not suggesting at this point that carers should not be assisted with their role, but I do propose that the current concept of 'carer' as an abnormal way of being may be unhelpful to both those who are functioning within that role, and those that seek to help them. Molyneaux et al (2011) argue that the term 'carer' is ineffective and contributes to the lack of utilisation of services designed to help those in informal caring contexts, as well as turning what can be perceived as *'a normal human experience into an unnecessarily complex phenomena'* (p. 423). They state that the original intention of the utilisation of the term 'carer' was to bring to political and public attention the experience of carers (a previously hidden population) and subsequently improve both the experience of carers and those that they care for. There are a range of services, charities, and support interventions that are available and targeted at carers. However, this research has identified that people may not self-identify with the 'carer' title, a finding echoed by Smith (2009) and identified at a national level (DH, 2008b), a factor likely to impact on their utilisation of such services.

Molyneaux et al's suggestion for addressing this situation is a reform of the terminology used in this area – from a 'carer' approach, to a *'relationship-based description of caring'* (p. 434), which would allow for the principles of individualised care as the relationship between the person receiving care and those that are providing it is identified. This approach could potentially have made a difference to the spousal-carers who participated in this research who so keenly identified with being a spouse, and who accepted the carer label secondary to this status. In this relationship-based approach, services would identify the relationship between the person providing the care, and the person receiving it. This approach challenges the assumption that 'caring' for someone with AD has the same possible implications regardless of relationship, and encourages practitioners to consider the person within the situation, rather than the role they undertake.

I wonder what the health professionals identified by these spousal-carers would say regarding their involvement with spousal-carers as a population? I suspect that they might be surprised by how they were perceived as not having an interest in the spousal-carers issue's, and by how alone this could make the spousal-carer feel. It would be interesting to conduct further research considering the spousal-carer and the health professional dyad in relation to this issue.

9.1.3 A desire for balance on the shifting sands of an alien embodied experience

I have used the metaphor of shifting sands to try to capture something I found hard to describe about the lived experience of AD. Shifting sands are not solid underneath your feet; they are continually moving, and changing shape. They can both reveal things that were once hidden, and hide things that were once present. On tidal beaches these shifting sands are washed and changed everyday – removing what has gone before and laying afresh a new landscape to experience. Sands can be hard to run on and run away from, they slow you down, they can be scary - sand can suck you in, drown and

suffocate you; but conversely can also be comforting - warm on your skin on a sunny day. Sand needs things to catch it, hold it and stop it from spreading to where people do not want it to go. Plant growth on sand dunes stops the wind whipping the sand away; trees planted by the side of the road in the desert stop sand spilling onto the tarmac. Sand is made up of millions of tiny grains that constitute its wholeness, these grains can be looked at individually, but it is not until you look at them all together that you can see the landscape that the sand has created.

If this metaphor is applied to the experience of people affected by AD, the complexity and uncertainty of this situation is highlighted. AD is a condition that develops and evolves; people frequently experience new symptoms, whilst old symptoms that once dominated experience recede or become better managed. The experiencing of AD changes people, it can reveal aspects to personalities that were once hidden: strength, resilience, determination, fear or anger. Every day living with AD is a new day, and some of these are good days, some are bad days. AD changes the pace of life; the embodied experience of symptoms reduces the ability to move quickly despite the mind potentially remaining active. There is no ultimate escape from the disease, or the experience of living with AD. However, there may be moments of respite where other aspects of life take precedence, and a sense of returning normality as unfamiliar embodied experience becomes more familiar. People need help to live with AD. They need support to learn about their situation, to manage symptoms, to address psychosocial consequences of disease, to adapt to a new way of living, and to reconsider the future. In understanding this experience we can break it into its constituent parts, but it is not until you step back from these parts and consider them together that it is possible to begin to appreciate this experience as it is lived.

The embodied experience of the person with AD has become alien as they experience continual changes within their body that affect their being-in-the-world. The embodied experience of the spousal-carer has also become alien; their own health possibly affected, combined with alteration in the embodied relationship with their partner who may feel and respond differently to physical

contact, and who may move differently within the environmental space that they share as a couple. In addition, there is a change to the physical limits of their environment, and the 'space' of the home environment as equipment and visiting health care professionals become a presence in what was once a private environment.

Amidst this abnormal world, there is a continual drive for balance. This balance was particularly discussed in chapter seven where I conceptualised the spousal-carer experience as 'searching for poise', but balance has been alluded to throughout the findings chapters and includes both physical and more existential concerns. In relation to service involvement, this desire for balance is evident in the everyday contacts that people had with the services involved in their care. A balance between being able to cope with illness, and gauging that support is required; between following the advice of a health-care professional, or following one's own instinct; between wanting to be independent of assistance, but desiring reassurance through a health professional's presence; between not wanting to burden those who help, but wanting to have problems resolved; between wanting to be included as part of a team, whilst being recognised as an individual.

Implications for practice and further research

Inherent in this balance is the need to make choices, and these decisions represent some of the many choices that people have to make in regard to their own care. Much has been made of 'choice' in recent palliative, supportive and end of life care initiatives (DH, 2008a; NEoLCP, 2008; NICE, 2004). These choices have been particularly highlighted around preferred place of care and location of death. However, I suggest that there are many other choices that are of significance to people living with AD. These daily choices, and the meanings attached to these decisions, have the potential to impact significantly upon the lived experience of individuals, although are undoubtedly much harder to measure and audit as outcomes for service development and delivery than preferred place of care and death. Bottorff et al (1998) also recognise this situation and describe how everyday choices are

linked to people's expression of their autonomy. They highlight that although these choices may appear mundane, they are important to people with progressive disease as they experience loss of personal control in other areas of their lives.

Practice needs to attend to people's experience of these choices, acknowledging their presence and providing people with the information to support them in their everyday decision-making. Additionally, many of these choices have implications for whether people access and utilise health care services. Research into how best to support people with these everyday choices, and consideration as to how to raise health professional's awareness of the presence of these choices, has the potential to positively impact on the lived experience of AD.

9.1.4 Health care services, and authentic relationships, are important when people experience an unhomelike being-in-the-world, or are striving for poise.

In chapters six and seven I discussed the notions of an unhomelike being-in-the-world, and striving for poise, and described how these conceptualisations of the embodied experience of illness helped to describe the experience of the participants in this research. In chapter eight, I explored the notion of authentic relationships being significant to individual's experiences, and as a positive factor associated with service involvement.

I have situated patients and spousal-carers as partners in the creation of authentic relationships. In this relationship the patient and spousal-carer felt listened to, valued as a person, that there was a shared understanding of the meaning of illness, that there was mutual respect and a sense of being able to relate to the person providing care, and that the health care professional was present with them in their illness experience. This challenges some of the prevailing consumerist influences within health care today. Rather than being

simply consumers of care, the patient and spousal-carer are active participants in an evolving human relationship that is responsive to the perpetual alteration in the being of people affected by AD. This relationship comes into existence because of a disease, but moves on to address issues of health and illness experience. The relationship between the service user and the health professional has known boundaries (for example, participants spoke of their relationship as being 'like' a friendship, not as an actual friendship) as constrained by the role of the health professional.

Where these relationships are absent, or when people encounter restrictive relationships that constrain their being, the chaos and uncertainty of AD is amplified. Their illness experience remains unacknowledged and a sense of isolation and sometimes desperation prevails.

Implications for practice and further research

This research has highlighted that relationships are very important in people's lived experience of AD. I am not suggesting that all health care relationships need to be of a very personal nature, or that the health care professional needs to attempt to build a strong connection with every person with whom they have contact. This is clearly an unattainable goal in a health service where staff have contacts with multiple people on a daily basis, and equally may not be wanted by every person receiving care (Barthow, 1997). Rather, I suggest that health professionals need to be open to a potential unfolding exchange between 'people'.

Hawthorne and Yurkovich (2003) suggest that human relationships have become a neglected and forgotten component of palliative care as the scientific model of care has taken precedence. They observe that the scientific contribution to developing knowledge and skill has been enormously influential and beneficial to palliative care, but highlight that human relationships are a fundamental element of human experience through which people achieve meaning and purpose in life:

> Nowhere is relationship more important than in illness, especially terminal illness. As a human experience, it overwhelms the body, mind and spirit and defines ones existence
>
> Hawthorne and Yurkovich, 2003, p. 262.

Although they do not directly discuss authentic relationships, Hawthorne and Yurkovich suggest that closeness, connection and sameness can offer comfort, peace and a supportive relationship for both health care professional and patient.

I have described this relationship as authentic from a service user perspective; it is authentic in that it enables them to be themselves. However, the creation of this relationship may require the health care professional to take on a persona that may not be congruent with their own, normal, everyday being-in-the-world, and in some ways could be seen as being inauthentic. This is not a criticism of the role of the health professional. Rather, it highlights the extremely skilled behaviours required of health professionals in order for them to engage with a range of service users. For the development of the authentic relationships described in this research, the health care professional needs to find a way to assess the person/couple's understanding of illness, develop rapport, engage with them on an appropriate level, create time and space (both physical and emotional) to listen to their experiences, and to open themselves to an unfolding human relationship, whilst also protecting themselves from the emotional impact of such a relationship. Aranda and Street (1999) propose that there is a problem with the concept of an authentic relationship, in that it implies that the nurse themselves has to be real and genuine. They suggest that the nurse has to act like a chameleon, changing themselves in response to any given situation, and that the relationship is developed intersubjectively between nurse and patient, who both chose to reveal or conceal aspects of themselves. I agree with Aranda and Street in this regard, however, I believe that the concept of the authentic relationship should not be dismissed from the patient/carer perspective.

Indeed, if the patient/carer are to experience authentic relationships, it may well require the health care professional to behave like a chameleon.

In practice, the development of authentic relationships not only requires practitioners to reflect on and reconsider their relationships with patients and families, but also potentially an alteration in philosophies of care from hierarchical relationships to those that embrace the unfolding relationship between people in a health care situation. Further research to explore the existing evidence base in relation to authentic relationships, and existing strategies to promote positive relationships in practice, would be an interesting starting point for exploring this concept in more depth.

9.1.5 The multiple services involved in an individual's care create a unique health care team.

All of the participants in this research created Pictor charts as part of their interview. The purpose of using this technique was to help them to consider their experience, and reflect upon what was anticipated to be a complex situation. However, use of this technique also highlighted another interesting aspect of this phenomenon. All of the Pictor charts were unique, indicating that they all had a different understanding of who was involved in their care at that time. Even when interviewed as part of a dyad, people recollected and discussed different services and individuals involved in care. This finding suggests that all people with AD experience a unique 'team' of people providing them with care and support. Additionally, participants were often surprised by the number of people and services that they identified for their Pictor charts, as it was not until they began to reflect upon their situation that the extent of service provision became apparent to them.

Implications for practice and further research

The fact that participants all described different people who were involved in their care, and in supporting them, is perhaps unsurprising – these participant's had different diseases, different specialists, and different

understandings of the meaning of illness. However, this observation does raise an interesting issue for collaborative working in primary care. I discussed in chapter one how there has been considerable emphasis on the provision of care for people with AD by primary health care teams. If every person with AD has a unique network of people providing their care, then there may be challenges in helping people to navigate, and utilise their own healthcare team, and indeed the varied health professionals themselves knowing who else is involved in care provision for the patient.

The problem of coordinating such a team, and supporting service users in navigating these networks of services whilst getting the care and support that they need, has been recognised on a national level. The Palliative Care Funding Review (Hughes-Hallett et al, 2011) suggests that a core element of good palliative care services should be an organisation or individual to co-ordinate the care of the patient. This guideline could be interpreted in different ways; either the introduction of new services, or the elaboration of a role for existing services, indeed, some services may argue that they already perform this key-worker function. For example, Dunne et al (2005) suggest that DNs should be identified as key workers for palliative care patients, and it is recognised that many DNs see palliative care as one of the most rewarding aspects of their care (Walshe and Luker, 2010). However, the focus of their role on nursing needs may limit their ability to effectively case-manage (King et al, 2010). Other primary care professionals who have involvement in palliative care may also see themselves as key-workers. Macmillan Nurses could see themselves as being a key member of the team for patients with advanced cancer. The Macmillan Cancer Support website (2012) suggests that Macmillan nurses have a role in coordinating care between hospital and home, as well as providing advice on accessing other support. These are potential components of a case-manager role, however their role is much wider than this, and they also provide specialist support to patients and families, as well as to other health professionals involved in care. Symptom specific nurse specialists may also see themselves as a key person for those under their care; however different services interpret their role in different ways. For example, one of the nurse specialist services that I recruited from

described how they did not feel that they had any role at all in the care of patients once their disease could no longer be medically improved, and felt at this point people with specific palliative and supportive skills were more appropriate care providers. Brogaard et al (2011) explored patient, relative, GP and community nursing perceptions of the palliative care key-worker in primary care. They found strong disagreement between patients, relatives and primary care professionals as to who acts as the key worker. Most participants identified themselves as the *actual* key worker, and patients and carers most often identified the GP as the *ideal* key worker. This study was undertaken in Denmark, which has a similar structure of health services to the UK with generalist palliative care being provided by GPs and home care, supported by specialist services (Strandberg-Larsen et al, 2007). Despite the similarities, cultural factors do need to be considered when transferring findings to the UK setting, however the findings do emphasise the complexity of the key-worker concept.

The Palliative Care Funding Review suggests that:

> It is essential that the coordinating organisation or individual is listened to and respected by all agencies; the role would not be effective without this.
>
> Hughes-Hallett et al, 2011, p.52.

However, the creation of new roles in primary care is known to be problematic. For example, the introduction of a Community Matron role in the NHS Improvement Plan (DH, 2004) received a cautious reaction, as there was concern about how this new role might drain existing skilled nurses from the workforce, and might duplicate with existing roles (Pollard, 2004). As Community Matrons have become established in primary care some of these initial concerns have continued to pervade the provision of services, and both duplication of role, and role ambiguity are still issues of concern (Dossa, 2010). In addition to this, palliative care is very important to the professional identity of community nurses, and threats to their involvement in palliative care can trigger a defensive response from existing nursing roles (King et al,

2010). This potentially compromises the effectiveness of any new service by inhibiting collaborative practice.

The findings of this research have highlighted the complexity and variation within the health care 'team' that is providing care. Indeed, potentially the only two consistent members of this team are the GP, and the patient/family members themselves. There are numerous new initiatives that are looking to address some of the issues of coordination of care for people with palliative and end of life related needs. The Marie Curie delivering choice programme has been running since 2004 and has supported the implementation of projects across the UK that support people with terminal illness to be cared for and die at home (Marie Curie, 2012). Several of these projects specifically focus on coordination of care, for example the Greenwich Care Partnership includes a palliative care coordination centre that act as a central point of communication for patients, carers and professionals (Greenwich and Bexley Community Hospice, 2012). There has been some initial evaluation of some of the services that have aimed to improve coordination of care. Payne et al (2008) evaluated the Lincolnshire delivering choice programme, which had been running since 2004. The programme included discharge community link nurses, rapid response teams and a palliative care coordination centre. The evaluation showed mixed success of some of the service initiatives. Interestingly, the palliative care coordination centre was perceived by DNs and specialist nurses to decrease communication between professionals, as direct lines of communication were lost.

Other initiatives are looking to use technological innovations to address some of the issues of coordination and communication of care amongst the very diverse and ever changing PHCT. 'Coordinate My Care' is a service being developed by the Royal Marsden Hospital to improve communication between primary and secondary care, including out-of-hours services and the ambulance service. The service is based around an electronic record which stores care preferences, as well as medical and treatment information to which all members of the team has access (Riley et al, 2011).

Certainly, it would be hard to argue against systems in which improved communication and information is available to all who are involved in care. However, information alone does not necessarily improve the patient experience. The findings of this research have highlighted the importance of the type of relationship in creating a positive care experience for patients and spousal-carers, which should be considered as a core care domain in the design and delivery of services for people affected by AD. This research has also highlighted that service users themselves may not want additional people involved in their care, and may feel confident in coordinating the care team, and managing information themselves. It would be interesting to explore methods of facilitating and supporting people in doing this where appropriate, whilst also ensuring that health care support is available to patients and carers as situations change.

9.2 Strengths and limitations of the research methodology

Phenomenology is a science of '*plausible insight*' (van Manen, 1997b, p. 345), and an effective phenomenological text will help the reader to see something in a way that enhances their understanding of everyday experience (van Manen, 1997b). The methods used in this research have enabled me to create phenomenological descriptions of the lived experience of people affected by AD, in relation to the involvement of multiple services in primary care. However, there are lessons that can be learned from the challenges that I faced in using these methods. I am going to focus on three areas in the following discussion. Initially I will consider an aspect of multiple service use that I had initially anticipated would be a potential finding, but was not evident in these participants' narratives. I will consider the challenges I had in recruiting for this research, a component of the research process that was considerably more problematic than I had expected. Thirdly, I will explore the effectiveness of the modified Pictor technique, considering the benefits I found using this technique. The final part of this discussion will look at the notion of transferability and quality in phenomenological research.

9.2.1 What this research didn't find: an absent story...

I initially approached this research from a stance of frustration. This frustration had developed from observations of families who were exposed to increasingly complex structures of care that baffled them, and sometimes me. In my nursing role, I heard stories of incomplete care, and of care promised but not delivered as health care professional A promised that health care professional B would provide something that health care professional C said was unnecessary. Stories of health care professionals arriving from different services at the same time, of families not knowing how to get hold of services when they needed them, and of services not communicating between each other were frequently given to me. I witnessed distressed and angry families who had lost faith in a system that they did not understand. I was also disillusioned myself, and unhappy that I was unable to give the care that I felt was satisfactory as the increasing demands on my role reduced my capacity to engage with the people whom I wished to help and support.

I have continued to work part-time as a DN throughout the development of this thesis. I have had clinical contacts with many families who are in similar situations as the participants in this research, and who would have met the inclusion criteria. I have continued to hear about, and sometimes be involved with situations like the ones mentioned above. However, to my initial surprise these factors were not discussed specifically by the participants' in this research. I propose several reasons for this; the changed 'voice' of people in a research setting, as opposed to a clinical setting; the possible stage of the illness trajectory of the participants; the influence of my dual role upon the data collection process.

In the clinical setting people are much closer to the events they are describing. Their embodied experience and reaction is heightened. In my current clinical role I am with patients and their families because they have requested help, often at times of crisis or in the face of rapidly deteriorating health. People are vulnerable and sometimes scared about what is happening; the emotional response to their situation is raw and immediate.

The stories they tell me are about events that have the potential to immediately affect their existence. In the context of the research interview this intensity is diluted, there is probably no urgent need for assistance with health issues, or immediate frustrations and concerns caused by this. Individual's responses were more considered, as they thought back upon their experiences and tried to order them so that they could share them with me as an outsider. Additionally, although these patients were all understood to be in the last year of life, and many were visibly affected by their illnesses, I do not know where they were in their illness trajectory, or when they died. It is possible that as diseases progressed, then the experience of multiple service involvement would have changed.

These participants also knew my background as a nurse, were aware that I worked in the PCT in which the research was taking place, and were informed that there was a small possibility of seeing me in my other capacity as a district nurse. It is possible that the participants' knowledge of my close involvement with these services could have contributed towards some 'editing' of experiences, although I did not feel that this was the case when I was talking with them.

One advantage of using an interpretive approach to research is that these factors can be recognised, whilst not undermining the validity of the findings that have been presented. Further research in this area may highlight other aspects of the lived experience of this phenomenon that this research has not identified, and indeed this would be welcomed to generate more insights into this complex area of lived experience.

9.2.2 Recruitment difficulties

The sample obtained for this research has been of a good size to be able to undertake the in-depth analysis required for a phenomenological study. However, obtaining this sample was problematic. Recruiting for research with people affected by AD is often reported as challenging (Addington-Hall, 2002;

Ewing et al, 2004) and this research has been no exception. I have been surprised however at where these challenges have been, as my biggest difficulties were recruiting people affected by cancer, and spousal-carers in general. I had anticipated that recruitment into these groups would be straightforward, because of the number of health care teams who had agreed to support the recruitment process.

Two strands were planned for the recruitment of cancer patients, firstly through the DNs and secondly through the Macmillan nursing team. I initially approached three DN teams from geographically diverse areas that were interested in participating. One of these teams recruited no participants, and the other two recruited one patient and one spousal-carer each, despite initially suggesting that they could identify numerous potential participants.

I had discussed the research with the Macmillan team in summer 2009, and they were keen to be involved. However, I then had great difficulty in gaining permission from their managers to allow them to recruit, a process that ended up taking nearly six months. Once permission was granted, I met with the Macmillan Nurses who again said that they could easily identify several suitable participants. Despite this initial enthusiasm, I received only four patient referrals, and no spousal-carer referrals, from the Macmillan team, and three of these patients subsequently withdrew for health reasons. The rest of the participants were recruited through specialist nursing teams (respiratory, heart and Parkinson's).

Informal conversations have taken place with some of the Macmillan Nurses and DNs about their difficulties recruiting. One of the DNs reported that *'it is much harder than I thought it would be – I don't really know when to raise it with people'*, indicating that there were communication challenges which she did not feel skilled to meet. Another DN stated that the team were too busy to recruit. A Macmillan Nurse claimed that their patients did not have many other services involved, and as such people did not meet the inclusion criteria; a surprising perception that contradicts both my personal experience of caring

for cancer patients and their families, and the literature regarding service use in palliative care.

The problems that these nurses faced, highlights an assumption I held about the recruitment process. I felt that once I had access to participants by gaining ethics and governance approval, and had identified teams that were interested in helping me recruit for the study, then my role was to give information to the recruiting nurses that they would pass on to potential participants. Although I had anticipated some gatekeeper issues, I had not anticipated that they might be uncomfortable about being involved in research processes or in recruiting people with AD. In retrospect, my recruitment strategy could have been improved by greater education and information for all the nurses who participated in recruitment, especially around how to broach the subject of research with people who are affected by AD.

I had anticipated some recruitment difficulties, and as such had not specified a specific sample beyond a mixture of diagnosis, and the transferability of this research is limited by the lack of diversity within the research sample. The final sample for this research did attain heterogeneity regarding participant diagnosis and gender. However, the sample is very homogenous in other characteristics. All participants were retired with an age span of 57-80 and all were of a white British ethnicity. This needs to be taken into account when considering the transferability of these findings.

Ultimately, more patients than spousal-carers participated in this study. The research protocol had planned that patients and spousal-carers would be given the same opportunities to participate and could be recruited separately. However, I received fewer carer than patient responses (and all the carer responses were attached to a patient response). Unfortunately I have no way of finding out whether this was due to fewer carer information packs being distributed, or whether fewer carers were interested in the research. At my initial meetings with patient participants, I took the opportunity to ask them if they identified a carer who had received information about the research. The responses were varied; Elsie did not identify such a person; George's wife

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worked during the day, he described how her evenings were precious time off, and that he did not want this to be taken away from her. There was a sense that some participants wanted to protect their partners, for example, Nora[14], a woman with breast cancer, described how her partner had not accepted her diagnosis or that she was going to die, and as such she did not want him to participate in research that may distress him. A flaw in my recruitment strategy is highlighted by these responses. Although I planned that there would be equal opportunity to participate for both patients and carers, I had not anticipated the potential bias that could be imposed by the health professionals' undertaking the initial recruitment who may not inform carers of their opportunity to participate, or that that they would be influenced by patient preference to include/exclude their carers. Jessica's[15] husband was present at the initial meeting, he had been given an information pack and he had considered the research, however he felt that he could not talk about the current situation. He was apologetic about this, but summarised it for me:

> I just can't talk about it, it's all just bloody awful – and you can write that in your thesis!

There is a dearth of literature regarding challenges in recruiting carers for research, but in this research there appeared to be an element of patients acting as gatekeepers to spousal-carer participation. Additionally, as I discussed in chapter seven, people do not always self-identify with the carer title, which may have been an additional barrier to their involvement in this research.

9.2.3 Reflections on using the Pictor technique

A central component of data collection for this research was the use of the Pictor technique, which has been used for the first time with a lay-population. This technique has been beneficial in this research, particularly in helping

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[14] Nora withdrew from the research for health reasons prior to her interview.
[15] Jessica also withdrew from the research for health reasons prior to her interview.

people to reflect on, and then communicate their experiences of service involvement.

Reflection is a concept that has different meanings in different contexts. As nurses, we are taught very early in our careers that reflective practice is an essential skill for learning and self-development, and ultimately for quality of care. As qualitative researchers, we aim to act with reflexivity (Bulpitt and Martin, 2010), examining ourselves in relation to our research with the aim of identifying presupposition and exploring the impact this may have on all stages of the research process. Reflection is also a central component of hermeneutic phenomenological methodology, which recognises the difficulty in looking beyond our own everyday way of seeing the world in order to attempt to understand others experience of phenomena.

We also expect our research participants to be able to reflect on their experiences. This is generally not as a means to individual self-development and understanding (although arguably this may be a side effect of participating in research (Murray, 2003)), but so that participants can share their experiences in relation to the subject under investigation. This requires the participant to consider and identify areas within their own lives that are pertinent to the research, to think of examples and anecdotes that illustrate these, and then to be able to communicate these to the researcher.

By using the Pictor technique, participants were given time within the interview to contemplate factors of importance. This structured opportunity gave individuals the chance to reflect on who had been specifically involved, and as such brought people to mind who might not otherwise have come to light through an ordinary interview. Many of the participants in this study were apprehensive as I introduced Pictor to them, often stating that they did not think they would be able to identify many people involved, or they were sceptical of the benefits of the technique. However, they were then often surprised by how many individuals and services that they identified as they created their Pictor chart. This enabled me to capture elements of participants' pre-reflective understanding of their situation (a lack of

awareness of the extent of service involvement), as well as then moving on to explore their own interpretations of their experiences.

For example, Aggie initially did not anticipate identifying many services of relevance. However, as she commenced the creation of her Pictor chart she became enthused by it, identifying many services involved, but also other factors that were having a significant impact on her life. Aggie included her dog on her chart and discussed how he was central to her ability to cope, as she felt loved and needed by him and this gave purpose to her life despite having advanced cancer. This would not normally be considered in the context of 'service' but for Aggie formed an essential element of her support team. This information was also valuable in exploring other aspects of her experience: for example, being needed was important to Aggie as she demonstrated in other areas of her interview in relation to the health services that were involved.

The second benefit of using Pictor to assist reflection is in the arranging of the arrows. Again, participants had time to consider their relationships and their experiences of the various services and people that they identified. This added depth to the ensuing interview as participants' explained their thinking and illustrated their experiences with examples. Referring again to Aggie's chart, she placed the community Macmillan Nurse very close to herself and described her as being *like a sister'*, this was in contrast to her biological sisters who she placed towards the outside of the chart. Aggie explained that they were not behaving how she thought they should as they persistently nagged her to explore alternative treatments, rather than supporting Aggie in the treatment decisions that she had already made. This affected her ability to talk to her sisters about her illness as the conversation often ended in an argument, and had made Aggie feel isolated until the involvement of the Macmillan Nurse.

Because Pictor encourages individuals to reflect on and discuss their personal experiences, it can be an emotive technique that can highlight elements of the participant's experience that they had not addressed before. This was

particularly evident in Amy's interview, the use of Pictor prompting her to discuss her estranged son because his absence from the chart was significant for her, and caused her to become tearful. These are similar risks to those that exist within any qualitative research interview and as such the usual ethical principles should be adhered to, ensuring that safeguards are in place to protect participants. For example, Amy was given the chance to pause or stop the interview, which she declined, and following the interview I went on to offer Amy further information about where she could receive support.

The Pictor technique also had benefits in helping people communicate their experiences. Because of the modification to the original Pictor technique (as proposed by King et al, 2010) these interviews had two definite breaks in them, the first whilst writing the post it notes and the second whilst arranging them. This unusual pacing of a research interview had particular advantages for participants who were breathless (Eric, Roger, Michael, Elsie and George) as they had opportunity to regain their breath during these breaks from speaking, indeed Chapple (2006) advocates regular breaks in interviews with people who have AD as they may tire easily. Of course, a break can be offered within a standard research interview, however the advantage with this technique is that the breaks are more natural, they did not rely on me having to assess the participants' need for a break, or on the participant being bold enough to ask for one. Because there is a purpose to these breaks they also avoid a potentially awkward silence for the participant. A further benefit of these mini breaks is that they allow respite within the interview, giving time out in what can be an intense process. For example, in interviews where participants became upset by the conversation, they would often pause, look at their charts, and take a moment to recompose themselves.

Some people with AD may also find it hard to concentrate for extended periods of time, either due to their illness, its treatments or other related factors. By creating and then discussing the Pictor chart, the participants generally remained focused on the subject under investigation. Some participants found this harder than others, for example Eric wanted to discuss his grievances with his former employer, whom he blamed for his COPD, and

it was difficult at times to retain his focus on my questions. However, I believe that this would have been more of a problem without Pictor, as the Pictor chart acted as a 'hook' for me into Eric's world, and ensured my questioning was closely related to his experiences. Once Eric had created his chart, I was able to pull him back to it when his narrative started to wander away from my questions. The chart was also useful in this way if the participant was 'drying up', because I could guide them to areas that had not yet been discussed, using prompts like 'why have you placed the arrows like this?' and 'why have you placed this service here?'

Spousal-carers may also find it hard to communicate their experiences of a situation. Carers have a complex dual role – both provider and receiver of care (Grande et al, 2009). Carers also have intense involvement in care provision and may focus solely on meeting the needs of the 'patient', and not identify their own needs (Stajduhar and Davies, 2005). Again, this has implications for research interviews. Spousal-carers who are focused on the care required by, and the experience of their 'patient' may find it extremely hard to verbalise their own experience of the situation. Pictor helps people to do this. For example, Sarah initially started creating a chart from her husband's experience, she was then asked to rethink and do the chart about her own experiences. Many interesting factors were revealed from Sarah's chart, the placement of herself, above her husband was indicative of how she saw herself protecting him from all the *'hassles'* of the organising and coordinating of the different people who were involved. Sarah placed her daughters surrounding herself and Paul, this was because they were a close family with the daughters providing emotional support, but they were also taking on many of the practical tasks that Paul could no longer do. The Pictor technique helped Sarah to communicate her experiences and without the tool I believe that I would have found it difficult to focus the discussion on Sarah's understanding of her own situation, as opposed to her husband's.

The creation of the charts did not always happen as I intended, and some spousal-carers still found it hard to focus on their own experiences whilst creating the charts. For example, Edward's chart shows how he saw services

in relation to his wife and he was unable to create the chart in relation to his own experiences with services. However, this demonstrated his experiences well; he was there to support his wife, behind her at all times. Services were there for her, as was he.

The Pictor charts were used alongside the interview text to assist with analysis. I had anticipated that the charts would help this process by adding another layer of data to support cross case analysis, for example, by looking at any patterns on the charts. I had not however anticipated how the use of the Pictor technique would influence my own way of discussing and representing these participants' experiences. Looking at the charts encouraged my own creative thinking around this experience, and opened up my thinking to a visual way of conceptualising and articulating the findings, for example, by creating the image of Ken's experience in chapter six, p.196.

The Pictor charts have also proved beneficial when it has come to sharing my findings. During the course of this research, I have had the opportunity to present my findings at a number of conferences and meetings. I have used the Pictor charts to help explain the findings. This has helped ensure that the participant 'voice' remained central to the discussion of this experience. This has been a powerful tool for dissemination of the findings, and has consistently received positive feedback. This was demonstrated at the RCN research conference (2010), where I presented a poster about the Pictor technique. During the course of the conference I had the chance to discuss the technique with a large number of nurses from a variety of settings, and subsequently received a delegate nominated prize for the poster I presented.

Pictor is an innovative research method that I believe enhanced these participants' ability to contribute to the research interview, as well as enhancing analysis and dissemination of findings. Pictor, when used with people affected by AD, is beneficial as it can accommodate the disease related difficulties that participants may experience, as well as helping them to collect and communicate their thoughts and experiences. I found that by using the Pictor technique, rich and detailed data were gathered on the

complex area of people's experiences of multiple service involvement. This technique is ideally suited to research that is exploring roles and relationships, and the benefits I found from using this technique are likely to be applicable to other research populations who experience complex health needs. Further research that explores and evaluates the Pictor Technique as a research tool in different contexts will expand the possibilities of this innovative research technique.

9.2.4 Quality and transferability in phenomenological research

The quality of research is vital if the findings are to offer meaningful insight into the phenomena under investigation, and it is both a professional and ethical obligation to produce high quality research (Whitehead, 2004). However, evaluating quality in qualitative research can be complicated due to the range of possible epistemological positions (Schwandt, 2007) and the multitude of methodologies that sit within this paradigm. Because of this, there is no set framework for quality evaluation. Guba and Lincoln (1989) suggested that establishing the trustworthiness of qualitative research involves considering aspects of credibility, transferability and dependability. These criteria have been extremely influential in the development of evaluation approaches to qualitative research.

In this research, I have attempted to maintain a methodologically consistent approach throughout all stages of the research process, which is suggested to be one measure of quality in qualitative research (Carter and Little, 2007). I have ensured that that my research methods have been synonymous with phenomenological philosophy, and more specifically the Human Science Research as proposed by Van Manen (1990; 1997a). The research methods employed have been described in detail. By utilising Template Analysis, and evidencing the evolution of the template that was developed in exploring the data (appendix 7), I have documented my decision trail (Whitehead, 2004) and been transparent in my research processes (Avis, 2005). This research

has also used reflective methods as part of an ongoing hermeneutic conversation with the data, an important component of trustworthiness.

Phenomenological research has value to the health professions as it offers the opportunity to attend to human experience, and enables increased understanding of others being-in-the-world (Madjar and Walton, 1999). However, it is important to consider the limitations of phenomenological research. These limitations are not related to failings in the method, rather, they are associated with the objectives of phenomenological research, which strives to give voice to human experience, and understand the meaning of experience, rather than provide causal explanation of that experience (Van der Zalm and Bergum, 2000). Although I have tentatively explored essential themes that have developed from this research, it remains important to consider, in line with hermeneutic phenomenological philosophy, that these are aspects of possible human experience (van Manen, 1990). The findings are context specific and no claims are made for the applicability of these findings beyond this research setting. Furthermore, it is acknowledged that if this investigation were to be repeated by another researcher, either utilising the same data or accessing different participants, then an alternative interpretation of this experience would be generated.

9.3 Original contribution to knowledge

An original contribution to knowledge can be demonstrated in this research. The research has been the first study to use the Pictor Technique with a lay-population, and I have had a paper on the use of Pictor with people affected by AD published in the peer-reviewed journal 'Nurse Researcher'. I have had the opportunity to share my experiences of using and adapting the technique for this population directly with other researchers who are now using the Pictor Technique with lay-participants in their own studies. This includes:

- PACE (Plans and Care Expectations): a study looking at palliative care for people with lung cancer and other conditions (Principal Investigator - Stephen Barclay, University of Cambridge).

- UTT (Unpicking The Threads): a study exploring how generalist and specialist nurses work with patients, carers and each to support cancer survivors (Principal Investigator - Nigel King, University of Huddersfield).

- Evaluation of the Midhurst Palliative Care Service (Project lead - Bill Noble, The University of Sheffield. Qualitative research undertaken at The University of Huddersfield, project leader Nigel King).

I have also had enquiries from other interested researchers as a result of presentations I have given on this technique.

This research is also original in its design. I have been unable to identify other phenomenological research that has looked cross-diagnostically at people with AD who have multiple services involved in their care. The advantage of this approach is that it has enabled me to explore this experience from the perspective of people who are at a certain stage in their lives, rather than who have a specific diagnostic label. This enabled a phenomenological analysis of this lived experience of multiple service involvement that has led me to describe the phenomenon using three broad concepts, an unhomelike being-in-the-world, striving for poise, and authentic relationships. In this way, the findings may be of particular pertinence to those working within a 'generalist' environment where services are designed to meet need, regardless of diagnosis.

9.4 Personal reflection: being a nurse, becoming a researcher

Throughout this thesis I have attempted to maintain a reflective stance in all stages of the research process. I take the opportunity here for some personal

reflection on the transformational nature of the research process which has led me to question many of my previously held beliefs about health, illness, and particularly the role of district nursing within this.

My early PhD experience was characterised by a sense of adventure. The change in my life was startling as I moved from a hectic district nursing caseload where the opportunity for any reading at all was scarce, to the life of a full time post-graduate student where reading was not only a pleasant treat but expected. However, it was not until I began to have contacts with participants that I really began to consider my involvement in the research process, and question my personal assumptions about the research topic, my nursing role, and about the health care system in general. I started to have contact with patients and spousal-carers in November 2009, the diary extract below was written after my first contact with participants, an initial meeting with a cancer patient and his wife:

> I felt very nervous, uncomfortable to enter this house or sit down, despite my having gone into patients' houses a thousand times! Initially I did not know how to interact and this new role feels completely out of my comfort zone. I felt pointless and imposing, my purpose here is not to make things better, although they were very willing to take part – as long as I wasn't going to give them any injections.

This participant's interview was arranged for a week later, following the interview, I noted down my experience of the interview:

> I felt powerless, worried about upsetting them and concerned that their emotional needs were so ignored by clinical services.

These extracts highlight different assumptions and beliefs that I held at this time, for example that I felt that my research role was very different from my clinical role, but that the research was less important to the participants than being supported with clinical needs. When I wrote this I was finding it

extremely hard to step outside my clinical role, I had also at times found it hard to focus on what participants where 'saying', mostly picking up on clinical clues in the narrative, which then informed my probing. As I have developed my skills during the research process I have learnt how to listen to people in a different way.

I mentioned in my opening remarks to this section that this research has led me to question many of my beliefs, particularly regarding my role as a district nurse. I will highlight one incident taken from my research diary which was of particular significance to me:

> As I sat on his sofa the surroundings were unfamiliar. I did not recognise anything about this house, or this man's face; indeed, he did not appear to recognise me in any way either. But the story that he was telling was so familiar that the sense of déjà-vu was almost overwhelming. I knew parts of this man's story but had no idea how or why. Had I been told this story by one of my colleagues? Had it featured in a clinical 'hand-over' that I had been part of? Or had I been here, in this house, delivering the clinical care that he was now discussing – had I been part of the team that seemed to have failed this man so desperately? I have no idea.

As you can imagine, this was a disconcerting experience. I began to question what kind of nurse I was. I had believed myself to be a 'good' nurse (although an over stretched one), demonstrated through my care for the patients I saw. Nevertheless, here was direct evidence potentially challenging my self-theory. This incident led me to question my clinical and personal involvement with patients. As a DN, a rewarding element of the job is the relationships that are formed with the people in your care, some of whom you may know for many years. I enjoyed the fact that I knew the names, faces and families of many of the people on the caseload. Increasingly however this is becoming a luxury as workloads increase, care delivery becomes more clinically complex, and the relentless change imposed by service redesign places extra a burden on

to clinical staff as they continually readjust their priorities in line with local and national objectives.

These factors are contributing to a change in the role of the DN and of nursing in general, but it appears as though my personal expectation of the role had not evolved correspondingly. I have been involved in the care of many people in the last months and days of their lives; I will have known some of these people for months or years, or some for only days or hours. It is unrealistic to presume that it is possible to have a personal relationship with all of these people and to subsequently remember them - however, I was deeply shocked when this was highlighted to me through my contact with this man, a familiar stranger, in the course of my research. If I put this in context of the findings of this study, I was measuring the quality of my care on a 'personal' relationship basis - which was an unachievable goal. If I adjusted this ambition to one which was based on development of 'authentic' relationships, then there could be opportunity to be personally rewarded for the care that I delivered whilst also recognising that this relationship was temporary in my world as the nurse, but may leave a lasting impact on the experiences of the people with whom I had contact.

These personal insights formed part of the hermeneutic cycle whereby I have continually questioned the impact of my assumptions and interpretations on the data. Further to this, there has also been an impact upon my clinical practice. I have attempted to incorporate the findings from this study directly into my clinical care, and that of my team. This has been undertaken in several ways. Informal discussions about this research project have triggered some interesting conversations around the role of nurses in the out-of-hours period. My increased awareness of palliative and end of life care issues has led me to question my own, and others practice, and initiating regular informal educational opportunities for staff in regard to roles and relationships. Ultimately however it is my own practice that has been changed the most. I have learned how to listen to patients and families in a different way. My awareness of the lived experience of illness has contributed to me altering the way I assess the situation that people are in, and informed my subsequent

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interactions. I have undoubtedly developed greater empathy with the experience of people who use health care services, and endeavour to make navigating these services as simple as possible. I have also learnt the limits of my abilities. Prior to commencing this research I was not aware that I was trying to solve people's problems, however on reflection, this was the dominant approach that I took to nursing care, and had a significant impact upon my own wellbeing when this ambition could not always be realised. This awareness not only has ramifications for the quality and appropriateness of my nursing care, but also on my self-care, a vital component of working with people affected by AD. Van Manen (1990) proposes that phenomenological research may have a transformative affect on researchers themselves, a suggestion which certainly resonates with my personal experience of this research process.

9.5 Concluding thoughts

Although the challenge of writing a PhD thesis is now drawing to a close, the work of influencing clinical practice, and improving the care of people with AD is just beginning. I plan to further publish the findings of this research, as well as directly taking some of the issues raised into clinical settings, in this way combining my clinical and research roles. I would also like to undertake further research in this area, continuing to develop the skills I have acquired during this PhD process.

On a final note I will go back to the phenomenological framework within which this research has taken place. Drawing once more on the words of van Manen (2011, online):

> It is also helpful to be reminded that phenomenological inquiry-writing is based on the idea that no text is ever perfect, no interpretation is ever complete, no explication of meaning is ever final, no insight is beyond challenge. It behooves us to remain as attentive as possible to the ways that

all of us experience the world and to the infinite variety of possible human experiences and possible explications of those experiences.

Bearing this in mind, I welcome additional research in this area that will further contribute to understanding the complex lived experiences of people affected by advanced disease, and their relationships with health care services.

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Appendices

Appendix 1: The Gold Standards Framework Prognostic
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Appendix 1: The Gold Standards Framework

Prognostic Indicator Guidance (PIG)

During the process of this research, the PIG has been updated. Details from version 5 (2008) were used to support the identification of participants for this study.

Three triggers for Supportive/ Palliative Care are suggested- to identify these patients we can use any combination of the following methods:

1. **The surprise question** 'Would you be surprised if this patient were to die in the next 6-12months' - an intuitive question integrating co-morbidity, social and other factors. If you would not be surprised, then what measures might be taken to improve their quality of life now and in preparation for the dying stage. The surprise question can be applied to years/months/weeks/days and trigger the appropriate actions enabling the right thing to happen at the right time eg if days, then begin a Care Pathway for the Dying. (See Needs Support Matrices)

2. **Choice/ Need** - The patient with advanced disease makes a **choice** for comfort care only, not 'curative' treatment, or is in special **need** of supportive / palliative care eg refusing renal transplant

3. **Clinical indicators** - Specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia (see over)

Trigger 3 – Specific clinical indicators of advanced disease

These clinical prognostic indicators are an attempt to estimate when patients have advanced disease or are in the last year or so of life. These are only indicators and must be interpreted with clinical judgement for each individual patient, but they can help to alert clinicians to the need for extra supportive are. They have been drawn from a number of expert sources from the UK and abroad, and are updated regularly. Some use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in primary care and in secondary services that patients may be in need of palliative / supportive care. Primary care teams may include these patients on their Supportive/palliative care registers and hospital staff may suggest to GPs in discharge letters that such patients are included on the registers, if helpful.

Co-morbidities or other General Predictors of End Stage illness[1/2]

Co-morbidity is increasingly the biggest predictive indicator of mortality and morbidity. Also-
- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / ECOG/Karnofsky score (KPS) < 50%. Dependence in most activities of daily living(ADLs)

1. Cancer Patients

Cancer[3]
Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less. More exact predictors for cancer patients are available elsewhere on the GSF website.

2. Organ Failure Patients

2.1 Heart Disease - CHF [4]
At least two of the indicators below :-
- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD [5]
- Disease assessed to be severe e.g. (FEV1 <30%predicted – with caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression
- >6 weeks of systemic steriods for COPD in the preceding 12 months

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b) Parkinson's Disease [8]
The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register
- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

Appendix 2: Literature review search results

Database	Specific search terms used (Boolean/wildcards/ truncations)	Number of accumulative hits	Number of hits (to review full text)
Cochrane Reviews	Advanced disease Palliative Supportive End of Life Terminal Carer Service user Partner	142 86 141 130 19 32 15 51	0 1 1 (D) 1 1 0 0 0
Cinahl	Advanced AND Disease AND Primary AND Care	428	3
	Relationship# AND Palliative AND Primary AND CARE	61	12
	Experience# AND Palliative AND Primary AND Care	197	8 (+ 6D)
	Advanced AND disease AND MDT	21	0
	MDT AND Palliative	3	0
	MDT and Primary	4	0
	MDT and Community	9	0
	End AND of AND Life AND Primary OR Community	81	1
	Terminal AND Primary OR Community	37	2 (+5D)
	Terminal AND Home	47	3 (+6D)
	End of Life AND home	166	12 (+7D)
	palliative AND Home	308	13 (+19D)
	Advanced AND	3	0

	Disease AND Home		
	District AND Palliative	132	5 (+6D)
	((General AND Practitioner) OR GP) AND palliative	11	0
	General Practi* AND palliative	48	0
	patient and experience and primary and care	9	0
	(AB) "primary health care team"	149	(1d)
	(AB) Continuity and palliative	74	(2d)
	(AB) "inter professional" AND primary	37	0
	(AB) "inter professional" AND palliative	6	0
	(AB) "inter professional" AND palliative	45	0
PsycINFO	((all(palliative) AND (primary care)) AND patient) AND experience	175	2 (8d)
	((advanced AND disease) AND primary) AND care	199	(1d)
	relationship* AND palliative) AND primary	119	(3d)
	ab((((experience* AND palliative) AND primary) AND care) AND patient)	85	1 (2d)
	ab(((((experience*	89	(4d)

	AND palliative) AND community AND patient)		
	ab((((experience* AND palliative) AND community AND carer*)	11	0(d)
	ab((((experience* AND palliative) AND primary) AND care) AND carer*)	10	3(d)
	(MDT OR "multi disciplinary team") AND palliative	16	0
	ab((MDT OR "multi disciplinary team") AND primary)	16	0
	ab((MDT OR "multi disciplinary team") AND community)	43	0
	ab("end of life") AND ab((primary OR community)) AND ab((patient* OR carer*))	379	2 (9d)
	ab(terminal) AND ab((primary OR community)) AND ab((patient* OR carer*))	64	0
	ab("end of life") AND ab((home)) AND ab((patient* OR carer*))	329	0 (2d)
	ab(palliative) AND ab((home)) AND ab((patient* OR carer*))	474	2 (11d)
	ab("primary health care team")	56	0
	ab("interprofessional") AND ab(primary)	108	0

	ab("interprofessional") AND ab(community)	0	0
	ab("interprofessional") AND ab(palliative)	18	0
	ab(Continuity) AND ab(palliative)	51	1
	ab(Continuity) AND ab("primary care")	239	1 (1d)

Appendix 3: Summary of papers included in literature review

Year	Authors	Sample	Services considered	Methodology/methods
1999	Beaver, Luker and Woods

(NB – Beaver, Luker and Woods (2000) are reporting on different aspects of the same study) | 15 patients (expected to die within twelve months. 14 cancer, 1 non cancer), 10 lay-carers
19 Health Professionals | Those used by terminally ill people in primary care (last 12 months of life). | Used a measure to assess individual's self-care ability to describe the characteristics of the study population. Content analysis of data. Interview data then rated into positive, negative and neutral comments. These then counted and presented. |
| 1999 | Jarett, Payne, and Wiles | 12 people with cancer, 1 person with Motor Neurone Disease (MND), and 8 lay-carers | Community services | Qualitative
Interviews – mainly dyadic.
Thematic analysis |
| 2000 | Beaver, Luker and Woods | 15 patients (expected to die within twelve months. 14 cancer, 1 non cancer), 10 lay-carers
19 Health Professionals | Those used by terminally ill people in primary care (last 12 months of life). | Used a measure to assess individual's self-care ability to describe the characteristics of the study population. Content analysis of data. Interview data then rated into positive, negative and neutral comments. These then counted and presented. |
| 2001 | Koffman and Higginson | Carers
Black Caribbean and white British (106 black Caribbean, and 110 white British participants.
(Highest proportion died of cancer, but other diagnosis included) | Services accessed in last year of life (primary and secondary care) | Mixed methods Retrospective Interviews and surveys.
Univariate analysis and content analysis |
| 2002 | Murray et al

NB – Boyd et al (2004) reporting on different aspects of this same study. | 20 people with lung cancer
20 people with cardiac failure, their carers and associated health professionals | Primary and secondary care services | Qualitative longitudinal
Interviews repeated every three months.
Focus group with HPs and lay-representatives |
| 2004 | King, Bell and Thomas | Bereaved carers (14 cancer 1 non | Out-of-hours primary care | Qualitative retrospective
Semi-structured interviews. |

Year	Authors	Sample	Services considered	Methodology/methods
		cancer)	services	Template approach to analysis
2004	Seamark et al	People with severe COPD (10 patients 8 carers)	This is a paper on lived experience. Section on service involvement (primary and secondary care)	IPA interviews
2004	Boyd et al NB – Murray et al (2002) reporting on different aspects of this same study.	20 people with advanced heart failure, their carers and associated health professionals	Primary and secondary care services	Qualitative longitudinal Interviews repeated every three months. Focus group with HPs and lay-representatives
2004	Grande et al	60 carers - had previously been known to a hospice at home service	Primary care	Qualitative, retrospective Interviews Content analysis of all data about GP and DN services Thematic framework developed through iterative processes
2005	Aldred, Gott and Gariballa	10 people with advanced heart failure and their carers	Paper on impact of Heart Failure. Section on services	Qualitative Joint interviews Thematic analysis
2005	Exley et al	11 people with cancer and their carers 16 people with cardio respiratory disease and their carers	Services for people dying in the community	Qualitative longitudinal. Mainly joint interviews. Repeated after four months where possible. Iterative thematic analysis
2006	Worth et al	32 people with cancer, 19 lay-carers And focus groups of local carers groups and hospice patients	Out-of-hours care	Qualitative Interviews (15 with dyads) Focus groups Thematic analysis
2008	Cotterell	25 people with AD (44% non cancer)	Health and social care (not exclusively primary care)	Qualitative participatory research. Interviews and discussion groups Thematic analysis – by researcher and by participant group.
2008	Conner et al	10 patients Demographic data not collected (however all known to specialist palliative care team).	Health services in primary and secondary care	Qualitative consultative approach Interviews Thematic content analysis.
2009	Boyd et al	30 people with advanced heart failure,	Primary and secondary care	Qualitative – longitudinal Serial interviews. Pt and LC interviewed

Year	Authors	Sample	Services considered	Methodology/methods
		25 family carers and 41 health professionals.	services	together up to three times each. Thematic analysis – constant comparison
2010	Hasson et al	15 bereaved carers of people with Parkinson's disease.	Primary and secondary care services	Qualitative. Retrospective Interviews. Content analysis
2011	Newbury	Carers (13 cancer, 1 MND, 1 renal failure)	Services at the end of life in primary care	Grounded theory. Longitudinal Interviews before and three months post bereavement.
2011	Richards et al	13 people with advanced cancer and 15 lay-carers.	Out-of-hours services	Qualitative Semi-structured interviews Thematic analysis

Appendix 4: Information packs for recruiters and participants.

You are being given information regarding this research as we hope you may be able to assist us with recruiting people to the study.

Study Title: Patients with advanced progressive disease and their carers experiences of receiving support from multiple services in primary care.

Background to the study:

Service for people with advanced progressive disease in primary care are currently the focus of much policy and service development for patients with cancer and organ failure diagnoses. This qualitative study aims to explore the patient and informal carer experience of receiving these services.

This research is being carried out by Beth Hardy, a nurse and full time PhD student at the University of Huddersfield, with support of Professor Nigel King, Jan Firth and Dr Alison Rodriguez at the University of Huddersfield.

Who can take part?

We are interested in the experiences of patients with cancer or organ failure in the advanced stages, and the experiences of informal carers for patients with cancer or organ failure.

Patients and informal carers need to be aware of the diagnosis and that it is a progressive disease. All participants need to be over eighteen years old. We are looking for both men and women, of a mixture of ages to participate.

Patients should be receiving support in primary care from 2 or more services, this could include district nurse, Macmillan nurse, hospice at home, nurse specialist, social worker, formal carers, allied heath professionals, and religious and voluntary support networks.

We cannot take people into the study if they present a known risk to lone workers.

Please refer to the checklist at the end of this information sheet for specific inclusion criteria.

How do we identify patients in the 'advanced stages'?
We are using the Gold Standards Framework prognostic indicator guidance to help identify patients in the last 'year or so' of life. See the attached sheet for detailed information regarding this.

Which diseases do you mean by organ failure?
For this study we are recruiting people with Heart disease, COPD, Parkinson's disease and people with multiple co-morbidities. We are not recruiting people with neurological conditions such as MND, and MS, or people with frailty, dementia or stroke.

What should I do if I identify potential participants for this study?
If you think that you have a patient on your caseload who may be eligible to participate in this study please give them the initial participant information sheet, ask them to read this carefully and discuss this with other people if they would like. If after reading this they are interested in receiving more information please ask them to complete the reply slip within seven days. Beth Hardy will make contact with them within seven days of receiving this form to arrange a convenient time to discuss the research further with them. At this point a date will be set with the participant for the interview.

What will happen to the people who take part?
Participants will be interviewed using qualitative semi-structued interviews. We know that sometimes people can be receiving complex services so participants will be invited to do a short diagram called 'pictor' which may help them describe the services they are receiving. This will be fully explained to the participant and they will be shown how to do this.

These interviews will be led by the participants, with the researcher acting as a facilitator. Participants will not be forced to discuss any issue that they do not want to. The participants can stop the interviews at any time and can withdraw from the research at any time without question.

Will I know who is participating?

We will be asking for consent from participants to inform the health professional who has referred them for inclusion, and their GP that they are participating.

What will happen to the results of the study?

Results from this research will be written up in an academic thesis. They may also be used in local and national publications including academic journals, and at events that are used to inform service development.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Yorkshire Research Ethics Committee.

Further Information/independent advice.

Patient Advice & Liaison Service (PALS)

Doncaster Primary Care Trusts

Health Focus

13, The Colonnades

Doncaster

South Yorkshire

DN1 3EG

Tel. 01302 768550 (Admin Line)

What do I do now?

If you have identified potential patients and/or informal carers to participate in this research the please give them a information pack, ask them to read this carefully and to return the reply slip for further information.

Thank-you for taking the time to read this information, and for supporting this research. If you have nay further questions please don't hesitate to contact me.

Kind regards

Beth

Researchers name and contact details:

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Checklist criteria for inclusion:

Patients

		Yes	No
1.	Does the patient have cancer (Stage 1) or COPD, Heart Failure, Parkinsons disease or co-morbidities in the advanced stages (stage 2)? Refer to attached sheet for further guidance.		
2.	Is the patient is aware of their diagnosis and that this is a progressive disease?		
3.	Is the patient is receiving input from 2 or more community services (excluding the GP)?		
4.	Is the patient over 18?		
5.	Does the person speak English?		
6.	Are there any known risks to a lone worker by interviewing this patient in their own home?		

The participant must answer yes to questions 1-5 and no to question 6 to be included.

Informal carers

		Yes	No
1.	Is the informal carer the main unpaid carer for someone with cancer (Stage 1) or COPD, Heart Failure, Parkinsons disease or co-morbidities in the advanced stages (stage 2)? Refer to attached sheet for further guidance.		
2.	Is the informal carer aware of the patients diagnosis and that this is a progressive disease?		
3.	Is the patient whom the informal carer is involved with receiving input from 2 or more community services (excluding the GP)?		
4.	Is the informal carer over 18?		
5.	Does the person speak English?		
6.	Are there any known risks to a lone worker by interviewing this informal carer in their own home?		

The participant must answer yes to questions 1-5 and no to question 6 to be included.

To identify appropriate participants for this study the prognostic indicator guidance in the Gold Standards Framework has been utilised. The prognostic indicator guidance is an aid to identification of adult patients with advanced disease in the last year or so of life.

Two triggers can be used to identify whether patients are eligible, if they meet either critera they are eligible to participate.

1. The surprise question, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.

2. Clinical indicators - Specific indicators of advanced disease (see below).

Cancer Patients

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer.

Heart Disease - CHF

At least two of the following indicators.

▪ CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion

▪ Patient thought to be in the last year of life by the care team - the 'surprise' question

▪ Repeated hospital admissions with symptoms of heart failure

▪ Difficult physical or psychological symptoms despite optimal tolerated therapy

Chronic Obstructive Pulmonary Disease – COPD

▪ Disease assessed to be severe e.g. (FEV1 <30%predicted)

▪ Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)

▪ Fulfils Long Term Oxygen Therapy Criteria

▪ MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness

▪ Signs and symptoms of Right heart failure

▪ Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression

Parkinson's disease

The presence of two or more of the following indicators:

▪ Drug treatment is no longer as effective / an increasingly complex regime of drug treatments

▪ Reduced independence, need for help with daily living activites.

▪ Recognition that the condition has become less controlled and less predictable with "off" periods

▪ Dyskinesias, Mobility problems and falls

▪ Swallowing problems

▪ Psychiatric signs (depression, anxiety, hallucinations, psychosis)

Definition of Informal Carer: An informal carer is usually a spouse or other family member, but may also be a friend or neighbour. We are looking for the person who considers themselves the main informal carer.

References: Gold Standards Framework Website. Accessed online at http://www.goldstandardsframework.nhs.uk/ on 24.02.09

<u>Carer information pack</u>

HHRB 2/12,

University of Huddersfield

Queensgate

Huddersfield

HD1 3DH

Phone – 01484 471427

Hello

This is an invitation to participate in a research study investigating what it is like to be a carer for someone with an advanced progressive disease and receiving support from multiple services in the community. You have been given this letter and attached information sheet as your health professional has identified that you may be eligible to participate. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take your time to read the attached information, and talk to others about the study if you wish.

If having read the attached information sheet you feel you may be interested in participating, then please complete the reply slip at the bottom of this letter and return it in the stamped addressed envelope. Once I have received this information you will be contacted to make an appointment to discuss the research further.

The care that you currently receive will not be affected by participating in this research, and if you change your mind about participating in this research you can withdraw at any time.

Thanks-you for taking the time to read this letter and the accompanying information.

Yours Sincerely

Beth Hardy
PhD researcher.
University of Huddersfield.
……
…………………

Reply Slip:

I (carer)………………………………………………… would be interested in finding out more about the research into patients and carer experiences.

Phone number……………………………………………………………………………………………………

Name of health professional who referred me……………………………………………………

Please return this form within seven days of being given the information. You will be contacted by Beth Hardy by telephone with seven days of her receiving this form.   Many Thanks.

<u>Carer Information sheet</u>

Title of research study: Patients with advanced progressive disease and their carers experiences of receiving support from multiple services in primary care.

What is the purpose of this research?

This research aims to discover what it is like to be living with advanced disease and receiving services in the community – from the perspective of patients and informal carers.

Who is doing this research?

This research is being carried out by Beth Hardy, a nurse and full time PhD student at the University of Huddersfield, with support of Professor Nigel King, Jan Firth and Alison Rodriguez at the University of Huddersfield.

Why have I been asked to participate?

You have been chosen as your views and experiences are important, and could contribute to creating a better understanding of what it is like to be a informal carer in this situation.

What is an informal carer?

An informal carer is anybody who acts as the main unpaid carer/support person for a patient. This is usually a husband/wife or other family member of the patient, although may also be a friend or neighbour.

Can I participate in this study even if the person who I am an informal carer for doesn't want to?

Yes, You may still participate in this study on your own.

What are primary care services?

Primary care services are very varied. For the purpose of this study, we are interested in your experiences with all the services you have contact with in the community as a consequence of any of the patients health issues.

What will I have to do?

If you decide that you may be interested in participating you will be asked to meet with the researcher on two occasions. At the first meeting she will give you more information about the research so you can decide whether or not to participate. If you do decide to participate she will then make an appointment for a second meeting. During the second meeting you will be asked questions about your experiences, and will be invited to draw a diagram which may help you to describe the services you are receiving.

What is the diagram? Is it a test?

No, it is not a test, and there is no right or wrong answer. The diagram is called a 'Pictor', and is a very simple method of helping you to think about the different types of services that you receive. It will be fully explained to you by the researcher. This diagram is not analysed or marked, it is just used as a basis of your conversation with the researcher.

What are the risks of participating?

You need to think about the time it takes to participate in the interview. Some people find discussing issues relating to situation upsetting. If this is the case you may stop the interview at any time.

What are the benefits of participating?

By taking part you will be contributing to increasing knowledge, which in the future may influence the development of health care services so that they are best able to meet the needs of patients and informal carers.

Participating in the research will not change the care that you, or the person you care for receive.

What will happen to the results?

Results from this research will be written up in an academic thesis, and in local and national academic publications. Results may be presented at events that are used to inform service development. We would also like your permission to use anonymous quotes from the study to help demonstrate our findings.

Will people know that I've participated and will my details be confidential?

With your permission we would like to inform the health professional that has referred you to the study, and your GP that you are participating in this research. They will not be given any information about what you say as part of the research. Your identity will be made anonymous in any written or verbal work which arises as a consequence of this research. All your personal information, such as name and address will be kept confidential.

The only time confidentiality would be broken is if you told the researcher about any intention you had to harm yourself or other people.

If I decide not to participate what will happen?

Nothing! You will continue to receive the same care as before.

What if I decide to participate and my situation changes or I change my mind?

You can change your mind and withdraw from the research at any point, just let Beth Hardy know. This will not affect the care that you, or the person you care for receives.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South Yorkshire Research Ethics Committee.

Further Information/independent advice.

Patient Advice & Liaison Service (PALS)
Doncaster Primary Care Trusts
Health Focus
13, The Colonnades
Doncaster
South Yorkshire
DN1 3EG
Tel. 01302 768550 (Admin Line)

Yes I'm interested. What do I do now?

Fill in the reply slip and post it in the envelope provided. Beth Hardy will then contact you to make an appointment to discuss the research further, where you will have time to ask any questions. At this appointment, if after hearing more about the research you decide to participate then a convenient time will be made for the meeting.

Thank-you for taking the time to read this information. If you have any further questions please don't hesitate to contact me.

Kind regards

Beth Hardy

Researcher contact details:

Beth Hardy
HHRB 2/12
University of Huddersfield
Queensgate
Huddersfield
HD1 3DH
Phone: 01484 471427
e-mail: b.hardy@hud.ac.uk

Patient information pack

HHRB 2/12,

University of Huddersfield

Queensgate

Huddersfield

HD1 3DH

Phone – 01484 471427

Hello

This is an invitation to participate in a research study investigating what it is like to be a patient with an advanced progressive disease and receiving support from multiple services in the community. You have been given this letter and attached information sheet as your health professional has identified that you may be eligible to participate. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take your time to read the attached information, and talk to others about the study if you wish.

If having read the attached information sheet you feel you may be interested in participating in this research then please complete the reply slip at the bottom of this letter and return it in the stamped addressed envelope. Once I have received this information you will be contacted to make an appointment to discuss the research further.

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Thanks-you for taking the time to read this letter and the accompanying information.

Yours Sincerely

Beth Hardy
PhD researcher.
University of Huddersfield.
……….

Reply Slip:

I (patient)……………………………………………… would be interested in finding out more about the research into patients and carer experiences.

Phone
number…………………………………………………………………………………………

Name of health professional who referred me…………………………………………………

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Title of research study: Patients with advanced progressive disease and their carers experiences of receiving support from multiple services in primary care.

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Why have I been asked to participate?

You have been chosen as your views and experiences are important, and could contribute to creating a better understanding of what it is like to be a patient in this situation.

You are also recruiting informal carers. What is an informal carer?

An informal carer is anybody who acts as the main unpaid carer/support person for a patient. This is usually a husband/wife or other family member of the patient, although may also be a friend or neighbour. Your health professional may have given a separate information pack to your informal carer, if not then please contact Beth Hardy and she will send your informal carer some information about the research and ask them to be involved too.

What if I don't have an informal carer, or I do and they don't want to participate?

You may still participate in this study on your own.

What are primary care services?

Primary care services are very varied. For the purpose of this study, we are interested in your experiences with all the services you have contact with in the community as a consequence of any of your health issues.

What will I have to do?

If you decide that you may be interested in participating you will be asked to meet with the researcher on two occasions. At the first meeting she will give you more information about the research so you can decide whether or not to participate. If you do decide to participate she will then make an appointment for a second meeting. During the second meeting you will be asked questions about your experiences, and will be invited to draw a diagram which may help you to describe the services you are receiving.

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Yes I'm interested. What do I do now?

Fill in the reply slip and post it in the envelope provided. Beth Hardy will then contact you to make an appointment to discuss the research further, where you will have time to ask any questions. At this appointment, if after hearing more about the research you decide to participate then a convenient time will be made for the meeting.

Thank-you for taking the time to read this information. If you have any further questions please don't hesitate to contact me.

Kind regards

Beth Hardy

Researcher contact details:

Beth Hardy
HHRB 2/12
University of Huddersfield
Queensgate
Huddersfield
HD1 3DH
Phone: 01484 471427
e-mail: b.hardy@hud.ac.uk

Appendix 5: Consent form and interview schedule

Patient Identification Number for this interview:

CONSENT FORM

Title of Project: *Patients with advanced progressive disease and their carers experiences of receiving support from multiple services in primary care.*

Name of researcher:

1. I have been fully informed of the nature and aims of this research and consent to taking part in it.

2. I understand that I have the right to withdraw from the interview at any time without giving any reason.

3. I understand that participating in this research, or withdrawing from this research will not affect any services I receive.

4. I give my permission for my interview to be tape recorded.

5. I understand that the tape will be kept in secure conditions at the University of Huddersfield.

6. I understand that no person other than the interviewer and their team will have access to the recording.

7. I give permission to be quoted (by use of pseudonym) in any written, oral or multi-media reports that arise from the research.

8. I understand that my identity will be protected by the use of pseudonym in any written or verbal work arising out of this research.

9. I give permission for my GP, and the health professional who told me about the research to be informed about my inclusion in this study.

10. I understand that data collected during the study, may be looked at by from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

11. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Interview schedule
Due to the nature of qualitative semi-structured interviews, this is intended as a guide only, and is subject to change.

Topic	Sub Topic	Key Questions	Potential detail/prompts
Introductions			• Introducing self. • Length of interview • Can stop at any time. • Permission to record.
History/Background.	Social	• Could you tell me about your home situation?	• Who do you live with? • Main support? • Family support?
	Medical	• Could you tell when you got diagnosed and describe what has happened since then?	• History of illness • When diagnosed • Treatment received • Current treatment plan
PICTOR		The following interview will be dependent upon what has been discussed from the PICTOR diagram, but may include the following.	
The contacts		• What happens when you see..........?	• Prompted by who discussed in pictor.
		• What types of things do you discuss?	• Illness/symptoms/family/ social factors/
The care environment		• Where do you see services? • Who decides where to see you? • Can you describe what happens during the visit?	• Home? • Where in home? • Who decides? • Day care? • GP surgery?

Topic	Sub Topic	Key Questions	Potential detail/prompts
Communication	With health professionals	• How do you feel about talking to services about issues you may have?	• You/them/family • what you talk about? • How long? • What you disclose? • how you benefit? • Who is present? • You/them/someone else?
		• How do you decide which service to talk to about issues?	• Able to disclose? Confide? Why/why not? • What prevents/encourages this? • Who decides what to discuss during visits? • Do you get chance talk to HPs away from your carer/patient. • Can you discuss sensitive subjects? Who raises these? • What happens when you raise sensitive subjects? Who raises sensitive subjects? How does this make you feel?
	Between health professionals	• How do the services communicate with each other?	• Do HPs talk to each other? • How do you know? • Do you have to tell the same thing to different HPs. • Do HPs know your treatment plans? Does this matter?
Relationships	With HPs	• Can you describe your relationship with……? • Do you use one service more often that others? Why is that?	• Who is the most important/useful HP? Why? • Who do you call when you need help and advice? • What makes you chose this person/service? • Personal elements. • Professional elements.

Topic	Sub Topic	Key Questions	Potential detail/prompts
	Between HPs	• What would you say were the important elements of a relationship with services? • Can you describe to me how services communicate with each other? • Can you describe for me how service work with each other?	• Do they work together? • Do they have good /bad working relationships? • Do they know what each other is doing? • How do you know this?
Choice		• Do you feel you have choices in about which services you see? • Can you give me any examples of this?	• Location of care? • Service? • Individual practitioner within that service? • Care plan? • Who gets told what? • Future choices? • What does choice mean to them?
Support		• Are there any factors that make you feel supported? • Can you give me an example of this?	• Is it important to feel supported? • Do you feel supported? • Describe what it is like to feel supported? • Give examples of things people do to support you?
Care planning	Current Care	• What issues do you discuss with your service regarding planning your care?	• A care plan is a plan about your care. • Is care planned? • How is care planned? • Is it negotiated? • With patient? • With carer? • Is it prescriptive? • Is care planned for the future? How?

Topic	Sub Topic	Key Questions	Potential detail/prompts
Education	Advance care planning	• What things are important for you to plan regarding your care?	• Who raises sensitive subjects? You? HP?
	Self care	• How do you feel about your care when you are on your own?	• Are you given the skills? • Do you want to have the skills? • Your goals? Are these facilitated? • Practical tasks? • Able to manage?
	Empowerment/ disempowerment		• Part of team? • Given skills to manage? • Who has the power?
		Anything else participant wishes to add?	
Thank-you		•	• Thanks for time.

Appendix 6: MacPacc Membership

MacPacc (2010) Log of publications, presentations and achievements. Unpublished report.

Stephen Barclay (Cambridge): Macmillan-funded Department of Health Postdoctoral Fellow (2006-2011). Based part time at the General Practice and Primary Care Research Unit at the University of Cambridge.

Collette Clifford (Birmingham): Professor of Nursing, School of Health Sciences, University of Birmingham.

Nada Khan (Oxford): Macmillan-funded Doctoral Fellow (2009-2011).

Nigel King (Huddersfield): Professor of Applied Psychology at University of Huddersfield.

Una Macleod (Hull York Medical School): Professor of Primary Care Medicine from September 2010, previously Senior Lecturer in General Practice (0.5fte) and GP in Glasgow (0.5fte).

Jane Melvin: Managing Director, CareMax International Limited. Formerly lead nurse, GSF (until 2005).

Dan Munday (Warwick): Associate Clinical Professor in Palliative Medicine, Warwick Medical School; Consultant in Palliative Medicine, Coventry PCT. Former GP.

Scott Murray (Edinburgh): St Columba's Hospice Chair of Primary Palliative Care, Uni. of Edinburgh. Trained as a GP and specialises in palliative care, spiritual care and other aspects of primary care.

Bill Noble (Sheffield): Senior Lecturer in Palliative Medicine, University of Sheffield.

Eila Watson (Oxford): Chair in Supportive Cancer Care, Oxford Brookes University.

Beth Hardy (Huddersfield): Working towards a PhD on 'Experiences of people affected by advanced progressive disease who receive support from multiple sources in primary care'.

People affected by cancer: Roberta Lovick, Mike Vincent

Group co-ordinator: Janice Koistinen, Macmillan Projects Support Manager.

Macmillan members: Jane Maher, David Wright

Macmillan GP Advisor member: Charles Campion-Smith

Appendix 7: Template development

<u>Patient and carer templates version one</u>

These initial templates used descriptive a-priori codes for the specific services that were involved, and a combination of descriptive and interpretative codes to explore some of the more contextual details of this experience.

Patient template version 1:

1. **Diagnosis**
    -   The disease
        -   Financial implications
    -   Changing pace of time
    -   The enemy within
        -   The fight
        -   Control
        -   Injustice

2. **Physical implications of illness**
    o   Symptoms
        -   External
            -   Visible illness/invisible wellness
        -   Internal
            -   Invisible illness/visible wellness
                o   Separation of mind and body
    o   Medical involvement
        -   Treatment
            -   Effects on body
        -   Technology/equipment
            -   Measuring the illness inside
            -   Reliance on equipment
            -   Embodied experience of using equipment
    o   Preserving what remains

3. **Health**
    o   Perceptions of health
    o   Blame for disease

4. **Ever changing world**
    o   Previous life
        -   previous identity
        -   Old me/new me
    o   Finding new purpose
    o   Adapting to a new normal
        -   preserving normality
        -   knowing limitations
    o   choosing how to see my world
    o   a future without me

5. **Changing social world**
    o   Diminishing personal networks
    o   Shrinking physical environments
    o   Leisure time
        -   Planning for leisure

6. **being 'special**
   - o desire to be 'witnessed'
   - o striving for independence
   - o being one of many –
   - o isolation from common experience

7. **roles and relationships**
   - o Health services as whole
     - ▪ Nurses
       - • Macmillan nurse
       - • District Nurse
       - • Staff nurse
       - • Allied roles
       - • chemist
       - • Nurse specialists
         - o Expectations of role
     - ▪ Doctors
       - • GP
       - • GP staff
       - • Hospital doctors
         - o Expectations of role
     - ▪ Allied health professional
       - • Dietician
       - • physio
   - o Familial
     - ▪ Partner
     - ▪ Parent
     - ▪ Sibling
     - ▪ Other
   - o Community
     - ▪ Support group
     - ▪ Neighbours
     - ▪ Church
       - • vicar
   - o Internet
   - o Whose who?
     - ▪ Similarities in role between services
       - • Dn and Macmillan
       - • Nurses and GPs
     - ▪ Identification of role
       - • Uniforms
       - • Names of services
       - • Location of services
     - ▪ Why are they visiting?
   - o Living in the web
   - o 'Like flys around a jam pot' changing as time passes

8. **Interagency relationships**
   - o Continuity
     - ▪ Gatekeepers
   - o Communication
     - ▪ Nurse/doc
     - ▪ Nurse/nurse
     - ▪ Other
   - o Friction
     - ▪ Nurse/GP

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- Nurse/nurse
- Between roles

9. **Own role**
   o Philosophy of self
      - Self perception
      - Personal details
   o Loss of old self
   o Host
      - Responsibility to those who help
   o New knowledge/skills
      - Becoming an expert
      - Experiential learning
         • Role models
         • Shared experience
      - Being taught
      - Sharing knowledge with others
   o Supporting others
   o Awareness of others experience of situation

10. **Management of situation**
   o Self
   o Partner
   o Other

11. **Who knows best?**
   o Challenging formal services
   o Family conflict
   o Self knowledge
   o Taking control
   o Whose problem
      - As I see it
      - As they see it

12. **The road ahead**
   o Others worse off than me
   o Changing understanding of condition as time progresses
      - Acceptance of support
      - Storing resources for when really needed
   o The future
      - Death
         • dying

13. **Evaluating services**
   o 'brilliant'
      - Timing of involvement
      - Expertise
      - Proficiency
      - Advocacy
      - caring
      - Availability
         • The promise of availability
      - Addressing the problem pertinent to me
      - Futility in face of death
   o Awareness of existence

14. **Experience of interview**
   o Pictor
   o Participating in research

Carer template version 1:

1. Employment
   o Current
     ▪ Colleagues understanding of situation
     ▪ Employer understanding
       • flexibility

   o Previous

2. Living
   o Wanting to continue with life
     ▪ Illness bringing new perspectives to life
   o Pace of life changing
     ▪ Life running away' (getting too much, pace of change, need to catch up, out of control)

3. Their illness
   o Perspective on diagnosis
     ▪ On being diagnosed
     ▪ On treatments
   o Knowing them and their illness – a shared prison
   o Their illness, their experience
     ▪ Witnessing something that is hidden to others
     ▪ Physically observing their suffering
   o Inevitability of future
     ▪ Helplessness
     ▪ Futility of all intervention.

4. Own health
   o Own health issues
     ▪ Neglect of own health
     ▪ Others situation taking precedent
   o Concerns about health

5. Own role
   o Physical care
     ▪ Being depended on 100%
   o Where once there were two, now there is one
     ▪ Running a household single handed
   o Other caring responsibilities
     ▪ Balancing roles
       • They all think they're the main one.... pressures of multi-role
   o Learning
     ▪ Being taught
     ▪ Learning by doing
     ▪ Being 'allowed' to provide care (medical interventions)
   o being inadequate
     ▪ inability to relieve suffering

6. The future
   o Discussions of...
     ▪ Death
     ▪ Dying
     ▪ Funerals
     ▪ After death
   o Observing others illness' as way of knowing
     ▪ 'non-disclosed/discussed fears

7. My experience too.
- o Being listened to
- o being acknowledged by others
- o Isolation
  - ▪ You have to have been through it know it...
    - • Sharing experiences with others who know

8. HPs – list as patient template version one.

Patient and carer templates version two

From these initial two templates, I then went on to further code the data from the participant's transcripts. At this stage, I created three templates to work with, a patient specific template, a spousal-carer specific template and a template looking across all data pertaining to service use.

Patient template:

1. Demographics
      1.1 age
      1.2. previous employment

2. The Disease
      2.1. Diagnosis
              2.1.1. Implications
              2.1.2. Changing pace of time
              2.1.3. The enemy inside – dualistic understanding
                      2.1.3.1. Control
                      2.1.3.2. Injustice
                              2.1.3.2.1. Blame for disease
      2.2. Physical implications
              2.2.1. Effects on body
              2.2.2. Treatments
                      2.2.2.1. Equipment/technology
                              2.2.2.1.1. Measuring unseen illness
              2.2.3 Preserving what remains
                      2.2.3.1. Striving for independence
      2.3.   Perceptions of health

3. Own role
      3.1. Self perception
      3.2. Old self/new self
      3.3. Responsibility to those who help
              3.3.1. Host
      3.4. New knowledge and skills
              3.4.1. Experiential learning
                      3.4.1.2. Role models
              3.4.2. Being taught
                      3.4.2.1 Becoming an expert
                      3.4.2.2. Sharing knowledge with others
      3.5. Maintaining independence
      3.6. Finding new purpose
              3.6.1. Supporting others

3.7. Preserving normality
        3.7.1. Adapting to a new normal

4. Our experience
        4.1. Awareness of others experience of this situation

5. Changing social world
        5.1. Diminishing social networks
        5.2. Shrinking physical environment
        5.3. Leisure time
                5.3.1. Planning for leisure

6. Being Special
        6.1. Desire to be seen ('witnessed')
        6.2. One of many
        6.2. Isolation from common experience

7. What is to come...
        7.1. Others worse off than me
        7.2. Changing understanding as time progresses
                7.2.1. Acceptance of support
                7.2.2. Storing resources for when I really need them
        7.3 The Future
                7.3.1. A future without me
                7.3.2. Dying
                7.3.3. Death

Carer template:
1. Demographic details
        1.1 Age
        1.2. Years Married

2. Partners Illness
        2.1 Perspective on diagnosis
                2.1.1 Run up to being diagnosed
                2.1.2 Treatments
                2.1.3 Symptoms

3. Own Health
        3.1 Own health issues
                3.1.1 Different priority to partners
        3.2 Concerns over own health
        3.3 impact of current situation on own health

4. Own role
        4.1 being available
                4.1.1 Being depended on 24/7
                4.1.2 Respite
                        4.1.2.1 Wanting
                        4.1.2.2 Receiving
                                4.1.2.2.1 alarm systems
        4.2 Provision of physical care
                4.2.1 Acquiring required skills and knowledge
                        4.2.1.1 Being taught
                        4.2.1.2 Finding own way
                        4.2.1.3 Being 'allowed' to do things
        4.3 Promotion of self-care and independence
        4.4 Inadequacy of self

4.5 Other caring responsibilities
    4.5.1 Who for?
        4.5.1.1 What doing?
        4.5.1.2 Balancing roles
    4.5.1.3 They all think they are the main one...
4.6 Being the eyes and ears (link in dyads to being protected form myself)
    4.6.1 Observing Physical change
        4.6.1.1 Assessing when assistance is required
    4.6.2 Others don't see what I see
    4.6.3 In health/social contacts

5. My experience
    5.1 being listened to
        5.1.1 A can of worms... (once opened..)
    5.2 having role acknowledged by others
    5.3 you have to have been through it to understand it
        5.3.1 Sharing experiences with others who understand

6. Our experience – Happening to two people. The loss of We. - ? integrative theme

7. Other Activity
    7.1 Employment
        7.1.1. Current
            7.1.1.1. Employer attitudes to situation
            7.1.1.2. Colleague attitudes to situation
        7.1.2 Previous
    7.2 Hobbies

8. The Future
    8.1 Discussion of/ with...
        8.1.1 Death
        8.1.2. Dying
        8.1.3 Funerals
        8.1.4 After death
    8.2 Observing others as a way of knowing
    8.2.1 Undisclosed fears (except to me!)

Service template:

1. Contacts with health/social services
    1.1. Accessing health professionals
        1.1.1 Gatekeepers
        1.1.2 Environmental challenges
    1.2. Arrangement of contacts
    1.3 The contact
        1.3.1 Dependence on contact
        1.3.2 Social Function

        Addressing the problem that is pertinent to me
            1.3.3.1 Validating my experience
        1.3.4 Focus on patient
        1.3.5 Content of contact
            1.3.5.1 Who decides?
            1.3.5.2 Reaction of contact on interpretation of situation
            1.3.5.3 Contact taking responsibility for tasks
        1.3.6 Nurse contacts

4. Organisational issues
    4.1 inter - service issues
        4.1.1 Communication between services
        4.1.2 Friction between services
        4.1.3 Disagreement between services
        4.1.4 Sharing information between services
            4.1.4.1 The blue folder
            4.1.4.2 Imagined processes
            4.1.4.3 Patient/carer role.
            4.1.3.1 Being between services
                4.1.3.1.1 Being passed between services
                4.1.3.1.2 Feeling caught between services
                4.1.3.1.3 Receiving conflicting information from different services
    4.2 Services working together
        4.2.1 Service redesign – implications on care received
        4.2.1.1 Continuity of staff
        4.2.1.1 Government blame.

5. Using a 'team' that works for me. ?This is integrative them
    5.1. They. We
    5.2. Coordination and management of 'team' (network)

6. The Web of services
    6.1 comforting
    6.2 stifling
    6.3 confusing

7. Others in
    7.1 community network
        7.1.1 neighbours
        7.1.2 Friends
    7.2 Family
        7.2.1 Practical support
        7.2.2 Emotional support
                7.2.3 Conflict

8. locating services within my total experience – the figure ground perspective (? Integrative)
    8.1 Impact of total experience of illness upon this

<u>Patient and carer templates version three</u>

As the templates developed and evolved they became increasingly simple and easier to utilise, but with a greater number of interpretative codes. At this point I had started writing the findings chapters, and as I wrote, and gained increasing understanding through writing, the templates further evolved to capture the thematic structure of the experience. I found that lots of the detail of earlier templates was unhelpful at this stage, and more focused coding helped the writing process.

Patient template

1. A named illness: health service involvement
    1.1 Like flies around a jam pot.
        1.1.1   The arrival of health services
        1.1.2   Transient involvement
        1.1.3   Whose problem?
        1.1.4   Validating me experiences
    1.2 Helping me face my illness: services as support.
        1.2.1   Previous invisibility of services
        1.2.2   feeling safe: clinical knowledge
    1.3 Reducing isolation
        1.3.1   Being different.
        1.3.2   being understood
        1.3.3   Acceptance of death and dying
    1.4 Recognising illness: recognising services
        1.4.1   What web?
        1.4.2   Parts and whole: illness within my total experience
        1.4.3   Service involvement focus on living with illness
        1.4.4   Service involvement focus on living with illness – individual rejection of medical model.
        1.4.5   Service involvement focus on living with health
        1.4.6   Making me a patient
    1.5 Services are for someone else
        1.5.1   Someone worse off than myself
        1.5.2   'it's no good moaning about it': futility of service intervention
        1.5.3   Saving resources for the future
        1.5.4   Being a 'good patient'. Hosting services
2. I don't know what I'd do without her': 24/7 lay-carer involvement.
    2.1 if she wasn't here, I wouldn't be here': dependence on lay-carers
        2.1.1   Altered roles
        2.1.2   Physical care
        2.1.3   Protecting me from myself
        2.1.4   Systems
        2.1.5   Continuation of normality
        2.1.6   Coordinating
            2.1.6.1   Knowing what is going on
            2.1.6.2   Record keeping

Spousal-carer template
    1.   A partner who is ill: health service involvement
        1.1 The patient focus
                1.1.1   And of course I said I am fine
                1.1.2   Trusting them with my partner
                1.1.3   The search for acknowledgement
        1.2 Lay-carer role within the web
                1.2.1   Physical care: approval from health staff
                1.2.2   Liaising with health services
                    1.2.2.1 Knowing better than HS
                    1.2.2.2 Always watching
                1.2.3   Supporting
                    1.2.3.1 Promotion of self care
                1.2.4   Helplessness
                1.2.5   A 24 hour responsibility

Universal experiences template
    1. Community network
        1.1 You have to have been through it to understand it

<u>Patient and carer templates version four (final version)</u>

I was not happy with the structure of the templates that had been developed, thus, in this final version of the template the chapters and templates were restructured slightly so that the first two templates focussed on unique elements of the experience of patients and spousal-carers, and the third template looked across all participants experiences to explore key relationships. The use of an integrative theme helped to tie these findings together

Chapter 6: Patient experiences

1. Recognising illness: recognising services

    1.1 They do things to me: we do things together

    1.2 Helping me face my illness: the comforting presence of services

        1.2.1 Previous invisibility of services

    1.2 Services reducing the isolation of illness

        1.2.1 Being different

        1.2.2 Being understood

        1.2.3 Acceptance of death and dying

Chapter 7: Spousal-carer experiences

2.   A partner who is ill: being a spouse, being a carer

    2.1 The patient focus

        2.1.1 *'There's no support for me'...*

        2.1.2 *'I don't want to cry in front of him':* Partners presence restricting the spousal-carer's opportunity for discussion with health services

    2.2 Declining service involvement

        2.2.1 *'And of course I said I am fine'*

    2.3 *'My strength'*: support from friends and family

    2.4 Always watching: a unique insight

        2.4.1 Specialist knowledge: contribution to, and rejection from the care team

Chapter 8: Key relationships with services

3.   My care team: using a team that works for me

    3.1 Coordinating and managing the team

    3.2 Significant health service relationships

        3.2.1 Individuals, not role

        3.2.2 *'like'* a friendship

        3.2.3 Knowing them, knowing me

        3.2.4 Listening to me

        3.2.5 Not solving the unsolvable

    3.3 *'My Doctor':* GP involvement

        3.3.1 Desire for holistic and supportive involvement

        3.3.2 Secondary to other services

        3.3.3 In acute illness