UNIVERSITY OF
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Experiences of end-of-life care from the perspective of older patients and bereaved carers:

A focus on transitions between place of care and resilience

Thesis submitted in accordance with the requirement of the

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by Louise Roper

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Dissemination

Peer reviewed dissemination

This thesis has contributed to the following peer reviewed publications:

Chapter Four: published in BMC Health Services Research in 2012;

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Chapter Five: published in Journal of Pain and Symptom Management in 2012;

Hanratty, B., **Holmes, L.,** Lowson, E., Grande, G., Addington-Hall, J., Payne, S., Seymour, J. (2012). Older Adults Experiences of Transitions between Care Settings at the end-of-life: A Qualitative Interview study. *Journal of Pain and Symptom Management* 44; 74-83. doi:10.1016/j.jpainsymman.2011.08.006

Chapter Six: published in International Journal of Nursing Studies in 2013;

Lowson, E., Hanratty, B., **Holmes, L.,** Addington-Hall, J., Grande, G., Payne, S., Seymour, J (2013). From 'conductor' to 'second fiddle: Older adults care recipient's perspectives on transitions in family caring at hospital admission. *International Journal of Nursing Studies 50:* 1197-1205. doi:10.1016/j.ijnurstu.2012.02.005

Chapter Seven: was published in Ageing and Mental Health in 2018;

Roper, L., Donnellan, W., Hanratty, B., Bennett, K.M (2018). Exploring dimensions of social support and resilience when providing care at the end-of-life; a qualitative study. *Ageing and Mental Health.* doi.org/10.1080/13607863.2018.1484886

Oral presentation of thesis

I have presented the findings within this thesis at the following conferences:

- Society of Social Medicine, 2010 in Belfast, Northern Ireland;
- British Society of Gerontology, 2011 in Plymouth, England;
- Marie Curie and Royal Society of Medicine, 2011 in London, England;
- International Association of Geriatrics and Gerontology, 2011 in Bologna, Italy;
- Gerontological Society of America, 2016 in New Orleans, USA;
- British Psychological Society, 2017 in Brighton, England;
- British Society of Gerontology, 2017 in Swansea, Wales;
- International Association of Geriatrics and Gerontology, 2017 in San Francisco, USA.
- British Society of Gerontology, 2019 in Liverpool, England.

Findings from this work stream that are not included in this thesis have also produced the following peer-reviewed publications:

1. Hanratty, B., and **Holmes, L**. (2011). Social Inequality in Dying Ch. 2, *In Death, Dying and Social Differences*, Second Edition Ed. Oliviere, Monroe, Payne, Oxford University Press

2. Hanratty, B., Lowson, E., **Holmes, L.,** Grande, G., Addington-Hall, J., Payne, S. and Seymour, J. (2012). Funding health and social services for older people: a qualitative study of the views of care recipients in the last year of life. *Journal of the Royal Society of Medicine: 105*: 201-207

3. Hanratty, B., Lowson, E., **Holmes, L**., Grande, G., Jacoby, A., Payne, S., Seymour, J. and Whitehead, M. (2012). Breaking bad news sensitively: what is important to patients in their last year of life? *BMJ Supportive and Palliative Care* 2 (1), 24-28

Abstract

My thesis uses qualitative methods to explore older people's and bereaved carers' experience of transitions between places of care at the end-of-life. I use Windle and Bennett's (2011) ecological framework of resilience as a lens to explore the data in a novel way. I address four research questions: first, what are the experiences of older people at the end-of-life who move from one care setting to another? I report that moves between health care settings can be characterised by inflexibility and a failure of professional carers to listen. Continued attention to basic aspects of care and communication between health professionals and patients is key. Second, what are the experiences of bereaved carers who have also navigated a move from one care setting to another? I find that older carers are typically 'conductors' of care, making strong contributions to maintaining good care throughout the illness trajectory. On admittance of the care recipient to hospital, family carers find their influence in decision-making vastly reduced, yet carers endeavour to act flexibility to provide continuity, support and enhance wellbeing across settings. Third, what role do social relationships play in the ability of carers to adapt and bounce back from this stressful situation? I find that social support for carers providing end-of-life care is almost exclusively based around end of life care 'work'. Multi-dimensional support is needed for carers to enhance their resilience. Fourth, what are the experiences of male bereaved carers and how does their experience of adapting to this stressful situation look? I find that informational and tangible support was forthcoming and timely for male caregivers but emotional aspects of caring where not always met. Providing respectful, timely support and clear information is a key way in which professional services could enhance the developments of resilience amongst caregivers. Together, the findings contribute to the literature on the importance of social ecological approaches to resilience. The ecological framework is modified to enhance its applicability to informal carers of people at the end-of-life.

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Chapter One:
Overview of the thesis

1.1 Overview of this thesis

My doctoral work is based on data collected within a larger study I worked on for three years, "Transitions at the end-of-life patient and provider perspectives" (Hanratty et al., 2014, National Institute of Health Service Research). That study emerged from the perspective that professionals and families often believe there is a mismatch between the services received and the experience that older adult patients and carers would choose (Cartier, 2003; Kralik, Visentin, & Van Loon, 2006; Larkin, De Casterlé, & Schotsmans, 2007). Movements between settings or places of care may be determined by external factors, and may not always be in the best interest of the patient or have the full support of the carers. The 'Transitions' study examined the patterns, causes and the nature of transitions between health service settings in the last years of life, adding to my understanding of the consequences of transitions for the patients and giving new insights into decision-making and constraints for people commissioning and providing the care (Hanratty, Holmes, et al., 2012b) . The project ran from 2009-2012, and comprised three phases. Phase one explored the experiences of patients over the age of 75 years old with lung cancer or heart failure or stroke and their experiences of health and social care. Phase two explored the experiences of bereaved carers of older people with lung cancer, heart failure or stroke. Phase three explored the experience of health professionals who worked in health and social care settings with people at the end-of-life, from front line staff to policy makers; I was not involved in Phase three.

This thesis draws on phases one and two of the 'Transitions' study data, but uses the Windle and Bennett (2012) ecological framework of resilience, as a lens to examine the data in a novel way. I have explored the experiences of older people, their carers, and bereaved carers. Using the ecological framework of resilience (Windle & Bennett, 2011), I have explored two elements of the data that I found to be lacking in the research literature: the concept of social support and its importance in end of life care 'work'; and the perspective of male carers.

1.2 An overview of the topic

Many of the conditions that were common causes of death in previous generations can now be prevented, managed or occasionally, cured. This has contributed to people dying later in life. Many people have more contact with services in their last year of life than at any other time (Lubitz & Riley, 1993). Movements between places of care may not always be in the interest of the patient or the patient's family. Transitions at the end-of-life are difficult for older people and carers to navigate and older people can lose a sense of continuity of care when their informal care arrangement is disrupted. Informal care is an important source of care for older people living in the UK (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). Analysis of the 2001 Census found that 5.2 million people in England and Wales provided care to a family member or friend and over 1 million of these provided more than 50 hours per week (Dahlberg, Demack, & Bambra, 2007).

One of the most important benefits of informal care provision is that it can prevent or delay a move to a more formal care environment, such as a hospital or care home. This is considered a benefit to both the person needing the care and also to the health and social care system (Arno, Levine, & Memmott, 1999; Hebert & Schulz, 2006). Informal care provided at home by family members, can enhance an older person's quality of life considerably (Farina et al., 2017). However, there are risks for the person who is providing informal care, including chronic stress, poor physical health and detrimental impacts on quality of life (Ewing, Austin, Jones, & Grande, 2018; Janda, Eakin, Bailey, Walker, & Troy, 2006; Janda et al., 2008; Solomi & Casiday, 2017; Williams et al., 2018; Wong & Ussher, 2009). Many studies have explored 'caregiver burden', which broadly relates to the overall impact of the physical, psychological, financial and social demands of care giving (Truzzi et al., 2012). This burden can originate from an imbalance between care needs and successfully fulfilling care tasks (Truzzi et al., 2012). Providing informal care at the end-of-life can be particularly difficult and stressful for carers (Schulz et al. 1997).

At the end-of-life, a move into or out of hospital, care home or hospice is potentially one of the most disruptive events for an older person and their family, with consequences for mental, physical and emotional wellbeing (Higginson & Sen-Gupta, 2000; Kralik et al., 2006; Teno et al., 2013). Ensuring consistency across settings can be important when caring for older people at the end-of-life. Patients and carers feeling supported, listened to and feeling they have been treated with

sufficient dignity are the aspects of basic care that are most likely to be lost when someone is admitted to or discharged from care settings such as hospitals, hospices or nursing homes (Hanratty, Holmes, et al., 2012a). A large number of health and social care professionals may be involved in delivering end-of-life care, including doctors, nurses, allied health professionals and social workers. This can make it more difficult to negotiate the multiple staff and service involvement.

Informal care provision is usually provided by one person, with the 'typical' UK caregiver being a 49 year old woman (Feinberg, Reinhard, Houser, & Choula, 2011). As men and women age, men are more likely to provide care. The experiences of men providing care at the end of life are less well known than the experiences of women (The Carers Trust, 2014a). Some research suggests that men experience less burden (Choi, Burr, Mutchler, & Caro, 2007) but others say it is because they handle their burden differently (Ussher & Sandoval, 2008).

In psychology, researchers are focusing on the positive processes people use to cope with adverse life events and the resources they have to manage these adversities. The ability to successfully tackle the adversity of caring for a dying person is to some extent dependent on assets and resources within the life and environment of the carer. Research on resilience is gaining increasing popularity within policy and practice because of its impact on health, well-being and quality of life (Windle, 2011a). Identifying protective factors in caregivers is important, as it may help in designing strategies and interventions to prevent burden in caregivers whilst helping them to better cope with caregiving tasks (Palacio, Krikorian, & Limonero, 2018).

Definitions of resilience vary and range from developmental psychology, biology, psychiatry, life course perspectives, process definitions and operationalised perspectives and are discussed further in chapter two. For this thesis the most appropriate definition is based on the systematic review, concept analysis, and consultation workshops of Windle (2011) where resilience is defined as,

> *"the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individuals, their life and environment facilitate this capacity for adaption and bouncing back in the face of adversity. Across the life course, the experience of resilience will vary* (Windle, 2011a, p. 163)."

This is a particularly useful definition when exploring the experience of carers providing end-of-life care as it highlights that individuals may fail to become resilient if the environment does not facilitate opportunities to adapt (Ungar, 2012). It also describes the assets (personal characteristics) and resources (external factors) as key to facilitating the capacity to adapt and bounce back. This corresponds with the literature exploring the experiences of carers.

My thesis explores the experiences of older people at the end of life and the experiences of bereaved carers. It then focuses in-depth on the bereaved carers' experience of resilience, specifically, how assets and resources contribute towards or hinder resilience and the contribution of social support. I then explore in detail the experience of resilience in male caregivers, as there is a dearth of research reporting their experience.

1.3 Research aims and objectives

1.3.1 My doctoral work

The aim of my thesis is to explore the experiences of older people at the end-of-life and bereaved carers, with a focus on assets or resources, which contribute towards resilience. The objectives are:

1. To explore the experiences of older people at the end of life who move from one care setting to another.
2. To explore the experiences of carers who have also navigated a move from one care setting to another, from the perspective of both older people and their carers.
3. To explore the resilience in carers providing end of life care including the role social relationships play in the ability of carers to adapt and bounce back to this stressful situation and the experiences of male bereaved carers and what their experience of adapting to this stressful situation looks like.

1.4 Structure of this thesis and my contribution

Table 1 My contribution to the publications

Chapter	Published	My contribution
One: Overview of the thesis	NA	Sole author
Two: An introduction to the literature	No	Sole author
Three: Methods and Methodology	No	Sole author
Four: A comparison of strategies to recruit older patients and carers to end-of-life research in primary care	Yes	Design, Data collection, Analysis, Author
Five: Older adults' experiences of transitions between care settings at the end-of-life in England: a qualitative study	Yes	Design, Data collection, Analysis, Author
Six: From conductor to second fiddle: older adults care recipient's perspectives on transitions in family caring at hospital admission	Yes	Design, Data collection, Analysis, Author
Seven: Exploring resilience when providing care at the end of life	Yes	Design, Data collection, Analysis, First author
Eight: Discussion and conclusion	No	Sole author

Each chapter briefly contains:

Chapter Two: The introduction to the literature is an exploration of how and why the ageing population in the UK is using more health and social care services. I also examine what this looks like for end-of-life service provision. The literature around moving between services at the end-of-life is then critiqued, being mindful of recent changes in the landscape of health and social care services. There is then an overview of what we already know about the experiences of informal caregivers. Specifically, I focus on the demography of carers, the gender related literature, health implications for those providing care, positive aspects of the caregiver experience and informal carer support. The introduction then moves to the factors influencing the resilience of carers, including the socio-environmental factors and the different approaches to exploring resilience. I was the sole author of this chapter.

Chapter Three: The research aims and objectives are outlined. The methodology section includes an overview of the philosophical underpinnings of this thesis and the use of qualitative methods in this study. The research setting is outlined including sampling and recruitment (patients and bereaved carers), how and what

data was collected, confidentiality, analysis and writing. Ethical considerations, researcher characteristics, the role of the researcher and reflections are described. There are some repetitions between sections in this chapter and chapter four. This is because chapter four has much, but not all of, the detail needed for a methods and methodology chapter. I was the sole author of this chapter.

Chapter Four: This chapter compares strategies to recruit older patients and carers to end-of-life qualitative research. We compared areas of England with different research network support and identified challenges in obtaining samples representative of those in need of end-of-life care. We found the sampling and recruitment resource intensive, but that the networks did provide invaluable assistance. I collected the data, analysed the data and contributed to the writing of the paper for publication. I was involved in both studies that the paper draws from.

The paper was published in BMC Health Services Research:

Hanratty, B., Lowson, E., **Holmes, L.,** Addington-Hall, J., Arthur, A., Grande, G., Payne, S. and Seymour, J. (2012). A comparison of strategies to recruit older patients and carers to end-of-life research in primary care. *BMC Health Services Research*, 12, 342 (doi:10.1186/1472-6963-12-342).

Chapter Five: This chapter explores the older person's experience of transitions at the end-of-life. This paper sets the scene of the experiences for older people moving between care settings at the end of life. Participants describe how they feel they are inconsequential within the machine of the health care system and how the institutional processes around them are prioritised. The older people describe how they lack or need further support when they move from one place of care to another. The lack of dignity and the feeling that they are not listened to are also important themes within this chapter. The concepts discussed by the older people at the end-of-life are important in later results chapters when I draw upon the significant adverse event (caring at the end-of-life) that the older people and carers have been expected to negotiate or manage. I contributed to the study set up, including the design of materials and topic guides, liaised with health professionals regarding the recruitment of participants, completed all recruitment, all data collection, all data analysis, and wrote the paper with my second supervisor. This chapter was published in the Journal of Pain and Symptom Management;

Hanratty, B., **Holmes, L.,** Lowson, E., Grande, G., Addington-Hall, J., Payne, S., and Seymour, J. (2012). Older adults experiences of transitions between care settings at the end-of-life: a qualitative interview study. *Journal of Pain and Symptom Management,* 44; 74-83. (doi:10.1016/j.jpainsymman.2011.08.006)

Chapter Six: This chapter explores the role of the carers in end-of-life care from the perspective of the older person who needs end-of-life care. Similar to chapter five, this chapter is key to my understanding of the contribution made by carers to older people at the end-of-life and how the end-of-life care 'work' that they provide maintains the rhythm of good care for older people. It touches on how carers invest considerable time and effort in maintaining continuity for the older person and filing in gaps in provision. They often advocate on the patient's behalf, taking responsibility for the participants care across settings.

The perspective of the older people being cared for is important in this thesis and is touched on in chapter five; but this paper sets up the next results chapters as it presents data highlighting the complexity of caring for older people at the end-of-life and the sacrifice that is frequently made by the carers. It roots the experience of caring for someone at the end-of-life and the way carers must continually adapt to significant sources of stress. This stress, and how carers manage and adapt, is explored in more depth in chapters seven and eight with a focus on resilience. I contributed by collecting all the data and analysing the data and writing the paper. The paper was published in International Journal of Nursing Studies;

Lowson, E., Hanratty, B., **Holmes, L.,** Addington-hall, Grande, G., Payne, S., and Seymour, J (2013). From 'conductor' to 'second fiddle: Older adults care recipient's perspectives on transitions in family caring at hospital admission. *International Journal of Nursing Studies, 50;* 1197-1205. (doi:10.1016/j.ijnurstu.2012.02.005)

Chapter Seven: This chapter explores resilience when providing care at the end of life. I examine two areas of interest within this chapter. Firstly, how the presence or absence of distinct dimensions of social support (Sherbourne and Stewart, 1991) could facilitate or hinder resilience in this setting of end-of-life care 'work'. I examine how the quality of bereaved carers' material or social support influences the level of resilience demonstrated by bereaved carers whilst they are caring for their loved ones. A range of different types of support were identified for this group of participants. Themes of emotional, affectionate, informational, tangible and

positive social interaction were present in the data, as well as themes focusing on health professionals' social relationships with the carers, and families' relationships with each other.   Analysis suggests that there is less emphasis on affectionate support and positive social interaction and that support and social relationships can be obstructed by health professionals and family. I generated the hypothesis, designed study materials, collected the data and conducted the analysis. I wrote the abstract and presentation for the conference then later wrote the paper for publication. A version of this chapter was published in Ageing and Mental Health;

Roper, L., Donnellan, W., Hanratty, B., and Bennett, K.M. (2018). Exploring dimensions of social support and resilience when providing care at the end-of-life; a qualitative study. *Ageing and Mental Health.* doi.org/10.1080/13607863.2018.1484886

This chapter also focuses on the experience of all the male carers from the wider 'Transitions' study, (N=30) who were caring informally for spouses or parents at the end-of-life with a range of illnesses. Previous research has posited the need for understanding male caregivers better (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, & Todd, 2009). Research has also suggested that it is the proportion of older carers who are increasing substantially and that we need to understand their barriers to caring, better. I classified the men as resilient or not using the Bennett and Donnellan classification system (2015). Utilising the ecological framework (Windle and Bennett, 2011) I examine factors promoting or hindering resilience. This sub-section of the chapter was presented at the recent British Society of Gerontology conference, Liverpool, 2019.

Chapter Nine: In this chapter, I outline the major findings of the doctoral work, and discuss the theoretical and practice related developments for future research. I critique aspects of the study design and method of data collection in the limitation section. I look to the future and give direction on further work that is needed. This includes revisiting the ecological model of resilience and modifying it for end-of-life care challenges. I have submitted the alternative modification of the Ecological Framework of Resilience (Windle & Bennett, 2011) to the British Society of Gerontology conference in July 2019.

Chapter Two:
An introduction to the literature

2.1 Scoping the literature

The literature was reviewed between 2009- 2012 and updated periodically by keeping up to date with new policies and peer reviewed papers and also by searching the reference lists of papers of interest. At first, reviewing the literature situated the focus of the research questions for my thesis and the wider 'Transitions' project. It also confirmed that there was a gap in the literature and that my data may help contribute to this gap in knowledge. As the literature review was refined and updated it clarified my own thoughts and supported the data around the difficulties of transitions at the end of life from the carer perspective. It also added to my understanding of resilience in this context, and helped establish some of the frameworks I used in the analysis of the data.

The aim of the literature review was to identify and then address the implications of the gaps in the literature for theory, practice and research by critically synthesising the evidence.

The first research question was, 'what do we know about the experience of older people and bereaved carers at the end of life who move between one place of care and another' and the second research question was, 'what do we know about resilience and carers'.

I searched electronic databases including Medline, PsychInfo, Web of Science, Cochrane database of systematic reviews. I also searched Google Scholar for subsequent policy reports papers and searched reference lists of key papers. I also engaged with experts in the field who periodically flagged new or key literature which in turn generated further exploration of the reference lists and citations of interest. I attended many conferences and again, this alerted me to some important work.

The inclusion criteria was peer reviewed journal articles where informal carers, bereaved carers, transitions, older people at the end of life, resilience was a key focus. There was no date specified and the articles needed to be published in English.

Papers were excluded if they were not published in English, or I was unable to get access to the full article.

Key papers were downloaded to Endnote and 412 papers and reports were included in this thesis.

2.2 An ageing population using more services

The life expectancy of the UK population had increased consistently for the entire twentieth century. Life expectancy was expected to continue increasing, with projections of a rise from 79.2 to 83 years for men between 2012 and 2032. However, in 2016, life expectancy had started to decrease. Women in the UK, on average, have lost 4 months of life since 2012 and the latest ONS data shows that men and women are now expected to live a year less than was thought just two years ago (Hiam, Harrison, McKee, & Dorling, 2018). This reduction in life expectancy is thought to be rooted in public service cuts and austerity measures introduced by the Coalition and Conservative governments (Hiam & Dorling, 2018). At present, national and international policies are not addressing the underlying factors reducing life expectancy.

Evidence suggests that biological, individual and societal influences on health all impact on life expectancy (Marmot, 2015). Recent research (Hiam et al., 2018) suggests "*something is making the population vulnerable to avoidable death*" and that *"it (decreased in life expectancy) is no longer being treated as a temporary decline; it is the new norm*" (p.463 The BMJ). The precise fluctuation in life expectancy going forward will depend on many factors including patterns of disease, individual socio-economic circumstances and lifestyle factors, and access to health and social care. The Department of Health (Health, 2010a) have previously reported that there is a life expectancy variation of seven years between the richest and the poorest people in the UK population, with people in the poorest socio-economic group expected to live seven years less than those in the wealthiest socio-economic group. There are also differences between men in the highest social group and men in the lowest social group within the UK (Department of Health, 2011). The Office of National Statistics (ONS, 2007) reported that over the next 70 years there could be a possible variation of 20 years between the life expectancy of some groups. Years of healthy life are reported to be increasing, albeit slowly. Public Health England reported that the recent trends in life expectancy at older ages show that men can expect to live for a further 19 years at age 65; 12 years at

75 and 6 years at 85. Women can expect to live for a further 21 years at age 65, 13 years at 75 and 7 years at 85 (Public Health England, 2016).

The King's Fund reports that the years of healthy life that have been gained have increased proportionally with overall life years gained. Life expectancy is a key consideration when planning health and social care services and the ageing population provides both opportunities and challenges when planning for the best ways to promote and protect health and well-being. The current environment of government policy is important when considering the service and resource use of the ageing population.

Place of residence and ethnicity also influence life expectancy. For example, people born in Scotland have a lower life expectancy than the UK average, as do some black and minority ethnic groups (ONS, 2007). However, researchers suggest that this might now plateau, because of the long period of austerity and cuts to public health services (Hiam et al., 2018).

> *"If we don't spend appropriately on social care, if we don't spend appropriately on health care, the quality of life will get worse for older people and maybe their life, too"*

Austerity and Life Expectancy Westminster Hall Debate 18.04.2018 quoting *(Marmot et al., 2017)*.

Although life expectancy in 2018 is reported to be static, and we are no longer seeing increases year on year, over the past 50 years it has generally increased. Many factors are contributing to this, including lowered fertility, increased longevity, and reduced mortality from infectious disease. With this increase, there are new challenges for medicine and society in terms of co-morbidities, frailty, and smaller family units to provide informal support for the ageing population (Lynn, 2005; Seale, 2000). There are also considerable strains on the healthcare systems due to the increase in population and a reduction in NHS budgets, services and staff. More older people are using limited services for more clinically complex illnesses (Murray et al., 2012). Despite efforts to reduce acute hospital expenditure in countries such as the USA and UK, the rise of ageing populations is associated with considerable healthcare costs (Kashihara & Carper, 2012; Lafond, 2015; Lafond, Arora, Charlesworth, & McKeon, 2014). The average annual cost of health and social care for an older person is significantly higher than for a younger person. This

is attributed to a variety of factors including a rise in long term conditions, polypharmacy and more intensive use of services in the time leading up to death.

Nonetheless, there are many societal and economic benefits that come with an ageing population (Marmot & Allen, 2014). For example, 2.7% of people over 65 years of age work full time, and 6.1% work part time, at a total of around 1.4 million people in the UK (Office of National Statistics, 2011). This enhances the economic stability and growth of the UK with more people in work. People over the age of 65 have an estimated spending power of £76 billion which is estimated to increase to £127 billion by 2030 (Berg, Taylor, Woods, & Nursing, 2013). The old age dependency ratio (OADR) is a measure of the number of people aged 65 and over for every 100 people of working age (15-64). A higher OADR implies that there are more people aged 65 and over relative to people of working age. The OADR currently stands at 1/5 in industrialised nations like the UK but it is expected to rise to 1/3 or more by 2040. This has implications for services including health and social care: the higher the number of older people there are proportionally to the number of young people, there will be an increase in demand for services which are primarily funded by a workforce which is decreasing in size. The provision of social care, already worth £34 billion, will grow to £53 billion by 2030. Finally, the hidden benefit of volunteering by people aged over 65 is estimated to be worth £10 billion per year, in addition to the £10 billion per year they contribute to charity and family donations (Berg et al., 2013). Overall, increasing the rate of older people who participate in the workforce decreases the impact of the ageing population on society and this is a positive feature of an ageing population.

Population projections suggest that there will be a higher proportion of older people living alone. Reasons for this include a reduction in women having multiple children, or children at all, high rates of divorce, women being more financially stable and therefore able to live alone, and adult children moving away from family roots to pursue careers (Nihtilä & Martikainen, 2008). Older people who live alone may be likely to need more formal care arrangements, resulting in increased expenditure in terms of health and social care compared to older people living with family members (Roberts, Marshall, & Charlesworth, 2012). In addition to a change in living arrangements, The Nuffield Trust showed that the number of older people with a moderate or severe disability was likely to increase by 32% costing an extra 37% by 2022 (from £9.3 billion in 2010 to £12.7 billion in 2022). If there was a shift

from the balance of informal care to more formal care (exceeding 20 hours per week) then this figure would significantly increase the expenditure on social care for older people. The Kings Fund has also projected that the number of older people with care needs will grow by 60% in the next 20 years. Furthermore, annual deaths by 2040 are projected to rise by 25%, but if the upward trend observed from 2006 to 2014 continues the increase will be of 42%, with approximately 75% of people approaching the end-of-life benefitting from palliative care. One study recently reported, that to sustain current trends, end-of-life care provision in care homes and the community needs to double by 2040, an increase of 160,000 older people being looked after per year, otherwise hospital deaths will increase (Bone et al., 2018). It seems that certain sectors of the economy will benefit from an increase in the number of older people in the population, but health and social care services will face the practical and financial consequences of an increase in demand. This is because near the end of a person's life, contact with health and social care services is typically intensify (Forma, Rissanen, Aaltonen, Raitanen, & Jylha, 2009; Pot et al., 2009).

It is clear from this brief overview of the ageing population, that public health action has a key role to play. If people can stay healthier for the longest time possible, their own health and well-being will benefit, and they can continue to make a much needed contribution to society and constrain demands on care services.

2.1.1 End-of-life services

The aim of end-of-life care services is to support people approaching the end-of-life until they die. End-of-life care may be delivered by a large number and wide variety of health and social care professionals, including doctors, nurses and allied health professionals and social workers. End-of-life care aims to relieve suffering and improve quality of life for patients with advanced illnesses and their families through specific knowledge and skills. Specialist end-of-life services include health professionals who are specifically trained in the management of pain and other symptoms. They will also often provide psychological, social and spiritual support to patients and their families. There are approximately 5500 health and social care professionals working in specialist end-of-life care teams in the UK but an unknown number of professionals working more generally in end-of-life care and hospices (National Audit Office, 2008). The Department of Health published the End-of-Life Care Strategy in 2008, which focused on improving provision, training health

professionals to deliver quality end-of-life care, and developing specialist palliative care services by collaboration with existing services across conditions, with the aim of reducing inappropriate hospital admissions (Department of Health, 2008a, 2008b).

Patients with terminal illnesses have health and social care needs that range beyond their medical diagnoses (Murray & McLoughlin, 2012). This can include complex psychological issues like anxiety, depression, denial or anger amongst other issues, and social issues like loneliness, lack of family support and financial difficulties. This can, and does, create pressure on health and social care systems as well as communities and families; looking after and caring for people when they are unwell, with no real chance of being 'cured' can be exhaustive and demanding for the people involved (De Korte-Verhoef et al., 2014; Werth, Blevins, Toussaint, & Durham, 2002).

An Age UK report published in 2013 showed an increase in the availability and use of specialist palliative care beds in England (Age UK, 2013). The implication of this being that people are accessing services appropriately. In September 2017, a Cochrane systematic review protocol was published with the aim of exploring, "The effectiveness and cost effectiveness of inpatient specialist palliative care in acute hospitals for adults with advanced illness and their unpaid caregivers" (Bajwah et al., 2017). This review aims to determine the effectiveness of a number of factors including resource use, caregiver burden, mental health and bereavement and compared inpatient palliative care with best usual care services for both patient with terminal illnesses and their caregivers with results expected next year. Research has outlined how the NHS must take a longer term view of palliative care services and has urged Clinical Commissioning Groups (CCGs) to look at how they create more capacity for palliative and end-of-life care services across a range of settings including hospitals, hospices and community settings (Ingleton, Payne, Sargeant, & Seymour, 2009). More health care professionals are valuing the contribution of end-of-life care teams, services, treatments and places such as hospices (Arnold, Finucane, & Oxenham, 2013; Bluebond-Langner, Beecham, Candy, Langner, & Jones, 2013; Gao et al., 2013). Health care professionals want to ensure people have a good end-of-life health care experience.

It has been reported that between 56-74% of people wish to die at home, but the number of people that do varies considerably with age, geographical location, and

condition (Higginson et al., 2003). In England, approximately 58% of people die in hospital. Two thirds of these are aged over 75 (National Audit Office, 2008). In a study of the priorities for patients and their families when dying in the hospital setting (Virdun, Luckett, Davidson, & Phillips, 2015) researchers found that effective communication and shared decision making, expert care, respectful and compassionate care, trust and confidence in clinicians were the top four most important priorities.

2.2 Moving between services at the end-of-life

Transfers between care settings usually occur when someone needs to move to a different place to receive care, for example, when moving from home to hospital, or from hospital to hospice. It may also represent a change in the nature of care such as from curative to palliative treatment. The proportion of people admitted to hospital in their last year of life rises with age, yet over the age of 85 years, people are less likely to be admitted to hospital in their last year of life, but when they do they stay for longer periods than younger people (Henderson, Goldacre, & Griffith, 1990). Risk factors for transitions include previous hospital admission, duration of hospital stay, morbidity and functional disability (Linertová, García-Pérez, Vázquez-Díaz, Lorenzo-Riera, & Sarría-Santamera, 2011), all more likely in elderly populations who are at the end of life.

Each transfer between care settings has been shown to represent a potential threat to continuity and safety of care (Coleman, 2003a). Studies from the USA have found that transfers between care settings at the end-of-life may produce little in terms of improvement in symptoms or quality of life (Trask, Teno, & Nash, 2006; Van den Block, Deschepper, Bilsen, Van Casteren, & Deliens, 2007). Ensuring consistency across settings can be important when caring for an older person with ill health, but this can be difficult to achieve. Older people with complex health problems can be sensitive to changes in their care, including setting, staff, changes to routine and to medications (Silverstein, Cong, & Li, 2006; Vogeli et al., 2007). Research into the movement between places of care is predominantly based in the USA, with little UK research literature. Research from the USA has suggested that specialised palliative or end-of-life care is more effective than conventional care (García-Pérez, Linertová, Martín-Olivera, Serrano-Aguilar, and Benítez-Rosario, 2009) and also that re-hospitalisation following a surgical discharge are prevalent and costly

(Coleman, Min, Chomiak, & Kramer, 2004; García-Pérez, Linertová, Martín-Olivera, Serrano-Aguilar, & Benítez-Rosario, 2009; Jencks, Williams, & Coleman, 2009; Linertová et al., 2011; Saliba et al., 2000)

Researchers suggest that the UK may have neglected this area of research as there may be an assumption that a universal health system will overcome problems posed by transitions between different settings (Hanratty, Holmes, et al., 2012b). However, following the Health and Social Care Act (Department of Health, 2012) the number of NHS services awarded to private providers increased thereby increasing the likelihood of disjointed services and calling into question the 'universality' of the NHS.

The NHS is currently moving the balance of care from hospital to the community while demand rises and it experiences the longest period of funding constraint in history (Imison et al., 2017). The failure so far, to bring together the records and data transfers for people who are moving from one place of care to another is also unhelpful for continuity of care. Evidence suggests that the goal for health policy in England includes the 'triple aim' of improving population health and the quality of patient care, while reducing costs (Sikka, Morath, & Leape, 2015). However, most recent analysis (Imison et al., 2017) suggests that although moving care from hospital to the community may be better for patients (particularly those in specialised care such as end-of-life care services) it is not likely to be cheaper for the NHS in the short to medium term.

My research has reported that each transfer between one place of care and another represented a potential threat to continuity of care and patient safety (Hanratty, Holmes, et al., 2012a) as has been reported elsewhere (Coleman, 2003a; Kind, Smith, Pandhi, Frytak, & Finch, 2007; Kripalani, Jackson, Schnipper, & Coleman, 2007). Most recently, the move to allow private providers to run services for the NHS further fragments services and issues with transfer of data of patients who move from one place of care to another. Patients also report feeling secondary to institutional processes that were already in place and find the current system to be inflexible to their needs or wishes. Factors that made the transitions more problematic for the patient or their families included older age (Fleming, Farquhar, Brayne, Barclay, & collaboration, 2016; Fleming et al., 2010), absence of a carer, an unexpected deterioration in health for the patient, and a non-cancer diagnosis. I have also reported that transitions were also more likely and more likely to be

problematic if there was poor communication with the GP or no ongoing relationship or contact with out of hours doctors prior to the hospital admission (Hanratty, Holmes, et al., 2012b).

Many older people do not only make one move of setting when they are nearing the end of their life (Abarshi et al., 2010; Coleman, 2003a; Hanratty, Holmes, et al., 2012b). Frequent transitions between places of care are common. Research has found that transitions after a hospital stay are particularly common and that patterns vary greatly, with a significant number of patients experiencing complicated care transitions (Coleman et al., 2004; García-Pérez et al., 2009; Jencks et al., 2009; Linertová et al., 2011; Saliba et al., 2000). Continuity and patient centred care can be challenging for health and social care professionals to provide. Families who usually coordinate a person's care can also face difficulties (Hanratty et al., 2014). Previous research has focused on recording patients' satisfaction with services, communication with staff and quality of care received at the end-of-life (Garratt, Danielsen, & Hunskaar, 2007; Magee, Parson, & Askham, 2008; Martin, 2009) as well as family carers' perspectives of end-of-life care retrospectively (Burt, Shipman, Richardson, Ream, & Addington-Hall, 2010). However, in the UK no research had been conducted prior to this work in 2009, which examined the patients' and carers' overall perspectives and experiences of end-of-life care across health care settings. This is explored further in chapters four, five and six.

2.3 Informal caregivers

Providing informal care to others is part of life for many people in the UK, with three in five people becoming carers at some point in their lives (Carers Trust, 2018). The term 'carer' is emotive and value laden, described by researchers as being "*perceived as good, although undervalued, performing arduous tasks for little, if any, reward and saving the state a great deal of money*" (Arber & Ginn, 1990). There are many definitions of what it is to be a carer. Professional bodies such as the National Institute of Clinical Excellence (NICE), defines carers as people who,

> "*may or may not be family members, are lay people in a close supportive role who share in illness experiences of the patient and who undertake vital care work and emotion management*" (NICE, 2004)

Carers UK uses the definition of,

> *"anyone, including children and adults who look after a family member, partner or friend who need help because of their illness, frailty, disability, a mental health problem or an addition and cannot cope without their support. The care they give is unpaid."* (In Poor Health: The Impact of caring on health, 2004)

Such representations can contribute to the shaping of the experience of carers either through their own or the public's internalisation of the concept of what it is to be a carer. Carers UK (Carers Trust, 2018) estimate that it would cost £71 billion to replace the care provided by family members and friends with professionals. The economic contribution made by carers in the UK is £132 billion a year (Carers Trust, 2018).

2.3.1 Who cares?

Informal care is an important source of care for older people living in the UK (Pickard et al., 2000). Caregiving is generally performed by family members, and in most cases, by one person (Payne, Smith, & Dean, 1999). Informal care is usually provided for older people by spouses (26%), offspring (58%), same generation family members (for example siblings or cousins) and friends (Health, 2010a). Unpaid care has increased at a faster pace than population growth between 2001 and 2011 in England and Wales (Office of National Statistics, 2011) with the number of people caring for someone increasing by 16.8% compared to the population growth of 6.2% in the same period. Literature suggests this figure would reach 9 million by 2037, as the proportion of dependent to independent people increased and people lived longer with more complex health and social care needs (Bond & Cabrero, 2007; *The State of Caregiving: 2015 Report*, 2015). A recent report found one in ten people provide care to a close family member or friend (Carers Trust, 2018) totalling 6.8 million people and over 1 million of these provided more than fifty hours per week (Office of National Statistics, 2011). Older people provide the most care compared to the rest of the population, with 20% of 65-74 year olds and over 24% of over 75 year olds providing fifty or more hours of care per week (Department of Work and Pensions, 2009) and older carers are the fastest growing group of carers in the UK (Age UK, 2013). Between 2001 and 2011 the number of unpaid carers grew by 600,000 and the largest increase was from people who provide fifty or more hours of care per week.

The National Centre on Caregiving reports that the 'typical' caregiver is a 49 year old woman who works outside the home and provides 20 hours per week of care to her mother (Feinberg et al., 2011). Nationally representative samples indicate that the majority of family carers of all ages provided up to 19 hours of care per week (Yeandle & Buckner, 2015). NHS England report that there is more than 2.4 million of these carers in the UK. People are juggling the demands of their own families with responsibility for parental caregiving (Lee & Tang, 2015). During end-of-life care, the hours of caregiving escalates to an average of 70 hours per week (Rowland, Hanratty, Piling, van den Berg, & Grande, 2017).

Carers may or may not live with the person they are caring for. There is an even split between caregivers who live with the person they care for, and those who live in a different household (Health, 2010a). Carers UK (Scrutton & Creighton, 2015) report that carers who care for someone in a different household usually live within 30 minutes of the person they care for. The type of care provided also varies by living arrangements. Those carers who live with the care recipient are more likely to provide personal care, physical care and to administer medications (Health, 2010a). Eighty-two percent of carers provide practical support such as cooking meals and providing transport and 38% provide personal care such as intimate care and physical help with dressing and washing (Scrutton & Creighton, 2015).

There is an increasing prevalence of 'sandwich carers' defined as carers who look after young children at the same time as caring for an older person, usually a parent (UK, 2012). This term is also used to describe other multiple caring relationships that span more than one generation. The 'Always on Call, Always Concerned' survey of the experiences of older carers (Carers, 2011) found that carers aged 60-69 often care for more than one person, a parent and an adult child or young grandchildren for example, and for those aged 70, the physical demand of caring can be very difficult.

Demand for intergenerational care is projected to exceed supply, with a projected growth of 27% between 2005-2041, whereby the number of people 'demanding' care is projected to grow by approximately 90% during that time (Pickard, Wittenberg, King, Malley, & Comas-Herrera, 2008). The amount of home care provided by local authorities in the UK has fallen by 4.3% since 2011. Recent funding estimates say that the discrepancy between the funding needed and the shrinking local authority budgets is £700 million a year (Local Government Association, 2015).

This is reiterated by research reporting there is an informal care gap emerging. By 2041 there is projected to be a shortfall of around 250,000 carers. This means around 250,000 older people receiving less informal care than if demand were to be met (Pickard et al., 2008). This emerging gap will be propelled by demographic changes, in particular the rise of the old age dependency ratios, previously discussed on page 14.

2.3.2 Socio-economic considerations

Socio-economic factors are another important demographic of carers. They can tell us something about the experience of cared-for people as well as carers, the options they may have or decisions they may face, and usually at a population level, the health of carers. Using the National Statistics Socio-Economic Status (NSSEC) and adult care provision data, the UK Harmonised Time Use Survey (Gershuny, 2017) reported that it is older people who provide the most care to other adults of other households, and people in routine and manual classification roles who provide the least care for adults of other households. This care provision rises for those in intermediate positions and is higher still for those in higher managerial/professional categories. This finding was the reverse for providing care for adults in the same household as it was higher managerial and professional households who provided the least care for people in their household. Possible explanations for these figures could be that people in routine and manual roles have less time to provide care to adults outside their household as they prioritise working to earn money. Another reason could be that the people in routine and manual classification roles are more likely to share their home with people of other generations (as they are less well paid) thus leading them to increase the care they are providing to people in their own home. Typically, people in well paid households may be able to afford to 'buy in' care for family members (Wiles et al., 2018), and are also likely to be in better health in general, as health is associated with income level (Mullahy, Robert, & Wolfe, 2018; Taib et al., 2018). This is important as the household income of the carer appears to have some bearing on the availability to provide care; thus meaning that it is more likely older people with wealthier spouses or offspring will be able to access informal care, and those with poorer spouses or offspring are less likely to access care. It may also mean that it is people from higher SES who are more likely to have choices over their end-of-life care, particularly the choice to stay at home. This highlights the inequity of current health

and social care provision and also raises questions about the future of older people care, if they do not have spouses or children.

Older people are more likely to get sick or suffer from a chronic illness and therefore be in a position of needing care from peers in comparison to younger people (Greenwood & Smith, 2016). Evidence suggests that older people are also more likely than younger people to have a spouse who needs caring for (Barnett et al. 2012). Older people would be expected to have more time to provide care as they are typically not active in the workplace or looking after children, and older people typically have less money available to source informal or formal care elsewhere than adults who are younger who need care (Barnett et al., 2012). Older carers are also more likely to have poorer health and are more reliant on services including social services and welfare than younger carers, but have a better quality of life and report caregiving being more rewarding and less burdensome (Pinquart, Sörensen, & Song, 2018; Raschick & Ingersoll-Dayton, 2004; Rosness, Mjørud, & Engedal, 2011). There are many potential reasons for this, such as the sociocultural expectation of older people having more time to provide care thus leading to an increase in care provision from older people (Sörensen, Webster, & Roggman, 2002). Older carers with low socio-economic status experience higher levels of anxiety and depression (Kajiwara, Noto, & Yamanaka, 2018).

2.3.3 Gender differences

The role of the carer was previously seen to be included in the domestic labour of women (Arber & Ginn, 1990), and caregiving is still viewed by many people as women's work. Evidence from over twenty years ago suggested that there were marked differences in how men and women experienced caregiving. For example, research suggested that women were more likely than men to provide more intensive and complex care and have difficulty providing care provision and balancing other family responsibilities (Allen, 1994; Miller & Cafasso, 1992; Navaie-Waliser, Spriggs, & Feldman, 2002). However, there is more recent evidence to suggest that men and women spend similar amounts of time caring for older people (Ferrant, Pesando, & Nowacka, 2014). However, this still involves the performance of typically gendered roles with, for example, men providing less personal care than women would provide (Carers Trust, 2018). According to Carers UK daughters report providing the most care to older people, followed by daughter-in-laws, then sons and husbands. Women have a 50:50 chance of providing care by the time they

are 59 compared with men who have the same chance by the time they are 75 years old (Carers UK, 2014). The balance for men and women is equal until they reach age 45 then at age 70 there are 6 women to every 5 men and at age 80 there are 4 women to every one man (Stuart-Hamilton, 2000). Men die younger than women, and therefore less informal care is provided by men, particularly in the over 75's age groups as there are fewer men alive to provide care (Kalben, 2000). As men and women age, men increase their likelihood of being carers (Carers UK, 2014), though it is unclear whether their experience of caring remains different. Women report higher rates of depression, anxiety, unmet needs, and burden of care than male carers (Ussher & Sandoval, 2008). Perhaps due to the historical expectation of the female role as a carer, women tend to find caregiving more demanding and difficult than men. This may be because there is less chance of delegation of carer duties and roles (Calasanti & King, 2007). Caregiving has also been found to be the fifth most significant factor associated with women's distress rates and the ninth most important factor influencing distress levels in men (Hirst, 2004). Women report having worse psychological health than male carers, and overall had worse general health than men (Grande, Rowland, van den Berg, & Hanratty, 2018). This may indicate that women are disproportionally affected by the caregiving experience compared to men, or that they are more likely to undertake end-of-life caregiving (compared to general caregiving) and at more intensive levels than men (Abernethy, Burns, Wheeler, & Currow, 2009). Some evidence (Barusch & Spaid, 1989; Friedemann & Buckwalter, 2014) suggests men experience less burden, but other research suggests how men express and handle their burden differently than women, taking a managerial and stoic-coping strategy approach to caregiving (Cherry et al., 2013; Gilbert, Ussher, & Perz, 2010; Ribeiro, Paúl, & Nogueira, 2007; Tooth et al., 2008). However, emerging research suggests that the caregiving experience is similar for men and women during end-of-life care, particularly concerning the support they need in the face of ongoing challenges.

From the perspective of the older person, women are also more likely to be institutionalised at the end of their life because there is no-one to look after them in their own homes, whereas men are more likely to be looked after at home by their wife, who is likely to live longer, are often younger and if they are the same age, be in better health as the cared-for husband (Klinkenberg et al., 2005). Researchers have reported that for older people, those dying in late old age are more likely to die in care homes or hospitals than at home or in hospice, especially

women (Seymour, Witherspoon, & Gott, 2005). The experiences of women providing end-of-life care are well reported. But the experiences of men providing end-of-life care are not. It is crucial to explore the experiences of male caregivers, to understand why there is a reported difference in the care than men and women receive. These issues reinforce the gender inequality at the end-of-life, and how in general, men at the end of life receive better and more personalised care than women

2.3.4 Health implications of a caregiver role

Much of the research exploring informal care focuses on the negative health implications of carrying out a carer role. Some of these health implications are interlinked to socio-economic status (SES), as previously discussed. A Carers UK report in 2004 reported that 21% of carers in the UK providing substantial care are 'not in good health' compared to 11% of those who do not have caring responsibilities (Carers UK, 2004). Providing care for someone from a young age is also reported to be riskier in terms of health problems, so a lifetime of caring can contribute towards poorer health from the carers perspective, compared to the health of a person who has been caring during their old age only (Aldridge & Becker, 1993; Jones & Peters, 1992). It is crucial for future health and social care service planning that research is conducted exploring the experience of caring for older people in low SES groups to fully understand the implications on health for those people who may not have been 'in good health' to begin with.

Increasing hours of care can result in the general health of carers deteriorating incrementally (Hirst, 2005). Unpaid carers who provide high levels of care for sick or disabled relatives and friends are more than twice as likely to suffer poor health compared to people without caring responsibilities (Hirst, 2004). For example, reduced immune responses and greater likelihood of physical illness and infection may result from the stress associated with providing intensive care. Poor health in the carer population has important implications for health and social services. These include unplanned admissions to hospital for the care recipient and delayed discharge from hospital or other care settings. If the carer is in poor health, the care recipient is also more likely to go into residential care or a nursing home (Coleman, Parry, Chalmers, & Min, 2006; Schulz et al., 2004). The NHS Long Term Plan outlines several important changes to the way the NHS should work to support patients and their carers. Improving care for older people living with frailty or multiple long term

conditions is one of its priorities and the identification of people in primary care may be helpful to people approaching the end of life, and carers who are older. This has the potential to improve access and increase much needed visibility.

2.3.4.1 Spousal health

Research suggests that it may be more difficult to care for older people as a spousal carer, as the carer is more likely to be older, and therefore is more likely to have physical health problems themselves, and have fewer social activities that could moderate the stresses associated with caregiving (Strawbridge, Wallhagen, Shema, & Kaplan, 1997). Physical injury from lifting and moving the person being cared for could impeded the carers ability to fulfil other roles. Previous research has reported that spouses experienced more burden from physical impairment, behaviour problems of the care recipient and longer duration of care than offspring carers (when caring for people with dementia) (Zarit, Reever, & Bach-Peterson, 1980). Evidence suggests that spousal caregivers are more likely to suffer caregiver burden compared to adult children caregivers. This is particularly in respect to physical impairments and behavioural problems of the care recipient as well as being a caregiver over a longer duration (Zarit et al., 1980). However, other research reports that being a spousal caregiver was associated with better physical health than being a non-spousal caregiver (Pinquart & Sörensen, 2007). This could be because only the strongest and fittest spouses take on the role of the full time caregiver. Grande et al. (2009) found that older people with a caring role were in better health than those of the general population of the same age (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne, et al., 2009).

2.3.4.2 Psychological health

Psychological and emotional health problems are associated with caregiving (Schulz et al., 2003; Schulz et al., 1997; Schulz, Visintainer, & Williamson, 1990; Yee & Schulz, 2000). Caregiving can have an intense emotional impact due to the commitment it requires (Arber, Hutson, de Vries, & Guerrero, 2013; Sterckx et al., 2013). Carers report worse mental and physical health compared to non-caring controls and may also suffer more anxiety or depression than patients themselves (Grov, Dahl, Moum, & Fosså, 2005; Haley, LaMonde, Han, Narramore, & Schonwetter, 2000). Caregiving is widely reported to negatively impact on emotional health, quality of life, and physical health, particularly for carers of

patients with terminal prognosis (Weitzner, McMillan, & Jacobsen, 1999; Wolff, Dy, Frick, & Kasper, 2007). Researchers have also reported that caregivers manifest feelings of not being ready to face death (Grov et al., 2005) and suffer negative repercussions in terms of physical and psychological well-being (Hudson et al., 2012).

For some carers, negative psychological consequences can be a result of poor physical health. Carers who experience good physical health are better able to cope with the demands of care and perhaps more willing to provide care. Similarly it has been reported that carers who express distress often have unmet support needs including help from service providers (Baillie, Norbeck, & Barnes, 1988). Analysis shows that caregiving is independently associated with distress on top of other key health determinants such as physical health problems, age, marital status, educational qualifications smoking behaviour, employment stats and others (Caputo, Pavalko, & Hardy, 2016; Hirst, 2004; Stewart et al., 2016). Evidence suggests that psychological distress is more likely to occur where carers have a close relationship with the person they look after and that women, particularly when caring for someone in the same household, can find caring stressful (Figley, 1997; Haley, Levine, Brown, Berry, & Hughes, 1987).

2.3.4.3 Strain, loneliness and support

Reasons for poor health amongst carers can also be explored from a social perspective (Stephens, Alpass, Towers, & Stevenson, 2011). For example, a lack of appropriate support can be detrimental to carers' quality of life. Carers reported that support that is, "*not appropriate, either poor quality, not the right kind or not sufficiently flexible*" places extra stresses and strains on them (Hirst, 2004). Social isolation can be another contributing factor to poor health (Aartsen et al., 2018). Carers are more likely than non-carers of the same age to miss out on appropriate support and therefore may become quickly isolated from services and find it difficult to socialise with family and friends due to the isolating experience of providing intense care (Neri et al., 2012; Robinson, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Rubinstein, Lubben, & Mintzer, 1994). The role of social support in providing a buffer against some of the negative aspects of caregiving is discussed more in chapter seven. It is very old people (Dykstra, 2009) and people who live in deprived neighbourhoods (Algren, 2018; de Koning, Stathi, & Richards, 2017; Gillespie, 2018; Kearns, Whitley, Tannahill, & Ellaway, 2015) who tend to be most at risk of loneliness. As previously discussed in chapter 2.3.2 and 2.3.3, it is older

people and those of low SES, who provides lots of informal care in the UK. It is crucial to develop interventions to help those most at risk, cope and manage better.

2.3.5 Barriers and benefits to providing care

Though in the UK, caring is part of many people's lives, there are currently many societal and economic barriers to providing informal care for family members. The changing nature and pattern of employment make it more difficult to provide structured care or to share care with other family members. The increase in female employment outside the home, and the need by most households to have two wages is an obvious barrier to providing care for loved ones, particularly for women who are expected to provide most of the care (already discussed in 2.3.3). The increase in geographical mobility and dispersion of families across large areas which do not facilitate providing care to others easily are barriers to providing informal care for family members. The increase in market insecurity makes it more difficult for employers to facilitate family friendly working hours and more difficult still for employees to request flexible hours. An increase in part-time and casual working can obstruct people in planning for medium-term futures in terms of caregiving roles and responsibilities (Neno, 2004; Pickard, 2004; Policy, 2002). These factors are likely to make caring for family members at home less appealing in the future, further exacerbating the caring 'crisis'.

Even so, despite the challenges and difficulties already outlined, providing informal care to someone can be a positive experience (Cohen, Colantonio, & Vernich, 2002). Research has found that more than 70% of caregivers do have positive feelings about caregiving (Abdollahpour, Nedjat, & Salimi, 2018; Cohen et al., 2002). Cohen et al. (2002) found that 23% of carers mention companionship as being a specific positive aspect and the sense of fulfilment and reward being the next most positive aspect (22%), both aspects of caregiving that directly positively affect the carer rather than the care recipient (Cohen et al., 2002). For carers of people with dementia, studies demonstrate that personal satisfaction, fulfilment, meaningful relationships, tolerance and being able to remain with care recipient are some of the positive aspects that carers report about their role as caregivers (Bennett & Soulsby, 2014; Donnellan, Bennett, & Soulsby, 2017; Ross, Holliman, & Dixon, 2003). Exploring positive factors from the perspective of the caregiver are fundamental in understanding how experiences of health and social care, communication, and other central aspects of care at the end of life are improved

(Kramer, 1997). Research suggests that caregivers want to talk about their positive experiences and taking into account carer perspectives can help clinicians and policy makers to understand what works most effectively.

Being cared-for by family carers is usually preferable to an older person. The presence of carers who are able and capable to care for a person makes a range of options possible (Payne, Laporte, Foot, & Coyte, 2009). One of the most important benefits of informal care provision is that it prevents or delays a move into more formal care environment such as a hospital or a nursing or care home. Fundamentally, it allows older people at the end-of-life to stay in their own homes, if this is what they wish for, certainly longer than if they did not have informal care provision. This care at home provided by family members on an informal basis, can enhance the older person's quality of life considerably. Similarly, the lack of available and willing carers limits the possibilities for end-of-life care options and choices and may make it difficult to avoid institutional admissions. A literature review by Gomes and Higginson (2006) found that the two strongest determinants influencing death at home for a cancer patient was living with relatives and having extended family support (Gomes & Higginson, 2006). These are major benefits from the perspective of the patient, the carer and also from health and social care services as it prevents inappropriate and costly admissions.

2.3.8 Statutory support for carers

The Carers Act (1995) entitles carers of any age to receive an assessment of their need for statutory support and services, if they regularly provide considerable amounts of care (Department of Health, 1995). Forty-five percent of carers in England receive an assessment even though the majority of carers who are assessed have modest service requests. These could include help required with domestic activities and payments to purchase equipment. With the development of the Care Act (2014) there is a requirement from local authorities to prevent and reduce the need for care and support (Department of Health, 2014). Research shows that the correct assessment of need and provision of appropriate good quality services have the potential to increase caregivers' quality of life and resilience (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016; Higgins, Garrido, & Prigerson, 2015; Tan, Molassiotis, Lloyd-Williams, & Yorke, 2018). Evidence also suggests that spousal caregivers, in particular, may benefit most from services that

reduce the objective level of stressors, such as respite care or adult day care (Pinquart & Sörensen, 2003).

2.4 Resilience

A recent policy development for carers is the 'Prevention is better than cure; our vision to help you live well for longer' green paper published in 2018 by the Department of Health and Social Care (DoHSC), which emphasised the importance of the wellbeing of carers and preventing their deterioration in health. This is important, as it complements the work reported in this thesis. The vision for the forthcoming strategy is,

"..*helping people stay healthy, happy and independent for as long as possible. This means reducing the chances of problems from arising in the first place and, when they do, supporting people to manage them as effectively as possible. Prevention is as important at seventy years old as it is at age seven.*" (DoHSC, pg4.)

Previous strategies designed to promote the health of carers have not had the desired effect of protecting or enhancing wellbeing. However, the recent move to integrate health and social care (via an Integrated Care System) may ameliorate some of the challenges carers have faced, which have been described earlier in this chapter. In particular it might help smooth the disjointed services that carers are currently expected to navigate. Resilience has been reported to protect against carer burden and is found to be associated with better outcomes for carers (Fredrickson, 2001; Palacio et al., 2018). Resilience is an important concept to study as it counterbalances the traditional research concern with risk factors. Instead of asking what makes people vulnerable or in poor health, studying resilience allows us to look at what it is that helps people to adapt and bounce back in the face of adversity. If resilience can then be promoted in older age and amongst those with a caring role, there could be health and social benefits for the individual and community as a whole.

In the last 20 years resilience research has broadened to include factors which may help to develop clinically relevant interventions that increase positive outcomes in the 'at risk' groups as well as promoting resilience in the general population as a whole (Windle, 2011a). Research has also explored resilience and bereavement and widowhood (Bonanno, Westphal, & Mancini, 2011; Sandler, Wolchik, & Ayers,

2007; Tinker, 2015). Researchers have suggested that other vulnerable groups including those who engage in care work could also benefit from research that promotes resilience (Luthar & Zelazo, 2003). Latterly, research has increased in the area of studying psychological resilience, positive emotions and successful adaptations to stress in later life (Ong, Bergeman, Bisconti, & Wallace, 2006; Ong, Edwards, & Bergeman, 2006; Resnick, Gwyther, & Roberto, 2010).

2.4.1 An ecological approach to resilience

Resilience is a complex concept. There are many different definitions and conceptualisations of resilience. Researchers do not agree on the operationalisation of resilience with "*substantial variations in operationalisation and measurement of key constructs*" (Luthar, Cicchetti, & Becker, 2000). General dictionaries define resilience as a "derivative of the adjective 'resilient' which has two uses: 1. Able to recoil or spring back into shape after bending, stretching or being compressed; 2. (Of a person) recovering easily and quickly from misfortune or illness; (of an object) capable of regaining its original shape or position after bending or stretching". This does not encompass the resilience present in accounts of caregiving, as the carer is neither 'in misfortune' or ill.

The American Psychological Association (APA) define resilience as, "the process of adapting well in the face of adversity, trauma, tragedy, threats or events of significant sources of threat- such as family and relationship problems, serious health problems or workplace and financial stressors. It means "bouncing back" from difficult experiences". They report that the primary resilience factor is supportive and caring relationships (APA, 2004). Researchers now agree that people do not exist in isolation and that it is their interactions with their social and environmental contexts that can hinder or facilitate resilience (Windle, 2011a). The APA definition is too individualistic in tone and does not mention the wider factors that may contribute to a person's ability to 'bounce back from difficult experiences'. This definition mentions nothing about adapting well, or thriving and nothing about what is it that may help a person to recover from their adversity or significant source of threat.

The World Health Organisation views resilience as something that "embraces positive adaptation, with protective factors and assets that moderate risk factors and therefore reduce the impact of risk on outcomes" (Friedli, 2009, p. 22). This is a more nuanced definition, as the WHO cite that there are internal and external

assets that moderate the risk or stress, and that can alter the course of the outcome. However, it does not take a life course approach, and does not mention that resilience across situations may be different depending on the factors and assets or the source of stress.

Rutter (1987) says that, "Resiliency is understood as the capacity to overcome adversity to achieve recovery, and to become stronger after exposure to a traumatic psychological event. It is considered a coping strategy" (Rutter, 1987). This is also a strong definition, but is focused on only psychologically traumatic events and providing care can also be physically and socially demanding. Masten (1994) categorises resilient phenomena into three groups: 1. individuals showing better-than-expected outcomes, 2. positive adaptation being maintained despite stressful situations and 3. a good recovery from trauma (Masten, 1994, 2001).

Disparities are often found in the conceptualisation of resilience. Some researchers argue that resilience is a personal trait (Hu, Zhang, & Wang, 2015; Yeager & Dweck, 2012) whilst others that it is a dynamic process (Rutter, 2012). Evidence in favour of resilience being a personal trait describes people having a set of characteristics or traits that indicate they have a general resourcefulness or sturdiness of character and an ability to respond flexibility and generally positively to environmental circumstances. This is problematic because it gives the perception that some people do not 'have what it takes' to overcome adversity and does little to help with the understanding need to explore processes underlying resilience. From a health psychologist's perspective, it also does little to help with the design of interventions that may increase resilience.

Other research suggests that resilience refers to a developmental process, or a reaction to and way of navigating a circumstance or situation (Masten & Wright, 2009). An often-cited example is the experience of significant adversity. This is the conceptualisation taken throughout my thesis. End-of-life care work can be considered as an emotional, developmental, economic and environmental challenge to carers in the same way much research has focused on such challenges for children during adolescence. Carers are a vulnerable group and their capacities can be compromised by the physical, psychological, social and financial demands of caregiving. This conceptualisation is important because it allows research to explore the factors that may enhance or facilitate resilience from an individual, community and societal level, giving space to design interventions and

opportunities for people to live positively through adversity. It is also important to note that because of the importance of navigating a specific situation, research should compare people across similar adversities not different adversities.

The definition for resilience used in this thesis is:

> "*Resilience is the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary*" (Windle, 2011a, p. 163).

Windle's definition synthesises the aspects and principles of resilience previously described. The emphasis here is on the relationships between the facets of caregiving that are common in the reported experience of carers: negotiating, managing and adapting to aspects of the caregiving experience.

Researchers (Bennett & Windle, 2015; Bonanno, 2005; Ungar, 2011, 2012; Windle, 2011a) have started to consider the social ecology of resilience including the psychological, financial and health related resources as well as social support, public and private services and service level and policy support. An ecological approach to resilience suggests that resilience is the result of both internal and external resources. Internal resources may include psychological, financial and health resources, and external resources would include informal family support, private, public and other services. The internal assets are inherent to the individual, whereas the resources are external. Plentiful internal assets and external resources do not prevent negative outcomes. But over time, they reduce the likelihood of a range of negative outcomes. This ecological approach draws on the social determinants of health model (Dahlgren & Whitehead, 1991) and Bronfenbrenner's (1994) Ecological Systems Theory (Bronfenbrenner, 1994). An ecological approach also sits neatly with the increased interest in policy and practice research. The aim is to understand resilience in an effort to "understand healthy development despite risk and strengths rather than weaknesses" (Windle, 2011a).

Individual and socio-environmental factors both play an important function in facilitating resilience for people experiencing a significant source of stress and trauma. People and situations do not exist in isolation and interact with their social and environmental settings (Bronfenbrenner & Ceci, 1994). Bronfenbrenner's

(1994) ecological systems theory helps us understand why we may behave and develop differently in distinct circumstances. It was firstly explored in the research around child development but has since been applied to the study of ageing and resilience (Windle, 2011). The five systems, applied to one possible scenario of a male carer, can be seen in Table 1.2.

Table 2 Bronfenbrenners' Ecological Systems Theory (1992)

Five systems	Example of male carer providing end-of-life care
The microsystem	The direct environment. The interactions with people closest to you such as your wife or parents.
The mesosystem	Involves relationships between the microsystems in ones life i.e. our relationship with our parents or spouses may influence our attitude in caring for them.
The exosystem	Is the context in which relationships exist. This can include the health and social care system e.g. our ability to care for elderly parents is influenced by the amount of support provided by the local GP and also influenced by the workplaces' policy on flexible working.
The macrosystem	The actual culture of an individual, their socio-economic status, ethnicity, their overarching beliefs and values. A son may feel it is not his place to care for his parents; it is his sisters' who does not have to work as she is financially stable.
The chronosystem	Includes transitions and shifts in our lifespan and can involve the socio-historical contexts that influence a person. A son may decide to take on a full time caring responsibility for his parents; his parents cared for his grandparents and his parents have always hated the idea of a care home.

Despite the clear interaction between the protective factors of resilience, it is typically examined on distinct levels either individually or solely social (Masten, 2007; Windle, 2011b). Windle and Bennett (2011) developed a theoretical model of ecological resilience applied to informal carers, which aimed to understand people in the environment in which they live and to evaluate their interactions with these environments (Windle & Bennett, 2011). The model theorises that each carer draws on individual assets as well as community and societal resources which interact to facilitate or under resilience. Carers may draw on none of the resources,

some, or all at the same time. As shown in Figure 1 below, the individual assets include psychological, biological, material resources and health behaviour. They also include characteristics such as age, gender, ethnicity and socio-economic status. Community resources include family relationships, social support and social participation, community cohesion and housing factors. The third (non-hierarchical) resources are societal resources; including employment, economic factors, health and social policy, and service provision. It is suggested that the absence of assets or resources may consequently result in negative consequences for well-being or further caring challenges. The framework has been tested empirically on carers of dementia patients (Donnellan, Bennett, & Soulsby, 2015) and used in developing theory (Joling et al., 2016). To my knowledge, it has not been tested on carers of older people at the end-of-life.
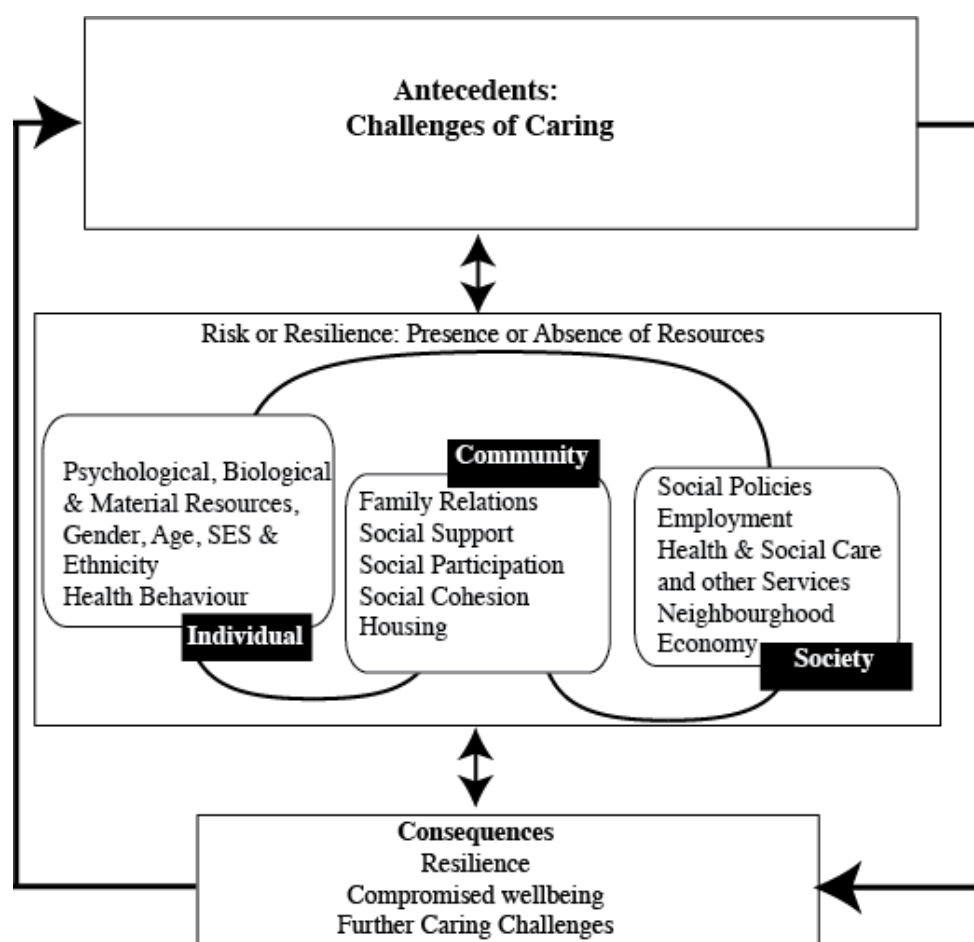
Figure 1 The Resilience Framework Applied to Informal Carers

2.4.2 Resilience and carer characteristics

As previously mentioned, most resilience research with adults focuses on trauma or those with dementia (Bonanno, 2004; Bonanno, Wortman, & Nesse, 2004). Most recent explorations of psychological resilience focus on older adults generally, less on carers, and less still on older carers (Donnellan et al., 2015). Often, research emphasises the burden on carers (Cherry et al., 2013). For example, caregiver burden is known to increase emotional distress (Donnelly et al., 2008). However, recent research reports that resilience does protect against the burden of carers and also is associated with better carer outcomes (Røen et al., 2018). Research suggests gender, ethnicity, and religion or spirituality are important when considering the personal characteristics of carers and the influence these factors may have on their resilience.

2.4.2.1 Gender differences

Gender can influence carers' perceptions of caring, and can be reflected in differences in their resilience (Duggleby et al., 2016; Geiger, Wilks, Lovelace, Chen, & Spivey, 2015). Female carers have been well studied (Kinsel, 2005) but usually within the resilience-as-a-character-trait framework. Male carers report experiencing less burden and report less need for social support than female carers (Choi et al., 2007; Chumbler, Grimm, Cody, & CBeck, 2003; Pinquart & Sorensen, 2006), although some studies suggest this is because of lower reporting of issues more generally in males. Pivotal research (Folkman, 2013; Folkman, Lazarus, Gruen, & DeLongis, 1986) using the stress appraisal coping model supports the idea of differences between males and females with regard to their coping style. Other research (Matud, 2004) has provided further evidence for the differences in emotional inhibition, somatic symptoms and psychological distress. However, gender-role socialisation should be considered in this context. Men historically report perceived weakness, failure, and loss of control following engagement with support groups (Applegate & Kaye, 1993). This historical gender-role socialisation may change as more men undertake caring roles and the focus moves away from 'women as carers' (Arber & Ginn, 1990). There is no definitive evidence to suggest a difference between men and women in the ability to adapt, manage or adapt to significant stressful events. This is worthy of further exploration to ascertain whether there are gender differences in the resilience of carers. If there are, it would then be pertinent to develop potential interventions to decrease the barriers and increase the factors that facilitate resilience.

2.4.2.2 Ethnicity and culture

There are reported differences in resilience of carers from different cultures or ethnic groups (Ottmann & Maragoudaki, 2015). Ethnic groups are defined as a "*group of people who share a common race, religion, language or other characteristic*". Culture is defined as the "*everyday practice that bring order to our experiences and the values and beliefs that support them*" (Berry, Phinney, Sam, & Vedder, 2006; Rogoff, 2003). For example, differences between carers experiences of resilience could be due to variances in social support, coping styles and psychological morbidity, rather than their culture or ethnicity per se. Cultural differences, and how they are developed, transmitted and applied, have been discussed in the anthropological studies of residential care (Henderson & Versperi, 1995). Some cultures have a shared 'culture of caregiving' and this culture shapes a shared national system of beliefs and actions. A culture for caregiving is evident in a number of places across the world. For example, in Hong Kong there is a great financial burden expected of adults who are caring for elders (Chan & Webster, 2010; Chu, 1991). In African-American and Latino culture caregivers are expected to provide long term care due to cultural norms that emphasise and place a significant value on the familial care of disable elders (Dilworth-Anderson et al., 2005; Gaugler, Kane, & Newcomer, 2007). White carers report experience higher levels of burden and role strain as well as higher levels of depression and lower levels of satisfaction with caregiving compared for Black or African American carers (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007; Smale & Dupuis, 2004). Ethnicity and the culture of providing care does shape the experience of caregivers. Individual level resources for resilience may not be activated unless the environment facilitates the opportunity to negotiate, manage and adapt (Windle & Bennett, 2011)

2.4.2.3 Religion and spirituality

The relationship between religion and spirituality and the influence it has on carers' resilience remains unclear. Most of these studies have explored religion and spirituality and carers resilience from the perspective of carers of people with dementia. It is thought to aid carers coping and meaning-making (Cherry et al., 2013). Studies are mixed with some research reporting no influence in the subjective burden or psychological morbidity (Coen, O'Boyle, Coakley, & Lawlor, 2002; Kaye & Robinson, 1994; Robinson & Kaye, 1994) of carers and others report

positive influences on social functioning and satisfaction (Rahmati, Khaledi, Salari, Bazrafshan, & Haydarian, 2017; West, Buettner, Stewart, Foster, & Usher, 2012).

2.4.3 Resilience and social support

Bennett (2010) explored bereavement and widowhood in men, and found resilience was achieved through either external interventions such as social support, joining clubs or getting out of the house and alternatively, through internal 'personal' characteristics such as a personality trait or philosophy of life (Bennett, 2010). Research led by Stroebe (2005) reviewed of the role of social support as a moderator of bereavement outcome and found an effect on depressive symptoms, but no indication of either a buffering or recovery effect (Stroebe & Schut, 2005; Stroebe, Zech, Stroebe, & Abakoumkin, 2005).

Good social support is reported to enhance resilience in carers. Material and social resources such as income, education, culture, housing, community and circumstances of care are all factors that can provide barriers to, or opportunities for resilience. Research evidence suggests that larger social networks facilitate resilience and increase overall well-being (Gaugler et al., 2007; Walsh, 2012, 2015). Social environmental factors have been identified that facilitate resilience amongst Canadian end-of-life family carers. Key to facilitating resilience was the carer's access to social networks, education, knowledge, awareness, employment status, housing status, geographic location and life course stage. Wilks and Croom (2008) reported that social support moderates the effect of stress on carer resilience (Wilks & Croom, 2008). Further research suggests it is not only social support that is important, but the satisfaction with the support (Fuller-Iglesias, Webster, & Antonucci, 2015; Roth, Mittelman, Clay, Madan, & Haley, 2005; Webster, Antonucci, Ajrouch, & Abdulrahim, 2014). The importance of social support has been reported across a number of carer contexts, for example, in carers of people with cancer (Grande et al., 2018) and with Duchenne muscular dystrophy (Glover, Hendron, Taylor, & Long, 2018). Carers of people with dementia have also reported the importance of social support in facilitating resilience (Donnellan et al., 2017; Donnellan et al., 2015; O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016).

Carers who maintained relationships and knowledge and were well supported by family, and in particular friends, reported having more resilience (Donnellan et al., 2015). This is particularly important as it would allow health professionals to predict which carers are more susceptible to burden or at a higher risk based on their social

support. The relationship with health professionals has a role in developing and increasing resilience in carers. Carers identified by health care professionals as an individual with their own particular strains and support needs was seen as particularly beneficial from the perspective of carers (Røen et al., 2018). Resilience was also found to be promoted in carers by health professionals providing support whenever needed (Røen et al., 2018).

2.5 Conclusion

The current health and social care service landscape means that reducing the costs of care are paramount to policy makers and government. End-of-life services are good quality, but a longer term view is needed to enhance quality end-of-life care for patients and their families. There are frequent transitions at the end-of-life for older people and a reduction in transitions would cost the health service more. Informal carers prevent and delay a large number of transitions, saving the health service money, reducing hospital admissions and most importantly increasing older people's quality of life and choice of place of care and death. However, providing care at the end-of-life is costly in terms of the psychological, physical and social aspects of the carers life. Literature suggests that the experiences of male and females differ when providing informal care, but this has not been well explored with carers providing end-of-life care. A focus on resilience allows for the exploration of what it is that helps people to adapt and bounce back in the face of adversity. If resilience can then be promoted in older age, and amongst those with a caring role, there could be health and social benefits for the individual, community and society.

Chapter Three: Methods and methodological considerations

The selection of an appropriate method for a study is one of the most important components of the research process. Researchers may start from a particular theoretical perspective, embedded in a set of beliefs on the nature and construction of knowledge. Alternatively, the aims and objectives of the study may drive the choice of methods (Crotty, 1998; Robson, 1993). In this study, the research question was a direct response to an identified need (in the form of a call for research by the National Institute of Health Research), for research exploring the experience of transitions at the end-of-life for older people and their carers. An in-depth qualitative approach allowed for unexplored experiences and values to be examined. As the study was designed to encompass experiences of death and bereavement, I chose to use the Windle and Bennett (2011) model of resilience as a lens to provide my own novel perspectives on the data.

3.1 Research aims and objectives

My doctoral work

The aim of this thesis is to explore the experiences of older people and bereaved carers at the end-of-life, with a focus on factors or resources, which contribute towards resilience. The objectives include:

1. To explore the experience of transitions between places of care for care providers and recipients.
2. To explore the assets and resources that facilitate or hinder resilience amongst carers.
3. To explore the role of social relationships on the development of resilience amongst carers.
4. To understand why some carers are more resilient than other carers, with a particular focus on male carers.

3.2 Theoretical basis of qualitative research

The early ideas that led to the development of qualitative research can be linked to Immanuel Kant who published in 1781 the 'Critique of Pure Reason', arguing that direct observation was not the only way of knowing about the world (Kant, 1908). He developed ideas known as 'interpretivism.' This supposes that our knowledge of the world is based on an understanding that arises from reflecting on what

happens to people, not just simply from having had such experiences. Kant asserted that knowing and knowledge transcend basic empirical enquiry, and was careful to distinguish between scientific reason and practical reason. The interrelatedness of different aspects of people's lives is very important to qualitative researchers (Ritchie, Lewis, Nicholls, & Ormston, 2003) and the psychological, social, historical and cultural factors are key in shaping a person's understanding of their world.

The goal of qualitative research is to study things in their natural setting and to try to make sense of the world in terms of the meanings people bring to things. Denzin and Lincoln (2005) define qualitative research as,

> *"involving an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural setting, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them"* (Denzin & Lincoln, 2005).

Other writers define qualitative research in terms of what it is not. Strauss and Corbin (1998) summarise that, "*by the term qualitative research we mean any type of research that produces findings not arrived at by statistical procedures or other means of quantification*" (Strauss & Corbin, 1998).

The many origins of research traditions within qualitative research vary considerably. They depend on 'how' the social world is studied, 'what' there is to know about the world (ontology) and the way in which we know and learn about the social world (epistemology). Phenomenology looks deeper than other interactionist approaches that focus on observable interactions by seeking to establish the taken for granted common sense assumptions of respondents.

The research design for this study was pragmatic. Pragmatic studies are designed to improve practice and policy and take place in everyday settings where care happens. Health research often has an emphasis on health services and plays an important role in having immediate practical implications that can engage health systems, providers, and patients as partners and to accelerate the integration of research, policy and practice. Pragmatic research has been defined as;

> *"The process of obtaining systematic knowledge and technology…(it) can be used for the improvement of the health of individual groups…it attempts*

to devise better approaches to health care for the individual and the community" (Bowling, 2014)

The increase of qualitative research has advanced the science of nursing as well as the collective understanding of the human health experience (Whittemore, Chase, & Mandle, 2001). The definition of health service research is,

> *"the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviours affect access to health care, the quality and cost of health care, and ultimately our health and well-being. Its research domains are individuals, families, organizations, institutions, communities, and populations"* (Lohr & Steinwachs, 2002).

The data for this thesis were drawn from a larger, multi-method research design which some qualitative theorists say leads to, "*a lack of analytical clarity because each method relies of different assumptions in data collection and produces different types of data which may be difficult to reconcile*" (Ritchie et al., 2003). Other researchers would argue that purism about epistemological origins of a particular approach undermines the ability to choose the best method to answer the particular research question. The study was developed after a nationwide call from a funding body (NIHR SDO) who commissioned,

> *"empirical research about the organisation and delivery of health services for older people...there has been a great deal of research about the health services which older people require and receive, there is a need for a new SDO programme which takes service provision as its starting point and key focus, and asks whether the organisation and delivery of services and service configurations are effective and whether they are meeting the needs of older people. Of particular importance is the match or mismatch between services or service processes and users' experiences and needs, and some of the key transition points in these processes and experiences."* (Research brief PCC198, NIHR SDO website).

There was no ontological or epistemological stance in the traditional way of developing and conducting qualitative research and both the wider 'Transitions' project and the doctoral work could be considered to be a form of 'generic'

qualitative research. The focus of this style of research is to produce qualitative evidence that has been rigorously collected and analysed, is valid and able to support wider inference, as neutral and unbiased as possible and clearly defensible in terms of how interpretations have been reached (Ritchie et al., 2003). However, the phenomenological perspective is the most clearly aligned epistemology as it is the study of the world as it is encountered by people and it asks, "what is this or that kind of experience like?" The definition of phenomenology is, *"the study of 'phenomena': appearances of things, or things as they appear in our experience, or the ways we experiences things, thus the meanings things have in our experience"* (Smith, 2018). The general goal of phenomenological research is to produce descriptions and understandings of the lived experience so as to disclose the character of an experience. Further, it means that research findings can be accessible and translated into policy planning and implementation.

3.3 The use of qualitative methods in this study

Semi-structured and in-depth interviews are the methods employed within this thesis. Qualitative interviews "*permit us to see that which is not ordinarily on view and examine that which is looked at but seldom seen*" (Rubin & Rubin, 2011). However, methodologists (Given, 2008; Kvale, 1987, 2006; Silverman, 2000) argue that the interview is a very artificial situation and usually involves a participant talking to someone they do not know, someone who is a complete stranger. The researcher is usually asking the stranger to create an answer under time pressure, and doing so by intruding into the social setting and potentially interfering with people's behaviour. This was true to some degree in data collection for this thesis. However, I took a number of steps to minimise these potential issues. For example, the participants opted-in to the interview. There was no time pressure; the interviews lasted as long as the participant wanted them to. The two participant groups in this thesis were interviewed in their own social setting (usually their place of residence at that point in time) and usually alone, although close family members were present during some of the interviews. The in-depth or semi-structured interviews allowed participants to answer the questions in varying levels of detail and to steer the subsequent questions to some degree. Based on the strengths of qualitative interview approach and the research questions of this thesis, it was determined that this was the best approach to meet the objectives of this research.

3.4 The research setting

The research base was in the Department of Public Health and Policy at the University of Liverpool over a period of three years from February 2009 to January 2012.

3.4.1 Patient sampling, recruitment and inclusion criteria

NHS Ethical Approval and Research and Development approval was gained (see Appendix 1) to recruit participants into the study from a variety of settings including through heart failures nurses in a local hospital (Hospital A), through a lung cancer oncologist at another local hospital (Hospital B) and through a stroke consultant at a further local hospital (Hospital C) see Figure 2 for a diagrammatic representation. We sought a purposive sample of older people aged over 75 years old who had moved at least once between care settings in the three months leading up to the interview and for whom specialist health professionals answered "no" to the question "would you be surprised if this patient was to die in the next 12 months?" Along with the criteria listed above, participants had to be aware of their heart failure, stroke or lung cancer diagnosis, but not necessarily of their end-of-life status. The recruitment aim was to interview ten patients for each of these three conditions.

Firstly, the principal investigator and I met with each of the recruiting hospital consultant clinicians. We discussed the aims and objectives of the research and the practicalities of recruitment. After agreement of the processes and identification of staff who would be involved as recruiters, potential participants were identified and invited by their specialist health professionals to contact the research team. On receipt of an expression of interest (see Appendix 3), I telephoned the patient to explain the study (see Appendix 5) and, if appropriate, send further information by post (see Appendix 10).

I arranged and conducted all the interviews between 2009 and 2010. They took place at the participant's current place of residence and lasted an average of 90 minutes. The interviews consisted of a single face-to-face structured interview, and were audio recorded with permission (see Appendix 9). The topic guide (see Appendix 7) was person-centred and flexible to the experiences of the patient. The participant was reminded throughout the recruitment process that they could

change their mind about taking part at any point and their care would not be affected.

Patient to have moved from at least one place of care to another in previous 12 months

- Diagnosis and awareness of heart failure
- >75 years old

Hospital A

Hospital B

- Diagnosis and awareness of lung cancer
- >75 years old

- Diagnosis and awareness of stroke
- >75 years old

Hospital C

Clinician asked, "Would you be surprised if this patient was to die in the next 12 months?" and must answer "No"

Figure 2 A representation of the inclusion criteria and patient sampling

3.4.2 Bereaved carer sampling

Family carer interviewees were identified in a two-stage process. Primary Care Research Networks (PCRN) in three NHS regions of England first advertised the study to GP practices enrolled with their Primary Care Incentive Scheme for research participation. Comprehensive local Clinical Research Networks (CRN's) facilitated the involvement of general practices, by funding service support costs.

The participants were recruited through GP practices in the North West and South Central geographical areas and through publicising the research. Two approaches to recruitment were adopted once GP practices were recruited to the study (see Figure 3).

3.4.2.1 PCRN support

In the North West region of England, the Merseyside and Cheshire PCRN in Merseyside and Cheshire and North Lancashire worked directly with GP practices. PCRN staff visited each practice, assisted with database searches and distribution of recruitment materials to eligible individuals, and collected some data about practice involvement in the study. For this second phase of data collection NHS

research governance approval was obtained from 44 NHS Primary Care Trusts (PCTs) out of the 46 PCT's that were approached. Two refused: one felt that the recruitment method would not work, the other gave no reason. The PCT who said the recruitment method would not work, had raised concerns about the prospect of me, or a researcher from the practice, phoning potential participants with information derived from their medical records. This was originally passed by the ethics committee (see Appendix 2), but on advice from the rest of the study management team and taking into account methods used in similar studies of bereaved carers, we proposed an ethical amendment to the study that was more restrictive in approach. A re-submission with this amendment to the first PCT was also unsuccessful. The practices received a financial payment for their involvement with the study; they were paid more if they carried out the searches themselves. Once the search for potential participants had been completed, a GP checked the selection of participants for the exclusion criteria and omitted people who they deemed were not suitable to be invited to interview. The GPs did not need to specify the reasons for exclusion but they were asked to exclude people who were unable to communicate, those who were either too unwell to take part, or for whom participation would be distressing. In practice, the exclusions encompassed people with dementia, cognitive impairment or other mental health problems and individuals with serious physical illness. The health professionals could also identify other people who had died but were not found in the electronic searches.
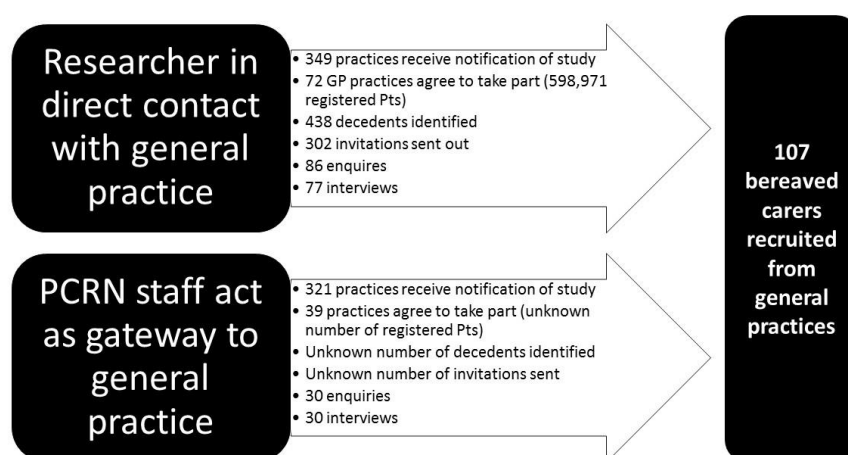
Figure 3 Bereaved carer recruitment through GP practices

Next, the researcher posted a number of participant information packs to the practice (see Appendix 10) who included a covering letter (see Appendix 4) and sent

the packs on to potential participants. Volunteers could then opt into the study by contacting the researcher and agreeing to be interviewed (see Appendix 3). For those who were not living in institutions such as a care or nursing home, the decedent's address was used to search for co-residents who were also registered at the same practice. For 107 out of 118 participants, carers were identified by the general practitioners who had looked after the older adult decedent. Eleven carers were recruited through local publicity, or word of mouth amongst health professionals in the study areas.

3.4.2.2 Researcher in direct contact with GP practice

In two regions in South England, the research network staff publicised the study to general practices that had previously identified themselves to the network as being interested and able to participate in research studies. The network staff then put the research team into direct contact with interested GPs.

PCRN staff dealt with initial enquiries from practices and passed on formal expressions of interest as they arose to the research team, who then supported practices through their involvement. In all regions, participating practices were provided with the recruitment materials; invitation letters (see Appendix 4), participant information sheets, reply slips and stamped envelopes.

3.4.3 Recruitment of bereaved carer participants

General practices were asked to identify people who had died within the last 3-9 months aged 75 years or older with lung cancer, heart failure or following a stroke. Most were able to scrutinise a list of patients who had died, though appropriate sets of clinical descriptions that practices could use to manage the data in patients records were made available for searching electronic databases if required. This was in the form of a list of read codes, that clinicians used to find eligible patients. The list of eligible decedents was restricted to individuals who had experienced more than one transition between care settings in the last three months of their lives.

The primary care team at the general practice identified carers for each decedent, if they were known to them as a result of providing care to the patient. The GP took responsibility for inviting carers into the study. Most were family members or friends. A small number of care home professionals who had known the decedent

well and were able to talk about transitions and end-of-life experiences were also included. These care home professionals were also identified by the GP.

The potential participants were sent an information sheet (see Appendix 4) from their local GP practice outlining the study. If they wished to participate they contacted me. If they did nothing, they would not be contacted again. The potential participant needed to opt-into the study to become known to the research team. Once they had shared their contact details with the research team, they were contacted by telephone to discuss the study and if appropriate, to arrange an interview date and time.

3.4.4 Inclusion and exclusion criteria

The inclusion criteria was people aged over 18 years, and who cared for a person aged over 75 years old who died with lung cancer, heart failure or stroke, breast cancer, colorectal cancer or Chronic Obstructive Pulmonary Disease (COPD). A suitable informant was defined as someone who had enough knowledge about the end-of-life care the person had experienced.

Exclusion criteria were people who are unable to give informed consent, inability to understand and converse in English, a physical or mental health status that does not allow the participant to converse comfortably and people who may be unduly distressed by the interview process, in the opinion of the responsible health professional(s).

3.5 Informed Consent

The Data Protection Act (1998) required "*that all potential participants must be informed of the ongoing research although they cannot be approached by the researcher*". As per the recruitment process, the potential participants would be approached by another health care professional and consent to their names and contact details being given to the researcher. The researcher would then approach the participant and discuss potential involvement. During data collection I had to be careful of not gaining access to the personal information of potential participants before the participants themselves had consented to opt-in to the study. This is discussed in the literature as a common occurrence (Addington-Hall, 2002; Addington-Hall, Bruera, Higginson, & Payne, 2007; Borgstrom & Ellis, 2017). All the participants involved in the project did provide informed consent. The

'informed' part of this requirement was that the participant received and read an information sheet outlining the study in further detail as well as an overview given on the initial telephone call. For the patients with stroke, a health professional or myself read out the information sheet. Further to this, before the interview was audio recorded they were re-informed about the nature and reasons for the research, confidentiality was explained to them again, and they had an opportunity to ask questions. The 'consent' part of this requirement involved the participant reading and signing a consent form, approved by the relevant ethical committee (see Appendix 9) (Sefton Research Ethics Committee number 09/H1001/51). In a small minority of cases, e.g. the participants who had stroke or, where there were sight or writing difficulties, I read out the information sheet then audio recorded the person giving verbal consent and audio recorded the person agreeing with the terms of the consent form. As the interview was a one-off face-to-face interview, and the participant was not contacted again, there were no issues about consent being an ongoing process.

3.6 Data collection methods

3.6.1 Patient data collection

Data collection took place across the North West of England in 2009-2010. Participants were usually in their final days or weeks of life and were interviewed in their own homes (n=24), a hospice (n=3) or rehabilitation centre (n=3). Four patients were below the specified lower age limit but were included because they had been invited to participate by the responsible clinician and had relevant experiences.

Interviews followed a flexible person-centred topic guide (see Appendix 7) that covered interviewees' social background, family circumstances and their experiences as a patient. Participants were asked about their illness, the health and social care they received, their experiences of the transitions that they had experienced, and how they felt about these moves between care settings. People were encouraged to talk about issues which were important to them, and to share their perspectives on the quality of the care received in different settings as well as on the impact of transfers between places of care. A comprehensive list of prompts for the interviewer ensured consistency across interviews. A typical interview question was, "Could you tell me something about the care you received in hospital

and the people who looked after you there?" Follow up questions were asked after the initial response by the participant, to explore issues of interest in more depth. All interviews were audio-recorded, sent to a professional transcriber, transcribed verbatim, and anonymised by the researcher (LR). The participants had the option to terminate the interview after one hour, prompted by me, but the average recorded interview duration was 90 minutes (range 45-180 minutes).

3.6.2 Bereaved carer data collection

The data collection took place in North and South England between 2010- 2011 and started before the patient interview phase had concluded, although the patient interview phase did inform some of the questions for the bereaved carers. The patient interview phase had also informed my understanding of the complexities that the bereaved carers may have faced.

Interviews were conducted between 3-9 months following the death of the cared-for person, as memories are deemed sufficiently fresh to provide details about the experience, but most individuals will have had sufficient time since the death to feel able to speak with a researcher about their experiences. Interviews were conducted at a time and a place chosen by each participant. For the majority, this was a face-to-face interview in their own home. One family carer living in Scotland and a care home professional were interviewed by telephone, two participants chose to be interviewed at the University, and one at their own place of work. One care home owner chose to be interviewed face-to-face at the care home where she lived. The carer experience was related to her personal rather than professional role. Written informed consent was obtained from all participants and interviews were conducted by either myself or another researcher both experienced in working with vulnerable adults and older people. Some carer participants chose to be interviewed with a relative or friend present. In some cases, this was prearranged, but in others, the person was present when the interviewer arrived. Informed consent was received and documented with all participants. Additional participants were almost always female: one widow and two widowers were accompanied by daughters; another widow had a female friend with them; five sons and one daughter had their spouses present.

Most interviews opened with a question to prompt an overview of the transitions experienced in the last year of life. This approach was used in order to tailor the

subsequent questions. Where it was difficult to obtain this overview, participants provided detailed accounts of each setting and transition. I then probed for details about the final transition, and asked a series of structured questions (see Appendix 8). If interviewees were reticent to provide a response after probing, structured questions were introduced sooner. If interviewees had an account they wanted to provide about later transitions, this was explored before introducing structured questions. There were sections on being cared for at their own home, a care home, a hospital, hospice or other place. Within each of these sections were questions about the admission to this place of care, for example, "who made the decision to be admitted to X place?", "were you involved as much as you wanted to be?", and "where there any practical problems with the admission?" The next section was called 'time spent in the place of care' and included how their pain treatment was managed, respect and dignity in X place, the involvement from the carer in the patients care, the experience of care from different staff groups, the quality of life for the patient and the practical problems experienced. Finally, for each place of care there was a 'leaving place' section, if the patient left one place of care to go to another place. This included questions about the information provided to explain why they were leaving, who made the decisions for the patient to leave the place, further places they went to and the choices they had in these places. For every bereaved carer there were also sections on 'out of hours' care, GP care, medication related questions and 'events around death and bereavement' including did the person know they were likely to die, where did they want to die and did they die in the right place. Finally, there was a section called 'overview of transitions and continuity' including questions on how services were coordinated, whether the patient had a main contact person, whether care was consistent, whether the care was flexible and whether the patient and carers where provided with enough information and support. I also explored how transitions could have potentially been avoided.

3.7 Participant characteristics

3.7.1 Patient characteristics

Thirty older people were interviewed by the researcher (LR). Of the people with heart failure who were sent information about the study, 13 out of 20 agreed to be interviewed. Thirty-five older people with lung cancer expressed an interest to participate (by returning a response slip or phoning my office) in the study team but only 14 were interviewed. Twenty of the 35 who expressed an interest were too unwell by the time of the interview and one person had died. This information was gathered when I arranged or confirmed interviews, depending on who answered the phone. These twenty participants were not different in average age to the participants who were interviewed. Stroke patients were difficult to include due to difficulties with cognition, speech or memory and because in the course of the recruitment period, some of the possible participants deteriorated further or died. I interviewed three people with stroke. Heart failure patients who were interviewed were between 69-88 years, lung cancer patients who were interviewed were aged between 73-89 years and stroke patients were aged between 81-93 years old. I monitored the socio-demographic composition of the participants, based on Index of Multiple Deprivation (IMD), derived from the participants' postcodes, and used the last reported occupation to allocate the participants to one of the five quintiles in the National Statistics Socio-economic Classification. My aim was to make sure that people from disadvantaged areas were represented and this was the case, without intervention. I also wanted to monitor the living circumstances of the participants, but similarly, we interviewed people with a range of living circumstances.

Table 3 Patient participant demographics by condition

Characteristics	Heart Failure	Lung Cancer	Stroke
Sent information	20	35	unknown
Interviewed	13	14	3
< 75 years old	3	1	0
Gender (Male/ Female)	9/4	3/11	2/1
Age (median range)	77 (69-88)	80 (73-89)	85 (81-93)
Social classification			
1 and 2 (least deprived)	6	4	3
3	1	0	0
4 and 5 (most deprived)	6	10	0
Living circumstances			
Home, alone	3	5	1
Home, with others	9	7	1
Institution (e.g. nursing or care home)	1	2	1

3.7.2 Bereaved carer characteristics

One hundred and eighteen carers were interviewed (77 from 302 invitations from GPs in South England, 30 from an unknown number of GP invitations in the North West of England and 11 recruited via other means). They ranged in age from 38 to 87 years (median 66 years). The majority (n = 88, 75%) were female, almost half (n = 55, 47%) had been the spouse or partner of the patient and 45% (n =53) were the adult child of the deceased. More carers were recruited from the southern regions (n=86, 73%) and a disproportionate number were from less disadvantaged areas. The participants' postcodes were used to allocate an Index of Multiple Deprivation score to the carer, which were then placed into quintiles, based on the scores for England. This provided a measure of relative disadvantage across my sample.

Table 4 Bereaved carer participant demographics

Characteristics	Number
Sent information	302 GP practices + 11 individuals recruited via other means
Interviewed	118
Gender (Male/ Female)	30/88
Age median (range)	65 (38-87)
IMD Quintiles*	
Quintile 1 (most deprived)	5
Quintile 2	12
Quintile 3	25
Quintile 4	35
Quintile 5 (least deprived)	40
Marital status	
Married or cohabiting	42
Widowed	59
Single	12
Divorced, separated or NA	5
Relationship to care recipient	
Spouse or partner	56
Child	53
Other relative	5
Friend	1
Professional	2

* IMD not calculated for one care home manager because they lived at the care home

The patients whose care was the subject of the interviews had a median age of 84 years (range 66-97 years) and half of them were female. Treatment had been received for at least one of the three main study conditions (heart failure, lung cancer, stroke) by 82 (77%) of the decedents. The sample was supplemented by carers of people who had had chronic obstructive pulmonary disease (18.6%), colorectal cancer (7.6%) and breast cancer (2.5%). The majority had lived at home (84%) or in a care home (9%), and hospital was the most common place of death (58%). Thirty-two per cent of patients had died in their own or a relative's home (17%) or in a care home (19%). Reported levels of co-morbidities were low. In the three months prior to death the vast majority of people had lived in their own homes (84%) yet tended to die in hospital (57%). With the exception of one telephone interview (two separate conversations two weeks apart), each individual interview was conducted on the same day, sometimes with short breaks.

3.8 Analysis and Writing

3.8.1 Analysis of data

Analysis was informed by the work of Braun and Clarke (2006) and their guide to thematic analysis. Thematic analysis is a method for identifying, analysing and reporting patterns (or themes) within data. Utilising a thematic analysis approach, I sought to provide accurate representation of patient and bereaved carer views to address the study aims and objectives. This approach allows for themes to be identified at a semantic level (i.e. surface meanings or summaries) or at a latent level (i.e. interpretive – theorising the significance of the patterns and their broader meanings and implications) (Patton, 2002). Often, researchers analyse only at the semantic level but for this thesis, I wanted to use the findings to explore theory as well as contribute to the literature with the implications for policy and practice and so also conducted interpretive analysis. NVivo 10 software (QSR International Pty Ltd., Melbourne, Australia) was used to assist in the organisation and coding of data. Table 5 shows the thematic analysis phases of analysis.

Table 5 Phases of analysis

	Phase	Description
1.	Familiarising with data	LR read and re-read transcripts noting down initial ideas
2.	Generating initial codes	Initially, a data-coding framework was developed using *a priori* codes identified from the project proposal and the interview topic guide. During the familiarisation stage LR identified additional data-driven codes and concepts not previously captured in the initial coding frame.
3.	Developing the coding framework	BH coded 10% of the transcripts using the initial coding frame and made notes on any new themes identified and how the framework could be refined. It was an iterative process so was refined continuously.
4.	Defining and naming themes	Following review and reconciliation by LR and BH, a revised coding frame was subsequently developed and ordered into themes (nodes) within the NVivo10 Database.
5.	Completion of coding of transcripts	LR completed coding of all transcripts in preparation for write-up.
6.	Producing the chapter/paper	LR and BH developed the manuscript using themes to relate back to the study aims ensuring key findings and recommendations were relevant to the study design. Final discussion and development of selected themes occurred during the write-up phase.

Initial analysis for the interviews drew on the framework approach (Ritchie et al., 2003). Reading and re-reading of transcripts (see Appendix 12 and 13 for examples of Transcripts) by two researchers (LR and BH) was used to develop a systematic coded framework covering key areas of participants' illness experience, and data extracts were coded according to the framework and entered into appropriate cells within an Excel spreadsheet. Concepts were discussed from the thematic analysis and this contributed to the emerging conceptual schema, reaching agreement. This involvement of the two researchers enables increased confidence in the analysis process and data interpretation, as agreement was reached (see Appendix 14 and 15 for examples of Coding Framework). In this thesis, this is how chapters 4-6 were analysed. For the development and analysis of chapters 7 and 8 I developed a further coding index of the presence or absence of resilience, using the operationalised definition of resilience. I then explored the assets or resources that facilitated resilience, including the quality and role of social relationships. These elements of the coding framework were drawn from the 'community' aspect of the Windle and Bennett Resilience Framework by using Sherborne and Stewarts' (1991) MOS dimensions of social support (Sherbourne & Stewart, 1991). From studying the literature I could see that there were only a few studies exploring the experiences of male caregivers particularly with reference to exploring resilience. I felt that further analysis of this data set, focusing on the male perspective could contribute to, and expand our understanding of how and why some carers negotiate, manage and adapt to significant stress and trauma better than others. For this analysis, I looked only at the perspectives of male caregivers (n=30). Another model that was utilised to enhance my understanding of the layers of influence of experience and resilience was Dahlgren and Whitehead's (1991) 'social determinants of health' model was useful to refer to when conceptualising the layers of influence in the participant's accounts of their experiences (Dahlgren & Whitehead, 1991). The model maps the relationship between the individual, their environment and health. Individual characteristics are placed at the centre and include age, sex, and other primarily fixed characteristics. Surrounding them are the various layers of influences on health, such as individual lifestyle factors, community influences, living and working conditions and more general social conditions.

3.9 Ethical considerations

Ethical considerations are a vital aspect of research, particularly when the research topic is highly sensitive and the research participants may be vulnerable members of society. The research is sensitive because it delves into a deeply personal space, exploring the experiences of end-of-life care, it is emotional and private, and we explored health-related experiences (Dickson-Swift, James, Kippen, & Liamputtong, 2007; Renzetti & Lee, 1993). It can also be described as sensitive because the topic was emotionally laden from my perspective as the researcher. Research ethics support values such as respect and fairness that are required for collaborative work, and particularly important in qualitative research (Resnik, Rasmussen, & Kissling, 2015). In the context of potentially vulnerable people, research ethics asserts the principle of doing no harm to others, alongside other social and moral values that serve to promote respect and protect the participants' interests. Stroebe, Stroebe and Schut (2003) discuss the methodological issues and ethical concerns in bereavement research and outline what they call 'central criteria' used to determine whether a research question is worthwhile in pursuing. They argue that: (1) the design and methodological adequacy, (2) the ethical responsibility of the researcher and (3) the theoretical and societal relevance of the study must be of good quality in order to collect data from people who are in a vulnerable position (e.g. at the end-of-life or recently bereaved). The study met these three criteria. The participants were first identified by their GP who knew their circumstances well enough to identify them. The participants (after reading the provided information outlining the research and what was required from them) had the choice whether to opt-into the study. This allowed participants time to consider whether they wanted to take part in the study and provided them with freedom of choice.

3.9.1 Ethical considerations for the participants

The data came from in-depth and semi-structured interviews with older people, aged over 69 and at the end-of-life, and bereaved carers, aged over 18 who had cared for someone who had been at the end of their life and experienced transitions between places of care. The main ethical considerations for this study for participants were around access to the potential participants, participant safety, the appropriateness of the research questions, the process of recruitment, data collection and analysis being ethically sound and the involvement of the ethics committee.

3.9.1.1 Access to the participants

Access to the potential participants was negotiated through health providers either via hospital consultants, hospice managing directors and nurses for older people at the end-of-life, or via general practitioners (GP's), for access to the bereaved carers. Health professionals are a meaningful process of protection for vulnerable people and engaging with them can foster good working relationships and is good practice. 'Gatekeepers', who are needed to facilitate the research by providing or often introducing research to the participants, can often be concerned about taking up the time of participants. The gatekeeper may aim to protect the sickest or most distressed potential participants and inadvertently create a barrier to study entry for individuals or groups with certain characteristics and/ or introduce inadvertent selection bias. These considerations were primarily overcome by clear and thoughtful discussion between the researcher and study team and the responsible clinicians. All of the recruiting consultants and hospice directors met with the researcher to discuss the research aims and objectives and the practicalities associated with recruiting participants from their locality.

3.9.1.2 Appropriateness of research and research questions

The main concern of carrying out research with people at the end-of-life, or people who are bereaved was that as a 'captive audience' they may feel pressure to participate (Raudonis, 1992). This issue is not unique to patients in health care settings at the end-of-life and because it is the health professionals involved in their care that are facilitating recruitment, it is important that the participants are not pressured into participating, either covertly or overtly. However, because of their reliance on the health care practitioners looking after them, and potential worries about the care after the research participation, it was important for the study team to ensure participants understood the role of the researcher and how the research was voluntary and had no bearing on their present or future care. It was also explicit that the researcher conducting the interview was not a member of the health care team. Research (Johnson & Clarke, 2003) suggests that in-depth interviewing can lead to unintended coercion in that however 'sensitive' the researcher may be to the needs of the participant, the relationship that is built up over the period of recruitment can result in the participant feeling obliged to participate in the research. During this study, the researcher did not build any relationships with the potential participants. The researcher waited until the appropriate health professional first approached the patient and then later confirmed with the patient

that they were happy to participate. It is likely that although the potential participants were told of their right to decline to be interviewed and how their medical treatment would not be affected in any way, the health care staff that negotiated the recruitment of the participants, are likely to have used their relationship with the participant to encourage the patient to take part. This is an unavoidable consequence of recruiting participants (known as 'unintended coercion') in a health care setting by health professionals who they know are involved in their care (Kon, 2010). It was reiterated by me, to participants that the research was voluntary and would not impact on their care in any way. Another ethical consideration included the autonomy of the participants. The autonomy of the potential participant was important in this study. But due to the nature of the study, it was unlikely there would be conflict over the decision to take part between the potential participant and their next of kin, or between the participant and the clinician.

3.9.1.3 Health considerations including potential distress

Other considerations from the perspective of protecting and ensuring the well-being of the potential participants included issues around their physical and mental well-being and frailty. Many end-of-life care patients have evidence of cognitive impairment or impaired decision-making capacity (Pereira, Hanson, & Bruera, 1997). The rapidly changing condition of many end-of-life care patients also meant that individuals' ability or willingness to participate in an interview study may change from one day to the next, and so all participants were approached by a health care professional and interviewed the same day. Some of the older participants were unable to tolerate a long interview, because they became fatigued and some questions were removed to shorten the interview. However, the vast majority coped well with the interview and the researcher judged that it did not seem to be burdensome for the patients. All participants were also given the opportunity to stop the interview at any time.

During the development and design of the study, consideration was given to how the researcher should respond if the interview process had appeared to distress the patient participants. A range of responses were agreed by the wider research team, depending on the setting of the participant at the time. If the interview was in an individual's home, I would discuss first with my supervisor (a practicing and experienced GP) who could then advise further. In the hospital, hospice or care

home setting, I would discuss the situation with the nurse in charge. Johnson and Clarke (2003) discusses whether the impact of the in-depth interview on the participants involved is ever really known, although it is usually suggested that the 'benefits outweigh the costs' and this is something that ethics committee's usually look for in terms of deciding whether projects can have ethical approval (Johnson & Clarke, 2003).

3.9.2 Ethical considerations for the researcher

The literature suggests that in-depth interviewing can come at a cost to both the participant and also the researcher (Beaver, Luker, & Woods, 1999; Davies, 2000; Johnson & Clarke, 2003). It is suggested that ethical interviewing must first begin with the interviewer (Smith, 1992) and due consideration of the sensitivity of the material was given by me, drawing on my personal past experience of end-of-life care and bereavement and also my professional past experience as an Assistant Psychologist. My past professional experience had equipped me with the skills and experience I needed to talk in-depth with older people and their families who had significant poor health. For example, I knew it was important to spend some time at the start ensuring the participant felt at ease in my company. I was also aware to look out for signs of fatigue in the participant.

Research suggests that the immersion of lived experience of others may still render the researcher vulnerable (Robley, 1995) although safeguards were in place to prevent distress or isolation for the researcher. For example, I had a structure of support I could readily access if I felt the interviews were becoming emotionally draining, upsetting, or I was concerned about any of the content of the interviews. If there was a disclosure of harm or something I saw or heard caused me to feel concerned, I knew I could access appropriate information and support through my second supervisor (BH). Personal safety was also a consideration as all of the bereaved carer interviews and some of the patient interviews were conducted across England, primarily the North West, at the private homes. Sensible precautions were taken. My supervisor or other staff member knew my whereabouts, and a process was agreed to contacting them by telephone at the beginning and the end of the interview, and a time agreed by which they would try to contact me and raise an alarm if necessary. The University of Liverpool lone worker policy was implemented and followed.

3.9.3 Ethical approval

The study was reviewed and approved by the Sefton National Health Service Research Ethics Committee (NREC) (study number 09/H1001/51). The ethics committee's role is to consider that what the study team plans to do is appropriate and proportionate to the research aims. At the committee meeting it was confirmed that the study was justified, the knowledge to be gained was important for research and practice purposes and the patients and the researcher would not be expected to come to harm by participating in the research. The NREC approved the study's participant information sheet, the interview schedule and topic guides, the sponsorship from the University of Liverpool, the curriculum vitae of the investigator and researcher, the participant consent forms and the protocol. The condition of favourable ethical opinion was that each host organisation was to provide further management permission or approval prior to the start of the study at the site concerned. Also known as Research and Development Approval (RandD), this was also gained for each of the sites at which we recruited for the different diagnostic groups in the patient phase of the project. For example, heart failure patients were recruited from Hospital A, the lung cancer patients from Hospital B and the stroke patients from Hospital C, and all hospitals were located in the Merseyside area.

3.9.4 Ethical integrity

The study recruited older people in their final twelve months of life, and bereaved carers who were between 3-9 months post bereavement. For the bereaved carers, the period was not recent enough to cause undue distress, but also not long enough so that they could forget important details that may have salience for the research. In the time between the participants identifying themselves and them being interviewed there was normally a further period of waiting of approximately one week. Once the researcher met with the potential participant, they went through the participant information sheet, answered any questions and recorded their consent. At all stages in the recruitment process, and after the interview had taken place, the participant was reminded that they could withdraw at any time. The research team felt that the relevance of this study in terms of adding to the existing

knowledge base, informing policy and practice were sufficient reasons to conduct research of this nature.

Findings from my work, it was hoped, would contribute towards the implementation of existing Department of Health policy, and offered data to inform future developments. The proposal was focused on some of the enduring policy themes of the NHS: care that is patient centred, efficient use of resources and the role of unpaid caregivers. In the health service, commissioning is developed at local levels, and a wider range of providers are able to offer care. The findings may have particular relevance to the development of end-of-life care networks and/or could lead to direct improvements in the appropriateness and efficiency of service utilisation in the last year of life. In the longer term, the implementation of appropriate changes in service delivery may lead to improvements in health related quality of life and health status before death.

3.9.5 Anonymity and confidentiality

It is important with this type of sensitive research, that the participants feel they can speak freely and describe their experiences, which may identify specific hospitals, members of staff, or themselves, in a safe, secure and confidential environment. Participants were asked to give consent so that the interviews could be audio recorded, but they were assured that their names would not appear in any publications or reports that are written as a result of their interview. They were also assured that health professionals involved in their care would not be able to identify the patients individually. This was ensured this by removing place names, locations, names of doctors and other identifiable information from the transcripts. The exception to this rule was if the researcher felt that participants are likely to be harmed or that someone else is likely to be harmed as a result of any disclosures.

Once the interviews were transcribed (see section 3.10), participants' details and transcripts were kept separately with an identification code assigned to them so that consent forms, participants' details and transcripts could be linked in the case of a participant later withdrawing from the study. Electronic records were stored on a University password protected computer, in an office behind a code-accessed door. Paper based records were stored in a locked filing cabinet in the same code accessed office. Only the researcher and principal investigator had access to

participant information. This was necessary to adhere to the University of Liverpool 'Lone worker policy' and also because the majority of interviews were conducted face-to-face so the researcher needed to know participants addresses.

Confidentiality is important for developing a trusting relationship with the interviewee and I think that acknowledging the boundaries and exceptions to confidentiality enhances the participant's experience of being interviewed. Participants are also more likely to describe their 'true' feelings and experiences on the subject matter, if they are assured that the data will only be used for the purpose that is stated and data will be anonymous to all but the immediate project group.

3.10 Transcription

In the original funding proposal for the project there was a budget for transcription. One experienced medical transcriber, transcribed all the interviews in full and all the interviews were checked for accuracy by me. The transcriber was not part of the research team.

3.11 The researcher characteristics

The 'Transitions' project group included of a number of senior academics and experts in end-of-life care and psychology, sociology and nursing. I was employed as the one North West based researcher for the three years of the project and a South Central based researcher (EL) for year three of the project. The Principal Investigator (BH) is a Professor of Primary Care and Public Health, and at the beginning of the study was a senior lecturer in public health and a practicing GP. The primary supervisor of this thesis (KMB) is a Professor and Chartered Health Psychologist.

At the beginning of the study, I was a Research Assistant who was studying part-time towards a PhD. I had completed a Masters in Health Psychology, after an undergraduate degree in Psychology, and was interested in becoming a Chartered Health Psychologist. By the submission of this thesis, I was a Post-Doctoral Research Associate and a Chartered Health Psychologist, having completed the Stage II Qualification in Health Psychology, between 2012-2016. In taking a symbolic interactionist approach to the research it is important to consider what I brought

to the research process. My ideas and values will have influenced the way that I perceived and generated knowledge through interactions with the research setting and participants.

3.11.1 A reflection on personal experience

I had some previous experience of talking to and being with older people at the end-of-life; I was close to my maternal grandparents who looked after me and my sister as children when my parents were at work. My grandfather died from lung cancer when I was 14 and he was 80, and we nursed my grandmother through various physical and mental health problems when she lived with us for four years, until she died when I was 18. Before these difficult times I had spent many happy years in the company of them and their friends and had a good understanding of the difficulties of facing the end of your life when getting older. I had experienced their loss of friendships, their loss of independence from the mundane (e.g. food shopping) to the excitement of attending dance classes and undertaking day trips with family. They had lost sisters, brothers and friends, and I was aware of, if not necessarily part of, the conversations around these bereavements. My older relatives had years of declining health before they died, so there were many doctor and hospital appointments. They also, particularly my grandmother, worried about being cared-for outside her own home, or more particularly being cared-for by people unfamiliar to her. She hated hospitals, although revered doctors. My grandmother lost my grandfather to cancer after 50 years of marriage and blamed him, later, for not being there to care for her. There was resentment towards him for the role my mum, dad, my sister, and I took on in caring for her. She lost her primary carer and her husband at the same time. When he was ill, he was unable to adopt the 'patient' role and be cared for (by us, or anyone), because of the care that she needed. Caring for someone from my personal experience, was complex due the mix of emotions and tensions that caring can create.

My experience of the deaths of my grandparents may have given me some understanding of the difficulties and experiences faced by bereaved carers, and some of the experiences that they faced, particularly reflecting back on care at the end-of-life. The end-of-life care for my grandfather was straightforward. He was diagnosed with lung cancer and radiotherapy and chemotherapy treatment followed. When the cancer returned, he died from pneumonia after a week in hospital, shortly before the next treatment was due to start. The end-of-life care

for my grandmother was more complex. After living with us, and often refusing to go into hospital when she needed acute care (e.g. she frequently choked on food or needed oxygen readjusting or medication increasing), she would eventually be admitted and then later spend some time in rehabilitative nursing care. She would return home to us and within a couple of months be re-admitted and the cycle would continue. The anxiety and depression that worsened due to her physical ill health (having only one failing lung as a result of tuberculosis in her youth), stifled any sense of hope or happiness in her life in the final few years. She also died on a busy hospital ward, a place that she would not have chosen. Trying to facilitate dignity and continuity during end-of-life care, from my personal experience was complex.

Observing the experiences of my parents as primary caregivers and coordinators of care; the care from clinicians; the day centres; nursing homes we visited 'just in case'; the cancer wards, respiratory clinics, the 'home help' we purchased- all added to my understanding of what it feels like for some people to be a carer. The ways in which we adapted our home (a stair-lift, oxygen concentrators fitted, bathroom adaptation) added to my holistic understanding of end-of-life experiences for older people and their carers. It helped me to see that care at the end-of-life was not something that happens in the final few minutes, but often happening for months and years before the death of a loved one. It was difficult for everyone. My experiences suggested that navigating a system you are unfamiliar with is not straightforward; it is difficult. Trying to adapt and manage a situation of pain and suffering and the unknown, from either the patient or carers point of view is a lot to ask, particularly of people whom may not have resources to cope well. We did all manage to adapt to the stress of the situation, but we had lots of resources: my parents were young and in good health in their 40s and able to balance family life, caring and work. We had some knowledge of the health care system and some prior experience; there was enough money and time to devote to caring for their parents. Support from wider family and friends was limited, but support from within our family unit was strong.

3.11.2 A reflection on professional experience

I started my degree in Psychology, a couple of months after my grandmother's death. After that I studied for a Masters in Health Psychology and worked as an Assistant Psychologist in an older adults' mental health inpatient setting and in a stroke rehabilitation ward. This gave me a clinical understanding of what it is like to

work with (assess, interview, provide therapy for) older people who are physically or psychologically unwell. I gained some understanding of the ethical issues and difficulties in interviewing people who may be upset or distressed by their health and their inability to influence the outcome of their health care (as have been highlighted throughout my thesis). However, although part way through the research I registered with the British Psychological Society as a Trainee Health Psychologist, I always approached the RA work on the project, as a researcher, not a Psychologist. Research has explored the role of the 'insider/ outsider' membership-roles, particularly with reference to observations, field research and ethnography. Researcher membership is a fundamental consideration when collecting qualitative data as whether or not the researcher shares characteristics, roles or experiences with the participants in the study is an ever-present aspect of the research. As previously described by other researchers (Dwyer & Buckle, 2009). I feel like I occupied the 'space between';

"The qualitative researcher's perspective is perhaps a paradoxical one: it is to be acutely tuned-in to the experiences and meaning systems of others—to indwell— and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand (Morehouse & Maykut, 2002), p. 123"

3.12 Role of the researcher

To ensure the questions asked were sensitive, thoughtful, caring and appropriate, and the interview was conducted professionally, I was trained in in-depth interviewing skills. The questions and probes I used were appropriate and responsible, and agreed by the research team. This training commenced before any interviews took place at the National Centre for Social Research (NatCen) and was 10 days in length. As previously mentioned I had prior experience of similar data collection methods through my previous post. I also had a major contribution to the development of the topic guide and the questions were developed with the aims and objectives of the study in mind. As well as the set-up of the study, I collected all the data from people at the end of life, the majority of qualitative data from bereaved carers and completed the majority of the analysis. I worked with health care professionals to gain access to, and then consent older people and bereaved carers into the study. I also aimed to form a good researcher/respondent

relationship. The first impression and rapport building was important as the participants were about to talk to me at length about either their or their loved ones experiences of end of their life care. My role was to make them feel at ease in doing so and to foster trustworthiness and openness between us.

3.12.1 Reflections on my role

The potentially upsetting nature of the issues discussed with the participants could have resulted in myself as the researcher being emotionally drained by the collection of data. However, I feel that I was appropriately trained for this post and therefore had the skills, gained from previous roles and more recent courses and training events, to manage and negotiate the experience of interviewing older people at the end-of-life and people who had been recently bereaved. Becoming familiar with the literature on end-of-life issues and patient interviews, I could see that there was certainly the potential for me to find this project difficult, both emotionally and intellectually. During the recruitment phase, which took part mainly during the first year in post for the patient data, I worked in multiple ways with multiple people. Different health professionals from different hospitals had different ways of working with their differing patient groups. Recruitment of participants did not pose too many ethical problems that we had not already considered within the project team. However, the obvious physical decline of some of the patients and the experiences and stories they shared did have an effect on me. The social environments of the patients and bereaved carers were also sometimes upsetting. However, I was aware and prepared for these situations and had regular supervision and a close, supportive relationship with my second supervisor, a practicing GP and Senior Researcher, as well as approachable co-applicants in similar senior positions, colleagues in the Department of Public Health and Policy and friends in Psychology and Clinical Psychology conducting similar research. A peer support group was also run by the Department; an experienced Clinical Psychologist facilitated this and I attended this once a month through the course of collecting the patient and bereaved carer data. Whilst keeping the experiences of the patients confidential, I did have a network of people to discuss concerns, bad experiences and upsetting days with. Reflecting on why I think the research did not affect me emotionally as it does some researchers, I think that the awareness of the study team helped. The study team and my second supervisor were acutely aware of the potentially distressing nature of the interviews through their own research. They encouraged me to see the tough and demanding

interviews not as a reflection on my ability to cope with data of this sort, but as a consequence of data of this sort, and therefore difficult issues were viewed by me as issues of the topic rather than issues of the participant or the interview process. I was also aware that my role was not to advocate on behalf of the participants, or to change their experience of care in any way. It was to allow them to tell me their experience so that poor or bad experiences may not necessarily have to be repeated by others in the future. If I asked the appropriate questions of the participants who were willing to tell me about their experience then I could document those experiences and share them with the wider academic and policymaking audience to ensure poor experiences were not repeated.

Chapter Four:
A comparison of strategies to recruit older patients and carers to end-of-life research in primary care

4.1 Foreword

This chapter explores the strategies used to recruit older people and bereaved carers to end-of-life research. There will be some repetition between this chapter and chapter three as they both describe the recruitment methods. I was the researcher on both of these studies and recruited the participants, analysed the data and drafted the manuscript for publication. This chapter is based on the recruitment and sampling strategies of both participant groups within this thesis: older people and bereaved carers. It was difficult to recruit both the older people and bereaved carers to the 'Transitions' project, because both pathways we needed to negotiate were resource intensive. Recruitment to both phases of the project was successful, but I recommend that a review of the regulatory and organisational barriers to end-of-life researchers in primary care is required to make this process easier.

This chapter was accepted for publication in BMC Health Services Research in 2012:

4.2 Abstract

Background Older adults receive most of their end-of-life care in the community, but there are few published data to guide researchers on recruitment to studies in primary care. The aim of this study was to compare recruitment of patients and bereaved carers from general practices in areas with different research network support, and identify challenges in obtaining samples representative of those in need of end-of-life care.

Methods Comparative analysis of recruitment from general practices to two face-to-face interview studies concerned with 1) carers' perceptions of transitions between settings for decedents aged over 75 years and 2) the experiences of older patients at the end-of-life.

Results 33 (15% of invitees) patients and 118 (25%) carers were interviewed. Carers from disadvantaged areas were under-represented. Recruitment was higher when researchers, rather than research network staff, were in direct contact with general practices. Most practices recruited no more than one carer, despite a seven fold difference in the number of registered patients. The proportion identified as eligible for patient interviews varied by a factor of 38 between practices. Forty-four Primary Care Trusts granted approval to interview carers; two refused. One gave no reason; a second did not believe that general practitioners would be able to identify carers.

Conclusion Obtaining a representative sample of patients or carers in end-of-life research is a resource intensive challenge. Review of the regulatory and organisational barriers to end-of-life researchers in primary care is required. Research support networks provide invaluable assistance, but researchers should ensure that they are alert to the ways in which they may influence study recruitment.

4.3 Background

End-of-life research presents a range of specific challenges. Deteriorating health for patients and strain on carers limit the desire and the ability to participate in research at the end-of-life. The resulting high rates of attrition and low levels of participation in studies have been widely discussed in the literature (Addington-Hall, 2002; Pleschberger et al., 2011). Whilst researchers are sensitive and accepting of these limitations on study accrual, the barriers presented by ethical and organisational reviews are more controversial.

The requirement for research to be approved by a Research Ethics Committee and the organisation where the research will be carried out (National Health Service (NHS) research governance in the United Kingdom (UK)) provides important safeguards for patients. These safeguards are in place to protect potentially vulnerable people from being exploited or distressed by research that is intrusive or inappropriate. In common with many other countries, the UK does not allow direct approaches by researchers to patients (Kirchhoff & Kehl, 2007). Data protection legislation prevents UK NHS organisations from sharing patients' contact details with researchers without the patients' permission. Death registration data may be used to identify informants for studies into end-of-life care but all contact must be made through the Office for National Statistics (ONS). A national survey recommended by the End-of-life Strategy in England and Wales was run by ONS, for the first time in 2011/12, for example. But for most projects, initial contact between end-of-life researcher and potential participant must be indirect, via clinicians responsible for a patient's care or advertisements placed strategically in locations considered visible to the target population (Alexander, 2010; Parkes, 1995; Sque, 2000).

As with all safeguards, it is important that protection should be commensurate with the level of risk (Daly & Rosenfeld, 2003). In the past, researchers have felt that research ethics committees were too restrictive in denying access to patients (Lee & Kristjanson, 2003). In end-of-life care research, the approach preferred by governance and ethical reviews is generally one where the invited participant must opt-in and contact the researcher to signal their interest in taking part. Opt-in approaches compared with opt-out can easily lead to a reduction in the size and representativeness of a sample (Hunt & Shlomo, 2012; Krishnasamy, 2000).

Referrals by health professionals into a study may be selective, and judgement on who is a suitable candidate can vary from one doctor or nurse to another (Ewing et al., 2004; Krishnasamy, 2000; Parkes, 1995; Sque, 2000). Greater participation in research amongst higher socio-economic groups is also well recognised (Harald, Salomaa, Jousilahti, Koshinen, & Vartiainen, 2007).

If end-of-life care research is to be methodologically sound and useful to clinicians (Bennett, Davies, & Higginson, 2010; Harris et al., 2008; Payne & Turner, 2008), it needs to be conducted in relevant, rather than atypical, settings. Extending studies beyond specialist palliative care is crucial for groups such as older adults who are more likely to be cared for by their general practitioner (GP) (Harris et al., 2008; Krishnasamy, 2000). The majority of people who receive specialist palliative care have a cancer diagnosis, though they comprise only one in four of all deaths (Addington-Hall & Hunt, **2012**). Almost every person in the UK is registered with a GP, thus there exists the potential for primary care to offer an ideal sampling frame for end-of-life care studies. Ensuring that a study population is representative of different subgroups of the population allows research to contribute to the development of equitable services. Subgroups of race, ethnicity, culture, gender, age, and disease states within the population are known to experience end-of-life care differently, and these differences remain poorly understood.

Participant accrual is one of the most important issues in end-of-life care research (O'Mara, St Germain, Ferrell, & Bornemann, 2009). There is much discussion of the difficulties in the literature, but few data to guide researchers who are planning end-of-life research in primary care. The practicalities of study planning have tended to be informed by personal experience and advice from colleagues. Estimating how many people a research project may need to approach to attain a certain sample, for example, can be very difficult. Ewing and colleagues sent 1871 letters to yield 36 participants in their primary care study of patients in their last year of life (Ewing et al., 2004). They felt that gatekeeping by health professionals and ethics committees contributed to their smaller than anticipated sample.

There have been a number of changes since much of the published work on the research process was completed. The processes of applying for NHS Research governance in the UK have recently been centralised. UK data protection law has been strengthened and applications for research ethics committee approval

streamlined. In the UK, there has been substantial investment in research infrastructure, with the establishment of research networks in every English region, with staff funded to assist recruitment to approved studies (NIHR, 2012).

The aim of this paper is to report on the processes of recruitment to end-of-life studies with carers and patients in three different health regions of England, and identify any common challenges. We compare recruitment in areas where researchers are in direct contact with GPs with those in which research network staff intervene between researchers and GPs.

4.4 Methods and results

Data in this paper are drawn from two separate studies.

4.4.1 Study one

This study aimed to understand bereaved carers' perspectives on the end-of-life care experiences of their friend or relative. The focus of enquiry was on movements or transitions between places of care in the last year of life. One hundred and eighteen bereaved carers were recruited and interviewed. They had looked after adults aged over 75 years who died with heart failure, stroke, chronic obstructive pulmonary disease, lung, colorectal or breast cancers. Interviews took place between four and nine months after the death of the care recipient.

4.4.2 Study two

Study two aimed to explore the experiences of and preferences for care at the end-of-life, amongst older adults in their last year of life. Participants were identified from lists of patients registered with general practitioners. They were eligible if they were in the study age range (75 years and above), had a cancer diagnosis recorded in their medical notes, and if the responsible health professional judged that the patient was in the last year of life. (To refer a patient to the study, the health professional was required to answer 'no' to the surprise question: 'Would you be surprised if your patient was to die within the next twelve months'?) Interviews were conducted with 33 older adults aged over 69 years and living with advanced cancer. A majority (20) lived alone, the rest had co-resident spouse or children.

4.4.3 Recruitment of bereaved carers

NHS research governance approval was obtained from 44 NHS Primary Care Trusts (PCTs). Two refused: one felt that the recruitment method would not work, the other gave no reason. A resubmission with more detailed argument to the first PCT was also unsuccessful. In 107 out of 118 cases, carers were identified by the general practitioners who had looked after the older adult decedent. Eleven carers were recruited through local publicity, or word of mouth amongst health professionals in the study areas. In all three regions of England, help with identifying general practitioners who were interested in participating, was given by NHS funded research support network. In the two regions in the south of England, the research network staff publicised the study to general practices that had previously identified themselves to the network as being interested and able to participate in research studies. The network staff then put the research team into direct contact with interested GPs. In the third region, network staff publicised the study, liaised with practices, and then visited to search the patient database. They also assisted with sending invitation letters to potential participants.

Figure 4 compares the recruitment process in the two regions where the researcher was in contact with the GP practices, with the region where network staff played a greater role in the study recruitment. Participants could be excluded if the GP felt that the likelihood of causing distress was high, as well for reasons of ill health or cognitive impairment.
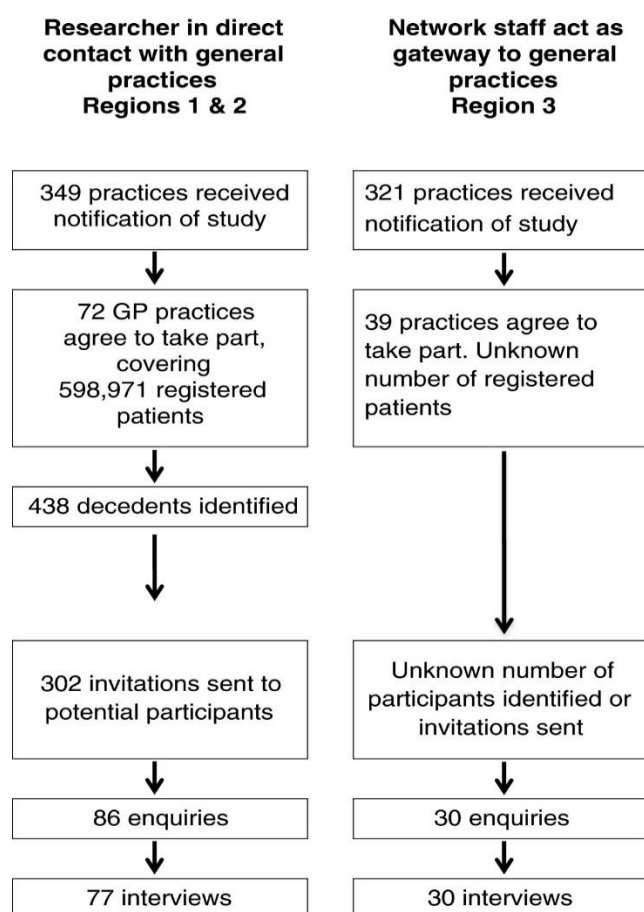
Figure 4 recruitment of bereaved carers by general practices with research network support

4.4.4 Recruitment of bereaved carers by general practices with research network support.

In regions 1 and 2 where detailed data were available on recruitment by GP practice, the number of people interviewed per practice was generally one or none. Three practices identified five or six interviewees. The number of potential participants identified was not related to the number of patients on the GP list. The proportion of people invited who went on to be interviewed, ranged from zero to 100%, with a median of 12.5%, (25th percentile 0%, 50th percentile 12.5%, 75th percentile 33.3%). Table 6 shows the number of carers drawn from areas of different socio-economic disadvantage, according to the Index of Multiple Deprivation. In regions 1 and 2 (Southern England), the sample is disproportionately drawn from less disadvantaged areas. In Region 3 (Northern England) the sample is more evenly distributed across the quintiles.

Table 6 Carer interviewees' area of residence: No. of carers recruited from areas categorised by the Index of Multiple Deprivation

	Number (%) of respondents Region 3 (Northern England)	Number (%) of respondents Regions 1 and 2 (Southern England)	Totals
Quintile 1 (most deprived)	4 (12.5%)	1 (1.2%)	5 (4.4%)
Quintile 2	9 (28.1%)	3 (3.7%)	12 (10.6%)
Quintile 3	8 (25%)	17 (19.8%)	25 (21.2%)
Quintile 4	6 (18.8 %)	30 (34.9%)	36 (30.5%)
Quintile 5 (least deprived)	5 (15.6%)	35 (40.7%)	40 (33.9%)
Totals*	32 (100%)	86 (100%)	118 (100%)

Footnote: Note 107 participants were recruited via general practice, the rest by word of mouth, study publicity or other health professionals.

4.4.5 Recruitment of patients

Twenty one patients were recruited via their GP practices, into an interview study of adults with advanced cancer aged over 75 years and thought to be in the last year of life. (A further twelve patients were recruited from hospice day care, to ensure the study was completed on schedule). In general practice, the number of patients identified as potential interviewees was unrelated to the size of the practice, or the level of socio-economic disadvantage with the Primary Care Trust. Two PCTs were amongst the most disadvantaged in England, whilst the other two contained a greater range of socio-economic experiences (Table 7).

Table 7 Recruitment of older patients with cancer by general practices in different primary care trusts

Area	Number of GP practices	Number of patients invited	Interviews conducted	Proportion of interviews from invitations
PCT 1	3	16	3	18.8%
PCT 2	4	14	3	21.4%
PCT 3	4	47	8	17%
PCT 4	4	62	9	14.5%
Total	15	139	21	15.1%

The PCTs are listed in order of increasing socio-economic disadvantage of the population served.

The number of patients identified and invited to participate by each GP practice are shown in Table 7. (Two practices were unable or preferred not to provide this information for the research team). The number of invitees per 100,000 registered patients ranged from 13 to 500, and was unrelated to the method used by the practice to identify potential participants. Approximately half of the reasons stated for excluding patients were clearly related to ill health (Table 8).

Table 8 Recruitment and reasons for exclusion of patient interviewees by general practice

GP list size*	Identification method	No. of patients identified	No. of patients invited	Invitations per 100,000 patients registered	Reasons for exclusion
3,000	Register of palliative care patients	6	2	66	Cognitive impairment (2) Nursing home residents (2)
3,000	GP knowledge	17	15	500	Cognitive impairment (2)
5,500	Register of palliative care patients	4	4	70	
6,000	Register of palliative care patients	9	9	150	
6,000	Read code search of database	3	3	50	
7,000	Register of palliative care patients	21	11	157	^
7,500	Read code and search of database	5	5	66	
8,000	Read code and search of database	4	4	50	
9,000	Practice 'care board'	2	2	22	
11,000	Register of palliative care patients and GP knowledge	16	9	82	
15,000	GP knowledge	2	2	13	
16,000	Register of palliative care patients	9	7	44	Too unwell (2)
36,000	Register of palliative care database	49	49	136	

*Data on two practices are not available. List sizes have been rounded to the nearest 500 ensure anonymity. Two practices listed in Table 3 did provide detailed information about exclusions. ^ Cognitive impairment (3), Nursing home (1), staying with family (1), emotionally vulnerable (1), near to death (1), does not wish to be invited (1), may live longer than one year (2).

4.5 Discussion

End-of-life care research is sensitive by the nature of the subject matter it seeks to investigate. Researchers working in this area must also consider the role of research networks, research governance authorities and gatekeeping clinicians, when planning studies.

The data in this study provide an insight into the efficiency of recruitment of bereaved carers or older adult patients into interview studies via primary care. The number of interviewees identified per general practice varied widely, and was unrelated to the size of the population from which the interviewees were drawn, or the socio-economic characteristics of the area in which the practice was located. In the areas where research network staff negotiated between researcher and GP practice, fewer interviews were completed and detailed information on the research process was not readily available. Refusal to grant research governance permission was unpredictable, and in this case, removed an area of high socio-economic deprivation from the study.

The variation in the number of potential interviewees identified by different practices was so wide, it suggests that there was significant selection going on at that level. This is not surprising in the case of carers, as we did not expect that GPs would be aware of the identity of the carer for all their deceased patients, or that they would necessarily feel comfortable contacting all of the known carers. The practices varied in size from fewer than two thousand to more than fifteen thousand registered patients, yet the majority managed to find at most, one carer to be interviewed. Similarly, the proportion of patients invited to be interviewed varied by a factor of 38 between practices. The carers were drawn disproportionately from less disadvantaged areas. This may reflect the socio-economic circumstances of the regions involved, but it is possible that GPs selected people who they felt would be better interviewees, because of their education, or availability, or people with whom they had built closer relations during the decedent's last illness. It is also plausible that people in less deprived areas felt more comfortable about responding to the invitation to be interviewed. We have no data to suggest that the social patterning in the group of carers is related to the way in which research network staff were involved in recruitment.

4.5.1 Comparison with other work

Data on recruitment are seldom presented in detail, despite this being a fundamental influence on the potential value of research outputs. The response rate of around 25% for carers was lower than some postal surveys of carers with broader inclusion criteria, and other disease-specific studies (Addington-Hall & McCarthy, 1995; Addington-Hall, Walker, Jones, Karslen, & McCarthy, 1998; Burt et al., 2010; Young, Rogers, Dent, & Addington-Hall, 2009). Ewing and colleagues have previously reported on the barriers presented by professional gatekeeping and NHS governance approvals (Ewing et al., 2004). When they used a similar opt-in approach to recruiting patients, approximately 1% of invited patients were interviewed. Our higher participation rate (15%) seems most likely to be due to patient related factors, rather than the provision of financial rewards to practices, in the form of modest research support costs. Staff understanding of the study inclusion criteria was not perceived to be a barrier to recruitment (Fischer, Burgener, Kavanaugh, Ryan, & Keenan, 2012), though we collected no data to test this assumption.

Low participation rates may be accommodated more readily in qualitative enquiry, when the aim is to extend our understanding of patient and caregiver experiences. However, it would be a serious limitation to any study where obtaining a representative sample was crucial. Qualitative studies with older people near the end-of-life often do not reveal how many people were approached to find their interviewees, and the denominator population is also unknown for studies that recruit via local or national advertising.

4.5.2 Strengths and limitations

Three different researchers were involved in the work reported here, and we cannot be certain that variation in their tenacity or sensitivity to the clinical context did not contribute to differential recruitment rates. The inclusion and exclusion criteria were specific to our studies, and may have made our recruitment of participants particularly challenging. Both the aim of interviewing carers between four and nine months after the death and the requirement for the decedent to have moved between places of care, limited our population of potential interviewees. Nevertheless, our choice of patients and decedents aged over 75 years captures the

majority of deaths in England and Wales, and the conditions specified account for the common causes of predictable death. It is a strength of this analysis that we have information on a large number of participants from qualitative interview studies. And by working across regions, we were able to evaluate the different modes of working with research networks.

4.5.3 Implications

The nature and extent of gatekeeping by health professionals is an important issue for researchers, as data protection or privacy legislation prevent direct approaches to patients. Gaining the trust of referring clinicians is thought to be important for success (Serge, Buckwalter, & Friedemann, 2011), and that may be missing when a research network employee acts as an intermediary between researcher and health professional.

The regulatory framework may leave some GPs with difficult judgements to make. Any desire they have to shield vulnerable older adults from potentially unwanted approaches by researchers, must be reconciled with avoiding paternalism, and a policy rhetoric that promotes empowering patients to make their own choices. In the UK, the combination of organisational reform, increasing workloads and greater involvement of private providers in NHS care present a particularly challenging context for researchers in primary care.

The UK Royal College of General Practitioners is currently encouraging its members to identify the 1% of patients on their lists who are likely to die within the following twelve months, in order to improve their care (RCGP, 2011). Even taking into account the fact that our search was restricted to aged patients with cancer, the number identified was considerably lower than could be expected, if every hundredth registered patient is in the last year of life. Identification of people with a short prognosis is still an important barrier to overcome. Financial compensation for general practices who took part in the research was modest, and did not result in a high number of patients being identified. It is possible that payment per participant would be a more effective incentive, though this is not likely to be judged acceptable for end-of-life studies.

People from lower socio-economic groups or areas are often classified as 'hard to reach.' This study provides some data to support that assertion, as the recruited sample of carers was made up of disproportionately fewer people from poorer areas. Allowing sufficient time for purposive recruitment by socio-economic status may help to overcome this problem, along with raising awareness amongst recruiting health professionals. Without particular attention to social patterning in study recruitment, research has the potential to inadvertently perpetuate inequalities in access to care. NHS authorities play a crucial role in study regulation, and the process by which they allow access to different populations should be transparent and follow nationally agreed criteria.

4.6 Conclusions

In summary, end-of-life research in primary care must often recruit to studies from a denominator population of unknown size, coping with inconsistent application of research governance regulations and gatekeeping by clinicians. In the short term, planning and funding of studies should take this context into account. To resolve these issues and enable investigators to develop robust research, review of the regulatory and organisational barriers to end-of-life researchers in primary care is required.

Chapter Five:
Older Adults' Experiences of Transitions Between Care Settings at the End-of-life in England: A Qualitative Interview Study

5.1 Foreword

This chapter explores the experiences of older people at the end-of-life as they move between places of care. Based on findings from interviews, the prioritisation of institutional processes, and support across settings, feeling listened to by staff and being treated with dignity were the main areas that need to be improved during transitions. Improving basic care and aspects of communication between health care professionals and families are crucial to improving the experiences of transitions. This chapter sets the scene of the chapters to follow. Without a detailed understanding of the experiences of moving between settings, it would be hard to appreciate the complexity faced by older people and carers in navigating this system.

My contribution to this work was to develop study materials, recruitment pathways, recruit and interview all participants, analyse all the data, and write this paper for publication.

This chapter was accepted for publication in the Journal of Pain and Symptom Management in 2012:

Hanratty, B., **Holmes, L.,** Lowson, E., Grande, G., Addington-Hall, J., Payne, S., Seymour, J. (2012). Older Adults Experiences of Transitions between Care Settings at the end-of-life: A Qualitative Interview study. *Journal of Pain and Symptom Management* 44; 74-83. doi:10.1016/j.jpainsymman.2011.08.006

5.2 Abstract

Context: Providing care that is shaped around the needs of patients, carers and families is a challenge in the last months of life, as moves between home and institutions may be frequent. Despite this, there have been few studies of end-of-life transitions in the UK.

Objective: To explore older adults experiences as they move between places of care at the end-of-life.

Methods: In-depth qualitative interviews and thematic analysis of the data. Thirty adults aged between 69 and 93 years took part. All were judged by their physicians to be in the last year of life, diagnosed with heart failure (13), lung cancer (14) and stroke (3). Sixteen participants were from the lowest socio-economic groups.

Results: Four themes were identified from the data relating to 1) the prioritisation of institutional processes, 2) support across settings, 3) being heard and 4) dignity. As they moved between different settings, much of the care received by older adults was characterised by inflexibility and a failure of professional carers to listen. Liaison between and within services was not always effective, and community support after a hospital admission was perceived to be, on occasions, absent, inappropriate or excessive.

Conclusions: Qualitative study of transitions provides valuable insights into end-of-life care, even in countries where there are few financial barriers to services. This study has highlighted a need for continued attention to basic aspects of care and communication between professionals and with patients.

5.3 Introduction

As life expectancy has increased, the end-of-life is increasingly associated with comorbid conditions, frailty, and smaller family units to provide support (Lynn, 2005; Seale, 2000). For many people, the last few months of life see most intensive contact with health and social services (Forma et al., 2009; Pot et al., 2009). Evidence from the USA indicates that transfers between care settings are frequent at this time, but may produce little improvement in symptom control or improved

quality of life for patients (Trask et al., 2006; Van den Block et al., 2007). Yet, each transfer represents a potential threat to continuity and safety of care (Coleman, 2003b). The availability of information on past events, knowledge of the individual personal and social context, and a consistent approach to management, are all important aspects of continuity of care that may be lost when someone is admitted to or discharged from institutional care (Kind et al., 2007). An older adult with complex health care needs is likely to be particularly sensitive to the consequences of inadvertent alterations to their care - failing to maintain existing medication regimes, or perform follow-up blood tests, for example (Kripalani et al., 2007). Welfare systems that do not present significant financial barriers to services, should be well placed to maintain good quality, appropriate care as patients move between home, hospital, hospice or care home. The provision of a "seamless service", one shaped around the needs of patients, carers and families is a core principal of the National Health Service in England, (Department of Health, 2010b) reiterated by successive governments. But, despite efforts in research and practice over decades, continuity of care is not clearly defined and our understanding is incomplete regarding how to evaluate and improve these aspects of service delivery, so that the patient receives coherent, consistent care (Parker, Corden, & Heaton, 2009). Extensive research has been conducted into older people's experiences of transitions in the USA. The relative neglect of this issue in the UK may reflect an assumption that a universal health system will overcome most problems posed by transitions between different settings. Tools do exist to measure many different aspects of patients experiences, such as waiting times and communication with staff, (Garratt et al., 2007; Magee et al., 2008; Martin, 2009). A well-validated questionnaire is available for use with family carers, to gather retrospective data on end-of-life care in a full range of settings (Burt et al., 2010). All of these are useful measures for service evaluation, but they fail to capture the patients' overall perspectives of their journey through the care system. This study employed qualitative methods to explore patients' experiences, forming the first part of a three-phase study funded by the UK National Institute for Health Service Delivery and Organisation Programme to look at transitions in care in England. In-depth interviews with older people with lung cancer, heart failure or stroke were conducted. These conditions have different disease trajectories, are common causes of death, and present a high burden of symptoms to patients and the health system. Together, they are likely to present a broad range of different needs and

challenges to welfare services. The aim is to explore the experiences of moving between care settings for older adults in their last year of life.

5.4 Methods

This study took place in northern England in 2009-10. It forms part of a larger project on transitions in health care settings at the end-of-life for people with stroke, heart failure and lung cancer. The study was reviewed and approved by Sefton National Health Service Research Ethics Committee (Study number 09/H1001/51).

5.4.1 Procedures

We looked for a purposive sample of people aged over 75 years, who had moved between at least two care settings in the previous three months, were aware that they had been diagnosed with heart failure, lung cancer or stroke, and were thought to be in their last year of life. Participants were identified by medical consultants and specialist nurse teams, if the responsible clinician was able to answer "no" to the question, "would you be surprised if this patient were to die within the next twelve months?" Four patients below the specified lower age limit were included in the study, as they had been invited to participate by responsible clinicians. To ensure that experiences from a range of care settings were represented in our data, we also interviewed patients identified from hospices (three) and rehabilitation facilities (three). The socio-demographic composition of the sample was monitored, to ensure that people from disadvantaged areas participated, but no intervention was needed. The last reported occupation was used to allocate the participant to one of the five categories within the National Statistics Socio-economic classification. Participants were approached by their nurse or doctor with an invitation letter, and those that agreed to be contacted by the researchers, received a phone call to explain the study and if appropriate, further written information. All the interviews were conducted by one researcher, a trainee health psychologist (LR), experienced in qualitative research interviewing. They took place in a location chosen by the participants. In all cases, this was their current residence; home for 26 participants, care home for two participants, one in hospice and one in an intermediate care facility. The interviews were recorded with permission and transcribed verbatim by a professional transcriber. Informed written consent was obtained from all participants immediately prior to the start

of the interview. The participants were offered an opportunity to terminate the interview after one hour or at any time if they were tired. The average duration of interview was 90 minutes. The interviews were semi-structured. A broad topic guide was developed by the research team to guide the interviewer, covering the participants' social context and relevant life history, their understanding of their illness, the nature of any transitions they had experienced, how they understood and interpreted their experiences of transitions. The interviewer had a comprehensive list of prompts under each topic, to ensure consistency between interviews. I asked participants to talk about their experiences, good and bad, of health and social care as they moved between care settings in the last six months. I sought perceptions of the quality of care in each setting in addition to the experience of moving between places and the care received immediately following a transfer. The questions were phrased to encourage the interviewees to express themselves freely and raise issues of importance to them. For example, a typical question would be "Could you tell me something about the care you received in hospital and the people who looked after you there?" Follow-up probing questions were asked, to explore issues of interest in more depth.

5.4.2 Analysis

The data were analysed using the principles of Framework, a modified form of thematic analysis that is designed to provide a systematic and transparent approach to data management and analysis (Ritchie et al., 2003). First the transcripts were read and re-read by two researchers. Line by line coding of each transcript was completed by hand. These codes were used to generate a coding index of initial categories, which were then grouped into initial themes. Data were assigned to the themes and categories in the coding index, using an Excel spreadsheet to manage the data. Each major theme was allocated to a chart, with a row for every case, and a category in each column. This format allows easy access to summarised data from the transcripts and great flexibility to move between case based and thematic analyses. The initial themes and categories were refined, to ensure that they summarised and synthesised the breadth and diversity of the coded data, and associations between themes sought. To develop explanatory accounts, the summarised data were examined repeatedly to find patterns across the themes and cases, and reflect on the meaning and explanation of the data. References were made back to the original transcripts and field notes at this stage to ensure that the participants' accounts were represented accurately and to allow

the researchers to reflect on their interpretation. To ensure the rigor of the analysis, five of the transcripts were coded by two researchers, and a third researcher coded a further two transcripts. The emerging categories and themes were refined in discussion with the study team, who had all read a sample of original transcripts. The detailed coding index was applied to data from three interviews by two researchers independently and minor discrepancies in approach resolved by discussion. As all the participants were thought to be in their last year of life, no respondent validation was planned. However, the findings and their interpretation were discussed with an external group of research partners. This group consisted of people who had been caregivers to older people themselves and were interested in advising on research design and conduct, to ensure that it is relevant and sensitive to patients' needs. In this paper, we focus in particular on findings that reflect participants' experiences of moving between care settings.

5.5 Findings

Thirty people agreed to be interviewed; they were aged between 69 and 93 years, diagnosed with lung cancer (thirteen), heart failure (fourteen) or stroke (three). More than half were living in disadvantaged areas of north-west England (Spearhead administrative areas, in the bottom fifth nationally for life expectancy, premature mortality or deprivation). Collectively, the interviewees had moved 67 times between care settings in the three months before being interviewed. Four main themes emerged from the data, relating to 1) the prioritisation of institutional processes, 2) support across settings, 3) being heard and 4) dignity. Implicit criticism of the overall experience was a cross cutting theme. In a number of the accounts this co-existed with descriptions of care from individual health professionals that was noted to be good or exceptional, but in no cases was the responsibility for perceived deficiencies in the system attributed to specific professional carers.

Table 9 Socio-demographic characteristics of study participants

Participant Characteristics	Condition		
	Heart Failure	**Lung Cancer**	**Stroke**
Age in years, median (range)	77 (69-88)	80 (73-89)	85 (81-93)
Sex			
Males	9	3	2
Females	4	11	1
Social classification			
1 and 2	6	4	3
3	1	0	0
4 and 5	6	10	0
Living circumstances	3	5	1
Home, alone	9	7	1
Home, with others	1	2	1
Institution			
No of people reporting adverse events related to HandSC	10	10	1
Total number	13	14	3

5.5.1 Prioritisation of institutional processes

Many of the interviews conveyed a sense that the care system was imposing processes on patients with limited recognition of, or flexibility to the individuals' needs or wishes. The problems ranged from administrative procedures such as outpatient appointments to the provision of aids and appliances. In some situations, the imposition of rules intruded directly into life at home. One 80 year old female participant with lung cancer described how a bed was installed in a downstairs room of her house against her wishes whilst she was in hospital. She was later deposited onto the bed when taken home from hospital, unable to get off.

> "..They told me I could come home when they brought a bed in, and I said I don't want a bed downstairs, because there isn't room. Anyway they sent people out while I was in hospital and [my husband] showed them round. And a particular person came and said that it could be done, so eventually they brought this bed, and it was a very expensive one and it had a mattress on it which went up and down it was regulated, went up and down. Anyway when I did come home, the nurses came, they lifted me onto this bed ….. So

and they said they would put me on the bed, and they had to leave me, they couldn't take me off.... that was the law, I suppose or something. They just said they had done what they were told to do, and so I would just have to stay, so that was it. Anyway [my husband] got me off" Participant 26, Female age 80, lung cancer.

The same interviewee described how they had to ask for fewer social services carers to visit, as they, too, intruded on her day-to-day routine. Another interviewee of similar age had taken to sleeping downstairs because the ambulance staff had warned her that their insurance cover would prevent them from helping her downstairs.

"..But I haven't to go upstairs, because the ambulance men can't get me out, and I have to sleep downstairs and I have done. And apparently they are not insured to handle me unless there is two, because I can just go out on them like that. There seems to be this insurance that the carers have to abide by, and they do." Participant 27, Female age 81, lung cancer.

Adherence to procedure is important for patient safety and the efficient running of a large organisation, but it may also leave staff unable to respond flexibly to an individual's needs or wishes. These issues emerged in discussion of the organisation of visits to hospital following hospital discharge. Appointments could be too early for people who waited for carers to arrive to help them get up and dressed in the morning. Bus travel was inflexible in its routes, ambulance transport was slow and meant travelling alone. Without a family member, patients who needed help with mobility, such as this 69 year old participant, felt stranded within the hospital.

"Yes getting in and out the taxis for me [is harder now] yes. See you could go by ambulance and that, but they might not take [my daughter] in with me, and I have to have her to push me round to my appointments and that. So, there is another, I forget the name of it, it's a bus and they do take the carers with them but they don't take you to the hospital. So, you can't win can you. ..." Participant 3, Female age 69, heart failure.

Reliance on working family members for transport was common, and time spent waiting and time taken off work was a source of annoyance and guilt.

"it was a long, long, long wait, you know we were there an hour and a half, of course my daughter was taking time off work to take me there you see, and when I got in there, the doctor asked me what was wrong with me and I said there is nothing wrong with me you know, I am in good shape. And he said well what are you doing here, I said you sent for me, I showed him the letter you know to prove it, [I was] annoyed. Apart from myself, my daughter had took time off work you know, which I mean she has got an important job herself, she is with the health service" Participant 6, Male age 73, heart failure

5.5.2 Support across settings

Some of the accounts suggested that the older adults felt that they were sent out of hospital without adequate time to prepare themselves, insufficient community support in place and little knowledge of how to access the services they required. The account below implies a lack of participation in the discharge planning process.

"They kept telling me I was going home and I was alright, I was going home. My legs hadn't been seen to, the infections hadn't gone, the swellings hadn't gone down, but they were quite willing to send me home, and then they decided to keep me in, and that happened to me four times in hospital and in the end, it came that.... they sent me home I had no medication to come home with, just I had just got my old insulin but they gave me no instructions, no knowledge, nothing and the sister was on the phone when I left, and she never bothered she just waved like that when I went out" Participant 26, Female age 80, lung cancer.

This participant was able to advocate successfully for his own care, but noted an apparent failure in communication between hospital and community.

"They told me in the hospital before I left that the district nurses would be in touch, and the occupational therapist. Now I was home for a week, now I had to phone up the district nurses and ask them when they were coming out to treat my legs. They said we didn't know you were out of hospital. We haven't had a referral. ...Now ever since then I have been fighting for my own benefit. No one has been, ….I have had to get it all for myself, try and get it for myself…" Participant 13, Male age 75, heart failure.

Many of the problems appeared to be minor, but the consequences for the elderly and unwell could be considerable. For example, one man was housebound for weeks by his inability to either put shoes on his swollen feet, or find the appropriate help with footwear. Sometimes, it was unclear whether the problem lay with interdisciplinary communication, or if the 'system' was used by professionals as an excuse to cover inability or unwillingness to act. A female participant described a social worker explaining that she could not refer to another authority, causing delay in obtaining home adaptations.

> *".. The social worker came to see me, and she said I can't recommend you to [your local area] social services because they won't take any notice to me, she said. ..we decided that the only thing I would need when I come out was a grab bar, whatever they call them for the shower really she said if you had been in [your local hospital] they would have recommended you but they won't take my recommendation because they are under different authorities aren't they, you know. So she tried, she tried her best to get them and doesn't do anything, and then my son started trying to get them and they said we will, oh we will have an appointment for her, make an appointment to come out and see your mother. And it was for 6 weeks hence, to come out and see me and assess if I needed anything.. - And then they didn't know when it would get done."* Participant 25, Female age 78, lung cancer

5.5.3 Being heard

A good understanding of the purpose of any move into or out of an institution, and the associated practical arrangements may help to minimise any distress associated with the transition. There were many examples of communication between health professionals and patients that was effective and well received by patients. The oncologists and specialist nurses were mentioned more often in this context than their colleagues in primary care. Sensitive discussion of prognosis and treatment options was recounted by most of the interviewees with lung cancer, for example. However, the feeling that, at times, no one was listening to patients or families, emerged as a theme from patients with all three conditions. This was particularly apparent when they had just moved into or out of hospital. For some, a perception that no one has time to talk created a potential barrier to understanding their condition and prognosis, as well as the rationale behind therapies. One elderly woman had not understood why she needed to be in hospital to receive only

tablets, for example. Others described the difficulty they felt as inpatients asking for information about their condition. Not being heard also created a barrier to basic care in hospital and for this participant, a care home:

> "...*They get very nasty when they come up here - we have got more to do than this, you know, there is other patients... they weren't very pleased no...If it causes embarrassment they shouldn't do it you know, I can't help wanting to go to the loo all the time. I think somebody has been treating me for a bladder complaint and I want to go all the time, yes*." Participant 11, Female age 84, heart failure

Family carers shared a sense of not being heard, either when advocating for their relative's care to be modified, or when discussing their own stresses involved in the responsibility of delivering care.

> "*And then the doctor decided to swap and change her drugs, with some advice from the pain consultants. And then they do it and then they are away for the weekend and they are not around to see consequences and what effect it has on her. So we sort of begged, because we could see a deterioration in my Mom, we begged them to swap them back to the drugs that she should be on. And they did after a load of arguing and getting the bed manager and everybody down, and then on the Monday the same doctor came back and changed the drugs back to the same drugs again. And then she went off again, and there was no communication between the… I think the problem is communication definitely*." Participant 23, Daughter of female age 82, lung cancer.

In addition, there were multiple accounts of literally not being heard, and the associated struggle to obtain help with toileting or other essential aspects of life in hospital.

5.5.4 Dignity

Clear examples of mistakes associated with transitions were rare in our study. Possible errors with medications were described by only two of our participants when they were leaving hospital. A third interviewee was concerned that medication dispensed from a hospital pharmacy may not have been for her, as the tablets were dissimilar to medications that she had at home. But as older adults were placed into new and unfamiliar situations, they described care that may have

lacked dignity. Loss of false teeth or being left unattended until early morning after an evening admission were not likely to have compromised patients health status. Similarly, being sent for an X-ray in a revealing gown, or having a nurse discuss personal details in front of crowded waiting room were sources of distress rather than concern over the quality of medical care.

5.6 Discussion

One of the most stringent tests of any welfare system, is how well it works for some of the most vulnerable patients. Our interviewees were aged, coping with life limiting conditions and in many cases, on low incomes. Their accounts appear to support the assertion in UK policy documents that convenience for the system sometimes takes precedence over convenience for the patients. Although the collective account suggests problems in different parts of the care system and how they link together, individual health professionals were singled out for praise by our interviewees and not held accountable for overall experience provided. Whether this reflects loyalties to familiar professional carers or the difficulty of identifying weak points in complex systems, it is in keeping with longstanding support for the English NHS amongst older adults in particular. Existing research has built a quantitative picture of frequent transitions between settings for older people. Medicare recipients have been shown to have high rates of readmission to hospital and multiple transfers after discharge, for example (Coleman et al., 2004; Jencks et al., 2009). The few studies that have focused on the time before death, notably in Belgium and the Netherlands, found that a majority of people were transferred at least once in the last three months of life (Pot et al., 2009; Van den Block et al., 2007). However, a mortality follow back study with relatives of cancer decedents in 22 US states suggested that such transitions were not associated with reduced levels of distressing pain for many people (Trask et al., 2006). Our qualitative analysis provides complementary data on patient experiences that could inform the way in which care is delivered. Reports of deficiencies in elderly care are not novel. The importance of our findings is in our focus on transitions between services at the end-of-life. This is a time when health and well-being may be at their lowest, and outcomes are sensitive to how well the components of the systems work together. As the older adults in this study moved between home and different institutions, they sometimes felt unsupported, unheard and treated with

insufficient dignity. Our participants were not selected with any prior knowledge of their experiences, but their accounts were similar to those reported by UK lobbying groups such as the Patients Association (The Patients Association, 2009). Our findings also overlap with failures in the care of older patients after surgery that were reported in the National Confidential Enquiry into Patient Outcome and Death, (Wilkinson, Martin, Gough, & Stewart, 2010) and a report by the Health Service Ombudsman into NHS care of Older People (The Health Service Commissioner for England, 2011). The standards of care in NHS hospitals are monitored by an independent regulator, the Care Quality Commission. Their large-scale annual surveys report that NHS care is well received, and improving, but some of the persisting problems are similar to those described by our interviewees. A high proportion of patients in their surveys lacked information on their medications, for example, and one in five needed more help with basic care such as eating whilst in hospital (Commission, 2010). Older people make up a high proportion of service users, so the similarities between the experiences of our interviewees and a range of reports appears to suggest that sub-optimal care may be the norm at older ages. The way in which the health system is structured may support and sustain poor care for older people, rather than our findings are supported by research on experiences of health care from differing perspectives. Research into end-of-life care stretching back over decades has highlighted many of the issues raised by this study, such as the provision of information, and care with dignity (Addington-Hall, Lay, Altmann, & McCarthy, 1995; Addington-Hall & McCarthy, 1995). Communication between patients and professionals and coordination across services certainly appeared to underpin some of the deficiencies in care for our interviewees. These are all characteristics of the emergency care system that are known to be important to patients of all ages (O'Cathain, Coleman, & Nicholl, 2008). Along with relationships with professionals, personal agency, and the sense of being treated as a whole person, communication and coordination have also been identified by patients with cancer, stroke, diabetes and mental health problems as important contributors to continuous care (Parker et al., 2009). Illness trajectories, individual characteristics and social circumstances are known to influence patients' experiences, particularly in relation to continuity of care, (Parker et al., 2009) but expectations of services are also crucial. In this study, patients' dissatisfaction with the system implies that they anticipated that the different services would work together as a coherent whole, providing the right

amount of care, without too many social carers or inappropriate appliances. This may be peculiar to comprehensive systems, such as the NHS, where most services are free at the point of delivery. Patients who purchase their own health insurance coverage may have different expectations of how their end-of-life care would be delivered.

5.6.1 Limitations

Our participants were identified by a range of health professionals, so some variation in the application of selection criteria is possible. A disproportionate number of interviewees, particularly those with lung cancer, were from disadvantaged areas. This may explain some of the difficulties described in negotiating the system, but as experiences of health and social services should not vary with the social background of the care recipients, this is also a strength of our design. There were differences in the patterns of transitions between care settings by diagnosis. People with lung cancer had fewer inpatient episodes, compared to those with heart failure or stroke. They also had more contact with hospital consultants than people with heart failure, in particular. We had anticipated that the different disease trajectories would be associated with varying needs for community and hospital or hospice care. In spite of this, the themes that emerged were common to all conditions and showed little or no variation with socio-economic status. This gives us confidence that our data have relevance beyond the older adults we interviewed.

5.6.2 Implications

The future vision for the UK NHS is of a service that is genuinely centred on patients and carers, achieving quality and outcomes that are amongst the best in the world (Department of Health, 2008b). Dignity and respect are fundamental components of such high quality care (Centre for Public Scrutiny, 2009; Magee et al., 2008). Considerable time, effort and funding has been directed at improving both the organisation and delivery of end-of-life care. An End-of-life Care Strategy has been implemented in England and Wales, and in family practice, financial incentives are offered for identifying patients at the end of their lives and holding multidisciplinary meetings (Department of Health, 2010a). Yet, if the experiences of individuals in this study are shared by others, major differences between theory and practice remain. The study of transitions between care settings provided a focus on particularly vulnerable points in the delivery of end-of-life care. The deficiencies

identified in the experience of health and social services were in basic care; assessment and meeting of needs, good communication and a sense of dignity and respect during interactions with care professionals. All our participants were aged, and whilst health professionals play an important role in delivering care, the possibility that the health system is structured in such a way to support the delivery of poor care to older people, is worthy of future attention. A proposed transfer of responsibility for commissioning services to family doctors in England, offers an opportunity for issues such as closer working with social care and transfer of information between hospital and community health services, to be given renewed emphasis. But as health systems in many countries look to increased competition between service providers and initiatives such as personal budgets, to reduce expenditure and widen choice, our findings imply that end-of-life care could have been improved for our participants with some very simple changes in practice, such as providing care with dignity, respect and communication.

Chapter Six:
From 'Conductor' to 'Second Fiddle' – Patients perspectives on transitions in family caring at hospital admission

6.1 Foreword

This chapter explores the experiences of carers navigating services during end-of-life care, from the perspective of the older people who are receiving care. This builds on the data presented in chapter five, which explored the experiences of transitions from the perspective of the person receiving care. In 12 of the 27 interviews a family carers was also present and made contributions.

Older people had much to say about how they felt the carer was instrumental to facilitating the co-ordination of care and influencing and guiding decision making, advocating on the patient's behalf. After a transition to a formal care setting, family carers became a 'second fiddle' with their influence vastly reduced. A greater appreciation of the contribution of carers by health professionals may contribute to improving the quality of care for older people.

This chapter highlights the important role carers play in the quality of care provided from the perspective of the older person. It also explores the difficult changes in role and challenges faced by carers during this stressful life event. It provides evidence as to why the carers need to adapt in this challenging environment and the lack of support carers have from the health and social care system.

My contribution was in developing study materials, recruitment pathways, the recruitment and interviewing of all participants, preliminary analysis of all the data, and contribute to drafting this paper for publication.

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6.2 Abstract

Background: Family carers provide strong support for many older adults, often enabling older adults to remain at home. Little is known about the care recipients' perspectives of the role and contributions of family carers, particularly when hospital admissions occur as part of end-of-life care.

Aim: This paper explores the meanings of family caring for care recipients by drawing on older adults' perspectives about the impact of hospital admission on established family caring relationships.

Design: Exploratory semi-structured qualitative interviews. Key findings reported in this paper emerged from within the inductive research design.

Setting: Interviews were conducted in older adults' place of residence in northwest England between June 2009 and July 2010.

Participants: Participants were 27 older adults living with heart failure (n=13) or lung cancer (n=14), aged 69-89 years (mean 79 years ± 4.3 years) and considered by their health professionals to be in their last year of life. In 12 of the interviews, a family carer was also present and made contributions.

Findings: For community-dwelling older adults, family carers are conceptualised as 'conductors'; making strong contributions to maintaining the rhythm of good care throughout the illness trajectory. Following older adults' hospital admission, family carers find themselves in the role of 'second fiddle', their ability to work with the individual and to make or influence decisions vastly reduced. Despite this, carers continue to invest considerable effort in maintaining continuity in the carer relationship to maximise the individual's well-being by identifying needs, filling gaps in provision and advocating on patients' behalf. Family carers act flexibly to provide continuity, support and take responsibility for older adults' well-being across settings.

Conclusions: Nurses and family carers working together, and greater appreciation of the contribution and role of family carers by health professionals may contribute to improving the quality and continuity of care for older adults.

Key words: end-of-life; hospitalisation; older people; patient perspectives; palliative care; qualitative

What is known about this topic

- Many older adults rely on the support and care of family and friends

- Admissions to hospital are common for older adults in the last year of life

- The care provided for older adults in hospital may not meet their needs

What this paper adds

- Family support, care and coordination of care provides important continuity when older adults move between care settings

- Providing this continuity of care for older adults requires considerable flexibility from family and friends

- Nursing staff working in partnership with family carers could enhance older adults' well-being and the quality of care during hospital stays

6.3 Background

Across the world, more people are living into old age. Globally, 650 million people are aged 60 years or older, and this figure is forecast to reach 2 billion by 2050 (WHO, 2011). In developed countries where life expectancy is highest, the great majority of people will die in old age. Although some deaths are unexpected, many older adults experience chronic health problems as they reach the end-of-life, with increased use of health services, including acute care (Barclay & Maher, 2010). Little is known about how transitions to acute settings affect caring relationships between older people and those providing family care. This lack of understanding matters, because family carers are known to play a key role in supporting older people with long-term conditions and enabling them to stay at home as the end-of-life approaches (Bridges, Flatley, & Meyer, 2010; Gomes & Higginson, 2006).

Increasing and complex health needs may necessitate transitions between different places of care during the final months of life, including hospital admissions (Busse, Krauth, & Schwartz, 2002). Yet such transitions may not reduce the burden of symptoms (Trask et al., 2006), may cause distress and may increase costs (Parker et al., 2000; Whynes, 1997). Inappropriate admissions to institutions may also have consequences in bereavement for relatives, including increased morbidity, mortality, and use of health services (Burton, Haley, & Small, 2006; Christakis & Iwashyna, 2003; Hart, Hole, Lawlor, Davey Smith, & Lever, 2007).

There is a substantial literature concerning relatives and close friends performing family caring roles. Much of it focuses on carers' assistance with household tasks and personal care and work to support and manage the emotions and mood of the care recipient (James, 1989). Recently, the relationships between family carers, health professionals and care recipients have received greater attention, including recognition of family carers' expertise relating to the illness experience, and the needs and preferences of the person in their care (Nolan, Keady, Grant, & Lundh, 2003). In palliative care, health professionals aim to listen to the needs and concerns of both patients and their families in planning care provision, and to provide support to families alongside patients' needs. Gaps often exist between these aims in family support and provision in practice (Burton et al., 2006). Existing and potentially complex family relations, limited time and resources add to the challenge of professional support to patient and caregivers at the end-of-life.

Despite the breadth and depth of research into family caregiving, care recipients' accounts of these relationships are rarely heard. Much of the influential research into end-of-life care has involved carers providing a proxy voice for people who have died (Boyd et al., 2009), or are too unwell to be interviewed. Many older people at the end-of-life may be dependent on family care for their well-being. Their accounts of how this care is delivered and its meaning for them will yield valuable insights into the overall experience of end-of-life care for older people, including how relationships between family carers and health professionals are expressed.

This paper therefore aims to explore care recipients' experiences and understandings of family caregiving during transitions between home and hospital at the end-of-life. Qualitative interview data are drawn upon to consider what characterises family care at transitions between home and hospital for older adults, how these roles are influenced by transitions and adapted, and similarities and differences in roles at home and in hospital.

6.4 Methods

This inductive study involved semi-structured qualitative interviews, designed to explore older adults' experiences as care recipients both in the community and as hospital in-patients, and to understand the meaning of family caring relationships

for older adults in both settings. The importance of family carers' roles within older adults' accounts emerged strongly within our data analysis.

The inclusion criteria were older adults aged 75 years or older living with heart failure or lung cancer, who had experienced one or more transitions between care settings in the last 6 months, and whose death in the next 12 months would be unsurprising to their specialist health professionals. This 'surprise' question is often used to identify people who may be near the end-of-life (Boyd et al., 2009; Murray, 2008), particularly where specific and accurate prognoses are difficult, as with individuals living with heart failure (Green, Gardiner, Gott, & Ingleton, 2010). Individuals living with heart failure or lung cancer were included to enable consideration of family caring in the context of contrasting disease trajectories: people with lung cancer usually experience gradual and progressive physical decline with obvious signs that the end-of-life is near, whereas for people with heart failure, physical health is usually more variable in a context of general decline, and death is often unexpected (Murray, Kendall, Boyd, & Sheikh, 2005). Initial sampling aims were 10 patients with each condition for this exploratory study: this was exceeded and data saturation reached. Exclusion criteria were individuals unable to participate in an English language interview or who were too unwell to participate. Participants were recruited through an oncology consultant, specialist heart failure nurses and hospice nurses in northwest England. Health professionals introduced the study by telephone or in person and then passed on details of interested individuals to the research team. Thirteen individuals with heart failure expressed interest and all participated. Thirty-five individuals with lung cancer expressed interest and fourteen participated: one person died before the arranged interview date and a further twenty people did not participate because they did not feel well enough or their family carer stated that they would not be participating.

Interviews were conducted between 2009 and 2010 in the older adult's residence. Each interview lasted between 10-90 minutes (mean duration 59.3 ± 21.1 minutes), with breaks taken at the participant's request or if they became tired or distressed. The interview was semi-structured, following a topic guide which included details about the older adult's background, family circumstances, employment and previous health and caring experiences, experiences of receiving family care and professional health care in the community and in a variety of health and care settings including hospices, hospitals, rehabilitation facilities, care homes and

nursing homes, and feelings about the impact of transferring between settings. Other aspects of findings from the Transitions at the end-of-life study have been reported elsewhere (Hanratty, Holmes, et al., 2012b; Hanratty, Lowson, Holmes, Grande, Addington-Hall, et al., 2012; Hanratty, Lowson, Holmes, Grande, Jacoby, et al., 2012). In almost half of the interviews (n=12), a family member or close friend was present and made a contribution to the interview, demonstrating through contributions and interaction how carers support older people and contribute to their illness trajectory. Contributing carers included spouses (4 wives, 2 husbands), relatives (2 daughters, 1 sister) and friends (2 female neighbours and 1 male friend). Carers, care recipients and the interviewer all agreed to this.

6.4.1 Ethical and research governance considerations

NHS research ethics and governance approvals were obtained from an NHS Research Ethics Committee and the appropriate NHS Trusts. Written informed consent was obtained from participants and interviews were conducted by an interviewer experienced in working with older people, and sensitive to participants' needs. Retrospective consent was obtained from carers to publish quotes from their contributions to the interviews. Each interview was audio-taped with the participant's agreement, and transcribed in full.

6.4.2 Data analysis

Initial analysis drew on the framework approach (Ritchie et al 2003). Reading and re-reading of transcripts by two researchers (Authors 2 and 3) was used to develop a systematic coded framework covering key areas of participants' illness experience, and data extracts were coded according to the framework and entered into appropriate cells within an Excel spreadsheet. This initial analysis identified the importance of family carers' contributions within patients' experiences of their illness trajectories. A third researcher (Author 1) conducted further thematic analysis concerning family caregiving. All three researchers discussed concepts from the thematic analysis and contributed to the emerging conceptual schema, reaching agreement. The three researchers have different disciplinary backgrounds (medicine and public health; psychology; and sociology and social policy); and different relationships with the data (study design, interviewer and initial data analysis, data analyst). This involvement of three different researchers enables increased confidence in the analysis process and data interpretation as agreement was reached.

6.4.3 Participants

Thirteen participants had a heart failure diagnosis (4 female, 9 male) and 14 had a lung cancer diagnosis (10 female, 4 male). Heart failure patients were aged 69 to 88 years (mean 78.1 ± 5.0 years) and lung cancer patients were aged 73 to 89 years (mean 79.9 ± 3.5 years). Three heart failure patients and one lung cancer patient were included who were younger than the inclusion criteria of 75 years because they had been invited to the study by a health professional. Interviews were conducted in participants' homes (9 lived alone; 9 lived with spouses only; 2 with spouses and adult children; 3 with adult children only) with a small number of interviews taking place in a hospice (1), rehabilitation centre (1) or care home (2) where the participant was resident.

6.5 Findings

6.5.1 Roles of family carers

Care recipients consider as very important the support and continuity provided by family carers who know them and their needs well. Two clear roles of family carers emerge from care recipients' accounts. The orchestral metaphors of 'conductor' and 'second fiddle' are drawn upon to structure and illuminate discussion of care recipients' perspectives on family caring and interaction with formal care providers. At home, as 'conductor', family carers take responsibility for coordination of all the care received by the older person and for their well-being. In contrast, when care recipients are admitted to another care setting, the family carers become 'second fiddle' to the paid staff but maintain the carer relationship within constraints imposed by the setting.

'Conductor'

Within this analysis, family carers are conceptualised as 'conductors' responsible for maintaining the 'rhythm' necessary for the older person's well-being. While they also carry out household and personal tasks, the essence of the conductor role is supporting and managing relationships between the older person and everyone providing care. Conductors are defined by their regular presence, emotional support of the older person, identification of emerging needs, and flexibility in coordinating care, liaising and advocating with other family and formal carers.

The importance of conductors' strong role in ensuring and maintaining the well-being of older people at the end-of-life is very clear throughout all the accounts of older people participating in this study, regardless of their socio-economic circumstances and the stage of their illness trajectory, and whether they have heart failure or lung cancer.

For most of the older adults, the family carer in the 'conductor' role is their spouse, adult daughter or neighbour. They are either always available through co-residence, or use frequent visits and regular phone calls to fulfil this role alongside other substantial commitments such as paid employment and responsibility for children. This regular contact, support, assessment of needs and flexibility in being available as required rather than according to a fixed schedule is key to the conductor role.

Care recipients express gratitude for being able to rely on 'conductors' to take responsibility for supporting them and coordinating their care. The extent and strength of this feeling is demonstrated by patients' descriptions:

"*our rock*"

(Heart failure patient, male, 81 years, and wife describing daughter)

"*She [neighbour] is the standby, she is the rod in my back*"

(Participant 20, Female aged 89, lung cancer)

These epithets are derived from the regular help and support which is offered and provided, and also the implicit understanding of the carer's commitment to helping the care recipient to meet any emerging and future needs, and taking responsibility for the care recipient's well-being.

A central strength of this family caregiving role is the continuity and long term nature of the relationship. The carer knows the individual very well, understands their personality and appreciates how they feel about being a care recipient. Carers can carry out emotional work appropriately to manage this. In being supportively present through community and outpatient health service provision, they have a clear overview of the older person's needs and preferences, and the progression of their illness trajectory. They are, in most cases, 'expert carers' (Nolan et al., 2003). This enables carers to identify needs, work with the older person to find an

acceptable solution, and then delegate the solution to timely formal care, or provide this care themselves. In many cases, family carers are in a position of coordinating responsibility for all of their care except that directly provided by health professionals. This can involve substituting care that the health service is unable to provide, or fails to provide in a timely manner:

"[A long wait for help installing aids at home] *That didn't go down very well with my son… I have got copies of letters here that he has sent them… he looked up, all that they promise on the internet, and he said you promise to have things that are necessary within a couple of hours, and it's 6 weeks before you can get an appointment… very sore point that… The day after I come home, my niece's husband, … who does a lot of work for me, … he said 'Oh I will go and get them', and he lives in [another town] and he works on shifts too and he went to work in the morning and he went to the shop who does this things and got the bar, the grip, whatever they call them, and it was £8 and within a quarter of an hour it was in place. Which … really made things worse to me, I thought well all that bloody messing round for £8, and a quarter hour.*

(Participant 25, Female aged 78, lung cancer)

Just as conductors encourage older adults to accept regular care and support according to their needs, care recipients' accounts illustrate how family carers work with older adults to identify and legitimise health problems and encourage them to seek help, or actively seek medical assistance on their behalf:

"*...I had to go to bed, I had this terrible, what I thought was a chest infection and I said 'Tell [neighbour] not to come round, I don't want her to get this before she goes away', me thinking it was infectious. And, twice I said that, and so she [neighbour] said to [husband] 'How long has she been like this'", and he said 'Oh a couple of months', and she said 'Well ring the doctor', and if I had known I would have picked the phone up and cancelled it... I could see him coming up and I thought 'What is Dr [name] doing here?'... He said 'I am coming to see your supposedly chest infection... are you thinking of doctoring yourself now?'... He said get out of bed tomorrow and go for an x-ray, and I did, and it was a big one. And then they said radiotherapy...*

(Participant 24, Female aged 81, lung cancer)

In this example above, the patient's husband and neighbour work together to "conduct" the patient towards the doctor's assistance which she had been resisting. The neighbour's close friendship and concern combined with the distance of not being a relative enable her to confirm and encourage the husband's desire to call for medical help which the participant herself did not consider necessary or appropriate. This intervention led to an important diagnosis and treatment which would not have occurred otherwise.

A common theme within care recipients' accounts is family carers working together, with one individual coordinating this activity in the conductor role. The involvement of other family carers can be seen in two ways: as a "solo"; and as a "guest conductor". Firstly, the primary carer may retain overall responsibility for the older person while another carer takes them on a "solo" shopping trip, providing a meal or carrying out some household repair work for the older person. This is exemplified by younger male relatives (including sons, sons in law, a nephew) and friends providing car lifts for shopping, hospital appointments, non-emergency admissions and returning home after an institutional stay. Providing a personal taxi service is regarded as particularly suitable for younger men, drawing on their car ownership, but without direct involvement as a conductor or the more personal and supportive caring often associated with very close relatives and women.

Alternatively, the primary carer may relinquish the baton to a "guest conductor" if the primary carer is unavailable through holiday or illness, or in circumstances when it may be more appropriate for a different carer to have key responsibility.

> Carer   *"Is your niece getting time off next Thursday to go with you [patient]?*
>
> Patient   I have got to ring her, she might come back again tomorrow.
>
> Carer   *I think you should have a family member with you, in all honesty. I have mentioned this to you before, I mean I know she works but there is ways and means,*
>
> Patient   Just wait and see
>
> Carer   *Because she will be able to ask the questions that you may not remember... I think you are better off*

with your niece. Women are a bit   more sensitive

in this area. I shouldn't be saying that with a woman sat

there, it doesn't make us blokes look very good."

(Participant 27, Male aged 80, lung cancer and male friend)

This extract of interaction between a male lung cancer patient and a close friend of many years demonstrates the carer's conducting work to support the patient by ensuring the most appropriate person is available to support him at an important hospital appointment. This reflects Qureshi and Walker (1989) 'hierarchy of care', indicating strong normative preferences for female family members to provide support during emotionally charged encounters with health professionals. The extract also illustrates how carers work skilfully to empower those receiving care to request care to meet their needs. In encouraging his friend after each hesitant response about the possibility of securing his niece's assistance, the carer acknowledges his friend's independence in decision making, but is also taking responsibility for influencing this planning process.

Family carers' conducting of older people's illness trajectories extends beyond coordination of other family carers to include liaison with health professionals and other formal care providers. This involves attention to care in the home, community, clinical treatment as outpatients and plans for inpatient treatment. This is achieved through regular care and support of the older person, presence during health professional home visits and at general practitioner and hospital appointments. Many of the carers also take responsibility for correspondence and telephone communication with health and social services.

Family carers' active liaison with formal care providers enables better support of the older person because the carer understands more about the illness and its symptoms, enabling more effective explanation and emotional support. This also means family carers can help further by collecting prescriptions, providing transport and also further support at future appointments.

Carers' presence at hospital appointments and especially those where diagnoses are discussed is encouraged by health professionals for assistance in supporting the patient and communicating information.   When asked about their experience of receiving their diagnosis, many of the older people state simply that a relative or

close friend was present. The tone of voice used, and the lack of discussion about emotional impacts of their illness generally, signals strongly that they felt supported by the presence of family carers.

A further element of carers' supportive presence at hospital appointments is conductors' advocacy to ensure appropriate provision for the older person, including challenging health professionals and their care provision as necessary. Older people in this study talk particularly about the value of one of their children being present to ask important questions of the doctor:

> *"Well they [adult children] tell me to be quiet. Because when they go to the doctors they do ask questions, and especially that one there, especially him [son – indicated in photo], he is asking all the questions you know, and the eldest daughter, and I am saying I wish they would shut up, but they are, they ask some good, sensible questions you know."*

(Participant 16, Female aged 73, lung cancer)

Care recipients' account of their position demonstrates complex negotiation of their different relationships with conductors and health professionals. These accounts include clear evidence of older people's delegatory distancing, as 'good patients' not wishing to "bother" the doctor, but with a simultaneous willingness to allow questions to be asked in the most beneficial way for their care.

Hospital appointments (especially those where diagnosis and treatment are discussed) appear to provide a symbolic microcosm in which the relationships between health professionals, older people at the end-of-life, and their family carers are brought into sharp relief at a juncture between conductor-led care at home and formally-led care in an institution. In this context, family carers draw upon their expertise about the older adult's needs to assess critically the treatment and care plans formulated by health professionals, and capitalise on doctors' attention in this consultation by advocating to maximise the older person's well-being.

'Second Fiddle'

When admission to an institution occurs, "conductors" often identify needs, summon help and are present alongside the older person to provide support and to liaise with health professionals. However, after admission to the institution has

occurred, and the institutional systems encompass the older person and take over from the primary carers' responsibility, "conductors" find themselves relegated to the role of "second fiddle."   Indeed, even their title in relation to health professionals may change from "carer" to "relative", with associated reduction in status.

Physically located away from their home and immediate community and within the physical space, systems and authority structures of the institution, there are considerable limits on family carers' involvement in hospital. Housework and personal care within the institution are carried out by paid staff and family carers are not usually involved in these tasks. Barriers to being present with the older person and supporting them are imposed by specific time-limited visiting hours, limited activity opportunities within a hospital ward and the costs, time and logistics involved in travelling to the hospital.

Despite the downgrading of their role to "second fiddle" within the older person's life in the institution, primary family carers make considerable efforts to maintain an appropriate rhythm in the carer relationship through regular visiting. In the designation of a particular period when relatives and friends are permitted to spend time with the patient, professional and institutional power over family carers is demonstrated. Care recipients' accounts demonstrate the symbolic significance of their admission in prompting extended family and friends to express their concern and care by visiting.   For most visitors, travelling to the hospital is problematic, involving a car journey through a busy city followed by problems finding a car parking space, usually with costly charges; the expense of a taxi; or travel by multiple buses. Despite this, most of the primary carers visit every day.

While many of the carers co-present in interviews indicate relief that needed professional care and treatment is being provided for the older person within the institution, this temporary remission from continual responsibility for physical care and their expert knowledge of the holistic needs of the older person provides carers with very clear insights into any shortcomings in the institutional care. Firstly, family carers often provide substitute care where limitations in institutional provision are identified. For example, providing supplementary or alternative food in hospital such as for diabetics; and helping with care tasks like brushing teeth where water is out of reach.   Secondly, family carers may challenge paid staff to ensure the most beneficial care is provided. This may encompass requesting

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assistance and further information to promote better understanding of the older person's condition; asking questions about the appropriateness of treatment and care or requesting changes to take account of the older person's preferences; and strongly advocating the need for changes in care deemed inappropriate to avert adverse events. The extract below illustrates how carers may challenge health professionals where they do not feel decisions about inpatient care recipients' treatment have been fully justified:

> *"...I get all mixed up... and [daughter] says, 'mom, sit I will go', and she does. Goes and asks them, every little question, until she is satisfied. Because first of all when the doctors said you could come home, and then they said they were waiting for the occupational therapist to bring him home… when [daughter] went in she would say 'Well, why won't they bring him home? Why does he need an occupational therapist?... he didn't fall...' and you know she gets right to the bottom of it."*
> (Participant 9, Wife of male aged 81, heart failure)

In this extract, the patient's wife appears to feel uncertain about the referral to occupational therapy, but also overwhelmed in the second fiddle role. So their daughter, who has not had previous contact with the health professionals, takes responsibility for ensuring full information is given so that the family can form an opinion about whether this proposed referral is in the care recipient's best interests.

This commitment to continual monitoring and challenging of institutional staff where necessary within the "second fiddle" role indicates the strength of responsibility carried by primary family carers. As "outsiders" within the institutional setting, subordinate in influence to the institutional staff and system, primary carers do not relinquish all responsibility to the professionals organising the institutional care of the older person, but continue to draw on their expertise to assess the older person's well-being, and then raise concerns with staff as necessary.

Such advocacy may extend to challenging health professionals when inappropriate or potentially dangerous practice becomes apparent:

> *"and before they got my files down, [nurse said] 'We will give you an aspirin', our [daughter] said 'she is allergic to aspirin, she can't take it, she*

gets stomach bleeds'.... So, [nurse] comes back, she says 'the doctor says
she can have this, other one with a bit of aspirin in', our [daughter] said 'She
cannot have aspirin.' 'But the doctor said', [daughter] said 'I don't care what
the doctor said, she is not having aspirin', so they took it away.... it was
when I was a bit groggy, so it was when our [daughter] was here, otherwise,
they could have give me the aspirin, I would have had a stomach bleed."
(Participant 3, Female aged 69, heart failure)

Within care recipients' accounts, there are several examples of family carers identifying problems with medication and raising concerns with health professionals. These include a patient being given someone else's medication; and another patient whose son was given incorrect information about when medication would be available, resulting in two wasted journeys. The example above demonstrates how carers' detailed knowledge and experience of care recipients' health needs can be drawn upon to safeguard patients when they are co-present in hospital. Given family carers' 'outsider' status within an institutional setting, this may require considerable assertive confidence, in challenging and rejecting the existing system and care provision. Carers may be particularly concerned to handle such situations in a balanced and sensitive way without confrontation to avoid any potential negative consequences for the patient.

In advocating for patients and challenging clinical care, family carers are drawing on their holistic viewpoint of the older person's well-being gained through their long term supportive presence and coordination of care to demonstrate the strength of their concern and to effect change beneficial to the older person. In advocating through dialogue with health professionals, family carers are challenging normative understandings of the limits of their role in providing physical care. They are also demonstrating the value of their continuity of care, their in-depth understanding of the older adults' needs, and their crucial role as partners of clinical staff. Their advocacy promotes the joint provision of holistic care, which maximises the well-being and quality of life of older people at the end-of-life.

6.6 Discussion

The importance of the family carers' 'conductor' role for older adults is very clear within care recipients' accounts. The second fiddle role following hospital admission is in stark contrast to the conductor role, and illustrates the flexibility demonstrated by family carers in continuing their support and care for their relative or friend within the hospital system. There are no clear differences in these roles between the accounts of older people with heart failure and those with lung cancer, despite the differing disease trajectories. However, this common experience reinforces the strength of these findings in demonstrating how much the welfare of older people at the end-of-life strongly relies on a network of family carers taking responsibility for coordinating and providing care.

A previous study examining family carers' roles following an older adult's admission to a nursing home reflects some similar themes including a focus on continuity of relationship with the older adult, monitoring and providing feedback to staff (Davies & Nolan, 2006). However, longer lengths of stay and a more homely environment in nursing homes compared to hospitals, may mean that it is easier for nursing staff to develop a detailed understanding of individuals' needs and integrate family carers into the community of the nursing home (Nakrem, Guttormsen Vinsesa, & Seimb, 2011). The accounts of our care recipients demonstrate the effort invested and perceived risks involved for family carers who feel the need to challenge staff to maintain their relative or friend's well-being while a hospital inpatient.

Research has found that some transitions between places of care at the end-of-life can fail to improve quality of life and may have negative impacts on patients and carers (Parker et al., 2000; Whynes, 1997). In this study, care recipients' accounts go beyond outcomes and provide insights into lived experiences and the meaning of hospital admissions for family caring relationships. This includes how family caring relationships are adapted and maintained following hospital admission, the complexity of family carers' roles including careful negotiation and liaison with the older person and other professional and family carers, and the centrality of family carers in maximising the well-being of older people at the end-of-life, whether they are at home or in hospital.

6.6.1 Strengths and limitations

This qualitative interview study could only include older adults willing to speak about their experiences, well enough to participate, and identified as likely to die within one year of recruitment. Conducted within the last year of life and with family carers co-present in almost half of the interviews, the interviews are focused on present and recent experiences of the illness trajectory and the 'doing' of family caring in that context. The co-production of some interviews with family carers means that although the focus of the interview was on care recipients' accounts, some of the interviews go beyond this, to include descriptions of family caring in practice. The presence of some family carers may have limited the interview's scope to a normative focus on being grateful care recipients. However, the interviews conducted with a carer present appear to be candid accounts, and include open discussion of conflict around dependence and the receipt of family care, demonstrating how this is handled within the caring relationship.

6.6.2 Implications for policy and practice

The recent UK Department of Health White Paper (Health, 2010a) encourages increased personal responsibility for health and health care including more choices and greater participation in decision-making. Some users of social care in the UK are already controlling their own personal budgets, but evaluation of the pilot scheme found that many older people considered that responsibility for their own budget was an unwanted burden (Glendinning et al., 2000), and their introduction may be inappropriate for people at the end-of-life who have not used them before (Addicott & Hiley, 2011). Care recipients in our study are already concerned about the burden falling on their family carers, and seek to minimise this wherever possible through not sharing all the information on their health and emotions about their current health status. Some families experience internal conflict and destructive relationships between carer and care recipient. If more engagement with information and choices is expected, this might be associated with greater and perhaps unsustainable pressures on both patients and their carers. As the population ages, and increasing numbers of older people have heart failure and lung cancer, it is likely that even more family members and friends will take on this crucial coordinating role.

The need to improve hospital care for older adults has been recognised in the UK (Health, 2001, 2006). Recent official enquiries and media reports all point to

problems with the provision of basic care (Abraham, 2011; CQC, 2011). Many of the older adults in this study indicated that family carers, rather than nurses, were meeting many of their care needs while they were in hospital. The controversy created by the Royal College of Nursing when they suggested that relatives might take on this role (PA, 2011), implies that there is a gap between the public expectation of standards of care in hospital and what the nursing and care staff feel able to provide.

It seems clear that a different approach to the care of older adults in hospital is needed based on mutuality and meeting priority needs of older people (Bridges et al., 2010; Sturdy, 2010). This might include re-considering the structure of relationships between formal and family care: rather than focusing upon family carers merely filling gaps between formal care during periods of acute health care need, perhaps understanding of family carers' roles would be furthered by considering how formal care for inpatients impacts on the continuity of family care led by conductors with detailed knowledge of individuals' needs. A key theme in the consultation preceding the recent publication of the UK Government's carers' strategy *Next Steps* (Health, 2010b) was "frustration and anger" (p.9) at feeling excluded by health professionals and their expertise not being recognised as partners in caring. Developing integrated ways for nursing staff to work with older people and family carers could improve the well-being of older adults by recognising the continuity which family carers provide, and might also improve the well-being of family carers and nursing staff.

6.6.3 Gaps in the research evidence

Little is known about the "opportunity cost" of family caregiving, in terms of how carers would otherwise have used their time (McCrone, 2009), or the financial burden that caring places on them. It is unlikely that the carer role could be replicated as a paid position because of the continuity and hours required (Hanratty, Holmes, et al., 2012b). Older people may be disadvantaged if they do not have a family carer in a "conductor" role but most of the evidence concerns the experiences of older adults who do have family carers available to assist and support them. Considerable research efforts have focused on continuity of care (Parker, Corden, & Janet, 2010), but not on the role of family carers in providing continuity. Our findings strongly suggest that further attention should be paid to the expertise, contribution and support of family carers within institutional settings

where older people are admitted at the end-of-life, as well as care provided at home.

6.7 Conclusions

Sensitive, carer aware professional practice across health and social care has already been recognised as essential to improved outcomes for carers, and the importance of caregivers is widely acknowledged in UK policy documents (Health, 2010a). Yet these care recipient accounts highlight the gulf between policy and practice. If family carers' contribution to older people's welfare at the end-of-life is to be more fully recognised and drawn upon, they will need to be regarded, empowered and supported as partners, whether the older person is at home or an inpatient. Finding ways to draw upon the expertise of carers, enable them to support their friend or relative at the end-of-life (Ferrell, Borneman, & Thai, 2009) and enabling their involvement in planning for transitions (Health, 2010a) presents a major challenge. The many contacts between nurses, patients and carers offer fora for closer partnership. The key to maximising older people's well-being at the end-of-life could lie in wider recognition and celebration of the role of caregivers in maintaining continuity of care.

Chapter Seven:
Exploring resilience when providing care at the end-of-life

7.1 Foreword

This chapter explores the experiences of bereaved carers and the extent to which resilience was present in the accounts of their experience. Within the chapter I focus on two sub-groups of the bereaved carer data I collected. Firstly, I explore how the presence or absence of dimensions of social support facilitate or hinder resilience in recently bereaved informal carers. This builds on chapter five and six. It also adds to the literature on the importance of social support for carers, in particular when facilitating resilience. The 44 (out of 118) carers were chosen for further analysis as they had spoken in detail about support and spontaneously mentioned areas of social support. Using the operationalisation of resilience described in section 2.4, twelve participants were classified as not resilient and 32 participants were classified as resilient. The majority of the sample who spoke about social support and classified as resilient were men (N=24/32). Secondly, I explored the experience of all male caregivers. This is pertinent, as from my sample, those who spoke in detail about social support, and classified as resilient were men. There is a dearth of literature exploring the experiences of men who care for a loved one at the end of life and so this sub analysis makes a meaningful contribution to the literature.

My contribution to this chapter was the development of study materials, recruitment of participants, interviews with participants and analysis of preliminary and further data and writing the chapter for publication and presentation.

A version of this chapter, focusing on the social support aspect of resilience was accepted for publication in Ageing and Mental Health in 2018;

Roper, L., Donnellan, W., Hanratty, B., and Bennett, K.M. (2018). Exploring dimensions of social support and resilience when providing care at the end-of-life; a qualitative study. *Ageing and Mental Health.*
doi.org/10.1080/13607863.2018.1484886

The second sub theme (the experience of men) was presented at the British Society of Gerontology in 2019:

Roper, L., Bennett, K.M. and Hanratty, B. (2019). Exploring resilience amongst bereaved male carers caring for a spouse or parent at the end-of-life care.

7.2 Abstract

Background: Clinicians are increasingly interested in resilience amongst those who care for someone at the end-of-life, and the factors that contribute to, and hinder, the development of resilience. Research shows that formal and informal social support can facilitate resilience in carers. There is a paucity of research exploring social support and resilience amongst recently bereaved informal carers, and in particular men.

Aim: To examine the account of resilience in carers of people who are at the end of life and particularly, how the presence or absence of distinct dimensions of social support facilitate or hinder resilience in recently bereaved informal carers.

Participants: Study 1: 44 bereaved carers (men=24, women=20), who had been identified by GP as 'main carer' of someone recently deceased (3-12 months) aged between 38 and 87 years old (mean= 67). Study 2: the remaining six bereaved male carers from the wider 'Transitions' study, plus the resilient men in study 1 (N=30) were included.

Methods: Study 1: Thematic analysis then the Ecological Framework of Resilience (Windle and Bennett, 2010) as an organisational tool to develop overarching themes in the data. I used Sherbourne and Stewarts' (1991) model to identify social support that was lacking as well as social support that was present. Study 2: Men were classified as resilient or not resilient using the classification of resilience operationalisation and examined factors promoting or hindering resilience.

Results: A range of social support types were identified across both studies. There was an emphasis on the importance of relationships with both health professionals and family members, including the care recipient. However, social support was not necessary for resilience if the participant had other resources.

Conclusions: Social support for carers providing end-of-life care is almost exclusively based around end-of-life care 'work'. Men request support infrequently. In comparison to other research our study suggests that relationships with family and health professionals are paramount. Multidimensional support is needed for carers to enhance their resilience. Respectful, timely, supportive and clear information could enhance the development of resilience in men.

7.3 Introduction

The end-of-life is increasingly associated with co-morbid conditions, frailty and smaller family units to provide support (Seale, 2000) alongside the increase in life expectancy (Public Health England, 2016). For many people, the last few months of life see the most intensive contact with health and social services, and transfers between care settings are frequent (Hanratty, Holmes, et al., 2012b). It is often the informal carers who bear responsibility of navigating this system (Lowson et al., 2012; Stoltz, Uden, & Wilman, 2004). Nearly 1.4 million people aged 65 and over provide unpaid care for a partner, family or others but only 77,635 (in 2012-2013 in England) receive any carer specific support services (NHS Information Centre, 2013). Recent research explores the contributions of family caregivers at the end-of-life in terms of hours of care and expenditure (Rowland, Hanratty, Piling, et al., 2017). Almost two thirds of older carers have a long-term health problem or disability themselves (Carers UK, 2014). Carers frequently report (68.8%) that their role has an adverse effect on their mental health (Carers, 2011).

Caring is a stressful life event. Carers must adapt to and manage social, physical and emotional challenges. The Ecological Framework of Resilience (Windle & Bennett, 2011) based on the Ecological Systems Theory (Bronfenbrenner, 1994) explores how people live in and interact in their environments. It reflects how resilience operates across multiple levels, which in turn interact with each other. Resilience is defined as:

> *"The process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity."* (Windle, 2011a, p. 163)

Multiple criteria have been used to classify people as resilient or not, most notably widowers, which removes the reliance on proxy measures and identifies resilient individuals and the characteristics that contribute to resilience (Bennett, 2010; Moore & Stratton, 2003). Bennett's (2010) operationalisation of resilience has been used to classify other carers, including older spousal dementia carers (Donnellan et al., 2015). The criteria included; 1. There must be a significant challenge (caregiving), 2. No sign of (di)stress, 3. Maintaining a life of meaning and satisfaction

(a sign of bouncing back), 4. Actively participating in life (a sign of managing), 5. Current life seen as positive (a sign of adaptation).

There is growing interest in resilience of people who care for someone at the end-of-life (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne, et al., 2009; Monroe & Oliviere, 2007). Recent literature contributes to knowledge of resilience during end-of-life care (MacArtney et al., 2015), the factors that contribute to, and hinder resilience (Donnellan et al., 2015) and which carers of family members at the end-of-life need more support from health services (McNamara & Rosenwax, 2010). Informal carers perform a crucial role in maintaining and supporting care recipients and consequently have support needs themselves (Moens et al., 2014). Some carers report not wanting to provide such care again (Currow et al., 2011).

An increasing number of older men are providing end-of-life care for a family member, but our understanding of men's experiences in this role is limited. Previous research suggests that male carers are less likely than women to express psychological concerns (Fromme et al., 2005; Shirey & Summer, 2000; Thomas, Saunders, Roland, & Paddison, 2015), and are more likely to suffer undisclosed strain (Fromme et al., 2005). Compared to female carers, men are also less likely to seek support for their caring role and may wait until crisis point before asking for help from services (Milligan & Morbey, 2013). In a survey of UK carers (The Carers Trust, 2014a) only half of the male carers surveyed felt that their needs were different from female carers. At the end-of-life, the physical demands of caring may be exhausting, and as death approaches, other needs become more complex, making it harder for carers to cope (NICE, 2015). The achievement of end-of-life care and death at home depends on a carer's ability and willingness to provide care (Gomes & Higginson, 2006; Grande & Ewing, 2008) including with intimate and domestic tasks, which may be particularly challenging for male carers (Calasanti & King, 2007). All of this suggests that older men may find caregiving at the end-of-life particularly stressful. However, other work (Joling et al., 2016) suggests that being a male caregiver was positively related to caregiver resilience.

Studies have explored the experiences of male carers who care for people with dementia (Baker & Roberston, 2008; Baker, Roberston, & Connelly, 2010), but no consensus has yet been reached on how to support male carers, and discussions about the nature of the way men express and handle their burden differently to females, are ongoing (Cherry et al., 2013). Supporting carers to continue to care is

important to patients and carers who already make a substantial contribution, in both hours of caring and expenditure, to end-of-life care (Rowland, Hanratty, Pilling, van den Berg, & Grande, 2017).

One factor that may be crucial in sustaining carers providing end-of-life care is social support, a 'community-level' factor in the Ecological Framework of Resilience (Windle & Bennett, 2011). International research suggests married people are able to die at home more frequently that those who are divorced, widowed or unmarried, highlighting the importance of family carer and social support (Cohen et al., 2015; Gao et al., 2013). Soulsby and Bennett (2015) defined social support as being "a transactional process whereby our relationships provide a platform for the exchange of emotional and practical support" (p.110); a concept fundamental to the experience of carers and patients negotiating health services, settings and professionals. Research shows that informal support is associated with high baseline resilience and lower levels of institutionalisation over time for people with dementia (Gaugler et al., 2007).

Sherborne and Stewart (1991) identified five distinct dimensions of social support related to people who are chronically ill: emotional support (positive affect, empathic understanding, attachment); affectionate (expression of love); informational (advice, guidance, feedback); tangible (practical assistance); and positive social interaction (availability of others to do fun things together). Exploring the different dimensions of social support (Sherbourne & Stewart, 1991) has been previously reported: how social support mediates the relationship between being optimistic and caregiver quality of life (Brand, Barry, & Gallagher, 2016), to explore psychological resilience (Isaacs et al., 2017) and to explore mental well-being and resilience (Khawaja, Ibrahim, & Schweitzer, 2017).

Research has reported that emotional support has been found to predict cognitive functioning better than physical support (Ellwardt, Aartsen, Deeg, & Steverink, 2013) and affectionate support and positive social interaction to reduce psychological burden in dementia carers (Han et al., 2014). Sherbourne and Stewart's (1991) dimensions have been used as framework for identifying social support in research on spousal dementia carers (Donnellan et al., 2017), but not to explore end-of-life caregiving. To my knowledge the Sherbourne and Stewart (1991) model has not been utilised to explore the experiences of carers providing end-of-life care.

There is a paucity of research exploring social support and resilience amongst recently bereaved carers. A review (Windle, 2011a) indicated that assets and resources are key features for resilience, and good outcomes can be achieved with a range of protective factors. Drawing on the importance of individual assets, community and societal resources which interact to facilitate or hinder a resilient outcome, the ecological resilience framework of Windle and Bennett (Windle, 2011a) is a theoretically driven approach to operationalising and measuring the key features of resilience as applied to caregivers.

This chapter explores the experiences of people who cared for a family member at the end-of-life. I will focus on two discrete analysis of the data in this chapter. Firstly, I examine the dimensions of social support that recently bereaved carers used to facilitate or hinder resilience when providing end-of-life care. Secondly, I explore the experience of men and the extent to which resilience was present in the account of their experiences.

7.4 Method

7.4.1 Participant selection

This study focuses on a sub-sample of 50 bereaved carers from a wider study of 118 (Hanratty, Holmes, et al., 2012b). A qualitative approach was appropriate due to the lack of exploration and understanding of the experience of moving from one place of care to another. The participants in study 1 (N=44) were chosen as previous analysis showed that had they had spoken at length about support whilst providing care at the end-of-life and spontaneously mentioned areas of social support that facilitated or hindered resilience. The participants in study 2 included all the men in the wider study sample (N=30/118). Recruitment was purposeful via opting in to the study team via reply slip after contact from their GP via the Primary Care Research Network or from the GP directly. It was not possible to track who did not opt in, and none of the participants once interviewed withdrew.

7.4.2 Setting

Study 1 draws from 20 women and 24 men interviewed, of which 19 were spousal carers, 20 were offspring carers, and 4 were classified as 'other' (1= friend, 1= granddaughter, 1=brother in law, 1=brother). The age of the carers ranged between 38 and 87 years old (mean= 67). Most participants (31/44) had previously lived with

the person they had been caring for. The care recipient died from a range of illnesses, including: heart failure (n=11); Stroke (n=13); COPD (n=8); Lung cancer (n=5); breast cancer (n=1); and colorectal cancer (n=5). Care recipients were aged between 74 and 97 (mean 85.7 years old). The usual place of care varied with most participants (n=32) living at home. Other places of care included nursing homes (n=4), residential or sheltered accommodation (n=4), hospice (n=1), hospital (n=1), and family members homes (n=2).

Study 2 draws on all the male participants in the wider study (N=30). Thirteen participants were spousal carers, 14 were offspring carers and 3 were siblings of the care recipient. The age of the participants ranged between 52 and 84 years (mean = 68 years old) with over one third of the participants (11/30) having lived with the care recipient.

The socio-economic status distribution of the participants (based on postcode data) was broadly representative of similar demographics in the British population (Office of National Statistics, 2011).

7.4.3 Data collection

Semi-structured interviews were conducted face-to-face during 2010-2011 and digitally recorded at the bereaved carers' homes. Interviews lasted between 60 minutes and 2 hours 45 minutes, and a topic guide was developed by the study team, and used by the author (LR) to illicit exploration of the experience of caring in different settings and the experience of the carer providing care. It focused on the places where the decedent had received care during the final few months of life, the transitions between places of care, the experience of the carer, and their support networks. The support received in terms of social, family and health professional support was also explored and there were also questions about how information was provided to the carer and who provided information. Interviews were conducted until data saturation.

7.4.4 Data analysis method

Study 1

Participants in this sample had been classified as resilient using the Bennett (2010) operationalised method of classifying resilience. The components of the classification of resilience include; there must be a significant challenge: caregiving, no sign of (di)stress, maintaining a life of meaning and satisfaction (a sign of

bouncing back), actively participating in life (a sign of managing), and current life seen as positive (a sign of adaptation). Twelve of the participants were classified as not resilient and 32 participants were classified as resilient using data from interviews.

We used a thematic approach as an exploratory method to read and code the full cohort of interviews (LR, BH). Social support was a key theme in the preliminary analysis. The lead author re-coded the transcripts looking at the emerging description of social support and supportive relationships described by the carer during their end-of-life caring responsibilities.

The remaining analysis then departed from the principles of thematic analysis. We used the Ecological Framework of Resilience (Windle & Bennett, 2011) as an organisational tool to develop overarching themes in the data. The Framework method was used to organise preliminary data and for detailed analysis of social support the software QSR NVivo10 was used to organise the data. We used the Sherbourne and Stewart (1991) model to identify social support that was lacking as well as social support that was present.

Study 2

The male carers (N=30) were classified as resilient / not resilient using the classification of resilience operationalisation (Donnellan et al., 2015) shown in Table 10. Twenty-four of the thirty male participants were classified as resilient. A thematic approach was used (Braun & Clarke, 2006) as an exploratory method to read and code the interviews for the initial focus of the study. Second, I re-analysed the transcripts from interviews with male carers, to explore the participants' descriptions of resilience, situations or events that seemed to hinder or promote resilience, all within an ecological framework (Windle, 2011a). Themes were identified inductively and deductively from the data and a pragmatic approach was taken as we sought to understand better the experiences of bereaved male carers. A Framework approach (Ritchie et al., 2003) was used, supported by software NVivo 10 to organise the data, develop relevant themes, and enable more detailed analysis of the presence of resilience in the accounts of male bereaved carers.

Table 10 Classification applied for illustration to Participant 09

i. There must be a significant challenge
Caregiving

ii. No sign of (di) stress
assessed throughout interview by lead author and included the carer too upset or emotional to continue with the interview, parts of the interview stopped due to distress.

iii. Maintaining a life of meaning and satisfaction (a sign of bouncing back)
"I have got all the other bits and pieces I was doing as well, you know it's quite weird really the way you try and keep other things normal, around it, because I mean I kept, I was going to the community choir and I was doing other bits and pieces and certainly up until Christmas" (009)

iv. Actively participating in life (a sign of managing).
"maybe it's worth mentioning the aftercare. Because I can't remember quite how long after it was but I received some leaflets and information from them, a few weeks after, I mean we had a card from them and straight away anyway [2.11.33] but one of their social workers made contact, with me encouraged me to contact her and every month for I don't remember I was seeing her once a month and I now see her every 3 months, and there was a plan that they do group sessions for bereaved and erm, I said I would like to go along to one since then on a regular basis, we have rolled it out to about every 3 months now, the first few months I found that a huge help" (009)

v. Current life seen as positive (a sign of adaptation)
" (the choir) it's been great because it's a really good distraction, plenty to keep me interested (009)

7.5 Results

The results from both studies are mapped onto the themes of the Ecological Framework of Resilience, to explore the presence of resources from individual, community and society perspectives and to examine how these resources map together with the social support model (Sherbourne & Stewart, 1991) for the participants in study 1. The final theme explores the resource hindering resilience

in male carers. Throughout the results section terms in [square brackets] refer to the dimensions of social support from the Sherbourne and Stewart (1991) model and some examples highlight the presence of support and others the absence of support.

7.5.1. Individual assets

Drawing on the support of the deceased care recipient

Participant 7 shows elements of individual/ psychological assets facilitating resilience; he refers to the 'continuity' of the patient in *'accepting dying'* and draws on his own identity '*I am hoping I can be the same'*. He also stays positive throughout the interview, captured here with '*life carries on"*. This participant has many features that appear to facilitate his resilience; he accepts the situation he is in, and he is positive when reflecting on the caring experience.

> *"…she knew she was dying and she accepted it… and I am hoping I can be the same [emotional]. I don't know, once someone tells you, you are going to die, it's difficult I can't, I can't comprehend what it might mean to me, I am hoping I would go the same way, accept it, it's part of life [emotional], it just ends and life carries on."* (Participant 7, Brother in Law, Resilient).

Participants benefited from the support of the person they were caring for, in particular the emotional support provided and the ability of the care recipient to navigate the system together.

Carer resilience is facilitated by this unique relationship between the carer and care recipient, particularly when adapting to and managing the stress of coping with bereavement. This participant shows insight and dimensions of emotional support when describing how his sister-in-law knew she was dying and how she accepted it. Elements of social support work together throughout this participants' transcript to facilitate the resilience he has during and after the death.

Material resources were also important, for both participants who were resilient and those who were not. Material resources facilitated the end-of-life care 'work' in some cases as well as the resilience of the participants. Those who had the ability to organise and pay for aids such as wheelchairs, stools and bathing equipment and enough money to pay for transport in difficult situations reported more positively on their care experience as well as had less distress about the caregiving

experience. A 61 year old son of an 89 year old woman describes how he bought a vehicle with disabled access so he could take his mother out, and says that his ability to pay for some additional care and aids such as the adapted vehicle, allowed his mother to avoid a nursing home;

> *"Even though she couldn't last longer than maybe an hour it was stimulus you know…We tried her for 2 weeks in a nursing home and she started to curl up like a bird dying so we took her out…she was happy to be home".* (Participant 3, mother had stroke, carer resilient).

However, having access only to tangible support, was not sufficient to facilitate resilience in this situation for most of the carers.

The flexibility of the participant's workplaces, childcare considerations and the carer's access to aftercare (such as bereavement counselling) was more widely reported in participants who were classified as resilient. Participant 31, who was classified as not resilient, reported material resources she accessed and this was important to her in the absence of other types of support,

> *"I have got a carer, I have got a care plan they come in the morning, one comes in the morning, one comes in the evening [tangible]."* (Participant 31, wife of deceased, not resilient).

7.5.2. Community resources

Carers wanting more support than they received from family

In general, carers reported needing more support from family than they received particularly emotional and tangible support as well as the wider family recognising their difficulties. The presence of emotional and tangible support facilitated resilience. Carers with little familial support were more likely to be not resilient. The next quote illustrates that caring for a person at the end-of-life can be emotionally and physically draining.

> *"…you think oh well they get in touch kind of thing, and you just don't realise time goes by and you are bloody knackered [lack of emotional support], I am tired out, my mother wasn't an easy person [lack of emotional support] …so emotionally I was completely drained as well as physically from going there, or just going there at lunchtime [lack of tangible support]…so you are too tired and knackered to kind of think*

> *straight really that's the big issue and they should be thinking for you [lack of emotional, informational and tangible support]."* (Participant 27, offspring carer of parent with stroke, Resilient)

Throughout the data, bereaved carers reported needing a multidimensional supportive network to facilitate resilience. In the example above, the participant describes how her husband was supporting her in caring for her mother but she still felt she needed wider support. An ecological perspective of resilience works well to explain how these dimensions are interlinked. For example, participants discuss many forms of support that they would have liked when providing end-of-life care for example emotional and informational support would have been welcomed. Material resources or practical assistance were sometimes lacking from the participant's community assets and participants said they were much needed, along with the support of the community including family, friends and neighbours.

Some resilient carers described having little or no familial support, implying that resilience is not exclusively centred on social support. Participant 30 described how she did not have the support necessary to undertake such a consuming role, but did have the insight and negotiation skills to manage the situation she was in and to protect herself from potential stress. The interplay here between the dimensions of social support and the way the carer deals with the resources they have is important to whether they are classified as being resilient or not. The participant explained:

> "(*my mother) said I don't want to (go into hospital)… her pleading with me, with her eyes*", the participant "*wasn't brave enough to do 24 hour care on my own [emotional, information and tangible support lacking] …and I know that I couldn't cope with that mentally [emotional and informational support lacking], emotionally I knew I couldn't cope with that*".

The reason the carer gave for not wanting to care for her mother '24 hours' was,

> "*I knew basically it would be all down to me, and then of course there was, my dad was still demanding to be visited every day [lack of tangible and positive social interaction]*" (Participant 30, Offspring carer of parent with heart failure, resilient)

This participant draws on her psychological assets to facilitate her resilience. She negotiates, manages and adapts to the stressful situation by opting out of the 24-hour care she reports she was implicitly expected to do, thus showing her resilience in the face of adversity. Here, the adversity was not providing care for someone at the end of the life, but providing care without the resources she felt she would need to successfully carry out this caring role. She lacked community support to carry out further caring duties, but had the insight to identify what she lacked and to take appropriate action.

Participants were also aware of the insecure nature of the caring; they may have been navigating the role at one point, but had awareness that one unexpected problem could have caused their fragile situation to become unmanageable:

> *"I said to him, which I feel very guilty about… on the day he died actually, that if I became ill or anything else that I wasn't too sure… how we were going to manage… because he needed… help undressing and getting into bed [tangible support lacking]…there was a lot of work, and it was, we were getting, I was getting rather tired [tangible and emotional support lacking], so, so we were getting to a point where probably we needed help"* (Participant 29, Offspring carer of parent with heart failure, resilient).

Carers often reported tangible support was valuable and required in the form of equipment to increase the independence or dignity of the cared-for person, or reduce burden of symptoms or illness at the end-of-life. A 60-year-old man who lived with, and cared for, his 87 year old father with colorectal cancer described how he accessed a carer's centre after seeing a leaflet in the mail, and how they offered him an assessment for his father to see if he could access any services;

> *"I mean the health and social, the carers and that, they have actually even been in contact with me after he died, and said, you know, it affects you, if you need to talk to anyone, come and see us, you know. So I have been, even followed up with them, so I mean they have been very good."* (Participant 5, father had colorectal cancer, carer resilient)

The carer felt that the carer's centre and the service they offered was a positive experience, *"'Here do you want a coffee' had a coffee, they were very helpful"* and offered him some timely, and useful respite for his father at a time when it was much needed.

There were plenty of examples of the tangible care, offered to carers by other family members and which was well received.

> *"[friend present] and her husband took me every day didn't you, except one weekend when Monica and Jeff took me didn't they. Because I can't drive [tangible support present]."* (Participant 28, spousal carer of stroke patient, resilient).

7.5.3. Societal resources

Multidimensional support from health professionals facilitates informal carer role

Many participants spoke at length of the time and patience the health professionals had for the care recipient and spoke in encouraging terms about the care received. The emotional, tangible and informational support offered by health professionals that was gladly received by carers was also frequently mentioned. In both excerpts below, the participants had been classified as resilient and a positive relationship with health care professionals did give the impression that it facilitated resilience in participants.

> *"The doctors when you were there, you know would ask you, you know if you had got any questions, do you want to know anything about this [informational, tangible], this, and this, and they were very good [emotional] 100% involved you."* (Participant 44, Offspring care of parent with breast cancer, resilient)

> *"Well every time I went in you know the doctors or the nurses would come up and put me in the picture [informational] as to what was actually happening. They were very good, very good, and they were very nice to me as well [affectionate], very courteous you know and sympathetic [emotional] you know."* (Participant 26, spousal carer of stroke patient, resilient)

Not all participants reported positive support from health professionals and sometimes participants felt obstructed by the interventions of health professionals.

Participant 43 describes a move to a hospice and how knowledge about the condition and prognosis was not forthcoming by the health care staff;

> "if anybody would have talked to us about that, then we might have been more, we would have been more prepared [lack of emotional, informational and tangible support], but there was never any mention anywhere, that death might overtake all plans that we had got. So that really was dreadful, that she had to die in the corner of a ward, behind a curtain [lack of tangible]. I asked twice for a private ward, but they couldn't find one." (Participant 43, spousal carer of person with colorectal cancer, not resilient)

Perceived lack of support from professionals hindered resilience and compounded difficulties in adapting to the caring role. A lack of informational support such as knowledge from professionals about how to access services or miscommunication about prognosis sometimes caused negative consequences for the carers. Participant 43 reports how he lacks reassurance, someone to help him navigate the health care system and a lack of support in deciding upon end-of-life care and place of care/ death. His lack of support contributed to him feeling regret about the way his wife died:

> "…it *was basically my fault… I didn't understand the situation because nobody had said you do realise this might not work [lack of informational support] …if only somebody had said, you do realise it can go like that then I would have got her home, and she would have been with her friends, they would have been here with her, visiting and the last day she didn't know much but she would have been here and loved it [positive social interaction]."* (Participant 43, spousal carer of person with colorectal cancer, not resilient)

Support that prioritises the system not the carers

Many of the interviews conveyed a sense that the care system was imposing processes on carers without any recognition of, or flexibility to the individuals' needs or wishes. It was sometimes unclear whether the problem lay with interdisciplinary communication, or if the 'system' was used by professionals as an excuse to cover inability or unwillingness to act. The participants discussed the health and social care system working against them, rather than for the benefit of the families, suited more towards the process and bureaucracy;

Being supported in preferences for place of care and death

It was important for carers to be part of the decision-making and to have a choice in where their loved one died, particularly in conversations about preferred place of care and place of death. There are many examples throughout the data, describing the importance of place of care and death (see Table 11).

Table 11 Male carers' descriptions of the importance of support for place of care or death

Participant 12, wife with stroke, caregiver resilient "I assumed it was my choice (to choose where his wife died) and that is what she wanted and she was obviously happier in surroundings that she knew … she was obviously much happier and she accepted her carers very much. And in fact the one carer who finally became the one who stayed during the night, erm and I think she liked very, very much. For her own peace of mind. We felt that, really in the hospital would be a bit, was unnecessary in a sense, it was foreign in a sense to her, it would be to anybody and being at home was obviously much, much better for her."
Participant 3, mother with stroke, caregiver resilient "I don't know how other families or people would have managed because there was 2 people and occasionally (another family member because he works part time) that could do the old fashioned family care at home…circumstances were fortuitous."
Participant 4, father had heart failure, caregiver is resilient "And over again and the very fact that if we had known, see these people they are doing it day in and day out, even if they are not doctors they have an idea that the, this is you know, he ain't going to be coming out, and if they had told us before my Dad had the heart attack, we would have said well we will take him home there is no point in him being here, and that is what, that is all at the end of the day because we could see he was getting progressively worse, that was all

> we wanted for someone erm, a professional to turn round and say, I am afraid he is getting worse, his prostate is you know and his aneurysm, that could go at any time, we don't know how long but it's not going to be very long. And we would have taken him home before he had the heart attack. But, there was no one there."

Resources hindering resilience in male carers

The analysis from the male carer data describes some issues that were pertinent for male carers in particular and were common across the interviews with male carers.

1. Lack of acknowledgement of the carers vital role

On occasions, health care professionals were perceived as unsupportive and did not acknowledge the carers' vital role. For example, a doctor implied that a carer's inability to cope was the reason why his mother was in the emergency department, though his mother had developed pneumonia and died within three days;

> *"I was insulted, how dare they. When I had taken care of her for 20 years. Awful, terrible people"* (Participant 15, wife had heart failure, carer not resilient).

2. Limited emotional support and relationships with health professionals and family lacking

Many of the carers felt that a lack of emotional support had contributed to their perceptions that the end-of-life was stressful, both for them and their loved one.

> *"it was basically my fault, this is the guilt isn't it, that comes with all this, because I didn't understand the situation because nobody had said you do realise this might not work… I was probably too thick to understand it and you don't want to see the signs I know that…if only somebody had said, you do realise it can go like that then I would have got her home…and she loved it"* (Participant 2, wife had COPD, carer not resilient).

Carers mentioned 'letting down' their loved one and how it was their 'fault' that their loved one died in hospital rather than at home, which was their preference. The 53 year old man caring for his mother with COPD (participant 02) says he was *"probably too thick to understand it all"* highlighting a strong, negative and painful feeling of blame towards himself of not understanding information which

throughout the transcript he describes as not forthcoming. These negative feelings about the last few weeks contribute to the feelings of helplessness and inability to manage the stressful event, which accords with the definition of resilience as carers being able to 'manage and adapt and bounce back'. However, carers are not only resilient if the place of death was the 'right' one; a 75 year old man caring for his 74 year old wife with lung cancer, who died at home (their preference), talked about his sadness and grief at losing his wife;

> *"But she died here, and I was near her when she died. It's hard yes. Sorry about this love, it's really hard. Because we were married 50 odd years, I miss her love, I miss her. It's hard. It's hard to lose a loved one"* (Participant 1, wife had lung cancer, carer not resilient).

These quotations highlight that although men may seek practical and tangible support and find it useful, they may also benefit from emotional support, both around the time of the end-of-life or death of their loved one and also during their bereavement.

3. Key informational support lacking and/or prognosis not being forthcoming

A lack of informational support included examples of carers not being aware of services they could access, tangible support they could procure, or the best ways to navigate the health and social care system or coordinate the health professionals involved in the person's care (see Table 12). Often, information about prognosis was not communicated with carers. The son of the woman who died of colorectal cancer describes errors in the dialogue between carer, patient and professional by explaining how, *"well I might as well have gone and asked [local supermarket] how she was going on you know because I got no information whatsoever"*.

7.6 Discussion

The emotional, informational and tangible support provided by both family and health professionals were fundamental to facilitating resilience for all carers in this study providing informal care at the end-of-life (Rose, 1999). I also found informational and tangible support was forthcoming and timely for all carers, but when I explored the data for the male carers, the emotional aspects of caring were not always met. All participants wanted positive recognition of their role as carers

from health service staff. To mitigate against the practical challenges of caregiving, material resources were important.

The Princess Royal Trust for Carers (2011) reported that a caring role frequently has adverse effects on carer's mental health. Older carers have worse long-term bereavement outcomes (Rossi, Bisconti, & Bergeman, 2007), suffer more serious health conditions (Stenberg, Ruland, & Miaskowski, 2010), and compared to younger carers (under 60 years old), report less distress, but have fewer social (Scrutton & Creighton, 2015), economic (Seymour, French, & Richardson, 2010) and service support to cope (Grande, Faraquhar, Barclay, & Todd, 2006). The majority of our carer participants were over 60 years old and their experience can contribute towards the evidence base for this under-researched group. Informal carers perform a crucial role in maintaining and support care recipients (Moens et al., 2014) and exploring factors that contribute to or hinder resilience is an area of growing interest.

Individual assets are important in this data, particularly how participants drew on the relationship and support of the deceased care recipient as well as other more obvious networks such as family and health care professionals. This supportive relationship facilitated resilience, in particular the emotional and tangible support offered from the deceased care recipient, and the way this increased positivity and acceptance of bereavement and death. Poor relationships with family members or health professionals did not prohibit a carer showing many resilient qualities, but poor support did seem to make life harder for the carers and they needed to draw on psychological assets more explicitly and use any material resources they had effectively to soften the loss of these relationships (Soothill et al., 2001). Many male carers spoke of poor care and a lack of respect for the cared-for person at the end-of-life, all of which contributed to the carers' distress. As reported in other research, sometimes institutional processes were prioritised over patient dignity (Hanratty, Holmes, et al., 2012b). Material resources helped with the practicalities of caring, and timely, tangible support was reassuring to carers. Informational support was often absent, and even when available, it was not timely. Previous literature (Hanratty, Holmes, et al., 2012b) has suggested that continued attention to basic aspects of care and communication between professionals and patients should be a priority. The General Medical Council (Shaw, Clifford, Thomas, & Meehan, 2010) in the UK provided guidance on addressing the emotional

difficulties including offering "carer support and advocacy services, counselling and chaplaincy services and ethics support networks" but this was only reported to have been offered in one out of the thirty interviews with the participants.

Carers in this sample generally wanted more support than they received from family. The discrepancies between carer's perceptions of social support and actual social support are important. Distinct dimensions of social support did contribute towards bereaved carers being classified as resilient or not, but the relationship between social support and resilience was not linear. Some participants were classified as resilient without having a supportive family providing all the support the person perceived they needed, and some participants were classified as resilient without good working relationships with the health professionals involved in the end-of-life care 'work'. But, *enough* support was needed by the bereaved carer to be able to fulfil their caring role successfully and to feel, on reflection, they had adapted and managed well. These dimensions of support did not need to be provided by support networks at the same time but needed to be provided by the most appropriate person. The quality of the social support the participants sought was almost exclusively based around their end-of-life 'work'. They sought emotional support from family and professionals around them, informational support to guide their knowledge and understanding of the situation or the trajectory of illness or dying, and tangible support to help make their caring role easier; for the patient, themselves and their families.

Carers and health professionals have complex relationships which have been well reported elsewhere (Bauer, Fitzgerald, Haesler, & Manfrin, 2009; Kirk, 2008; Murray, Boyd, Sheikh, Thomas, & Higginson, 2004; Ward-Griffin & McKeever, 2000). In this study we explored how multidimensional support from health professionals facilitates informal carer roles and in contrast, how the perceived lack of support from professionals hindered resilience and compounded difficulties in adapting to the caring role. The provision of a seamless service, one shaped around the needs of patients, carers and families is a core principle of the UK National Health Service (Department of Health, 2010b) but this was not always the experience of the participants in these two studies. Participants conveyed the sense that the care system was imposing processes on carers without any recognition of the participants' needs or wishes (McPherson, Kayes, Moloczij, & Cummins, 2014).

This chapter has many strengths: I have explored the experience of bereaved carers shortly after their bereavement, a difficult to reach group, who were identified by GPs as being a key carer in an older person's life. This point in time is often difficult to explore and relies on participants reflecting on their experiences with accuracy. The interviews took place soon after (3-9 months) their bereavement, allowing good recall of events and insight into experiences at the very end-of-life that cannot be captured in any other way. The distance since the loss also affords time for reflection. However, it is possible that some carers 'reinterpreted' the past, perhaps retelling experiences in a way that is consistent with a revised sense of self. Inclusion of carers who had looked after family members with a range of different conditions broadens our knowledge of carers, much of which is based on experiences in cancer (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, & Todd, 2009). Although the interview was semi-structured in nature, there was opportunities for participants to discuss in detail their caring experiences. There is a dearth of information exploring the experience of bereaved men and there is growing interest in resilience, and in the factors that contribute to resilience. Twenty five percent of the wider sample is male, more than 60% of the sample of participants in this chapter, and this helps us to explore men's experiences in greater depth. Other strengths are the nature of the relationship between carer and care recipient: carers cared for close family members (typically spousal or offspring carers) and the care recipient was terminally ill with one or more of a range of illnesses. Carers also had experience of providing informal care in at least two places of care, so they typically had a number of experiences to draw on. They spoke at great length about their experience of caring for someone at the end-of-life. The carers were broadly representative of the UK population in terms of socio-economic status. Our methodology brings other strengths to this study; the in-depth nature of the interviews allowed carers to discuss their experiences of the last few months, weeks and days of the cared-for person's life. The analysis of the data supports two models previously cited in the literature; the ecological framework of resilience (Windle & Bennett, 2011) and secondly, the Sherbourne and Stewart model (1991) exploring dimensions of social support.

There are several limitations to our study. It is unclear to what extent the role of resilience is reframed by the experiences of loss and grief. This means that we cannot be sure that these men were resilient at the time of their caregiving, or whether resilience was influenced by caregiving. It is also difficult to unpick

whether we have explored 'stress related growth' as well as resilience amongst the recently bereaved male carers, as literature suggests that growth emerges when substantial distress occurs, although not necessarily for the resilient and hardy (Bonanno, 2005; Caserta, Lund, Utz, & De Vries, 2009). Most of the deaths were anticipated and the grief experience is known to begin prior to the actual loss, giving time to process the event (Schaefer & Moos, 2001). It is possible that the bereaved carer may, by accepting the situation earlier, be able to give more attention to the relationship that will be lost (Folkman, 1997). Therefore our sample may be reporting resources we classify as 'resilient,' when it is the expectedness of death, rather than the participants' own protective factors, that have contributed to their resilience in this situation.

Qualitative research rules out causality and directionality between social support and resilience cannot be assumed. We did not explicitly ask about factors that facilitated or hindered resilience from the perspective of the carers. However, this could be considered a strength as the carers were asked about support and spontaneously discussed the themes above (Becker, 1996). Our total sample of carers in the wider study was 118, but we focused on a subsample of 50, 44 of which in the previous analysis had spoken about social support and thirty of the fifty were men. The other participants in the sample may have something to add to this exploration in terms of why they did not access social support available to them or whether they did not feel they had social support. They also may have contributed to whether or their access to or use of social support hindered or facilitated their resilience. Recruitment of carers for this study was exclusively through GP surgeries with support from the primary care research network. Previous research has reported that friendships are key supportive relationships for carers facing difficult challenges (Donnellan et al., 2017) and in this data, friends were almost completely missing as a group mentioned in the data. GP lists are more likely to contain family member carers than other carer relationships, although this does not explain why family carers only drew on the support of other family members.

I propose an additional two major subthemes in the facilitation of resilience in carers at the end-of-life: the relationships of the health professionals with the carers; and the families' relationships with each other. When exploring social support in a bereaved carer sample, I suggest at least one element of the Sherbourne and Stewart model (1991) is not applicable to the experience of carers

at the end-of-life (positive social interaction). I also propose that the Sherbourne and Stewart (1991) model can be used to describe how dimensions of social support are lacking and that this lack of social support dimensions compromises the carers' ability to negotiate, manage and adapt to significant sources of stress or trauma.

To conclude, my findings suggest that multidimensional support is needed for people who provide informal care for older people at the end-of-life and this is for all carers, male or female. Social support that facilitates emotional well-being and understanding (emotional), increases advice, guidance and feedback (informational), and provides practical, timely support (tangible) is important to people providing informal care at the end-of-life. Health services and other professionals in supportive roles should be sensitive to the tendency of male carers to request and access support infrequently. Social support is not crucial for informal carers to be resilient at this time. However, *enough* support is needed by carers to successfully negotiate, manage and adapt to the end-of-life caring 'work'/ role. If social support is not evident, carers seem to draw strength from individual resources (psychological assets, staying positive, material resources) *if they have them.* Along with drawing on other community and societal resources they may still 'bounce back' and adapt in the face of this stressful event but it seems more difficult to do so without this valuable support. Literature suggests some carers who have previously provided end-of-life informal care would not do so again (Currow et al., 2011) and it is therefore essential that we explore ways to facilitate informal carers in adapting and bouncing back from the adversity of caregiving. Respectful, timely, supportive and clear information would address many of the barriers reported by male carers, and may offer a pathway to promotion of resilience.

Chapter Eight:
Discussion and conclusions

8.1 An Overview

The aim of this thesis was to explore the experiences of older people and bereaved carers who have experienced a move from one care setting to another at the end of life. I have also explored the changing nature of carer support when older people are moved between care settings. Later in this thesis I focus on assets or resources that contribute towards the development of resilience. I addressed four research questions: first, what are the experiences of older people at the end-of-life who move from one care setting to another? Second, what are the experiences of older people and their support from carers when they navigate a move from one care setting to another? Third, how is resilience experienced by bereaved carers who provide care at the end of life? What role do social relationships play in the ability of carers to adapt and bounce back from this stressful situation and what are the experiences of male bereaved carers and how does their experience of adapting to this stressful situation look?

To address research question one, chapter five explored patients' experiences of transitions between care settings at the end-of-life using in-depth interviews. To address research question two, chapter six explored the experiences of carers, from the perspective of the care recipient and the transitions in family caring when their care recipient was admitted to hospital. Chapter seven answers research question three by exploring the dimensions of social support and resilience of bereaved carers when providing care at the end-of-life, and providing an overview of a range of social support types that facilitate resilience. It also explores the extent to which resilience was present in male carers' accounts of their experiences of providing care. Finally during chapter eight I critique the research questions, integrate previous research and synthesise my findings.

There are three important findings of my doctoral work that have implications for theory development. These include:

1. I have suggested building on the existing model of social support (Sherbourne & Stewart, 1991) to include two additional subthemes. I suggest the inclusion of both 'the relationship between health professional

and carers', and 'the carer's relationship with the person they are caring for' as key resources within the experience of end-of-life caregivers. These could be additions to the model or viewed as a way of understanding the existing dimensions in the specific context of end of life caregiving. I also suggest that one element of the model is not applicable to the experience of carers at the end-of-life (positive social interaction) because of the importance at this time of 'end of life care work'.

2. I have explored in detail the experience of men and resilience and reported that being a male caregiver was positively associated with caregiver resilience. However, male carers do not often have their emotional needs addressed and request support infrequently. This has important implications for health services and professionals in supportive roles, as they should be aware of the different ways in which male carers access support.

3. Finally, I propose that the Windle and Bennett (2011) model is modified to take into account the findings from my thesis, including the health care professional and carer relationship in community resources and including special services (end-of-life care provision and/or bereavement services) in to the societal resources list.

8.2 Implications of findings

8.2.1 Research question one: What are the experiences of older people at the end-of-life who move from one care setting to another?

As the participants in my study moved between different health and social care settings at the end of their life, much of their care was characterised by inflexibility and a failure of professional carers to listen. One of the key themes identified was a lack of support across settings. This confirms other research that reports how each transfer between care setting represents a potential threat to continuity and safety of care (Coleman, 2003a). The prioritisation of institutional processes seems

to counter the current drive in the UK to provide personalised care, and may represent a potent barrier to delivering individualised services. As health and social services move to become more integrated, the ways in which institutional processes are harmonised may be particularly important to the delivery of care. The themes of not being heard and the lack of dignity in new and unfamiliar situations also help to portray a picture of a care sector focussed on its own internal workings, rather than the individual care recipient. These are important findings at a time when services are facing austerity measures and may be having to prioritise what they provide. The findings in chapter 6 around the provision of information and care with dignity also supports research stretching back over twenty years that reported it is relatives that provide the majority of care and there is a lack of adequate formal care at home to facilitate the informal care (Addington-Hall et al., 1995; Addington-Hall & McCarthy, 1995).

More recently it has been reported that effective communication and shared decision making, expert care, respectful and compassionate care, trust and confidence in clinicians were the top four most important priorities for patients and their families when dying in the hospital setting (Virdun et al., 2015). Some of these issues are known to be important to patients of all ages (O'Cathain et al., 2008). Such reports of deficiencies in elderly care are not novel, but the experiences of these participants and a range of reports (McGlynn et al., 2003) appear to suggest that suboptimal care may the norm at older ages. Yet, it is older people who are the main recipients of health care, and who stay in hospital for longer periods compared to younger people (who are more likely to have complex health problems). Older people are also more sensitive to changes of setting, changes of staff and routines, medication and information being altered (Henderson et al., 1990; Silverstein et al., 2006).

However, recent analysis suggests that although moving care from hospital to the community may be better for patients (particularly those in specialised care such as end-of-life care services) it is not likely to be cheaper for the NHS in the short to medium term (Imison et al., 2017). The implication is that a reduction of

movements between places of care for older people at the end-of-life is unlikely to decrease in the immediate future, as NHS England looks to further reduce costs.

The importance of this study is in the focus of transitions at the end-of-life. This is a time when older people are at their most vulnerable and movements between places of care have been found to do little to increase their quality of life or improve their symptoms (Hanratty, Holmes, et al., 2012b). I found that that illness trajectories, individual characteristics and social circumstances influence patients' experiences, particularly in relation to continuity of care (Hanratty, Holmes, et al., 2012b). The implication for practice is that as the population ages, and more people join the oldest age category, transitions between care settings become more problematic for both individual and system.

Finally, expectations of services are crucial. The dissatisfaction with services found in the accounts of the participants implies that they expected the service to work as a coherent whole. Although the media support the narrative of an NHS in crisis, the participants in this study, perhaps because of their respect for the NHS, still felt let down when it did not work well for them. It is possible that information provision about what the public, and older people can realistically expect of the NHS in the current funding climate, would be useful in managing their expectations.

Recommendations

My evidence suggests that addressing simple, basic care needs is a relatively inexpensive option that could enhance patients' experiences (Hanratty, Holmes, et al., 2012b). This would contribute to the goal for health policy in England, particularly the 'triple aim' of improving population health and the quality of patient care, while reducing costs (Sikka et al., 2015).

There is work to be done around communication of end of life stage to carers and sometimes, to patients. If this was done appropriately then some of the confusion over the reasons for transitions would be mitigated.

8.2.2 Research question two: What are the experiences of carers who have also navigated a move from one care setting to another, from the perspective of both older people and their carers.

Using qualitative interview methods I explored older people's perspectives on the carers experiences about the impact of hospital admission on established caring relationships. This study, chapter six, included older people with heart failure and lung cancer, but the stroke patients from chapter 5 were not included in this sample. In 12 of the 27 interviews a family carer was also present and made contributions. I found family carers were seen as making significant contributions to maintaining a level of good care throughout the illness trajectory, particularly when the older person was being cared-for at home. On admission to hospital, the influence of the family carer changed and family carers were provided with a less central and crucial role. Their ability to influence decision making and to help or provide care for the older people was greatly reduced. Despite this change in role, my data suggests that family carers endeavoured to provide continuity, support and take responsibility for older adult's well-being across settings. Participants reported that their carers continued to invest considerable effort in maintaining the participant's well-being. This confirms previous research that family carers provide strong support for many older people who are moving from one place of care to another (Payne et al., 2009). This support is thought to enable older people to stay at home longer than they would be able to do if they did not have this support.

This study complements previous findings that family carers facilitate choices for older people about their place of care and death that would otherwise not be viable (Gomes and Higginson, 2006). My data also support previous research that older people who do not have a family carer are at a disadvantage in terms of receiving person centred care (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne, et al., 2009). I have emphasised the role of family carers in providing continuity of care and continuity of care is the focus of considerable research (Parker et al., 2010) but research has omitted the importance of family carers in providing this continuity. These findings contribute to this gap in the literature. My findings highlight how the family carers are relied upon by older people to provide part of their network of professional caring support and how this directly impacts on their

quality of life and welfare. The data that I have presented suggest that supportive family carers improve quality of life and well-being for older people. This study also emphasises the importance of the professional health and social care staff and the informal carers working together; particularly around how the professionals recognise the importance of the role of family carers. The family carers in this sample were drawing on their holistic knowledge of the long term health and well-being of the older person. This is something unlikely to be at the forefront of the minds of the professional carers in a hospital setting when someone is at the end-of-life.

Recommendations

This study yields new insights into the overall experience of end-of-life care for older people, particularly around how the relationships between patients, family carers and health professionals function during this period in time.

The participants in this study told me how it was the family carers rather than the professional carers who met their well-being needs in hospital, even though they may have been demoted to 'second fiddle' in this environment. Given the 'outsider' status of family carers in the hospital setting, providing this level of support for older people in hospital would take a high level of communication skills and sensitivity. There are ways of harnessing this support from carers for the benefit of older people at the end-of-life, particularly as the need to improve hospital care for older adults has been recognised in the UK (Department of Health, 2001, 2006). One option to improve quality of life and well-being in the hospital setting for older people at the end-of-life might be to change the emphasis on family carers filling gaps in professional care, to one where the role of family carers was better understood and integrated into the management of care for older people in hospital.

Secondly, research has highlighted carers feeling excluded by professional health and social care staff as an issue (Department of Health, 2010c; Lowson et al., 2013). By recognising the continuity provided by family carers there might also be scope to improve the well-being of the family carers and the staff involved in the older

persons care. This could include empowering carers to be more at the centre of decision making around the patients care.

8.2.3 Research question three: What is the role of resilience in the experiences of bereaved carers at the end of life, particularly focusing on social support and later, the experiences of male carers.

I report in chapter six that family support plays an important role providing strong support to older people at the end-of-life in a number of ways. Family carers were described by older people as maintaining good levels of care during hospital admission, adapting to their change in role over time (moving from "conductor to second fiddle") and providing continuity of care across movements between care settings. Older people and the family carers who were present in the interviews also reported that the carers drew on their holistic knowledge of the older person when carrying out this caring role. This holistic knowledge would benefit health and social care professionals if time could be taken to encourage joint working.

In Chapter seven I explore the experience of bereaved carers (n=50) drawn from a larger sample of 118 bereaved carers of the 'Transitions' study. The 50 bereaved carers included in this study included 44 who had spoken in-depth about support. They had spontaneously mentioned areas of social support that facilitated or hindered resilience. Resilience was an interesting concept to look at and research has exploded in this area recently (Grande, Stajduhar, Aoun, Toye, Funk, Addington-Hall, Payne, et al., 2009; MacArtney et al., 2015; Monroe & Oliviere, 2007). In the previous studies we explored the experience primarily of older people and one of the key themes was how carers supported older people. In exploring my data on social support from the perspective of bereaved carers, we understand better how carers themselves accessed support and how this support may have contributed to their ability to adapt to and manage social, physical and emotional challenges. I then looked at the males included in the sample above (N=24) and the other men in the wider 'Transitions' sample (N=6/30), a total of 30 men.

My study is crucial in starting to understand what may facilitate resilience in this setting, as bereaved carers reflect back on the situation. It is of particular importance in the current landscape; research reports that some bereaved carers do not want to provide such care again (Currow et al., 2011). If, in the future, family members are unwilling or unable to provide end-of-life care for older people, health and social care will face an increase in demand and costs. Some carer roles that were perhaps expected to be mentioned by men were not. For example, literature reports that intimate and domestic tasks that are part of the role of end-of-life carer may be particularly challenging for men (Calasanti & King, 2007), but issues of this nature were not described by participants in this sample. There are a number of possible reasons for these issue not being described. The nature of the movements between place of care could have resulted in carers not needing to provide this type of care unless the patient was being care for at home. Even at home, men may have accessed more formal help with household tasks and nurses or carers may have provided more intimate care for patients whose main carer was male.

Caring is acknowledged to be a stressful state and it is often informal carers who navigate the changes in the system when people move from one place of care to another (Stoltz et al., 2004). In common with the older people chapter 6 (Hanratty, Holmes, et al., 2012a), and other recent literature (McPherson et al., 2014) the carers in my study had a perception that the system was imposing processes on them, without any recognition of carers' own needs or wishes. These are important findings; no matter the perspective and situation of the person (patient or carer) users of the health and social care system at the end-of-life do not find the system to be "person-centred". Patients, from the perspective of bereaved carers, did not receive respectful treatment. These factors contributed to caregiver distress. This did not seem to be the case when I explored the male data as a discrete set of participants (The Carers Trust, 2014b). It could be that men expect better care from professional health providers (similar to the discrepancy between expectation of services and reality that I reported in chapter five). This may lead them to assume that it is the female caregivers who are receiving better support. It could also be that men expect women to cope better in this role and internalise the shortcomings of the service provision rather than understanding that the service is similar and

that women have an equally difficult experience providing care at the end-of-life Added to that, carers are often in poor physical health (Carers UK, 2014) and caring may have an adverse effect on their mental health (Carers, 2011). Poor physical and mental health are understood better when placed in the context of how carers are expected to operate in a system that dismisses their expertise and creates barriers to their existing role.

Previous research has used the Ecological Framework of Resilience (Windle & Bennett, 2011) to explore how carers interact with their environment, and the operationalisation of resilience amongst dementia carers usefully explores what may contribute to carer resilience in this situation (Soulsby & Bennett, 2015). Other studies have contributed to understanding resilience at the end-of-life (MacArtney et al., 2015), and the factors that contribute to and hinder resilience (Donnellan et al., 2015), although the researchers report that facilitating factors emerged primarily at an individual level. Research has also reported how carers of family members at the end-of-life need more support from health services (McNamara & Rosenwax, 2010). There is a dearth of literature about understanding resilience during end-of-life care work from the perspectives of bereaved carers, and in particular from male carers.

The participants discussed a plethora of examples of resources facilitating resilience such as material resources and emotional support in caring for the patient. Useful, timely and tangible support and decision making and choice were also key themes. A lack of acknowledgement of the caregiver's role, limited emotional support, poor relationships with health professionals and family, and a lack of informational support were seen as barriers to resilience in the participants accounts. These findings confirm previously published research in carers of people with dementia (Donnellan et al., 2017).

Older carers have worse long term bereavement outcomes on a number of measures (less social, economic and service support to cope well) and I have contributed to this literature as the majority of participants (83%) in this study were over 60 years old. Men are generally underrepresented in research into caring,

even though reports suggest that 40% of carers of older people are male. This in-depth exploration of 30 male carers adds to the limited literature on this topic.

My data suggested that the relationship between social support and resilience is not linear. For example, some participants were classified as resilient without having a supportive family providing all the support that the person perceived they needed. Other participants were classified as resilient without good working relationships with the health professionals involved in the end-of-life care work. The second way in which my work is novel lies in my use of the social support model (Sherbourne & Stewart, 1991) used to identify distinct dimensions of social support in people who are caring for people at the end of life, rather than caring for people with dementia. This model identifies five dimensions of social support including emotional support, affectionate, tangible, informational and positive social interaction. I explored the five dimensions in my data. I then used the ecological framework of resilience to organise the dimensions of support into assets and resources. The individual assets that were paramount to building resilience for carers included support from the care recipient. Carers particularly benefited from the emotional support of the person they were caring for, and the ability of the care recipient to navigate the system together with the carer. Carers wanted more support from wider family than they received and this was conceptualised within the 'community resources' element of the ecological framework of resilience. This indicates one of many possible reasons as to why carers often report feeling isolated and in poor physical and mental health; caring is particularly stressful without support from their own immediate family. Multidimensional support from health professionals and a system favouring processes over carer's wishes are facilitators and barriers to resilience respectively. Similarly to findings from chapters five and six, 'the system' is seen as imposing, in both the way it imposes its agenda on carers as well as being an imposing barrier to facilitating informal care, and is hindering carers carrying out their role to the best of their ability.

Recommendations

I propose two additional subthemes in the social support model; the 'relationship between the health professional with the carers' and the 'family's relationships with each other'. These were both paramount relationships; in the absence of them

working well, it was difficult for the carer to enhance resilience through social support. The 'positive social interaction' element from the model (Sherbourne & Stewart, 1991) was not useful in analysis of these data because of the important at this time of 'end of life care work'. This is important because although my analysis supports the model it also highlights how the model could be adapted to better conceptualise the experience of carers of people at the end-of-life.

Further research is needed to explore the individual context and individual expectations from the perspective of the users of the services. These perspectives are crucial to develop a more personalised health care experience. It would be useful for services to be proactive and offer support particularly as it is the older males who have worse long term bereavement outcomes as men infrequently seek support. There is guidance in the UK to offer caregiver support and advocacy services but that this was only reported to have been offered in one out of the thirty interviews with the participants (Relf, Machin, Archer, Smale, & Rushton, 2010). Merely increasing the importance of social support, from an education or interventional perspective (difficult itself to do) would not ensure that all carers have more resources to facilitate resilience.

8.3 Limitations of this work

8.3.1 Participant selection

The recruitment of participants for my doctoral work was challenging. Gaining access to this potentially vulnerable population required me to build relationships and liaise with a number of gatekeepers. As described in the methods section, and chapter 4 comparing the methods of recruitment, many health care professionals were involved in the recruitment to this study. This meant that it was difficult to keep recruitment selection consistent across settings, and there was inevitably some variation in the application of selection criteria. For example, although the medical consultants were asked to select people over the age of 75 years for inclusion in the patient perspective studies, this was sometimes overlooked. When challenged, consultants confirmed they had selected some people they thought to be over 75 years old, based on physiological, physical and cognitive presentation,

but who were in fact in their late 60's or early 70's (n=3). This apparent lack of coherence in the sample was a problem when presenting findings and discussing the experiences of 'older people,' when in fact a couple of participants were only just older than retirement age. However, it is also a strength, because the consultants identified participants who they felt would be able to discuss at length their condition, treatment and end-of-life care and this was not arbitrarily defined at a set number of years of age. It is also interesting that the consultants identified these participants by their physiological presentation rather than their chronological age. Looking forward, the former is perhaps a better guide to experiences at the end-of-life, and an appropriate way to select participants for this sort of research.

Related to this, are the decisions the clinicians made when selecting participants to be approached about the studies. We do not know whether there was a sampling bias so that participants were selected by health care professionals on the basis of their (perhaps positive) experiences of the health care setting, although there is no evidence that this is the case. It was certainly not typical for the participants to have had overall positive experiences moving between places of care, or caring for someone at the end-of-life. They might have also selected particular participants because they might 'cope well' with the interview, be particularly eloquent or have particular views that HCP's thought might support the study hypothesis. It is also possible that the participants selected were chosen because they were in better health than the average person on the clinicians list. This may have been pertinent if the clinicians wanted to ensure the participants were not overburdened by the interview. This could have implications for the experiences in the last few months of life as perhaps some of the participants were not experiencing end-of-life care that we explored with the other participants. It is difficult to ascertain whether participants were selected on this basis. However, the data is rich, and the experiences are varied, representing both positive and negative aspects of care and as the HCP's played no part in any other aspect of the study it is unlikely that any selections they did make influenced the study. Moving forward, brief information (verbal or written) could be provided to health care professionals that are recruiting to studies to explain to them how it is important they do not influence participant

selection based on ideas of what we might be looking for as researchers, or the experiences, good or bad, of the participants.

8.3.2 Participant recruitment

There were a disproportionate number of participants from disadvantaged areas included in the patient perspective studies. This may have skewed the sample so that the experiences of higher socio-economic status older people were not being explored. This could also have implications for the issues described with navigating the health care system as people who have low SES are more likely to have poor education levels creating potential difficulties with communicating and working within complex health care structures. However, on balance this was also less of an issue than first thought. Participants from low SES groups are under-represented in research studies and are likely to have greater needs. It is more difficult to access participants and include them in research when they are from deprived backgrounds. This is therefore a key strength of this work. The participants from low SES groups are likely to have less resources to facilitate resilience than other people. The participants were also largely representative of the area they lived in and they represented the population that typically would have lung cancer or heart failure. The diversity of the sample in this sense was good, and participants had a range of experiences. Enough familiarly of experience was present to focus on a dominant message within the analysis. We did explore the experiences of a number of participants from higher socio-economic statuses so they are still represented within the data. The experience of health care services should not vary with the social background of the patient, so this was also a strength of the sampling strategy. For future research, it would be interesting to have a broadly equal socio-demographic population and this could be achieved by requesting that the HCP's recruit both lower and higher SES participants recruit to these groups in equal numbers. Alternatively, we could sample and recruit participants from high SES backgrounds and compare experiences.

Another recruitment limitation is the differences in transition experience. Firstly, looking at the older people's end-of-life experience, collectively, participants (n=30) had moved 67 times between care setting in the final three months before being

interviewed. However, some participants had one movement and other may have had five. Some participants moved backwards and forwards (hospital to home to hospital to home) and other had moved to a variety of care settings (home to hospital to care home to hospital). Typically, lung cancer patients had less inpatient hospital admissions compared for those with heart failure or stroke. They also had more contact with consultants than participants in the other illness categories. We expected that different disease trajectories would be associated with different needs for different care settings and this was the case, but the themes that emerged were common to all conditions. This gives confidence to the findings having relevance beyond the older people we interviewed. Focusing on a limited number of transitions in detail would perhaps have provided us with richer data about a specific experience, but it would not have the breadth of data we have in this study. Older people move from a variety of places of care, to other places of care, and the number of moves differ based on many factors. Future research could explore the experiences of stroke patients in greater detail as we only recruited 3 older people and 36 bereaved carers of people with stroke, so this aspect of the study requires further investigation.

Finally, the final limitation I will discuss is the selection of discrete groups of participants for analysis in chapters within my thesis and subsequently in the papers published. The main difference between this chapter and the other results chapters is that the other results chapters were analysed inductively and through taking this approach to chapter seven, which had the objective of testing theory, we analysed the data deductively. This approach did fit with the aims of this thesis in that it explored a model of social support (Sherbourne & Stewart, 1991) whilst using the Ecological Framework of Resilience (Windle & Bennett, 2011) to organise the data. A strength of this thesis is the contribution I have made to develop the social support model from the perspective of bereaved carers caring for a loved one at the end of life.

There are a number of problems with this way of analysing data. It is possible that we missed other accounts from participants because we did not explicitly ask about social support in the interviews. It is possible that the participants who did not

explicitly talk about social support had so little social support that it did not occur to them to mention it. This would mean there was a variation in the support carers received in providing care at the end-of-life. It is also possible that their experience of caring for someone at the end-of-life was so stressful that they did not have time to accept social support. This could imply that the participants who did not speak about social support had a more demanding caring experience than people who did talk about it, not because of the access to social support but because of the fundamental end-of-life care work. Social support if present, which we are unsure about, could have made their end-of-life care work more difficult or stressful. It is also possible that those participants who did talk about social support and who accessed social support did less end-of-life care work than the people who did not have time to access social support and so the fundamental experiences of the group who accessed social support and the group who did not, was different. Conversely, it could be formulated that participants who did talk about social support were more resilient because they utilised resources available to them. On balance, this study does add to the literature about how formal and informal social support can facilitate resilience in carers. It also adds to existing psychological theory in extending a model of social support (Sherbourne & Stewart, 1991) from the work on dementia carers to people who provide end-of-life care. It also highlights other uses for the Ecological Model of Resilience as a form of conceptualising and organising factors that facilitate or hinder resilience. Although the nature of the analysis was deductive in using the data to test existing theories and models, it was also inductive in that the theme of social support was spontaneously mentioned in many participants' accounts and therefore the exploration of the theme in the first instance was inductive. In future work, it would be important to ask similar questions of all participants. We could then be clearer about the reasons for the lack of social support and the reasons why social support was not, or could not be accessed would be clearer.

However, discrete groups selected for further analysis are not always a limitation. For example, in chapter 7, I have explored the experience of men who have provided care at the end-of-life as a sub section of this chapter. When scoping the literature, it seemed an area of research that needed further exploration as over

40% of men are caregivers, yet typically their experiences are not reported in the literature as frequently as the experiences of women. Selecting discrete groups within large data sets are particularly useful when focusing in-depth of the experience of that group. Less is known about what facilitates or hinders resilience for men and whether men experience the factors differently to women. I think that exploring discrete groups of participants or themes within this thesis is a strength of the work as it provides in-depth exploration of discrete issues and because of the breadth and richness of the data, it adds to the limited literature on the experience of male caregivers.

8.3.3 Methodological limitations

It is unclear to what extent the role of resilience is reframed by the experiences of loss and grief. It is possible that we could have explored stress related growth (SRG), not resilience, particularly in the chapters exploring the resource of social support and resilience and, in the chapter exploring the experience of male caregivers. Stress related growth (SRG) is when, after a traumatic event, the individual emerges with a new-found sense of strength. It suggests a transformation on the part of the individual that goes beyond adaptation or "not simply a return to baseline" (Tedeschi & Calhoun, 2004, p. 4). Literature reports that SRG is experienced more frequently by older people than younger people and this is thought to be due to their propensity to learn from prior experience (Schaefer & Moos, 2001). The majority of bereaved carers in my sample were in the second half of their lives, so this is a plausible argument. Social support is a resource typically associated with SRG, and social support could potentially help bereaved carers address the challenges of stressful situations. However, research by Caserta, Lund, Utz and de Vries (2009) reports that social support has virtually no relationship with SRG and it is other factors, like religiosity and the anticipated nature of the death, that increase SRG. Religion was not explored in my analysis, but many of the participants in the study did anticipate the death of the older person. The implication here is that it could be the anticipatory nature of the death that has contributed to resilience rather than other assets and resources. Other research posits that it is the culmination of surviving past challenges and potentially previous bereavements that could increase resilience in this situation (Bonanno, 2005; Windle & Bennett,

2011). This latter research supports my focus on social support and resilience. The social support described by participants in my study focused on what was received at the time of end-of-life care work, and was not a reflection on social support during the grief stage. Also, the two additional subthemes of the Sherbourne and Stewart (1992) model of social support, suggested for inclusion in my study, were the relationship between health professionals and bereaved carers and the relationship between bereaved carers and patients. Without these relationships working well it would be difficult for social support to facilitate resilience. These aforementioned relationships will have (usually) ceased with the death of the cared-for person. Therefore, we can be sure that it is not social support that is facilitating stress related growth, but facilitating resilience.

Wortman (2004) suggests that men are more likely to experience growth after bereavement because the bereavement tends to be more challenging for men than women (Wortman, 2004; Wortman, Silver, & Kessler, 1993) and this is confirmed by other studies (Bonanno, 2004). However, research has since reported no statistically significant relationship between SRG and gender and reported that men and women are equally likely to experience SRG during bereavement (Caserta et al., 2009). However, further exploration of the relationship between SRG and resilience is needed. We cannot be sure that the men in our study were resilient at the time of their caregiving, or whether resilience was influenced by providing care.

8.4 Future directions

End of life research often recruits to studies from a denominator population of unknown size and inconsistency of gatekeeping by clinicians. To resolve these issues and enable researchers to develop robust studies a review of the organisational barriers to end of life research in primary care is required. There are many things we did not ask about during data collection and also there is data that is yet to be fully explored. I explored transitions at the end-of-life from the perspective of patients and bereaved carers and also added to the psychological literature on resilience, specifically the importance of social support and the factors that facilitate or hinder resilience in men who are bereaved. One interesting

oversight in the bereaved carer data, is that I did not find out about the opportunity costs of providing care at the end-of-life, and what the carers might otherwise be doing with their time. This is crucial; it may be that the carers have self-selected as people who have the time and resources to provide end-of-life care. This would imply they already had many of the assets and resources to facilitate resilience. In some ways, this self-selection would contribute to their resilience before the 'adverse event' of providing care at the end-of-life. It is also important because it would mean we have missed out on exploring the experiences of people who have not self-selected, but for other reasons have become carers. It would be interesting to find out how the carers would classify themselves, and how their experiences may be different to the other group, if they identify with one of these groups.

We also did not ask about the financial burden on carers. This is an important area to explore. Finances influence whether or not a range of resources are available for the carer to draw upon (e.g. material resources, access to health and social care support, housing, employment, family and social participation). In the interviews, costs were described, in terms of providing equipment and car parking charges and similar expenses. However, if the carers were all able to have the financial resources to care for someone then this equips them with another factor known to increase resilience- material resources. We do know the socio-demographic structure of the sample, but this does not necessarily correlate with the financial resources they have available to provide care. Literature suggests that many carers would not offer to care for someone at the end-of-life again (Currow et al., 2011). We are unable to determine if this is also the case in our sample of bereaved carers. If this is the case, it is unclear, how society will strive to replicate the expected decrease in informal carers, not least because of the numbers of hours and continuity required. It would be useful to explore some tangible options with bereaved carers who may be able to advise on how their informal role could be made more attractive.

Finally, some of these data were collected almost a decade ago. The landscape of the health and social care service and the provision of end-of-life services has changed. Services have been under funded and under staffed since the experiences of the participants in this study were collected. Integration of health and social care,

and bridging the gap between hospital and community services have risen up the policy agenda, though translation into service change is slow. The social world has changed too and social media and the internet are used by older people more than ever before. The implications for this include the availability of wider support networks (including virtual ones) and easier access to health care information. Availability of support and information may change the experiences of both patients and carers. Even so, it is unlikely to contribute to the basic care aspects like continuity of care and being treated with respect. It is also more likely to increase the importance some of the individual assets that facilitate resilience such as age, material resources and health behaviour. As typically it is younger and better educated adults who make best use of technological advances. Further research should explore whether transitions are still so disruptive for older people and their carers; whether men's experiences of seeking support are the same even in the super connected world we live in now; and whether social support and relationships with health care professionals are still key to facilitating resilience for carers providing end-of-life care.

8.5 Conclusions

Simple, basic care needs to be addressed to enhance patient and carer experience, contributing not only to better experiences from the perspectives of service users, but also to the 'triple aim' of improving health and quality of care whilst reducing costs. Carers draw on a range of individual assets, community and societal resources to facilitate their capacity for resilience in this stressful situation. One obvious resource that could facilitate carers resilience in this end-of-life care 'work' is increasing the communication and positive relationship between health professionals, carers and patients, and more generally, increasing social support. Carer support across health care transitions needs to be harnessed and integrated into formal care settings and increasing the positive working relationships between staff and carers would address both of these areas of concern. In addition, it would be useful for services to be proactive and offer more specialist support, to all carers, but perhaps particularly older males who have worse long term bereavement

outcomes than women. My doctoral work has made a start by exploring the experiences of carers providing care at the end-of-life and assets or resources that contribute to their resilience. The Windle and Bennett (2011) ecological framework of resilience was useful to explore the factors that facilitate or hindered resilience. This data has highlighted that there are a number of previously unexplored assets and resources during end-of-life care work. Although it has been widely used with other groups, modification could perhaps be made to enhance its applicability to informal carers of people at the end-of-life (see Figure 6). I propose adding 'social support' to the community resources as I report in chapter seven that social support is fundamental to facilitating resilience.
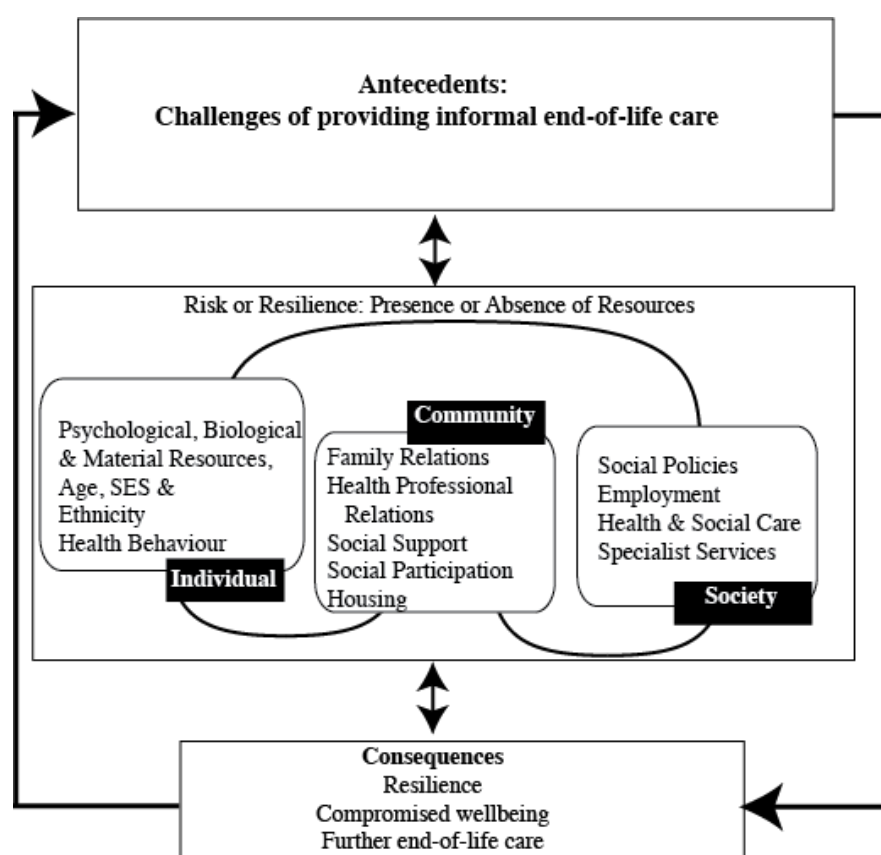
Figure 5 The Resilience Framework Applied to Informal Carers of People at the End of Life

I would also include 'health professional relations' within community resources, as throughout the data chapters in the thesis (chapters five, six, seven) the relationship between patient, carer and health professional seems crucial in enabling communication, participation in decision-making and good quality care. It is when these things are absent, as well as other aspects of basic care like continuity and dignity that the carers seem to have a particularly stressful time co-ordinating and providing care. Therefore, the relations with the health professionals when providing end-of-life care are an important resource that facilitates resilience and may be beneficial to include in the model. I have also removed 'social cohesion', as during the intense period of end-of-life care 'work' this did not seem to contribute towards resilience. Finally, in the societal resources, 'neighbourhood' could be removed. In terms of the geographical 'neighbourhood' of older people and carers, the (in)accessibility of services didn't seem to hinder resilience. Many of the carers reported traveling long distances to visit older people who had been moved from one setting to another. Looking at 'neighbourhood' in terms of people like friends and neighbours, it was striking in the data that friends and neighbours were not mentioned as providing support or assistance, contrary to other studies of dementia carers (Donnellan et al., 2017). This is discussed more in chapter seven. I have also included 'specialist services' in the societal resources because it is the specialist service provision (e.g. hospice care, end-of-life community care, palliative care treatment) that seems to make a difference in terms of the carer adapting to the change in situation. This revised model may be useful to further explore end-of-life carer perspectives. It may also be useful in developing practice and policy that is personalised for carers during end-of-life care.

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Appendices

Appendix 1: Objectives of the NIHR SDO funded 'Transitions' study

The Transitions study

The aim of "Transitions" was to understand the patterns and causes of health service transitions and their association with older people's experiences at the end-of-life. The objectives were:

1. To map transitions in and out of hospital at the end-of-life for older people in England.
2. To estimate the financial costs of transitions at the end-of-life.
3. To identify individual and service level factors associated with frequency of transitions.
4. To explore the effect of transitions towards the end-of-life on health status, quality of life, symptom control and satisfaction with care.
5. To understand the factors that influence decisions about transitions in the nature and location of care.
6. To elicit patient and provider views on the appropriateness of different transition patterns and the factors that constrain or shape decisions.

Citation:

Hanratty, B., Lowson, E., Grande, G., Payne, S., Addington-Hall, J., Valtotra, N., *et al*. Transitions at the end of life for older adults- patient, carer and professional perspective: a mixed method study. Health Service Delivery Research 2014; **2** (17)

Appendix 1: Ethical approval for patient interview phase

Sefton Research Ethics Committee
Victoria Building
Bishops Goss Complex
Rose Place
Liverpool
L3 3AN

Telephone: 0151 330 2051
Facsimile: 0151 330 2075

06 May 2009

Dr Barbara Hanratty
Division of Public Health
Whelan Building
University of Liverpool
L69 3GB

Dear Dr Hanratty

| **Full title of study:** | **Transitions between services at the end of life for older people - patient and provider perspectives** |
| **REC reference number:** | **09/H1001/51** |

The Research Ethics Committee reviewed the above application at the meeting held on 29 April 2009.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date	
Interest form	1	08 April 2009	
Participant Consent Form	1	08 April 2009	
Participant Information Sheet	1	08 April 2009	
Letter of invitation to participant	1	08 April 2009	

Interview Schedules/Topic Guides	1	08 April 2009	
Letter from Sponsor		08 April 2009	
Protocol	1	08 April 2009	
Investigator CV		08 April 2009	
Application		08 April 2009	

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Vice Chair.

Further information or clarification required

- Question A18 states the research assistant Louise Holmes will interview participants. What is her experience? Question A6-2 states that the researcher in Liverpool has a first degree and masters in Psychology and experience of working with vulnerable adults in a clinical setting. Does this refer to Louise Holmes? Her CV should be provided as this is a very sensitive role.
- Who will be taking consent? A30-1 states a meeting will be arranged. Will consent be taken at this meeting and participants then continue to be interviewed in the same slot?
- What will the researcher do if there is a lack of care or major complaint against the healthcare team disclosed?
- Clarify how aware the participants are of their life-limiting diagnosis.
- Question A6 mentions that participants may have an unrealistic expectation of the role of the researcher. It should be made clear on the PIS that researchers will not act as an advocate.
- Question A22 mentions a counselling service for the researchers. More details are required to show the adequacy of the support for participants
- Permission to speak to patients should be obtained from care home managers.
- The University indemnity certificate should be provided.
- Question A31 states that participants could respond to publicity about the research. What is this? A copy should be provided.
- The Participant Information Sheet should state that confidentiality will be broken if risk of harm to participants or others is revealed.
- The Consent Form should include a standard statement to allow access to medical notes by regulatory authorities.

> 'I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [company name], 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.'

- There is no need to inform the GP and this could be deleted from consent form.
- Consent for audio taping should be gained from participants on the consent form.
- Question A12 states that the results will be complemented by analysis of national data and interviews with bereaved care givers and with providers and commissioners of health and social care. The Committee confirms they are only reviewing the part of the study involving terminally ill patients.
- Please note typo in A13 – should read 'don't' underestimate?

When submitting your response to the Committee, please send revised documentation where appropriate <u>underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates</u>.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 03 September 2009.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. However, all researchers and local research collaborators who intend to participate in this study at NHS sites should seek approval from the RandD office for the relevant care organisation.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| 09/H1001/51 | Please quote this number on all correspondence |

Yours sincerely

Mrs Elizabeth Sinker
Vice Chair

Email: kayleigh.roberts@liverpoolpct.nhs.uk

Enclosures: *List of names and professions of members who*
                       were present at the meeting and those who
                       submitted written comments.

Copy to: *Dr Sarah Fletcher*
                      [RandD Department for NHS care organisation at lead site]

Sefton Research Ethics Committee

Attendance at Committee meeting on 29 April 2009

Committee Members:

Name	Profession	Present	Notes
Dr Adegoke Adejumo	Consultant Anaesthetist	No	
Dr Douglas Anglesea	Retired Senior Lecturer in Microbiology	No	
Dr John Brindley	GP	Yes	
Mr James Burns	Lay member	No	
Mr D Eccleston	Senior Chief Biomedical Chemist/Manager of Cellular Pathology and Immunology	No	
Ms Gillian Grundy	Rheumatology Specialist Nurse	No	
Ms Patricia Harvey	Hospital Chaplain	Yes	
Mrs Christine Haywood	Clinical Services Manager	Yes	
Mrs Maureen Hendry	Pharmacist	Yes	
Dr Ben Johnson	Consultant Psychiatrist	Yes	
Miss Karen Knowles	Biomedical Scientist	No	
Dr Peter Owen	Chairman	Yes	
Mrs Elizabeth Sinker	Vice Chair	Yes	
Ms Lyvonne Tume	Lecturer Practitioner of Paediatric ICU	Yes	
Mr Mike Williamson	Consultant Urologist	Yes	

Appendix 2: Ethical approval for bereaved carer phase

08 February 2010

Dr Barbara Hanratty
Clinical Senior Lecturer in Population and Community Health
Division of Public Health
Whelan Building
University of Liverpool
L69 3GB

Dear Dr Hanratty

Study Title:	**Transitions between services at the end of life for older people - patient and provider perspectives**
REC reference number:	**10/H1005/16**
Protocol number:	**1.0**

The Research Ethics Committee reviewed the above application at the meeting held on 03 February 2010. Thank you for attending to discuss the study.

Ethical opinion

The Chair welcomed you and Louise Holmes to the REC

The Committee commented that this is a very full and comprehensive Participant Information Sheet and wondered whether people would be prepared to read it all. You said that you had followed the guidance but acknowledged that you do expect a high proportion of participants and carers to be elderly. The intervention will take about 90 minutes but you will acknowledge the fact that participants might tire and if this happens they can stop.

The Committee asked about translation given the response at A33 and you said that you had not applied for funds for translation but could do so if the Committee requests. However, this could potentially cause other problems as to methodology

In response to the Committee's enquiry you advised that the questionnaire

is a combination of VOICEs which is well validated and some questions adapted from an American tool which has also been validated. The qualitative element does not require validation. In other words the first two component parts have been validated separately but not the unit as a whole.

The Committee asked why only three conditions were being studied and you explained that this was to give some coherence – they are three very contrasting conditions which they hope to be able to generalise to similar conditions

The Committee pointed out that participant medical notes are not being accessed and therefore the reference should be omitted from the Consent Form

The Committee asked whether the questions can be analysed separately and you stated that this is the intention – the qualitative part will be analysed separately and the quantitative should be comparable to the VOICEs questionnaire

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC RandD office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("RandD approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the RandD office should be notified of the study. Guidance should be sought from the RandD office where necessary.

Sponsors are not required to notify the Committee of approvals from host

organisations.

    a.   the Committee would like the questionnaire to be checked for grammatical mistakes e.g. question 24 of the Admission to hospital which does not make sense and should be corrected

    b.   the Committee would like the reference to medical notes to be omitted from point 4 on the Consent Form

   The Committee suggests you make enquires for funding for translation but this is not a condition of the favourable opinion

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date	
REC application	2.0	15 January 2010	
Protocol	1.0	14 January 2010	
Investigator CV			
Participant Information Sheet: Research into services for people at the end of life	1.0	14 January 2010	
Participant Consent Form: Participant copy	1.0	14 January 2010	
Letter of invitation to participant	2.0	14 January 2010	
Letter from Sponsor		17 April 2009	
Participant Consent Form: Reseracher copy	1.0	14 January 2010	
Questionnaire: Non Validated	6.0	14 January 2010	
Advertisement	3.0	14 January 2010	
Modified Life Grid	1.0	14 January 2010	
Script	3.0	14 January 2010	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures. We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1005/16	Please quote this number on all correspo

With the Committee's best wishes for the success of this project

Yours sincerely

Professor Sobhan Vinjamuri
Chair

Email: carol.ebenezer@northwest.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers"

Copy to: *Miss Sarah Fletcher*

North West 2 Research Ethics Committee - Liverpool Central
Attendance at Committee meeting on 03 February 2010

Committee Members:

Name	Profession	Present	Notes
Dr Derek Adams	Consultant in Restorative Dentistry	Yes	
Professor Ronald Anderson	Lay member	No	
Mrs Julie Brake	Specialist Diabetes Nurse / Vice Chair	No	
Mrs Joanne Charing	Lay member	Yes	
Miss Carmel Dersch	Lay Member	Yes	
Mrs Sheila Gill	Lay Member	Yes	
Mr Christopher Herring	Senior Pharmacist	No	
Mr Derek Hollingsbee	Pharmacist	Yes	
Mr Frank Killen	Lay Member	No	
Dr Fred Mostafa	Consultant Anaesthetist/Intensivist	Yes	
Mrs Jennifer Newman	Lay Member	No	
Dr Stephen Pennefather	Consultant Anaesthetist	Yes	
Dr Rebecca Smyth	Research Midwife	Yes	
Professor Sobhan Vinjamuri	Consultant in Nuclear Medicine	Yes	
Dr Helen Wong	Lay Member / Statistician	Yes	
Mrs Dorothy Zack-Williams	Health Visitor	Yes	

Also in attendance:

Name	Position (or reason for attending)	
Mrs Carol Ebenezer	Committee Co-ordinator	

Written comments received from:

Name	Position	
Dr Derek Adams	Consultant in Restorative Dentistry	
Miss Carmel Dersch	Lay Member	
Mr Christopher Herring	Senior Pharmacist	
Mr Derek Hollingsbee	Pharmacist	
Dr Fred Mostafa	Consultant Anaesthetist/Intensivist	
Dr Stephen Pennefather	Consultant Anaesthetist	
Dr Rebecca Smyth	Research Midwife	

Appendix 3: Agreement form for patients to opt in

Interview Study –
Research into Services for Older Adults

RETURN THIS FORM IF YOU ARE INTERESTED IN TAKING PART

I have read the information sheet and am interested in being interviewed for this study.

My name is……………………………………………………..

My telephone number is…………………………………….

OR, DON'T telephone me, INSTEAD please call

Name……………………………………………………………………

Number………………………………………………………………

Relationship to me………………………………………………

MY address is (OPTIONAL – you do not have to tell us if you do not wish)

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

……………………………………………………………………

………………………………….

POST THIS TO US IN THE ENVELOPE PROVIDED.

<u>YOU DO NOT NEED TO ADD A STAMP.</u>

Send it to Louise Holmes, Division of Public Health,

University of Liverpool. L69 3GB

0151 795 0376

Appendix 4: Invitation letter from GP surgery for bereaved carers

UNIVERSITY OF
LIVERPOOL

SURGERY LETTER HEADED PAPER

Dear [**Name of potential participant**],

[**GP Surgery name here**] is involved in a study with the University of [Liverpool or Southampton], which aims to understand more about older people's experience of health and social care at the end of life. We are writing to you because your own doctor or nurse has suggested that you may be eligible to take part.

The researchers are interested in talking to local people who cared for a relative or friend aged over 75 years who died recently with chronic obstructive pulmonary disease (COPD), heart failure, stroke, breast cancer, colorectal cancer or lung cancer. People who take part will be asked to spend up to an hour and a half talking about their experiences and any services that their relative or friend received.

We have enclosed an information sheet about the study with this letter. If, after reading it, you think that you may wish

to be interviewed, please contact the researchers. You can either send them your name and telephone number in the stamped-addressed envelope, or contact them by telephone [researcher telephone number]. If you don't want to take part, then you do not need to do anything. No one will contact you.

If you have any questions please contact [Researcher name] on [Researcher number] or email [Researcher name] at [email address].

Thank you very much for taking the time to read this letter. We realise that it may be upsetting to talk and think about your experiences at this time, and hope that this letter has not brought back too many painful memories. We hope you will share our interest in improving care for people at the end of their lives, and understand why we have contacted you at this sensitive time.

Yours sincerely,

[GP Surgery name here]

Appendix 5: Telephone script to arrange interview

ARRRANGING FURTHER INFORMATION/ INTERVIEW

My name is Louise Holmes. I am a researcher at the University of Liverpool. Your GP or nurse has recently sent you some information in the post about our study called "Transitions". It was asking you whether you would be interested in talking to me about the care your relative received at the end of their life.

You may remember from the letter that we like to know more about our impression of the health and social care that your relative received.

Might you be interested in taking part in the research/ do you think you might like to be interviewed?

IF AGREES TO PARTICIPATE –

That is great- The interview will take about an hour and I would like to tape record the interview so I can type it up later, will that be acceptable to you?

Would it be possible to take your address so I can send you some further information about the study? (take address). I can then either phone you in a week or so, to arrange an interview day and time, or we can do that now? (participant chooses as appropriate).

Can I just say a few words about confidentiality? What we talk about during the interview will be kept completely confidential. Only direct members of the research team will hear the recording of your interview. Recordings will not be labelled with your name and any written record of your conversation will be fully anonymised – no one will be able to identify you and what you have said to us.

If you think of any questions for me relating to this study, please make a note of them, and I will try and answer all of them when I see you. If you change your mind about taking part, that's OK, please let me know. You can contact me by telephone or post or email if you have access to it.

Give out contact details, in case they need to rearrange interview or if they change their mind about taking part. Agree convenient time to telephone them prior to interview, to ensure that they are still willing to take part (on the day of the interview, or the day before) or agree a convenient time to telephone them to arrange the interview after receiving the information.

Check address/directions.

Thank-you and goodbye

IF DECLINES TO PARTICIPATE –

That's fine, I understand that not everyone will want to talk to me. Thank you for your time.

IF EXPRESSES INTEREST –
Would you like me to explain a little more about what would happen if you do agree to take part? [Provide explanation as appropriate]
Do you have any questions that you would like to ask me, at this stage?

IF REMAINS UNSURE WHETHER TO BE INTERVIEWED, AND WOULD LIKE MORE TIME TO CONSIDER / DISCUSS WITH OTHERS:

Here is my number (give number). If you think you might be interested when you have had more time to think about it, then please give me a call.
I would like to reassure you that I WILL NOT contact you again, although I am happy for you to ring me, if you change your mind.

Remind them where the contact details can be found if they change their mind.

Thank-you and goodbye

Have you cared for someone aged over 75 years old who has recently died from stroke, lung cancer or heart failure?

Researchers at the University of Liverpool are looking into people's experiences of health and social care towards the end of life.

They want to talk to people aged over 18 years old, who have cared for a relative or friend who died in the last year

- Aged over 75 years

- Who had a stroke, or heart failure, or lung cancer

- Who moved from one place of care to another in their last months (e.g. from home to hospital, hospital to care home/hospice etc)

You do not need to have lived with the person you cared for.

Please contact Louise Holmes on 0151 795 0376 or email her on louise.holmes@liv.ac.uk if you would like to know more, or are interested in taking part.

Appendix 7: Topic Guide for patient interviews

Transitions between services- patients' perspectives

'Transitions' – Note for Research Ethics Committee

- 'Transitions' occur between locations or settings of care, as in a move from hospital to care home. They may also represent a shift in the nature of care, such as the decision not to continue with curative treatments.

- Our interviews will focus on moves between care settings. However, the interviewees will also have the opportunity to talk about shifts in the nature of care, if they wish.

Objectives

- To explore number and nature of transitions
- To explore experience of transitions from patient's perspective
- To explore understanding of disease and impact of disease
- To explore effect of transitions on physical, mental and emotional health as well as financial concerns and family relationships

---

Content of Topic Guide

1. Introduction

2. Life History

3. Understanding of Illness

4. Nature of Transitions

5. Understanding of Transitions

6. Effects of transitions

7. Ending

8. Questions

1. Introduction

-Name and position of researcher

*RA within University of Liverpool- experience of interviewing before.

-Nature of study- collaborative partners and reason for study.

*Other Universities mentioned.

*Outline and purpose of study

2. Brief Life History

Encourage detailed coverage of level of education and occupation for socioeconomic analysis.

-Childhood and family background

-School life/ education

-Working history

-Family life previously and currently

*Where has main home been

*Number of children/grandchildren if any

*Living arrangements before illness/ after illness

-Marital status

*Changed throughout life

3. Illness Understanding

-Lifespan of illness

*First diagnosed, how long, other illnesses

-Who diagnosed and explained illness

Numerous people/ Person in authority/ Family members

-Family knowledge

Family expertise

Family support

Family issues which have increased/ reduced support

-Own previous knowledge

Increased since diagnosis

Lacking

Improvements regarding type/amount of information.

-Expectation of future

Knowledge of expected course

Emotions-hope/denial/frustration/upset/control

4. Nature of Transitions

-How many in last 12 months

Where to/ where from

Why

Decision of yourself/carer/family/services

Feelings about decision

-How many in last 3 months

Where to/from

Why

Decision of yourself/carer/family/services

*Feelings about decision

Feeling about nature of care

*For patient/Family/Care staff

*Knowledge of team/familiarity with main health professionals

-Satisfied with number/nature

*Happy with information

*Choice

*Practicalities

*Care services

*Improvements

5. Understanding of Transitions

-Transitions explained? How? By whom?

*How did you feel

*How did family feel

-Understanding of place of care now

*Would like to stay at place/ Wouldn't like to stay

*Move on/would like to move on

6. Effects of transitions

-Physical/ Mental/Emotional/Social

*Impact on physical health problems- pain, discomfort, medication

*Impact on mind- feel better/ worse/ are you worried at all/ scared

*Emotional- do you feel more comfortable here/ happier/ peaceful

*Social- more/less visitors/ better surroundings

-Family relationships

*Effect on close family/ distant family/ primary caregiver

*Practical issues- bus routes, areas, distances, childcare, visiting times

*Strained/closer relationships

*Has transition changed relationship between family members

-Financial

*Has there been any financial changes due to the transitions

*Resulting in transitions

*Cost of old setting/new setting

-Other –

Any other issues that the interviewee would like to raise?

7. Ending

-Confidentiality

*Anonymous data.

*No health care related impact.

*Ability to withdraw at any time.

*Use of results without names.

-Use of results

*Published journals, articles, conferences.

*Help the Aged and other reports

*DoH who funded research want to know experiences

-Newsletter

*Option of newsletter on summarising results

Appendix 8: Topic Guide for bereaved carer interviews

Transitions between services- carer perspective

Objectives

- To explore number and nature of transitions

- To explore experience of transitions from carer perspective

- To explore understanding of disease and impact of disease on carer and patient

- To explore effect of transitions on physical, mental and emotional health as well as financial concerns and family relationships

---

Content of Topic Guide

1. Introduction

2. Life History

3. Understanding of Illness

4. Nature of Transitions

5. Understanding of Transitions

6. Effects of transitions

7. Ending

8. Questions

1. Introduction

-Name and position of researcher

*RA within Uni of Lpool- experience of interviewing before.

-Nature of study- collaborative partners and reason for study.

*CECo members and purpose explained.

*Other Universities mentioned.

*Outline and purpose of study

2. Life History

Encourage detailed coverage of level of education and occupation for
socioeconomic analysis.

-Childhood and family background

*Place of birth-country, city, area within city

*Family Members- brothers and sisters

*Relationship with patient

-School life/ education

*Where went to school

*Experiences/memories of school

*Favourite subjects

*Qualifications including highest qualification

-Working history

*Age when started work

*Types of jobs

-Family life previously and currently

*Previous responsibilities- job, childcare, caring for others

*How has that changed since illness of patient?

*Better/ worse

Health Status

*Previous physical and mental health before illness of patient

*Health currently

*If any changes, why (from perspective of carer)

-Relationships throughout patient illness

*Change in friendships

*Change in partnerships/relationships

*Pressure in relationships

*Change in family relationships

3. Illness Understanding

If main carer is child of patient- has the illness also affected their children
or partners?

-Lifespan of illness

*First diagnosed, how long, other illnesses

-Who diagnosed and explained illness

Numerous people/ Person in authority/ Family members

-Family knowledge

Family expertise

Family support

Family issues which have increased/ reduced support

-Own previous knowledge

Increased since diagnosis

Lacking

Suggested improvements regarding type/amount of information.

-Expectation of future

Knowledge of expected course

Emotions surrounding future-hope/denial/frustration/upset/control/relief

4. Nature of Transitions

Focus on their perspectives as carers but also elicit their perspectives of the patient's beliefs/ understanding

-How many in last 12 months

Where to/ where from

Why

Decision of patient/you as carer/ other family/services

Feelings about decision

Feelings about patients view on decision

-How many in last 3 months

*Where to/from

*Why

*Decision of patient/you as main carer/family/services

*Feelings about decision

*Feelings about patients view on decision

Feeling about nature of care

*For you as a carer

*For the patient from your point of view

*Knowledge of team/familiarity with main health professionals

-Satisfied with number/nature

*Feelings about decision- for yourself, for wider family, for patient

*Feelings about information provided

*Feelings on choice

*Practicalities

*Care services

*Improvements for future services

5. Understanding of Transitions

-Transitions explained? How? By whom?

*How did you feel

*How did family feel

*How do you think the patient felt

-Understanding of place of care now

Would like patient to stay at place/ Wouldn't like to stay

6. Effects of transitions

Focus on effects to caregiver. Also elicit the perception of the caregiver to the effects on the patient.

-Physical/ Mental/Emotional/Social

Impact on patient regarding physical health problems- pain, discomfort, medication

Impact on mind of patient- feel better/ worse/ are you worried at all/ scared

* *Impact on caregiver regarding physical/ emotional health*

Social aspects of transitions for carer- easier to cope/ more/less visitors/ better surroundings

-Family relationships

Effect on close family/ distant family/ primary caregiver

Practical issues- bus routes, areas, distances, childcare, visiting times

Strained/closer relationships

Has transition changed relationship between family members and yourself

-Financial

Has there been any financial changes due to the transitions

Resulting in transitions

Cost of old setting/new setting

-Other

7. Ending

-Confidentiality

Anonymous data.

No health care related impact.

Ability to withdraw at any time.

Use of results without names.

-Use of results

Published journals, articles, conferences.

Help the Aged and other reports

DoH who funded research want to know experiences of carers

-Newsletter

Option of newsletter on summarising results

<u>Consent form - Participant copy</u>

<u>Transitions between services for older adults</u>

Please initial each box.

1	I confirm that I have read and understand the information sheet dated ....(version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3	I agree to take part in the above study and that the interview can be audio taped.	☐

Name of participant…………………………………………………………………………………………

Signed..   Date......................................

Name of person taking consent…………………………………………………………………………..

Signed..

       Date......................................

Contact: Louise Holmes 0151 795 0376, Division of Public Health, Whelan Building, Brownlow Hill, University of Liverpool, L69 3GB

Consent form – Researcher copy

Transitions between services for older adults

Please initial each box.

1	I confirm that I have read and understand the information sheet dated ....(version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3	I agree to take part in the above study and that the interview can be audio taped.	☐

Name of participant…………………………………………………....

Signed..Date.............................

Name of person taking consent…………………………….........

Signed...................................... Date.............................

Contact: Louise Holmes 0151 795 0376, Division of Public Health, Whelan Building, Brownlow Hill, University of Liverpool, L69 3GB

Participant Information Sheet

Research into Services for Older Adults

You are being invited to take part in a study, which aims to help to improve care for older people with serious illnesses. We would like to find out more about why older adults move from one place of care to another to receive care; what their experiences were, and how they and their family felt about the care. It does not matter if you moved to or from your own home or a relative's house, hospital, care home or hospice. We are interested in all of these experiences.

Part 1 of this leaflet tells you why the research is being done and what would be involved if you choose to take part. **Part 2** is further information you should read if you choose to take part. Feel free to discuss this research with anyone that might help you to make a decision on whether to take part in it including friends and family.

Part 1

What is the purpose of this study?

Older people are sometimes moved between different health care settings such as hospital, hospices and their home. We are studying the statistics about people moving in and out of hospital and other places. But we need your help, to tell us the real story behind the numbers.

We would like to know about your experiences of moving between different places where you have received care,

such as home, hospital, care home or hospice; why you moved, or did not move from one place to another, and how you felt about any moves and your overall experience.

Why have I been chosen?

We would like to talk to people who have experienced stroke, lung cancer or heart failure. Your doctor or nurse has given you this information sheet as they think that you might be interested in taking part.

Do I have to take part?

Taking part or not is entirely up to you. If you want to take part, we would like you to put your name and telephone number on the yellow form and send it to us in the stamped addressed envelope.

The research will not affect your health or medical care in any way. Whether you take part or not, any care you receive from your doctor will not change. If you decide to take part and then change your mind, your doctor or nurse will not know.

What will happen to me if I take part?

We, the researchers, do not know who you are, unless you tell us your name and telephone number. No one will contact you until you do this.

If you do send us your contact details, a researcher will phone you and tell you more about the study. If you decide not to take part at this point, we will not contact you again.

If you *do* decide to take part, we would arrange to meet you where ever may be convenient for you, at a convenient time. We will answer all your questions about the study and ask you to sign a form saying you are happy to talk to us. If you agree, we will record the interview so that the interviewer can remember more accurately what you said.

The interview will not last longer than 90 minutes, and we will stop at any time if you wish.

Whatever you tell us will be confidential. No one will be able to identify you from any of the reports we produce and no-one will know that it is you that made any particular comments.

Only if the researcher uncovers information that suggests that you, or others, are at risk of coming to any harm, will they break this promise of confidentiality

What are the possible disadvantages and risk in taking part?

A possible risk is that we might upset you by asking questions about your current circumstances. If this happens, we can move on to another question, return another day, or just finish the interview there and then.

What are the possible benefits?

We cannot change the experience that you have had, but we might be able to use the information that you give us, to make the experience better in the future for other people.

Sometimes, people find it helpful to talk to someone about what happened, the good things and the bad things. Some people find it comforting to know that by giving their opinion, they might help to improve care services in the future.

What happens when the research study stops?

After your interview, we will telephone you the following week to check that you were happy with the way in which the interview was conducted. After that we will not contact you again. If you would like to receive a newsletter summary of the outcome of the study (which could take up to two years, as it is a big study) then we will be happy to send one to you or your family.

What if there is a problem?

If there are any problems with the research that we can sort out, we will try and do this. If you are unhappy about the questions, or anything to do with the researcher, we will tell you who to contact. The details of this are in part 2.

Will my taking part be kept confidential?

YES. All details about your participation will be kept confidential.

However, if we think that there may be a risk of you or someone else being harmed in any way, we will break confidentiality and report what you have told us to the relevant authorities.

Contact Details:

Any questions, queries or problems please contact **Louise Holmes on 0151 795 0376.** Or if you or your relatives would like to send us an email, the address is; Louise.holmes@liv.ac.uk

Please note that the researcher is not a medical doctor or a trained counselor, and she is not able to act as your advocate. She will not be able to help you to complain about your care in any way. Details of the NHS Complaints Procedure can be obtained from your hospital doctor or GP. The researcher can answer questions relating to this research and the person you speak to on the telephone will be the same person who visits you, if you decide to take part.

Part 2- Please read this if you are interested in taking part in the study.

What will happen if I decide not to carry on in the study?

Nothing at all will happen. We will not contact you unless you give us your name and telephone number. If you decide not to carry on, once we have phoned you and arranged to meet, just call us and let us know.

Can I complain?

If you are unhappy with the research in any way please tell us. We will try to put things right. If you would prefer to talk to someone outside the research team or if you are not happy with the way we deal with your problem you can formally complain through the NHS Complaints Procedure. Details can be obtained from your hospital doctor or GP.

Am I likely to be harmed?

In the very unlikely event that something does go wrong and you are harmed whilst taking part in this research there are no special compensation arrangements. If the harm is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Liverpool, who employs the researcher, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you, if appropriate.

Will all my thoughts and answers be kept confidential?

Yes. Any information about you will have your name and address removed. The only person that knows what you said is the researcher who interviewed you. Any tapes will be kept secure and then destroyed and any written information will be kept strictly confidential. The procedures for handling, processing, storage and destruction of data from the study are complaint with the Data Protection Act 1998. After five years, recordings will be destroyed.

Involvement of the GP

Your hospital doctor has suggested that you might be interested in taking part in the study. We will not ask for any personal or medical information about you from them. We will not tell your GP that you are taking part in the study, unless you ask us to do so.

What are you going to do with the results of the study?

The results of this study will be published in academic journals, and presented at conferences, and reports will be prepared for the NHS and the participants. You will not be identified in any publication even if we use your words. We are happy to send you a newsletter with a summary of the findings if you wish.

Who is organising and funding the research?

Researchers from the University of Liverpool are organising this research. Other Universities are also part of the team, although they will not see any identifiable information. The main research is funded by the NHS and it is being conducted in two regions of England.

Who has reviewed the study?

This study has been given favourable ethical opinion for conduct in the NHS by the Sefton Research thics committee

Please keep this information sheet. If you would like to ask any other questions regarding the research, or what is expected from you, please ring Louise Holmes on 0151 795 0376.

Alternatively, please send your name and telephone number to us in the stamped addressed envelope and the researcher can call you.

Participant Information Sheet

Research into services for people at the end of life

You are being invited to take part in a study, which aims to help to improve care for older people with serious illnesses. We are interested in the experience of the people caring for their relatives or friends who died of either lung cancer, heart failure or stroke.

We would like to find out more about why older adults move from one place of care to another to receive care; what their experiences were, and how they and their family felt about the care. It does not matter if they moved from their own home or a relative's house, to a hospital, care home or hospice. We are interested in all of these experiences.

We are interested in speaking to carers of people who died from stroke, lung cancer or heart failure. This is because carers are the people most likely to know about the care the older person received in the months before their death. They are also most likely to be able to tell us about the things that could improve the care given, and also the things that affected the family the most.

Part 1 of this leaflet tells you why the research is being done and what would be involved if you choose to take part.

Part 2 is further information you should read if you choose to take part. Feel free to discuss this research with anyone that might help you to make a decision on whether to take part in it including friends and family.

Part 1

What is the purpose of this study?

Older people are sometimes moved between different health care settings such as hospital, hospices and their home at the end of life. We are studying the statistics about people moving in and out of hospital and other places. But we need your help, to tell us the real story behind the numbers.

We would like to know about your experiences of caring for someone who was moved between different places in the last 3 months before they died. We would like to ask you about where they received care, such as home, hospital, care home or hospice; why they moved, or did not move from one place to another, and how they and you felt at the time about any moves. We are also interested in how the care that your relative/loved one/ friend received affected you and your family. This may have been emotionally, socially, physically, or financially. We are also particularly interested in the care that they received just before they died (from about 3 months before they died).

Why have I been chosen?

We would like to talk to people who have looked after, and cared for people over 75 years old who died from stroke, lung cancer or heart failure. This is because we are interested in talking to people who know about the care the person over 75 years old was receiving before they died. You do not have to have lived with them, or be a member of their family. You just need to have played a close part in looking after them. You might have been their friend or neighbour or a paid carer for example. We would still like to talk to you.

This information sheet has been sent as you have already expressed an interest in taking part in this study.

If you think that there is someone else who may be able to help us and who would be interested in talking to us, then please pass this information on to them.

Do I have to take part?

Taking part or not is entirely up to you. We will contact you by telephone in a week or so, and ask you whether you would like to take part. If you would like to, I will arrange a time to interview you at a place and time of your choosing (most people choose their home). If you would not like to take part, then let me know when I phone you and I will not contact you again.

The research will not affect your health or medical care in any way. Whether you take part or not, any care you receive from your doctor will not change. If you decide to take part and then change your mind, your doctor or nurse will not know.

What will happen to me if I take part?

A researcher, Louise Holmes, will phone you and tell you more about the study and answer any questions you may have. If you decide not to take part at this point, she will not contact you again.

If you *do* decide to take part, we would arrange to meet you where ever may be convenient for you, at a convenient time. We will answer all your questions about the study and ask you to sign a form saying you are happy to talk to us. If you agree, we will record the interview so that the interviewer can remember more accurately what you said.

The interview will not last longer than 90 minutes, and we will stop at any time if you wish.

Whatever you tell us will be confidential. No one will be able to identify you from any of the reports we produce and no-

one will know that it is you that made any particular comments.

Only if the researcher uncovers information that suggests that you, or others, are at risk of coming to any harm, will they break this promise of confidentiality

What are the possible disadvantages and risk in taking part?

A possible risk is that we might upset you by asking questions about the few months before your loved one died. If this happens, we can move on to another question, return another day, or just finish the interview there and then.

What are the possible benefits?

We cannot change the experience that you or your loved one have had, but we might be able to use the information that you give us, to make the experience better in the future for other people.

Sometimes, people find it helpful to talk to someone about what happened, the good things and the bad things. Some people find it comforting to know that by giving their opinion, they might help to improve care services in the future.

What happens when the research study stops?

After your interview, we will telephone you the following week to check that you were happy with the way in which the interview was conducted. After that we will not contact you again. If you would like to receive a newsletter summary of the outcome of the study (which could take up to two years, as it is a big study) then we will be happy to send one to you.

What if there is a problem?

If there are any problems with the research that we can sort out, we will try and do this. If you are unhappy about the questions, or anything to do with the researcher, we will tell you who to contact. The details of this are in part 2.

Will my taking part be kept confidential?

YES. All details about your participation will be kept confidential.

However, if we think that there may be a risk of you or someone else being harmed in any way, we will break confidentiality and report what you have told us to the relevant authorities.

Contact Details:

Any questions, queries or problems please contact **Louise Holmes on 0151 795 0376.** Or if you or your relatives would like to send us an email, the address is; Louise.holmes@liv.ac.uk

Please note that the researcher is not a medical doctor, and she is not able to act as your advocate. She will not be able to help you to complain about your care in any way. Details of the NHS Complaints Procedure can be obtained from your hospital doctor or GP. The researcher can answer questions relating to this research and the person you speak to on the telephone will be the same person who visits you, if you decide to take part.

Part 2- Please read this if you are interested in taking part in the study.

What will happen if I decide not to carry on in the study?

Nothing at all will happen. If you decide not to carry on, once we have phoned you and arranged to meet, just call us and let us know.

Can I complain?

If you are unhappy with the research in any way please tell us. We will try to put things right. If you would prefer to talk to someone outside the research team or if you are not happy with the way we deal with your problem you can formally complain through the NHS Complaints Procedure. Details can be obtained from your hospital doctor or GP.

Am I likely to be harmed?

In the very unlikely event that something does go wrong and you are harmed whilst taking part in this research there are no special compensation arrangements. If the harm is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Liverpool, who employs the researcher, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you, if appropriate.

Will all my thoughts and answers be kept confidential?

Yes. Any information about you will have your name and address removed. The only person that knows what you said is the researcher who interviewed you. Any tapes will be kept secure and then destroyed and any written information will be kept strictly confidential. The procedures for handling, processing, storage and destruction of data from the study are complaint with the Data Protection Act 1998. After five years, recordings will be destroyed.

Involvement of the GP

Your general practitioner (GP) or nurse has suggested that you might be interested in taking part in the study. We will

not ask for any personal or medical information about you from them. We will not tell your GP that you are taking part in the study, unless you ask us to do so.

What are you going to do with the results of the study?

The results of this study will be published in academic journals, and presented at conferences, and reports will be prepared for the NHS and the participants. You will not be identified in any publication even if we use your words. We are happy to send you a newsletter with a summary of the findings if you wish.

Who is organising and funding the research?

Researchers from the University of Liverpool are organising this research. Other Universities are also part of the team, although they will not see any identifiable information. The main research is funded by the NHS and it is being conducted in two regions of England.

Who has reviewed the study?

This study has been given favourable ethical opinion for conduct in the NHS by the Liverpool Central Ethics Committee.

Please keep this information sheet. If you would like to ask any other questions regarding the research, or what is expected from you, please ring Louise Holmes on 0151 795 0376 (Monday to Friday 9am-5pm). Or, Louise's email address is louise.holmes@liv.ac.uk

Louise will be contacting you by telephone in the next week or so, to see if you are still interested in taking part in this study.

Thank you for taking the time to read this information.

Appendix 12: Example of a patient interview transcript (HF75M013)

Can I start by asking you a little bit about your background, where you grew up things like that?

I grew up here.

█████████

Here

In this house?

Yes

Ok,

Lived here all my life. Well, I was born in █████████ and came down here after a couple of months, to live here. I have been here ever since.

Are you part of a big family?

There is 7 of us in the family with mother and father. I had 3 sisters, 2 of them have died now, and my brother he lives down in █████████, down the South of England. I have got about 4 or 5 nephews. One lives over in the Wirral he is an electrician. I have got one lives in █████████, Oxfordshire, he is an airline pilot, I have got another one that lives in █████████ he is an engineer, some kind of engineer, I have got one that lives in ████ he is my brother's son, he has something to do with computers when he is working and the other ones, I have never seen the other ones, another nephew and couple of nieces, down south lives with my brother, well from down there, we never see them.

So you have been brought up here, you went to school locally?

Yes

How old were you when you left school?

15

and then what job did you go into?
Right, I tried to get a job on the dredges but my eyesight was bad they wouldn't take me, and yet I got, I ended up on the bread vans for a couple of years, then I was an order boy in a shop, in a local co-op, then a couple of my mates joined the

army, and when they come back on leave they told me how great it was, so I thought I would have a go. So I joined the army, but I didn't pass my medical so I waited about 6 months before they discharged me, came back and got a job, in the steel works in ██████, constructional engineers, as a what you called a hot lad, used to hot the rivets up, for the riveters, and after that I was promoted to, what they call a platers mate on the machine. When they closed down I went on the buses, as a conductor, I was the conductor for 13 years, and with them going one man operated in the 70s, I went behind the desk in the garage and I was behind, what they called, I was a travel coaches assistant, I worked shift, early shift and a late shift. Now that lasted until 86 when it went private, then I got, I moved over to a garage clerk, there was 2, I was one of them and when the fella left the other fella that was above me, I got the job as the clerk, now I only had that job about 2 - 3 years, then that job finished, so I was going to pack in then, finish work, but they asked me to go down for an interview for an engineering clerk, so I went for an interview and I passed it, and I ended up as a relief engineering clerk, going to the different garages from [5.13] ██

[interrupt]

and I finished up, in 1998 then retired then. I was of age for retiring properly then and I have done nothing since. So.

Ok, I am just, I am a researcher from the University. I rang Mr [name] and asked if I could come and speak to him, so we are just, it's like an interview really, just about him being in hospital and what is it like.

We haven't come to that part yet.

Oh haven't you. [6.12] 18 months you had in the hospital didn't you. Best part of 18 months,

18 months?

No, no tell you, telling lies,

I was 8 weeks last year wasn't I?

Yes, yes.

A month this year.

This time, this year it was only 4.5 weeks wasn't it.

Yes, yes.

I had a bad experience in hospital. Do you want to know about it?

Yes.
Right, I collapsed in the bedroom here.

Right when was this?

Last year. March / April.   March wasn't it the end of March?

No it wasn't it was April 4th when you collapsed.

Yes and to all intents and purposes I had died. Because I had, I believe I had 3, 2, the paramedic and 2 ambulance crews came and worked on me, and they must have found something there but they took me to hospital, and I came to in hospital after a day, it was a day or so.

Yes you were semi-conscious, you were going in and out of this, whatever it was every couple of days you know, he went in on a Wednesday morning 3 o'clock, 3.30 in the morning you went in wasn't it and then they brought him round, but a couple of hours later he went off again. In a shocking state. If I hadn't have been there, I live here I am his sister you see, well he would have died, definitely died.

Knew nothing about it. I collapsed, I fell awkward on my arm, I was paralysed in this hand, I couldn't, do anything with this hand it was just like that I couldn't do anything else.

What did they say it was the result of?

Emphysema. Chronic bronchitis, pulmonary disease, heart disease and I was waiting for a, I had all the tests going, scans and what have you, brain scans, neck scans, everything and I ended up they told me I had, I needed a bypass I had 3 blocked arteries in my heart, and they were going to transfer me to [hospital], and when I went to [hospital], they wouldn't operate.

They had him all dressed and ready to go.

I was ready for the operation, and I was dressed and everything I was going down and then this specialist that was going to do the operation Mr [name] his name was, explained to me he wouldn't do the operation as I have got a 15% what was it

Chance of a recovery.

Of recovering and having strokes, so he would not take that chance. Now he said to me, if you are in any pain, we can put a stent in, what they call a stent, but I have had no pain since. All I have had been is shortage of breath, couldn't, now this last time, when I went in, this March was it? When I went in this time March?

No April

Again, April again?

Yes April 24th.

I had to send for the ambulance because of shortage of breath, they took me in, and I was in the same ward actually as I was in last year, and they cure you know you know they stop, they fixed me up for the breathing, they didn't cure it like but I could breathe a lot better and I was getting my legs treated then because I had complained about my legs filling up with, you know coming like tree trunks and they got water retention they said, and they were treating me for that. But, at the end

of 3 weeks a month really, they said we have treated you for your medical, your chest and that and you seem to be ok, we can't do no more, but they didn't finish off my legs I had, didn't, all they were doing was testing my legs, and while I was in hospital, last year and this year I was complaining all the time you know, about my treatment and not doing anything. And what was it, the oh last year, Mr [name] at [hospital], that's it they transferred me to [hospital], I was only at [hospital] 2 days, because when I went in, I went for a test and they got me ready for the operation, then they told me they wasn't going to do it, but when I went in, back into the [hospital] this year, I was in the emergency place, what was it?

Oh intensive care.

Yes. They said I am going back up to this ward. I said I am not going. They asked me why and I explained to them, I said I was in here last year I said, and I had a terrible time you know, meals and everything you know, food was terrible. But they talked me round, I went back, the food was just as bad and that was it really. They sent me home, but since I have been home, see they told me in the hospital before I left that the district nurses would be in touch, and the occupational therapist. Now I was home for a week, now I had to phone up the district nurses and ask them when they were coming out to treat my legs. They said we didn't know you were out of hospital. We haven't had a referral. I said well what is happening now, she said well you will have to get in touch with the hospital, so I got in touch with the hospital, the ward, and they said hang on Mr [name] we will find out, and they had a look on whatever it was like, they come back and they said your referral has gone out, but it's gone to the wrong number. You know. So they had to, send it out again to the district nurses, because they district nurses phoned me back and said they have got your referral and we will organise to come to see you. Then the other one, what was that one, occupational therapist it was, I had to get in touch with them, they didn't know anything about it, they said we can't come out until we get the referral from your doctor, so I had to phone the damn doctor then for then to send a referral to the other people. Now ever since then I have been fighting for my own benefit. No one has been, I have had no help, at all, nothing at all from, oh I get on with the district nurses and everything now, and I have had no help, I have had to get it all for myself, try and get it for myself. I have got a carer now, he comes in 3 times a week,

He is marvellous

He is marvellous fella this fella

Do you have to pay for him?

Not at the moment, I will have to when they sort my money because I have got a visit from the social services today, this morning, and she was making forms and forms out you know, but I expect to get something from. I know I have to pay for the carer within 6 weeks of coming out of hospital, well I have been out of hospital a couple of months, a few months yet and I am only waiting for them.

So what does he do for you?

Well they come, they are see that I have taken my tables, had my breakfast, I have had a wash and that. That is Monday and Wednesday, now on a Friday they give me a shower because I can't get in the bath. I haven't had a bath for over 12 months because my legs, I have got no strength in my legs, I can only lift my leg up like that, I can't get in, I could get out of the bath when I get in, if someone put me in because you bath is a different height inside from the outside. So, they have given me a swivel seat, now what I do, I get ready and sit on this swivel seat, then the carer lifts me legs up and gets them into the bath, and we use the shower then. Now actually we are in line for a walk-in shower, but when we get that we wouldn't know. We wouldn't know.

And is that something social services have told you, you will be getting?

Occupational therapist I think it was. What was that girls name? She got me the different things, she got, she got me a commode which I don't need,

Because he can make it to the toilet you see.

These chair risers here.

And that cushion there.

Yes that cushion.

So it sounds like you have got quite a lot for us to talk about. I have got questions, but I have wrote some notes so we can go back to some of them things. Because it sounds like you have had quite a few problems.
Yes. It's come, now it seems to be coming a lot easier because I haven't been out since, I have been out once I think since I come out of hospital, that is to go for a haircut and that was only because the bus stopped practically outside the door, the barber's door because I can't go

There is, the bus comes along [18.36] Road here,

To go to the doctors I have got to get a taxi down to the doctors, now where are those, oh they are upstairs, they are like a slipper shoe, very, what do they call, they are the only ones I have got. My shoes here, I can't get on because the water retention my foot is like a rugby ball, see how swollen it is.

His toes, that one isn't so bad, but this one,

I have trouble getting my shoes on. I have got these like a slipper shoe,

Do you want me to go and get them?

If you like if she wants to have a look at them, they are in my bedroom. And they are the only shoes I have got really, I can wear. If we go out for a meal on a Sunday, down to the pub, I have got to wear them like and I get a taxi to the pub and back, but my carer when he first came he said, what you need is surgical slippers, well I can't get them, but he said you need shoes, special shoes, you might need shoes

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making. So I asked around who would do these shoes, I asked social services, the therapist, occupational therapist and all sorts, but they don't do it now you have to go through your doctor. Well I went through the doctor, I think it was the end of June or beginning of July, then I got a thing to go to the clinic in [hospital], orthotics whatever it is, in October, now the other week I got a letter stating

Here you are.

These are the only ones I have got yes.

They are the only ones

See they are no good in wet weather.

No,

And he has got a wardrobe with about a doze and a half pairs of shoes up there, some he has never had on his feet.

And, I got a letter, stating that the appointment at the clinic orthotics, is cancelled, and give you another date for November, so I lost my rag again, I said, it's going to be next year before I can get out, to go to the bank, post office, dentist, and get my eyes tested. We are awfully sorry she said, the woman said, she said that is the only date we have got, I said can't you bring a date earlier, she said no they are all booked up. She said the only way you can get through, get an earlier appointment is when we have a cancellation oh I said oh for God sake I said, keep hold of my name and my phone number, in case you get a cancellation and let me know. She phoned me back

Half an hour later.

She said we had two cancellations this morning, that didn't turn up, she said but I have got you an appointment for a week Friday. So I am going a week Friday now.

Oh great, ok. Ok, if I just go back to the first part we were talking, I was going to ask you about have you been married?
No

Have you and your sister always lived in this house?

Yes.

Ok, when were you diagnosed with heart failure?

Last year when I was in hospital. I had, actually, I had a print out that size paper with what it was wrong with me, and I took it to the [hospital] a couple of weeks back because I had to go and see the cardiograph doctor, they took them off me, because it had all my pills and what I was taking them for like but I didn't get it back. Otherwise I would have been able to show you what it was, what

So you collapsed and you went into hospital, this was last year, and that is when they tested you for a variety of things, and that is when they told you?
Yes, yes. But, actually a few years back, I complained about pain here, because I have always been told it was the stitches inside, where I had my gall bladder bile duct taken out, but one time I went to the doctor a few years back, they said I think you have had angina, that was the only thing [24.16]

Ok, so, when you were diagnosed with the heart failure were you given any information about your condition? Did someone explain to you what it was?
Not really, not outright, not outright. Because it was Julie explained the other day didn't she,

Yes

Explained my condition, do you remember when she was here.

Yes I asked her, if you remember, it was just because we didn't know what his condition was in the hospital, nobody told us. And this has come as a great shock to the both of us.

Yes

What has come as a shock, the heart problem?

The heart problem,

Yes, yes. You see, the only way I can explain it, or the way it was roughly explained to me, and [name]. One of the parts of the heart, you see there are 4 parts of the heart, and one of these parts is deteriorating. See it's not a sponge anymore she said, and that is one of the problems, and in time, it is doing it now, it's affecting his kidneys as well. And of course we were upset weren't we?

Yes,

Terribly upset.

So it was the community nurse that told you not long ago and that is why you were upset?

Well it was the nurse, the nurse I thought she was, she is a heart failure nurse, community nurse.

That's her title.

Her title on the badge as well.

Ok so when you went into hospital this year can you tell me about what happened then, why did you go in?

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Because I had shortage of breath and good God what was this doctors name again? See on this form, that they took off me a couple of weeks back, it had the specialist's name. I seen Dr [name] from the cardiologists team, but the doctor I was under was [name] or something now I can't remember his proper name. And, he was looked after me, but they didn't explain, well he might have explained but I couldn't understand what it was like. But when it came to be discharged they said we have treated you with all we can medically, they said we can't do anything else, medically, but there is only this problem with your leg, the water retention.

So when you say you can't understand him is that because he wasn't clear or?

Well I think it's these words, you know,

So it was a bit too

High up for me yes.

His language was very medical was it?

Yes, well it wasn't medical I don't think I took it in really like I should have done.

I think I said something to someone, speak in a language we can understand. You know, the English language they come out with these long words, yes.

And so then you weren't quite sure, what was happening it sounds like when you came out. And Julie has since told you all about heart failure and what it is and what the problem is?

Yes

So has anyone explained to you what happens next?

No.

Ok.

Because I had been to the heart failure clinic and has taken blood, sounded my chest out, the same thing that Julie has done, but I don't think Julie has taken blood. I have to go down to the hospital to do that. The heart failure, I went to see the heart failure nurse in the [hospital] about twice, Pam. Twice or 3 times I can't remember. She discharged me but she looked after my tablets, told me what tablets she was giving me extra or taking me off, [29.14] Now. They put me on, I think she put me on warfarin.

Warfarin yes.

Now I go down now it was every fortnight but it's, I went last week I have got to go this week,

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Yes

On Thursday for warfarin because they changed my dosage now, where I was on 1 and 2 tablets, one 1 day, two the next, they went to 2 tablets one day, three the next, now it's gone from one tablet

You take 4 don't you.

Yes I was taking 1 mg, milligrams one day, 2 milligrams the next, now the next time they changed it, it was 2 milligrams one day, then 3 milligrams the next, but the 3 milligrams come in one tablet. A different type of tablet, different coloured tablet. Because I was trying to get it sorted out and it was only the receptionist in the doctors that told me, about how these tablets work. Now, when I went last week they checked me and when I got back home, she came, is my letter there? That's it, is that the one, that is the one, they put give me on there the dosage,

So one day you take 2 and the next day you take 3?

Oh no, no it's changed again hasn't it. It will be on there. That's it 3 mg one day and 4 mg another. But I can take the 3 mg in one tablet because it is a blue tablet and it's 3 mg, now the 4 mg, I take a blue tablet and one of the brown tablets, makes up the 4.

Is that easy to remember to do?

It wasn't at first. Because I was complaining about I am going to run out of warfarin tablets, but I have got to go back down, on Thursday, I only went down last Thursday,

Why are you going again this week?

Going this week for the test. Because they have put me on a different dosage. And there is the one for Julie, my blood one I have got to take that down with me, to give blood for that again. But she said, when I went last week and I had a blood test on that, on my kidneys she said they were ok, they were ok didn't she.

Just going back to when you were taken to hospital in April, you were taken by ambulance?

Oh aye, yes.

So it was an emergency admission?

Yes, I called the ambulance.

So you were rushed in,

Well I wasn't rushed in, I phoned the ambulance and they came, and we explained to them like you know, what the symptoms were, they said oh we will have to take you in. You know, and that is what they done.

And did you have to wait when you got to hospital to be seen?

Not really. Not really.

Can you tell me more about what happened on that day?

No. No.

Do you not remember?

I can tell you what happened about 6 weeks afterwards.

What was it like being in hospital, what was the care like?

The care is not too bad. The only thing I complain, well a couple of things I complained about. The food mostly, couldn't eat it, couldn't eat the food.

What was wrong with it particularly?

Yuck. The only food I could eat was the breakfast, I can't complain about the breakfast.

He never got what he put on the menu, he always got something else.

Yes, a few times yes.

So was it the amount of food or just the

No it's, yuck, couldn't eat that you know.

Did you have to bring food in then?

Oh aye, you brought stuff in for me, yes. In fact I think everyone on the ward was the same, I think everyone on the ward was the same, and had emergency rations brought in. The only, another thing I complained about, only when I got home to other people, the district nurse and that, is I couldn't do anything for myself. Especially last year when I was in, I couldn't do any, I couldn't with this hand, I couldn't if I went to the toilet I couldn't use any paper, you know, clean myself off. Now I had to call the nurse and they didn't like it. Because they had to clean me up.

So that was this year as well?

No, no, other things. But, there was a couple of nurses there that looked down their nose at you, saying this fella is playing the old soldier here, but I wasn't, I

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couldn't do anything. No this time when I went in, it was a similar thing, I couldn't have a shower, on my own, at first, the first week or so, and I had to get the nurse to do it but a couple of them looked down their nose and say, he is only doing this for the thrill, but I wasn't, I couldn't do it. I was, see I have got no strength in my legs, and the same practically in my arms,

So they are quite similar things in a way aren't they, like personal care, what made you think they were looking down their nose? Like was it their attitude or

They didn't, tell me off or show me, it's, they look, their attitude, I don't know if you would call it that, when they are looking at you, you know, this fella is getting a thrill of me showering him, well I wasn't. I needed a shower, I couldn't care a damn who was doing, it was ok with the men, when they done it they enjoyed it because they give me a shower properly. Now even a couple of the younger nurses, they were about 2, older nurses, it doesn't have to be nurses, there are helpers aren't they.

Yes, like health care assistants.

Like with this lilac uniform, but the younger ones, used to take me to the shower, put me in and they used to say if you need any help, just pull the string you know. Well more often than not I needed help in drying myself, that was all. I was doing the rest myself, I was determined to do it, but I just couldn't dry myself.

How did that make you feel when they were being not very helpful.

Terrible, terrible. I couldn't believe it myself you know. It was, you go into hospital because you can't do anything, I couldn't do anything, you know, I thought, they should be there to help you. But, there were a couple of elderly nurses, helpers like, that were wonderful, that couldn't do enough for you. Just, a certain amount, certain nurses.

Was there anything else like that, that you would like to tell me about?

No, not really.

So what about the medical care in hospital, like the doctors what were they like?

Oh they were ok the doctors. Yes.

You were in there for a month?

This, just over a month this time.

The end of April to the beginning of June?

Yes, yes.

And why were you in so long?

They were trying to cure me. Clear my lungs really.

Is this related to the emphysema?

Yes, and shortage of breath which, it was clearing up like you know. The other wait I was waiting for was, my legs, water retention.

And did that improve or change in any way while you were there?

The water retention one?

No it didn't improve really because I had to complain about that because, no one was dressing my legs, they should have been dressed every day, but they weren't dressing them every day. In fact, a couple of nurses didn't know how to do the job, the nurses themselves didn't know how to do the job.

A couple of times, when you had them dressed, the next thing you knew they were down on your ankles yes.

Yes. Yes, they put the catheter in, I had the catheter in, the catheter was in, nearly 2 months and it was leaking like hell, I had to have a towel small town down the front to catch my, because otherwise all my legs and trousers were soaking wet, and smelling. Then all of a sudden it stopped like that. Because I had when I [40.35] I had two district nurses came round and changed it, then even a doctor came round and changed it, but as soon as you got downstairs after changing it, it was just as bad leaking again. And, another time, how long was it, I called you I said I have got blood in my catheter, so we called the ambulance then, and I was leaking, I it was, I don't know if I had started leaking or what, but it was leaking down my leg, my urine, and I had these blinking big ulcers on my leg, there was and there was blood in my catheter, so they run me into the hospital, when I got to the hospital they said, it will be a 4 hour wait for your doctor,

Was this a while ago?

Yes, after, was it in June, a couple of weeks after I come out?

Yes

So you have been back since?

Only for 1 day. Yes, you can call it that. But even the ambulance man had to wash the stretcher thing I was on, because I was leaking that much. And I couldn't stop it, now I was on a bed thing, I was leaning back and I stinging like hell, the pain was terrible and I asked two nurses, both proper nurses, Malaysian nurses, could they cut my dressings off, and wash it, in saline water to ease the pain, they just looked at me, like that, disappeared. I went in 11 o'clock, 11.30 at night, and I

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seen the doctor at 5.30 in the morning. And the nurses, the nurse that dressed my legs after they had been cut the blood off, the dressings were on too tight,

Regarding that episode then, what do you think needs to be improved for other people, you know what should change, so things like that don't happen?

Well I think they should take, I know they are mad busy in the hospital they can't look at everyone but if I ask for something in the hospital, the nurses disappear and you thought you are going to get something done, but she had forgotten about the thing, that is what I mean like. Because they had, not one ward, they have the whole lot don't they, some sort of where if you have asked for something, they can mark it down somewhere, what wants doing. Yes. And whoever do come up to do it can tick it off as being done.

Ok, so you mentioned the ward then, were you on a mixed or a single sex ward?

Single sex ward.

So there was a couple of fellas in there?

Yes, yes

And what was it like being in hospital generally?

It wasn't so bad. It wasn't so bad. No, last year was ok, because they used to joke with me, I am getting a long service medal.

Ok, so it was clean and comfortable?

Yes. oh aye yes.

And was it, the other patients in there did they talk?

Oh aye, yes, yes.

So you had something to do?

Yes, yes. If you were struggling, although the fella in the next bed was bad he said do you want a hand you know, if he seen me struggling. I said no I can manage myself now.

Ok, did you have any visitors?

Only my sister.

Ok, and how did you find the visiting times?

It was ok.

Not too much or too little?

No. No.

How did you find getting in to see him? How was transport and things getting to see your brother?

Oh it cost me a few bob, taxi all the time because it's an awkward place to get to, the [hospital] from here.

Yes, I was getting a taxi every time I went down, and every time I come back. It cost me about £17 a day.

And you used to go in every day?

Well not every day, every other day or every 2 days.

5 times in a week I did it.

Yes, about 4 or 5 times

5 times in the week. And I nearly always had, one day that was a Friday to do my shopping, didn't I,

Or a Monday to do your washing.

Do the washing and the ironing.

A lot of people from ▮▮▮▮▮▮▮▮▮ have said that it's difficult to get there on the bus.

Yes it is.

Yes, yes

Because there is no bus direct. There is a bus direct of an afternoon, I think you get, some around 1 o'clock the next one is about 2.30 I think the next one is after 3 o'clock, there is nothing, nothing like the north end where every, nearly every bus comes down and passes the [hospital], there is nothing from here going round.

So what can be improved then?

Transport.

How would you like it improved?

They should have some special transport for anybody that is going to the hospital, regardless of whether it's going for to be an appointment, you know or going to see relatives, regardless of what time of day or night it is.

See they could put a bus on, to run say every hour, up that way somewhere to park and come back again.

It's a handy bus really but I think they could do better, a lot better. See we have a little mini bus that comes around here, along Garston Old Road, goes through to Garston, down into Garston, up to the New Station, then goes down from the New Station, and goes under the bridge and picks passengers up there, comes along St Mary's Road, Aigburth Road, Beechwood Road, and comes round again, it's like a round trip you know and people are glad of it, it's nearly all pensioners that get on it, they are more than grateful. And so am I, I don't know what I would do without it. But,

When you were told that you were leaving the [hospital], who told you that and how did that come about?

Well they said they would discharge me, and referred me to the district nurses for my legs.

So you were told by a doctor you were to be discharged?

Yes, yes

And were you quite happy with that decision?

Yes, I put the flags up!

Ok, and how did you get home?

Taxi I came for you.

No you didn't.

I did. Both times. Both times.

Oh you brought my clothes in didn't you?

You went into the reception room, you know where they all go in, when they are waiting for their transport.

Yes. Yes. I got a taxi coming back didn't we.

Ok, regarding the care that you received in hospital then, over all was it what you expected?

No. No. No. I thought they could have done better. I think what it is, it just depends what ward you are on. I have heard people talking about the ward they are on like, it's great. Well,

In your opinion how do you think your sister felt that you went into hospital?

She worried. She worried. She worried a heck of a lot. Because she thought she was going to lose me you see.

Ok, how did you feel?

When was this?

When he was in hospital ?

When he first went in I was very, very upset. And I mean upset. I didn't want to leave him to be honest with you. And I was in the hospital with him until, nearly 5 o'clock, I just didn't want to leave him, when I first saw him honest to goodness I thought this is it, it's the first thing you think of. He was in a terrible state and I just couldn't help, I just had it let it go, just had to let it go.

So you weren't relieved that you had gone into hospital because you were unwell?

Yes, yes, yes

Relieved?

Yes, some people are so unwell,

Well what it was, I wasn't worried over it, it was only, I had got up out of bed, I had gone to bed and later on she had come to bed, and the dog was in my room, and I could not, just could not get my breath. And I had to get the dog, I said go and get, go on, go on.

Go and tell Doreen he said. And she knew what he said, even though he couldn't say the words he mouthed them and she knew what he said.

And when she came in the room I could just whisper, ambulance, ambulance. And while she came downstairs I collapsed. But they worked on me an hour or so wasn't they,

Oh about an hour to try and get your breathing stabilised. He was all colours, all colours. His eyes, you know, they seemed to be coming out of his sockets, you know and it, he was purple, blue, red, you name it, he didn't need any make-up on that day I can assure you.

Can I ask you about the care that you receive from your GP, and whether you do receive any or what it's like?

Well that could be improved.

Down at ▮▮▮▮▮▮▮ you mean?

Yes. There are two doctors there, two women doctors. Dr R when I go to see her, she has always got a blinking clicking away at the television in front of her, listening to you, and I always think oh she is taking no damn notice of me here.

Is that typing on her computer?

Yes. Bringing my history up most probably. But the other one, she seems to

She gets the case up on the screen and then she starts asking questions.

Yes. Yes.

I saw her yesterday.

Is that better or not?

Yes it is, yes. This other Dr, it's Dr W who later came out to change my catheter, you know.

So you think that the GP talks, doesn't talk to the patient?

We have heard a few people don't like her you know. Don't know whether it's the same thing or not.

So you think they need to talk, pay more attention,

Yes, yes.

That's what I say with Dr W, she does sit back and she is like this and talking to you, you know. Nice and easy. I didn't care for her very much when she first came but I am getting to like her now.

What care do you receive from the GPs? Do you see them regularly?

No. Only when I have to.

So it's more the hospital?

Yes. Because I only see the doctor about every month over my tablets, I am always complaining about my tablets. Or, when I ask for a repeat prescription not all the tablets I am on end up where they should. I have had to ask for extra tablets you know.

So is that something wrong with, is that the chemist?

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I don't know whether the chemist or the doctors, they because, the doctor will need after seeing the ██████████, they will need the results, which I get, which is posted to me the next day. And I have to go down to the doctor for them to Photostat to see what, any changes in my dosages.

I took it yesterday, and she insisted didn't she that she got a copy.

Yes. That is the only time we ever see them.

And are you quite happy just seeing them once a month?

Yes. I have more trouble with the chemist.

Right,

I am always arguing with the chemist.

What are you arguing about?

Tablets.

Tell her about your warfarin

Warfarin. He sent 28 tablets warfarin, and I had worked it out and I needed 90 I think it was 90 tablets. 18 a week, 72 tablets, for a month, and just sending 50 you know, or just 28. And when you phone up, the chemist comes on and says that is how the doctor has put down, a month. I said I am on 18 tablets a week I said that's, 72 tablets a month to me, I said and another thing I said, there is 30 and 31 days in a month not 28, I said you are getting 28 tablets but you are losing out. This last time, we had an argument, was over a blinking plaster bandages for my leg. They reckon they can't get them now, well the people they order from doesn't have them, and the people they order from said they don't make them anymore, so I have had to go through the doctor, have a word with the doctor, don't know what is happening there like.

So who picks up your tablets for you then?

They come round, we have a delivery yes.

Right, so that's quite useful, because it's difficult for you to get out.

Yes,

It's mainly for the pensioners.

Right, ok. How do you feel about being at home?

Ok. The only thing, I don't feel glad about is not getting out. You know.

Also, it's he has lost some interest in some of the things he used to read. He used to read the Echo and the papers up until there were no lettering on them type of thing, he doesn't even read, he reads his magazines, but he doesn't read his books like he used to. That kind of thing.

Have you noticed that as well? Is that since you have come out of hospital?

Yes.

And why do you think that is?

I think my eyesight is going worse.

Have you thought about buying the audio books where it's on a CD and it reads it out to you, like a CD that you can listen to but it's a, you can buy popular books, on a disk so you can listen to them, instead of having to read them.

No,

Maybe I don't know, maybe that is something worth talking to the nurse about she might know where to get some.

Yes, yes.

So it's your eyesight and not, it's not your concentration or anything going?

No, no.

Ok, how do you feel in yourself since you have been out of hospital?

Ok. Except first thing of a morning, now, this past week or two. I am gasping for breath.

He has his good days and he has his bad days.

But mostly of a morning I am gasping for breath.

Might have the odd pain in his lump you know, down here, but

Yes.

I would like to ask you if it's had any effects on different parts of your life. So was there any physical effects from going to hospital to home, such as was there any change in pain?

No

Was there any change in discomfort?

No the only discomfort I have is like I said earlier on, when I get ache here, and the doctors keep telling me it's the stitches inside, it's pulling, so this one doctor said I have got angina, I had this pain the other day and it lasted me 2 or 3 days you know.

And that was the same before you went in, then when you went in and now you have come back out it's just the same?

I used to get it, about once every couple of months. I used to take a pain killer and it had gone within ¼ hour, 20 minutes, but this last time, I had it about 2 or 3 days you know.

Have you told her about the angina attack?

Yes

I had one yesterday.

Did you?

Yes

Oh that's wonderful.

Did you come out with any different medication than you went in with?

I wouldn't know. I might have done yes, extra.

What about personal care, we talked about this at the beginning you said that you had problems last year with going to the toilet and things, and you had problems this year with shower, in hospital.

Yes

How about now that you are home?

I have problems with the shower,

Yes. As I said I can't get into the bath to get under the shower.

So has it got better or worse since you have been out?

Oh just been the same

As before you went in?

Yes.

Ok. How about how you feel in yourself? Like you know your mood?

Oh I have been ok. If I sit down for any length of time, especially at meal times, I have trouble getting up, standing up, and my feet go to sleep, if I stand up, I have got to stand there for a couple of minutes, a minute or so.

Do you feel better that you are home, or happier or anything?

Oh aye, yes, yes. Because there is nothing to do in the hospital. There is no, nothing, no radio, no television, all I depended on was a book or a daily paper. Years ago they used to have a television room in the hospital, they don't have them now.

They have the ones attached to your bed don't they, they are like swinging ones.

Yes you have to pay through the nose for them.

Ok. There are a couple of questions about whether the transition, the move had any affect on family relationships, but you are very close anyway aren't you, so

Yes

Yes

And you said it caused your sister a bit of upset.

Yes

And it cost you quite a bit of money to get into see him.

Yes, yes

But nothing else has changed?

No

It hasn't caused any problems or anything?

No.

Ok the last question is about money things. Has there been any changes in benefits or anything you have had?

Get nothing. But, the social services were here this morning and reckons I should be able to get attendance allowance and carers allowance.

Is that for you the carers allowance?

I get a carers allowance already.

And she will get another allowance as well.

So currently you have just got your pension and the carers allowance?

Yes, yes

Yes. He is incontinent now you see so I am the same way, and it's costing me a bomb to buy pads and that. I have got to go to the women's hospital for them. I don't get them in the chemist shop, I would be broke by the time I got them from there.

Ok

But what is the others, I can't think what else I am getting.

Pension credit.

I have already had that down.

Can I ask you, if you had had to pay yourself for carers, would that influence whether you would have them?

If I had to pay for 3 days a week, I would drop the Monday and Wednesday one visit, only had the visit on the one day. Well, as I said to her before, it wouldn't be worth it, because they only come and see if I have had my tablets, and am washed and dressed and that.

Also to see if he has got any problems.

Any problems you know.

Ok, so if you had to pay yourself you would have less care?

Well I would just cancel the Monday and Wednesday one because really I don't need them. I only need the one on a Friday, where he will give me a hand to shower, or shower me.

This is a general question not necessarily relating to you but, what do you think about people who can afford to pay for care, like nursing homes and things like that, do you think there should be a difference between those who can afford it and those who can't?

Well, not really no because we have been paying in for years haven't you, for the same national health service, you know. They should be all on the one, but I say that, see, we might be destitute and having to go into a nursing home, the fella next door might be a multi-millionaire, he will be going in a nursing home, but he is in the same one we are, doesn't pay but if they were made to pay it would be a

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different thing like. The multimillionaire can afford to pay, if he is paying I don't know how much a week it would cost him, he would be making that in blinking profit on his firm. You know,

So do you think then people that, there should be a certain standard of care free for everyone?

Yes, in a way. Yes.

I know myself, I think he was a millionaire really, he had the shop round here, Tushi,

Tushingham yes.

His daughter, was Rita Tushingham, they had two shops and he ended up in the nursing home, and he would be getting the same as the woman next door but one, she was a widow. She was in the same nursing home, but she would get the same thing as he would get. But he wouldn't be paying for his the same, like her she shouldn't be paying for it. Mind you, as I said, they could, they do do it though, don't they, they take so much of their pension now don't they?

Yes, some care homes are private aren't they so you have to pay.

Yes.   But even the council ones, do they have to pay?

I think if you have got any money, something is taken, even just if it's a little bit.

They take so much. I think you have to have so much savings before they start. Say if I had £10,000, she has £12,000 she would be paying before me.

Do you think that's fair?

No because they would take all the damn money.   There should be some better way like of doing it. Even if it means putting the insurances up for [1.09.12] people you know.

What gripes me over this business of paying out, I think myself, there is a lot of people, I know there is 3 maybe 4 in this street, could be a few more down the bottom, are getting plenty of money from the social security, and they have never worked for it. That is what annoys me. There is me, I worked from 14 years of age, until I retired at 60. I wouldn't even when I retired, I wouldn't go and ask for any help, I am not a cadger, neither is he. We wouldn't do it would we?

No

It was only the suggestion.

I know a couple of fellas myself, I went to school with, they have never worked in their life, they have never worked in their life, see them occasionally when I used

to go out down Garston way, they have never worked in their life, no. That is what used to get me as well, you know, they know all the ways and means, it's what they, I think don't call it institutionalised do they or what? But they know all the tricks of the trade.

Yes.

They know all the tricks of the trade. And they are getting more than what you are getting working. Yes.

Ok. Can you think of any improvements on how to make anything that you have experienced better for someone else? You have mentioned the food, and you have mentioned the nursing care should be better in hospitals.

Yes

And you have mentioned your shoes that would make it easier. And also the cost of getting into hospital for visitors,

Yes, yes

Could be addressed.

Yes.

Is there anything else you can think of?

Not at the moment no. No.

See we are alright, we have got travel cards you see.

Ok, is there anything that you would like to ask me?

Yes, when you have gone.

He usually thinks of something when the visitor has gone.

Well I have got most things, let me turn this off.

Appendix 13: Example of a carer transcript (BCNW89HF64M003)

I don't know whether I should start with care at home, because he went from home to hospital or do you think there was not that much

Well there wasn't much. My Dad was a little bit of a

Stubborn bastard.

But also at times, because, because he was lonely and we had an example of that when we went into hospital and we were sitting in AandE in the cubicle, and I turned to my Dad and said Dad how are you, he said I am a lot better now, it's better than sitting in 4 walls, and that, then, even then, even then I thought this lad is swinging the bloody lead.

Well we got to the hospital, he was sitting in the ambulance waiting to be taken in, laughing and joking with everybody and he had been crying when [name] was there.

Could I add, it was a Monday and it was a Monday and it was erm, a day for my sister to go down to see him, she gets down there at 10.30 which is when she normally gets there, and he was crying, I don't feel well and she got upset so she phoned me, she said can you come down. So I walk in thinking he is swinging the lead again, so I just said come on what's the matter, I don't feel well, I have got tummy pain, I have got a back pain, so I said well ok, I thought I would shock him out of it by saying we will ring an ambulance and get you into, went along with that, quite happy with that.

He had cried wolf too many times.

Because you know, and I thought that would kind of shock him out of it, not realising the severity

Yes, that he was in pain.

That he was in pain but he went in there a jovial guy, he went in there that when we first went to see him, he would walk us to the end of the ward, to say cheerio, and every day we went there and he got progressively worse. Now I don't know whether this is the time to say it, he had an x-ray, very first day he was there, it took 9 days for them to come with the results, he had a large aneurysm in his back,

No in his stomach,

Sorry, well is it the aorta at the back, he had an aneurysm in there, and they didn't find that for 8 days. And then when I challenged the consultant about it he said well the radiographers there are a couple of days late, so I said well hang on a

minute this is 8 days late, a couple of days perhaps we can understand, this is bloody important why has it taken 7 – 8 days to get that, oh he said, he said perhaps it's been looked at but missed by a junior person and when it's gone a little further down the line someone has noticed it. But,

You have digressed from home care, there wasn't any real,

No, no, no there wasn't any home care. We tried to get him to come home because we knew the experience we had had with my mom, but because he was on 50% oxygen, they wouldn't allow him to come. If he was, apparently if he was on 40% oxygen they would let him come home, which is what we wanted to do wasn't it, well he was going to come here anyway, but

But before he went into hospital we are talking.

So before he went into hospital it was yourself, both of you and your sister who were his main help?

Yes and my brother, my brother as well

Family

So there were no nurses or meals on wheels or anything like that?

No, no, no. My sister used to make, my sister used to make his meals for him and erm, she would, we had adapted a microwave so she would set the time, and all he had to do was press start and when he has his, she would take, he had butties for lunch, and he had a cooked meal for his tea.

And how long had he had prostate cancer?

I think he had had it about 20 odd years. He had long, he had had it a long time.

And had he had treatment?

Yes he was on, he was on a tablet for it.

Ok, in that case then I will start with just being in hospital. So which hospital was he admitted to?

It was the [hospital].

Ok, and he was living at home,

He was living at home yes.

Why was he admitted to hospital on that occasion?

Erm, he was admitted with stomach pain and back pain.

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Stomach pain and back pain.

And who made the decision for him to go into hospital?

Me. Well I made the decision to phone the ambulance and the ambulance lads when they came over, remembered my dad from they were saying once they had took my mom into hospital and because of his pains they decided he was better go and have check-up at hospital.

Ok, so were you involved in the decision about the admission as much as you wanted to be?

Erm,

You were really.

I if my Dad, I suppose I was erm because erm, I suppose if they had said no I would probably turned round and say you know, they weren't take him to hospital I would probably said yes [6.11] to have him checked out but that never came, you know, that is a difficult question to answer to be truthful with you. Because that wasn't my decision they had already made it that he was going to be taken into hospital.

Once the decision was made for him to go into hospital how long did he have to wait before he actually went in?

Well that was the ambulance,

So it was emergency ambulance?

It was an emergency ambulance, I can't remember whether we phoned, did we phone the doctors to make the phone call or did we phone it ourselves? I can't remember which way round it was whether we phoned the doctors to tell them that he wasn't, no I think we did phone 999. Yes.

And do you think that this length of time was too short, acceptable, too long waiting for the ambulance?

It wasn't long.

It wasn't too long. The ambulance side of it, I suppose it could have been quicker but because he wasn't you know stressed, stressed. You know if had had a heart attack or something like that, you know I don't think there is, everybody would be saying they should be quicker but you know.

Ok, were there any practical problems that had to be overcome when he was admitted to hospital, so things like did anyone have to take time off work, or have children minded or any kind of

No because we are old fogies,

There was me and you because we were the only ones retired at the time.

Yes.

And how did you both get there, did you go in the ambulance?

No went in the car. To pay these exorbitant fees.

How did you feel about him going into hospital?

Well I was happy, very happy for him to go in there because at the time I actually thought he was swinging the lead. Because he was fine, and once the ambulance came he was laughing and joking and as I said to you, when we were there, he said to me this is better than sitting at home in the 4 walls. And I really thought he was swinging the lead then.

Ok, and on reflection what do you now feel about him going into hospital?

Erm, it was the only course of action to take at that moment in time, because obviously the lad was ill with his back pain with his aneurysm I think it was more of his, I don't know whether the back pain was causing the stomach pain, erm but erm but he was, he was not well. This is something else we also noticed as well, is that they had been given by the doctors loads of erm, not paracetamol, is it paracetamol?

Paracetamol

I think they used to store them, you know go back and ask the doctors for more. They had about 6 boxes of

They had 10 boxes

10 boxes of paracetamol, and when he passes away we found that he had only got left was it 2?

4.

So he had had 6 so, we get the feeling that he had been ill

He had been in pain

He had been ill for, and taking the, the only course of action we can think is that he had been ill for a long time, or for longer than he had been telling us, and taking the paracetamol to take the pain way. We don't know we are only surmising that.

During his hospital stay did he experience any pain?

Oh he had pain in his back. What did they say his

They said the stomach pain was constipation.

Yes. That is

That was before the x-ray results come back?

Well that's what they kept telling us, they didn't tell us any different for over 8 days.

That was the worrying thing. When I signed my dad in to hospital, I signed in as next of kin, and when my dad passed away, the next of kin on his file was my mom. Now we don't know whether that was the reason that whenever I went to discuss with the, they wouldn't give me, they wouldn't give me a definitive answer or let me see somebody but because my mom had passed away 18 months prior, I don't know that is the only,

We are assuming that's why because nobody would tell us anything.

No one would tell us what was, those, the x-ray, the x-ray we didn't find out about the aneurysm and all of that until just before my Dad died.

Until he was in ICU.

Until he was in ICU.

Because he did on admission you put, he put himself as next of kin but obviously the didn't relay that to his notes on the ward.

Did he have any treatment of his pain?

Paracetamol.

Paracetamol.

And did the treatment relieve his pain?

No

Not at all?

Not really no.

How much of the time was he treated with respect and dignity by the doctors, nurses and other staff?

I think in the beginning he was. Because they moved him when he asked to be moved, it was just in the last sort of 10 days I think.

I think because he was in, he was in AandE, they do tend to spend a little bit more time with you because they don't know what is wrong with you. When he ended up with moving to two wards,

I think the first ward was ok it was when they moved him to the other one that they suddenly left him and

Because it was the geriatric ward and there is so many other people of a similar ilk in there, it was,

That was when they sort of left him to his own devices really, but the first ward he was in was fine.

But that,

Too hot

Is that like the overspill from AandE I think isn't it?

Yes, then they moved him to the other.

Ok, thank you. Are there any examples of anything that you can give that happened in hospital that demonstrates how the staff treated him with respect and dignity?

Well when he wanted the person in the bed next to him on one of the wards was very noisy and talking a lot, so when he, he couldn't sleep so he asked to be moved and they moved him. And you know so things like that, whatever he asked they did listen to him.

Yes

Did you feel that there were sufficient opportunities for you and your Dad to talk privately or spend time together whilst he was in hospital?

Erm,

Privately?

Privately no because you are in a, you know you are in an open ward and that is, that is private as it can be. You know it's in an open environment it's not,

There was no where to go and sit and just talk and be with him was there?

No

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Was there a TV room or anything like that?

No

Because they have the little things that come out.

Yes

How many people were in the ward?

6 was it?

Erm,

6 or 8?

6. Each one that he went into was 6.

How many times was he moved?

He went into AandE, he went into the ground floor ward, he went to the upstairs ward. And then he went into Ward 53, and in Ward 53, he moved

Twice

No he moved into the other room, then he moved to ICU, and then he moved into the room where he passed away, so he moved 7 times.

In 3 weeks?

Yes

In 3 weeks.

I never realised it was that long actually, that many times, but yes it was. From admission to him dying. It was.

To him passing away.

During his time in hospital how involved were you with the decisions made about his care?

We weren't. We tried to be. No one would tell us anything.

And so the next question is were you involved in decisions about his care as much as you wanted?

No [laughs] not at all.

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How would you have liked to have been more involved?

We would, the questions were asking or I was asking, I wanted, he had an x-ray the very first day he was there, the staff nurse or the manager would go into his file, and would attempt to go and have a look at the results of the x-ray, now whether they were doing it on purpose I don't know and it wouldn't let him access it, so we never, the number of times I went in to that room and have a private conversation with the assistant manager about the things that they were doing to him, what was,

We would have liked to have discussed it, because we would have liked to have had him home, while he was still fit enough and well enough and with us, to know that he was coming home and being cared for at home.

So could you see then at, was there a point that you thought he, this is it now he is going to pass away, he needs to come home?

No, not until he had the heart attack.

Right, so that was when you wanted him home, when he had had his heart attack?

Yes,

Well we would have brought him if we had had answers we would have brought him home before that if they had said, well

Because no one told us

We didn't know how ill he was.

We could see he was getting progressing ill,

But he was getting mentally,

He was,

Losing his mind.

He was going strange and shouting at people and

Yes hallucinating

Getting delirious. And then,

We knew that your mom had gone through something and he had gone through that when he had been in hospital before,

Yes,

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So we knew he wasn't sleeping and wasn't getting rest so we thought well if we could bring him home, if we could get answers, to know how long it's going to be, but we couldn't get any answers off anybody.

Was there anyone, was there any kind of key person that you could speak to?

All the time, that was the problem that was the problem. It's like learning, learning you know, again and that was the problem. And this consultant who he was under for 10 days, prior to him having the heart attack was on holiday never seen him, and it wasn't, the morning of him having, after he had had the stroke,

Heart attack

The heart attack we go into ICU and this, the consultant's registrar was there talking with the consultant from ICU as if he knew everything about my Dad, he had never even seen my Dad

We never seen him

And we had never even seen him before, he was someone, who are you. And he was someone who I had been trying to get to see asking what is wrong with my Dad, why is my Dad getting worse every day, he came in here, seemingly with a pain in his back and a chest pain why is he going down, down hill I know he is 89 but someone could tell us that he, because we weren't, we weren't prepared for it being, for him passing away we didn't think he went in,

We didn't think it was that close

We didn't think you know

And if we had been told it was, then there was no way we would have put him through what your mom went through because as a family we had all decided that wasn't going to happen to anybody else in the family you know and we didn't get that opportunity.

Can I just ask them, this is a bit of a digression but what happened to your mom because that has obviously played a big part in the way that you were looking after your Dad?

Yes well what happened my mom had a stroke and went in, and she had a baby off Steven Gerrard by the way. Who she hates, because she is a Manchester United fan. And she hated Steven Gerrard, but she went in there and she shouted out all over the ward, I have had a baby, and it's Steven Gerrard's. But, and then, and she was in there for 10 days and then she had another massive stroke, and what they did is, she was right near where the sister was when she had her first stroke and then she was moved into the corner, the furthest away.

Well she moved 3 times on that ward.

She moved next to where she ended up, and then they moved her into the corner because they knew she was dying. So they put her on the syringe driver, and had a curtain around here and we were, we were there 24/7 and the problem with that was as we said to you before, is that we were going past everybody and we knew what was happening and everybody else knew what was happening and we kept on asking is there a room or a ward, where people like my mom who are in the stage she is, could be moved to so we don't disturb everybody else, and we could have a bit of dignity,

Plus the people on the ward wouldn't have to know that she was dying because they were in a similar situation.

Yes so it's almost like looking at what could happen to them.

Happen to you yes, and you could see it on some of their faces.

Because

And that was a mixed ward as well, which wasn't helpful because there was more men in there and she was the only woman at that point and sometimes her clothes were up and she didn't have the dignity that she needed.

So what we didn't want is my Dad to then move out because he was going to move out of ICU and back to the ward he had come from but we knew he was on his last legs and what we didn't want to do, was to get into that situation that my mom was in, that's why we said, no matter what happens we are going to have him home. So what the hospital ended up doing is they have these isolation rooms where people with the

MRSA?

MRS, yes go in they said we have got one of those free, we will move you in there so as a compromise so that I didn't kick up too much of a fuss they moved us in there, with the proviso to say that if they have anybody that comes in with that, you will have to move out. Fortunately, we were in there for 7 / 8 days, and he was on a syringe driver, you know we were there 24/7 and we didn't get moved out. I don't know what I would have done if we had been told we had to move out, I think I would have really gone berserk.

I would have just brought him home anyway regardless.

But they wouldn't let us bring him home you see,

They wouldn't let us

Because of this,

Well they said he would only last 24 hours the consultant,

And was he unconscious

Oh aye he never regained

Well they said they were, I mean that wasn't good either because they said they were going to take him off the ventilator, please come in and be here so if he can speak you will be there when it happens and we waited all day, and the nurse said oh I a not doing it today now, so we came home. And within half an hour of us being home she rung and said they had taken him off the ventilator

Can you come back in he might wake up

You know so that was like we had sat there, all day you know from 8 o'clock in the morning,

Everybody was there, everybody was there all day. You forget these things don't you?

I don't forget that one because I was really annoyed about it.

In your opinion did the staff know enough about his condition and treatment?

No

Did you have confidence and trust in the staff that were caring for him?

I think we did in the nurses.

Yes. I think,

There were a couple, well one wasn't but the rest

That's a double edged answer really,

Yes

In as much as I was complaining that my Dad wasn't getting the attention because he was, that he needed because of the way he was going downhill so quickly. And, I was told that, I said that he needed more attention, to the extent he needed looking after 24/7. And to be told that we can't do that, we don't have the staff for that. So what do you do,

I think on the general wards but once he was like he had come from ICU then the staff were really, really good. The last week.

Oh well you see the, staff, once he was in the cubicle and we were sitting in there, staff were fantastic, but they didn't have to look after him,

No because you were there.

No because there was nothing to do.

Because there was nothing to do. Do you know what we seen the consultant every day for those 7 days, whether he was worried that we would make a formal complaint, but he would stick his head round the corner, he obviously didn't look at Dad because there was no point in looking at him but he was coming to see how we were and up until then he never even, because he had been on holiday. It was, oh I don't know.

So yes in some of them, you did have in some of them. Did you feel that the staff had time to listen and discuss things?

They did under their terms.

Were you able to discuss with the staff any worries or fears you may have had about their condition, treatment or tests?

You did but you didn't get any answers.

No although I tried to discuss them?

Yes.

In your opinion were there enough staff on duty to care for him while he was in hospital?

Before he had the stroke no, erm, before he had the heart attack no.

But again that is generalising. When he first went in yes, and then when he started moving from pillar to post, up until he had the heart attack.

Ok so there was sometimes enough staff, depending on,

Yes, yes.

Over all do you feel that the care he got from specifically nurses in the hospital was excellent, good, fair or poor?

Fair

Fair

Ok, have you got an example of fair care?

Fair care was the very fact

They were there.

You could see them,

We probably should say poor I suppose.

Do you want the example of the fact that he needed a wee, and he said I need a wee, so I, I think it was Chris that went to see the staff nurse to say could you get a bed pan and he just burst into a loud noise and aah you know that he had had to do it. He said I have wet myself, I have wet myself, I have wet myself and he was so distressed and 10 minutes, ¼ hour later the staff nurse comes along with a bed pan. It's under their, it's under their terms rather than,

When they want to do it rather than

Rather than the caring for the person. I know they have got other things to do, but that is why I say to you he was at the stage where, he was at the stage where he needed more care than was being offered in that particular location.

I think it's because old people can't control the same as younger people can they, they can't wait when they need help, they need help.

Do you feel that the care he got from doctors in the hospital was excellent, good, fair, or poor?

Fair because he never saw a consultant. Until it was too late really.

How would you describe his quality of life during the hospital admission? Would you describe it was excellent, good, fair poor?

Poor.

And do you think his quality of life changed as a result of being admitted to hospital?

Yes I do.

In the way that he went much worse?

He just deteriorated mentally and physically. Whereas he was getting drinks and food and care really and he was just ignored a lot of the time especially at meal times. And the fact that he couldn't have a hot drink because they were afraid of him spilling it on himself, well, somebody should have been there to give him one.

Yes. Do you think that his health changed as a result of being admitted to hospital?

Yes.

How?

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He deteriorated.

Did you as a couple experience any practical problems when your father was in hospital, with getting to the hospital?

No, just having to make sure you have got £2.50 every time. And once he had been in there, how long

Yes we did get, the last week we got a pass.

Yes. I think

[29.52 – talk over]

Have to wait 2 weeks or in ICU, we didn't realise when he was in ICU we could have got the pass then didn't we.

Did you experience any practical problems with visiting times?

No

No.

Car parking?

Only paying for it.

Ok, practical problems with extra expenses? Was there any kind of,

No we had to go to maternity to have something to eat, it was wonderful. They do the best, if you ever go

Yes you could put that as a good thing maternity café is wonderful.

Yes, cheese on toast, absolutely wonderful.

Anything with arranging time off work?

No

There is a thing about experiencing difficulty because on the weekends there were no cafes open for visitors, we had to use the staff café. And you are charged 30% more because you weren't staff.

You go into, you go into the staff canteen and you walk in there and they obviously realise that you are not a member of staff so you know you get whatever you want and you go to the till, and the girls says to you, you do realise

that there is a 30% surcharge on top of the price. Why? Because you are not a member of staff.

And also you can't sit in here, you have to sit in the corner.

And also you have got a big canteen there that was empty, and there is a little, a little corridor, with a few chairs in, you have got to go and sit in there,

Were there any practical problems when your father was in hospital with other arrangements, so childcare for anyone?

No, no

No my wife looked after me.

How about care for pets?

No

Anything else at all? Any other practical problems?

I don't think so because we were free weren't we, so it didn't really, if nobody else could go we were there.

We were always there.

Is there anything else you would like to tell me about the time he was in hospital for?

In terms of?

Anything. Any good things, bad things?

I think, it is appalling that a hospital that is looking after people that are ill, only works 9 – 5, 5 days a week. I think it's absolutely dreadful. I gave you an example of when my mom was there, and the physio came running to me at 4 o'clock panicking that she wouldn't be seeing my mom until next Monday and wanted to give her exercises. So, I think you know, people don't,

At weekends it's just a skeleton staff,

It's not like a

[33.17] dead, that you can't get anybody, you can't get answers,

You can't get a doctor

You can't get a doctor, you can't get anything at all and it's just the basic staff on, on the ward, so if there was a real, well for an emergency yes they get there, but

as far as relatives are concerned, it's a waste of space the weekends. And it is when [33.37] people visit.

If I worked in a steelworks or I worked in a plane factory or anything that is working 24/7 people that work there would be working on shifts and every particular discipline would cover 24/7 so I don't understand why doctors are not on shifts, I don't understand why consultants are not on shifts, the nurses are on shifts, so why are the, why are the chiefs not on shifts, why do the Indians have to be, I don't understand and these are the people that are earning mega bucks I think it's dreadful.

So the next sections, unfortunately as your father moved many different parts of hospital, other people actually move into hospital, into a hospice, back into hospital, into a care home, and lots of the interview is addressing that type of thing. He didn't have any out of hours medical care?

No

Is there any kind of relationship or care he had from his GP?

Oh he used to go, he used to go for a 3 month check-up at the doctors.

So did he have any contact in his last 3 months of life?

Yes he had been to the doctors. But because he had got so many other, he would always go with

A new ailment

A new ailment. And, when I told, when I told the doctor that his PSA had gone up the doctor to a certain extent was slightly horrified because he hadn't taken his PSA for quite a while. And, when he found out that it had gone up he felt very guilty,

But he did contact us, straight away and we had a good conversation with him.

Yes, and I think he said I would have to report this as a near miss, so I don't know what they mean by that, as whether, something might come out of this but he was just,

He has been the family doctor a long time, since he first started as a GP.

He is a great doctor

We have a lot of faith in him.

So did he know enough about your father's condition or treatment?

Yes

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Yes, oh aye. Yes.

Did you have confidence and trust in the GPs caring for him?

Yes

Totally, totally.

Did you feel that his GP had time to listen and discuss things?

Hmm

And were you able to discuss with the GP any worries or fears that you might have had about his condition, treatment, or tests?

Yes, I have been to see him about it and we have had a long discussion with [name]

So you discussed them as much as you wanted to?

Yes

Very much so

How much of the time was he treated with respect and dignity by the GP?

Totally

Always.

He always classed my mom and my dad as his favourite patients.

Oh right ok

He loved them. He would give him a load of hassle, he always gave them a hard time.

He used to shout at them because they used to go there as [37.13] hypochondriacs,

His mom would go I am doing that, why aren't you giving me that, and but he loved them.

Have you got an example of something that demonstrates how the GP treated him with dignity and respect?

I think he just always had loads of time for them and we have had loads of messages off him haven't we about like when he knew his Dad was ill erm we got

a message didn't we off him to say that he was ill and that we need to go and talk about it, and then when your mom passed away and your Dad, he left a message to say they were my favourite patients, and you know I will miss them and I am really sorry and, really nice.

Always had time for my Dad because

He has time for, us as a family actually.

Yes, because both my mom and my dad as I had slightly hypochondriacs, and they used to go and have a, and I think sometimes he shouted at them and told them to don't be silly and you know, which is the kind thing that he needed you know because he was treating them as a friend you know.

Well yes I think as a family we trust him completely he is one of the best GPs we have ever had anyway.

If we go, I mean we have had trouble with our son and we have been there and just talked to him about it, because he knows my son as well, and he just give us as much time as we needed. So it's really good, and my daughter used to go when she wasn't so good as she is now, but he had a lot of time for her as well.

I think if we went there to see somebody else he would be quite upset with us for not seeing him. And he always does make time, he will ring us up and say I am away but if you come here, you know if you want to see me, so he has been really good like that.

I think you are probably right that if we were in a bigger practice and we didn't have the same doctor, and that is what you are alluding to really isn't it, these days it's unusual to have, for someone to go to see the same doctor over and over again and we are very fortunate in as much as, that is,

We are, it's excellent.

You know and if we can't get him we would wait until the next day or, ask the reception if there is a cancellation let us know and we will come in.

I think that, going forward as well it will be a lot more uncommon because buildings are being designed to now to host a load of GPs so going forward there won't be any,

To get to know people

It's a shame really, because

That is one of the worse things you could possibly do.

I think it's part of your care because they know you as a person as well so they understand more what you may be going through, and what is causing your illnesses and things a bit more than somebody who has never seen you before.

Doesn't that also put pressure on, the clarity of the notes that are put on the doctors file about the individual? So how does the doctor have sufficient time to put it in the clarity so that someone can understand the person that is the difficulty isn't it?

Yes. Yes.

That's sad if that is the way, is it going, the doctors are going more like a mini hospital are they?

Yes so I think I suppose you could still ask for your doctor but whether people do or, new patients probably wouldn't have that.

No you would just on whoever is available.

I think probably the younger generation, erm because they have not been perhaps brought up on having that one doctor, like my daughter wasn't too bad about going to any other doctor there was she?

She hasn't changed her, only the children because she lives next door to the doctors surgery so it's easier to take the children from school and the house and the surgery is all in a little compact area, so rather than have to get in her car, to take them when they are ill but she is still with our GP.

Oh is she, I didn't realise she had just changed the kids.

She trusts him for her, and she said if I don't like this one I will be going back to him, but it's for convenience, because she is a child minder, so she has always got a load of kids, and it's hard to get them all in the car.

How often did the GP visit your father in the last 3 months of life at home?

He never visited, he never visited my brother used to, my brother used to take him to see the doctor on a 3 monthly basis.

And were any home visits needed?

No

Is there anything else you would like to say about the GP's care.

The GPs care was excellent. Got no fault in any shape or form. We are lucky to have,

Can't praise him enough

We are lucky to have the doctor that we have got.

Ok,

Is that unusual? Is there a lot of complaints about doctors?

Well, as I say you are only the third people that I have interviewed from this phase

Luck of the draw then is it?

I think we are lucky in that respect as well because when I had that heart murmur and I had to go for a scan it was one of our GPs that actually did the scan in the hospital so that was continuous care there as well.

And I think what they have also been doing now, at the Countess and I think it's just to try and get people off the books, my Dad had prostate cancer, and the consultant at the hospital couldn't do any more for him, because my Dad used to go there, have his PSA done every 6 months, and because he couldn't do anything more for him because he didn't have an operation or anything, he was just treating him on tablets rather than him going to the hospital, he passed him back to the doctors,

Well he has passed you back as well.

He has done exactly, I go for PSB because my Dad had prostate cancer I have regular PSA tests, and I used to go to the hospital but now they have passed me back to the doctors, so the doctors you are better off with the guy that you know rather than have to go to hospital, pay £2.50 wait ages to get seen and then nothing, we will see you in 6 months, so there is a lot to be said for doing something, for, for passing it whenever they can back to the doctors because they can be more on top of the, because they know you.

Well you are not just a number are you? You are a face and a person to a doctor, to a GP.

There is 3 very small sections now, this one is ok, the next one might be a bit upsetting,

Go on.

Ok. Erm, he didn't have any [46.07] medication,

He didn't have medication he was on loads of tablets.

Ok when he was moved was any medication changed? So when he was taken into hospital was any of his normal,

Yes they dropped some things and added other things didn't they?

Yes

I don't know what they were.

Ok, do you think that you were given enough information about the medications he was taking?

No

Why do you think that?

Because we weren't told anything.

Nothing at all?

No, that was one of my biggest beef, to the extent I used to spend, I used to go there for an hour was it an hour or an hour and a half visiting and I used to spend about ¾ hour, 50 minutes in the room, with the staff nurse trying and trying to find out what was wrong with my Dad.

Do you think that your father or you were given enough choice about medications or treatment?

No. Weren't given any choice.

Was that because you were not given any information about?

Didn't know what, we couldn't understand why he was, other people that were in there with him, seemed to be getting better and he was doing the reverse, and it was trying to crack my head open to find out why on earth that was happening to him and not to others.

Were there any incidences in the last 3 months of his life when there was a misunderstanding or error regarding medication? He was given the wrong medication or not given any?

Not that we know of no.

Ok, throughout the last 3 months of his life do you think that all the health professionals knew enough about the medication he was taking?

Can't answer for them can I? I assume they knew what he was taking.

It was only the GP, he knew what he was. Because they used to provide blister packs, on a daily thing for him, so he didn't get confused.

In November, before he died, he did, remember I was at the hospital, I was at the surgery, and with our John and he had had a scan on his heart hadn't he and the outcome of that was that [name] took him off, he changed his tablet didn't he, because they were concerned about having listened to his heart.

Yes but the GP knew what,

The GP knew exactly what he was on.

Ok this is the possibly upsetting bit. Did he know he was likely to die?

No

Did he ever say where he would like to die?

No

Did you have enough choice about where he died?

No

And how important was it to you to have choices?

Very

Total and utter.

Can you tell me more about that then because I think we discussed that before.

We discussed it before and because of the experience we had with my mother, when she passed away in hospital we sat with her for 7 or 8 days on a syringe driver, and watched her body get white, until she did finally pass away. The thought of, in an open ward with a curtain behind us, erm around us. The thought of going through that and the fact that there were other patients outside, realising what was happening or like we assumed they realised and we would have to traipse past them and we were there 24/7, the thought of that happening to my Dad, horrified us. And as soon as he had the, he had the heart attack, and we, we then decided, if we had known before he was dying but until he had the heart attack, we didn't know until then, we would have brought him home so he could have, so that we could have made him comfortable, we would have brought him here, we would have made him comfortable and anybody could have come and seen him and it's more personal. As I said to you before, if it hadn't been for the fact that at the hospital they had a room available which is for the, what did you say it was?

MRSA

The MRSA room available, they offered that to us, because my Dad was on 50% oxygen they say anybody that is on 50% oxygen and above they will not allow to

come out of the hospital, if he was on 40 apparently they would, why they couldn't try 40 I don't quite know but, and but they did say to us that if anybody came in with the bug, they would have to move, they would have to move him out. And fortunately for the 8 days we were sitting waiting for him to pass away, they didn't move us. I will say from the people that were, the family members that were around his bed, the staff then were fantastic, they didn't have to, they came and turned my Dad, you know just to make sure he didn't get, and they were excellent, they were excellent up until then I don't think they were, because they had so many other things to do, he needed more than what was being offered.

But as a family we wanted him to die at home because we thought he would be happier. Because he wanted to die anyway since his mom had gone.

Oh since my mom died, you know his will and the very fact, you see the thing, his life would have been a lot easier if he could have seen, and because he had macular degeneration it meant that erm, he couldn't really go out, erm, he used to walk down the road from where he lived and cross a road and we got a white stick for him, so, the cars used to stop because he had, but then he started getting brave and not taking his stick, and used to put the fear of God up us.

He wanted a mobility scooter and somebody tried to sell him one, luckily [52.47] was there to stop him.

Someone was there,

And he was blind almost

Someone was there when I went down to see my Dad he was just about to sign on the dotted line for a mobility scooter and I thought Dad what the hell have you done. He would have killed someone.

But I think it was more as a family we wanted him where we could be with him 24/7 all the time.

Yes, I think because we did that anyway I think we wanted it so it wasn't,

But we could all be, rather than just one or two.

Yes, it was more personal rather than going to,

We could have fed him, [53.23] and drinks and made sure he was, and I think, I actually do think because my daughter used to do the home care that it is better than what you get in hospital, I think we would have had better care at home. Off the, you know the nurses.

Is it district nurses

And the carers. My daughter did that for 5 years and she said if you could get him home, we would get better care, we just couldn't.

And the reason was the oxygen?

Yes,

They said whether that was an excuse I don't quite know.

He did say if he was on 40% and as my daughter said we could have had an oxygen thing at home for him anyway.

Like a machine.

Yes.

But in answer to your question for the reasons that we had 18 months previous we wanted him home.

So do you feel that he died in the right place?

No

No

Ok, the last section, did he receive any care from health and social services at home?

He used to go to day care twice a week which he used to enjoy, moan about it, but enjoy it.

How long did he go there for?

He went on a Monday and a Tuesday and a Wednesday.

Was that for years or?

He had been doing it since, we had a fight to get him to go to the first one,

About 12 months.

Probably yes, probably about 14, 15 months he had been doing it and it took us a while to get him to do that.

Did he have a main contact person at the hospital or the GP or elsewhere in the last 3 months? Someone that you could, who knew everything that was going on.

Well not really no

Just our GP

The GP knew everything medically but with regards to his day care and everything else,

That was down to us

There was no focal point if you want.

Ok. Do you think everyone involved in his care had enough information about his needs?

No

Over all do you think that you and your family got as much help and support from health and social services, as you needed when caring for him?

From just social services?

Well we group health and the social services

Is that the hospital and everything?

It's everything.

No. You should split that up into two I think.

Do you think that any of the admissions or moves between places of care, so in your situation it was just from home to hospital, could have been avoided?

I don't think so

I don't think so. No.

But perhaps there could have been an extra one, because he could have come home,

Could have come home yes, yes.

Over all what effect do you think moving between places of care had on his quality of life?

Moving ward to ward didn't help him.

No

I think that made the quality deteriorate. I don't think going in hospital particularly made it deteriorate, apart from when he got there he didn't get the care he needed.

I think, when you reflect like now, I think you, we still don't know even now why someone who went in with a back pain, we knew he had got an aneurysm and someone who went in with a chest pain, got on a 24 hour basis, got progressively worse. No one has explained, alright he had a heart attack but up until that heart attack he was getting worse. And no one even now has explained to us why he was getting worse.

So you said earlier that the prostate cancer had spread do you feel?

Well we are only assuming that because nobody has told us.

Nobody has told us. He didn't have, he was supposed to have a bone scan to see whether it had spread, but they didn't end up doing it. He went in, he went in on the,

He was supposed to have it the first week.

He went in on the Monday and he was supposed to have the bone scan on the Thursday,

And they cancelled it.

And they cancelled it for whatever reason we have no idea. And,

Then he was having one on the Friday but he had a heart attack

Then he had a heart attack on the Thursday.

We honestly

They didn't say that

I don't think cancer, I don't know.

I don't think cancer come into it.

I don't think cancer works like that does it, I don't know.

But they told us that he could have been, his mind was going possibly because he had a urine infection but he didn't.

Right, urine infections they do say that,

They can do that, but he didn't have one.

But they

They did say he didn't have one. So we have no idea.

Right, so it's just a bit unknown.

It's just unknown why he, as I kept on saying to the assistant ward manager, why on earth is he getting worse,

My theory is that he was getting dehydrated, and that was what making him [59.06] because he wasn't getting enough drinks and that was actually and it was so hot in there, you know it's a wonder they didn't pass out and there was a lack of fans.

Oh there was no fans at all.

To keep them cool

They were fighting for them like, everybody was fighting for fans.

I actually bought wipes to cool him down every time, you know so I could wipe his face and cool him down because he was so hot.

Yes it was a hot summer wasn't it.

Yes, so I think that contributed to it.

Do you think, what affect do you think going into hospital had on his health?

Finished him off I think. Which sounds rough but I think it did.

Yes, I think

I am sure if he was at home he would have lasted in a better quality and maybe longer.

What affect do you think it had on this emotional wellbeing?

It sent him

That finished him off.

That definitely finished him off emotionally.

Is there anything else that, because this is the last question, now is there anything else that I haven't covered, or you want to tell me more about.

About his emotions before he had the heart attack, a couple of days before, he spent the whole visiting time crying, asking for his wife to come and take him and he asked

me to get him a knife so he could kill himself, he was in despair, so it really, really did get to him.

Was that his pain or his situation?

I think it was the whole situation. I think it was everything because he didn't say then that he was in pain, he just said get me out of here didn't he.

Yes. Because

Tell her to come and get me and give me a knife, I have had enough and

Before he got to that stage, he had been complaining to me about his legs, saying his legs have stopped working, so I mentioned it to the ward manager and she said oh I will get the physios to have a look at him, next day. So, I come in, and the physios were just finishing with him and sits him down, you know the big chairs they have at the side of the bed, sits him down on there, they come back all laughing and cheery with him, and just as he is sitting in the chair, the physio that is helping him, he grabs hold of her knee, and you know joking

Yes he was very naughty. Naughty but that's how he went towards the end.

But it's like

Out of character

But that was early, when he went down to have the x-ray on the Monday he went in, the girls that were down there doing the x-ray said I am not letting you in here again because you have to do, apparently you have to do that to the x-ray machine, and he didn't want to do that, to the x-ray machine, he wanted to grab them, and that was the kind of jovial he went in, in that vein and then just go progressively

That he didn't want to live, even more, you know. He loved company but and me and him hadn't seen eye to eye for a long time but he just hung on to me and kept saying get my a knife, get me a knife didn't he, I don't want to

And we don't know why

That was the day, I think it was 2 days before he had his heart attack.

So we don't know why.

I am sure it's because he was dehydrated, and not eating.

I don't know whether lack of I suppose lack of food and lack of liquid would have especially in an 89 year old would have an adverse effect on somebody.

And they had also told us that he hadn't, the day before that, that weren't worried about his heart.

They did say that, they weren't worried about his heart and he ended up dying with a heard attack.

Because his heart rate and everything was good for his heart because he had a, one part didn't pump properly did it, and he had had that 3 years. So they said they weren't worried about his heart so they didn't monitor him they took him off

Oh aye he didn't have a monitor or anything like that on his heart. When he had the heart attack.

They took him off everything once he had moved to the last place, before ICU and that's when they stopped like giving him warm drinks and his food wasn't being eaten and even for the first few weeks, he lived on custard cream biscuits and hot chocolate, that is all he had while he was in there and nobody bothered did they?

No

So when I started you said that kind of just the reason, you know just that I am here has made you think that you might complain, or might take something further, what would be the main, I am not asking you to choose one for your complaint just,

It's, to say it's a complaint is perhaps taking it a little bit overboard, I think it's a, it's an observation that I would like someone to look at, and see if the experience we have had, could be, could be

I think

Stopped and make sure it doesn't happen to another family. You know, with the best will in the world with 20:20 vision, everybody would do a lot of things a lot different, but, the way it is set up at the moment, I think, I think the main thing that I would like to see is a 24/7 hospital because I

I would also like to see more information to the relatives, about the patients. Because that gives you an informed choice, and we didn't have an informed choice. And I think that needs to alter, I think that, the relatives need to be consulted more and told exactly what is going on. Especially the next of kin. Or the children you know, make sure you have got it right that the next of kin is the next of kin and give them enough information to have the proper choice. Because we had no choice on anything, at all,

And I think, and I think also I think also something that needs to be considered, is that when anybody is admitted to hospital, a fact sheet should be given to the people that are coming in with a list of all the badges, or the uniforms that people that, because you see so many different people in so many different coloured uniforms and you have no idea who. I know there is a chart, I think I seen a chart

once with a few of them on, but you need to know, so you can pick the right person to go and have a word with, I think that is the most important

It's just administration really isn't it?

It's, I think

How they administer the care that they are going to give and what part the relatives can play in that, so that they have an informed choice I think that makes a big difference. Yes and that it's there 24/7 you know not just 9 – 5.

And also with regard to this resuscitation which did we cover it on that.

I am not sure but I have got notes, but you can say it again.

With regard to the resuscitation, the very fact that we never, you know my Dad is 89 years of age, he has got that many things wrong with him we never had the discussion with anybody about if, because and we didn't have it because they said we are not worried about his heart, I assume if they had been worried about his heart someone perhaps in AandE would have had the discussion that if he does have a heart attack should we resuscitate. No one ever had that discussion.

Yes because the cancer nobody knew whether it had spread or not because they didn't do all the tests, we just assumed,

But I also think that they ought to consider, they ought to consider when a patient comes in of a certain age, say 80, whether that is, I believe they do that I cancer, don't they when someone comes in a cancer patient that is, they don't feel as got long to live or they have that discussion straight away.

Well they have it with heart attacks as well,

it is called a pathway and if you are in the last 12 months of

Well he was put on the Liverpool pathway,

At the end

After, after he came out of ICU

When he was unconscious.

When he was unconscious.

Because they had got the Macmillan nurses in then as well.

That's when the Macmillan nurses and he was put on a syringe driver.

It was a bit late.

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And you know how long a syringe driver takes to

But they weren't going to do that either until the Macmillan nurse come in because the consultant was off.

That's right

So she insisted that he did have that, so she took over the care really she kept coming in to see him,

And was it explained to you what the pathway was?

Yes, well I knew anyway

Like palliative care.

It was, it was,

Our daughter had told us that.

We were told it was the palliative care, because we knew that he was never going to recover that he was, but I think what was horrifying us all was because we knew how long we had to sit with mom to pass away, we knew it was going to be 7 or 8 days, and the number of times, at the start when it was late at night and he was [breath] and then he would stop and then he would stop breathing and then suddenly, that was dreadful wasn't it.

It is awful for the relatives and I know there is nothing you can do about that, but, at home that would have been a lot easier to cope with than in a hospital. And plus the other patients in the ward who were walking past and they all knew he was dying, you know and they would pop in and it was just, if it had been at home it would have been so much more personal, but it was having an informed choice so that you could do that.

Are they moving more to people staying at home now, is that what they would like to do?

No not really but I suppose it's more difficult in certain areas, who haven't got things set up, District nurses are often linked to GP practices and if you have these big clinics, then you might not have enough district nurses, and the it depends on the population of the area, so if everyone is elderly you are going to need more again, so it is very, very many things

I think that's our main bugbear that, we didn't have the choice. I mean not everybody would want their relative at home anyway, you know but I had had experience with my mom because me and my sister nursed her at home for the last 2 weeks, just us two didn't we? And it was so much better, than the hospital because you were closer to them, for the last few, you know my mom was

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conscious until the last day, so it was a lot easier and you didn't feel like you were intruding on other people, by being there all the time because they have a hospital to run and you have got to have a routine otherwise nothing gets done, and sometimes you felt like they were going oh they are here again, you know but we wanted to be and we needed to be.

Well I felt like that every time I went to see the assistant ward manager, it was almost like, he would almost like try and duck me because it was the same thing over

Well because his hands were tied he wasn't allowed to tell you anything.

And over again and the very fact that if we had known, see these people they are doing it day in and day out, even if they are not doctors the have an idea that the, this is you know, he ain't going to be coming out, and if they had told us before my Dad had the heart attack, we would have said well we will take him home there is no point in him being here, and that is what, that is all at the end of the day because we could see he was getting progressively worse, that was all we wanted for someone erm, a professional to turn round and say, I am afraid he is getting worse, his prostate is you know and his aneurysm, that could go at any time, we don't know how long but it's not going to be very long. And we would have taken him home before he had the heart attack. But, there was no one there.

END

Appendix 14: Example of coding framework for patient data analysis

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7.10 General Complaints

Appendix 15: Example of coding framework detail

	D	E	F	G
	1.2	1.3	1.4	1.5
	l status/living arrangemei	Employment/Education	Family networks	Other
	with wife, most of sons earby pg1,	Welder apprenticeship pg1, left school aged 14, worked in factory for 33 years, retired when he was 65 pg1, wife p/t work on school meals pg23	10 people in the family "no room" pg1, now got 6 sons all married, mostly living nearby pg1,	
	1, been married 52 years 5 years ago pg2	Left school with no qualifications, worked in a factory and then got married and had 4 children pg1, one daughter is a teacher pg3	One of 4 childre pg1, one lives in Newcastle, the other are nearby pg2, grandchildren visit frequently too pg2, close relationship with daughter and son pg3, son was taking pt to Clatterbridhe as he could get time off work (univeristy) pg8, husband also drives but not far anymore pg11	
	p in St Helens pg1, lived for 4 years pg3- there is ng on which sometimes ξ3, lots of single people the flats pg4	Left school aged 15 pg1, worked in Rainhill hospital then on school meals pg1	Has 2 sisters living relatively locally pg1, has 2 sons, 6 grandchildren and 2 great grandchildren pg1	
	arried aged 31, lives with ed to be a train driver, airdressers for 16 years problems, sold it and n in local hospital pg1	Owned haridressers for 16 years then worked in admin in hospital pg1. Husband was a train driver for 46 years including royal train pg1	Worked in Pilkingtons Triplex pg1, mother and father died before age of 21 so she lived with her older sister pg1. No children, miscarriage aged 30ish and 'tilted womb' pg2. Close to niece who has 'lung disease' she is 'like a daughter'. Pt has 4 brothers (dad and brother died of LCa), 1 sister (died aged 59 LCa) pg2	
	nd married aged 26 for , until she died pg1	In the army when he was younger for 2 years, then worked as a clog maker, furniture remover and in the post office until he retired pg1	One of 11 children, lived in a pub with aunties family, father in the arimy pg1, had 6 sons and 1 daughter with his wife and 'now I find I cant go wrong, they are all smashing' pg1. Also has 17 grandchildren pg2	"Its been a good life and I have enjoyed it" pg2
	slums' of Liverpool pg1, arriage and kids' worked years pg2. Married aged en, 4 are alive, first baby (smallest 9lb) pg2	Left school age 14 working in a pen factory, making diving suits, and then ammunitions, finally working for Birds Eye for 20 years pg1/2	13 children born to mother, 7 survived, mother lived until 96, father unitl he was 78 pg1, doesnt speak 'to the boy, I hate him- sisters are very good' pg1. Sons live nearby pg2	
	r and 7 children, father work on the docks pg1. r Arm Sailor (lasted 10 ld) then married again, n pg1. Both sons in army pg1	Worked until I was 50 and got made redundant	Has 3 brothers and 3 sisters, a couple of them live locally. Pg1. Dad died aged 70, mother died aged 97- for 10 years giving her 24 hour care between the 3 sisters pg1, brother also has dementia now, her brother in law has Alzehemiers, all sisters caring for them, lots of nieces and nephews too pg1. When Pt was in Clatterbridge she could have 17 visitors at a time pg2	
	ςh pg1, went to live in ied then moved back to d aged 23, two daughers sons pg2,	14 years old when she left school pg1	10 children in family, 6 bos and 4 girls, mostly living in Liverpool area, pg1, daughters live near (Pt lives with one for 4 years) and son lives in Bristol pg2	
	me when she was first ed aged 31 pg2, daughter uutes away pg4	Worked as a crane drivers and cleaned cars, working in canteens, husband worked at glass factory pg4	Part of a family of 11, two siblings killed as children, 8 brothers and 3 sisters pg1,All lived in the same 4 room house pg3 , two daughters pg3, no grandchildren pg4	Died a few hours after the interview finished.
	of Liverpool 40 years ago current house with wife, ildren pg1	Worked in the fruit trade in Liverpool Market pg1, 43 years in the same firm pg1	Family network- 2 nephews, a niece, brother and sister, brother in law pg1, wife died with alzehemiers 6 years ago pg1	

	A	B	C	D	E
1	Care Received	3.1	3.1.i	3.1.ii	3.1.iii
2	Participant Identifier number	Carers	Relationship	Carer roles	Carer burden
3	LC81M001	Wife is recovering from Ca pg4, "she brings me, she looks after me well. Its a good job Ive got her like, I would be lost without her" pg20,	They have a very close, sometimes argumentative relationship- quite firey pg3. Usually they are arguing pg5,	Wife speaks to Macmillan nurses about pts problems pg3, she also monitors his sleeping and exercise pg4, she has started to tend to the garden, previously his job & she explains about teaching his to cook when she thought she would die of Ca pg5, she is also the main cook pg6, and looked after their 6 sons 'doing everything for them' pg6, wife goes with pt to all appointments pg19	Wife losing sleep because of toilet trips during the night pg3, felt that she was the one to blame for his constipation because of her cooking pg3, couple think that they dont want to burden their children with their illnesses because 'they have their own life to lead' pg12	Wi wi wi ta: ch pt go an wi
4	LC73F002	Husband is her main carer. "He is happy to be with me at the hospital...sometimes I feel terrible, I wish he wasnt with me, I want to be therre by myseld and just get on with itm because I dont want anyone to worry, and I know they get worried about me" pg8	"He has been a great husband you know, he has also been, he said the other week he said listen, he had done all the cooking, its always me that did it, and he said listen, you have done it for 50 odd years for me , he said its my turn now" pg10	Daughter is mother to two young children and looks after parents pg6, whichever of her children are with her during her appointments, they ask lots of questions 'good sensible questions you know' pg9. Husband goes food shopping without her, something she misses pg10. If the Pt needs palliative care (which she does) her husband has said that he will look after her pg12. daughter wants to help her change her bed etc but she wont let her pg13	Pt was a 'burdened carer' looking after her mother who suffered from depression and then cancer **. She repeats during this passage that she was 'not a strong woman' and 'she would never ever accept it' so she and her brother kept the diagnosis 'away from her for a couple of years' and 'i thought, its a horrible thing to have on your mind and I didnt want my children to go through the same. So I though, if the doctors are going to say anything, tell it to me' pg9	Hu sta ma wa wi rel dic pg
5	LC77F003		They have a close relationship and don't need to much help "we just help each other" pg10		"I think myself, I have told them, if it comes to the push that we had to go into 24 hour care they must put us in, I mean...they have got to bring their own family up haven't they" pg14	Hu ev hir ha
6	LC79F004		Niece has sarcoids disease and can be breathless. She is 43, and does not work pg7	Niece always takes her to appointments pg7		Hu he tal pg
7	LC81M005			Son had to 'run round' getting medication from the hospital after the Pt was discharged pg10	One daughter took him the hospital and then another son stayed with him. Another son then went to the hospital twice to pick up medication after he was discharged pg7	