ONE DAY AT A TIME

Living with frailty: Implications for the practice of advance care planning

A multiple case study

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ABSTRACT

Background: Advance care planning (ACP) was originally designed to promote autonomy and is commonly conceptualised as informing treatment and decisions in the event of a person's loss of capacity. In the UK, healthcare policy has emphasised the potential for ACP to significantly contribute to improvements in experiences of death and dying for patients and their significant others. Older people with progressive frailty are at high risk of mortality, loss of capacity and increasing dependency on carers and care services, yet uptake of ACP in this group is poor. Little is known about whether frail older people regard advance care planning as relevant or what perspectives they have on decision making for the future.

Aim: To explore the expectations, experiences and understandings of frail older people and their significant others of planning for future care and to examine the implications of this for the practice of ACP.

Methods: The study adopted an exploratory case study design using serial qualitative interviews and the responsive interview technique. Frail older people and their nominated carers were recruited from hospital wards in a large University Hospital NHS Trust prior to discharge. They took part in up to two interviews either in hospital or in their homes. Within and cross-case qualitative analysis was undertaken.

Findings: Sixteen frail older people and eight significant others were recruited (Seventeen female, seven male, age range 70-96). The study found that frail older people experience profound uncertainty, associated with rapid changes to their physical and/or mental state and complex challenges in everyday life. Consequently, their attention is focused on day-to-day maintenance of quality of life, rather than on future care or advance decision making.

Many had difficulty imagining a future; as dependency grew, so did reliance on care services to support their needs. What once would have been deemed an unacceptable way of living became routine. For many, the care system offers a lifeline without which they would not be able to exist at home. However, it also appeared to offer little individual flexibility, meaning that frail older people struggled to assert the control over day-to-

day decisions and choices that others take for granted. This increasing dependency and reliance on care and care services has the potential to undermine the decision-making capacity of frail older people. For many, autonomous choice and decision making gave way to relationships, partnerships and negotiations that are commensurate with a more relational model of autonomy.

Conclusion: The end-of-life orientation of current ACP policy and practice is at odds with the dynamic nature of frailty and does not correspond to individuals' needs to maximise their current quality of life. The liberal ideal of autonomy as self-determination and self-interest presented by the legalistic and ideologically driven policy of ACP is out of step with the lived worlds of frail older people. For those facing increasing dependency on care and care services, frameworks that acknowledge a more relational approach when planning future care will be needed in order to engage this group of frail older people in ACP.

SCHOLARLY OUTPUTS FROM THIS THESIS

Published abstracts:

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This thesis is dedicated to the frail older people who took part in the study and have since died. May you rest in peace.

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LIST OF ABBREVIATIONS

ACP   Advance care planning

AD   Advance Directive

ADRT   Advance decision(s) to refuse treatment

DNACPR   Do not attempt cardiopulmonary resuscitation

DWP   Department for Work and Pensions

EOLCS   End of Life Care Strategy

GSF   Gold Standards Framework

LCP   Liverpool Care Pathway

LPA   Lasting Power of Attorney

NIHR   National Institute for Health Research

NRES   National Research Ethics Service

PPC   Preferred Priorities of Care

RPCP   Respecting Patient Choices Programme

UK   United Kingdom

CHAPTER 1. INTRODUCTION AND OVERVIEW OF STUDY

1.1. INTRODUCTION

Advance care planning (ACP) is commonly conceptualised as promoting autonomy and informing future care and treatment decisions in the event of incapacity. It is widely promoted in UK policy as a means of improving end-of-life care (National End of Life Care Programme, 2011, Thomas and Lobo, 2011), especially for those living with frailty (British Geriatrics Society, 2014). Frail older people are at greater risk of incapacity and death (Clegg et al., 2013, Morley et al., 2013) and yet in a UK context, ACP is uncommon (Abel et al., 2009, Conroy, 2011, Tan et al., 2013, Musa et al., 2015, Pollock and Wilson, 2015). Little is known about whether frail older people regard ACP as relevant or what perspectives they have on decision making for the future.

This thesis explores the perceptions of the future and expectations and experiences of advance planning for older people living with frailty and their significant others. In particular, it examines this in relation to policy and best-practice guidance relating to ACP and raises questions as to whether as currently conceptualised ACP is applicable for those living with frailty in today's society.

This introduction starts with an explanation of my own journey into this field, offering a reflexive account of my background and what I, as a nurse, bring to the study. It then seeks to situate this research study in the wider body of literature and provides an overview of the structure of this thesis as a whole.

1.2. PERSONAL REFLECTIONS/MOTIVATIONS

In designing and executing this study, I have become an integral part of the study itself. My 'voice' represents my values, knowledge, ethics and morals, and all of these have influenced and motivated me in designing the research questions and methodology used in the study (Clough and Nutbrown, 2012).

I embarked on this research study as an experienced clinical nurse working in an acute medical admissions ward. I had just completed a Masters in

research methods from a scholarship awarded by the National Institute for Health Research (NIHR). My clinical profile has included jobs that span staff nurse to ward manager. I have also held positions teaching undergraduate nurses and developing nurses as a practice development matron. This study is heavily influenced by my work in acute medical admissions, which I have continued while undertaking the research study.

Prior to commencing the study, the ageing demographic and diminishing physical ability of many patients in a clinical setting was becoming difficult to ignore. The term frailty had become commonplace within the clinical setting and was used in association with many older people being admitted to hospital. Although I had witnessed end-of-life decision making throughout my practice, it was becoming increasingly common to witness patients with diminishing physical and cognitive ability, and their relatives and significant others, contend with end-of-life decisions. I became interested in how I, as a nurse, might better facilitate these conversations about end-of-life issues. I also began to ask questions about how patients and relatives might be more prepared, which I felt might enable them to avoid making these difficult decisions in acute crisis. I wondered what the acute service could do to contribute in this area and if there was value in exploring the decision-making experiences of those who are vulnerable to death and at the end of their lives.

During this time, I saw an advertisement for a PhD studentship, which was orientated towards research at the end of life in resource-poor contexts. Although the number of people to whom this research study relates is great, research relating to frail older people and those at the end of life has not traditionally been well funded. I therefore saw this studentship as an ideal opportunity to increase understanding in this under-explored area, and I commenced my PhD studies in late September 2012. At an early stage, I took the opportunity to reflect on my thoughts and ideas about this area of study. Excerpts from a research diary from this time are reproduced below:

> "*From my initial limited enquiry, it is apparent that there is a large amount of literature on advance care planning. It is encouraging that there are frameworks, supported by policy that would enable*

those I care for to plan ahead for the times of acute crisis. It is also worrying that despite this I have never seen an advance care plan in practice.

"Making clinical enquiries with my colleagues in relation to my study has revealed that frailty is a descriptive term that is used by nurses in practice. Many have told me that all the patients they care for are 'frail', and yet just looking around me in the hospital ward, I can see that there is a good deal of variation between the appearances of individuals. I find this inconsistency in the use of terminology confusing and am becoming acutely aware that my own views on frailty are based on physical appearance alone."

[Field notes December 2012]

1.3. SITUATING THE STUDY

From my reflections above, it is clear that despite using the term frailty within clinical practice, it is difficult for staff to articulate or describe what it means. This is hardly surprising given that attempts to agree on a definition for use in clinical practice have yet to reach fruition (Morley et al., 2013, Rodríguez-Mañas et al., 2013).

Frailty is set to be one of the most challenging and problematic expressions of population ageing (Clegg et al., 2013). It occurs in between 50 to 75% of people over 85 years of age (Morley et al., 2013), and the number of people living in the UK aged over 85 is expected to quadruple to four million by 2051 (Office for National Statistics, 2013). This shift in age profile towards older people is accompanied by a change in patterns of disease, with causes of sudden death such as infectious disease replaced by progressive chronic conditions (World Health Organization, 2004, World Health Organization, 2011).

Frailty has important implications for the care needs of older people right up until the end of life. Timely recognition of frailty and assessment of the needs of the person with frailty may enable health professionals to plan care and better engage patients and carers in difficult discussions about end-of-life care (Koller and Rockwood, 2013). However, little is currently

known about the process of identifying the care needs of those with frailty and how end-of-life care needs are represented in the care planning process (Muller-Mundt et al., 2013).

ACP *(Box 1)* is a voluntary process that can provide opportunities for individuals to make decisions regarding future care in the event of incapacity (National End of Life Care Programme, 2011).

"…a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses".

(National End of Life Care Programme, 2011 p.6.)

Box 1: Definition of ACP

Originally designed to promote autonomy, empirical work on ACP conducted from patients' perspectives also suggests that it aids preparation for death and dying and involves the recognition of the value of personal relationships (Martin et al., 1999, Singer et al., 1999). This view has subsequently been reflected in a body of literature, resources and materials that have been orientated towards and reconceptualised ACP as a means of helping patients prepare for death (Pollock and Wilson, 2015).

Despite the broad definition provided by the National End of Life Care Programme (2011), the bulk of UK policy, which is promoted under the banner of the end-of-life pathway, has a tendency to associate ACP with end of life. According to the UK Department of Health (2008a), to enhance quality at the end of life, patients and carers should have the opportunity to discuss personal needs and preferences with professionals who can support them.

A report from Alzheimer's Society (2012) has also underscored the importance of giving patients and carers the opportunity to discuss personal needs and preferences with professionals who can support them. This report was based on the experiences of patients and carers and calls for greater public awareness of the importance of talking about death and dying and planning for end-of-life care in advance (Marie Curie, 2015, National Palliative and End-of-Life Care Partnership, 2015).

More recently ACP has been heralded by some as a solution to all end-of-life decision making (Seymour and Horne, 2011). However, ACP can be in relation to, but is not exclusive to, end-of-life care. Moreover, a direct causal link between ACP and improved quality of life has yet to be established. Empirical evidence thus far describes the positive effects of the decision-making process on patient and family satisfaction (Zhang et al., 2009, Detering et al., 2010, Brinkman-Stoppelenburg et al., 2014). Although there is some evidence of an enhanced effect on quality of end-of-life care, this is predominantly emerging from the international literature (Detering et al., 2010, Brinkman-Stoppelenburg et al., 2014). Despite policy exhortation, the effects of ACP on end-of-life care have yet to be firmly established in a UK healthcare context.

When interviewed in relation to ACP, older adults are quick to recognise the benefits of enhanced choice and autonomy (Carrese et al., 2002, Seymour et al., 2004, Jeong et al., 2011b, Sutton and Coast, 2012). They also report being happy to engage in discussions surrounding end-of-life care (Seymour et al., 2004, Davidson, 2008, Seymour et al., 2010, Venkatasalu et al., 2013). There is, however, some reluctance among participants to record these decisions because of a likelihood that current decisions might not apply to future circumstances and that these preferences might change (Seymour et al., 2004, Sutton and Coast, 2012).

There are some gaps within this literature. Although some studies look at perceptions of older adults in relation to ACP, none of the participants in these studies were described as frail, and their physical health was unclear. Frailty is an emerging healthcare problem, and numbers of frail older adults are set to increase dramatically in the next 50 years. However, as an approach that places an emphasis on capacity, ACP may have limited

applicability to frail older people. Previous studies do not represent this group of patients within their study populations; indeed, often this group are excluded from research, especially if they are experiencing fluctuating or permanent incapacity.

Like many nurses in the area I worked, I was not familiar with ACP. Like many colleagues, I had not been presented with any of the documented formal outcomes of ACP by a patient or their carer during my time in clinical practice. With many of those experiencing frailty being admitted to acute care several times leading up to death (Abel et al., 2009, Bardsley et al., 2010, Georghiou et al., 2012), this would seem the ideal place to be presented with such.

Given this experience in acute care and the policy documents that advocate for ACP, I was asking what I can do to help frail older people to engage in advance care planning. But in clinical practice, we often try to fit individuals into the policy, frameworks and theory that already exist (Munhall, 2012). Moreover, if more frail older people knew about ACP, would this automatically mean that they would engage and commit to the ACP process?

My opportunity to study at PhD level had come by way of asserting that frail older people are a minority voice in the generic literature. There is a dearth of literature that articulates the voice of the frail older person in the conceptualisation and practice of ACP. This thesis aims to address this gap, not by asking questions among participants about ACP that research suggests that they had little experience of, but instead, but by exploring their perceptions and experiences of the main concepts relating to ACP. These concepts include:

- Understanding of current health
- Communication and decision-making practices
- Uncertainties and concerns regarding future care
- Potential deterioration in health and/or cognitive ability
- Wishes and preferences for future care.

1.4. STRUCTURE OF THE THESIS

Chapter 2 is the literature review, which provides the background and context for the empirical study. This chapter considers ageing and society and the contemporary challenges of frailty to healthcare. It goes on to detail the history and origins of advance care planning and its philosophical and cultural challenges. The evidence in relation to advance care planning is then discussed from the perspectives of healthcare staff and patients and their carers, followed by a discussion on policy and best-practice guidance. The evidence for ACP and frail older people is then considered, before closing with a justification for the empirical study.

Chapter 3 is the methodology chapter, which begins with the empirical study aim and objectives. The underpinning philosophical assumptions of the study are detailed, followed by a detailed description of the study design. The ethical aspects of the study are then detailed with particular attention being paid to the process of reflections and reflexivity which occurred throughout the study.

Chapter 4 is the first of four data chapters that reveal and discuss the findings of the study. It provides a preliminary introduction to the three main data chapters by presenting each of the sixteen case studies. In this chapter, the frail older participants and their significant others (where applicable) are introduced as detailed vignettes.

Chapters 5, 6 and 7 begin with a foreword, which is intended to add further context to the main findings of the study. The interpretations in these chapters are a synthesis of the sixteen case studies, divided into three main themes that form the title of each chapter:

- Living with frailty: Developing an understanding
- Negotiating care and care services
- Planning for the future.

Chapter 8 is the final chapter and discusses the core findings in relation to existing research and theory. It also considers the implications for future research and clinical practice. The thesis concludes with reflexive and methodological insights from the study.

CHAPTER 2. LITERATURE REVIEW

2.1. INTRODUCTION

The broad concern of this thesis is to explore the planning of future care from the perspectives of frail older people and consider this in relation to the practice of advance care planning. To begin, this chapter will consider the ageing demographics of the population and how frailty has emerged as one of the largest challenges facing contemporary healthcare. The nature, rise and conceptualisation of advance care planning will then be discussed, paying particular attention to the strength of evidence pertaining to the outcomes of ACP and the barriers to its implementation. This chapter will then consider the current literature and evidence regarding the perspectives of frail older people and advance care planning, before closing with a rationale for the empirical study being conducted.

2.2. AGEING, FRAILTY, SOCIETY AND DEATH

According to the Department of Health, the age profile and primary causes of death in the United Kingdom (UK) have changed dramatically over the last century. Infectious disease, once a major killer, has given way to chronic illness, with most people's deaths being related to conditions such as heart disease, liver disease, renal disease, diabetes, cancer, stroke, chronic respiratory disease, neurological diseases, dementia and frailty (World Health Organization, 2004, Department of Health, 2008a, World Health Organization, 2011).

The age demographic of the population is accelerating rapidly worldwide with a projected increase from 461 million people being over 65 years in 2004, to an estimated two billion by 2050 (Kinsella and Phillips, 2005). These changing demographics have led to an ageing world population, with the greatest percentage increase of the population as a whole among people aged 85 years and older (Gott and Ingleton, 2011). Most people are now dying in old age following an extended period of frailty and decline, and these trends are set to continue and even accelerate far into the future (Leadbeater and Garber, 2010). Now more than ever before, there is a spotlight on end-of-life care (EOLC), which has become one of the most significant activities to be provided by the NHS (Pollock and Wilson, 2015).

2.2.1. Ageing and frailty

Chronological age alone, however, does not determine the vulnerability of a person or whether they need health and social care. Frailty is a non-age-dependent dynamic process, which results in vulnerability to sudden health status changes and frequently leads to a spiral of decline. This is often irreversible with an increased risk of worsening disability, delirium, pain, falls, admission to hospital and death (Fried et al., 2001). Many clinicians believe that to successfully combat frailty, medical practice must be targeted and sustained (Morley et al., 2013). It would seem that the key to this is to implement the screening and management of frailty into clinical practice worldwide (Morley et al., 2013, Rodríguez-Mañas et al., 2013).

Medical experts have, however, been unable to agree on an operational definition of frailty for use in clinical practice. To date, there are two established international models, the frailty phenotype (Fried et al., 2001) and the cumulative deficit model (Rockwood et al., 2005). These models are based are biomedical markers such as disease, decline and loss and seek to identify adverse outcomes such as institutionalisation, dependency and premature mortality (Harrison et al., 2015).

Some researchers have criticised these biomedically orientated models of frailty (Markle-Reid and Browne, 2003, Gobbens et al., 2010a, Van Campen, 2011, Nicholson et al., 2012b). Following a review of the literature regarding conceptualisations of frailty, Markle-Reid and Browne (2003) concluded that a lack of attention to the whole person when considering frailty could lead to the fragmentation of care. They also contended that if frailty is defined predominantly in terms of physical losses, then assessment and management strategies will consequently focus solely on this aspect (Markle-Reid and Browne, 2003).

Subsequently, alternative representations have emerged that present a wider model of frailty. These more holistic definitions are derived from the perspectives of frail older people and incorporate a broader conceptualisation, taking account of the psychological and social aspects of living with frailty (Van Campen, 2011, Bergman et al., 2007, Gobbens et al., 2010b). Moreover, research conducted by Nicholson et al. (2012a) highlights that the stereotypical image of frailty portrayed by the medical

model rarely equates to a person's own lived world of frailty. Frail older people retain enormous capacity to work with the challenges of accumulated loss in physical, social and psychological domains, and this can have a substantial impact on how they use health and social care services (Nicholson et al., 2012a).

Considering the lived world of frailty alongside the biomedical models can give healthcare professionals a much more informed and holistic view. However, it is also important to understand how older people perceive the term frailty. This is because perceptions regarding health can have an important role in determining illness progression and use of future healthcare services (Petrie et al., 2007). Although studies conducted with those who are frail highlight the complex nature of its progression, to date, there are few studies that examine the use of the term frailty among older people themselves (Warmoth et al., 2015). The limited evidence that is available suggests that there may be an active wish among older people to avoid association with the term, given its traditional negative connotations of ailing health, infirmity and old age (Fillit and Butler, 2009, Warmoth et al., 2015).

2.2.2. The challenges of frailty in healthcare

An ageing and frail population has profound implications for the planning and delivery of health and social care, much of which may be needed in the last year of life (Georghiou et al., 2012, Clegg et al., 2013). This increase in absolute numbers means that older people in almost every society will face the risk of indifferent or poor healthcare (World Health Organization, 2011).

Resourcing the economic and social care needs of an ageing population is a significant challenge. This has led to initiatives designed to avoid duplication of care and to prevent unnecessary high-cost hospital care (Knickman and Snell, 2002, Bardsley et al., 2010). Adequate care is required for those with frailty to live well but also to die with dignity. Although these two aspects of care are vastly different, the emphasis placed on the act of death and dying often means that the necessary focus on quality of life and living well are overshadowed (Kellehear, 2011). This view has been reinforced by reports of gross deficiencies in the care of

those with frailty at the end of life in institutions such as hospitals and care homes (Health Service Ombudsman, 2011, Francis, 2013, Parliamentary and Health Service Ombudsman, 2015).

In recent years, the increased interest in how frail older people die in the UK has been reflected in policy. In 2008 the End of Life Care Strategy (EOLCS) was launched. This strategy provides a framework for local health and social care to build on and aims to promote high-quality care for all adults at the end of life (Department of Health, 2008a). It brings together work previously carried out by the National End of Life Care Programme and sets out a strategic plan for health and social care services. This plan aims to provide the best quality in the care of patients at the end of life. One key element of the strategy is that:

> *"All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan."*

> (Department of Health, 2008a p.12)

The EOLCS also promoted the use of the end-of-life care pathway (*Figure 1)* that is hinged on identifying those in the last year of life. Reflecting an acknowledgment of the importance of patients' involvement in decision making regarding their future care, it also focuses on preferred place of death (Department of Health, 2010, Pollock and Wilson, 2015).

Step 1	Step 2	Step 3	Step 4	Step 5	Step 6
Discussions as the end of life approaches	**Assessment, care planning and review**	**Co-ordination of care**	**Delivery of high quality services in different settings**	**Care in the last days of life**	**Care after death**
• Open, honest communication • Identifying triggers for discussion.	• Agreed care plan and regular review of needs and preferences • Assessing needs of carers.	• Strategic co-ordination • Co-ordination of individual patient care • Rapid response services.	• High quality care provisions in all settings • Acute hospitals, community, care homes, extra care housing hospices, community hospitals, prisons, secure hospitals and hostels • Ambulance services.	• Identification of the dying phase • Review of needs and preferences for place of death • Support for both patient and carer • Recognition of wishes regarding resuscitation and organ donation.	• Recognition that end of life care does not stop at the point of death • Timely verification and certification of death or referral to coroner • Care and support of carer and family, including emotional and practical bereavement support.

Social care

Spiritual care services

Support for carers and families

Information for patients and carers

Figure 1: End-of-life care pathway[1]

2.2.3. Preferred place of death

Over the last century, society has seen a major change in the places in which people die. At the turn of the 20th century, dying at home in England was commonplace. At the start of the 21st century, this had fallen to as low as 18%. However, government initiatives to increase home deaths have since seen this figure rise to 23% (Gomes et al., 2012). Currently, the largest proportion of deaths among older people in England occurs in NHS hospitals, and there is evidence that a significant proportion have palliative care needs related to frailty (Department of Health, 2008a,

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[1] Reproduced under Open Government licence. Crown Copyright 2008. (Department of Health, 2008a)

Gomes and Higginson, 2008, National Audit Office, 2008, Office for National Statistics, 2013).

Given the predicted increase in numbers of those with frailty, researchers estimate that this could mean as much as a one-fifth expansion of inpatient facilities in England and Wales (Gomes and Higginson, 2008). In a climate of austerity and with many hospitals closing beds in an attempt to save money, this seems unlikely. Therefore, alternatives need to be identified in order to allow improvement in efficiency that does not affect quality of care. Infrastructure, however, is only one part of a wider problem. Increasing numbers of patients expected to die in acute hospital care create challenges for health professionals. Increasing pressure to provide good-quality care that runs alongside productivity and shortened hospital stays is challenging, especially in end-of-life care.

There is consistent evidence that, when asked, more people would prefer to die at home as long as good-quality care can be provided (Higginson and Sen-Gupta, 2000, Gomes and Higginson, 2004, Koffman and Higginson, 2004, Munday et al., 2009, Department of Health, 2012b). However, this evidence does not take account of the views of those with frailty. Moreover, additional evidence suggests that this may change as death draws closer, as care needs increase and if the expectations of support at home cannot be met by current resources (Department of Health, 2008a, Sampson and Burns, 2013).

2.2.4. Talking about death and dying

One of the key barriers to delivering good end-of-life care is a failure to openly discuss it with patients and their carers (National End of Life Care Programme, 2010). Over the last century, there has also been a huge shift in the way society as a whole views death. With people living longer, many do not experience death until they lose a close relative or friend later in life and, as a society, we do not openly discuss it (Department of Health, 2008a). Sociologists argue that death has been sequestered; it has been removed from the public sphere and located in the private world of the individual. This sequestration of death is reflected in the fact that most dying in the UK occurs in institutions, away from public gaze (Howarth, 2007).

For some, this social invisibility of death can translate to fear of death and a general unwillingness to discuss it. However, according to Cox et al. (2012), reluctance to engage in discussions about death as part of normal life may have wider consequences. A lack of general knowledge about social and health services can affect individuals' independence and quality of life. Moreover, when family members are unaware of their loved one's wishes, it can lead to inappropriate interventions, fear of isolation and fear of the dying process (Department of Health, 2008a). Increasing public awareness is a prerequisite for engaging in a dialogue about death and dying and for appropriately managing future needs, expectations and resourcing of end-of-life care (Cox et al., 2012).

Encouraging people to engage in conversations relating to end-of-life care reflects a wider approach taken by the UK government and policy makers to offer individuals more choice about their care and to promote partnership in such decision making (Department of Health, 2008b, Department of Health, 2012c). ACP has been widely promoted as a means of achieving these goals and of improving care for those at the end of life (National End of Life Care Programme, 2011). However, in a UK context this has yet to be established.

2.3. ADVANCE CARE PLANNING: AN OVERVIEW

Internationally, there are many definitions of ACP. For the purposes of this section and throughout this thesis, I am working with the UK definition of ACP; a formal version is provided in *Section 1.3 (Box1).*

Advance care planning can give people the opportunity to state any preference they have about their future care, should they find themselves in the position that they can no longer make decisions for themselves. It is an opportunity for those with capacity to voluntarily discuss how their condition may affect them in the future and, if they wish, to record choices about treatment. This then enables clinicians to provide care consistent with this wish in the event of loss of capacity (National End of Life Care Programme, 2011).

Under the terms of the Mental Capacity Act (2005), an advance care planning discussion may lead to more formalised outcomes *(Box 2).* Not

everyone who engages with advance care planning will want to make such formal records. Less formally, the person may wish to name someone who can be consulted in the event of incapacity (Royal College of Physicians, 2009, National End of Life Care Programme, 2011). Where individuals retain capacity, it is their current wishes and decisions about their care and treatment which should be considered and respected.

Similarly, not everyone will want to engage in the advance care planning process. There are those who would prefer to avoid conversations which may potentially pose questions about their own mortality. However, there are a number of commentators who believe that advance care planning should be part of routine healthcare provision. These commentators argue that although they may be difficult conversations, they are necessary to improve care, to reduce costs and to reduce considerable unnecessary suffering from overuse of healthcare interventions (Scott et al., 2013, Steinberg, 2014).

- **Advance statements** of wishes and preferences to inform subsequent best-interest decisions. This is promoted as a useful record to guide future care.
- **Advance decisions to refuse treatment** (ADRT) which are legally binding if valid and applicable to the circumstances at hand. These can set on record views about specific life-prolonging treatments such as ventilation. However, patients cannot request treatments in the UK that are not seen as being in their best interests. They can, however, instigate refusal of treatments such as 'do not attempt cardiopulmonary pulmonary resuscitation' (DNACPR) decisions.
- Appointment of **Lasting Power of Attorney** (LPA) ('health and welfare' and/or 'property and affairs'), under the Mental Capacity Act (2005). This is the nomination of a proxy that has the authority to represent the patient once they have lost capacity (Seymour and Horne, 2011).

Box 2: Formalised outcomes of ACP

2.3.1. The history and origins of ACP

Prior to the 1970s, it was commonplace for physicians to make all patient care decisions based on professional authority and beneficence (Oddi, 1994). These decisions were often grounded in religious and philosophical thought that gave little provision for personal control (Brown, 2003). Medical paternalism, however, has moved on, and this movement has been accompanied by a trend of 'open awareness' around death and dying (Sanders et al., 2008 p.983).

The concept of the 'living will' was first proposed in 1969 in the USA, amid a backdrop of discussions focused on the rights of individuals to refuse or withdraw treatment (Kelley, 1995). It subsequently became embedded in US legalisation following two high-profile court cases, with the introduction of advance directives (ADs) and the passing of the Patient Self-Determination Act (1990). In this Act, individual rights on decision making were enshrined in healthcare law. They came with a mandate that all patients must receive information concerning end-of-life decisions and have the right to prepare advance statements relating to future medical care (Brown, 2003).

It is not clear from the literature when the term 'advance care planning' was introduced, and it is often used interchangeably with the term 'advance directive'. There is also a plethora of terms associated with the legal frameworks and documents that are used internationally. This makes searching the literature difficult and reliant on research being descriptive when using terms. It also makes translating research for use in clinical practice a challenge. Essentially, the original goal of ACP, from the perspective of ethicists and legal scholars, was to assist patients to make treatment decisions in the form of an advance directive or advance care plan. It was also to identify a proxy in the event of incapacity, drawing on the principles of autonomy and informed consent (Martin et al., 2000).

However, in the late 1990s, the application of theoretical concepts from law and ethics alone in the advance care planning process was challenged. Despite major drives to implement ACP in the USA and Canada, a systematic review carried out by Miles et al. (1996) concluded that advance treatment decisions had been difficult to form and implement. As

a result, Singer et al. (1998) and Martin et al. (1999) sought to conceptualise a model of advance care planning that was rooted in the perspectives of the individuals who engage in it. This evidence, from the perspectives of those with HIV and chronic kidney disease, suggested that the philosophical underpinnings of autonomy be reconsidered and broadened to account for the value of personal relationships (Singer et al., 1998, Martin et al., 1999, Martin et al., 2000). This new evidence from Canada highlighted that the originating principles of autonomy in decision making was out of step with patients' needs. It only takes a moment's reflection to appreciate that the interests of one person are often wrapped up with the interest of others. This can often create an ethical challenge to fully autonomous decision making (Martin et al., 2012) and is particularly relevant to those living with frailty as they are often interdependent or dependent on others for their care.

2.3.2. Philosophical and cultural challenges

Despite this challenge, the theoretical concepts of autonomy and self-determination from ethics and law remain the central underlying philosophical principles of advance care planning. Ethics are based on considerations of what is morally right or wrong, and law is concerned with what is legally permissible. When considering advance care planning, both of these become intertwined with medicine enabling individuals to plan their future care and refuse treatments.

Martin et al. (2000) suggest that when thinking about autonomy in relation to advance care planning, it may not primarily be in the sense of controlling each treatment decision, but more in achieving an overall sense of control in the dying experience. However, despite this broader conceptualisation, autonomy in the sense of a right to refuse medical treatments has been embedded as an underlying principle in the UK through the inception of the Mental Capacity Act (2005).

Winzelberg et al. (2005) agree that patients often show differing views of autonomy and do not value it equally. They assert therefore that emphasising autonomy as it is traditionally defined only serves a small proportion of dying patients. End-of-life decision making is also influenced by culturally shaped values, and while the principle of autonomy is

dominant in some Euro-American cultures, it may not be a prevailing value in other cultures (Martin et al., 2000).

Some evidence has emerged to support this viewpoint. Research conducted by Seymour et al. (2007) with Chinese older people in the UK and Worth et al. (2009) with South Asian Sikh and Muslim patients with life-limiting illness in Scotland clearly shows the differences in preferences and end-of-life care in different ethnic groups. More recently, work carried out by Venkatasalu et al. (2013) highlights that ethnicity also shapes decision making and choice. Wilson et al. (2013) warn that ACP may be an ethnocentric goal and calls for more culturally sensitive end-of-life care and decision making.

Research conducted by Caplan et al. (2006) also highlighted how the cultural and personal beliefs of healthcare staff can affect the implementation of advance care planning. This is particularly relevant when precedent decisions seem to contradict the well-being and best interests of the individual being cared for (Sheather, 2013, Hebron and McGee, 2014). Although the Mental Capacity Act (2005) supports the principles of precedent autonomy for decisions that have been made legally binding, there is more of a grey area when there is an absence of such documents in favour of the less formal endeavours of advance care planning.

Failure by healthcare staff to understand and respect wider belief systems may impact on the ACP and care experience (Frey et al., 2013, Jeong et al., 2015). Winzelberg et al. (2005) also suggest that ACP needs a more flexible approach that embraces diverse perceptions of autonomy. Only then will the needs of the patients be truly encompassed in advance care planning.

2.3.3. Advance care planning and end of life

Care at the end of life in the UK has often been recognised as being crisis driven and inadequate (Department of Health, 2008a, Health Service Ombudsman, 2011). Decision making during this time can be traumatic and very difficult (Department of Health, 2012c). Communication is a key factor, and even the most detailed plan is likely to be of little use without

continued communication between patients, their family and healthcare professionals (Teno et al., 1994).

Since 2000, research has been instrumental in providing a conceptualisation of advance care planning that emphasises that the written outputs of an ACP are not the major focus. Rather, they have become an assisting device embedded in a process that encourages communication and preparation for death and dying between patients and their loved ones (Singer et al., 1998, Martin et al., 1999, Martin et al., 2000). This emphasis on enhancing openness and discussion about end-of-life care was a nuanced shift in focus from the original conceptualisation of advance care planning, giving equal importance to living and dying the way individuals want to.

> "Advance care planning ought to increase the odds that people will live and die the way they wanted to, within the limits of the clinical situation and society's moral and legal boundaries."

> (Teno et al., 1994 p.33)

In the UK, advance care planning is supported by legislation and is designed to promote autonomy in decision making where individuals lose mental capacity (Mental Capacity Act, 2005). However, since the inception of the end-of-life care pathway, the large body of resources and materials made available to support it have been orientated towards healthcare professionals helping patients to prepare for death (Pollock and Wilson, 2015).

In turn, the potential for advance care planning to positively contribute to quality of end-of-life care has been well documented in policy via the End of Life Care Strategy (Department of Health, 2008a, Department of Health, 2012b). It has also been championed by national initiatives such as the

Gold Standards Framework[2] (GSF) and Preferred Priorities of Care[3] (PPC), which have been used to involve and encourage practitioners to engage patients in advance care planning. Policy and practice guidance relating to ACP are discussed in more detail in *section 2.6.1*. However, despite evidence relating to some positive benefits of ACP, the evidence relating to the ability of ACP to contribute to quality at the end of life has been much less forthcoming.

2.4. ASSESSING THE EVIDENCE: OUTCOMES OF ACP

Advance care planning has received increasing attention in the last fifteen years, and its effectiveness in terms of useful outcomes has been questioned (Martin et al., 2000, Prendergast, 2001, Perkins, 2007). Early research in the USA in this area concluded that advance treatment decisions were difficult to form and implement, and found that outcomes of any advance care planning initiatives have frequently frustrated expectations (SUPPORT, 1995, Miles et al., 1996, Perkins, 2007). Commentators began to ask whether advance directives were too focused on specific treatment decisions that rarely equate to real scenarios in clinical practice, thus making them difficult to implement in the real world (Prendergast, 2001).

Since then, although the evidence is conflicting, some studies have reported benefits relating to advance care planning. In these studies, positive benefits are related to increasing rates of patients' completion of advance directives; compliance with treatments; upholding of patients' wishes at the end of life; preferred place of care and death; and increased

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[2] GSF is an approach to optimising care for all people nearing the end of life, given by front-line care providers. This includes care for people with any life-limiting condition, in any setting (home, care home, hospital and others) at any time in the last years of life. It involves early assessment and listening to patients' wishes through advance care planning discussions and providing care to meet their needs upon death (National Gold Standards Framework Centre, 2013).

[3] PPC is recommended as the tool for documentation of ACP in the UK (Department of Health, 2008a, Department of Health, 2012a). It can be used to enable the patient or their significant others to document the discussions and outcomes of an advance care planning conversation. It was initially developed and implemented by the Lancashire and South Cumbria Cancer Network. Initially called the Preferred Place of Care document, the name was later changed to reflect that where a patient dies is only one of the possible priorities or concerns facing people at the end of life.

carer satisfaction and reduction in symptoms (Molloy et al., 2000, Ratner et al., 2001, Schwartz et al., 2002, Song et al., 2005, Jeong et al., 2007, Newton et al., 2009, Detering et al., 2010, Hockley et al., 2010, Blackford and Street, 2012, Hammes et al., 2012, Kirchhoff et al., 2012, Robinson et al., 2012c, Abel et al., 2013, Brinkman-Stoppelenburg et al., 2014, Houben et al., 2014, in der Schmitten et al., 2014).

Many of these studies are implementation studies, where highly trained facilitators often go beyond the completion of advance care planning documentation and embrace a wider process of communication (Seymour and Horne, 2011). However, differing models of ACP and numerous differing outcome measures have made it difficult to generalise about its usefulness in clinical practice (Brinkman-Stoppelenburg et al., 2014). Moreover, most of these studies have emerged internationally; the most well-known of these is the Respecting Patient Choices Program (RPCP) from Wisconsin, US (Hammes and Rooney, 1998, Briggs et al., 2004). This, alongside the 'Let Me Decide' programme from Canada (Molloy et al., 2000), takes a whole systems approach to implementation, which enables communication and retrieval of any advance care planning at the point of care. They also encourage the use of a well-informed relative or carer (proxy) to communicate any wishes and preferences that patients may have.

Critics of this type of approach question the validity of advance care planning because patients may poorly understand medical care and unwittingly make plans that misrepresent their wishes (Hoffmann et al., 1996, Thorevska et al., 2005, Perkins, 2007). In addition, the role of the proxy can be difficult to instigate in a crisis situation (Bloche, 2005). In general, a whole systems approach to change requires expertise, consistent leadership and commitment from staff (Caplan et al., 2006, Jeong et al., 2007, Hockley et al., 2010). Sustainability of these initiatives is an important issue and can be problematic when staff turnover is high and a whole system cultural change is not achieved (Hockley et al., 2010). In reality, despite the evidence that advance care planning can have positive outcomes if instigated properly, the fact remains that regardless of education initiatives and efforts to clarify and advertise them, there have been a few successes but many disappointments (Perkins, 2007).

Despite endorsements in policy, ACP has been relatively slow to take off in clinical practice (Conroy, 2011). With little supporting evidence of its successes in a UK context, it is presumed, but not clearly established, that it enhances the quality of end-of-life care. This was demonstrated recently by Borgstrom (2015), who noted conflicting messages on the progress in this area in the two latest published reports in the UK. Although, according to ComRes (2015), we are more comfortable talking about death and dying than we were ten years ago, the recent Parliamentary and Health Service Ombudsman (2015) report suggests that end-of-life care is continuing to fail the public, especially in relation to documenting preferences and discussing dying (Borgstrom, 2015). These conflicting reports and the evidence of outcomes that are presented here from previous research suggest that concentrating future efforts on establishing a better understanding of ACP and its effects in a UK context may be a worthwhile endeavour.

2.5. BARRIERS TO ADVANCE CARE PLANNING

While relatively few studies have been concerned with the implementation and effects of initiatives, many others have concentrated on reaching an in-depth understanding on individuals' perceptions of advance care planning. These studies have provided some evidence of the barriers to ACP, but they relate to many different patient groups, carers and healthcare staff. In order to get an understanding of some of these barriers, they will be briefly discussed first in the context of the wider literature, before taking a more in-depth look at the literature relating to frailty.

2.5.1. Healthcare professionals and ACP

As people who spend a great deal of time with patients, healthcare professionals are thought to be in an ideal position to support patients with ACP (Cohen and Nirenberg, 2011). However, there is often much variety in the job roles, experience and clinical specialty of those involved. Moreover, the literature suggests that the philosophy and process of ACP is multi-factorial and complex. ACP is often narrowly defined in terms of advance directives or living wills, and differing international perspectives on what

ACP is have led to considerable ambiguity among health professionals (Colville and Kennedy, 2012, Russell, 2014).

There is some evidence suggesting that this ambiguity is due to a lack of understanding among healthcare professionals about the complex legal aspects of the advance care planning process such as the Mental Capacity Act (2005) and the Patient Self-Determination Act (1990) (Badzek et al., 2006, Duke and Thompson, 2007, Seymour et al., 2010, Hinsliff-Smith et al., 2015). In addition to this, research with health professionals shows that knowledge is often directly related to previous exposure to ACP through local and national initiatives (Seymour et al., 2010, Rhee et al., 2011).

Nurses, in particular, held a general assumption that those with more experience ought to be able to conduct conversations about ACP with patients (Blackford and Street, 2012). However, this was not the case, and communication via professional mandate was simply not enough to ensure that staff would conduct ACP conversations with patients. It was found that further specialist education and training were needed in relation to conducting conversations of this nature; without this, nurses felt that ACP was not within their remit. Where education was lacking, knowledge and confidence to facilitate ACP discussions were more likely to be felt to be in the domain of specialists in end-of-life care (Horne et al., 2006, Jeong et al., 2007, Boyd et al., 2010, Robinson et al., 2012a, Boot and Wilson, 2014).

While many healthcare professionals feel that ACP is a good idea in theory, ACP remains problematic to enact (Seymour et al., 2010, Robinson et al., 2012a). This evidence suggests that well-defined education initiatives which concentrate on enhancing health professionals' knowledge about ACP and its associated legislation can impact on confidence to undertake ACP, as well as increasing its uptake by patients (Colville and Kennedy, 2012). However, practical barriers, such as time and finding suitable places to hold such private and potentially lengthy conversations, act as additional impediments to ACP (Munday et al., 2009, Almack et al., 2012, Lund et al., 2015). Minto and Strickland (2011) also alert us to the emotional labour of

ACP and its potential impact on healthcare professionals and raise the importance of support for staff in the delivery of the ACP agenda.

2.5.2. Documentation of advance care planning

According to the UK Department of Health (2008a), not everyone will want to formally record their wishes and preferences. However, if plans are not documented and shared among healthcare professionals and carers, they are much less likely to be implemented. Studies often find that documented evidence of advance care planning is poor or non-existent and even when records are kept, the depth or length of the discussion is not recorded and would seem to vary greatly (Abel et al., 2009, Cox et al., 2011, Pollock and Wilson, 2015).

Documentation of ACP is of particular concern to healthcare professionals who are already apprehensive about the vast array of documentation available, its complex nature, whether or not it is legally transferable and its compatibility with computerised systems within the NHS (Robinson et al., 2012a). Boyd et al. (2010) warn that the lack of a structured planning process does not necessarily mean the absence of proactive advance care planning discussions. However, it is feared that a bureaucratic process for external monitoring purposes could potentially lead to a blunt 'one size fits all' and 'tick box' approach (Boyd et al., 2010, Seymour et al., 2010, Thomas and Lobo, 2011, Pollock and Wilson, 2015).

2.5.3. Prognostication and timing of conversations

The Royal College of Physicians (2009) and National End of Life Care Programme (2011) advocate that ACP conversations should not be conducted in the context of illness progression, but at the earliest opportunity. However, much has been made of policy drivers that require community services and GPs to identify and target those who are considered to be in the last year of life.

These initiatives are intended to trigger specific support to ensure people 'live well until they die'. It is part of the Quality and Outcomes Framework

(QOF)[4] and ACP is a key part of this work (National Gold Standards Framework Centre In End-of-Life Care and Royal College of General Practitioners, 2011, National Palliative and End-of-Life Care Partnership, 2015). Identifying those in the last year of life, however, can be difficult, especially when individuals do not access services until they become unwell. It is the complexities around prognostication and uncertainty of disease trajectory that healthcare professionals cite most frequently and find the most challenging in relation to ACP, especially when considering long-term conditions and frailty (Murray et al., 2005, Black, 2006, Horne et al., 2006, Almack et al., 2012, Robinson et al., 2012a). Yet this could be cited as precisely the reason why we need to engage patients in ACP discussions.

With more sophisticated treatment options, prognostic trajectories of chronic disease and frailty are far from certain. Survival prognostication and projection of need for health and social care is inherently challenging in individuals, especially when there are multiple co-morbidities and variable trajectories (Koller and Rockwood, 2013). Understanding disease trajectories is challenging, but it is important because it can assist with identifying those with multiple co-morbidities who need palliative care (Boockvar and Meier, 2006). Moreover, patients and families need to be fully informed of the outcomes that may be available to them, and they can only plan appropriately if they are aware of illness severity and prognosis (Mallery and Moorhouse, 2011)

Three typical trajectories *(Figure 2)* have been described for patients with progressive disease: cancer, chronic disease (organ failure) and frailty (Murray et al., 2005). For those with cancer, a period of being relatively well is followed by a clear terminal phase and rapid decline. Those with chronic disease and organ failure often have episodes of acute deterioration throughout a slow decline and seemingly unexpected death, while those with frailty have a slow deterioration and can have periods of

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[4] The Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing GP practice achievement results. It rewards practices for the provision of quality care and helps standardise improvement in the delivery of primary medical services (Health and Social Care Information Centre, 2015).

feeling well, before a gradual decline into death (Murray and Sheikh, 2008).
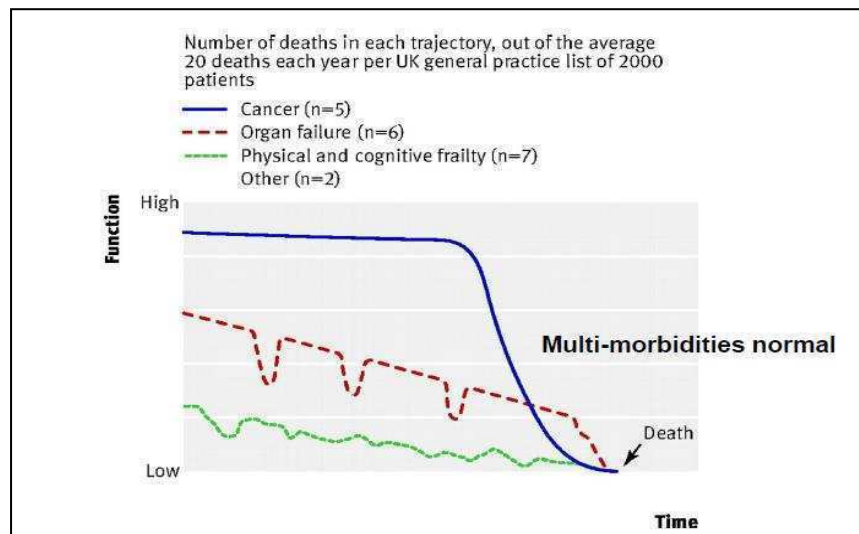
Figure 2: End-of-life trajectories[5]

Although there is an understanding that all disease trajectories lead to death, death for some may be sudden. It is easy to see how healthcare practitioners would feel more comfortable discussing the inevitable and more predictable death of some cancer trajectories. When considering frailty, predicting when decline and death will occur is much more difficult; however, advance care planning may be considered essential given that cognitive impairment and loss of capacity is common. Murray and Sheikh (2008) acknowledge that trajectories are not definitive and do not take account of spiritual or existential elements that affect the disease process, nor do they account for those who will die at any given point in the trajectory.

To date, there is no evidence that suggests that there is a right time to introduce ACP to patients although it must be while they are well enough to engage and before they lose mental capacity (Royal College of Physicians, 2009, Mullick et al., 2013). Conversations may be instigated by the

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[5] Reprinted with permission from the Copyright Clearance Centre via BMJ publications (Murray and Sheikh, 2008).

individual or the care provider at any time. Specialist palliative care nurses report responding to patient triggers such as generally talking about the future as being the best way to open conversations (Robinson et al., 2012a)

Healthcare professionals often feel that undertaking advance care planning activities too soon could take away hope for some patients (Barnes et al., 2007, Curtis et al., 2008, Boyd et al., 2010, Seymour et al., 2010, Robinson et al., 2012a). They report feeling much more comfortable with end-of-life treatment decisions rather than planning for death (Boyd et al., 2010). However, some research conducted with patients who had end-stage renal disease found that timely and facilitated ACP can positively enhance hope by determining future goals and enhancing personal relationships (Davison and Simpson, 2006). Green et al. (2015) also reported that when talking to patients with advanced cancer, doctors need not avoid ACP out of concern for diminishing hope.

2.5.4. Willingness of patients to engage in ACP conversations

Evidence suggests that willingness of patients to engage in ACP varies greatly, and this is reflected in a considerable amount of ambiguity in the literature. Advance care planning discussions can be emotionally complex, and often, engaging patients in the process is highly unpredictable. As a result, policy directives present healthcare professionals with the problem of trying to identify those they believe to be accepting of an ACP conversation and those likely to be resistant (Lund et al., 2015). Moreover, willingness to engage in discussions with some may change over time (Mullick et al., 2013).

Some studies show that there is a reluctance to engage in ACP as it forces patients to think about deterioration in their condition (Barnes et al., 2007, Perkins, 2007, Billings, 2012, Robinson et al., 2012c, Abel et al., 2013). Evidence from research conducted with patients with chronic obstructive pulmonary disease, heart failure and kidney disease suggests that people do not want to engage in advance care planning while they are relatively well (Knauft et al., 2005, Davison, 2009, Momen and Barclay, 2011).

However, some studies report patient willingness to engage in advance care planning (Detering et al., 2010, Abel et al., 2013, Brinkman-Stoppelenburg et al., 2014, Cheang et al., 2014). Even for those who are reluctant to engage in it as a process, there is evidence to suggest that patients are happy to discuss aspects of care related to death and dying and are waiting for healthcare professionals to do so (Singer et al., 1999, Davison and Simpson, 2006, Barnes et al., 2007, Seymour et al., 2010). Research conducted by Andrews et al. (2010) though found that despite being engaged in ACP, patients are often still confused about the terminology associated with it. The authors suggest that additional education is required for patients, and advocate for this education, which as a process should be ongoing (Andrews et al., 2010).

Sutton and Coast (2012) and Carrese et al. (2002) found that funeral arrangements and preferences following death had often been discussed and recorded with family members. However, little is known about the extent and nature of discussions that go on within families and how these relate to the advance care planning process (White et al., 2014). In a recent survey conducted by Musa et al. (2015), a significant percentage of those who had undertaken any advance care planning activities had done so with family members. This evidence suggests that policy mandates for healthcare professionals to engage people in ACP may be unnecessary. In turn, this may risk over-medicalising conversations that are already occurring within families.

The evidence pertaining specifically to the perceptions of those with frailty about engaging in ACP conversations will be discussed in greater depth later in this chapter.

2.5.5. Legal, moral and ethical issues with ACP

Research has also revealed some legal, moral and ethical issues relating to advance care planning. Healthcare professionals worry about the ethical implications of raising expectations of patients and their families, especially when adequate support services may not be available to meet preferences and wishes (Horne et al., 2006, Munday et al., 2007, Boyd et al., 2010, Minto and Strickland, 2011, Robinson et al., 2011, Colville and Kennedy, 2012).

Policy rhetoric purports choice and promotes ACP as a way of increasing the number of home deaths (Department of Health, 2008a). However, there is reluctance among healthcare professionals to promise what may be difficult to achieve with either financial constraints or limited provision of care. In addition, research conducted by Gott et al. (2004) seeks to highlight that home may be more than just a physical location to those nearing the end of their lives.

As well as cost of provision, in one study, healthcare professionals also raised the issue of financial costs of some of the legal aspects of ACP (Robinson et al., 2012a). Participants felt that encouraging patients and families to seek Lasting Power of Attorney often had a monetary burden that may not be easily met. This aspect of such a large financial burden may also be seen as a barrier to patients and families. The broader conceptualisation of ACP that encourages the communication of wishes to families and carers may be a more desirable and certainly cheaper alternative. However, it also raises the issue of the legally binding nature of this type of decision making and does not account for matters that may arise when differences in end-of-life decisions between patients and their carers occur.

Healthcare professionals also have a responsibility to act upon the instructions of an advance care plan. This aspect is of particular significance in acute care where, in the absence of ACP decisions, life-sustaining measures and cardiopulmonary resuscitation may be routinely implemented (Black, 2006, Jeong et al., 2007, Seal, 2007). Research highlights that without legally binding decisions, medical staff may be reluctant to abide by patient preference, especially if it is contrary to their own ideas of what constitutes best interests (Coleman, 2013).

2.6.   FRAILTY AND ADVANCE CARE PLANNING

Although consensus on the clinical definition of frailty remains elusive, there is agreement among those working in the field that whichever definition clinicians are working to, those designated frail are at increased risk of incapacity and mortality. Evidence suggests that comprehensive

geriatric assessment[6] (CGA) and early intervention can result in measurable health improvements for frail older people (Welsh et al., 2014). However, while medical interventions in this group can often result in desirable outcomes, aggressive and unwarranted treatments may have limited success and result in uncontrolled symptoms and distress while dying (Travis et al., 2002, Mallery and Moorhouse, 2011).

When considering frailty in particular, treatment uncertainty and prognostication difficulties are especially challenging and complex given that they exist within a wider government agenda that promotes choice and partnership in decision making with patients and carers. Patients who are frail have multiple conditions and complex needs, which makes it difficult to distinguish between treatable conditions and reducing protracted suffering and acknowledging the end of life. This is true of both healthcare professionals and patients.

By the very nature of their condition, those with frailty are an ideal patient group with whom healthcare professionals might engage in the practice of advance care planning. However, the polarisation and complexity of pursuing active treatment and recognising dying has left healthcare practitioners unsure as to how and when to engage those with frailty in advance care planning activities. Policy and best-practice guidance is often conflicting, and the messages that are portrayed in these documents compound confusion when it comes to implementation.

2.6.1. Policy and practice guidance, ACP and frailty

Advance care planning is an important part of the policy and best-practice agenda, which is designed to promote autonomy in the event of incapacity, to increase palliative care provision and to improve end-of-life care (Department of Health, 2008a, National End of Life Care Programme, 2011, British Geriatrics Society, 2014, British Geriatrics Society, 2015). It also

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[6] CGA is a multifaceted, complex intervention that has been shown consistently through research and meta-analysis to improve outcomes for frail older people. It is a multidisciplinary team (MDT) approach that includes doctors, nurses and allied health professionals and takes account of not just medical needs but also functional impairments and social and environmental issues to improve outcomes for frail older people (Welsh et al., 2014).

features highly in some initiatives to reduce unplanned admissions and promote home as the preferred place of care/death (Department of Health, 2008a, National End of Life Care Programme, 2010, National Gold Standards Framework Centre, 2013, British Geriatrics Society, 2014). However, despite frailty being the most common cause of death in older people, advance care planning has yet to become well established for those with frailty (British Geriatrics Society, 2015).

The initial vision of the National End of Life Care Programme through policy and guidance was to extend specialist palliative and end-of-life care services to a wider audience (Department of Health, 2008a). Those living with frailty were acknowledged and highlighted as a group in this programme of work. Alongside this, initiatives were launched in Primary Care to identify those likely to die within twelve months and target them for support. This included ACP among other interventions (National Gold Standards Framework Centre, 2013).

Since this initiative, over 90% of UK GP practices now have registers of patients approaching end of life. However, these registers have been criticised, and statistics show that in 2009 only 27% of all patients who died in primary care were on the register. Moreover, a large proportion of those registered were reported as being attributed to cancer (Omega the National Association for End of Life Care, 2009). This has led to concerns being raised that end-of-life services focus more on the needs of those with cancer (Barclay et al., 2011, Sharp et al., 2013). Criticism of this approach has also been rife in the media, with controversial headlines branding GP registers as 'death lists' and claiming that advance care planning is being used to save the NHS money, by cutting the costs of hospital deaths (Petre and Adams, 2013).

Given that more than half the deaths in the UK occur in hospital, the End-of-Life Care Strategy also emphasises the crucial role that the acute sector has regarding advance care planning. It emphasises that the delivery of quality and productivity of end-of-life care in acute hospital settings includes open and honest communication, thereby identifying triggers for discussion and ACP (National End of Life Care Programme, 2010). Yet this goal is rather inconsistent with the evidence-based guidance of the Royal

College of Physicians (2009), which advises that ACP may not be appropriate when patients are acutely unwell and requiring hospitalisation (Randall, 2011).

Evidence suggests that of those frail older people who die in acute hospital care, many have already accessed inpatient services, often several times in the lead-up to death (Abel et al., 2009, Bardsley et al., 2010, Georghiou et al., 2012). Although this may present opportunities for healthcare staff to assist patients in recognising the need for ACP and assisting them to do this, ACP in this area has been slow to progress. Moreover, a dearth of research in this field has left commentators with questions about its suitability, especially in relation to frail older people.

More recently, there has also been a flurry of reports and guidance released by organisations on behalf of the patient population. These call for opportunities for patients to have increased autonomy and choice in their future healthcare by making advance decisions as part of a process of advance care planning (Alzheimer's Society, 2012, National Voices, 2014, Leadership Alliance for the Care of Dying People, 2014, Parliamentary and Health Service Ombudsman, 2015). Existing research with frail older people in this area is discussed below.

2.6.2. Frailty and ACP: Existing research

Despite the implementation of policies and initiatives that promote ACP, research suggests that there is little evidence of frail older people engaging in advance care planning unless it is as part of a whole systems approach involving structured conversations with trained facilitators (Schwartz et al., 2002, Wu et al., 2008, Abel et al., 2009, Robinson et al., 2012c, Houben et al., 2014, in der Schmitten et al., 2014). The outcomes and positive and negative aspects of these studies were discussed previously *(section 2.4).* However, identifying studies of any kind in this area is difficult because of the different terminology used to describe frail and older people. Some of these issues are due to the lack of consensus over a clinical definition of frailty, but also because disciplines other than medicine may use different terminology such as 'oldest old' (Wu et al., 2008) or 'fourth age' (Nicholson et al., 2012a, Lloyd et al., 2014).

When interviewed in relation to ACP and AD, older people were quick to recognise the benefits of enhanced choice and autonomy (Seymour et al., 2004, Lloyd-Williams et al., 2007, Malcomson and Bisbee, 2009, Clarke and Seymour, 2010, Jeong et al., 2011a, Sutton and Coast, 2012). They also recognised that discussing future care was a positive step towards ensuring that family members were not burdened by decision making on their behalf (Tushna Vandrevala et al., 2002, Seymour et al., 2004, Clarke and Seymour, 2010).

However, despite articulating the importance of ACP, many were unlikely to record decisions in the form of an advance care plan. Concern was raised over the future applicability of such plans, especially as preferences for care may change over time (Seymour et al., 2004, Fried et al., 2006, Fried et al., 2007, Sutton and Coast, 2012). Lack of support and knowledge about the existence and formal processes of ACP were also cited as barriers by older people (Tushna Vandrevala et al., 2002, Samsi and Manthorpe, 2011, Sutton and Coast, 2012, Dickinson et al., 2013). It is worth noting though that in all of these studies, none of the participants were described as being frail; these studies were all reporting on the views of healthy older people.

One small body of research considers ACP from the perspectives of frail older people who are resident in care homes. This research highlights that most of these residents are uncertain about what the future holds for them and as a result they prefer living day to day (Jeong et al., 2011a, Mathie et al., 2012, Bollig et al., 2015). Planning was not something that they felt able to do, with most of them preferring to leave it up to the care home staff or their families (Mathie et al., 2012). Death, for them, was inevitable, and given the limited control they had over their current circumstances, they found it difficult to envisage control over the future (Mathie et al., 2012). Despite the fact that this research was conducted in care homes, none of the studies reported the inclusion of participants with cognitive impairment or those lacking capacity. This is surprising given that some reports have suggested that up to 75% of those living in UK care homes have some degree of cognitive impairment, with one-third of those having a severe cognitive impairment (Macdonald et al., 2002).

For those living with frailty in their own home, there was also uncertainty about the future, which led to a perspective that emphasised living in the moment. Many preferred only to confront future difficulties, which were outside of their imagination, when they arose (Carrese et al., 2002, Van Campen, 2011, Ebrahimi et al., 2013, Piers et al., 2013, Lloyd et al., 2014). Several of these studies, however, were focused on living with frailty and did not consider planning future care directly (Van Campen, 2011, Ebrahimi et al., 2013, Lloyd et al., 2014).

2.6.3. Justification for the study

The findings from this literature review suggest that frail older people may not be receptive to the offer of an advance care plan. They also suggest that there may be differences in perceptions between those who are facing the reality of impending death, and well older people who are considering ACP. In general, there is a dearth of research that considers the perceptions of those living with frailty and how this aligns to the current policy and practice regarding ACP.

Frail older people are not clearly represented in the research in this area, and as a result, it is not clear how planning for end of life may be achieved in this group. This is particularly true for an increasing number of frail older people who have fluctuating or loss of capacity. There are various definitions and models of ACP, all of which rely heavily on capacity in decision making and are based on the principles of autonomy. Increasing levels of frailty and thus dependency of older people who are moving along the dying trajectory may not only impact on capacity for autonomy but also create a tension for those patients who have differing views of autonomy. Moreover, there is conflicting evidence from older people and their views of ACP. While some studies report an openness and willingness for discussion, others conclude that this group of people live in the moment and do not see a need to plan.

While ACP for frail older adults may be recognised by the healthcare profession as an important endeavour, there is little known about what planning future care looks like to frail older people themselves and what elements, if any, may be important. The recent work carried out and described in this literature review demonstrates that what is represented

by the medical model may be quite different when a wider conceptualisation is considered from the perspective of frail older people themselves.

The UK Department of Health End of Life Care Strategy has stated the importance of planning for the end of life and that it should, where possible, be responsive to the needs and preferences of individuals. However, all too often patients' needs and those of their families and carers are not adequately addressed (Department of Health, 2008a), and there is little available empirical evidence from the perspectives of frail older people and their significant others.

Those with frailty are emerging as the biggest users of health and social care services. In the past, those with frailty have been excluded from research that has been instrumental in creating evidence-based treatment guidelines (Van Spall et al., 2007). As a result, lack of guidance for healthcare professions when caring for those with frailty makes it difficult to deliver relevant and responsive care, and that can sometimes lead to inconsistency (Mallery and Moorhouse, 2011). Research that is inclusive of this population is essential for improving services and direct patient care.

2.7. CHAPTER SUMMARY

This chapter has provided an overview of the literature pertaining to frail older people and the practice and policy associated with advance care planning. It concludes by highlighting the gaps in the literature and providing a robust justification for the conduct of the study. The aims and objectives for the study will now be discussed alongside the methodological approach.

CHAPTER 3. METHODS AND METHODOLOGY

3.1. INTRODUCTION

This chapter presents the methods and principles of enquiry used in the study. A qualitative exploratory, multiple case study design was used to generate data from sixteen case studies involving a total of 24 individual participants. Frail older people were recruited from acute hospital wards towards the end of an acute admission and took part in up to two serial interviews (Murray et al., 2009) in hospital and/or at home. The interviews were conducted using the responsive interview technique (Rubin and Rubin, 2005).

This chapter begins by describing the study aim and objectives that were developed and designed following the review of the literature outlined in chapter two. It goes on to consider the use of the qualitative exploratory case study design and discuss the interpretive constructivist standpoint of the study. As frail older people were central to this enquiry, the ethical, methodological and practical challenges that are pertinent to this group are then discussed. Finally, the empirical techniques used in the data analysis are presented to address the construction and interpretation of the data.

3.2. STUDY AIM

To explore the expectations, experiences and understandings of frail older people, and their significant others, of planning for future care and to examine the implications of this for the practice of advance care planning.

3.3. STUDY OBJECTIVES

- To identify and critically evaluate contemporary frameworks, policies and best practice guidelines for advance care planning and examine their applicability to frail older people
- To gather narrative accounts of the expectations and experiences of frail older people and their significant others in relation to planning for future care
- To identify factors from the perspectives of frail older people and their significant others that may enable or constrain the practice of advance care planning

- To examine the implications of the study findings for the practice of advance care planning with frail older people and their significant others

3.4. METHODOLOGY – UNDERSTANDING THE APPROACH

Studying the dynamic and complex nature of frailty requires a robust methodological approach that is capable of revealing that complexity.

According to Tewksbury and Gagné:

> "*The research process is fuelled by the raw materials of the physical and social setting and the unique set of personalities, perspectives and aspirations of those investigating and inhabiting the fluid landscapes of those being explored*".

> (Tewksbury and Gagné, 2001 p.72)

In the context of clinical practice and society as a whole, frail older people are described as a vulnerable group, and within the scope of research, they are notoriously difficult to access (Seymour et al., 2004, Seymour et al., 2005, Lloyd et al., 2011, Pleschberger et al., 2011, Aldridge, 2014). Throughout the design and implementation of the research, it was the fundamental care needs of the frail older participants that helped frame this study. This, together with answering the questions raised by the underpinning epistemological and philosophical debates, then proceeded to influence the study across all stages of the research process.

For many, the idea of what constitutes vulnerable groups is both context dependent and socially constructed (Liamputtong, 2007, Larkin, 2009). In healthcare discourse, those with the physical, psychological and social effects of frailty often have increased health and social care needs and as a result are often deemed susceptible to risk and harm. Similarly, sensitive subjects such end-of-life care pose challenges that have the potential to compound the vulnerability of such populations (Economic and Social Research Council, 2012).

3.4.1. Defining the inclusion criteria

Frail older people are present in many different communities within society, but their notoriety in research as a difficult-to-reach population was a challenge for the study. This was compounded by the lack of a consensus definition for frailty (Morley et al., 2013, Rodríguez-Mañas et al., 2013).

In order to enhance the ethical probity of the study (INVOLVE, 2012), I had established early collaborations with a user group who all had experience of caring for frail older people towards and at the end of life. Their experience revealed that frequency of admission to hospital had been greatest in the last year of life and that information and help to plan for future care during this time would have been of most use. Research has also found that unprecedented numbers of frail older people access acute hospital care in the last year of life (Abel et al., 2009). It is during this period of time that some literature suggests they be considered for advance care planning (National End of Life Care Programme, 2010, Koller and Rockwood, 2013, British Geriatrics Society, 2014).

Given that many frail older people access acute care in the last year of their lives and that my own interest and experience in this area had begun in acute hospital care, this made the hospital environment a sensible place to start thinking about accessing the study participants. However, research into frail older people being admitted to acute hospital care had found that up to three-quarters of them may be experiencing some degree of delirium or cognitive impairment (Goldberg et al., 2012).

From early on in the design process, I was determined not to exclude patients with potential and fluctuating mental capacity issues: a group who have largely been excluded from research (Stone et al., 2013). This led to the exploration of a person-centred approach to inclusion that satisfied the ethical and legal frameworks for participation in research. As a result, permission and approval was sought from the ethics committee to use the process of consultee agreement under the Mental Capacity Act (2005). This will be discussed in greater detail in *section 3.8.1*.

From the outset, the lack of a consensus clinical definition of frailty and how it manifested for potential participants was a persistent issue.

> *"In the land of frailty, confusion, contradiction, and ambiguity reign supreme".*

> (Ferrucci et al., 2006 p.260)

Interestingly, on an exploratory visit to potential clinical areas, nursing staff described all their patients as frail. This posed a problem to the research study because just by looking around, I could see that there was huge variation in the patients on each ward.

On the basis of this, establishing a steering group at the outset of the project became a valuable source of expert advice from clinicians and nurses who agreed to act in the capacity of clinical advisors to the project. Steering groups are advocated as part of a wider recruitment and retention strategy (Mody et al., 2008, Seppet et al., 2011). This group consisted of a Consultant Geriatrician, Consultant Honorary Lecturer in Medicine of Older People, Comprehensive Geriatric Assessment Lead Nurse and a Practice Development Matron for Older People and Dementia. Their expert knowledge in this field was crucial for defining frailty for the purposes of the study and identifying potential sites for participants.

Consultation over several meetings led to the use of a definition of frailty that was accessible and easily understood by all clinical staff:

> *"A medical syndrome with multiple causes and contributors that is characterised by diminished strength, endurance, and reduced physiological function that increases an individual's vulnerability for developing increased dependency and/or death."*

> (Morley et al., 2013 p.393)

This definition was chosen because the group, including myself, felt that it was concise and acknowledged a broader conceptualisation of the causes of frailty that can be physical or psychological. It also emphasises the potential serious nature of its outcomes. However, in hindsight, this definition now seems somewhat naïve, given that throughout the construction of this thesis there emerged a much broader and more complex picture from of the lived world of frailty.

In addition to this, an established framework by Rockwood et al. (2005) *(Figure 3)*, The Clinical Frailty Scale, was used to offer a pictorial view of frailty that was identified as giving busy practitioners an 'at a glance tool' to identify suitable patients who may be part of the study.

Clinical Frailty Scale*

1   **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2   **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3   **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4   **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5   **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6   **Moderately Frail** – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7   **Severely Frail** – **Completely dependent for personal care,** from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8   **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months,** who are **not** otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia,** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia,** they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Figure 3: Clinical Frailty Scale[7]

Given the unpredictable nature and prognostication challenges of frailty, identifying participants that are accessing hospital in their last year of life was always going to be challenge. Those working in end-of-life care often identify their population by what has become known as the 'surprise question' (Lynn, 2005 p.17):

> *"Is this person sick enough that it would be no surprise for the person to die within the next six months, or a year?"*

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[7] Reproduced with permission which is granted for the purposes of research and education (Rockwood et al., 2005).

This in turn can trigger support services and ACP with the aim of supporting people to live well until the end of their lives (National Gold Standards Framework Centre, 2013). This question is more about needs than time frames and is meant as more of a recognition that a person is in a fragile state so that a relatively minor worsening of condition could result in death.

Such is the uncertainty of the frailty trajectory: that those designated by the 'surprise question' could live for years. However, by using the 'surprise question' in the study with the definition provided by Morley et al. (2013) alongside the Clinical Frailty Scale (Rockwood et al., 2005), the clinical advisory group felt that those patients deemed moderately and severely frail *(see number 6 and upwards in Figure 3)*, whose initial reason for admission was resolving, most clearly represented the population the study identified as appropriate for ACP within the current established frameworks.

Those that were defined as very severely frail, including those with severe cognitive impairment and/or on an active end-of-life care pathway, were excluded. In addition to this, I remained clinically active as a nurse during the course of the study. To avoid a conflict of interest, those patients whose care I had been involved in as a nurse were also excluded.

Conducting real-world research is untidy, variable and complex (Robson, 2011). Reflecting on the design and implementation process, I now realise that it would have been impossible to foresee and plan for all eventualities that occurred throughout course of the study. The details, dilemmas and decisions relating to the ethics and participants' well-being during the study are explored in more detail throughout the chapter.

3.5. THE QUALITATIVE RESEARCH PARADIGM

A qualitative approach is essential to understanding the experiences and expectations of end-of-life planning in frail older people for a number of reasons. Firstly, it is the perspectives of frail older people that are missing from the literature. Qualitative research is an activity that situates and locates the observer and the observed frail older person in the world; it involves an interpretivist, naturalistic approach that sees researchers study

their subjects in their natural setting (Denzin and Lincoln, 2005). This approach for some has been the cornerstone of successfully researching traditionally hard-to-reach populations and end-of-life care (Liamputtong, 2007, Pleschberger et al., 2011, Aldridge, 2014); this study is no exception.

Secondly, the vulnerability of frail older people and the complication of researching sensitive issues called for a dynamic approach:

> *"Qualitative investigations are not explorations of concrete, intact frontiers; rather, they are movements through social spaces that are designed and redesigned as we move through them."*

> (Tewksbury and Gagné, 2001 p.72)

By using a qualitative approach, I was able to respond to the self-perceptions and changing needs of those living with frailty. Flexibility and adjustment are the hallmarks of qualitative enquiry and are opposed to the aspiration to bring everything under control (Eisner, 1991). This approach encourages attention to the ethical challenges that occur in research of this nature and that are dictated by the research governance structure and bioethical frameworks. It also allows for encountering the less predictable micro ethics that are inevitable but are often impossible to predict in a study of this type.

Thirdly, qualitative research can, by its very nature, be idiosyncratic. The researcher's experience with the subject tends to be fluid, dynamic and prone to variation (Eisner, 1991). This is very similar to how I see the nurse–patient relationship, and it is this person-centred approach that forms the basis of my research study.

Given that my research study is located in the qualitative research paradigm, it is also making assumptions about how we acquire knowledge. Although the use of quantitative, positivistic methods and assumptions are often refuted by qualitative researchers, my own view like that of Seale (1999) and Vidich and Lyman (2003) is more tolerant and demonstrates respect for a variety of positions. These methods just address different research questions and tell a different story (Lincoln and Denzin, 2003) and

can contribute to evidence-based practice that raises quality and standards across all areas of healthcare.

Over the past 30 years, nursing and the social sciences have made a distinction between quantitative and qualitative research, and both of these approaches are associated with a characteristic ontology, epistemology and methodology (Avis, 2003). This has also been extended throughout history to the fundamental question of axiology (Lincoln and Guba, 2013). In order to situate, frame and understand the analytic efforts of my study, it is important to consider each of these in turn.

Ontology is the study of reality and the kinds of things that constitute the world (Schwandt, 2001). Epistemology derives from the Greek word meaning knowledge and refers to a fundamental branch of philosophy that investigates the possibility, limits and truth of knowledge (Delanty and Strydom, 2003). Methodology is the philosophy of the method (Jupp, 2009), the underpinning assumptions, principles and procedure that guide the researcher (Schwandt, 2001). Axiology is a qualitative assumption that all research is value laden and acknowledges the social and cultural norms of both the researcher and participants (Creswell, 2007, Lincoln and Guba, 2013). The next section provides a brief overview of the interpretive constructivist approach taken within this study.

3.5.1. Interpretive constructivist theory

Proponents of the interpretive and constructivist paradigms share the goal of understanding the complex world from the point of view of those that live in it (Schwandt, 1994). In direct contrast and in reaction to the positivist approach, interpretivism emphasises the world of experience as it is lived, felt and undergone by people (Schwandt, 2001). Arising from neo-Kantian German historians and philosophers such as Dilthey (1900) and Weber (1904), the interpretivist argues that social sciences are just as scientific as a more positivistic standpoint (Benton and Craib, 2011). According to Taylor (1971), interpretation is essential to explanation and aims to bring to light an underlying coherence or sense.

The social world, or in this case, the world of frail older people and the problems they encounter towards the end of life, can only be understood

by studying their own meanings of social constructs such as planning future care. Only by negotiating through their language and interactions can a full understanding of their experiences and expectations be understood (Dilthey, 1900).

The constructivist paradigm grew out of this interpretivist view of understanding, with constructivists interpreting from a certain situation or standpoint (Mertens, 2005). Also known as a postmodern paradigm (Schwandt, 2000), constructivism has entered the debate relatively recently and can be seen in the contemporary writings of Crotty (1998), Schwandt (2000), Lincoln and Guba (2000) and Mertens (2005).

Constructivists continue to seek meaning about the world in which they live and work and in which they will ultimately die. Knowledge on an individual level is not discovered; rather it is a construction of experience and interactions with others (Creswell, 2007). Moreover, many constructions are possible; especially in an enquiry of this type, which cannot be value free and incorporates the cultural and historical norms that often operate in individuals' lives.

The ontological position of the constructivist is a relativist view and presupposes that all individual knowledge therefore exists only in the mind of those who are contemplating it (Lincoln and Guba, 2013). It is true to say that over recent years, Geertz's (1983) prophecy of 'blurring of genres' is being fulfilled (Guba and Lincoln, 2005); however, he asserts that researchers should be free to shape their work in terms of need (Geertz, 1983). By seeking the views of those affected by frailty about the future, an interpretive constructivist approach seeks to elicit shared meaning while acknowledging each person interprets and encounters in a distinct manner (Rubin and Rubin, 2005).

Like most qualitative research, interpretive constructivism places emphasis on the subjective or emic perspective. The epistemology of various perspectives of those who live with frailty has been essential in encouraging me to consider looking at planning future care in different situations and from different angles. When considering the virtues of subjectivity and multiple perspectives, I agree with Eisner:

"It is a matter of being able to handle several ways of seeing as a series of differing views rather than reducing all views to a single correct one."

(Eisner, 1991 p.49)

The handling of the research process is also laden with my own personal, historical and cultural values. With some 20 years' experience in clinical practice, friends often tell me that nursing is so culturally ingrained in me that I often use language they find difficult to understand. I find it hard to remove myself from this, and complaints over the years from patients have taught me that other health professionals also struggle to use simple language when trying to help others make sense of illness. During the design and implementation of the study, it has been essential to explicate what influence my own experience has brought to the research process.

3.5.2. The insider/outsider debate: Reflexivity and reflection

In employing qualitative methods and inductive enquiry, it is essential for researchers to use 'thoughtful, conscious self-awareness in a process of reflexivity aimed at increasing the integrity and trustworthiness of research (Finlay, 2002). For me, learning how to engage in critical reflexivity was fundamental to maintaining the underlying philosophical principles and interpretive constructivism frame of this study, as well as the day-to-day interactions with participants.

From the outset, finding ways to analyse how subjective and intersubjective elements influence the research process was part of the development required to achieve the co-construction of the finding (Finlay, 2002). Giddens highlights that this process is continual and constant throughout social life but lends itself well to the research process:

"The reflexivity of modern social life consists in the fact that social practices are constantly examined and reformed in the light of incoming information about the very practices, thus constitutively altering their character".

(Giddens, 1990 p.38)

However, understanding how my own social world and experiences as a nurse played a part in the production of data was not always easy. Being a nurse brings with it requisite skills in assessment, planning, implementation and evaluation of patient care, but this is not the full story. I am not only a nurse; I am a mother, a bereaved granddaughter of a very frail older grandmother and a self-confessed champion of older people who over the years has seen many deaths of those who are frail.

Elliot Eisner states that:

> *"Seeing rather than mere looking requires an enlightened eye".*

> (Eisner, 1991 p.1)

The benefits of being a nurse in some types of research are well documented. In more sensitive areas of research particularly, nurses who have a combination of expertise have the potential to make important contributions to the development of evidence-based patient care (Leslie and McAllister, 2002, Morse, 2010, Department of Health, 2012a). However, others believe that being more of an outsider can bring 'a new look' from the perspective of the participants which in turn can help with new ideas and theorising (Holloway and Biley, 2011 p.972).

I read early on that some commentators warn that the process of reflexivity, if not well understood, can become narcissistic and self-absorbent (Holloway and Biley, 2011, Doyle, 2013). This in itself was not an attractive prospect, and being aware of the pitfalls of this complex process went some way to helping to avoid them. It was also a reminder that reflexivity can and should be a constructive process. Through a process of reflexivity, timely recognition of how my nursing skills both complemented and hindered me was essential to encourage rigour throughout the study (Bishop and Shepherd, 2011).

In addition to this and more latterly as a professional group, nurses have been encouraged to use reflection as part of the process of clinical supervision in order to identify solutions to problems and improve practice. Reflexivity and reflection are often used interchangeably in the literature, and as a result considerable ambiguity has arisen in their meaning. For the

purpose of this study, I agree with Finlay (2002), who upholds that the concepts are best viewed on a continuum. At one end of the scale is reflexivity, which is an immediate and dynamic process of self-awareness. This also takes account of the relationships within the research and is continuous throughout. At the other end of the scale is reflection, which is about taking a more critical stance at the end of the task at hand (Finlay, 2002).

As a nurse, I have found reflection a useful tool throughout my clinical career for professional development and practice improvement. During this study, it has proved helpful as each stage of the research process has drawn to a close and was a useful tool at the end of each interview and during the writing of the initial case studies. Reflexivity on the other hand has been ongoing and integral to the research process. It has been particularly valuable throughout this study in identifying pivotal moments of my own personal transformation as a researcher. It has also proved useful with the micro ethical dilemmas that have become evident during its course.

Throughout the study, I also kept a research diary that was used to record my thoughts and feelings as I conducted the fieldwork. It was also used to record reflections on the interviews themselves and keep detailed notes in the field. These notes were then used to add richness to descriptions of the interviews when constructing participant re-storied and biographical accounts. The diary was also a useful reflexive tool and provided an opportunity to capture awareness and thoughts of my role in the interview interaction.

When reporting the process of reflexivity and reflection, therefore it does not make sense nor satisfy the underlying principles of the study to produce a whole dedicated written piece. Rather the reflection and reflexivity manifest through the writing of the whole thesis and are integral to the reporting process at its various stages.

3.6.   SELECTING A STUDY DESIGN

During the course of designing and conducting the study, the fluid landscape and fragile nature of frailty often meant that a dynamic

approach was required. This was also used to ensure the research objectives were realised, while staying true to its frame within the timescale of the study. Moreover, and on a more personal note, negotiating my own transition from experienced nurse to a nurse researcher challenged my own notions of vulnerability and also influenced the methods and ethical strategies throughout the research design process.

The need for a greater understanding of perceptions of frail older people regarding future care planning meant that it was imperative that frail older people themselves were central to this research. However, the ethical issues relating to researching vulnerable frail older people and end-of-life care meant that I needed to take a flexible approach to the research driven by the needs and wishes of the frail older participants themselves.

Over recent years, my clinical experience has shown me that the lives of frail older people are interdependent with those they rely on for care. These significant others can be spouses, children, friends, paid and unpaid care workers, and accommodating these relationships, if required, in the research study was important. This approach was instrumental in maintaining adherence to the underlying core principles of autonomy and informed consent, as well as safeguarding those at the heart of the study.

Walshe et al. (2004) recognise the value of using case studies when researching end-of-life care with often difficult to reach populations, as complex, context dependent situations can be dealt with and there is flexibility in addressing multiple perspectives if required. This, alongside the need to take a transactional method of enquiry that is commensurate with the interpretive constructivist approach (Anthony and Jack, 2009, Hyett et al., 2014), made a qualitative multiple case study design an appropriate method of enquiry.

3.6.1. Multiple case study

Intended to capture the complexity of the object of study, case study research can be predicated towards the interpretive constructivist worldview and allows for an investigation and analysis of a single or collective case (Stake, 1995). Originally describing three approaches to case study design *(Table 1)*, Stake (2005) uses the term instrumental case

study to describe the examination of a particular case to primarily provide insight into an issue. In this context he asserts that the case itself is of secondary interest; rather, it is used to facilitate understanding of a wider phenomenon. When a number of cases are studied in this way it becomes a collective or multiple case study[8] (Stake, 1995, Stake, 2005).

Intrinsic case study	Used because first and foremost intrinsic understanding of a particular case is required. Is not used to represent other cases.
Instrumental case study	Used to describe the examination of a particular case to primarily provide insight into an issue.
Collective/multiple case study	Used when a number of cases may be studied jointly to investigate a phenomenon.

Table 1: Types of case study

Stake (2005) emphasises the point that a larger collection of cases can often lead to better understanding and perhaps theorising in the longer term. For this study, using a multiple case study approach to gather the voices of frail older people was intended to add value to the individual voice and assert its strength. It was not to generalise as such, but more to accumulate knowledge in a field where it is somewhat lacking.

Once the case boundaries are determined the case itself can be built around the main unit of analysis (Yin, 2014) before the data gathered and analytic methods used are defined (Stake, 1995). The collective case study design within a healthcare context allows for the use of multiple data generating opportunities that are useful to the overall aim of the study.

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[8] These terms are often used interchangeably in the literature.

Stake (1995) asserts that the types of data gathered and analytical methods used are dependent upon the research purpose.

My initial enquiries revealed that the perspectives of healthcare professionals in this area are well represented. This view is confirmed in the literature review *(Chapter 2)*. Because of this, it made little sense, unless requested by the frail older people, to include health professionals as part of the individual case. Moreover, although case study allows for the use of document review, previous research suggests that there is little or no evidence of advance care planning in patients' medical notes (Abel et al., 2009, Pollock and Wilson, 2015). As the central focus of this study, frail older people are the main unit of analysis, and as a result they form the basis of each case. Harnessing their voice was fundamental to this study aim, and conducting multiple interviews was deemed the most appropriate way to gather data.

3.6.2. The serial interview technique

In this study, the serial interview technique as advocated by Murray et al. (2009) was used. Serial interviews are suitable for research that aims to explore evolving and complex processes or when time is needed to foster relationships between researcher and participants to facilitate the discussion of difficult subjects including end-of-life care (Murray et al., 2002, Murray and Sheikh, 2006, Kendall et al., 2009).

Hospitalised frail older people and their significant others were invited to take part in up to three in-depth face-to-face serial interviews either together or alone. Taking into account that the study participants were to be interviewed during or as close to hospital admission as possible and then followed up within a time frame of four to eight weeks, participation in the study was not expected to exceed twelve weeks. However, flexibility was also needed to accommodate those patient participants whose

discharge may be delayed from hospital despite being deemed medically stable[9] for discharge or readmitted.

In some studies, those experienced in research that addresses difficult subjects have had success in the use of a single interview (Gysels et al., 2008, Pleschberger et al., 2011). However, as a novice researcher and at the beginning of this study, I felt that this was a high-risk strategy. Addressing the future with frail older people could involve in-depth discussions relating to end-of-life care, and this was a prospect I found daunting. Murray and Sheikh (2006) advocate that a single interview, especially with ill people, might be inadequate to fully explore issues, especially if addressing a sensitive or complex one. Having the opportunity to build a relationship between myself and the participants and return for a further interview was a sensible strategy.

Although a major focus of the serial interview technique is to capture evolving and complex processes in a longitudinal way over time, this was not the original objective of the study. Rather it was hoped that it would offer some flexibility for the dynamic nature of frailty. Serial data collection allows for deeper understanding of the whole person and is able to capture all dimensions of human experience, especially if it is done with significant others (Murray and Sheikh, 2006).

I was worried that those with severe frailty may not be able to tolerate long interviews, so being able to return at a later date was essential. There is no precedent time limit between interviews, so the period of twelve weeks seemed a sensible length of time to allow data collection to complete without leaving long periods of time in between interviews. In addition, there needed to be flexibility in the event of the death of participants and opportunity provided to return to conduct interviews with bereaved significant others who remained in the study (this is explained in further detail in *section 3.7.6*).

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[9] Patients can often be deemed 'medically stable for discharge'. This means that they no longer need acute medical and nursing care but may have additional rehabilitation needs or be awaiting social care packages. In this case the hospital has a duty of care to provide care until a safe discharge can be arranged.

3.6.3. Responsive interview technique

While the serial interview technique allows for multiple data collection points, it does not dictate the content or style of the interview itself. The responsive interview technique is an approach to in-depth interviewing research that relies heavily on the interpretive constructionist philosophy that frames this study (Rubin and Rubin, 2005). Its goal is one of generating depth rather than breadth of understanding. It also recognises the importance of the relationship that is engendered between interviewer and interviewee, built up over the course of the serial interviews.

Previous research regarding ACP has resulted in various models and conceptualisations. Some of this research has resulted in policy and best-practice guidance, which places emphasis on end-of-life care in the UK. It was an important challenge from the outset to avoid imposing questions on the frail older participants that represented this viewpoint. Rather, the emphasis needed to be placed on what elements of future care are important to those at the centre of the study.

Prior to the interviews, two aide memoires were prepared *(Appendix A)*. When interviewing on sensitive subjects, it is essential to initially discuss safer ground that ensures participants feel comfortable and in control (Schulman-Green et al., 2009). With this in mind, each interview began by asking participants about themselves and their current health status. Key concepts *(Box 3)* arising from the literature review relating to planning future care were then used to devise a series of prompt questions. Given the sensitive nature of the subject area in this study, this preparation was also an essential component of the ethics application.

- Communication and decision-making practices
- Uncertainties and concerns regarding the future and future care
- Potential deterioration in health and/or cognitive ability
- Wishes and preferences for future care

Box 3: Key concepts used to devise prompt questions

During the interviews, the aide memoires were an essential tool that enabled the key issues to be addressed, while still maintaining the flow of the interviews. According to Rubin and Rubin (2005) the desired depth required to understand perspectives of those at the centre of the enquiry can be achieved by paying attention to context and meanings, situations and history. As a result, questions often emerge during the course of the research and cannot be fully worked out in advance. The elements of the responsive interview technique in relation to the study are captured in *Table 2.*

Elements of the responsive interview technique	Relevance and application to the study
Gives flexibility within the bounds of the interview context and allows for a degree of uncertainty throughout the study.	The pace, length and participants of the interview was dictated by the needs of the frail older people in the study. Safeguarding was a priority.
Synthesis of understanding that comes about by combining different individuals.	Encourages the use of a lifetime of participants' examples through narratives, histories, stories and explanations, while preserving the direction of the study. Commensurate with the case study approach.
Allows and encourages a process of self-reflection.	Essential in identifying the boundaries between the research context and professional practice.
Analysis is ongoing and uses individual interpretations as viewpoints to construct an understanding.	Participants in the case studies were determined by the frail older people. Care was taken to ensure that the voice of the frail older person was preserved while representing any alternate views within the narrative.

Table 2: Study elements of the responsive interview technique

3.6.4. Establishing rigour in qualitative case study design

Throughout the design and implementation of this study, attention has been paid to ensure its methodological rigour through multiple elements.

One important element was to make certain that the key features included in the multiple case study design were commensurate with the interpretivist constructivist research paradigm (Fossey et al., 2002, Rubin and Rubin, 2005). Combining the approach of multiple case studies with the serial and responsive interview techniques was essential to ensure the study design was flexible enough to adapt to the real-life situations of the frail older participants. Returning to the underpinning philosophical assumptions of the study when these decisions were made was useful in guaranteeing this was the case.

Further methodological rigour was ensured throughout the study with consideration and thick description of the contextual factors of each case. Transparency in the data collection techniques is also fundamental to assessing quality (Geertz, 1983, Stake, 2005), and these are described in detail in this chapter. In doing this, I have also paid particular attention to negative or exceptional cases, providing a variety of quotations and descriptions where necessary to identify when this occurs (Stake, 1995, Lauckner et al., 2012). Seeking out multiple perspectives throughout the course of the study was essential to its success.

Throughout the study, I often heard the same stories repeated, from both individual and multiple perspectives. This is referred to as triangulation in qualitative case study enquiry and has generally been considered a process of using multiple perspectives to clarify meaning (Lincoln and Guba, 1985). However, the frame of this study recognises the multiple realities in which people live and uses triangulation to help identify these (Stake, 1995).

Care has also been taken to ensure interpretive rigour within the study. Interpretive rigour refers specifically to the trustworthiness of the interpretations of the interview data (Fossey et al., 2002, Lauckner et al., 2012). This took place through extended and persistent engagement with the interview materials and relates to transcription, use of quotes and the writing up of the thesis. Achieving rich contextualised descriptions, although overwhelming at times for me, was preferable to reducing and oversimplifying a complex phenomenon.

During the analysis and interpretive phase of the research study, expert debriefing (Lincoln and Guba, 1985) took place as part of the PhD supervisory process. This was achieved through critical commentary of the re-storied case studies and writing up of the data chapters and discussion. In addition, the research diary was also used as a reflective tool throughout the analysis phase of the study and was instrumental in critically examining my interpretations of the data. A thorough description of reflexivity and the data analysis procedures are provided in *section 3.5.2* and *section 3.9* respectively.

3.7. STUDY PROCEDURES

3.7.1. Ethical approval process

Ethical approval was sought and gained from the NHS National Research Ethics Service NRES Committee East Midlands – Nottingham 1 in February 2014 (Ref: 14/EM/0004). The study was also given approval for the purposes of the Mental Capacity Act (2005), and the committee was satisfied that the requirements of section 31 of the act would be met in relation to research carried out with a person who lacks capacity to consent. Site Specific approval was also given by the Department of Research and Innovation of the NHS Trust where the research study took place *(Appendix B).*

3.7.2. Patient and public involvement

Advice on the acceptability of the research study focus was sought from an established user group; they also commented on ethical aspects of the study. This was augmented with critical commentary on the acceptability of all participants' study materials, which helped enormously in ensuring the accessibility of these to those living with frailty and cognitive decline.

3.7.3. Study setting and sampling

The study was conducted with frail older people and their significant others that were recruited between February and September 2014, from one of seven wards specialising in healthcare of older people in a large NHS teaching hospital in the Midlands, UK. Of the seven wards, three were mixed sex with the remainder being single sex: two male and two female. These wards were chosen because they were the main wards that admit

frail older people within the hospital. Most patients arrive on these wards following emergency admission from their home,[10] either via their own GP, the emergency on-call GP service,[11] the Emergency Department or Clinical Decisions Unit. In addition to this, some patients are also admitted from other specialties within the hospital, in some cases post-surgery for rehabilitation services.

Purposive sampling was identified as the most suitable to recruit up to 20 frail older people and their significant others. This number was chosen to reflect the potential complexity of the case study approach where it was difficult to predict who would be interviewed and how many interviews would take place within the scope of the study and its timeframe (Morse, 2000). Schwandt (2001) asserts that in qualitative fieldwork, participants are chosen for their relevance to the research question. In this study, the purposive sampling strategy was chosen to maximise variation of participants within the recruitment criteria (Gobo, 2006).

3.7.4. Characteristics of the cases

In total, 58 frail older people were approached to take part in the study with sixteen eventually consenting to take part, aged between 70 and 97 years. The characteristics of the cases are represented in *(Table 3).*

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[10] In this case, home also refers to care home or other residence that the participant has been residing at.

[11] A local 'not-for-profit' company that holds contracts to deliver NHS services on behalf of local commissioners. This is usually restricted, although not exclusively, to an out-of-hours service.

16 cases in total were recruited 16 frail older people and 8 carers n=24	
8 frail older people interviewed alone	**6** female **2** male
8 frail older people interviewed with relatives/carers	**4** male with spouse **1** female with spouse **2** females with daughters **1** female with family friend
30 interviews in total (between 5 and12 weeks apart)	**12** frail older people 2 interviews **4** frail older people 1 interview **1** carer (following capacity loss) interview **1** carer (post bereavement) interview
3 frail older people died during the study and **1** lost capacity to consent	

Table 3: Characteristics of the sixteen case studies

Throughout the study, some participants' circumstances changed, and although the aim was to interview again within four to six weeks, this did not always work out as anticipated. Detailed vignettes of these circumstances are reported in *Chapter 4*, but a simple matrix *(Table 4)* is provided below to capture the permutations of who participated in each interview, where the interview took place and an explanation of additional individual circumstances that had a fundamental effect on when and where the interviews took place.

Pseudonyms (age)	1st interview	2nd interview	Relationship with relative/carer	Time between interviews	Living circumstances during study	Additional information
Clara[12] (70) and Vicki	Clara and Vicki at Clara's Home	Clara alone at home	Close family friend	5 weeks	Lived alone in a small ground-floor flat	Vicki was not available to attend the 2nd interview due to an admission to hospital for a minor operation.
Josie (86)	Josie alone in hospital	Josie alone in an interim care home	N/A	6 weeks	Lived alone in a bungalow with her dog	During the course of the study, Josie was discharged from hospital to an intermediate care bed in a care home before being discharged home. She fell within a few days, was readmitted to hospital then went back to the care home where she was considering her future.
Alan (84) and Margaret	Alan alone in hospital	Alan and Margaret at their home	Husband and wife	11 weeks	Lived together in a large house	Alan was admitted for a major operation during the course of the study and was unavailable for the 2nd interview for 11 weeks. He openly admitted afterwards that he wanted to make sure I was trustworthy during the first interview before he exposed Margaret to the study.
Elsie (82)	Elsie alone	Elsie and	Husband and	6 weeks	Lived together	Jack was unable to come to the hospital to

[12] Frail older participant is depicted in bold

and Jack	in hospital	Jack at home	wife		in a modest house	visit because of his own mobility issues. Margaret was keen to be interviewed during her stay as she was waiting for her care package to start and she enjoyed the company.
Wilfred (84) and Joyce	Wilfred and Joyce in hospital	Wilfred and Joyce at home	Husband and wife	6 weeks	Lived together in a large house	Joyce was happy to come to hospital to take part in the interview.
Pamela (77)	Pamela alone in hospital	Pamela alone at home	N/A	6 weeks	Lived with husband in a large house	Pamela did not want her husband to be part of the study with her; she specifically requested to take part alone.
Harry (84)	Harry alone in hospital	Harry alone at home	N/A	7 weeks	Lived alone in a retirement complex	The 2nd interview was held 7 weeks later because of my own personal circumstances.
Rose (96)	Rose alone in hospital	N/A	N/A	N/A	Lived alone in a bungalow	Discharged to a temporary care home while her daughter was looking for a care home nearer to her. Was readmitted back into hospital before being discharged and died 5 weeks after the 1st interview.
Mary (87) and Stella	Mary and Stella in hospital	Mary and Stella in Mary's home	Mother and daughter	14 weeks	Lived alone a ground-floor flat	Illness and bereavement of another family member prevented Stella from taking part in an interview until 14 weeks later. Mary would not participate without her.
Bert (90) and Kathleen (81)	Bert and Kathleen at home	Kathleen at home	Husband and wife	12 weeks	Lived together in a large house	Bert died unexpectedly 3 weeks after the 1st interview. Kathleen agreed to a bereavement interview after 12 weeks.

Stanley (92)	Stanley alone in hospital	Stanley alone at home	N/A	5 weeks	Lived alone in a mobile home on a retirement complex	
Jim (79) and Norma (79)	Jim and Norma at home	Jim and Norma at home	Husband and wife	11 weeks	Lived together in a modest terrace house	Jim sustained a fall a few days after the 1st interview and was in hospital for 11 weeks. Jim did not have capacity to consent, and Norma wanted the interview at home.
Annie (91)	Annie at home	Annie at home	N/A	5 weeks	Lived alone in a large bungalow	
Nancy (83)	Nancy at home	Nancy at home	N/A	5 weeks	Lived alone in a large bungalow	
Brenda (84)	Brenda at home	N/A	N/A	N/A	Lived alone in a small terrace ground-floor flat	Brenda was not expected to survive more than a few days when I contacted her for the 2nd interview. She was unable to communicate, and I spoke to her carer.
Maud (95) and Sandra	Maud in an interim care home	Sandra alone in her own home	Mother and daughter	1 week	Lived alone in a ground-floor flat	I was worried about Maud's capacity to consent. Her daughter agreed to an interview but not with her mother present. Follow-up interviews were declined, but they were happy for data already collected to be used in the study.

Table 4: Interview matrix

3.7.5. Recruitment and selection

Participants were recruited using the criteria as discussed in *section 3.4.1.* An abridged version of this is presented in *Table 5.*

Frail Older Adult	
Inclusion:	Frail older adults scoring 6 or more on the Rockwood et al. (2005) Clinical Frailty Scale who are able and well enough to participate in an interview and whose reason for admission is resolving. Frail older adults identified by the 'surprise question'.[13] Frail older adults admitted to the healthcare of older people wards as an emergency admission from either home or care home.
Exclusion:	Frail older adults without a significant other and who do not have capacity to give informed consent. Frail older adults who are seriously ill and requiring intense medical care. Frail older adults who are on an active end-of-life/care of the dying pathway. Frail older adults who I had cared for on the acute medical admissions ward.
Significant Others	
Inclusion:	Significant others, but not in a paid capacity and **nominated by the frail older adult.**
Exclusion:	Under 18 years of age. Nominated significant others in a paid position.

Table 5: Recruitment criteria

As previously stated, the standpoint of those with frailty and the elderly is missing from the literature, and I wanted to represent this. In view of this, it felt right to define frailty, but there was a question surrounding the

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[13] Those working in end-of-life care often identify their population by what has become known as the 'surprise question' (Lynn, 2005): *"Is this person sick enough that it would be no surprise for the person to die within the next six months, or a year?"*

defining of age. Chronological age alone does not determine frailty or the vulnerability of a person towards the need for health and social care. From my preliminary investigations *(see reflections section 1.2)*, I learned that the nurses who work in healthcare of older people in the trust in which the participants were recruited no longer hand over[14] age of patients at the beginning of each shift. Instead, they talk in terms of ability, comorbidity and discharge planning, which in turn incorporates the patient need for rehabilitation and involvement of external agencies.

All the wards from which I recruited only accept patients who are over 65, but this is where defining patients in terms of age ends. Many of my eventual participants are the 'oldest old' (Wu et al., 2008 p.152), 85 plus, but frailty and its challenges extends to those who are younger than this and representing this in this piece of work was important.

Initially, preliminary explorations had revealed that there would be a large number of potential participants matching the recruitment criteria. Yet, with a paucity of primary research in this field, it was impossible to tell how successful recruitment would be. In addition to this, reasons for admission among the potential participants were so diverse that I realised quite quickly that representing this diversity in its entirety with the proposed sample size would have been impossible. Moreover, a recent systematic review incorporating 31 studies of frailty showed that twice as many women were likely to be frail than men (Morley et al., 2013). This was reflected on the wards where the study was located, with the ratio of female beds being greater than male.

Given that this was the case, a pragmatic approach to finding participants was taken in the initial stages. Stake (2005) reminds us that choosing the case from which we can learn the most is fundamental; even with multiple case studies, selection of sampling attributes should not take precedence. It is true that balance and variety are important, but so are accessibility and the opportunity to learn (Stake, 2005).

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[14] Hand over refers to the communication between nurses at the beginning and end of every shift.

3.7.6. Access to participants

Working alongside health professionals was crucial to ensuring appropriate and ongoing access to participants (Murray et al., 2009). Initially, senior nursing and medical staff were approached as the clinical gatekeepers to accessing the wards. I also attended a monthly ward manager meeting to introduce the study to ward managers. Their support was vital in determining access to participants as the usual care staff[15] were asked to help identify those who matched the inclusion and exclusion criteria.

It was at this stage that mental capacity was discussed, and those potential participants who were assessed via the two stage test[16] as determined by the Mental Capacity Act (2005) as not having capacity to consent, and who did not have a significant other, were not approached. Potential participants were identified and approached by their usual care staff for permission to talk to me about the research study, in order to prevent coercion and give ample opportunity for them to refuse. At this stage, if patients and their significant others refused, no further contact was sought.

Once potential participants agreed to discuss the research study with me, I was introduced by the staff member and gave an explanation of my study. I then gave a copy of the participant information sheet to the potential participants. Separate participant information sheets were designed to meet the needs of the patients and their significant others *(Appendices C&D).* In addition to this, the participant information sheets were designed to ensure accessibility for older participants with larger writing and clear intention of the study *(Appendix E).* The potential participants were then given a cooling-off period of 24 hours to consider the study information.

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[15] This extended to all qualified members of the multidisciplinary team (MDT) including nurses, doctors, physiotherapists and occupational therapists.

[16] Under the Mental Capacity Act (2005) the two stage test determines capacity to consent. This can be carried out by any registered healthcare professional and is as follows: Stage 1 – Is there an impairment of, or disturbance in, the functioning of a person's mind or brain? If so, Stage 2 – Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision? Can the person, free from being under pressure, understand the information, retain it long enough to make a decision, use it to make a decision and communicate that decision?

With their permission, I then returned the following day to see if they had made a decision.

Throughout the recruitment period, I kept an invitation log of those approached and those who agreed to take part. This acted as a prompt to invitation for the second interview and also ensured that potential participants were not approached again once they had declined an invitation.

Initially, a date for the second interview was agreed within four to six weeks, and participants were contacted 24 to 48 hours before on an agreed telephone number. This approach had to be amended after the first few interviews as it became clear that participants needed more flexibility with the second interview date. Instead, permission was sought to contact the participant by phone three weeks after the first interview. An interview date and time was then agreed that was convenient. Prior to the interviews, hospital records were checked for evidence of readmission, deterioration of condition or death to try and prevent distressing telephone calls. The local lone worker policy was adhered to throughout.

In the event of discovering the death of a participant, a condolence letter *(Appendix F)* was sent to any significant others who had taken part in the study. As well as condolences, the letter offered those already in the study the opportunity to remain in the study and take part in a post-bereavement interview. If participants did not have significant others, no further action was taken.

3.7.7. The reality of recruitment and gatekeeping

Interviewing participants was the part of this PhD journey that I was looking forward to the most. As a nurse, I was familiar with the ward setting, and I had found swapping this environment for the world of academic study a difficult adjustment. Attending the ward as a researcher, however, was not as I had expected. I immediately felt uncomfortable as I was not wearing the uniform I was used to. In addition, my role had changed from nurse to nurse researcher and being reliant on very busy staff to help with recruitment felt uncomfortable. I found myself feeling awkward, a hindrance rather than a helpful pair of hands.

New staff every day, and even every shift, meant relentlessly explaining the study with varying degrees of success as some staff were more receptive to helping with recruitment of participants than others. As gatekeepers to the participants, staff can sometimes become protective and paternalistic with worries about fatigue, preventing them from being part of the research (Addington-Hall, 2002). However, I did not feel that this was necessarily the case; in many instances the busy nature of the ward meant that staff were simply too busy to engage or listen for long, and so approaching those who smiled and gave eye contact was often more productive.

During research projects, access may not necessarily ensure representativeness, but when time is short, perhaps too little can be learned from inhospitable people, and emphasis must primarily be on opportunities to learn (Stake, 2005). Moreover, the biggest danger from gatekeeping actually came from my own clinical voice. I often found myself assessing patients with my eyes and making assumptions about their ability or willingness to cooperate. I really had to challenge myself to hand the decision back to potential participants by giving them the opportunity to learn about the study and thus make their own decisions.

The large number of eligible participants made identifying them easy, but in reality accessing them in between other members of staff in the MDT and avoiding meal and rest times was more difficult. Often frail older people seemed interested and happy to hear about the study, but many, as reported in the literature by Pleschberger et al. (2011), were reluctant to make it more formal and consent to be interviewed.

In addition to this, there was a limit on the number of patients that could be approached at any given time. I realised early on that the emotive nature of the interviews reduced the capacity of the number of interviews I could conduct in a week. This in in turn meant that I could only approach two participants at a time with often days passing before I knew if they wanted to consent because their significant others had to be consulted.

Fatigue and fluctuating conditions of potential participants also had an impact on recruitment. I learned quickly that it was impossible to predict

when would be the best time to approach patients; everyone differed so much. On occasions, I would arrive to speak to potential participants and they were sleeping; I would go back and they were still sleeping. Other times patients who had looked well the day before deteriorated overnight and were no longer able to participate.

Participants were offered initial interviews either in hospital or at home. On occasion, the ward set-up meant that the only private room did not accommodate participants in wheelchairs or with walking frames. It also became a point of frustration that despite requesting privacy, staff would often enter rooms to talk to their patients. For those that chose to be interviewed at home, there was often a delay of a few days as they settled into being back at home. On one occasion, I arrived to interview a patient and was unable to enter the property because of a key safe system.[17] I had not been aware that this system was in place, and the participant was unable to answer the door because she could not walk. Fortunately, I was able to phone and speak to the participant, who gave me the number to enter the house.

3.8. ETHICAL CONSIDERATIONS AND ISSUES

Ethical conduct is ongoing throughout the research process and can at times be difficult to define because of individual participants' needs (Goodwin et al., 2003). Frail older people often face challenges both physically and cognitively, a fact that makes conducting this type of research more difficult (Chouliara et al., 2004, Hall et al., 2009). Moreover, the use of serial interviews can promote over-disclosure as an unintended consequence of fostering trusting relationships with participants throughout the interview process (Hewitt, 2007). I realised quite early on that I was not going to be able to foresee all of the ethical issues that arose during the study, so it was important that I had an awareness of this and remained responsive to those issues arising during the data collection process.

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[17] A key safe is a system that allows care staff to enter a property without older people and those less able needing to answer the door. It is usually a number lock system attached to a box that has a key inside.

3.8.1. Ensuring informed consent

Although participant information sheets were available in varying font sizes to accommodate poor eyesight and varying lengths for those unable to read large volumes of text, the reality was that many of the participants preferred to talk at length about the purpose of the study before signing the consent form. It was during this conversation that many of the issues that occurred in the study surrounding informed consent materialised.

All but one of the participants who had capacity to consent signed and dated the consent form. A copy of the form was then given to the participant; one was kept for the study records and for those interviewed in hospital, a copy was placed in the medical notes. One participant was registered blind and unable to read the forms; in this case, the ethics committee were consulted and agreed to allow the participants information sheet to be read out loud and taped verbal consent gained. This process was witnessed independently by a staff nurse and verified with a signature. All significant others were able to read and sign the consent forms as required.

The cooling-off period of 24 hours was given to ensure that potential participants had an opportunity to change their minds; however, in many cases, this period was much longer. The reason for this was that when interviews were conducted in hospital, they were often delayed due to fatigue or participants undertaking rehabilitation. Similarly, for those who were interviewed at home, there was usually a few days' delay while they settled back into a routine.

Capacity to consent to research participation was assessed using the two-stage capacity test (*Appendix G)* as determined by the Mental Capacity Act (2005) in conjunction with the usual care staff. The two-stage test involves gauging the understanding and retention by the patient of the information given, including the consequences of taking part. My considerable clinical experience in this field meant that I was familiar with using both the two-stage test and working with patients who lacked capacity. When the usual care staff were unsure, capacity was assumed. However, on one occasion, during an opening conversation with a potential participant, I felt that

capacity to consent was lacking. When I alerted nursing staff to this, a new onset delirium was identified.

According to Mitchell et al. (2006), the social and cultural vulnerability of older persons with cognitive decline is compounded by continued exclusion from many fields of research. One of the reasons for this is their cognitive impairment and lack of capacity to consent. However, older people with cognitive impairment represent a large group whom clinical services often struggle to manage, and for whom the healthcare experience is often poor.

In order to include those lacking capacity to consent, a consultee agreement was sought. Under the Mental Capacity Act (2005), the consultee must be involved in the person's care, interested in their welfare and must be willing to help. They must not be a professional or paid care worker. They will probably be a family member, but could be another person (Department for Constitutional Affairs, 2007). As part of a consultee agreement, the consultee does not give consent but advises whether the participant without capacity would want to be involved in the study. It is the job of the researcher to consent on behalf of the participant once they have established what their wishes would be if they had capacity to decide. A separate consultee participant information sheet and consultee advice form was devised for the study *(Appendix H).*

In addition to seeking permission to include participants without capacity to consent under a consultee agreement (Mental Capacity Act 2005), a more person-centred approach to consent, called process consent, was also adopted (Dewing, 2002). Used independently and alongside consultee consent procedures, process consent was used to judge how participants responded to a paced experiential involvement in research using facial, behavioural and bodily communication (Dewing, 2007). This was very useful when I interviewed Jim, who did not have capacity *(section 4.13)*. It also proved a useful tool for Annie, who displayed fluctuating cognitive functioning but retained the ability to give informed consent *(section 4.14).*

Owing to the dynamic nature of frailty, informed consent was gained before the initial interview and then verbally re-validated prior to the second interview. During this process, mental capacity was reassessed using the

two-stage test. Throughout the study, only one participant lost capacity to consent to a second interview. Although her daughter agreed to be interviewed alone, she did not feel able act as a consultee, and as a result her mother was withdrawn from the study *(section 4.17).*

3.8.2. Confidentiality and anonymity

Every effort has been taken within this study to safeguard and protect personal identities by changing the names of participants and not giving exact research locations. However, despite going to these lengths, watertight confidentiality would be impossible (Christians, 2005). While most readers of this thesis would not recognise any of the participants, some close family members or friends may well do so. Throughout the study, participants were made aware of this fact via participant information sheets and in general conversation. During one of these conversations, I was asked by a participant to leave something that they had disclosed out of the study findings as a result.

3.8.3. End-of-life care: A sensitive topic area

Given the demographic and aim of the study, there was always a high likelihood that issues relating to end of life would be raised. Although limited in frail older people, previous research has shown that people want to talk about sensitive issues such as end-of-life care and that often talking to a researcher can be easier than talking to a health professional (Murray et al., 2009).

At times, participants did become upset, and many tears were shed throughout the course of the study *(e.g. Josie, section 4.3).* This was often compounded by the difficulties associated with the uncertainty of frailty and participants questioning their life expectancy and the quality of the time they had remaining in their lives. Inevitably, when considering the future, the conversations with participants often turned to considering their own mortality and that of their significant others. This is discussed throughout the data chapters in this thesis.

It did not become necessary to temporarily suspend any of the interviews due to participants' distress. However, I had underestimated the time need for debriefing following the interviews. I often spent time chatting with

participants in order to ensure they were not left unduly distressed. This was particularly pertinent in the interviews with Josie and Clara, who were both tearful throughout the interviews.

Protection of participants' emotional well-being was of upmost importance, and with their permission, written contact was made with the patients' hospital consultant and GP to fully inform them of the study *(Appendix I)*. Significant others were also given information on local support via the Carers Federation Adult Carer Support leaflet.

End-of-life research can also bring about emotional challenges for researchers (Murray et al., 2009, Pleschberger et al., 2011). This need not be unduly stressful for researchers if they seek debriefing and adequately trained support (Kendall et al., 2007, Kendall et al., 2009). During the data collection period, clinical supervision was provided by a senior nursing colleague. Furthermore, for the duration of the study and in order to understand the impact of serial interview methodology, careful contextual documentation of interviews was undertaken and the effects of the research study on the researcher recorded in a research diary. Throughout the study, both of these methods acted as valuable tools to manage the day-to-day toll of discussing such emotive topics, which I had found surprisingly challenging given my previous experience.

3.8.4. Safeguarding vulnerable frail older adults

Safeguarding participants was an important aspect of the study throughout. As previously discussed, all frail older participants were given the opportunity to invite a significant other to be present during the interview. I am also bound by the Nursing and Midwifery Council (NMC), my own professional registration and code of conduct and have been trained in safeguarding frail older people and in the use of the Mental Capacity Act (2005). Although they were not required, the clinical advisory group were also available for advice.

Participants were informed that, should sensitive details arise concerning the care received by the patient that were deemed to be contrary to hospital policy and/or professional code of conduct, they would be reported accordingly. Although this did not occur, it did at times make me think hard

about how other people live. I was shocked at times with the surroundings that people lived in. With one participant in particular, Stanley *(section 4.12)*, my shock was not a good enough reason to suggest neglect.

3.8.5. Maintaining professional boundaries

In qualitative research, intrusion, dependency and distortions of real-life processes is a risk (Holland et al., 2006). Throughout the interview process, I was mindful of this aspect of the study, but from the beginning I was overwhelmed by how lonely some participants were. My knowledge of local services that worked to reduce this aspect of living with frailty was not extensive, but I felt that not highlighting what I know would be wrong. Following discussion with more experienced researchers, I decided to produce an information sheet with available services to give to the participants that I felt would benefit them.

Throughout the study, all participants were aware of my status as a nurse. At times this attracted direct questions about clinical care which I answered as openly and honestly as I could within the scope of my professional practice. Leslie and McAllister (2002) agree that nurses should reflect on their dual role and declare rather than deny it during the research process. This also meant that when I experienced a situation of clinical importance with Clara's excessive breathlessness I could intervene in the research relationship and strongly advise her to seek immediate medical attention.

3.9.   ANALYSIS

3.9.1. Data transformation and management

All interviews were digitally recorded with consent of those present and transcribed verbatim. Once transcription was complete, audio files were deleted from the recorder. All data[18] were managed and stored in accordance with the Data Protection Act (1998). All digital files, transcripts, field notes and reflective diary extracts were coded and all personal data removed for confidentiality and anonymity purposes as they were shared

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[18] When using the term data throughout this analysis section, it is referring to the interview transcripts, field notes and reflective diary extracts.

with supervisors. Hard copies were stored in a locked cupboard and computer files on the university server. A password-protected database of the unique code identifiers and pseudonyms was created; this also contained other details that were collected during the course of the study, such as GP names and addresses and participants' addresses. Following completion of the study, data will be stored for a period of seven years as per local policy.

In order to allow for emerging themes and concepts to be explored and developed further (Murray et al., 2009, Kendall et al., 2009), all initial interviews were transcribed before the second interview. Personally transcribing the interviews allowed for this initial phase of analysis of the transcripts alongside the field notes and reflective diary. This approach is also a fundamental part of the responsive interview technique (Rubin and Rubin, 2005). By also personally transcribing the second interviews, this process continued until data collection was complete. During these very early stages of analysis, reading and re-reading the transcripts helped to identify points of interest that could be explored in more depth with participants.

Early on in the process, transcripts were also shared with supervisors for feedback and critical commentary. This process not only gave some reassurance about the type of data being collected and their relevance to the research objectives but also contributed to initial reflexive accounts. This process in particular was instrumental at the beginning of the transformative phase from nurse to nurse researcher.

Research using serial interviews produces complex and multi-dimensional data sets that require innovative strategies to analyse and display data (Holland et al., 2006). This research study was no exception, and the interview matrix *(Table 4)* demonstrates the complexity that was faced throughout my analysis. Within this study, the serial interview technique was not being used longitudinally to show evolving processes over time, so analysis was not taken across all first interviews and all second interviews. Rather, each case was analysed separately in its entirety before cross-case analysis and theme building began.

3.9.2. Individual case analysis

Once data collection within a case was complete, coding of the data began. Initially, and in a bid to manage the large volumes of text created by the serial interview approach, this was done by utilising NVivo 10. However, I quickly abandoned this approach as the text became easily disconnected from the transcripts, and as a result, the emerging stories that contextualised and influenced many of the emerging themes began to become disjointed. Stake (2006 p.39) refers to this as the 'unique vitality' of the case, which without caution during data analysis can become 'mangled' and lost when moving towards the cross-case analysis. Moreover, although showing change over time was not in the original intended use of the serial interview technique, at times even five weeks between interviews was enough to show the fluctuating nature of the frailty trajectory. Although this fluctuation at times showed positive as well as negative changes, it was important to hold on to this chronological change throughout the initial stages of analysis to preserve the 'unique vitality' of each case. It was these times of uncertainty in the lives of the frail older people and their significant others that proved a unique influence over their conceptualisation of planning future care.

Personally transcribing the data and repeatedly reading the transcripts made applying comments to connected parts easier. Line-by-line coding resulted in numerous notes being made on paper copies, with words and phrases highlighted. The sensitivity and hands-on nature of this technique captured the sequenced events and nuances of emotion and turmoil that were central to many of the interviews. Bazeley (2013 p.101) refers to this initial foray into the data as the 'read, reflect and connect' approach which allows for a more contextual and holistic understanding of the participants' lives and events that have influenced them. Following on from this, each individual case was re-interrogated for themes relating to the a priori issues highlighted in the original research objectives.

This approach then facilitated the writing of sixteen overarching re-storied narrative accounts. These accounts, of which edited versions appear in *Chapter 4*, are sequenced biographical accounts (Denzin, 1989) which identify a beginning, middle and end point. This was fundamental in classifying links between parts of the dispersed narrative across the serial

interviews as well as incorporating all perspectives, when these were available in the form of significant others (Bazeley, 2013). This meant that the lives of those frail older people and those closest to them, which in some instances had been intertwined for over 60 years, could be represented as a single coherent narrative.

Each account also contained notes of analytic importance, observations and interpretive comments, which in turn provided a platform for the cross-case analysis. They also contained a reflective account and elements of reflexivity, which encouraged these important elements in qualitative research to continue throughout the whole of the research process (Seale, 1999).

3.9.3. Cross-case analysis

During this phase, a process of coding across narrative accounts was performed with constant reference also being sought from the original transcripts to ensure that meaning was not lost. This was also undertaken manually and was time consuming due to the sheer amount of text being managed.

Throughout, attention was paid equally to both recurrent themes and those that were contrary or deviated from any dominant discourses. As is commensurate with the study's interpretive constructivist frame, individual perspectives were used to inductively develop a pattern of meaning (Creswell, 2007). The initial return to the research objectives in writing the re-storied narrative accounts helped enormously with answering the research study questions. It also helped to reduce distraction caused by the sheer intensity of the individual stories that were present in the data.

Taking detailed notes about thoughts at this stage also helped to maintain a sense of the origins of ideas and concepts, be it from participants or my own interpretations of their contexts. Throughout this process, it was particularly difficult not to become preoccupied with the struggle that some participants faced on a daily basis. This dominant narrative was a substantial part of living with frailty, and as the themes began to emerge, it was clear that this affected conceptualisations of the future which are discussed in the data chapters.

On a number of occasions, I caught myself being dominated by these difficulties and scouring the text with this at the forefront of my mind. Laying aside my own assumptions often meant returning to the transcripts time after time to ensure that I had not missed the important codes which revealed a much more complex and fragile story.

My search for a prescribed formula with which to analyse the data was not successful. As a novice researcher, a framework from research based evidence would have provided the safety net that I needed to ensure I was doing the research study properly. Stake (1995), however, reminds us of the importance of techniques developed by individual researchers. It is the attention paid to ensuring clear communication of the techniques used that gives rise to the quality of the research process.

Every effort has been made to be transparent through the analytic processes that have framed this study and where appropriate the distinction made between what the interviewees actually said and my own thoughts and interpretations of the data.

3.10. CHAPTER SUMMARY

This chapter has provided a detailed discussion of the methodological person-centred approach used in this study. Rationale has been provided for the use of an exploratory qualitative, multiple case study design, alongside the serial interview and responsive interview technique. Discussion relating to the bioethical considerations has been provided, and this is combined with reflections on the reality of how these played out in the field and demonstrates the importance of a reflexive approach.

CHAPTER 4. INTRODUCING THE PARTICIPANTS

4.1. INTRODUCTION

This chapter provides a preliminary introduction to the three data chapters by presenting each of the sixteen case studies. It is meant as a bridge between the methodology and findings chapters. The frail older participant and significant others (where applicable) making up each case study are introduced as detailed vignettes. These vignettes are not based on medical facts but are stories, made up of information that I gained as I observed each participant throughout their time in the study. Vignettes can be used as a data source in qualitative research to give the reader context to the findings and the circumstance in which the data collection took place (Jenkins et al., 2010). Each case is presented chronologically in the order I met them in the field. This context also provides a platform from which to view and gain clearer understanding of the cross-case analysis and synthesis of the data presented subsequently.

For each frail older participant, their frailty status, circumstances of their hospital admission(s), health on discharge, living arrangements, care support needs, significant others and interview schedule are provided. Each interview was a unique opportunity to gain a deeper understanding of planning future care from the perspectives of frail older people and their significant others. It was also an opportunity to be critically reflexive of my own influence on the research study and reflect on my thoughts and feeling as each interaction and research relationship drew to a close. Being reflexive and providing reflections for public analysis is considered a key element of ethical and rigorous qualitative research (Bishop and Shepherd, 2011). As I introduce the case studies, I also illuminate the case vignettes with some examples of this process and use field notes from my research diary to illustrate this.

4.2.   CLARA

Age	70
Frailty Status[19]	**Moderately to severely frail**
Circumstances of hospital admission	Emergency admission with acute onset breathlessness. Inpatient for several weeks as a result of extensive pulmonary embolus.
Health on discharge	Legs very swollen and mobility very poor. Walked short distances (bed to chair) with frame.
Living Arrangements	Lived alone in sheltered housing with on-site warden and access to 24-hour emergency help through an alarm system.
Care needs on admission/ discharge	Admission: Independent with signs of slowing down. Discharge: Needs help with all outside activities, keeping house and dependent on others for help with personal care.
Significant others	Supported by family friend Vicki. Has 3 children but does not have regular contact with them.
Carer support	Carers 4 times daily as part of an intermediate care package.[20]
Interviews	Interview 1: Home, with a family friend Vicki – within 2 days of discharge. Interview 2: Home, alone – 4 weeks and 5 days later.

Table 6: Clara

Outwardly, Clara was chatty and cheerful, but as our conversation progressed it became clear that she was struggling with her recent ill health and the day-to-day management of it. Throughout her time in the study, she was not recovering her independence as quick as she would

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[19] As designated by the Clinical Frailty Scale (Rockwood et al., 2005) on entry to the study.

[20] An intermediate care package consists of a structured programme of care provided for a limited period of time (in this case nine weeks) to assist a person to maintain or regain the ability to live in their own home or a care home as required (Age UK, 2013). This is to prevent the unnecessary use of acute hospital care during a period of rehabilitation and can include therapies as well as carers.

have liked. As a result, she was very anxious about what would happen to her when the intermediate care package came to an end.

On both occasions Clara was wearing her nightgown, and she looked dishevelled as though she had just got out of bed. Visiting patients in their own home was new to me in my role as a researcher. Even as an experienced practitioner, this was the first time I was confronted with the reality of how some people cope in a community setting with such huge challenges. This early tension between practitioner and novice researcher was evident in my research diary.

> *"I feel sad and a little tearful because Clara's circumstances are really challenging for her. I feel like I should be doing something for her, giving her advice or pointing her in the right direction to services that could help her. I am not sure where the boundaries are for this, if they really exist or how binding they are."*
>
> [Field notes 01/04/2014]

Vicki, who Clara described as being like a daughter to her, was only present in the first interview. Although she does appear in the transcripts at times, her contribution to the interview was very minimal, and Clara was the main voice throughout. It was impossible to tell what impact Vicki had on our conversation and whether Clara was more reserved as a result of her being there. She certainly was more open in the second interview, but it was difficult to know if this was as a result of a relationship building between us and her feeling more trusting to share her personal information.

4.3. JOSIE

Age	70
Frailty Status	**Severely frail**
Circumstances of hospital admission	Had been in hospital 1 week following a fall from her wheelchair and an injury to her knee. Was readmitted to hospital once during the study.
Health on discharge	Admitted to a local nursing home intermediate care bed.[21] Discharge delayed by a week due to an infectious outbreak that had closed the home. Josie's independence at home rested on her ability to transfer independently to her wheelchair, but this deteriorated throughout the study.
Living arrangements	Lived alone in sheltered housing with on-site warden and access to 24-hour emergency help through an alarm system.
Care needs on admission/ discharge	Admission: Wheelchair dependent and completely dependent on others for all personal care. Weight bearing for transfer to wheelchair with help of 2. Discharge: Unable to weight bear, fully dependent.
Significant others	Daughter and granddaughter visited once weekly as they lived one hour's drive away by car.
Carer support	2 carers 4 times daily, before being admitted to the nursing home full time halfway through the study.
Interviews	Interview 1: In hospital in a private room, alone. Interview 2: Alone in a nursing home, following permanent admission, 6 weeks and 2 days later.

Table 7: Josie

In the first instance, Josie gave me the impression she was coping well. She viewed this episode in hospital as a temporary setback, and she had

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[21] Intermediate care beds are available for those who do not need acute services but need an additional period of rehab. This can be either patient's own home or a nursing home and is dependent on the individual (Ali et al., 2010). In Josie's case this could not realistically be done in the home due to her level of dependency.

every faith in the system that her life would soon return to normal. However, as the interviews unfolded, it was clear that this was a coping mechanism. I began to realise that she was bravely trying to cope with diminishing physical fitness and the impact this was having on her life.

After a week, Josie had been discharged home from the intermediate care bed, but after two further falls at home and an additional spell in hospital she was now back in the nursing home. This time she was very tearful. She had made the decision to remain in the nursing home full time; returning home had become impossible. Throughout the interview, Josie sought reassurance from me regarding many of the difficulties she faced. She was tired and described not wanting to 'struggle' anymore; she felt she just needed looking after. This interview offered me valuable insight into how rapidly things can change for frail older people following an acute stressor event.

Josie's initial interview was the first in the study to be conducted in a hospital setting. It was a huge logistical challenge and the first indication that I had underestimated the difficulties of interviewing this group of patients within a hospital or other institutional setting.

> *"It has occurred to me today that interviewing people who are frail and elderly in hospital is riddled with issues. Multidisciplinary team members are constantly coming into the ward, bay, room, etc. to interrupt. For some patients it is difficult to mobilise and be taken to a private room; for others it is impossible. This represents a huge challenge to the study."*

> [Field notes 04/03/2014]

4.4.   ALAN

Age	84
Frailty Status	**Moderately to severely frail**
Circumstances of hospital admission	Admitted with breathlessness due to pulmonary oedema. Was admitted to hospital 2 further times during his time in the study, with the final admission being for a heart valve replacement.
Health on discharge	With each admission, never felt able to gain previous level of function. Mobilised only short distances with a frame.
Living arrangements	Lived in a privately owned 3-bedroom house with wife, Margaret.
Care needs on admission/ discharge	Admission: Not dependent on others but very limited with activities. Discharge: Significantly less able and needing help with all his personal care from Margaret following the operation.
Significant others	Wife Margaret. Had 2 sons who were unable to offer help.
Carer support	2 carers 2 times daily. Cancelled very soon after discharge, and Margaret took on the role of carer.
Interviews	Interview 1: In hospital, in a private room alone. Interview 2: Home with wife, Margaret, 13 weeks and 3 days later. The delay was due to Alan being too unwell and the operation.

Table 8: Alan

Alan was clearly distressed and shocked with the speed of his recent decline in health and his inability to get his breath. This was physically evident when he spoke to me as he would gasp for breath part way through a sentence.

Throughout the time we spent together, I found Alan to be a very proud and strong man. He did not like the fact that he was so dependent on Margaret for his physical care but was glad that he was able to continue to sort the household affairs on their behalf. At times, he became quite

emotional but recovered composure quickly. I felt that this show of emotion did not sit comfortably with him, as he often apologised or tried to hide his feelings with humour. From time to time, he was obviously in some considerable pain.

By using a flexible approach to building the cases driven by the needs and wishes of the frail older participants themselves, I always knew that there would be differences in each case. With Alan, I realised that I had not fully anticipated how complicated things might get or how difficult it would be to conduct a timely second interview. Initially I interviewed Alan alone, but the second interview was with Alan and Margaret together. He told me that he wanted to protect his wife, who had some degree of cognitive impairment, until he was fully aware of what the study entailed. When I arrived in their home for the second interview, I asked if Margaret would participate. While I was in their home, it seemed inconceivable to Alan that this would not be the case, and consent was taken accordingly.

In the early days of the study, I often became anxious when things did not quite fit the pre-requisite model of the ethics application. This was the case with Alan. It was also the case with several other participants as the study progressed. Having access to the ethics committee advisors, experienced supervisors and other PhD students was invaluable to me for discussing issues as they arose. It taught me very early on that a collaborative approach to problem solving in research when the unexpected happens can be of enormous value.

4.5. ELSIE

Age	82
Frailty Status	**Severely frail**
Circumstances of hospital admission	Chest pain and feeling generally unwell for 2 to 3 months.
Health on discharge	Feeling stronger but requested help because she felt they were not coping well at home. Elsie's son had been instrumental in requesting help against her husband Jack's wishes.
Living arrangements	Small council-owned semi-detached 2-bedroom house.
Care needs on admission/ discharge	Admission: Fully dependent on husband Jack for all care needs since becoming wheelchair bound following an accident some years previously. Discharge: Remained the same.
Significant others	Husband Jack. 1 son who lived locally and helped out most days.
Carer support	Carers 2 times daily which were cancelled soon after discharge when Jack began to care for Elsie again.
Interviews	Interview 1: In hospital in a private room, alone. Interview 2: At home, with husband Jack, 6 weeks and 1 day later.

Table 9: Elsie

What struck me about Elsie from the minute I met her was her determination and ability to remain positive about her worsening health and circumstances. I thought she looked older than 82 because her teeth were missing and her grey hair was flat on one side from where she had been lying on it. She was very thin and looked frail, but despite this description of her physical form, her mental strength was remarkable, and throughout the time I spent with her, I found her inspiring.

Elsie was the first participant to question my motivation for inviting a significant other to join her in the interview. Below is an extract from my research diary.

"I had planned to ask frail older people if they wanted to be interviewed with their significant other(s). This is a difficult task as very often carers are old themselves; this, however, is not the full story. Some participants do not seem to want to ask or put on people and would rather just be interviewed alone. I had not expected this; they seem vulnerable physically, but in many cases are mentally strong (although at times muddled)…strong about their own capacity to decide and be in control over who they talk to."

[Field notes 13/03/2014]

During the interviews, Elsie enjoyed talking about her life and telling stories, especially about her memories from the war years when she was a young girl. She loved poetry and on occasion quoted poems to make her point. When I interviewed her together with her husband, Jack, it was difficult to get them to talk about the things I wanted to ask them, because they loved telling stories and bouncing off each other, often laughing. They shared everything and had been especially close since Jack had become her full-time carer.

Elsie was the first interview I did following feedback from my supervisors about the 'nursedness' (Leslie and McAllister, 2002) of the interviews. Although I tried to reduce the amount of nursing and clinical information I gained following the first few interviews, making them less like a nurse–patient interaction was sometimes a difficult task. Although Elsie and Jack largely responded to my interview enquiries, they also seemed more comfortable talking about their illness and at times seemed confused by my enquiry based on their thoughts, feelings and future care. As previously mentioned, I did not make any secret of my nursing background, and although it seemed obvious to shoulder the responsibility myself for the nurse assessment track of the interviews, I began to realise that for many of the frail older participants, their own personal illness narrative also dominated our conversations.

4.6.   WILFRED

Age	84
Frailty Status	**Moderately to severely frail**
Circumstances of hospital admission	Admitted with acute onset confusion and a fall. Treated for urinary tract infection.
Health on discharge	Mobility very poor, walking with frame short distances. Had developed a small pressure sore on his sacrum. Had fallen twice at home between interviews.
Living arrangements	Lived in a privately owned large 4-bedroom house.
Care needs on admission/ discharge	Admission: Mostly independent but was supported by his wife, Joyce. Borrowing equipment from friends and neighbours. Discharge: Needed help to maintain personal hygiene and transfer from bed to chair. Had ordered stair lift and wheelchair. Awaiting work to commence on house alteration to make using the bathroom easier.
Significant others	Lived with wife, Joyce. Had a daughter and son who lived close by and offered support.
Carer support	Carers 4 times daily as part of an intermediate care package[20]
Interviews	Interview 1: In hospital in a private room, with wife, Joyce. Interview 2: At home with Joyce, 6 weeks and 3 days later.

Table 10: Wilfred

Joyce, Wilfred's wife, was present at both interviews, and although she walked with a stick, she was able to drive to the hospital each day to visit her husband and negotiate the lengthy journey from the car park to his bedside on foot. Throughout the interviews, I found Wilfred and Joyce to be very thoughtful and respectful towards each other, and I greatly admired the patience Joyce displayed with the physical demands that Wilfred unwillingly placed on her.

Helping Wilfred to maintain his dignity in light of his frailty was something that she seemed to do with equal measures of care and pride, something that was clearly important to him. On his request, and prior to our first interview, I had to wait for several minutes while she spent time with him behind the curtain helping him to get dressed and feel a little smarter to participate in the interview.

When I read the transcript of the first interview with Wilfred and Joyce, I realised that the interview had come to an abrupt end. The trail of conversation prior to this was interesting, and I remember closing it because I had thought that Wilfred looked tired and uncomfortable. This may have been the case, but I didn't even ask; I just made the decision by following my instinct. In hindsight this should have been a decision for Wilfred.

4.7. PAMELA

Age	77
Frailty Status	**Severely to moderately frail**
Circumstances of hospital admission	Weight loss, generally unwell with increasing pain. Unable to manage at home.
Health on discharge	Diagnosed with Parkinson's disease and following treatment was feeling better.
Living arrangements	Lived in a large privately owned house with her husband.
Care needs on admission/ discharge	Admission: Had been deteriorating for some time and had become fully dependent on her husband for all care. Discharge: Regained some independence with personal care but needed help with all outside activities.
Significant others	Lived with husband. No other immediate family.
Carer support	Employed a private carer at night and to take her out in the daytime.
Interviews	Interview 1: Hospital in a private room, alone. Interview 2: Home, alone, 6 weeks and 5 days later.

Table 11: Pamela

I had chatted to Pamela on at least three other occasions prior to the interview because she had been bedbound and unable to get to a private room to be interviewed. On each occasion she asked me to return again as she was not well enough to be interviewed and she wanted to talk to me.

Pamela was very thin, having recently lost weight; she suffered from severe osteoporosis that caused her to walk very slowly and stoop over her frame. On the day of the first interview, she was dressed in her own clothes and looked smart. I felt that she had a very pragmatic way about her and the circumstances that she found herself in. It was an interesting interview in some respects because she was very expressive, and unlike many participants, I knew when I had asked her something that she did not wish to talk about, because she closed me down or remained silent.

More than most, Pamela seemed to be affected by the digital recorder. She was chatty and relaxed before I switched it on but then immediately became very formal in her interview style. This was something that did not leave her until the tape was turned off. Despite my best efforts to put her at ease, she waited for the tape to be turned off before she felt able to relax again. The only time I saw emotion from her was when the recorder was off. Below is an extract from my research diary.

> *"Pamela is a 'no nonsense' lady. The tape did seem to impede her as she was much chattier when it was turned off. With some of my participants I have been able to leave pauses in the course of the conversation to encourage them to talk. But not with Pamela! If she didn't want to talk about a subject, she gave me a look that I quickly learned meant no more on that subject."*

> [Field notes 12/05/2015]

4.8.   HARRY

Age	84
Frailty Status	**Moderately frail**
Circumstances of hospital admission	Emergency admission following being found on the floor of his flat by his daughter 12 hours after he fell.
Health on discharge	Felt bruised, weak and tired.
Living arrangements	Lived in a retirement village with 24-hour access to emergency help through an alarm system.
Care needs on admission/ discharge	Admission: Needed help with all outside activity and keeping house. Discharge: Needed help with all outside activity and keeping house. Confidence was starting to wane.
Significant others	Lived alone following the death of his wife at the end of the previous year. 2 daughters visited regularly.
Carer support	Refused all carer support.
Interviews	Interview 1: Home, alone
	Interview 2: Home alone, 7 weeks later.

Table 12: Harry

Although Harry was happy to chat, he seemed a little subdued. Once we got talking, it was easy to understand why. He lived alone following the death of his wife at the end of the previous year in a purpose-built retirement village that they had chosen and moved into together. Her death had been very rapid, and Harry felt that they had never got the opportunity to enjoy their new home together.

The retirement complex reminded me of a large hotel. It was very smart and secure, and I was required to sign in, wear a visitor badge and go through several doors using the swipe card I was given. There were lots of people milling about and lots of information displayed about the different activities and support that was on offer. When I thought about it, it seemed incredible that with all this, Harry had lain undetected on his flat floor all night.

During our second interview, Harry somehow looked frailer than when we had met the first time. At first it was difficult to grasp how, but it occurred to me later that when I saw him just out of hospital he was clean shaven and smart. Now, just seven weeks later, he looked a little rugged, sort of rough around the edges because he had sections of his facial hair that had grown longer, which he had missed shaving. His clothes were stained and crumpled.

At the end of our conversations, Harry asked me if I could return as he had enjoyed talking to me. I felt quite guilty that the answer was no; in truth I had enjoyed talking to him too. The reality is that Harry, like many of the frail older people in the study, didn't remember the finer details of what would happen at the end of the study. This conversation was a timely ethical reminder that I needed to gently prompt participants with the aims of the study, how many times I would visit and what would happen at the end.

4.9. ROSE

Age	97
Frailty Status	Severely frail
Circumstances of hospital admission	Emergency admission following a fall with oedematous swollen legs. Diagnosed with heart and kidney failure. Was found by neighbours who could not see her sat in her usual chair. Was readmitted to hospital and died during the study.
Health on discharge	Registered blind, unsteady on feet and finding it difficult to be at home all day alone.
Living arrangements	Lived alone in a privately owned small bungalow.
Care needs on admission/ discharge	Admission: Completely dependent on others for all outside activity and keeping house. Discharge: Completely dependent for all personal care.
Significant others	Lived alone. Daughter who visited her weekly.
Carer support	Private carer visited a minimum of 4 times daily. Neighbours across the road who were very supportive.
Interviews	Interview 1: In hospital in a private room, alone. Died 9 weeks after first interview before completing the 2nd interview.

Table 13: Rose

Physically, Rose looked much younger than her years, and I was surprised when she told me that she was 97. She was tired of all the hustle and bustle of the hospital and was happy to be interviewed as long as she could lie down. She was dressed and looked smart in a pleated woollen skirt and blouse. As I helped her into bed, I noticed she was very petite. She clung to me for support, and as she stood up, she was quite unsteady on her feet.

I found the interview I did with Rose very challenging. She spoke very slowly and quietly; time passed very quickly and, with several interruptions by ward staff, I felt frustrated that I had not been able to ask her about many aspects of her life. She was clearly uncomfortable when talking about

the future, and I was relieved when the interview ended because she was tired and hungry. I felt like I was intruding into Rose's deepest thoughts and maybe pushing her to think about uncomfortable things; this was not a natural place to be.

Looking after dying patients as a nurse on a ward, I have become quite comfortable talking about death. On reflection, I realise that in most cases this is following a course of treatment that has been unsuccessful, and by this point, there is some certainty that death will occur. With Rose, I found talking about death difficult, especially as she was aware that, at 97, she was likely to be staring it in the face. I realised as a nurse I like to try and fix things or at least in most cases access services which can help patients. Frailty is not, if at all, an easy fix. It has been difficult throughout this process as a researcher to learn to just listen and not try and fix the lives of others in this domain.

4.10. MARY

Age	87
Frailty Status	**Moderately frail.**
Circumstances of hospital admission	Emergency admission with severe hip pain. Developed septicaemia and was very unwell for 6 weeks. Transferred to a rehabilitation bed in another hospital for 2 weeks before being discharged.
Health on discharge	Was able to mobilise with frame, but taking large amounts of morphine-based analgesia to control the pain. Was on a waiting list for a hip replacement.
Living arrangements	Ground floor 1 bedroomed flat in a council-owned complex.
Care needs on admission/ discharge	Admission: Independent in own home but needed help with all outside activities and keeping house. Discharge: Needed help with some personal care and all outside activities and keeping house.
Significant others	Lived alone. Daughter visited regularly.
Carer support	2 carers 2 times daily.
Interviews	Interview 1: Hospital with daughter present. Interview 2: At home with daughter, 14 weeks and 3 days later.

Table 14: Mary

During the first interview in hospital, I was taken by surprise at the serious nature of Mary's recent medical problems. As a result of her septicaemia, she had been so unwell that on a number of occasions the family had been phoned to come to the hospital because she was not expected to survive. Understandably, this experience dominated both interviews, and it was difficult to move beyond this during the time we spent together. Mary's memory of her experience was very limited, so throughout the interviews, much of this story was told from Stella's perspective.

With Mary and Stella, the boundaries between nurse and researcher were very difficult to maintain.

As the ninth participant recruited, I had completed eleven interviews and I was feeling more confident about my researcher skills when I met them. Very quickly I realised that Stella thought the reason I had asked to speak to them was because of a complaint she had raised with the ward sister. As a result, it took a while to disentangle this, and I felt that it set a tone for the interview that was more one of nurse and patient than a research interview.

I found it difficult to listen to some of the care practices that they witnessed and described. I wanted to try and explain how they could have happened or try and defend my clinical colleagues. Rather than tell me about some things, they often asked my opinion of a situation or a question that was impossible to answer. I reflected after the interviews in my research diary.

> "*I felt that Mary and Stella were constantly asking my opinion – it would have been easy to give but I tried to remain focused. I do wonder if I could have allayed some of their worries and fears, but somehow I got an overwhelming sense that I would just have fuelled them.*"

> [Field notes 17/09/2014]

4.11. BERT

Age	89
Frailty Status	Moderately frail
Circumstances of hospital admission	Emergency admission following a fall which sustained a fractured wrist. Was readmitted to hospital and died during the study.
Health on discharge	Mobility had deteriorated since falling and felt very tired.
Living arrangements	Lived in a large privately owned 4-bedroom house.
Care needs on admission/ discharge	Admission: Minimal assistance but lots of encouragement from wife, Kathleen. Discharge: Needed help with personal care and all outside activities.
Significant others	Lived with wife, Kathleen. Also had 1 son and 2 daughters who visited regularly.
Carer support	Carer once daily in the morning to help with personal hygiene.
Interviews	Interview 1: Home with wife, Kathleen. Bert died just 10 days later. Interview 2: Bereavement interview with Kathleen 12 weeks and 1 day later (10 weeks after Bert's death).

Table 15: Bert

I had often wondered during data collection if the participant information sheet I gave to potential participants was too ambiguous and not easily understood. In the early phases of the research study, I attended and consulted with some user groups that were attended by older people. They gave lots of feedback and suggestions which helped to create the final product. However, with strict controls put in place by the sponsor and the ethics committee, they were not as forthright as I had envisaged.

When I met Bert, I realised that the reality was that many of the participants knew that I wanted to talk about decision making, end-of-life care and how they might plan for this time. With some, it felt difficult and awkward, but despite only interviewing Bert and Kath together once, they

were very open and honest about their future and what it might bring. They talked candidly about a time when either one of them might not be around anymore. When I think back to the interview, I realise that it would have been impossible for them both to know that their fears would be realised so soon.

Sadly, the thing that I feared at the beginning of this project happened when I tried to contact Bert to arrange a follow-up interview. Despite going to lengths as stated in the protocol to check hospital records before I called, I had missed that Bert had died in hospital just ten days after I interviewed him and Kath together at their home.

During the call, Kath was very kind. I thought afterwards how thoughtful she was to spend some of her time helping me to get over the shock I felt when she told me. It must have been obvious to her through my voice. Although frail, Bert had seemed very strong, sturdy almost, and he gave me no clinical indications, like I had seen so many times before at work, that he would die so soon. Of course I always knew that there was potential for participants to die, but Bert was the first one, and as a result, I was overwhelmed by the sadness I felt. I wrote the following extract in my research diary.

> "This week has been really tough. I feel weary with interviewing frail older people and I still feel like I have a mountain to climb with my data collection. I hadn't realised how emotionally difficult it would be. I have many questions and thoughts about frailty and the practice of ACP that I am struggling to articulate!"
>
> [Field notes 02/07/2014]

4.12. STANLEY

Age	92
Frailty Status	Moderately frail to mildly frail
Circumstances of hospital admission	Emergency admission after collapsing at home.
Health on discharge	Walked with a frame and felt much better.
Living arrangements	Large 1-bedroom static caravan situated on a caravan retirement park. No phone contact so arranged to call on a set day and time.
Care needs on admission/ discharge	Admission: Needing help with personal care. Discharge: Regaining independence but showed signs of slowing down and needed help with heavy housework.
Significant others	Lived alone. Sister and nephew who visited once a week. Supportive neighbours.
Carer support	Refused carer support and sheltered housing.
Interviews	Interview 1: In hospital in a private room, alone. Interview 2: At home, alone, 5 weeks and 5 days later.

Table 16: Stanley

When I first met Stanley, he was very gentlemanly, and even though he was obviously frail, he stood and immediately offered me his chair. It was mid-morning, the sun was shining and despite the summer heat, he was dressed in a full suit, with a shirt and tie.

Stanley's living arrangements were unusual. I made the following observations in my research diary.

> "I was shocked by how Stanley coped with his living environment. I had no idea how such a small frail man could navigate the step at the entrance to his caravan as it was good deal higher than the average step. Inside it was dark and damp despite being the height of summer. I wondered how he managed to live alone under such difficult circumstances, but he was very proud of his home. He told

me he had worked hard to own his own property and he had no debts to worry his family with."

[Field notes 24/07/2014]

Stanley's was the shortest of the interviews to date. In some ways this was unnerving, and I found myself repeating questions. I worried that such a short interview would not give me the information I needed. Even though I was trying to ask open-ended questions, Stanley only gave monosyllabic answers, and I felt it was a difficult interview. As I read the transcripts back during initial analysis, I realised that Stanley was not too different from many of the other participants in relation to his frailty and hopes for the future. He may not have been overtly chatty, but the story of how frailty impacted his life and decision making for the future was as clear as those who provided fuller answers.

4.13. JIM

Age	79
Frailty Status	Severely frail
Circumstances of hospital admission	Emergency admission following a fall. Was readmitted to hospital 3 times during the study. Suffered from chronic hydrocephalus.
Health on discharge	Deteriorated throughout the study and after each admission. Went from walking short distances to not being able to walk at all.
Living arrangements	2-bedroom end-terrace house at the top of a very steep hill. Jim lived downstairs as he was unable to climb the stairs.
Care needs on admission/ discharge	Admission: Completely dependent on carers for all care. Discharge: Completely dependent on carers for all care.
Significant others	Lived with wife, Norma. Son lived close by and visited regularly.
Carer support	2 times daily at the start of the study to 4 times daily during the study.
Interviews	Interview 1: At home with wife, Norma, 6 weeks after discharge. Interview 2: At home with wife, Norma, 11 weeks and 2 days later.

Table 17: Jim

Jim had suffered multiple falls over the past ten years. Initially, the medical staff who saw him had suspected dementia. Following extensive investigations, the family were initially relieved when they discovered that he had hydrocephalous and an operation could alleviate the symptoms. Eventually, however, surgery was ruled out as there were too many risks, leaving Jim with permanent memory problems that had got progressively worse. As a result, Jim was the only participant that did not have capacity to consent when he entered the study. His wife, Norma, acted as a 'consultee' on his behalf in accordance with the Mental Capacity Act (2005). Norma told me that Jim had always been a man that helped

everybody; he was kind and generous with his time and liked to talk. She felt sure that he would want to be part of the research study.

It was six weeks in total after discharge before I finally interviewed Jim and Norma. I had already visited the house once as well as meeting Jim in hospital prior to the interview. Norma told me afterwards that because of his 'memory problems' she wanted Jim to meet me on a number of occasions before the interview.

At the beginning of each interview, I tried to direct my conversation towards Jim and Norma. Throughout it was Norma who mostly took the burden of the interview; Jim did say things from time to time that were appropriate to that point in the conversation, but he was often repetitive due to his cognitive impairment. I realise that what I have here is mostly Norma's story, well, at least Jim's story through Norma's eyes. I cannot help but think that owing to Jim's current mental state, aspects of what it is like to live his life and for them to plan their future together would not be accessible if it were not for Norma's willingness to share them.

4.14. ANNIE

Age	91
Frailty Status	Moderately to severely frail
Circumstances of hospital admission	Emergency admission following a fall on a bus that had resulted in a broken hip.
Health on discharge	Walking with a frame but finding it difficult to come to terms with her loss of independence.
Living arrangements	Large 3-bedroom privately owned bungalow.
Care needs on admission/ discharge	Admission: Independent walking to the shops every day. Discharge: Needing help with all personal care and unable to leave the house independently.
Significant others	Lived alone. Son visited weekly.
Carer support	Carers 4 times daily as part of an intermediate care package[20].
Interviews	Interview 1: Home, alone. Interview 2: Home, alone, 5 weeks later.

Table 18: Annie

Annie was very thin and stooped when she walked. Her movements were exaggerated as she tried to negotiate walking with either her stick or frame. When I watched her, I felt anxious because she looked as though she might fall at any moment.

It was difficult to interview Annie as she was obviously muddled in her thinking at times. She was very quick to become disoriented when the conversation moved too quickly from one subject to another; this seemed to overwhelm her, often to the point of tears. She did not confirm to me that she had dementia, but I could see that she did suffer from problems relating to her memory, and she also told me that she was receiving care from a local organisation that I know specialises in dementia care. During the interviews, I tried to minimise any distress for Annie by moving very

slowly through the conversations we had. I offered to stop when she was upset and was respectful to her wishes to stop when she became tired.

On reflection, I am pleased that I took the time to include those with mental capacity issues as part of the ethics application. Although Annie did have capacity, the information that I had read on assent (Dewing, 2002) alongside my clinical experience gave me the confidence to continue to include Annie in the study and encourage her participation rather than gate keep her out of the study through fear of being unethical.

4.15. NANCY

Age	83
Frailty Status	**Moderately frail**
Circumstances of hospital admission	Emergency admission with swollen and painful legs that affected her ability to mobilise. Was readmitted to hospital once during the study after falling and being on the floor for 12 hours.
Health on discharge	Legs remained swollen and painful but slightly better than on admission.
Living arrangements	Lived in a large 3-bedroom bungalow.
Care needs on admission/ discharge	Admission: Needed help with all outside activities. Discharge: Needed help with all outside activities and keeping house.
Significant others	Lived alone following the death of her husband at the start of the year. Three children who visited periodically.
Carer support	Refused all carer support. Was considering some help with keeping house.
Interviews	Interview 1: At home, alone. Interview 2: At home, alone, 5 weeks and 4 days later.

Table 19: Nancy

The day I conducted the first interview, I had telephoned ahead to make sure that Nancy was happy for me to visit, and I arrived in good time. Her bungalow was set back from a busy main road, along a small private drive, and the garden was so overgrown I could hardly get up the path to the door. The house itself looked run down, and there was a rusty old car parked on the drive with moss and weeds growing from it. It took Nancy sixteen minutes to answer the door. I had noticed the time on my mobile phone because I had called her when she did not come to the door. Looking through the windows to make sure she was all right was not possible, and I was unable to get around the back due to the overgrown nettles and brambles.

Nancy was very happy to talk, and her interviews were some of the longest I conducted. She was a storyteller, and I enjoyed the many stories she told me.

4.16. BRENDA

Age	84
Frailty Status	**Severely frail**
Circumstances of hospital admission	Emergency admission after being found collapsed at home.
Health on discharge	Was unable to walk, speech was slightly slurred and she was registered blind.
Living arrangements	Small council-owned bungalow. Apart from getting up and going to bed when her carers were present, she spent all day in the same chair in her living room.
Care needs on admission/ discharge	Admission: Completely dependent on others for all care. Discharge: Completely dependent on others for all care.
Significant others	Lived alone. Family friend who visited daily.
Carer support	2 carers 4 times daily.
Interviews	Interview 1: Home, alone. Unable to return for 2nd interview as she became bedbound and disorientated.

Table 20: Brenda

I first met Brenda when she was in hospital awaiting discharge the following day. She was 'medically stable'[22] but her discharge had been delayed because, due to staffing issues, her four-times-a-day care package could not start immediately.

During the interview, Brenda often became muddled. We discussed this and she surprised me when she told me that she realised the extent of this. She often lost track of days and had decided to mark them off on her calendar to help herself. Although I only interviewed her once and was unable to ask her many of the questions about future care, I do wonder, as

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[22] This is a term used clinically in the trust to represent those who no longer need acute medical care and are ready for discharge. The distinction is made because it impacts on who finances the patients if they have an unnecessary wait to go home.

her mind deteriorated, if she got her future wish to remain and die at home.

The continuum of frailty and capacity to consent was very evident with Brenda. She did have the capacity to consent when I interviewed her, but was very slow to think about the things I asked her. At times, I found it difficult to understand her words as her speech was slurred. Often, she answered a different question to what I had asked, and I did wonder if she couldn't hear me or she simply could not remember what I had asked. I tried to ask questions in several different ways, but I think this just confused her and made it more difficult. She often lost focus, and it was a challenging interview for me.

In Brenda's case, I was not unduly surprised when her carer told me that she had deteriorated significantly and was not expected to survive much longer. This is the last contact I had with Brenda or any of her carers, and at this point she was withdrawn from the study. Since the study ended, I have often wondered what happened to her.

Brenda is not the only participant I think about as I write up this thesis, and I expect it is natural to wonder what has happened to all the other participants and difficult not to do so. Throughout the study design and ethics approval process, I was forced to think about many of the dilemmas that this type of study may bring, but I never really considered the aftermath and the interest I developed in the well-being of the participants.

4.17. MAUD

Age	95
Frailty Status	Moderately to severely frail
Circumstances of hospital admission	Emergency admission with dizzy spells and confusion.
Health on discharge	Walking with frame. Admitted to local nursing home intermediate care bed before going home halfway through the study. Family were worried that her cognitive impairment was deteriorating. Maud felt well and was ready to go home.
Living arrangements	Lived alone in a small council-owned ground-floor flat.
Care needs on admission/ discharge	Admission: Family support with keeping house and all outside activities. Discharge: Needed help with all personal care due to cognitive impairment.
Significant others	Large family with 7 children.
Carer support	2 carers 4 times daily. Family visiting up to 4 times daily for support.
Interviews	Interview 1: Alone in nursing home. Interview 2: With daughter Sheila as Maud had lost capacity to consent.

Table 21: Maud

Interviewing Maud on the ward was difficult as there was no private room available during the several times I visited her. During these visits, we chatted, and it was clear that she repeated some of the things she said. I discussed her capacity to consent with the staff, and although she did have some cognitive impairment, all the staff agreed that she could retain information long enough to make a decision and her informed consent was valid.

At 72, Sheila was the eldest of Maud's seven children and undertook the role of next of kin. Despite having a difficult relationship with her mother,

she visited her every day and tried to help her maintain her independence. Sheila thought that her mother's overall condition and cognitive ability was declining, and with each daily visit, she wondered how her mother could survive and continue to live alone in her one-bedroom ground-floor flat.

Maud was a good example of how easy it is to make assumptions about frailty just on appearance. On initially meeting her, she seemed able to chat and answer questions appropriately, and although she was repetitive at times, she was able to give informed consent. It demonstrated to me first-hand the difficulties and complexities of this age group and their sometimes fluctuating capacity.

In the end, Maud's condition had deteriorated to such an extent that she was unable to give informed consent to continue in the interviews. Sheila was not prepared to offer a consultee agreement, and although she was happy for the interview data already collected to be used, they withdrew from the study.

4.18. CHAPTER SUMMARY

This chapter has provided a detailed introduction to the sixteen frail older participants and their significant others that make up the case studies. It also gives an account of my own influence on the research process alongside reflections on the interviews and research relationships as they drew to a close. Collectively, the information presented contextualises the findings set out in the following three data chapters.

FOREWORD TO THE INTERPRETIVE CHAPTERS

The objective of this study was to gather narrative accounts of the expectations, experiences and understandings of frail older people and their significant others in relation to planning future care. It was also an opportunity to understand, from the perspectives of the frail older people, factors that may enable or constrain the practice of ACP. Through the iterative process of immersing myself in the individual stories of participants, both commonalities and diversity of experience in relation to these objectives have emerged.

The current policy and frameworks relating to ACP assume that individuals have a stable identity. It is from this identity that they are asked autonomously to imagine a time when they may not have the mental capacity to make, or ability to communicate, decisions relating to their healthcare wishes and preferences. It is also assumed that there are sufficient resources within the healthcare system to provide experienced healthcare practitioners, who can facilitate and encourage these conversations.

In the following chapters, I contend that the multifaceted challenges of frailty that are described here in detail by the participants pose complexities that have the potential to marginalise those living with frailty from engaging in ACP as it is currently conceptualised. Moreover, the social care system that many participants in this study are dependent upon to maintain their basic care needs is at odds with the theoretical frameworks underpinning ACP of autonomy and informed choice. The uncertainty posed by diminishing physical ability, often coupled with fluctuating capacity, results in difficult circumstances for any decision making to take place, let alone decisions relating to the future that are required for ACP.

By taking the time to understand what is important to those who are frail towards the end of life, I found that the participants in this study expressed an overwhelming need to enhance the quality of their existing daily lives. Their individually expressed but shared desire to strive towards an improved quality of life seemed to cast a shadow over any focus on planning for the future.

The interpretations in the following chapters are a synthesis of the sixteen case studies, an abridgment of which has already been presented in *Chapter 4*. With each case came a privileged yet unique opportunity to briefly enter into the world of the frail older person and their significant others. Analysing their individual narratives revealed that they had gathered a wealth of experiences over a lifetime, the detail of which would be impossible to present fully within the confines of this thesis. The themes emerging from the data have been categorised into three chapters:

- Living with frailty: Developing an understanding
- Negotiating care and care services
- Planning for the future.

Reflections on developments in the field of end-of-life care

Over the last few years, end-of-life care has been highly topical in terms of media attention, policy and research. In turn, these developments may have influenced the data generated by the study.

During the course of the data collection in particular, there were several high-profile news reports highlighting deficiencies in end-of-life care in hospitals. This resulted in the national review and subsequent withdrawal of the Liverpool Care Pathway[23] (Neuberger, 2013, Neuberger et al., 2013). Since then, hospitals have been forced to review how they deliver end-of-life care.

There were also several TV programmes profiling poor care of frail older people in nursing home settings. This subsequently resulted in a number of professional and public inquiries into how older people are cared for in society as a whole and the cost of this to human life. The frail older people in this study may have been affected by these reports, and they may have influenced the co-constructed accounts that are derived from the interviews.

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[23] Liverpool Care Pathway for the Dying Patient (LCP) is an approach to care, including a complex set of interventions, which resulted from a desire to replicate within the hospital sector the standard of care for the dying found in many hospices (Neuberger et al., 2013).

In addition to this, there was also a statement from the Resuscitation Council in conjunction with the British Medical Association and the Royal College of Nursing following the Tracey judgement from the High Court.[24] The statement emphasises the importance of clinicians achieving effective communication and shared decision making with patients and their significant others concerning cardiopulmonary resuscitation and other treatments (Resuscitation Council UK, 2014).

These high-profile occurrences have resulted in a notable shift that I have witnessed in clinical practice. More than ever before, frail older patients are being consulted about resuscitation and end-of-life decisions. Such was the media spotlight on these issues, they were difficult to avoid. As a result, this came through in some of the participants' narratives, but it may also have had an impact on the way other participants viewed their future care and conducted themselves in the study.

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[24] The judgement stated that by failing to discuss the making of a do-not-attempt-cardiopulmonary-resuscitation (DNACPR) decision with a patient who had capacity and had expressed a clear wish to be involved in discussions about her treatment, the first defendant was in breach of Mrs Tracey's human rights under Article 8 of the European Convention (Resuscitation Council UK, 2014).

CHAPTER 5. LIVING WITH FRAILTY: DEVELOPING AN UNDERSTANDING

5.1. INTRODUCTION

Throughout the data collection period, the intricacies of the lives of study participants came alive through the narratives they shared with me. Each case study provided a powerful and rich description of what it was like to live within the many confines and uncertainties of frailty. It is through these stories that I began to fully understand that the operational definitions used for research and policy did not enable a phenomenological understanding of the experiences of frailty. I entered this research project all too aware of the challenges of caring for those with frailty in an acute hospital setting. However, my regular twelve-hour shifts as a nurse did little to prepare me for the challenges faced by frail older people after they left hospital.

Research and policy suggest that this group should be engaged in ACP, yet uptake among this population remains poor. Despite being designated as the target population (one participant lost capacity to consent, several talked about spending periods of time incapacitous during hospital admission and three died during the study), very few of the participants talked about engaging in writing any of the formal outcomes of advance care planning with health professionals.

Such is the complex nature of living with frailty that it has since occurred to me that I would find it difficult if I were the health professional approaching frail older people, at this stage in their lives, to engage them in ACP as it is currently conceptualised. My experience during this study also makes it unsurprising that the literature shows that even the most experienced practitioners are anxious about the ACP process (Badzek et al., 2006, Duke and Thompson, 2007, Boyd et al., 2010, Seymour et al., 2010, Robinson et al., 2012c).

This chapter presents the experience of frailty from those who are living with it. It begins with how the participants identify with the term frailty and goes on to describe how their passage into becoming frail has affected their lives. It then charts the impact that living with frailty has on their

confidence and independence and describes in depth further effects on their psychological, physical and emotional selves. This chapter goes on to describe how the identity of those living with frailty changes over time and how participants attempt to adapt to the daily adversities they face. Finally, it looks at how those with frailty perceive the challenges they face within today's changing society.

The purpose of this chapter is to add to the literature on the lived experience of frailty, of which there is a dearth. It offers a detailed representation of the lives of the very people that best practice guidance and policy suggest may benefit from ACP.

5.2. IDENTIFYING WITH FRAILTY

As identified in *Chapter 2*, the notion of frailty exists in a variety of forms in the literature and is common in healthcare discourse. Despite emerging evidence to support a broader conceptualisation of frailty that recognises the frail older person's lived experiences (Becker, 1994, Nicholson et al., 2012b, Ebrahimi et al., 2013), to date, many definitions remain based on a biomedical model of frailty, which emphasises aspects of physical or cognitive decline. Many of the clinical staff who helped identify participants in the study described all their patients as frail; however, only one participant, Pamela, referred to herself as frail.

> *"Well, I am getting older and a little bit frail; I am not as concentrated on my action as I should be."*

[Pamela 26/03/2014 L8-9]

Pamela talked openly about herself as frail, and she was all too aware of its ability to be life limiting if it did not improve.

> *"…Because if you are very frail, it might be only a short time [until death], but if I can get some of my frailty back it might be longer, so it is looking into how long is a piece of string…"*

[Pamela 26/03/2014 L447-449]

Despite not using the term frail, many other participants also talked openly about aspects of their declining physical, cognitive, emotional and social health. This was somewhat challenging for most, especially those participants who also endured diminishing cognitive function. As demonstrated in the above quotation, Pamela articulated clearly the level of uncertainty she experienced when coping with frailty; all the study participants were similarly aware of this. Not all, however, were as insightful as Pamela about the potential impact of frailty on length of their lives.

5.3.   BECOMING FRAIL

Despite not always recognising it, all of the study participants had been living and coping with various stages of frailty for quite some time. For five of them, this was as a result of a chronic health condition that had slowly progressed. For these individuals, frailty had developed as a result of their diminishing physical fitness or mental capacity, which they linked to a disease process such as Parkinson's disease, ischaemic heart disease or chronic hydrocephalus. During the interviews these participants often found it difficult to talk about anything other than their current situation, and this often dominated the interviews.

Clara was one such participant, and from the outset, it was clear that her physical condition was poor, she was morbidly overweight and the breathlessness she was experiencing was debilitating. This combination had led to severely impaired physical function that had contributed to her frailty. All of this had had a profound impact on how she felt.

> *"…and I just feel like crap…it is as simple as that."*

> *"…it has just knocked me for six, my confidence the lot away."*

> *"Well it has just knocked me off my feet completely…I couldn't walk or nothing…"*

> [Clara 7/02/2014 L26, L40 and L60]

In direct contrast to Clara and others with a chronic illness, seven participants did not describe themselves as ill and rather attributed their

slow decline to simply getting older. For these people, there was no particular reason for the decline; rather, it just happened over a period of time, and they often found it hard to articulate when things had started to change. Despite this less sharply demarcated onset of frailty that individuals in this group perceived, the effects of frailty on their lives were profound.

Wilfred: *"I mean, I think the most worrying thing and it must be the most common too is er…realising the way your life is going to contract…"*

Joyce: *"Sorry?"*

Wilfred: *"Visualising the way that our lives are going to contract…And the loss of freedom to do things in our lives in our own way."*

[Wilfred and Joyce 18/03/2014 L566-580]

In addition to the two latter groups of participants, there were also four participants who thought their status of frailty had become established much more rapidly. This was often as a result of a catastrophic health event such as a stroke or as a result of an accident which had led to a substantial change in physical condition. For three of these participants, this event had transpired a number of years previously and had subsequently been followed by a further slower decline. For Annie, the slow decline had been accelerated by a fall, which for her had been catastrophic and had changed everything.

"Oh definitely because I have to take this everywhere [frame]. It is terrible trying to remember that and I can't…you can't; I am not allowed to bend from the waist. I can't put me shoes on…I can't wash me feet and it, you know, it is very, very difficult."

[Annie 25/06/2014 L49-52]

Despite describing herself as a 'coper', I really felt as though Annie had found every day since her fall and discharge from hospital an endurance test, and I was left in no doubt that her fall had been traumatic for her. She had seen her life change from managing to go out most days to being

fully confined to the house; her distress was evident when she talked about how different things were now. Even the tasks that she would ordinarily take for granted were now a chore following the fall, which had resulted in a fractured hip. What I found interesting was that, during our conversations, I realised that although Annie attributed her problems solely to the fall, what she was actually describing was a slow decline in her health; things had begun to change long before the accident.

It would be impossible for anyone to say exactly if the fall came as a result of the slow deterioration in her mobility that she described. But this is significant, because like the other participants who were prone to falling, she did not make any connection between deteriorating physically and falling; rather, she attributed her deterioration entirely to the fall. Although Annie strove to get back to what she was doing before her hospital stay, she realised, like so many of the other participants, that at this stage in her life this may not be possible.

During our discussions, many of the participants alluded to some level of cognitive decline. In two cases this was a particular problem and was especially difficult for the significant others involved in the study. In both of these cases, the extent of the cognitive decline over a long period of time had left their loved ones looking the same but behaving very differently. In Maud's case, her recent spell in hospital had exacerbated her tendency to repeat herself and be forgetful, which her family found difficult to understand.

> *"I know, they said she hasn't got dementia, in hospital they said she has not got dementia, but it's got to be some form of dementia because she just, she repeats herself continuously; you can't have a conversation with her anymore."*

> [Sheila (Maud's Daughter) 25/08/2014 L7-10]

Despite the family disagreeing, doctors were resolute that Maud had the capacity to consent and supported her wish to remain independent in her own home. After a recent series of poor decisions regarding finances and increasingly erratic behaviour, Shelia and the family were not so sure; they were worried about her being home alone and were concerned about her

welfare. Maud seemed unaware of this tension between the medical staff and her family; she was desperate to go home and continue her life.

5.3.1. Extremes of frailty: Small changes, protracted consequences

Although Annie's fall could be seen as a catastrophic event that instigated change, most of the participants described much less dramatic physical changes in their health status that had brought fundamental changes to the way they lived. These changes often came on slowly, culminated in an acute hospital admission and often left participants bewildered as to why they were unable to do the things they had done before.

Despite being wheelchair bound following a previous stroke, when Josie banged her knee during a fall from her chair, she was sure that it was temporary. Once the swelling had subsided, she thought she would be able to transfer again from her wheelchair so that she could be independent at home again with carers visiting four times a day.

> *"No, I think when they are ready to send me home my legs will be as good as what they were before I came in…I mean, I know they will not be perfect because they never have been perfect."*

> [Josie 04/03/2014 L159-162]

Josie never regained her ability to transfer and live independently. Just six weeks later, she had little choice but to give up her independence and move into a nursing home.

> *"…I have struggled and struggled until I can't struggle any more [voice breaks]…it's too much of a battle, and I am fed up at home."*

> [Josie 04/03/2014 L110-117]

This was devastating for Josie, given her desire to remain independent, and it meant that things were about to change significantly for her. I really felt as though she had been unable to exercise any autonomy over this 'choice' which seemed to be dictated by her physical and emotional state during this time.

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Unlike Josie, most participants during their time in the study were able to remain in their own home, but the consequences of these changes involved substantial alterations for them. This included creating and living a completely downstairs existence, having an increased dependency on significant others and/or the care system, having decreased mobility and, for some, becoming fully housebound.

For three of the participants in the study, infection had meant that they had endured a brief but instantaneous period of confusion and loss of capacity.

"Well, I don't know what happened. When they tell me, I say I don't know; I don't remember."

[Mary 18/09/2014 L476-477]

"I started getting confused…I was not aware of it; I knew there was some funny things going on, but I thought it was just funny things going on…"

[Wilfred 18/03/2014 L9-12]

Although not permanent, this was worrying at the time and all talked about how this spell of infection had left them feeling weaker than before. Several weeks between interviews had not seen them get back to their former levels of fitness, and they all questioned what might come next.

While not a major focus, many participants articulated some level of cognitive decline and simply described it as a poor memory. This often meant it was difficult to concentrate on things that they had once loved to do. Reading books and watching television had become difficult. Bert told me that he found that he couldn't remember what was happening when he watched a film for more than an hour, so he had given up trying. It was, though, his love of books and being unable to read them that caused him the most distress.

Kathleen: *"No, so he does not read the same as he used to, so we don't go to the library anymore."*

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Bert: *"I keep on turning back to the page before."*

[Bert and Kathleen 13/05/2014 L376-379]

5.3.2. The changing faces of frailty

Throughout the course of data collection, I interviewed all but three of the participants twice. Following deterioration in their conditions, most of the participants' lives had been turned upside down post discharge from hospital, but for others this was not the case.

Time in hospital and treatment for their health-related issues meant that two of the participants were feeling stronger when I met them for a second time. Despite this improvement, however, like many of the other participants, both still had to confront what would happen if their care needs were to increase more permanently. Pamela explained the effect this had on herself and her husband.

Pamela: *"…but I have been affected by it…and my husband has too of course…"*

Louise: *"Is that something you have talked about?"*

Pamela: *"Briefly…we both resent actively getting older…"*

[Pamela 26/03/2014 L372-377]

Although their overall condition had improved, like all of the other participants, they both described each day as different. Some days were better than others, and the periods of time where they felt better would often be outweighed by longer periods where they felt unwell. For Elsie, the fear of being a burden to her husband, Jack, remained.

"…I worry because I feel like I am putting on him all the time, and I should hate anything to happen to him…"

[Elsie 13/03/2014 L230-231]

5.3.3. Establishing new routines: Adapting to change

Regardless of the overall outcome of their illness following discharge, a change in condition, either for better or worse, often signalled a change in routine. What I found striking was the rate at which, for some, this change took place. In most cases, this meant adapting daily routines to accommodate their fluctuating condition. Often, participants rested and did very little on the days they felt unwell whereas capitalising on a good day was essential for overall morale. This change in condition and routine also had a big impact on significant others.

Although the serial interview technique was not specifically used to capture change over time, for some the change was so fundamental it was difficult to ignore. Such was this significance of the change in frailty status that a whole new routine had to be created. For some, this was difficult to come to terms with. For Jim (who did not have capacity to consent throughout the study) and his wife Norma, each hospital admission had signalled a change in care needs. In just a few short weeks, Jim could no longer walk and needed increasing help from social services. Norma was finding the constant change difficult to comprehend.

Norma: *"My sister said it is a new chapter [becomes tearful]. She comes all the time; I am expecting her later today…"*

Louise: *"Do you feel it is like a new chapter?"*

Norma: *"[sighs] No, I am trying to carry on like we did before, but it is not the same, is it?"*

[Jim and Norma 05/09/2014 L510-516]

The importance of routine cannot be underestimated to those coping with frailty. Most participants talked about the routines they had established and the changes that would need to be made to accommodate a change in condition, no matter how small. Routine was particularly significant to those with diminishing cognitive impairment which meant it took a while to adapt. Brenda had surprising insight into the extent of her confusion and told me 'I have started marking me calendar off so I know where I am'. Her spell in hospital had meant that she had missed over two weeks, and

as a result she became tearful when she realised it was July rather than June as she had thought.

> *"I went in in June, must have gone in on the…last month, I didn't realise it was July; somebody said it was July… I said it is still in June [becomes tearful]."*

> [Brenda 09/07/2014 L421-422]

With progressing frailty, speed of change often meant that there was little time to become accustomed to one change before another came along. I got an overwhelming sense that for many of the participants this meant that any change and subsequent change in routine, whether day to day, or hour to hour, brought a new level of uncertainty to those experiencing it.

5.3.4. Living and coping with uncertainty

The fluctuating nature of the physical and cognitive aspects of frailty led to living with a level of uncertainty that most had found difficult to come to terms with. In reality, this meant that often things that had been planned had to be cancelled. For some, it was holidays and family weddings, and for others, it was going out for meals with family and friends or missing scheduled appointments with healthcare professionals.

> *"Slowly I am getting a bit better and a bit worse; some days I am better and some days I am not…"*

> *"…I take each day as it comes and that is me done…"*

> [Brenda 09/07/2014 L68-69 and L370]

In many cases, like Brenda in the above quotation, participants had found this so overwhelming that they had simply stopped planning to do many of these things and had opted to live their lives on a day-to-day basis. This left them feeling guilty for letting others down and at risk of missing out on momentous occasions.

"…like a week before the wedding he had a couple of bad days…we got a bit worried that he was not going to pick up for the weekend, but he was fine you see and it did pass over…but…"

[Norma 05/09/2014 L48-51]

This was especially difficult for those caring for the frail older participant, who found themselves torn between attending something that they had been looking forward to and staying with their loved one when that person felt too unwell to go. Even when Jim had insisted that Norma carry on without him, Norma felt uncomfortable and guilty.

"No, felt very guilty...Well I should not be at the seaside enjoying myself while Jim is lying in hospital."

[Norma 05/09/2014 L708-713]

There was, however, an altogether wider issue relating to uncertainty. Throughout the study, the narrative of participants alluded to that fact that their experiences had taught them that change could happen quite quickly and that this would have a profound effect on not only their physical health but also their psychological and emotional well-being.

"…if you knew exactly what was going to happen…"

[Wilfred 02/05/2014 L283]

Some participants had come to terms with this uncertainty; Bert described it as part of 'life's rich tapestry'. But for others, like Wilfred and Joyce, it was rather more worrying.

Wilfred: *"I do think you worry about it a lot; I am aware that things are going to happen, but er I just have to er…take them as they come really…"*

Joyce: *"…I don't think any of us like to think too much about the immediate, but you don't know; you just don't know…"*

[Wilfred and Joyce 18/03/2014 L492-498]

This seemed to be a particular problem for those with a persistent problem with falls or who were living with a chronic disease that could deteriorate very quickly. For many, even their current state of health was uncharted territory, and this made comprehending the future impossible. When this was the case, they described 'waiting for something to happen'.

> *"There is a definite sense of waiting for something to happen, especially as Wilfred is so prone to falling".*

> [Field notes 02/05/2014]

In response to this, some participants had tried to find ways of dealing with this uncertainty. For Clara, it was important to keep her mind active during the long hours she spent alone; I think this helped her to stop thinking about the potential outcome of her personal situation.

> *"Well, I need to keep my mind going, love, because if I didn't, I would just give up. I know I would because there is nothing here, is there? There is nothing I could do…I don't like it…I am just sitting here waiting for something to happen…that is not a nice feeling…"*

> [Clara 01/04/2014 L463-466]

5.4. THE EFFECT OF FRAILTY

Alongside their diminishing physical and cognitive abilities, participants talked about a number of emotional, psychological and social effects from living with frailty. These were often evolving and influenced by the day-to-day changes and challenges that they endured. Where optimism existed in the first interview, it was often missing in the second interview or vice versa. This was yet another reminder of how fragile those living with frailty could be.

At times, it was harrowing to listen to as the participants talked about the many difficulties they had endured. However, moving stories of hope and resilience were also heard, and I was surprised to find that even in the most difficult circumstances, most participants still had a zest for life in spite of their current health challenges.

"I am pleased with my little flat, er I've come to the conclusion that at my age…I am happy in my own flat, and like I say, I have got loving people around me, my neighbours."

[Rose 30/04/2015 L134-136]

This dichotomy between enduring difficulties versus the hope and resilience displayed by participants was one of the most extraordinary findings in the study. Although at times there were some notable exceptions (which are discussed throughout the chapters), many participants, often through adversity, endeavoured to focus on the positive aspects and see the benefits to their current circumstances, albeit with varying degrees of success.

5.4.1. Loss of independence and fear of becoming a burden

All of the participants without exception talked about losing elements of their independence. Often their biggest fear was that they would become or felt they had already become a burden to others. For the most part, this was a physical burden which meant that the frail participants were reliant on others to help them with the activities of daily living. However, participants also talked about an emotional toll that they feared they placed upon their family members with the constant worry they gave to others about their safety and well-being.

In most cases, the frail older people referred to their significant others: spouse, children, other family members and friends, but at times this also extended to external care agencies. Those who were married worried that their own physical needs were too much for their significant other, who was often ageing themselves. Those with children talked about them having families of their own who needed them more.

Harry told me that he did not like to discuss his problems or his health. The reason to him was quite simple; he didn't think it was anybody else's business. His daughters were incredibly supportive, and he felt lucky to have them, but he didn't like to burden or worry them with how he felt. He was very much their father, and supporting them in this role was important to him.

> *"They have got enough worry without worrying about us; well, that is the way I look at things. I have just said to my daughter just now, 'Don't worry about me'…yes, I say, 'Don't worry about me', and they say, 'But I do'…"*

> [Harry 04/06/2014 L534-537]

In some instances, this caused a huge amount of frustration for participants. It was as though they blamed themselves when they could not do the things that they needed to do and had to ask for help. While on the one hand, there was an acknowledgement and acceptance that help was needed, many participants expressed that it was not something they accepted lightly.

Clara: *"I get really frustrated with myself…"*

Louise: *"Why is that then?"*

Clara: *"Because I cannot do what I want to do….it is killing me sitting here watching people doing it for me…"*

> [Clara 27/02/2014 L293–299]

For the most part, the significant others in the study did not feel their loved ones had become a burden. Or at least if they did, they did not feel that they could share this with me during the interviews. However, there was a notable exception to this concerning two significant others of those with advanced cognitive impairment. Norma talked candidly about the burden placed upon her and how over time this had become increasingly difficult. Being unable to leave Jim alone had meant she was not able to get out as much as she would have liked.

> *"I don't go out much…I go to the WI once a month…church once a week…but we do things together, and that is what I want us to still be able to do…"*

> [Norma 05/09/2014 L425-427]

Despite these difficulties, Norma was committed to helping her husband as much as she could, but it did bother her that he may eventually have to be cared for away from home. Sheila's case was slightly different. She wanted to be respectful of her mother, Maud's, wishes, but deep down she thought it would be safer for her to be cared for full time.

> *"I don't know, because I would feel guilty if I said go in a home, and yet really deep down I think that is what I want her to do, and then I know she is being looked after properly and there is somebody there. Well, I hope; you know, you do hear some things about the homes but…"*

> [Sheila 21/07/2014 L381-384]

This level of honesty was not without remorse. Both Norma and Sheila were torn between the life in which they had found themselves in a major caring role and the guilt of still wanting to live a life of their own.

5.4.2. Maintaining independence

In the face of much adversity with their frailty and despite a growing dependency on others, I felt that many participants really did actively look to maintain their independence in some small way. Although this was not always explicit, it became apparent when participants talked about not being able to do many of the things they loved in the same way as they used to. Despite barriers including diminishing eyesight and hearing, participants strived to pursue the things they enjoyed by adapting them to suit their changing health needs. Where Harry had once enjoyed going to his allotment and digging his vegetable patch, he now liked to 'play around with his pots' outside his back door. Where Rose had once loved cooking but now was unable to use the hot stove, she still managed to make some things herself.

> *"Well, I am independent. I love to, well, I still do my own pickling; I do like pickled cabbage…"*

> [Rose 30/04/2014 L101-102]

Both Harry and Rose talked with pride about these aspects of their lives. Maintaining some independence, as long their circumstances allowed, was important to them.

5.4.3. Losing confidence and living with fear

Despite trying to maintain a level of independence, almost all of the participants throughout the study talked about losing their confidence as their independence waned. For most, this had been a slow and steady loss that had developed alongside their frailty and was often as a direct consequence of their diminishing physical health. Their recent hospital admission had only sought to compound the feelings, and in a number of cases had caused much anxiety prior to hospital discharge. At times, loss of confidence and becoming dependent on others was so interrelated it was difficult to determine which came first. Prior to her discharge from hospital, Pamela told me how she was feeling about being discharged home.

> *"A little bit anxious…erm…I think I have lost a certain amount of confidence…"*

> [Pamela 26/03/2014 L29-30]

This loss of confidence also extended to other parts of Pamela's life. She had been very active and had attended sewing classes, enjoyed driving and loved clothes shopping. Slowly, however, over the last eighteen months, things had begun to change and get harder.

> *"…but er it slowly creeps up on you, and I have been aware that I don't like driving with a big vehicle….on either side of me like this [shows the road narrow with hands], and I had a generous-size car anyway, but there was nothing there and these people in big waggons, I felt intimidated…and so I was gradually giving up my independence, which of course was not good…because now my husband, he has got a health problem, but he could drive, but I think even he is losing the want to drive…"*

> [Pamela 26/03/2014 L70-76]

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For those that had seen a sudden and dramatic decline in their physical health, it was not uncommon during their time in the study for me to tangibly see their confidence ebbing away. On discharge, they expressed optimism that they would soon return to their former self and be able to do many of things they did before. Sadly, just a few short weeks later, when progress was much slower than anticipated, fear of falling seemed to set in, and this had a fundamental effect on their confidence.

Annie: *"No, I can't go out, I can't…I have only been out once and then that frightened me so…I thought well I won't do that again…"*

Louise: *"What was it about it that frightened you?"*

Annie: *"Well, falling over, you see…"*

[Annie 30/07/2014 L163-170]

It was common throughout the study to hear that participants were afraid of something. Most had been hospitalised following a fall at one time or another; a few had sustained nasty injuries such as broken bones and severe bruising. Although this fear was often palpable throughout conversations, mostly it did not dominate them. In one case, however, fear did dominate the conversation, and for Clara it was having a huge impact on her well-being.

On numerous occasions Clara had experienced breathlessness which had led to panic. These episodes of panic had in turn left her feeling as though she could not attempt to do things that she had previously taken for granted.

"…I am still out of breath…very much so…er…and like I say, I am too frightened to go outside. I mean, I stood outside the other day with two carers with me, and I just went rigid. I panicked and I just stood in the street and cried you know…I am a fighter, love. I don't give in, but this time it really got me, you know, and took a lot out of me, you know."

[Clara 01/04/2014 L103-110]

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Clara's panic attacks had meant that she no longer wanted to leave her house. This meant that she had missed her desperately needed follow-up appointment at the hospital with a specialist, at the time she probably needed it the most. Throughout the interviews I heard stories from others who were unable to access the things in their lives that they wanted or enjoyed doing. Although most tried to change their expectations to meet their changing health needs, this loss of independence and confidence had led to a loss of freedom and varying degrees of social isolation.

5.4.4. Living with loneliness and isolation: The loss of freedom

For the eleven participants in the study that lived alone, loneliness was a real problem. Most participants had family or friends that visited them regularly, but this did nothing to compensate for the long hours that they spent alone in their homes unable to leave. Often their spouse, friends and siblings had already died or were too old and frail themselves to visit. This loss of their social circle compounded their sense of isolation. Despite spending long hours during the day with their significant others, even the five that did not live alone also talked about a sense of loneliness resulting from their loss of freedom.

Things were particularly difficult for Brenda, who described herself as being fully reliant on the care visits she received each day. Beyond weekly trips to the day centre, she was totally isolated and was often left sat in her chair awaiting the carers to get her up, give her meals and put her back to bed in the evening. For her the day centre was a lifeline.

> *"Well, it is a change, because otherwise I am sat here, but…now I can't do as I used to do for here, not same as what I used to…"*

> *"…I don't do too bad because I never used to have anybody come and visit me…so I says well I may as well try something, and I do at the day centre…"*

> [Brenda 09/07/2014 L99-105]

Those who talked about a slow decline in their health and mobility often reminisced about leaving their home. However, over time, as this had become increasingly difficult for them, they had stopped going out

altogether. Wilfred talked about his life 'contracting'; he and his wife Joyce felt a real sense of loss regarding their freedom.

> *"And the loss of freedom to do things in our lives in our own way."*

[Wilfred 18/03/2014 L580]

Wilfred's description was also experienced by many others in the study who were unable to articulate exactly when they had stopped going out, but equally shared this sense of loss.

5.5. ADAPTING TO FRAILTY

For many of the participants, their advancing frailty had meant that they simply had to learn to cope and make the best of the situation they found themselves in. With so little control over what was happening, this was not always easy, and it was apparent at times that it was overwhelming.

> *"Well…to be honest there is not much I can do about it. I mean, I have got it, I have got to live with it, I have got to make the best I can with it, which is what I am doing, but I am very, very limited to what I can do, and what frightens me is this: my wife is not well, as you know…and what frightens me is she is working her socks off to keep me going. What happens if something happens to her, you see."*

[Alan 13/06/2014 L328-333]

Like many of the other participants, Alan had not relinquished his independence lightly, and it had been difficult for him to come to terms with his own need and to ask for help. Pamela *(section 5.3.2)* talked about resenting getting older, and others talked about their pride. Asking for help after years of independence was often warranted but for many a very difficult task.

5.5.1. Managing adversity to remain independent

Some participants were still struggling to come to terms with their frailty and need for help. They wanted to continue the life they had in their own

home, despite others believing that they should accept help. Stanley was one such participant. Despite its run-down and damp appearance, he was determined to stay in his own home; he had worked hard to buy it, and he was happy with his location and neighbours. He was proud not to have any debts and had managed to save a little bit to look after his family. Since discharge from hospital, he had been visited by his GP, who had offered to help rehouse him. He had also spent some time away from home while recovering from a previous illness, and he did not like it.

> "Oh it is lovely, yes; they wanted to give me a flat and that, but I am all right here. I have got good neighbours, and I am independent, and my sister comes, and I like it here. They sent me to, when I first had pneumonia a bit back, I went to a nursing home at, a rest home at er…now I had to pay for it…I was glad to get out of it. I didn't like them, but er I just put up with it. I was in there for a fortnight and got out, but here it is not too bad. It's humble, but I keep it clean."

> [Stanley 24/07/2014 L52-59]

Stanley, like many others, also coped by not taking unnecessary risks. This meant that he did not go out much in winter when it was icy and cold, or he always got home before it went dark. Others simply learned to do things slightly differently or give them up altogether. It was easy to see how people coped from the descriptions they gave, but I felt that for many there must have been an easier way. This was particularly true of Stanley and Brenda; it was difficult not to intervene and accept that they were happy to carry on as they always had for as long as possible.

5.6. ACCEPTANCE, POSITIVITY AND GAINING CONTROL

Although they lived with adversity, for most there was a degree of acceptance of the situation they found themselves in. They certainly didn't like it, but they accepted that they now needed help and that their age and ongoing frailty was going to have a profound effect on the rest of their lives. This acceptance also extended to recognising there was little control that could be asserted over this process, and as a result the participants

often looked towards things that they were able to assert more control over.

Despite everything they had endured, through multiple hospital admissions, diminishing physical health and cognitive impairment most were really happy to still be alive.

> *"Well, in a way it makes you feel down a bit, because I am here; don't get me wrong, I am happy because I am here, that is it, that's me…"*

> [Harry 16/04/2014 L225-226]

Remaining positive was a fundamental part of this, and although on a day-to-day level, this was in a state of flux, it was important for individuals to express a more positive outlook on the future. Part of this was that often participants would look to those around them to normalise their own situation. Despite the challenges she faced everyday looking after Jim, Norma told me that many of her friends were now on their own.

> *"A lot of my friends are widowed…they are living alone and we have got each other…a bonus."*

> [Norma 18/06/2014 L652 653]

During these conversations, there were always others worse off than themselves, and these social comparisons, for some, were clearly a way of feeling better about their own worsening situation. This was especially the case for those, like Norma and Jim, who were struggling to keep up with the pace of change that Jim's rapid deterioration over the course of their time in the study had bought about.

For some, remaining positive was a challenge in itself and had become a daily battle. Despite the many things that they talked about which bought meaning to their lives, Bert and Kathleen told me that remaining positive was especially hard in the mornings.

Kathleen: *"I think well I try and keep Bert positive, because I am positive and it does help, doesn't it Bert? You can get down, can't you? He is down in the morning."*

Bert*: *"The first couple of hours in the morning after I wake up is pretty horrible, only this last month or two."*

Kathleen: *"Yes, and then he improves as the day goes on."*

[Bert and Kathleen 13/05/2014 L908-913]

When I interviewed Kathleen after Bert's death, she reflected on the difficulties of keeping Bert positive and talked earnestly about his daily struggle.

"…so it was time, he had had enough I think, Louise, yes…so in the end it was a blessing [voice breaks and becomes tearful]…but it is so strange without him."

[Kathleen 06/08/2014 L420-422]

There was no hint of this during the first interview, and I realise now that it was important for them both not to acknowledge, in front of me and possibly each other, how hard it was for Bert to remain positive towards the end of his life. Kathleen was very proud of Bert regarding his ability to remain cheerful and not complain despite his difficulties.

5.6.1. The importance of motivation, purpose and hope

Like Bert, many of the participants did not like to talk negatively about their situation. From time to time, this was inevitable and often led to an outpouring of emotion that most, but not all, fought to gain control over as quickly as it had started. At times, I felt as though acknowledging the difficulties that were being encountered might somehow make it more real. It often left me wondering if they were just being positive for the interview, but I don't believe this to be the case.

On a basic level, remaining positive and being motivated were essential for most participants. It was important for them to continue to forge ahead

with their lives, despite not knowing what kind of day they would have. I was often astounded by the level of resilience that was displayed by those coping with frailty in adverse circumstances. However, it was much more fundamental than just remaining motivated and positive. Despite losing independence and control over their physical selves, they still hoped that this would improve, and working towards this goal gave a sense of purpose. For most, there was also hope of something better in the future, something to work towards and enjoy.

Over recent years, Wilfred's health had deteriorated slowly, leading to a gradual decline in his mobility; this had had the biggest impact on his life. He and his wife, Joyce, enjoyed dancing, and he was an accomplished painter. He told me that he felt that not being able to do his painting and dancing to his satisfaction had meant that he had lost all motivation to try.

> *"I would be inclined to think that because it happened it is like the fire going out, you know."*

> [Wilfred 18/03/2014 L95-96]

On the one hand, he had accepted that his mobility was deteriorating and he needed additional care. Yet on the other, he talked about other aspects of his health that were stronger and referred to a future time when things may improve enough to return to painting.

> *"Erm not bad really because in a lot of ways I am pretty fit…one system [of my body] is working extremely well and…hopefully that will continue…"*

> *"Yes, hopefully when I get this mobility thing sorted out, I can get back to it…"*

> [Wilfred 18/03/2014 L 234-244 and L158-159]

It is difficult to know whether Wilfred and the other participants believed any of this was really possible. His positive thoughts, however, did make me think differently about the uncertainty of the frailty trajectory. During times of uncertainty and change in condition, there seemed to be a more

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existentially driven need to think that maybe there is a chance that things may well get better instead of worse. Moreover, although this left people living in a state of flux between whom they once were and the uncertainty of whom they might become, I felt as though this was easier to deal with than to confront head on what the future may hold.

5.7. LOST AND CHANGING IDENTITIES

Alongside their developing frailty, many of the participants articulated changes in their close relationships. They talked with great sadness about how this aspect of getting older, intertwined with the change in attitudes towards them from others in society, had affected their own personal identity. Since the death of her husband and then more recently the tragic loss of her daughter's husband, the relationship between Josie and her daughter had changed. Although Josie felt like she was still a mother and grandmother, I really felt like she was struggling to maintain her identity in this role.

> *"I like to think about it myself, when all said and done; I am not silly, am I?…and I say to my daughter sometimes when she talks to me, er 'I am your mum not your', you know, and she says, 'I am sorry, Mum'. …you know what it is like; she goes above. My granddaughter will say, 'Momar [sic], listen to Mummy', and my daughter will say, 'Momar is your mummy's mummy.'" [Laughs]*

> [Josie 04/03/2014 L257-262]

Significant others also talked a lot about how diminishing physical and cognitive ability had seen familiar relationships change as their caring role had developed. This had an effect on the lives of all the participants, and many were still coming to terms with it and the feelings this evoked.

Like Josie, many others felt that even though their frailty was progressing and they could no longer do the things they used to do, they still wanted to offer a parental role to their children and grandchildren. This, however, was difficult when their children were taking on more responsibility for their parents' personal affairs and their care role was expanding. At times this

caused some friction among families and left those with frailty with feelings of inadequacy.

For the couples in the study, this also extended to swapping roles within the household and changing the way they lived their lives, which for some meant altering routines that had been established over entire lifetimes. Norma had to learn how to deal with the household finances when Jim no longer had the capacity to do so as he had always done. Alan told me that by agreeing to have paid carers in the house, Margaret, his wife, had 'lost her sovereignty in the house'. Kathleen was embarrassed to tell me that she and Bert had not shared a bed since Bert's stroke; she never thought this would happen, but once she had plucked up the courage to speak to her friends about it, she had found it surprisingly common. She felt that there are 'things that are never discussed among the older generation', but surprisingly this was also something that other couples shared with me throughout the study.

5.7.1. Loss of significant others

Like Josie, some participants were also coming to terms with the death of their spouse and lifelong partner. For some, this had been more recent than others, but they were all, in some way, trying to deal with their individual grief. For those that had experienced this more recently, making these adjustments to living alone was tangible, especially when interviews took place in their own home. Nancy's husband had only died a few months before I interviewed her. As our interview progressed, I realised that many of his things were still present in the house, most notably his coat, which was still draped over the back of one of the kitchen chairs where he had left it the day he had suddenly died.

> *"Oh yes, it changed. It wasn't even that really. It is just, I don't know, just not having him there with me anymore; erm, yes a lot of the little things he used to do…"*

> [Nancy 29/07/2014 L286-288]

I found it difficult to comprehend the amount of change on a personal level that Nancy and many of the other participants were dealing with. However,

they were not just dealing with change individually; they were also dealing with changes in the outside world.

5.8. MAKE DO AND MEND: A LIFETIME OF SOCIETAL CHANGE

All of the participants in the study had seen many changes in society throughout their lifetime. For many, this extended to being born before and experiencing living through World War II. Along the way, I heard many stories from this period, and I found it shocking that most participants had been exposed to things that I, and most of my generation, have little concept of other than from representation in films or stories in the media. Early on in the study, I realised the extent of the changing times that many frail older people had been subject to and the impact that this had on their lives.

For some, this was overwhelming while others took it more in their stride. Hearing stories of what it was like to live in a bygone era made me think more about what effect 80 years of societal change could have. Most notable throughout many conversations was the 'make do and mend' attitude of the participants.

Nancy: *"Oh I imagine so. I imagine the school years and everything, yes, yes…and the war-time years, make do and mend…"*

Louise: *"Do you still live by that philosophy, do you think?"*

Nancy: *"To a certain extent yes…I do, yes…"*

[Nancy 27/06/2014 L475-490]

It was this attitude in particular that made an individual's ability to cope in adversity makes more sense to me. Being raised and living through times when this ethos of 'make do and mend' had been essential to survival had meant that many still carried this philosophy with them into their current situations.

5.8.1. The technological revolution

Some participants told me that they found the technological revolution they had witnessed particularly challenging. Although some did try and use computers, they found it overwhelming, and the pressure to use this facility to pay bills and access information online made it more complex. In reality this meant that they felt as though they burdened their family members with yet another task that they found difficult. This bothered Elsie in particular who wanted me to understand that she was a 'good scholar' but was finding it all too difficult.

> "I would get through it if I had to, when I paid the gas bill. I don't like direct debits and I paid the gas bill at the end of three months, and you have got so much to get a discount back; some of it I don't mind phoning but when you have got, if you want so and so press 1 and so and so press 2, and by the time it comes to the end, I think I have forgot what to press [laughs]…but I paid the electric bill because they won't accept being done on the internet because I have given my son my bank number, and he does a lot of it on the internet for me…and he said, 'Why don't you let me do it so they can take the money out of the bank every month? It will be no different'. Some will allow it, some won't, and there is no consideration for somebody that is not capable of having any internet."

> [Elsie 13/03/2014 L489-499]

It was not difficult to understand why accessing the internet was perplexing for frail older people; most would agree that its complexities are challenging. But for Elsie and others, it was more than that; they seemed to feel as though this was just one more thing that their advancing years excluded them from and yet another reason to have to ask for help. Over time, this was adding to the erosion of their independence, which they felt, in the twilight of their lives, was unlikely to return.

5.8.2. Attitudes of society

As well as technology, many also talked about being marginalised from other activities.

"Yes…I had a car, drove…I was pretty confident. I used to go to the dressmaking class once a week…erm and had a good giggle…but that was upstairs, that was all right because they had a lift, but their loos, and they had only got one, sometimes there was up to 30 people in that showroom so I had to accept…"

[Pamela 26/03/2014 L38-42]

Public amenities were not accessible to those who managed to get out, or at least they severely restricted the choice over where to go. Joyce talked about it being more of a 'deterrent' for her husband, Wilfred. Pamela was angry that this had stopped her from attending her beloved sewing class, way before her frailty had prevented her going out altogether.

In addition to this, Pamela talked about attitudes towards older people in general. At times, during conversation with others, she had felt talked down to and patronised. Her response to this was to 'bristle', which she felt only served to perpetuate the stereotype that older people are grumpy and can be very difficult!

Although this was distressing for those that had experienced it, it was the attitudes of others in society towards their ageing appearance that upset them the most. Pamela was angry, but she was also resigned. She was too tired to fight against something she had little or no control over. Even if it were possible, this was just another reason not to venture out, perpetuating further the cycle of isolation and loneliness that she was suffering.

5.9. CHAPTER SUMMARY

This chapter highlights what it is like to live with frailty as it develops from the perspectives of those who experience it and their significant others. It details both the commonalities and diversity of experience of becoming frail and its physical, emotional and psychological effects. For many in the study, routine played a significant part in their day-to-day management of frailty. Moreover, the fragile nature of their lives meant that even the slightest change in condition could result in long-term consequences.

Often changing circumstance bought about great uncertainty; this threatened their identity, which was compounded by a lifetime of societal change and the attitudes of some towards older people. In a bid to engender some control, many participants had already begun to shift their focus to living day to day. It is this element in particular that suggests, for some living with frailty, planning for their future care may be an unrealistic expectation.

CHAPTER 6. NEGOTIATING CARE AND CARE SERVICES

6.1. INTRODUCTION

The focus of this chapter is to illuminate how those with frailty and their significant others negotiate the care and care services that they need to live their lives. Despite describing their concerted efforts and personal will to remain independent, all of the participants in this study were coming to terms with either an emergent or sustained dependency on others. Throughout the study, participants often told me about how interactions with carers played out and the effects that this had on their lives. For some, the dependency was such that it dominated the interview. In these cases, the impact it had on their daily lives was evident not only in their conversation but also tangible in their homes, in some cases transformed to accommodate their physical needs.

The beginning of this chapter looks in detail at the coordination of care and the services that individuals in the study required each day. It goes on to chart the importance of the hospital in the lives of those who are frail and the feelings that this dependency on the acute service provokes. This chapter also looks at services that are provided at home and how participants balance their own needs and comfort versus the burdening of others. Throughout, it demonstrates the importance and value that is placed on living within the care system and the negotiations required by participants as they attempt to live well within this bounded system.

Among the detailed explanations of the levels of dependency on the care system that individuals experienced, there emerges a threat to their agency and autonomy. This is also discussed in depth throughout the chapter. It is this threat, with its potential to destabilise decision making and limit choice for individuals' future care options, which cannot be ignored as it is fundamental to the philosophy of ACP.

6.2. CARE, COORDINATION AND CONFUSION

On the whole, participants were able to describe in great detail the levels of care and support that they needed to live their lives. Although there were similarities in the services that were offered, people in the study often

experienced them in very different ways. During the study, four of the participants were able to live with help from family and friends, whereas the increasing needs, both medically and socially, of the other twelve meant they had an increasing reliance and dependency on a variety of primary, secondary, third-sector and private healthcare services.

At times I felt as though some participants were just waiting for the next care visit, simply existing between services offered so that their basic care needs could be met, and they could continue with their day. For others in the study, care interactions were less of a focus during our conversations. They remained, however, of equal importance to the participants in order for them to accomplish many of the things that most of us take for granted, such as getting out of bed in the morning and going back to bed at night. Occasionally, care interactions dictated the timings of interviews as I was often in participants' houses when scheduled carers arrived. Moreover, on occasion, interviews were cut short or subject to many interruptions to accommodate carers. This almost certainly had an influence on the dynamic of the interviews, particularly when the flow of conversations was disrupted.

The complex nature of frailty meant that each individual reported constant change and disruption to their daily routine as they negotiated a variety of problems including readmission to hospital, changes in their condition and the increasing challenges of daily life. Assessment of these needs was an ongoing and dynamic process and was enacted by a variety of healthcare professionals, social care personnel, non-registered nursing care staff, family, friends and the frail older people themselves. Such was the complexity of some packages of care, it appeared chaotic to me as an outsider. On many occasions it was difficult to ascertain who, if anyone, was coordinating the care. As a result, people found themselves having to try and coordinate their own services, often without the knowledge of what was available, something that Annie in particular was struggling with.

"But I don't know where they [care services] are, you know, and the knowledge is that there is probably something out there, but where do you get the knowledge from, you know?"

[Annie 06/08/2014 L347-349]

Without a single point of contact, Annie and some of the other participants were confused about who they should contact when they needed help. At the time I visited her, I estimated that Annie was receiving visits from no less than five different disciplines. In order to facilitate understanding of each frail older person's care networks, *Table 22* below gives a synopsis of the care needs of each person on entering into the study. It also charts the readmissions to hospital that occurred throughout the duration of the study and the corresponding changes to care needs this engendered.

Pseudonyms (age)	Number of readmissions to hospital[25]	Care needs before admission	Care needs on discharge	Funding and delivery	Additional information
Clara[26] (70) and Vicki	0	Independent	Intermediate care package[20] for 6 weeks. Included 2 carers 4 times daily, occupational and physiotherapy.	Secondary care funding for intermediate care.	Clara was anxious about future funding after the 6-week period as her care needs were ongoing.
Josie (86)	1	2 carers visiting 4[27] times daily.	Fully dependent.	Partially self-funding. Delivered by a private service contracted by social services. Receiving Attendance Allowance.	During the course of the study, Josie was discharged from hospital to an intermediate care bed in a care home before being discharged home. She fell within a few days, was readmitted to hospital and then went back to the care home. She was considering her long-term future and had decided to remain in the nursing home.

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[25] During the study

[26] Frail older participant is depicted in bold

[27] Morning, lunchtime, early evening and bedtime

Alan (84) and Margaret	2	Help with shopping and gardening. Meals on wheels.	Carers in the morning and evening in addition to pre-admission help.	Private gardening service. Receiving Attendance Allowance.	Alan and Margaret cancelled the carers shortly after they started and returned to their pre-hospital routine.
Elsie (82) and Jack	0	Elsie was cared for exclusively by Jack.	2 carers visiting 4 times daily.	Delivered by a private service contracted by and paid for by social services.	Elsie and Jack cancelled the carers shortly after they started and returned to their pre-hospital routine.
Wilfred (84) and Joyce	0	Wilfred was largely independent with help from Joyce.	Intermediate care service for 6 weeks. Included 2 carers twice daily, occupational and physiotherapy.	Secondary care funding for intermediate care. Self-funding for ongoing services.	Visited twice by the emergency services to help Wilfred off the floor. Looking to private care companies to help and support following the 6 weeks.
Pamela (77)	0	Carer visiting once a day in the morning.	Night carer who slept in the house and assisted in the morning.	Self-funding initially by a private service that was arranged by social services and then privately for night care.	Pamela had employed a private independent carer following a chance encounter with another family in hospital who no longer needed her services.

Harry (84)	0	Independent	Independent with some help from his daughter with shopping.		Care services had been offered but declined with Harry wishing to remain independent as long as possible.
Rose (96)	1	1 carer approx. 4 times daily, sometimes more.	Fully dependent	Self-funding by private agreement.	Discharged to a temporary care home while her daughter was looking for a care home nearer to her. Readmitted back into hospital from the care home and on discharge went to live with her daughter to wait for a bed to become available in the care home that had been chosen. Sadly, died at her daughter's home before this happened.
Mary (87) and Stella	0	Independent with some help with shopping and cleaning from Stella.	Continued as before.		Mary had been given equipment to help her, but this was now being stored under the sideboard and was not in use.
Bert (90) and Kathleen (81)	1	Bert was largely independent with help from Kathleen.	Carers twice daily.	Self-funding. Delivered by a private service contracted by social services.	

Stanley (92)	0	Independent with some help from neighbours and his nephew.	Continued as before.		Care services had been offered but declined with Stanley wishing to remain independent as long as possible. Offers of rehousing also declined.
Jim (79) and Norma (79**)**	3	2 carers visiting 4 times daily, morning and evening.	2 carers visiting 4 times daily.	Delivered by a private service contracted by and paid for by social services. Also receiving Attendance Allowance.	Equipment to help was arriving constantly; this had forced Norma to rearrange the house to accommodate it.
Annie (91)	1	Independent with support from her son.	Intermediate care service for 6 weeks. Included 2 carers 4 times daily, occupational and physiotherapy.	Secondary care funding for intermediate care. Self-funding ongoing care needs.	Annie was very confused about the care she was receiving. She invited me to look at some papers that contained the information as stated here. She was unsure of what would happen when the 6 weeks were ending. She had been trying, unsuccessfully, to find somewhere to go for respite when her son went on holiday.

Nancy (83)	1	Independent with help from her daughter and son with shopping.	Continued as before.		Care services had been offered but declined with Nancy wishing to remain independent as long as possible.
Brenda (84)	0	2 carers visiting 4 times daily with occasional help from a friend.	Continued as before.	Delivered by a private service contracted by and paid for by social services.	
Maud (95) and Sandra	0	Independent with help from family.	2 carers visiting 4 times daily with support from family.	Delivered by a private service contracted by and paid for by social services.	Maud often refused to let carers in the house.

Table 22: Participants matrix of care

6.3. HOSPITAL ADMISSION: AN UNWANTED NECESSITY

All of the participants within the study were recruited in hospital, and for many, hospital was a necessity that they had experienced on a number of occasions over recent years. Feelings about being in hospital were mixed. Some were ambivalent about their experiences and preferred to talk more about other aspects of the care they needed. For others, this increased dependency on hospital services had been a negative experience and had made them feel vulnerable. On some occasions, that had even led to them questioning their own safety.

Alan was one such participant. During the thirteen weeks he was in the study, he was admitted to the hospital three times with fluid retention and increasing breathlessness. On his most recent admission, he had been in for two weeks to have a heart valve replacement operation, which for him had been lifesaving. He was happy that the surgery had gone well and felt that overall his experience had been positive. However, he also expressed anger and at times fear of his situation. On each admission he had faced a lengthy wait for a bed on a ward following admission to the emergency department. He felt that the time he had spent with other very unwell people had put his own health at risk.

> *"Oh, the other thing about it was in there it was like a battleground. There was coughing; people were coughing all over the place. It is a wonder I didn't end up with double pneumonia or something like that…"*

> [Alan 11/03/2014 L81-90]

Alan needed his physical health to be optimised so that his operation could go ahead. This became paramount as the weeks progressed, and Alan was faced with wanting to be at home but also wanting to stay and have his surgery before his condition deteriorated. He recognised that his life was time limited, but more so if the operation did not go ahead. He found it difficult to understand why he had to wait so long.

> *"Yeah well, they kept sending me home, saying I was all right, and of course what happened was I would regress because I was getting*

no support. I was getting breathless, erm, couldn't get my breath each time I had to go back."

[Alan 13/06/2014 L221-225]

I could see that Alan was torn between being grateful for his life-saving operation and the guilt of expressing his worries and anger.

Mary and her daughter Stella also shared Alan's frustrations with the system on admission to hospital. Care was so variable, and on occasion Mary had felt very vulnerable. She felt lucky to be alive but was angry that her experience of care had been so inconsistent.

"Well, I suppose I am lucky to be alive, aren't I? I mean, I don't know, I mean, I didn't know what was going on. They would perhaps have been going to my funeral today…"

[Mary 18/05/2014 L295-297]

It was evident from our conversations that both Alan and Mary were recovering from a very difficult and traumatic experience with the extent of their illness. I did wonder afterwards what the implications of this experience might mean for any possible future admissions to hospital.

Alternatively, Elsie, among others, talked positively about her hospital experience and expressed a level of gratitude that the services she needed were there for her. Hospital was a necessity that was just required from time to time, but more so now she was older. In fact, when she was feeling unwell and was no longer able to manage at home, for her it was the only alternative.

"Well, of course if I cannot manage at home, and I need to go to hospital, where else would I go?"

[Elsie 25/04/2014 L647-648]

I could see that it was inconceivable that she would not go to hospital, and perhaps she was also a little suspicious of why she would need to reinforce this with me. She very much felt that when she was unwell, she should and

would be treated in hospital like she always had been. More recently, keeping frail older people out of hospital has been prominent in the rhetoric that focuses on reducing acute hospital admissions. Alan was the only participant who seemed to understand and could articulate the dangers he faced to his health in hospital with so many ill people around him.

6.3.1. Readmission to hospital or failed discharge

During the course of the study and in between interviews, just fewer than half the participants experienced further hospital admissions. Being readmitted so soon after their previous discharge was confusing for participants. Annie in particular was struggling to understand why she had ended up there so soon after her last discharge.

> "I don't know what happened but, anyway, I ended up in hospital again."

> [Annie 30/07/2014 L320-321]

Jim had been admitted to hospital on three separate occasions during the eleven weeks he spent in the study. This had led Norma, Jim's wife, to question if the care he had been receiving before discharge was effective. She was also puzzled as to why Jim had returned from hospital less able than when he went in. This had led her to contemplate if the initial hospitalisation had been detrimental to his overall heath.

> "Yes, I think, I think myself he has been [in hospital] too long and he is sat too long, but I might be wrong. He might be like this if he had come home a fortnight later; you don't know. We won't know, will we?"

> [Norma 05/09/2014 L319-321]

Norma voiced this opinion on several occasions. She was struggling to find answers for Jim's deterioration, and like many of those who had experienced readmission during the study, desperate to make sense of their situation. In particular, she questioned why the medical profession was not able to help make things better for Jim. I worried that this loss of faith in the system would resonate strongly with any care he may need in

the future. Moreover, it was difficult to know if this readmission was because their support and care services were not adequate enough for Jim's needs.

6.4. CARE AT HOME: MAINTAINING CONTINUITY

Following on from their time in hospital, many participants experienced changes in the levels of care that they had needed before admission. Some told me that they had been managing, albeit 'just'. This was the first time they had accepted care services via more official channels, either through social services or privately. Others had been receiving primary care services that needed to be increased or were returning to well-established routines that had been in place for a long time.

It was unclear for some participants how long they would need their allocated services following discharge from hospital. Others accepted that this was now a lifelong need that they had. For many, it was about trying to maintain some continuity in their lives as they adapted to the changes in their circumstances. Coming to terms with how the care system would shape their future was something that differed enormously among participants. Often it was how individuals experienced care that largely dictated how they came to terms and coped with the levels of dependency they now had.

6.4.1. Just managing: Balancing comfort, burden and guilt

A number of participants described in detail how, as a result of their declining health and mobility prior to hospital admission, they had been borrowing or buying equipment to try and make things easier at home. For some, this had been over an extended period, and at times I found it incredible, given their current circumstances, how they had been able to manage, largely unaided, for so long. When this was the case, there was often a supportive network of family, friends and neighbours that had been generous with their time and support. In the main, they helped with shopping and strenuous household chores like hoovering and changing bed sheets.

> *"I have got good neighbours; the bloke next door is a nice bloke, a marvellous bloke…he does a bit for me if I am bad, and I treat him in a small way, and he is a marvellous fellow. I am very lucky with regard to that…"*

[Stanley 18/06/2014 L67-70]

More often than not, participants were grateful for this help, but it also came at a cost. For many this meant balancing their own comfort with the feelings of guilt associated with burdening others.

In some cases, when there were no informal networks of relatives or carers, participants simply managed without the help of others as best they could. Household chores did not get done, and this only became obvious when I visited participants in their own homes. Sometimes during data collection when I met participants at home, they somehow looked frailer. I wondered if this was because in hospital there was access to 24-hour support and nursing care. I made the following observation in my research diary after the second interview with Harry.

> *"Harry looked older and somehow frailer today. When I saw him in hospital, he was clean shaven and looked clean and really well. Today he looked a little rugged, sort of rough around the edges because he had sections of his facial hair that had grown longer and which he had missed shaving."*

[Field Notes 04/06/2014]

In Harry's case, it was facial hair, but with others it was different aspects of their personal appearance, un-hoovered carpets or dusty surfaces. For some, this is how they had always lived, but for others it represented clues that living independently was getting more difficult. Sometimes this was a case of not being able to do it anymore. But in some cases, it was also about not wanting to ask or not knowing where to go for help. When this was the case, hospital admission was often a signal that they needed social care and could no longer continue to live without help.

6.4.2. Negotiation and compromise to maintain independence

In some of these cases, carers had been offered by social work staff, but participants in the study had chosen to exercise their autonomy and self-determination, and this care had been refused.

> *"You see, when I came out of hospital this time, they said to me, 'You want a carer'. I says, 'I don't want a bloody carer…I can walk around and things like that…I have got a button on there…' [points at the lifeline]. I press that to say I am all up on the morning; like that, yes it is a good thing."*

> [Harry 04/06/2014 L174-177]

Participants refusing care was a particularly difficult situation when close family members felt that care was needed. Often, those who were able to manage without help were loath to give up their independence, despite the well-intentioned pressure placed on them to do so. However, simply saying that care was refused does not fully describe the level of compromise and negotiation that was required in this situation.

Harry felt strongly that he should cope alone while he could, and he was resolute in this, but he was also worried about burdening those he loved with his own needs. Despite being unyielding in his will to remain independent, Harry also found he worried about falling again and not being able to call for help. Compromise with his family had come in the form of his lifeline button, which he felt helped to maintain his safety.

> *"…I have got this band now [points to lifeline button attached to wrist], and I have got to press it and someone will come straight away, and now that stops me, you know, worrying about the things being up there [point to orange cord]…"*

> [Harry 16/04/2014 L52-56]

Nancy shared this view, but she was also prepared to compromise by considering a cleaner to help her out, if it meant she could maintain some of her independence. Often, where there was a difference of opinion

between the carer and the cared for, delicate negotiations were needed to reach a compromise.

6.4.3. Exercising autonomy with care services

For others, hospital admission had given them time to reflect on their deteriorating situation, and they had reluctantly agreed to a care package. This was the case for Elsie, who since being admitted to hospital had voiced her concern for the welfare of her husband, upon whom she was fully dependent for care. For her, the burden of worry she carried around had got too much, and she no longer felt Jack's own health was strong enough for him to look after them both. The subsequent spotlight on her home circumstances had meant that things were set to change quite dramatically when she was discharged.

> "…my son went on Monday and he transferred the bed from upstairs…they have bought that downstairs and changed my dining room…"

> [Elsie 13/03/2014 L29-31]

Given that such effort was being put into changing their living circumstances, when I visited for the second interview, I was surprised to see that there was no sign of a bed on the ground floor of the house. When I asked about this, Elsie and Jack told me that although Elsie's physical condition remained up and down, they had both got 'fed up' of the care system and the intrusion to their routine that came with it. Jack was now caring full time for his wife again. He told me about the overwhelming pressure he felt to have the carers when she was discharged.

> "Yeah, they just keep throwing that at us, didn't they? 'Yes, you have got to have carers'…have we? Yes!"

> [Jack (Elsie's husband) 25/04/2014 L133-134]

Elsie and Jack were not alone; Alan and his wife, Margaret, had also cancelled their newly initiated care services. For them this was down to the day-to-day variation in Alan's condition, which meant that his care needs

differed on a daily basis. The logistics of the care services were simply unable to respond flexibly to this.

> *"The trouble is, every day is different…so we can say early, but maybe another day, I would hate to think, I'd hate to think I have got to be up a certain time, I have got to be out, unlock that door for them to come…"*

> [Margaret 13/06/2014 L729-731]

This inflexibility and perceived intrusion on their lives had made them angry enough to cancel their service and complain. However, they both recognised that being together and having supportive friends afforded them this luxury, something that others could ill afford to do. They voiced their worry over those that were 'not quite so lucky' and acknowledged that for others options were more limited. For some people, cancelling services meant cutting off the lifeline that enabled them to stay at home and retain some independence. With no other help available to them, this was not an option.

6.4.4. Control, dignity, safety and risk: A delicate balance

Recognising their ongoing need for additional help and care outside of hospital was difficult for all of the participants to come to terms with. It was especially difficult for those that had not previously needed care services. In some cases, participants no longer needed hospital care, but their injuries from falling meant that there was medical concern for their safety and further falls were a particular risk. Desperate to go home, Wilfred was frustrated at the lack of control he had concerning his own discharge and the level of concern towards him shown by the hospital staff. His wife, Joyce, shared this concern and was anxious for him to accept help. I understood the concern from staff, but I also realised that from Wilfred's perspective this situation was compromising his dignity and compounding the erosion of his independence. Although his risk of falling had increased exponentially since the decline in his mobility (he had sustained four falls throughout the seven weeks they were in the study), he understood the risks of this and wanted to go home.

"Well, I am quite happy to have help, erm….as long as it is not too negative…erm since I have been in hospital here, erm they pick up that the fact that I have fallen, and they got terribly worried about it, and I got the impression with some of the nurses it makes such an impression on them that if it was left to them, I'd never walk a length again…"

[Wilfred 18/03/2014 L234-238]

Wilfred, like some of the other participants in the study, talked about not being allowed to do things until 'deemed safe' by hospital staff. While on one level they knew that this was sensible and for their own safety, I felt it definitely contributed in some way to the loss of freedom and dignity they felt. Annie was particularly frustrated at the lack of control she was able to exert even in her own home.

"The physiotherapists will not, they won't allow me to; they won't pass me as fit to go out yet…"

[Annie 30/07/2014 L91-92]

All these participants were deemed to no longer need acute hospital care and services, but they still needed additional help and therapies to improve their ability to manage more independently. As a result, on discharge they received a short-term intervention which is called an intermediate care package[20].

6.4.5. Anxiety and insecurity: Reflections on short-term care

With the help of an intermediate care package, discharge from hospital had been expedited for three participants. As part of this, they all received regular physiotherapy as well as getting carers to help them maintain their activities of daily living. However, it was the temporary nature of this service that was causing great anxiety.

When I arrived for the first interview with Clara, she had been at home for less than 24 hours. From the outset she was worried about how she was going to fund care if it was required beyond the time afforded to her by intermediate care package. During the interview she answered the

telephone to the Department for Work and Pensions (DWP), who she had contacted to find out information about funding future care.

Clara: "…I do not know what I can get. I ain't got a clue because nobody tells you…and I think that is wrong…I think people should tell you what you are entitled to. That's what the phone call today was. He is going to find out; he thinks my Disability Living Allowance should be reviewed and updated…because he thinks I am entitled to a bit more…I don't know…"

Louise: "Do you think that would help?"

Clara: "It would help at lot because I have to get care, after this team has gone then the money I get from the DLA will help me pay for whatever care I need, that's why…"

[Clara 27/02/2014 L263-274]

I found the telephone conversation difficult to experience because Clara was gasping for breath while trying to understand what financial help she might get. At one of the most challenging times of her life, Clara seemed to face an uphill struggle to ensure that essential daily care would continue to be provided beyond the six weeks.

The anxiety that this provoked in Clara was repeated in the experiences of other participants. They did not seem to have any idea what would happen once the care stopped. As their time in the study progressed and I interviewed them again, this anxiety became heightened as their time with intermediate care was running out. This led to an uncertainty which was overwhelming for some. It caused anxiety and fear over how they would manage if the service was withdrawn. They were completely reliant on the decisions made by the intermediate care services and subsequent support by social services as to whether the care would continue. This left some participants such as Clara feeling completely powerless. Even though they felt they needed care, there were no guarantees they would get it, and they were all too aware of this and the implications to their well-being if they did not receive it.

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6.4.6. Losing control: Reflections on long-term care

For many participants in the study, the reality was that they needed extra help at home and this was unlikely to change. Short-term care was no longer suitable, and they had to accept that this was the case. The previous chapter charted the many losses connected with frailty that are experienced by those who face dependency on provided care. However, that was only part of the story, and frail older people and their significant others face wide-ranging practical difficulties that come from living more permanently within the care system.

Despite trying to find innovative ways to maintain some independence, when living alone, the degree to which help was required was largely dependent on physical or cognitive ability. As ability waned, even those that had good support networks found themselves requiring additional help from social services, care agencies or private carers. In this instance, it seemed that individuals had little 'choice' but to accept it. At this point, they became powerless and described handing over control of some of the most intimate aspects of their lives to relative strangers.

Josie talked in earnest about the realities of receiving carers four times a day. Despite bearing the majority of the financial burden personally for her care, she was frustrated with the regimented nature of the home care system. For her, this often meant that she felt rushed to get out of bed in the morning or was left in bed too long, sometimes until mid-morning. On a daily basis, she had no idea what time the carers would arrive.

> *"I say to them in a morning when they are rushing me, 'Don't rush me, please', 'cause I get an hour in the morning, and I get half an hour at lunch time, I get half an hour at tea time and I get a quarter of an hour to put me to bed. Well, that is the only thing I don't like, and I will be honest with you is sometimes they put me to bed at eight o'clock, but they are not supposed to put me to bed till half past eight, twenty to nine…"*

> [Josie 04/03/2014 L275-280]

It was this very issue that had also been instrumental in driving Roy and his wife, Margaret, and Elsie and her husband, Jack, to cancel their care visits. Any autonomy that Josie felt she once had had been completely stripped away by the dependency her physical frailty had imposed upon her. Unlike the others, however, she felt there was little choice but to accept the system. Her circumstances dictated that she felt powerless and was unable to assert any control over the care she needed. Sadly, I also got the sense that she felt as though she should be grateful for the service she received.

Josie: *"I just have to accept it. I am silly really because I should say no, shouldn't I…?"*

Louise*:*   *"How do you think it would make you feel if you said no?"*

Josie: *"Guilty…"*

Louise: *"Guilty?"*

Josie: *"…Yes because they are doing me a favour by coming to put me to bed, aren't they?"*

[Josie 04/03/2014 L284-294]

Alan and his wife, Margaret, had asserted control and challenged the service they had received when it did not match their expectations. With this, they felt able to retain some of their independence and in doing so were able to preserve a sense of themselves. With Josie, such was her vulnerability and reliance on the care system, I could see that challenging poor standards of care was out of the question. She was afraid that in doing so it would affect her care, and as a result she felt unable to exercise any autonomy. As a result, she seemed to have lost some sense of herself.

Not everyone who received outside help was unhappy with the situation. Bert and his wife, Kathleen, felt that their experience had been altogether a more positive one.

"…we are having someone to come in a half hour each morning to get Bert up and to wash him and help him get dressed and help him

down the stairs, and they have been very good. We have been very
pleased with all the ones they have sent. Well, we are most
impressed with them; they have been lovely."

[Kathleen 13/05/2014 L841-845]

Bert and Kath just seemed to accept that they needed help, and they wanted to make the best of their situation. The relationship they had with their carers was important to them. This level of acceptance was also seen in other participants who had become dependent, but I got a real sense that they had to work hard to maintain these relationships.

Despite their overall feelings towards the system, all of those that were reliant on carers visiting felt a loss of control over their day-to-day lives. They were no longer able to autonomously decide when they got up in the morning, ate their meals or went to bed at night. Although they were given a time slot, carers often came late or early; on occasion, they didn't turn up at all. On many occasions, participants reported the arrival of someone different who they had never met before.

6.4.7. Adapting and adjusting to focus on the positive

All of the participants told me that they could never have envisaged a time when they would be so dependent on others for such personal care. Despite often adverse circumstances, participants tried to make the best of the situation they found themselves in. It seemed as though most of the time they had little choice but to accept what help they needed. As a result of the change in their circumstances, they were constantly being forced to modify what were acceptable levels of care to match their requirements.

On the whole, this was the first time many of the participants had experienced the care system. With so little previous experience of frailty for themselves or their loved ones, it was often difficult for participants to imagine what might come next. On occasion, the serial interview technique enabled me to see that some participants' deterioration in condition dictated that they had no choice but to consider care options that had once seemed inconceivable. Often 'choice' was not really a choice, and an individual's need had a real impact on what future care options were

available to them. For Josie, Jim and Wilfred, living in a nursing home was once beyond comprehension and was definitely not an option for them. Nevertheless, with their increasing care needs, it was now being considered as a real possibility, something that Norma, Jim's wife, dreaded.

> *"Splitting you up I suppose is the main thing, after 57 years of marriage. I am not saying it won't come if things get worse as I can't manage, but what they do now is try the best to keep you at home, don't they?…so that, I mean, if that's permanent then that is how it has got to be, but I think for what that fall he had, I think to be away from home eleven week, in my wildest dreams, I never…no…"*

> [Norma 05/09/2014 L135-143]

Adapting and adjusting to their care circumstances was a challenge. In contemplating the differences experienced by those in the study, it started to become clear that the relationships formed with carers was paramount to the experience that individuals had.

6.5. THE IMPORTANCE OF CARER RELATIONSHIPS

For the most part, Norma felt that the staff that came to care for her husband, Jim, did their best. They tried to manage the time they were given to visit the best they could, and she felt they were nice and caring. Over time, they, like many of the others, had built relationships with care staff that visited them on a regular basis. These relationships developed in importance over time and helped to ease the sense of loss that losing independence had brought. Although the system did not always work well, they were grateful for having them around when they needed them most.

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"…that morning when Jim fell when he was going in the hospital, we should have had two carers, and I don't know what had gone wrong; only one came and he had just fell…she stayed with me till the ambulance came, and it was gone nine when the paramedics came, and she sat with me until they put him in the ambulance, and so I cannot grumble on that. If they are going to be a bit late odd times, it is, as you say, give and take, i'n't [sic] it?"

[Norma 05/09/2014 L742-748]

However, on admission to hospital, care visits were immediately suspended before being cancelled if the length of stay was drawn out. As a result, those carers moved on to care for others, and when participants were discharged, this often meant getting used to new carers. For those who were being regularly admitted to hospital, this meant suffering the indignity of barely getting to know a new face before they delivered their most intimate personal care.

"…well, in fact, they told me we wouldn't be able to have the same care company, and I thought that were bad…they say after six week that they sever the contract; well, it is money for them, i'n't [sic] it? They are not getting money if Jim is in the hospital…"

[Norma 05/09/2014 L470-473]

This left those who experienced frequent admissions such as Norma and Jim unable to form any relationships with carers. When this was the case, the grief associated with the loss of independence was more apparent.

I was surprised to discover that this also affected the carers as well as the participants in the study. In some cases, relationships meant as much to those caring as to those that were receiving the care.

"…she comes in the morning, and she is ever so worried in case she does not get me back [when I leave hospital]. But she will, won't she?"

[Josie 04/03/2014 L229-231]

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When there was a good strong relationship between carers and those being cared for, it had a positive effect on the frail older person and facilitated acceptance of the dependency. These relationships, however, could also be fragile and under certain circumstances severed quite quickly. Those who experienced frequent changes in care staff were constantly reminded of this fact.

6.5.1. The value of charitable care arrangements

From time to time, participants talked about the value and importance of the information and support they had received from charitable organisations. This was particularly important in the form of day centres and lunch clubs. For participants such as Brenda and Jim, who would otherwise be completely isolated and housebound, they were a lifeline. Annie also recognised their value and was trying to locate some services in her area.

Both Jim and Norma described a very supportive local organisation that ran a lunch club that collected them from the house and dropped them off. For a very reasonable price, they got their lunch and it was a chance for them to socialise together. Someone had visited Jim in hospital when Norma went away, and they felt that they got a lot of useful information from others in similar circumstances.

> *"I think without the day centre and things [the lunch club], they would be long weeks and long days when you don't quite know…"*
>
> [Norma 18/06/2014 L793-794]

Without doubt, Jim's cognitive impairment meant that Norma took a large proportion of the burden of looking after him. It occurred to me that the importance of the charitable organisation that she was using cannot be underestimated. It gave her some freedom each week to be herself and maintain an identity that was not just as Jim's carer; to her this was invaluable. While relationships with significant others are of importance to those with frailty, so are those in a wider network. In Jim and Norma's case, these relationships were able to create a sense of normality, of keeping going. While many things were changing in their lives they, like

many in the study, used whatever resources were available to them to anchor themselves and retain continuity. They wanted to live well for as long as possible.

6.5.2. Facing reliance and dependence on the emergency services

From time to time, the need for help with care for some participants was immediate and urgent. Usually this was as a result of a fall which rendered them unable to get up unaided. As a result of this, participants had little choice but to request help from the emergency ambulance service.

For Mary, this had been a one-off, but it just did not sit comfortably with her and her daughter Stella.

> *"I knew I could not get my mother in the car, you see; otherwise I would have just took her. If I could have got her in the car, I would have just bought her down to casualty. I was worried that it had fractured, but because I couldn't physically get her in the car. I know it was not right to ring 999; I needed to get her here."*

> [Stella 08/05/2014 L21-25]

Despite not being able to move due to unbearable pain radiating from her hip, Mary was upset that her only option was to rely on the emergency services. She was anxious that she might be burdening the service and taking it away from someone who really needed it. She was not alone in this thought. Wilfred and his wife, Joyce, also talked about the indignity of having to rely on the ambulance service to get him up every time he fell.

> *"…the ambulance crews have been, well, I have completely lost count over the years, because you have had blackouts before…we have had ambulance crews out so many times…"*

> [Joyce 02/05/2014 L771-773]

Neither Mary and Stella nor Wilfred and Joyce liked the idea that there was no alternative to an emergency ambulance to help them. Wilfred in particular faced a lengthy negotiation each time with the ambulance service, who often insisted he was taken to hospital. This mostly resulted in

four hours in the emergency department before being sent home again. I knew, from spending time with them, that they recognised that there was little alternative, but this increasing dependence on what they understood to be an 'emergency service' did not sit comfortably with them at all.

6.6. THE FINANCIAL BURDEN OF CARE

Four of the people in the study were fully dependent on state welfare to pay for their essential care services. When this was the case, the financial burden of care was not a focal point during the interviews and often only received a cursory mention. In direct contrast to this, the other eight who received care bore all or some of the financial contribution, and feelings about this differed greatly.

It was very clear from the outset that Pamela and her husband were able to make choices about their care based on their financial position. She talked about this a lot, but it was not as straightforward as just paying for the care to maintain their independence.

> *"…I have already spoken to our financial advisor and our accountants to find out the best way of funding basically and trying to anticipate how much we shall need and how long we have got, because of course that has an impact…"*
>
> [Pamela 12/05/2014 L443-449]

Pamela was not alone, and those that had money to pay for their care were also able to employ a more bespoke service. However, finding the carers willing to undertake such a service was a challenge, especially in more rural areas where care services were less prevalent. Although empowered to act independently to take care of their care needs, this was undermined by uncertainty about the future. Working out the long-term possibilities of this was a worry and as a result negated any sense of well-being from the initial control that had been gained from having financial security.

Others also resented having to pay for basic care needs when they had 'worked hard all their lives'. It was particularly difficult for them knowing that others got their care services without having to contribute.

"Well, because I have saved all my life, and you don't like to see it frittered away, do you?...I mean, I had a good job and I have plenty of savings and so really I can't rely on the state for anything because they say I am not eligible, you see. Some of them swing it though, don't they?"

[Annie 30/07/2014 L375-378]

Paying for care presented a burden financially for those with the means to do so, but on face value, this appeared to give autonomy and choice. However, in reality this bought about a burden of worry which was not altogether different from those that were unable to finance their care.

6.6.1. Media spotlight on poor care and its effects

During the course of the study, there were a number of high-profile cases reported in the media regarding poor care in nursing and residential homes. In one interview in particular, with Wilfred and his wife, Joyce, the effects of this were raised following a rather distressing Panorama[28] programme the previous evening. The programme had presented evidence of abuse and other distressing findings from an undercover operation in a nursing home.

"Yes and of course what you don't see is the good side; there are very many good places, that's the, you know. I think it tends to frighten everybody off the whole idea and but it does do that, it does frighten you off…undoubtedly."

[Joyce 02/05/2014 L250-252]

This was particularly pertinent to them as Wilfred's physical deterioration had meant that they needed to look at the options for long-term care available to them. Others in the study also raised aspects of poor care that had been reported in the media.

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[28] Panorama is a BBC Television current affairs documentary programme.

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Watching programmes like this at any time is distressing, but being exposed to this when living with frailty compounded the fear and reinforced the stereotypes of becoming completely dependent on care and care services. Although participants reported trying to ignore this, it was clear that for those fighting to maintain some sense of normality amid change and uncertainty, this was challenging.

6.7. THE CHANGING FACES OF HEALTH SERVICE DELIVERY

Throughout their lives, all the participants had seen an enormous amount of change in the way healthcare is delivered. They were all born before a time when healthcare was free at the point of delivery and the inception of the NHS, but it was the change in the way GP services were delivered that was cited most.

Eight of the participants felt that they no longer had the same relationship with their GP that they had once had. Over recent years, Harry told me that he never got to see the same doctor twice. In general, this had affected his motivation for seeking help and the trust he had in the service.

> *"I mean, I am not sure if is me or what, but I don't see why you see one doctor and the next time another doctor and the next… I don't like that that. I like to stick with one. Like my doctor did with me when I had my first stroke, fantastic he was, but he is getting old and there's someone else now…I know he has all my records like, but you don't know, they are not the same people to me…*
>
> *"When I had my first stroke, he looked at me and he said 'Do this' and 'Don't do this and that; keep going, Harry, for Christ's sake', and he was good, he was…"*

> [Harry 16/04/2014 L384-388 and L398-399]

In particular, he noted the encouragement he had received from his family doctor after his stroke many years previously. He even thought that his encouraging words had been instrumental in helping him recover, and he mused over whether doctors now had enough time for each patient.

> *"I don't believe that ten minutes is enough for you to speak to a doctor; they have not got time. To me they haven't got time to look at you and say how you going on; they haven't got time…that is a big thing."*

<div align="right">

[Harry 16/04/2014 L415-417]

</div>

Bert, on the other hand, felt that he was lucky with his GP, and as a result he had recently changed surgery to be with the same one. Although he often had to wait longer to see his own doctor, he was happy to do so and felt lucky that he had such a good relationship.

> *"I have got a splendid doctor, which is very much a rarity these days; instead of sitting at his computer and fiddling with the keyboard, he actually looks at you and listens to you."*

<div align="right">

[Bert 13/05/2014 L44-46]

</div>

In addition to this, Bert and his wife, Kathleen, felt that to a certain extent they could control the way health carers behaved towards them with their own actions. The relationship they had built up over the years with Bert's GP in particular was an example of this.

> *"No, we have been fine. It's been fine because we are very, well, we are used to being hospitable, and, you know, you make them a cup of tea if they want a cup of tea, and you let them get on with it. So they have been very good, very good."*

<div align="right">

[Kathleen 13/05/2014 L852-855]

</div>

Rose gave a similar story and felt that her doctor, who she had known a long time, looked after her well. In direct contrast to this, Jim had recently been assigned a new GP, and despite not knowing her long, his wife, Norma, was feeling very supported. They had recently been told that Jim's rapid decline in condition meant that he would now see the same doctor each time and that she would come to the house.

6.7.1. Paternalism: 'Dr knows best'

Some participants found it really difficult talk to their GP and the doctors at the hospital. They, really felt the changing times when it came to their medical care and talked about being brought up in a time when you 'didn't bother' the doctor with your worries unless they were really serious. This was the first time that I had realised that their worry about being a burden also extended to medical professionals. Elsie still felt that she did not have the right to question what they were discussing at the bottom of her bed during her latest admission.

Elsie: *"It's just a shock to the system when they're standing at the bottom of the bed discussing things, and I want to know what they are discussing, which is never going to be possible anyway, is it?"*

Louise: *"Why not, do you think?"*

Elsie: *"Because that is the way it has always been… I don't know, I don't seem as if I can converse, convey to them how I feel…because some of them are all right. But you do not always know if they think you are malingering, but it is up there that is thinking that [points to her head] not reality…But I give an opinion that I am more confident than I am."*

[Elsie 13/03/2014 L138-145]

Overall, Elsie did seem to be a confident person, and I was surprised when she told me it made her feel that way. She just felt that the culture was different back then; you didn't question the medical profession. It seemed that her upbringing, in a time when the nature of medicine was more paternalistic, had a huge impact on how she viewed the doctors and other hospital staff. It also affected how she communicated with them, and I wondered about the potential for this to undermine her future care and that of others. These paternalistic notions that were also shared by other participants almost certainly had an effect on how participants interacted with healthcare professionals. In some cases, it had the potential to undermine any level of autonomy they have over healthcare choices.

6.7.2. The importance of information and communication

Overall, participants felt that communication in general with healthcare professionals could be improved. This was especially true in hospital when being seen and cared for by so many different doctors and healthcare professionals. It was common that they felt they had to ask rather than the information being more readily available.

> *"Nobody has ever sought, apart from that Friday night, Saturday morning nobody has ever sought; no doctor has ever asked to see us. It was always us having to go and ask."*
>
> [Stella 08/05/2014 L374-376]

Mary's daughter Stella often felt as though she was bothering staff, but she was prepared to ask on behalf of her mother, who she knew would not be so forthright. Mary worried about other patients who may not have others like her daughter to advocate on their behalf. She questioned if it may affect the care they received.

> *"…and that is the worrying thing that you have said that some of these old ladies never had anybody come to see them…in that sort of situation, what happens to them?"*
>
> [Stella 08/05/2014 L963-965]

In some instances, participants felt that the way information was delivered had a bearing on how it was received. This was not always positive and had the potential to be very upsetting.

> *"…there was one doctor, a lady doctor, who wasn't as diplomatic as she might have been, most brisk and you almost don't want to hear it, if you know what I mean, but it all depends how it is put over…"*
>
> [Pamela 12/05/2014 L217-220]

Although this was upsetting, for the most part, I got the impression that participants were just frustrated about the lack of forthcoming information

about their overall condition. When this was delivered in a negative way, it was often only isolated individuals that were responsible.

At times throughout the study, I found that participants would not remember me despite meeting me on a number of occasions prior to interview. I did wonder if this was the same with the medical professionals and information which had been given but not recalled. I also found myself wondering if, as I had witnessed in clinical practice, the healthcare professionals themselves felt that they had told the participants the information, but it was not accessible or understood. Regardless of the reason, the general lack of information that patients experienced receiving was an issue for many.

6.8. THE OVERARCHING PICTURE OF CARE

Generally, when frailty began to manifest and subsequently deteriorate, participants in the study were faced with increasing numbers of interactions from many different healthcare professionals and carers. They often remarked over this and the confusion it caused, and it was especially difficult for those with some elements of cognitive decline. On arrival to one interview with Jim and his wife, Norma, they had mistaken me for a carer who had arrived early.

> *"At the minute he has come home, we have people coming in to look after him four times a day. It is like we have not got any time [laughs]; fancy me thinking you were the carer. I mean, I must have dozed…"*

[Norma 05/09/2014 L464-466]

Moreover, Annie was very confused about all the services she received and where they came from. This was a problem because she needed to contact them and did not know how. I later found out that she did have the information, but it was in the form of a large stack of papers which sat neatly next to the television. On request, I passed her the papers; she looked through them a couple of times before becoming frustrated and tearful and put them down again.

Annie seemed to have many questions about her care; she was also looking for something to help while away the lonely hours she spent at home. Despite the many health professionals and carers that visited her, she didn't know who to ask. Clara was in a similar situation, and it occurred to me that there was nobody with an overview of her care, no single point of contact that she could speak to. She, too, was being visited by multi-professional agencies but it seemed as though they were only looking at the element of her care that was most pertinent to them.

Elsie, on the other hand, told me about the community matron that visited her from time to time.

> "I have got a community matron coming, and I am going to discuss with him, because…I don't like the confusion so much that you get from all the tablets…"
>
> "…he is lovely; I have got a lot of trust in him, and he has been away on holiday, and he's coming on May 1st, so I shall explain to him. He does all the blood tests and things like that, takes my blood pressure."
>
> [Elsie 25/04/2014 L40-42 and L58-60]

He was a single point of contact for her and her husband, Jack. He had assisted her in the past with getting help, and she felt confident that he would help her with her recent predicament. He made things easier for her to negotiate the care she needed, and on occasion even advocated on her behalf for other services she required.

6.9. CHAPTER SUMMARY

This chapter highlights what it is like to negotiate the complexities of the care system and demonstrates that in many cases as dependency grows so does reliance on support systems. What would once have been deemed an unacceptable way of living had become the norm.

The chapter goes on to highlight the importance of relationships with carers, healthcare staff and organisations in maintaining continuity as participants adapted and adjusted to change. Where strong relationships

existed, participants were able to maintain some sense of self and retain some sense of autonomy. Conversely, where relationships didn't exist, participants found it difficult to retain their voice in decision making and the care they received.

In most circumstances, with frailty also comes old age. Throughout their lives, most people in this study had seen vast amounts of change in the way healthcare is delivered. One significant change is the demise of paternalism and the rise of a partnership-centred approach to care services. As demand on services has increased, changes in delivery have resulted in frail older people often not knowing who to ask for help or being reluctant to ask at all.

This chapter demonstrates that for some participants, the care system offers a lifeline that they couldn't exist without. However, they struggle at times to assert control over a system that appears to offer little flexibility. It is this very dependency and reliance on others that undermines the autonomy needed to make decisions relating to future wishes and preferences, yet promotion of autonomy underpins the framework that is central to current ACP policy.

CHAPTER 7. PLANNING FOR THE FUTURE

7.1. INTRODUCTION

One of the main objectives of the study was to explore the expectations, experiences and understandings of frail older people and their significant others of planning for future care. This chapter looks at and reflects many of those discussions, starting with how the frail older people and their significant others in the study perceive and relate to their future. It goes on to perceptions relating to making plans for the future and future care. This is followed by how participants' value planning when faced with uncertainty. Latterly, this chapter also addresses the worry that is associated with incapacity and how this may affect any decisions that are made in relation to the future.

Throughout the study, none of the participants mentioned ACP by name. However, some participants had considered or undertaken the more formal outcomes of ACP by appointing Lasting Powers of Attorney (LPA) for health and welfare. Many also talked about the plans they had made regarding their death. In all but one of these instances, this had been done by the participants alongside their family or significant others. Many had not consulted health professionals and for the most part wondered what health professionals may be able to contribute to this process.

Without doubt, the uncertainty surrounding physical and psychosocial change lays down a challenge to those with progressive frailty. This was reflected in participants' conceptualisations of the future and thoughts about planning for their care during this time. Only two participants in the study had been exposed to real-time conversations with healthcare professionals regarding 'do not attempt cardiopulmonary resuscitation' (DNACPR) and withdrawal of treatment. Both cases are represented here and describe the emotions that were experienced at this time. They also expose the legacy that these experiences have left behind.

Current policy and best-practice guidance highlights the importance of planning future care for those with frailty. This chapter provides an insight into just how difficult this concept may be to achieve with frail older people.

7.2. TALKING ABOUT A FUTURE WITH UNCERTAINTY

While some participants were reluctant to talk about their future, others were more open to discussing what the future meant to them. For all the participants, the future represented an uncertainty in their lives that they coped with in many different ways. Throughout the study, some found it easier than others to share the thoughts and feelings that living with uncertainty bought about.

Alan's recent illness had led to his increasing frailty and meant that now, more than ever, he and his wife, Margaret, felt that they did not know what the future held for them. Alan's breathlessness had come on rapidly, and they had been surprised by how much it had affected their lives. Neither of them could have imagined living with a severe unexpected and debilitating illness. Alan's dependency had made him vulnerable, and both he and Margaret realised that predicting the future and planning for this was impossible. As a result, they had stopped thinking about tomorrow and began concentrating on one day at a time.

Alan*:*   *"Well…we don't really talk about the future if you like. There is not a lot we can do about it; we are living it now."*

Margaret: *"The future really is today; we are not thinking about tomorrow…right, as long as our bills are paid, we are not worried about tomorrow; if one of us goes, that is it."*

[Alan and Margaret 13/06/2014 L348-353]

7.2.1. The future is today: Maintaining continuity

The concept of not thinking about tomorrow and living for today was also described by many other participants in the study. It was a way of maintaining continuity in their lives through the adversities that living with frailty had bought about. Elsie and Jack felt that addressing the future meant worry, and this undermined their current desire to live well and stay positive.

Elsie: *"I mean, all this having plans for the future in your old age; you would never live if you had got to live like that…"*

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Jack: *"No, you wouldn't."*

Elsie: *"You wouldn't because if you are going to worry what am I going to do tomorrow, what am I going to do tomorrow?"*

Jack: *"That is why we say live one day at a time. I will never forget old Arthur next door. He was older than me, and he used to say don't worry about anything; it is no good…nothing to worry about now."*

[Elsie and Jack 25/04/2014 L391-396]

Harry was also reluctant to talk about the future. He wanted to concentrate on living well for today and like others in the study felt that he just wanted to keep going. He was aware of the uncertainty in his future and worried that he might learn something that he didn't want to know. I got the sense that this undermined his desire to carry on for as long as possible and stay positive.

"No [laughs], oh no that, you know, dying, I am not bloody bothered about dying. I want to carry on; that is the main thing, you know what I mean."

"…well, I don't want them to tell me that I might go tomorrow; well, they don't know, do they?"

[Harry 04/06/2014 L77-78 and L99-100]

Contemplating beyond the day to day was not something that Harry wanted to face in any in-depth discussion with me. He knew that his age and physical condition meant that he was closer to death than most. It seemed that the uncertainty he faced in relation to his frailty and current condition was such that looking further ahead than the day to day was a challenge.

7.2.2. There is no future

Although uncertain about what the future may hold, many others, like Harry, were also open and honest about how their age and current health status dictated their proximity to death. Bert's reaction in particular

captured how some felt and prompted the following reflection in my research diary.

> *"Interestingly, when I told Bert about the study and mentioned 'future care', he laughed. I was taken aback by his honesty as he told me to be careful how I used the term future. At 90 years old, there was probably less 'future' to be had".*

> [Field notes 13/05/2014]

Bert felt his proximity to death. He, like some of the others, seemed to have reached acceptance that this was the case. He didn't seem unduly distressed and was even happy to joke and talk about it open and honestly. Others, like Rose, had also reached acceptance that this was the case and understood all too well the position they were in.

Rose: *"Well, I do [think about the future], and I think I have not got much longer to live…"*

Louise: *"Does that worry you?"*

Rose: *"Well, I do not like to think about it…"*

> [Rose 30/04/2014 L379-383]

Although she didn't seem unduly concerned when she told me this, Rose didn't like to think about what might happen. She did not like to confront the uncertainty she faced. Like Bert, Rose was well into her tenth decade. It seemed as though they were both happy that their lives were complete, enabling them to be philosophical about their proximity to death.

Not all participants felt this way; Clara was one such participant, and she felt very differently. She didn't see a future for herself and was upset that her life may be over so soon. The first time I met her, she was optimistic about the future. It was only after she did not seem to be getting any better that she began to lose hope.

> *"I don't think I have got a future; I don't think I have got one, love…it don't bother me dying. Don't get me wrong; I am not*

bothered. I am just not; whether I am giving up or not, I just don't know, but I just don't care… [becomes very tearful]. It does make me feel teary now and again, you know, but…"

[Clara 01/04/2014 L358-362]

Clara really could not see beyond her current illness and related frailty. As time passed and she was unable to recover her previous fitness, she became reflective about the things she may never get to do in her life. She was worried that this period of illness was not just temporary, and she was beginning to lose hope of a return to her former self.

"No, just when I talk about it…when I talk about it, it upsets me, but then again, it is going to, isn't it?…I had so much that I wanted to do, love…I suppose I could still do it, but like I say, it [my illness] is stopping me…"

[Clara 01/04/2014 L365-367]

This really did set her apart from the others, and I wondered if this was related to age as Clara was still only 70 years old. While Rose and Bert seemed to have reached a point in their lives where they had come to terms with their impending death, Clara was unable to come to terms with some aspects of her life. She still felt as though there were things that she wanted to achieve, and she was finding it difficult to accept her limited future. Her former self was rapidly disappearing, and despite her best efforts, she could not control the decline.

It felt as though Clara had begun to question the very foundations of her life. She was isolated and alone much of the time, and she could not make sense of what was happening to her. Without any help and support, recent events had engendered an existential crisis for Clara. She was unable to see beyond the present day, was giving up hope and had begun to give up on her life.

7.3. MAKING FUTURE PLANS

Throughout the study, participants talked about planning and making plans in various ways. Nobody mentioned ACP by name, but they did refer to

some of the more formal outcomes of the practice of ACP. None of these had been done with the help of healthcare professions.

Without formalising them as future plans or writing them down, participants talked about the conscious decisions they had previously made. They had done this with their future health in mind or for when their circumstances changed. They felt that now was the time they had been planning for. Bert and his wife, Kathleen, had once been keen dog lovers, but they had actively chosen not to have dogs in old age as they felt that there may come a time when they were unable to look after them.

"Well, we lost the last one [dog] 15 years ago, and we did not have another. We were worried then with his walking, but Bert said 'Have a little dog, Kath', and I suppose we would have done, but we were frightened he would trip over a little dog, and we had always been used to big dogs anyway, so we didn't; it was hard to start with because I longed for another one, although it would be difficult now."

[Kathleen 13/05/2014 L524-529]

Bert and Kath had also thought about moving house, but they never 'got around to it'. Given Bert's deterioration in health, this gave them both a sense of regret as he was now too unwell to undertake such upheaval. Wilfred and his wife, Joyce, shared a similar story with me.

"…we did in the past talk about moving to something smaller, but we have rather tended to fall back on the well, we are all right at the moment, which you do and then, you know...I used to say yes but we ought to make the decision while we are all right and that they are our decisions and not somebody else's, but there were lots of reasons why we didn't, and they were perfectly legitimate ones. I still think about it sometimes, but it would be too much to cope with now…"

[Joyce 02/05/2014 L661-668]

When his wife had been alive, Harry told me that they had thought about their future together. Moving into the retirement village where he now lived

had been the realisation of their planning, but sadly she had died soon after moving in. It was a decision that he was pleased they had made together, especially as many of their friends had died, and younger people were moving into the area that had once been their family home. He was sure that the move had been instrumental in his ability to remain independent since the death of his wife.

> "…living here is fantastic, but if I was at my old house, I would not be able to do what I do now, and people talk to me as though there is no tomorrow…they are fantastic, the people here, and they are fantastic."

> [Harry 04/06/2014 L454-457]

Although not formalised in writing, realising the plan to move to the retirement village had been positive for Harry. He gave me a sense that he was organised and now there was nothing left to plan for. On the other hand, having not realised their plans, Bert and Kath, and Wilfred and Joyce, gave me a sense that now they were too unwell; it was too late to plan for the future.

7.3.1. The value of planning for uncertainty

Living with uncertainty meant that many participants struggled to define what they may be planning for in the foreseeable future. With no tangible idea of where their journey on the continuum of frailty was headed, they really struggled to identify what value, if any, that planning for this time could bring to their lives. Rapid change meant that their day-to-day existence was unpredictable, and in most instances, it was difficult to know what would happen next with their health and cognition.

This uncertainty led to some questioning of what exactly they were supposed to be planning for.

> "I mean you might be able to plan for something if you knew exactly what was going to happen, but as you don't know what form the problem will take, you cannot think too much about it."

> [Joyce (Wilfred's wife) 02/05/2014 L282-284]

7.3.2. Planning for death

Throughout the study, life continued for those living with frailty, and many participants found that projecting forward was impossible. However, whereas participants had struggled to articulate what may happen in the future, many were able to talk articulately about the plans they had made upon death. In total, eleven out of the sixteen frail older participants had made arrangements for their financial affairs and written a will. Many had also planned their funeral.

Although not a pleasant task, Elsie and Jack felt that, given their age, it was essential to put their finances in order.

Jack: *"Well we have solved one thing. We haven't got to worry about if anything happens to any of us; we have got that [the funeral and wills] sorted, haven't we?"*

Elsie: *"And that is a horrible experience."*

Jack: *"It is a horrible experience."*

Elsie: *"But I am glad it is done, and we have not got to worry about it."*

[Elsie and Jack 25/04/2014 L440-447]

Despite the chaos and uncertainty of Elsie's condition, this was something that Elsie and Jack felt they had at least some control over. They were not alone, and for most, this aspect of planning for death was familiar to them. This was something that participants had seen their parents do and felt an expectation that they would not leave a negative legacy regarding their finances for their significant others.

"I do not want kids arguing over it and things like that…the house will be shared between the two sons 50/50 right down the middle…and er my son asked me if I would be more specific than that, and he wanted with all my sons, my two sons and his wife's; it would have made it so I have to divide into seven, you see, but I never felt free to do that. Erm if people want to argue about it then,

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that is up to them…but as far as I am concerned, I don't want that sort of thing…"

Throughout the study, I got an overwhelming sense that participants could continue to protect their family by not burdening them with outstanding financial affairs. They were keen to promote the future independence of their closest family members. There was a certainty in death that did not exist in their current lives. At a time when they felt so little control, this seemed to be a way of asserting themselves and making sure that their loved ones would be protected when they died.

Alan was keen to sort his affairs out and leave instructions for his family, but I could see that he felt burdened by the effect his wishes may have on them. With the diminishing cognitive ability of her mother, Maud, Sheila really wanted to understand what was important to her when she died. Yet this had become a burden to her, given their complicated family circumstances.

> *"I have talked to her about funeral plans, and I said to her two or three times I have asked her just in case I have got it wrong; she has got two graves, you see. She has got one with my dad and her aunty…her new husband [Albert] and his first wife…she wants to go with Albert…"*

Maud had been very clear with her daughter, but I could see how much this upset Sheila. She was devastated that her mother would not be buried next to her father but had little choice but to accept it.

Kath had previously told me, when interviewed with her husband, Bert, that they were not people who planned. But just before he died, Bert had prepared a folder for their son with all the information that was needed to help with the household finances and funeral plans. He had told Kath about the folder a few days before his last trip to hospital, which had ended in his death.

"…so that was his folder, but he had got everything organised ready for my son to tell him what to do."

[Kath 06/08/2014 L653-654]

Kath was learning to cope one day at a time without Bert, who she had been married to for 60 years. It was a great comfort to her to know that he had been so thoughtful before he died in his preparations to protect her as far as he could after his death. Like Bert, many of the participants in the study did not want to burden their families with having to deal with their affairs after their death. Others felt the burden of making sure the decisions they made on behalf of their family were the right ones.

7.3.3. The cost of death: Financial and ethical dilemmas

Participants who had sought legal advice were overwhelmed by the cost of planning for death. Writing a legal will and seeking LPA via a solicitor is expensive. For Maud's daughter Sheila, her mum's diminishing capacity had given rise to a race against time to ensure that they could manage her affairs more effectively. This in turn had led to anxiety within the family of who should bear the brunt of this cost.

"You know to get the, erm we need a letter from the doctor to get the original copy from the solicitor…and it needs to go to court and it is all expense though. If the solicitor do it for you, it's £380 plus £100 for the court, and so I said can we go straight to the court and that £100 so you know…That is a big expense…I might take it out of mum's money… Because it was me and my brother that paid for it last time [when undertaking LPA for finances]."

[Sheila 21/07/2014 L475-491]

Others had found the financial burden of planning for the event of death a barrier, and although Clara tried to remain optimistic, she did not know how she was going to make it happen.

"I can't afford to go through a solicitor [to write a will]. I know I have got to I think it is £130 or £150; you have got to register to do it. That I don't mind…and then whoever does it then give them a bit

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of money that way. I can't afford thousands of pounds with a solicitor…I haven't got it…"

For Clara, this was yet another thing that with her diminishing physical condition she could not do. Even those with the finances to pay were left questioning the ethics of this for something that was an inevitable necessity.

7.3.4. Planning for life: Maintaining hope

Despite their obvious physical and cognitive frailty, a number of participants were making plans that were focused on having something to look forward to. Planning holidays were common, and Annie was contemplating trying again despite a recent disastrous holiday.

"…I am starting to sort of look in the adverts, singles holidays, you know; I wouldn't go on my own without a company again because I tried it in Scotland, and as I say it was a disaster…"

"No, we never thought about that [future care]…we were still thinking about holidays, I think…"

[Annie 25/06/2014 L256-258 and L482-483]

I wasn't sure if Annie really believed that going on holiday was possible, but it was something that was important to her. She, like many other participants, needed something to live for. This had not changed from when her husband was alive and she was much younger.

Even those that could not leave the house as such were focused on celebrating personal milestones like anniversaries.

Norma: *"Yes, it how it is…I mean 57 years together; it is a long time, isn't it?…"*

Jim: *"In other words, we are all right, me duck."*

Norma: *"We are looking forward to 60, aren't we?"*

Jim: *"Yes."*

Many of the participants tried as far as possible to carry on as normal. They tried to adapt to the circumstances that they found themselves in regarding their health, and planning for the future was no exception. With all the difficulties they faced as a result of their frailty, they really needed to concentrate on remaining motivated, nourishing both purpose and hope.

> *"…because you have got to have something to look forward to, isn't it?"*

Planning to do things in the future was their way of doing this. It was a way of maintaining continuity with their previous lives and retaining a sense of self during a time when their personal identity was under threat.

7.4.   PLANNING FOR FUTURE CARE

For many in the study, living with frailty meant living with constant change and adaptation to the circumstances that their diminishing physical and cognitive ability dictated. Adapting to these challenging circumstances led some people in the study to question the value of making plans for their future care.

> *"Well, there is no point because whatever we decide may turn out to mean absolutely nothing when the time comes…"*

An individual's constant appraisal and change of their care needs meant that they were faced with choices that they did not want to make.

Norma: *"I am not saying Jim will never have to go into a care home; we don't know…but at the minute…"*

Jim: *"I hope not."*

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Norma: *"Well, we do hope not, but who knows? We don't know that, do we? If I took ill or got a bit, you know, less able…we will see…"*

[Jim and Norma 05/09/2014 L420-421]

For some, there simply was not a choice; their physical needs dictated what care they needed. Despite being desperate to take control of their situation, in many cases it was this physical dimension of care, rather than personal choice, which would dictate future care. Bert recognised this and felt that he had little autonomy in future planning; his fate was mainly related to his physical need and his dependency on others.

In some cases, participants had experience of significant others whose plans had not been followed. Elsie told me that she had nursed her mother until she died. She was angry that despite her mother having been clear about what she wanted to happen, none of her wishes were followed. As a result, she questioned the value of planning.

"Well, if I could say about the past when my mother passed away, it was just as though all hell had been let loose, and she had prepared everything, but unfortunately her wishes were not carried out…"

[Elsie 25/04/2014 L428-430]

This negative experience had been down to family members who were unaware of her wishes. Elsie felt that by discussing things with her son directly she could avoid this for herself and Jack.

"Well, it is a case with us that we have done it so that everything is straightforward; my son knows everything that we want doing and that is the end of it. It is like I say; we get on with the next day…"

[Elsie 25/04/2014 L457-459]

This, however, was the extent of any conversation Elsie and Jack had with their son. They did not like to dwell on conversations regarding the future.

7.4.1. Acknowledging the burden of loss

Elsie and her husband, Jack, were worried about losing each other, and talking about it only served to make it more real. For their own self-preservation and fear of burdening one another, this was something they just did not talk about.

Elsie: *"It is the parting that would be terrible."*

Jack: *"That is the worst part…"*

Elsie: *"You see, we don't talk about these things because it is a depressing thought. If you are feeling happy, that is all that matters to us, what will be, will be qué será, será, you cannot do anything about it…"*

[Elsie 25/04/2014 L660-667]

Having difficulty talking about the future with a spouse was common in the study. Although Bert and Kath were able to be open with me about the future, the care they might need and their own death, they had not discussed it with each other. Burdening each other with discussions about a future where loss was inevitable was a prospect that held no appeal to those in the study.

"We have never planned or discussed…what will happen when one of us dies or how we will cope with it or what we will do; we just accept that this is going to happen one day, inevitably, and when it does, then we or I or she will decide what to do."

[Bert 15/05/2014 L989-992]

For some, contemplating their own future care also meant acknowledging painful memories of loss from the not-too-distant past. It was really important to Nancy to stay in her own home and then to die at home, but talking about this meant recalling painful memories of her husband's death.

"I would rather stay here and then die here in my own home…well, Bill didn't quite die here, but he practically did [became tearful]

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because they took him to the hospital and they rang up to say he was dead…"

Reflecting on the death of her husband, Nancy told me that although she thought they may have had conversations, she could not really remember much about them.

"Not really, I used to, I suppose we did sometimes. I can't really remember so much about it…"

For Harry, talking about his own care also bought back painful memories of his wife's death. He had decided that he didn't want to talk to his daughters about any of these issues. He felt sure that they would know what was important to him. It was just another burden that a father should not place on his daughters, no matter how frail and old he had become.

"…they will do that [arrange my cremation]…they will know what to do."

Pamela did not want to talk to her husband about the future. However, this was a worry because she was not confident that her husband would know what was important to her, if she were unable to make her own decisions.

"…if he could make the decisions for me… [whispers] I don't know…I really don't know…because we are very, our views are very opposite I think…"

Pamela was all too aware that her husband would not be around forever. She had no idea who might die first and felt it important to plan something for either scenario. I found it interesting that she had not discussed this with him or anybody else. She didn't feel able to open the conversation

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with him directly, and she didn't think it was anybody else's business. She was resolute in her need not to appear vulnerable. She had always been independent, and in planning for her future, things would not be any different.

Some participants in the study had tried to broach the subject of the future with their family. Rose had tried to talk to her daughter but had been closed down.

> *"Well, if I do [try to talk to my daughter], she says that there are loads of people worse that you, Mum…lots of people older than you…"*

> [Rose 30/04/2014 L377-388]

The many physical, emotional, psychological and social adversities that Rose was experiencing meant that, from time to time, she needed to seek reassurance about her future. In replying the way she did, it seemed Rose's daughter was socially comparing her to others worse off.

For the most part, those that chose not to talk to their family did so because they did not want to burden them. Like many other aspects of their frailty, becoming a burden to others was something that they feared.

7.5. THE WORRY OF FUTURE INCAPACITY

On the whole, participants were worried about their 'mind going'. Stanley accepted that old age was something that he was unable to control, but he was worried about 'losing his mind'.

> *"Yes, it is one of them things; we all get older. As long as my mind doesn't go, that's a big worry."*

> *"Well, you cannot look after yourself [if you lose your mind], and they put you in a [nursing] home and people have got to do things for you; I know some very intelligent people who have gone down like that."*

> [Stanley 24/07/2014 L323-325 and L329-331]

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Stanley was very perceptive; he acknowledged it could just as easily happen to him. Like others in the study, Harry realised that 'losing his mind' was not limited to certain people and could happen anyone.

For participants, 'losing their mind' represented a situation that they may well be faced with where they had little control. It signified a total loss of their independence, where any individual wishes would be inconsequential. It was worrying and burdensome to face the prospect of not being able to make decisions or have control over what was happening. Dwelling on and worrying about it also seemed to present another threat to their well-being and undermine their need to stay positive.

Stanley's rationality was borne out of what he had witnessed with others. He was quick to point out that if this should happen to him, then people would simply have to do things for him. His physical needs would dominate the options available to him. He would have little choice but to be put in a nursing home, something that he had previously expressed that he really did not want.

Some participants told me that they felt that their age alone was enough to give some health professionals, and on occasion society as a whole, the impression that they did not have capacity. Mary had experienced a very brief spell of delirium during her hospital admission. She and her daughter Stella felt that during this time her identity was completely stripped away.

> "… I think it is that last two or three times she has been in hospital she has been in with dementia patients, and that was another point; I think it is wrong that automatically because of your age you are put on, I think it is care of the elderly, and that is going to have a high number of dementia patients…I am sorry that they have got dementia really, but that doesn't help me mum you know…"

> [Stella 18/09/2014 L894-899]

Being nursed with others who had fluctuating or no capacity offered Mary a glimpse of what could happen to her future self. Constantly pressed to answer questions and being subjected to capacity assessments by numerous health professionals further compounded the threat to her

identity. She was struggling to come to terms with what all this had to do with the hip pain that had bought her into hospital in the first place.

> "I didn't get them [the assessments]…I said, 'Can I have another go?' and she said, 'No [laughs], no you can't' and I thought 'Well, what has that got to do with my hip?'"

[Mary 18/09/2014 L813-819]

All this had led Mary and Stella to question that if Mary didn't have capacity, would she still have received the care she needed in hospital? She was frustrated and angry and felt the indignity of the constant questioning of her capacity to consent. Even with delirium, she had retained capacity to make decisions but was worried that she could not communicate. Without being able to communicate effectively, Mary was worried that she may not get the care she needed.

7.6.   CONVERSATIONS WITH HEALTHCARE PROFESSIONALS

For fourteen out of the sixteen frail older participants, all interactions and communication with healthcare professionals had been regarding current medical care. Most participants had found these conversations useful and wanted to continue having opportunities to speak to a healthcare professional when the need arose.

In relation to discussing future care with healthcare professionals, many participants felt that the uncertainty they faced in predicting their future was also something that healthcare professionals faced. Alan had had some very forthright conversations with medical staff about his operation prior to it being undertaken. But he recalled that these had largely centred on what the operation would involve and the importance of his previous health on the outcome of the operation.

Despite this being major surgery, neither Alan nor his wife, Margaret, could recall ever talking about what would happen if the surgery did not go to plan. They were not convinced that they could expect anybody to know the answer to questions relating to what the future may hold.

Alan: *"No…nobody ever said, you know, what if or anything like that. No, not that I am aware of. I cannot remember any doctor saying, 'Well, if you go under, how will your wife do?' or anything like that; it was never mentioned."*

Margaret: *"Yes and I don't think anyone can answer that till that time; you cannot expect someone to say, answer that question, because nobody knows how one would react…"*

[Alan and Margaret 13/06/2014 L459-465]

At the time of the interview, I had thought that Alan meant 'go under' to mean being anaesthetised. I realised afterwards that he was referring to his own death. He was always open about the fact that he desperately wanted the operation so he could continue to be the main carer for his wife, Margaret. I am not sure he had ever voiced the 'what if' or if it simply had not occurred to him that there was a chance that he might not survive. He was simply driven to improve his own quality of life to continue his caring responsibilities.

Largely, the expectations that participants voiced regarding healthcare professionals were related to their current care. This was particularly in relation to those who felt that additional care services and help should be available to help them in order to improve their current quality of life. Clara was the only notable exception to this. She had asked her paid carer to find out about Lasting Power of Attorney,[29] but acknowledged that this was something that was difficult for him to do.

"Yes, I have asked the carers for it…I asked one of the lads to do it for me, and he has tried to find out. I am sure they said I had to register as what is it called? If you want the Power of Attorney changed?"

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[29] Lasting Power of Attorney (LPA, ('health and welfare' and/or 'property and affairs')), under the Mental Capacity Act, 2005. This is the nomination of a proxy that has the authority to represent the patient once they have lost capacity (Seymour and Horne, 2011).

> *"…a lad who works with the carers is trying to set this up for me, but he doesn't seem to be getting anywhere, bless him…I don't know who else to go to…"*

> [Clara 01/04/2014 L215-217 and L232-234]

Even though she had her carer for help, her expectations of what he could tell her were low. She did not want him to have Lasting Powers of Attorney on her behalf, just find out some information. She told me later when the tape was off that she found it difficult to ask about the future. I made the following observation in my research diary.[30]

> *"I am no good at opening a conversation. You have asked and I don't mind talking about it but I cannot ask, I won't ask because I am frightened of the answer; normally I don't mind talking about anything…"*

> [Field notes 01/04/2014]

7.7. END-OF-LIFE CONVERSATIONS: A NEGATIVE LEGACY

Such was the anticipated vulnerability of those taking part in the study, the ethics committee felt strongly that discussions using the term end-of-life care could only take place if they were initiated by the participants or their significant others. Despite recognition that older age and frailty meant proximity to death, there was no personal formal recognition by the participants of the period of time that policy and healthcare professionals refer to as 'end of life'. Participants were busy getting on with their lives and living each day. Reference was either to living for now or what would happen upon death.

During the study, two participants described being involved in very forthright conversations with healthcare professionals regarding their end of life. In both of these cases, participants recognised that they had been identified as dying or could die imminently as a result of their current

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[30] Clara agreed to the use of her words despite them not being on tape.

condition. As a result, they had been engaged in discussions relating to this while they were in hospital.

Both had been part of crisis discussions with medical staff around 'do not attempt cardio pulmonary resuscitation and withdrawal of treatment. For both women, this was the first indication that they may have reached the end of their lives and may not survive much longer. As a result, both women had been left with unanswered questions and feelings of helplessness about their future care in or out of hospital.

When I interviewed Mary and her daughter Stella, Mary was recovering from septicaemia, which had almost killed her. She had been so unwell that on a number of occasions her family had been summoned to the hospital because she was not expected to survive. Stella also recalled being asked for permission to withdraw treatment from her mother, which she had refused. Although Mary had little recollection of the events and was bewildered by them, she fully understood the gravity of her recent experience, which had had a profound effect on her.

> *"Well, I suppose I am lucky to be alive, aren't I? I mean, I don't know, I mean, I didn't know what was going on. They would perhaps have been going to my funeral today…"*
>
> [Mary 08/05/2014 L295-297]

From the outset of their interview, the impact of this harrowing experience on Mary's daughter Stella was evident. Mary's diminished recollection of what had happened had meant that the burden of reciting the chain of events to her mother fell largely on her. She was angry about this and tearful at times.

They were both concerned about what the 'do not resuscitate' order meant for the future and were concerned that it may lead to treatment being reduced, withdrawn or simply not offered. They also shared a fear for other patients in hospital who may be unable to voice their wishes and who did not have loved ones to advocate for them. They questioned that if this were the case, would patients just be allowed to die without anyone at least trying to help them?

Stella was clear that this type of conversation should not be had during a crisis when people would be especially anxious. It had been a traumatic time for both her and her mum. She wondered if it would be better for healthcare professionals to talk to them about what to do in the event of a serious illness somewhere other than in the hospital environment.

> *"…it is a roller coaster. You know we have been up and down and up and down; just things have happened that you could not anticipate…"*

> *"I do think it [DNACPR conversations] is something that should be approached outside if at all possible, outside of the hospital situation because it is maybe not the kindest and best place to do it?"*

> [Stella 18/09/2014 L447–458]

Clara was also struggling to come to terms with the conversations she had had with medical staff while in hospital.

> *"…they just said I was on a time bomb if anything was to happen. If I was to die, they will not resuscitate me. I said that is good because that is what I want; I don't want resuscitating anyway…"*

> [Clara 27/02/2014 L140-150]

Her memories of the conversations she had had in hospital were having a negative impact on her confidence. She was afraid to leave the house in case her 'time bomb' went off, and she had to suffer the indignity of an undesired resuscitation attempt if she was found on the street. Clara had tried to rationalise this by taking control of her surroundings and not leaving the house. Over time, this had turned into a fear of going outside.

In both these instances, reaching crisis point had forced healthcare staff into having discussions about end-of-life decision making. Both participants had been left traumatised by this and had many unanswered questions and anxieties about the implications of what these decisions may mean regarding their future care. I got the sense that they both felt powerless in

relation to this: Clara over her inability to control the 'time bomb' within her and Mary over how the decisions she had made when confused and disorientated would affect her future options and hospital care.

7.8. EXPERIENCE OF CARING ON DECISION MAKING

Throughout the study, there were a number of participants who talked about how their experiences of caring for others with frailty had affected their own wishes and preferences about their future care.

Sheila was becoming ever more exasperated with the increasing confusion of her mother, Maud, and the burden it was placing on her whole family. She was determined that she would not put her own family through something similar. This had led to some very forthright conversations with her daughter which she was looking to cement in a more formal way.

> *"No, I won't put them through what Mum is putting us through; it is not fair and it is not nice."*

[Sheila 21/07/2014 L534-535]

7.9. CHAPTER SUMMARY

The purpose of this chapter has been to chart the expectations, experiences and understandings of frail older people and their significant others about planning for future care. Reflecting on my own thoughts at the time of data collection, my intention was to get a sense of what frail older people perceived to be important to them. I was interested in how they may plan for their future, what expectations they had of healthcare professionals to help them do this and what experiences of this they may have had already.

For the most part, there was ambivalence among participants when it came to discussing the future. On the whole, uncertainty meant that participants felt more comfortable with talking about the immediate 'day to day'. Planning for the inevitability of death was firmly rooted in people's values of what was acceptable and expected. For some, it was a bid to protect family members from having to deal with it when it happened. For others,

it was more fundamental to their ability to continue to live, knowing that their personal affairs on death would not burden their families.

This chapter highlights that it is the time between their current state of health and the inevitability of death that participants find difficulty in foreseeing. Their experience of frailty thus far has left them living with uncertainty, where any further deterioration in health could mean that any plans that may make for the future would become quickly obsolete. The implications of these findings are considered in the next discussion chapter in relation to ACP.

CHAPTER 8. DISCUSSION AND CONCLUSIONS

8.1. INTRODUCTION

This chapter presents the discussion of the major findings and novel insights from the current study. Initially, an overview of the core findings from the data chapters is presented. These findings are then examined in line with previous research and relevant theory. The implications of these findings are then explored for the conceptualisation, policy and the practice of advance care planning. To conclude the thesis, the theoretical contributions to the field are set out, methodological reflections, strengths and weaknesses discussed and the implications for future research and clinical practice are made clear. This is followed by a reflexive account of my own personal development as the PhD journey draws to a close before the concluding remarks are made.

8.1.1. Overview of core findings

This study set out to address a number of gaps within the current evidence base by:

- Developing an in-depth understanding of the experiences and expectations of frail older people and their significant others of planning and decision making for future care.
- Identifying factors from the perspectives of frail older people and their significant others that enable or constrain the practice of advance care planning.
- Examining the implications of the findings of this study for policy and the practice of advance care planning.

This research study is particularly timely, given the emergence of UK policy and international research that suggests that frail older people should be identified and engaged in ACP (Abel et al., 2009, Bardsley et al., 2010, National End of Life Care Programme, 2011, Georghiou et al., 2012). The recruitment of sixteen frail older adults and eight of their significant others towards the end of a hospital admission has enabled a greater understanding of this period of time. By conducting this study, the issues

that are important to those living with frailty and their significant others in relation to future care have been illuminated.

Throughout the study, I sought to maintain frail older people at the centre of enquiry, and as a result, understanding of what it is like to live with diminishing physical and cognitive ability was illuminated. Through listening to individuals and then synthesising their perspectives, what emerged was a complex and dynamic story of living with frailty. This story is charted in *Chapter 5*, where participants described in depth how persistent and rapid changes to their physical, emotional and psychological selves presented a continual threat to their identity. As a result of this threat, constant adaptions and adjustments were necessary to maintain some continuity in their lives.

The continuous state of flux and imbalance bought about a need for those with frailty and their significant others to redirect their attention and focus to their 'day-to-day' lives. In doing so, participants actively concentrated on health-strengthening behaviours and placed emphasis on positive aspects of their daily life. *Chapter 7* goes on to describe how this uncertainty and subsequent emphasis on just 'one day at a time' influences thinking about, discussing and planning the future. It then highlights the question raised by participants as to how decisions made today could be determinative or hold any relevance for a future that is uncertain and unpredictable. The chapter goes on to stress how, rather than plan for this time, participants were resigned to having little or no control over it. This apparent lack of interest for future planning has major implications for the current conceptualisation of ACP.

For most frail older people, a growing dependence on an inflexible care system also undermined their ability to have the day-to-day control that most of us take for granted. *Chapter 6* describes in detail this increasing dependency on carers and care services and the influence it has on those living with frailty and their significant others. It highlights how in the lived world of frailty, the significant and legalised importance that is placed on 'autonomy' in care and decision making gives way to a more relational approach. This approach highlights and identifies the importance of personal relationships, partnerships and negotiations between the carers

and cared for. It is also more commensurate with the interdependency and dependency described by those in the study.

This study shows that frail older people and their significant others need any attempts to engage them in the current conceptualisation of ACP to be part of a wider programme of (palliative)[31] care. Such a programme should not focus specifically on end-of-life care and diagnosis of dying, but more on health-strengthening behaviours relating to the frail older person's day-to-day quality of life and existence. For those with frailty, ACP needs to be one aspect of a holistic, relationship-centred care approach that focuses on issues meaningful to the person and their significant others. Highlighting these elements via the study findings has made a novel addition to the existing research in this field.

Throughout the study, there has been a tension surrounding my own thoughts about ACP. At times, I struggled to separate ACP from end-of-life care. I now realise that my view was heavily influenced by UK policy and best-practice guidance that discusses ACP in the context of end of life. Like many practitioners, I felt that the commencement of ACP was reliant on recognising that a person is dying and should be initiated and promoted by a significant change in condition heralding a final illness or decline. Thus, I saw it as something only to be used when death is approaching. Although this view still resonates with me, I now recognise that ACP is not exclusively an end-of-life endeavour but should be much wider than this. In essence, its definition allows for a much broader conceptualisation based on what is meaningful to individuals.

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[31] Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It considers all aspects of care including physical, psychosocial and spiritual. Although the definition offers a broad conceptualisation, clinically, palliative care has become synonymous with end-of-life care. In the context of this study, it is argued that discussing ACP in the context of end-of-life care has the potential to undermine a complex process of adaptation experienced by those who are frail. Therefore, I use the term palliative here in relation to all aspects of care that are aimed at improving quality of life and therefore maximising the health-strengthening behaviours elicited by those in this study.

8.1.2. Discussion of core findings

The findings of this study illuminate that the lived world of frailty is complex and challenging. It is this complexity and challenge that has the potential to limit the applicability of the current conceptualisation of ACP in UK policy and frameworks to frail older people. In examining these findings in relation to the existing literature and theory, it is clear that they do not fit into any one single discipline. Instead, they traverse a number of disciplines congruent with understanding not only physical effects but also emotional, psychological and social perspectives of living with frailty. This multi-perspective approach aligns with how nursing as a discipline draws on approaches from social sciences and medicine to enhance understanding of a complex range of issues through compassionate enquiry (Munhall, 2012).

Guba (1990) asserts that there is always more than one theory, either explicit or implicit, that can be used, at any given time, to explain a body of 'facts'. This assertion emphasises that no unequivocal explanation is possible. When trying to make sense of the data in this study, I have used relevant theories to understand the findings in relation to the existentialist and fragile nature of frailty and identity. I have also looked at how existing theory on autonomy relates to and influences future care planning and decision making in relation to the practice of ACP. Although I have tried to be as comprehensive as possible in this endeavour, I acknowledge that the theory I have included is not exhaustive and other theories may well hold relevance to these findings.

8.2.   FRAILTY AND IDENTITY

In spite of patients being defined as in varying degrees of frailty by healthcare professionals, fifteen out of the sixteen participants in this study did not use the term or define themselves as frail. This finding is supported by the work of Van Campen (2011), Nicholson et al. (2012a) and Warmoth et al. (2015), who acknowledge that regardless of its use in mainstream healthcare practice and policy rhetoric over the last 20 years, those who are living with frailty do not identify with the term. Instead, participants in this study presented a holistic view of the lived experience of frailty. This

view incorporated the progressive and dynamic narrative of the physical, emotional, psychological and social adversities they faced day to day.

Despite concerted efforts by experts, attempts to reach consensus over an operational definition of frailty have yet to reach fruition (Morley et al., 2013, Rodríguez-Mañas et al., 2013). Many of the definitions presented in the literature remain centred around a biomedical model of frailty (Gilleard and Higgs, 2011, Nicholson et al., 2012b). Within practice, it is often used as a classification that can influence priority and fund care. It can also be used in this arena as a synonym for a slow and dwindling dying trajectory (Markle-Reid and Browne, 2003).

Seminal and subsequent works from the disciplines of anthropology, sociology and psychology highlight how medically driven models of frailty inadequately represent the complexities of the lived experience (Becker, 1994, Kaufman, 1994, Gilleard and Higgs, 2011, Nicholson et al., 2012a, Nicholson et al., 2012b). These studies represent a much more dynamic and holistic view of frailty and ageing that is described by those in the current study. This view is one that integrates and values embodied knowledge (Becker, 1994). It also forces us to consider the meaning of independence and dependence of old age (Kaufman, 1994) and acknowledges the social losses alongside the physical ones experienced by frail older people (Nicholson et al., 2012a). This study adds to the small but growing body of literature that looks at frailty from the perspectives of those that live with it and their significant others.

Throughout the study, participants' stories giving insight into the lived world of frailty were a dominant theme, particularly in relation to the impact of frailty on their identity. Diminishing physical ability was often accompanied by a loss of independence and a fear of burdening others. For many, this resulted in a decline in confidence and waning social networks that led to loneliness and isolation. These experiences, accompanied by a lifetime of societal change and exposure to negative stereotypes of ageing, prompted individuals to describe alterations to their lives that were often beyond their own recognition.

Previous research suggests that individuals have the capacity to adapt and alter their lives to accommodate significant losses and disruption (Bury, 1982, Charmaz, 1995). Yet it was the rate and complexity of change, disruption and losses described by participants in this study that engendered a persistent threat to their identities.

In some instances, this extended to existential crisis, where accommodating and adapting to such loss became impossible. Fillit and Butler (2009) describe this phenomenon as the 'frailty identity crisis', which they characterise as a psychological syndrome that may accompany the transition from independence to frailty (Fillit and Butler, 2009). Their work draws attention to the persistent and progressive nature of frailty that can transpire over several years. They also highlight the need for research that focuses on the psychological and emotional adaptation described in detail by the participants in this study.

Hockey and James (2002) argue that identities in older age can be conceptualised as 'liminal'. Liminality was described by Turner (1975) as a transitional point, a threshold space between social identities. However, the continuous state of flux described by those with frailty in this study does not suggest a transition between one identity and another. Rather, its findings resonate more with research conducted by Nicholson et al. (2012b), who also described the experience of frail older people as a state of imbalance where there is no resolution from one identity to another. Nicholson et al. (2012b p.1426) go on to describe this as 'persistent liminality', where frail older people, as was seen in this study, are continually being forced to re-define their identities.

8.2.1. Sustaining connections: Living day to day

In response to this constant threat to their identities, participants in the study sought continuity by redirecting their attentions to focus on day-to-day living. Alan and Margaret *(section 7.2)* described taking 'one day at a time' and like many other participants preferred to concentrate on health-strengthening behaviours and the more positive aspects of their lives. Research conducted by Ebrahimi et al. (2013) with frail older people also found that focusing on a manageable everyday life creates a sense of assurance and strengthens experiences of health. This approach enabled

participants in the current study to adapt to the challenges of living with frailty and actively seek to minimise the sustained threat to their identity.

Part of this health-strengthening process was the importance of maintaining motivation and purpose. Participants also placed increasing importance on nurturing hope in order to preserve their well-being. In a recent review of the literature concerning hope, Nash (2015 p.2) concluded that 'hope is critical to life'. It is the raison d'être and main purpose of human existence (Marcel and Viator, 1962).

For many, hope was used to both counterbalance their diminishing health (Miller, 2000, Fitzgerald Miller, 2007) and adapt to their current circumstances (Bickerstaff et al., 2003). Strategies such as light-heartedness and humour and minimising isolation (Ersek and Cotter, 2006) were employed. Plans for the future which concentrated on positive endeavours, such as holidays and anniversaries, were prevalent throughout the study.

In addition, participants also engaged in socially comparing themselves to others in their personal networks whom they perceived as less fortunate than themselves. They did this to influence in a positive way how they felt about their own circumstances (Wood, 1989, Gibbons, 1999, Henchoz et al., 2008, Ebrahimi et al., 2015, Song and Kong, 2015). This approach allowed participants to accommodate some of the hardship and negativity they experienced, to maintain equilibrium within their lives and carry on living in the present (Gibbons, 1999, Netuveli and Blane, 2008).

This emphasis on affirmative aspects of daily life seems to be at odds with the more clinically orientated view of frailty, which has become a synonym for a slow, dwindling dying trajectory with a focus on end of life and impending death (Markle-Reid and Browne, 2003, Gilleard and Higgs, 2011). Paradoxically, however, this study also showed that contemplating their chronological age and experiences of loss strongly signalled to participants their proximity to death.

Many participants were comfortable discussing their death with me and what would happen after they died. Most of them had already planned their

funerals and written wills, which is consistent with previous research (Singer et al., 1998, Carrese et al., 2002, Barnes et al., 2007, Seymour et al., 2010, Samsi and Manthorpe, 2011, Sutton and Coast, 2012). However, for many in this study, death remained an indeterminate entity, and concentrating on it, discussing it or predicting its timing was of little interest to them.

8.2.2. Living day to day: Uncertainty, planning and the future

Before becoming frail, many participants and their significant others had not been exposed to the effects of frailty that they were able to describe in great detail throughout the study. This meant that many of them were living a life of uncertainty, the extremes and challenges of which they could never have predicted. Out of necessity, many were constantly forced to accept help from carers, which once they may have deemed unacceptable. However, despite these difficult circumstances, many participants endeavoured to remain optimistic and focus on positive aspects of their lives. On the whole, the notion of dwelling on what they were not able to do anymore was seen as counterproductive to living.

Nicholson et al. (2012b) describe how elders work actively to retain anchorage in this state of imbalance, through developing and sustaining connections to their physical environment and routines. Similarly, this study captures a complex process of adaptation and adjustment that is needed to allow individuals to sustain their connections and retain their identity day to day.

This process of adaptation and recalibration of internal standards in theoretical terms is referred to as 'response shift' theory (Schwartz and Sprangers, 1999, Sprangers and Schwartz, 1999). Research conducted by Schwartz et al. (2004) found that response shifts allowed patients with chronic illness to maintain continuity in their lives. Within the current research study, frail older participants and their significant others described response shifts, which resulted in them reconceptualising what they deemed as an acceptable way to live. However, others were unable to keep pace with the rapid changes, and as a result, found themselves in the aforementioned state of 'persistent liminality' (Nicholson et al., 2012b p.1426).

Consequently, many found it difficult to contemplate what would happen in the future. Some voiced resistance to talking about it, while others felt that the 'future really is today'. In some cases, participants felt that their age and proximity to death meant there was no future, while others felt they were living the life they had planned for many years previously. Overall, the future represented uncertainty for participants and was yet another reason to concentrate on living one day at a time.

Previous studies that focus on older people have also found a preference for living in the present and concluded that there was some resistance to thinking, discussing or planning for future care (Carrese et al., 2002, Samsi and Manthorpe, 2011). For participants in this study, the reasons for resistance to planning the future were complex and represented the scale of uncertainty that living with frailty bought about. High levels of uncertainty meant that participants questioned exactly what they were planning for. Moreover, if they did plan, rapid change and subsequent adaptations meant that any plans may become obsolete quite quickly.

Like previous studies, participants were worried about burdening their loved ones with conversations that they might find upsetting (Seymour et al., 2004, Malcomson and Bisbee, 2009, Clarke and Seymour, 2010, Stewart et al., 2011). For those in the study, talking about the future meant addressing dying, which was not only burdening for their family but also for them. Participants had little choice when it came to placing burdens on loved ones for their diminishing physical needs; upsetting them with talk about future care was seen as an unnecessary additional burden, one that they could control and assert their dwindling autonomy over.

Like research conducted by Gott et al. (2004), Samsi and Manthorpe (2011) and Bollig et al. (2015), some participants felt that future care plans were unnecessary as family members would know what was important to them. This finding reminds us of the importance placed on relationships for those who are coping with frailty. However, previous research suggests that family proxies, who may not have engaged in conversations with their loved ones, often have contrary views about what care their loved ones would want in any given situation (Black et al., 2009, Fried et al., 2009, Sudore, 2009, Vig et al., 2011, McMahan et al., 2013).

This study also gives a good account from the perspectives of frail older people and their carers of what it is like to be asked to make these decisions in the moment of acute crisis. Carers in other research have also reported in the past of the distress and guilt of 'doing the right thing' for their loved ones (Sudore and Fried, 2010, Torke et al., 2012). Both Mary and her daughter Stella were left with a legacy of worry about what decisions made in hospital may mean for the future. They both felt that having these discussions earlier would have been of greater value (Seymour et al., 2004, White, 2005, Malcomson and Bisbee, 2009).

Where there was evidence of formalised future plans, these were often fraught with problems relating to access, understanding or extortionate financial implications. Recent research conducted by Samsi and Manthorpe (2011) found that older people were confused by the legal terms that are used in making plans for future care. Similarly, research conducted by Robinson et al. (2013) found that healthcare professionals worry about the financial burden of this process on older people.

Throughout the study, the day-to-day focus of those with frailty was also reflected in their expectations of healthcare professionals. Opinion among participants was such that healthcare professionals also faced uncertainty of what future care any given individual may need. Any interaction was generally focused on 'getting better' or receiving care to maintain daily activities of living. Unable to leave the house, Clara had tried to access information regarding some of the more formal outcomes of ACP with little success. She, like the many others who are living with frailty, was not known to primary care or the local authority until she had become immobile (British Geriatrics Society, 2014).

8.2.3. Identity and incapacity

This study also highlights the fear of incapacity and what this will mean for future care. Approximately one-third of those in the study reported fluctuating capacity due to delirium or exacerbation of their dementia symptoms during admission to hospital. As a result, they had little memory of many aspects of their care or communication.

This finding is commensurate with previous research that identified growing numbers of frail older people whose capacity is affected during an acute hospital admission (Goldberg et al., 2012, Bradshaw et al., 2013). Consequently, these findings raise ethical questions about the validity of decisions made by those deemed capacitous according to the Mental Capacity Act (Office of the Public Guardian, 2007) when the person concerned has little recollection of those decisions being made.

Additionally, findings from this study also show that, as the loss of their physical, psychological and social selves proliferated, some participants developed a sense of rationality regarding what would happen to them. For them, it was a case of questioning who would consider their wishes, when their experience suggests it was more likely to be their physical need, dependency and limited resources that would dictate outcomes, rather than an active informed decision. These findings are commensurate with Mathie et al. (2012), who found that frail older people in nursing homes also felt that they had limited control over their current experience, and as a result, could not envisage doing so in the future.

8.3. FRAILTY AND AUTONOMY

Throughout this study, participants were able to illuminate the emergent or sustained dependency on both carers and care services that living with frailty brought about. Many faced disruption to their lives because of multiple admissions to hospital. Constant change in condition and circumstances of those in the study meant that their care requirements were frequently changing. Findings suggest that the constant appraisal of care by healthcare professionals required to meet the evolving needs of this dynamic process was not always forthcoming. These findings support that care should reflect the needs and preferences of patients and those who are important to them (Leadership Alliance for the Care of Dying People, 2014).

Asking for and subsequently accepting help was a major challenge for those in this study living with frailty. For many it represented a shift from independence to dependence (Janlöv et al., 2005, Janlöv et al., 2006, Van Campen, 2011). It also forced them to acknowledge that things in their lives were changing and that they were unlikely to return to their previous

level of independence (Themessl-Huber et al., 2007). As dependency grew, so did reliance on family, friends and care services.

Over time, this reliance bought about a loss of control and self-determination in day-to-day activities; feelings of powerlessness ensued. Those reliant on carers to help them to fulfil their activities of daily living[32] found themselves in a situation where there was no autonomy in even basic decision making.[33] Relationships with carers became of paramount importance, and where these relationships were strained or there was evidence of constantly changing care staff, these feelings of powerlessness and loss of control and autonomy were intensified (Themessl-Huber et al., 2007, Breitholtz et al., 2013, Goodman et al., 2013).

In his classic exposition of autonomy, Dworkin (1988) espoused autonomy as liberty or freedom to act, as dignity, as freedom of will and as independence (Dworkin, 1988). Findings from this study suggest that despite the will of many of the frail older people to retain their autonomy, as dependency on carers increased, their autonomy was slowly eroded away.

A recent systematic review of older persons' experiences and perspectives of receiving social care reveals that for some older people, receiving social care also means loss of autonomy (José de São et al., 2015). While coping with the challenges of frailty, participants in the current study often found themselves in the position of balancing their own comfort with the guilt of burdening others. This viewpoint is also echoed by evidence from other studies (McPherson et al., 2007, Pleschberger, 2007, José de São et al., 2015).

Some participants, such as Elsie and Alan, exercised personal choice and disengaged from formal care services because they were dissatisfied. This evidence is supported by research conducted by Valokivi (2005), who also

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[32] An activity of daily living refers to everyday routines of functional mobility and personal care such as washing, dressing, toileting and preparing meals.

[33] This included what time they got up in the morning, ate meals and went to bed at night.

found that frail older people disengaged from services if they were unhappy. However, Elsie and Alan did acknowledge that this was something that others who needed services to remain at home could ill afford to do. The current study also found, like other studies (Gott et al., 2004, Janlöv et al., 2005, Janlöv et al., 2006, José de São et al., 2015), that some frail older people worry about burdening carers or care services that they perceive are already busy or overstretched.

Loss of self-determination and autonomy in decision making for participants in the current study also extended to the acute care service. Wilfred *(section 6.4.4)* discovered that his own autonomous wishes were overlooked by healthcare professionals in a bid to protect him from harm. Participants often found this lack of autonomy in decision making frustrating and annoying; however, they felt that there was little they could do to challenge it. Recent research by Tadd et al. (2011) found this risk-averse and defensive culture has the potential to severely compromise patients' dignity.

8.3.1. Healthcare provision and autonomy

Throughout the current study, participants' narratives spanned many decades, revealing fundamental changes in the philosophy of healthcare decision making over these years. For many, their formative years saw medical decision making that was based on paternalistic notions of professional authority and beneficence. More latterly, this model has become outdated, and there has been a shift towards a model of patient partnership. This model is based on informed choice, supported by the principles of autonomy.

Many commentators (Oddi, 1994, Coulter, 1999, Ikonomidis and Singer, 1999, Stirrat and Gill, 2005) have drawn attention to the positive aspects of this evolution in healthcare. However, participants in the current study found this change overwhelming. It was difficult for them to move away from the culture that 'Dr knows best', and as a result, for some, it had negatively affected their communication with medical staff.

Burke (2008) asserts that cultural changes and the way services are delivered have the potential to threaten active participation in healthcare

decision making for some groups. The current research study suggests that frail older people may be one of these groups. Participants described how never seeing the same GP twice affected any hope of building the same level of relationship that they had enjoyed in previous years. This led participants to question if doctors in particular had enough time for each patient and affected their level of trust and motivation for seeking help. This highlights the importance that those with frailty and their significant others place on relationships and interactions with medical staff. Without these relationships and trust, engaging in ACP conversations may be a difficult task.

Many participants in the current study also felt that their physical needs undermined the choices that were available to them. They were acutely aware that in a healthcare system that relies heavily on public funding, 'choice' is an ideology that is constrained by limited resources. Even those who had finances to pay for care were worried that their lifetime would outstrip such resources or that they would be unable to find the level of care they required.

Research conducted by Lloyd et al. (2014) highlights that older people acknowledging the realities of life does not mean that they have given up on the exercise of autonomy. Instead they argue that remaining realistic can engender control and continuation of identity. The loss of self-determination, however, on a day-to-day basis in the current study meant that although there remained a will to exercise autonomy, the opportunities afforded to them to do so were lacking. Over time, this meant that dependency not only posed a continual threat to autonomy but also was contributing to slowly eroding identity.

8.3.2. Relational autonomy

Autonomy has been a leading principle in healthcare discourse for several decades and is widely valued within this context (Entwistle et al., 2010, Perkins et al., 2012). However, for many in this study, increasing needs meant that they had become reliant on complex systems of care and care services. Individuals' lives were so dependent upon and interlinked with those caring for them that any decision making necessarily took on a relational aspect. For many, autonomy and self-determination gave way to

relationships, partnerships and negotiations, which are more commensurate with a relational model of autonomy.

In her relational theory of autonomy, Nedelsky (2011) argues that a relational approach better advances concerns than an individualistic one. She asserts that we should not regard autonomy as a conceptual tool to assign individual rights, but as a notion that can be nurtured or weakened through the relationships individuals inhabit (Nedelsky, 2011). She goes on to say that:

> *"It is the very nature of human selves to be in interaction with others".*

(Nedelsky, 2011 p.55)

Findings from this study suggest that when caring for those with frailty, upholding individuals' autonomy above all else can have devastating effects on family carers. For example, healthcare professionals in Maud's care *(section 5.3)* affirmed her capacity to consent and upheld her autonomy by supporting her decision to go home. However, the family felt that their own interests and emotional concerns were not taken into account and this had created an unsustainable situation for them. By staff inadvertently disregarding the well-being of her family, there was a risk of denial of social justice (Ikonomidis and Singer, 1999) and potential for social breakdown in the very relationships that were vital to Maud's wish to remain at home.

Research conducted by Carrese (2006) and Poole et al. (2014) draws attention to the complexities involved in decision making, especially when honouring patients' wishes has the potential to threaten their well-being. Providing person-centred care may be desirable, but enhancing autonomy of patients at the cost of infringing on the rights of their significant others also raises ethical dilemmas (Winzelberg et al., 2005, Carrese, 2006, Gillett, 2008, Poole et al., 2014).

Taking account of interactions between the patient, significant others, carers, and health and social care staff, which are essential components of

care for frail older people, is becoming more commonplace (Oliver et al., 2014, Gordon and Oliver, 2015). The current research study raises questions as to whether a person-centred care approach that overemphasises independence and autonomy may be problematic for the care of frail older people. It suggests that taking a relationship-centred approach, a concept that is becoming increasingly accepted in older people's nursing (Nolan et al., 2006), may be a more effective strategy with frail older people when planning future care.

8.4. IMPLICATIONS FOR CONCEPTUALISATION OF ACP

The aim of the study was to investigate the expectations and experiences of frail older people and their carers about advance planning for future care and examine these in relation to the practice of ACP. ACP offers a framework, supported by policy and enshrined in law, to those who want to discuss and plan for a time when they are unable to make their own healthcare decisions. This can be in relation to, but is not exclusive to, end-of-life care.

Despite this broad conceptualisation of ACP, in the UK, policy and best-practice guidance place emphasis on end-of-life care. The practitioner views that are represented in *Chapter 2* also reflect this perspective. This focus, however, is problematic for those living with frailty. In light of the findings from this study, I strongly believe that exclusively focusing ACP on the context of end-of-life care could undermine any strategies employed by frail older people to maintain positivity and motivation; in some cases, these are very finely balanced.

This study suggests that the future and end-of-life orientation of ACP in policy and practice is at odds with the dynamic nature of frailty and does not correspond to individuals' needs to find ways to maximise their current quality of life. The permanent state of flux and dialectic between body and self of those living with frailty in this study meant that they were focused on one day at a time. Strategies to maximise daily health and well-being became of paramount importance in an attempt to maintain continuity of their identity. It is only when contextualising this in relation to the future orientation of the decision-making components of ACP that we see the potential difficulties this process poses for frail older people.

This shift in focus to the day to day brings into question whether current models and conceptualisations of ACP can offer relevance to those living and adapting to the challenges of frailty. Moreover, policy and best-practice emphasis on dying rather than living have the potential to undermine any complex process of adaptation.

Research by Nicholson et al. (2012b) also found that the experience of those living with frailty sits in opposition to the dominant cultural binary models such as 'living' or 'dying'. They agree that this notion of ACP as an end-life endeavour is prevalent in the policy and best-practice guidance around frailty. As a result, they argue for a rebalance in this polarisation of living and dying which acknowledges frail older peoples' losses. Only by accepting the uncertainty and transition experienced by those with frailty can they be supported over time (Nicholson et al., 2012b).

There is a need for any future planning to be sensitive to the difficulties frail older people have with envisioning the future. The commonly held view that ACP should be initiated on prognostication of dying is out of step with the level of uncertainty that frailty poses. Clinical prognostication of dying in frailty is challenging (Fried et al., 2001, Travis et al., 2002, Hanson et al., 2008). It is even more challenging when individual resilience to adversity and personal reserve are considered alongside more traditional biomedical models (Rolls et al., 2011, Piers et al., 2013). Moreover, frail older people risk being marginalised from ACP decisions when uncertainty dictates that they have little knowledge or comprehension of what they may be planning for.

Murtagh and Thorns (2006) also question if it is ethically sound to inflict open discussions on frail older people when it is to satisfy the legally enforceable requirements of informed consent in the context of end-of-life care and decision making. Their research study found that there is increased risk of harm when delivery of information is discordant with the pace and preference of individuals. The current research study demonstrates the uncertainty facing individuals with frailty and suggests that framing ACP conversations with some of the more predictable clinically orientated goals of care such as DNACPR may well risk pseudo-participation in decision making to satisfy a medically orientated checklist (Piers et al.,

2013). This would mean that ACP is not representative or meaningful to frail people themselves but instead is aligned to a more medical model of care.

8.4.1. Frailty, autonomy and ACP: A paradox

Despite wishing to remain independent as far as possible, diminishing physical and cognitive abilities meant that interdependence and dependence became an integral part of the lives of the frail older people in this study. Through reliance on others, loss of control and day-to-day governance and decision making was undermined, and this has implications for the practice of ACP. Autonomy and self-determination represent fundamental theoretical commitments that underlie ACP. They are also explicit in current UK public policy and law as determined by the Mental Capacity Act (2005). This study highlights that asking frail older people to make autonomous decisions regarding their future when they have little control over day-to-day decisions may be an unrealistic expectation.

According to Beauchamp and Childress (2013), autonomous decisions within healthcare contexts are those made intentionally and with substantial understanding and freedom from controlling influences. Such was the dependency of the participants in this study that even basic decision making was controlled by those on whom they relied for care. In their research with older people in residential care and assisted living respectively, Agich (2003) and Perkins et al. (2012) also found that the liberal ideal of autonomy as independence presents an ethical challenge. They advocated for an ethical framework that brings into focus the full range of caregiving interactions and relationships. It is this type of framework that is required by those in this study in the context of any future care planning.

Previous influential research has also called for a more relational approach to decision making within ACP that recognises the value of personal relationships (Singer et al., 1998, Martin et al., 1999). These studies were instrumental in creating a broader conceptualisation of ACP, but the legalistic elements of current ACP practice continue to support and uphold a more autonomous approach. This latter approach creates a tension,

especially for those in clinical roles who are trying to uphold the principles of person-centred care.

This research study, like previous research (Perkins et al., 2012, Sutton and Coast, 2012), suggests that some frail older people are interdependent and dependent on others to such an extent that autonomy in decision making is impossible. Moreover, this study also suggests that frail older people themselves recognise that their dependency means that autonomy is not afforded to them in a way that the current conceptualisation of ACP in UK policy intends. As a result, ACP in its current form is an exercise that, even with the will to do so, frail older people cannot easily or fully participate in.

8.4.2. The problem of setting precedent

The constant adaptation and shifting of internal values and standards in response to changes in frailty status led participants in the current study to question the value of planning in relation to future care. As a result of having to adjust, they recognised that future decisions made now may become obsolete quite quickly as their health status changed.

Previous research has highlighted inconsistency over time of older people's preferences for life-sustaining treatment, concluding that these changes would have implications for the process of any ACP (Winter et al., 2003, Fried et al., 2006, Fried et al., 2007, Winter and Parker, 2007). In addition to this, the participants in the current study also recognised that their changing circumstances and preferences would have implications for any future planning. Findings also echo that research by Van Campen (2011) and Barrio-Cantalejo et al. (2013) showing that changes in health status or the death of significant others would also have implications for decisions that related to their own future care.

As far back as 1884, John Stuart Mill disputed attempts to decide irrevocably now what will be best for some future and distant time. This view was formed partly on the grounds that we are insufficiently informed about the future to make good judgments about our interests that far ahead (Mill and Laughlin, 2004). Since then, this argument has moved on to one of precedent autonomy and now focuses on whether former wishes,

based upon values and desires that may no longer be recognised, can still be determinative (Sheather, 2013, Hebron and McGee, 2014).

Notionally, precedent autonomy is defined in terms of former preferences. According to Davies (2002), patients who retain the capacity to make decisions can, if they so wish, change this decision when it comes to its implementation at the point of care. However, problems occur when these former preferences are not legally binding and a decision to respect precedent autonomy is seen to contradict the best interests of a patient who no longer has decision-making capacity. Precedent decisions raise difficult questions about identity, especially when the health status of those with frailty changes and they adapt and adjust to their circumstances.

This study reveals considerable reservation among some frail older people about planning for a time they are unable to imagine. This suggests that in doing so, they feel that any form of ACP should be largely related to who they are now, not who they may become in the future. This perspective casts a shadow over whether any advance care planning activities in this group can be considered relevant to their future care. Consequently, this, alongside the day-to-day focus of the lives of those living with frailty, questions if the futuristic nature of ACP can be considered relevant to this group.

8.4.3. Challenges and tensions of ACP and frailty

Experience of dependency, care needs and limited resources left participants questioning whether their informed decisions could actually have any influence on their future care. This finding raises an interesting point, given that research suggests that clinicians find advance directives challenging, especially when they conflict with what they determine may be in the patient's best interests (Kelner, 1995, Bond and Lowton, 2011, Coleman, 2013, Robinson et al., 2013). Moreover, further research conducted with geriatricians revealed that they were positive about the use of ACP. Yet, when it came to enacting the decisions they contained, unless precise to the situation in hand, they may only serve to have limited influence (Bond and Lowton, 2011).

For frail older people such as those in this study, there is a danger that ACP can offer 'false promise' (Sampson and Burns, 2013 p.387) that limited resources and complex need cannot support. The moral and ethical implications of this are also shared by healthcare practitioners who cite this aspect as a barrier to ACP (Horne et al., 2006, Boyd et al., 2010, Minto and Strickland, 2011, Colville and Kennedy, 2012, Robinson et al., 2012b).

It was the reality of witnessing similar situations to the distress described by Mary and Stella *(section 7.7)* in clinical practice that encouraged me to look in depth at this area and engage in this study. Although their experience in the study was unique, it demonstrates well the reality and tensions of best-interest decision making in acute crisis that ACP is designed to try and avoid. Their experience had left Mary and Stella wondering if making decisions earlier would have been beneficial. Living with uncertainty and being unable to envisage the future means that ACP in its current conceptualisation for those living with frailty is set to be challenging. However, while ACP is not a panacea for all decision making in the event of incapacity, it does offer those who want to plan an opportunity and framework to do so.

This study has found that ACP in its current conceptualisation has the potential to marginalise frail older people and undermine their need to live well day to day. In a recent editorial, Godfrey and Hackett (2015) assert that there is considerable dissonance between the conceptualisation of ACP in policy and how many older people wish to convey preferences and choices at end of life. This study offers some empirical evidence to support this view.

This evidence suggests that ACP in its current format does not hold any relevance for some frail older people. It may be that in this group the term or practice of advance care planning needs to be abandoned altogether. Rather than pursuing conversations with a purpose based on end-of-life care, frail older people need an ongoing wider programme of care that concentrates on health-strengthening behaviours. This programme would also need to abandon the preoccupation with diagnosing dying and engage with the major principles of palliative care that are aimed at improving quality of life.

As part of this programme, healthcare practitioners could promote and nurture hope. They could also work with frail older people and their significant others to understand what helps them to live well. Rather than projecting forward to a time that is difficult to comprehend, frail older people can be asked to use their current and recent experiences of the care system. Only by doing this will we be able to understand what may be acceptable to them in the future. By underpinning this with a relational approach, healthcare professionals could work together with frail older people and their significant others to understand what is of most importance to them.

Ultimately, by doing this, the process of planning future care for those with frailty can undergo a complete paradigm shift. This shift can be achieved by moving away from the end-of-life focus of ACP which is prevalent in current UK policy and moving it towards a process of strengthening their day-to-day experiences of health.

8.5. CONTRIBUTIONS OF THIS STUDY

This research study is one of very few that contemplates future care planning from the perspectives of those who live with frailty. To my knowledge, it is the first to consider this in relation to ACP and UK policy. It is also the first study of this focus that has sought to be inclusive of a substantial group of those with frailty who have problems with fluctuating or loss of capacity. As a result, this study has made a number of theoretical and methodological contributions to the field. These contributions will now be discussed, alongside the study's implications for practice and future research. Following these insights is a personal reflexive account of my experience as a practising nurse and nurse researcher.

8.5.1. Theoretical contribution

In line with its interpretive constructionist frame, this study takes an inductive approach and uses theory to make sense of and explain the patterns identified in the data (Guba, 1990, Blaikie, 2007). As a result, there are three main areas in particular to which this study contributes: frailty, identity and autonomy.

In relation to frailty, this thesis adds to a small but growing body of literature about the lived world of frailty. This literature (Van Campen, 2011, Nicholson et al., 2012a, Nicholson et al., 2012b) describes a dynamic and holistic view of frailty that is experienced by the participants of the current study. This perspective acknowledges the psychosocial losses of frailty as well as just the more traditionally defined physical losses. It also supports the notion that those who are frail do not identify with the term frailty. Instead, they seek to concentrate on day-to-day, health-strengthening behaviours to preserve continuity and maintain their identity through times of challenge and uncertainty.

Findings from this study also suggest that rapid and constant change creates a state of imbalance for frail older people. In some instances, adaptations and adjustments promote 'response shifts' that have previously been described in those with chronic disease (Schwartz et al., 2004). While previous research (Galenkamp et al., 2012) has found that older people have the potential to change what they perceive as good health over time, the current study provides empirical evidence of this phenomenon. Many of the participants were forced to change how they perceived their health over time, in order to promote continuity and control over their lives.

In addition, this study also adds further empirical evidence building on work by Nicholson et al. (2012b) which identifies a state of 'persistent liminality' in those who are living with frailty. During this persistent state, those in the current study were unable to adapt and adjust to keep pace with the changes they were experiencing. It is this state of flux and imbalance that this study shows can potentially lead towards an existential 'frailty identity crisis' (Fillit and Butler, 2009).

The current study also contributes to theoretical discussions regarding autonomy in healthcare and decision making. It suggests that as dependence and interdependence on others increases, the idealistic and legalised nature of autonomy in decision making is out of step with the lived world of frailty. Findings suggest that even with the will to retain autonomy, the ability of frail older people to do so is significantly reduced by the relational nature of their lives. Loss of autonomy for frail older

people is not necessarily related to loss of capacity. Rather, it is a reduction of the frame in which they are able to independently make decisions.

8.5.2. Methodological reflections

As previously discussed in the methodology *(Chapter 3)*, although the use of the serial interview technique is common in longitudinal qualitative research, it was not specifically used here to elicit data over time. Findings from this study, however, revealed that in just a few short weeks, many participants in the study described significant changes in their lives. Having worked closely with frail older people in a hospital setting, I had anticipated there may be some rapid decline which may well lead to death. What I hadn't anticipated, however, was how small changes could be so frequent and have such fundamental consequences.

I believe that this insight raises methodological questions regarding the nature and time frame of 'longitudinal' research within the context of frailty. Saldaña (2003) identifies the three foundational principles of qualitative longitudinal research as duration, time and change; he is also quick to emphasise that:

> *"Longitudinal means a lonnnnnnnng time".*

> *(Saldaña, 2003 p.1).*

What constitutes long in longitudinal research is the subject of debate, which seems to differ dependent upon discipline and subject focus of the study (Holland et al., 2006, Corden and Millar, 2007, Koro-Ljungberg and Bussing, 2013). Paradoxically and despite his emphasis on the word long, Saldaña also emphasises the importance of time and change processes as being contextual (Saldaña, 2003).

In relation to this study, it is the lived world of frailty that is important when considering the use of longitudinal research. Time and duration in the study for some was short, but change was seen in abundance. It is with 'considerable excitement' that Holland et al. (2006 p.38) highlighted the importance of longitudinal research in theorising the dynamic and processual dimension of human life. Throughout this study, I have been

witness to what may be seen as a short time in chronology but was the rest of a lifetime to those who died during the study.

This study intended to investigate planning for future care from the perspectives of frail older people and their significant others. However, while the research was designed to be exploratory, it may have influenced participants' knowledge and actions around ACP. It was never intended as an ACP exercise in its own right, but as a result of the serial interview technique, it may have acted as such.

In some cases, evidence of ACP existed without any of the formal and medicalised interventions that are in currently in existence. In others, however, many of the conversations that arose during the interviews prompted questions that encouraged participants to engage in matters of importance to them and of relevance to ACP. Although none of the participants had heard of the ACP process, it should be acknowledged that the content of the first interview may particularly have influenced some thoughts about the process of future planning. This is likely to have influenced the second interview.

At the end of their participation in the study, those who had expressed an interest in the ACP process were given a widely available leaflet. This leaflet was designed by the National Council for Palliative Care and National End of Life Care Programme in conjunction with the University of Nottingham and is called *Planning for your future care: a guide* (National End of Life Care Programme, 2009). This leaflet contains information designed to help the public understand and access help regarding ACP.

8.5.3. Methodological strengths and weaknesses

By interviewing some frail older people and their significant others together, multiple perspectives within those interviews was inevitable. In some cases, there was nobody that the frail older person wanted to share their stories with. In others, participants were happy to be interviewed in hospital alone as it was difficult to arrange interviews with relatives/carers given their own personal circumstances. When follow-up interviews took place in the home, it was inconceivable for some that an interview should

take place without a wife or husband who had been part of their lives for the last 60 years or more.

Sometimes, interviewing people together can constrain a discussion; alternatively they can act as prompts to each other or expand on experiences or issues of relevance (Kendall et al., 2009). For example, conducting a bereavement interview with Kathleen, following the death of her husband, revealed that in her first interview she had very much been constrained by her desire to have a positive outlook on their situation. However, without the significant others who took part, some of the participants in the study may well not have been able to take part at all.

One of this study's weaknesses is that the sample does not represent the ethnic and cultural diversity of the UK population. This is a particular problem when considering autonomy in relation to ACP. This is because previous research suggests that levels of importance placed on autonomy and end-of-life decision making differ throughout different ethnic groups (Caplan et al., 2006, Seymour et al., 2007, Worth et al., 2009, Wilson et al., 2013, Musa et al., 2015). As a result, any conclusions drawn from this study are not meant to be used to generalise throughout the population. Rather, by providing a rich, contextualised account to enhance understanding of human experience, it is hoped that trustworthiness in the findings can be sought (Guba and Lincoln, 2005, Polit and Beck, 2010).

Accessing those with frailty is notoriously difficult. The methodology used in this study was successful in providing a framework to identify the required number of participants, gain access and interview them. Conducting the research using a flexible case study approach was effective in engaging frail older people and their significant others. Moreover, recruiting them in the hospital setting prior to discharge was an effective recruitment strategy.

Throughout the study, I also sought to include some frail older people with cognitive impairment. It is this group who are rarely represented in research of this type, and yet as much as 30 per cent of this population has some degree of cognitive impairment (Goldberg et al., 2012, Bradshaw et al., 2013). Where this was the case, significant others were responsible for

providing the majority of the interview data. However, when interviewing those with cognitive impairment, useful information was gathered about their lives at that moment in time. This in turn gave an insight into the value that was placed on particular activities and relationships.

8.5.4. Implications for practice and research

From the outset, it was an aspiration of mine to use the findings to influence clinical practice. Narratives from research can be helpful in an experiential learning context and can provide clinicians with valuable insight (Benner et al., 2011). The stories that emerged from this study of the changes associated with frailty were powerful and emotive. They also revealed a process of adaptation that was complex and challenging. Understanding and supporting those with frailty as they adapt to the changes they are facing is essential (Van Campen, 2011, Lloyd et al., 2014, Oliver et al., 2014). Moreover, this can then help reinforce their efforts to maintain some level of security and control (Ebrahimi et al., 2013). This study suggests that having a manageable everyday life creates a sense of assurance which can in turn strengthen frail older peoples' experiences. Only by doing this can healthcare professionals begin to work with frail older people and their significant others to understand any future wishes and preference they may have.

Throughout this research study, participants relayed stories relating to care practices, both within the community and acute service for frail older people that are related to lack of dignity and compassion. Although this is recall data, research has shown that dignity and compassion are areas of care that are of paramount importance to patients (Philp, 2007, Tadd et al., 2011, Bramley and Matiti, 2014) and should be fundamental to every care interaction. This study suggests that experiences of poor care may strongly influence decisions regarding current and future care. Practitioners need to be mindful that choices over care should not be dictated by previous experiences that were deemed to be lacking in compassion, unsafe or frightening. In light of this study, it is also necessary to examine with further research how older people's relationships to health and social care services can influence them in decision making in both life and future care. This is particularly important in the practice of ACP as decision relating to future care should not be based solely on poor experience.

Hopelessness can severely compromise health and well-being and in some cases hasten death (Frank and Frank, 1991, Nash, 2015, van Wijngaarden et al., 2015). The findings from this study demonstrate the importance of hope to those living with frailty in terms of maintenance of continuity and coming to terms with the losses in their lives. Kelly (2008) found that frail older people have little support to manage and express emotion or formal care support to help them manage their 'living losses'. This research study suggests that those who are isolated and lacking support networks may require external help from healthcare professionals and carers to nurture hope and manage loss. Further research is needed to understand how healthcare practitioners may nurture hope among frail older people and the effects, if any, this may have.

Previous research highlights that practitioners' worry that ACP can take away hope (Seymour et al., 2010, Boyd et al., 2010, Robinson et al., 2012a). However research conducted with renal patients (Davison and Simpson, 2006) and those with advanced cancer (Green et al., 2015) found that ACP does not adversely affect hope and in some cases can be used to positively enhance it. Further research is required to determine the role of healthcare practitioners in nurturing hope among frail older people and what part if any ACP may have in this.

In view of the complex and multifaceted nature of frailty, the legalistic and ideologically driven policy of autonomy as independence certainly does not seem to capture the interconnectivity of the lives of those living with frailty in this study. Further research is required to inform a model of ACP that is inclusive of and commensurate with the needs of frail older people. Such a model would be one which does not consider the process of discussion of decisions about future care and treatment as an individual autonomous stand-alone endeavour, but instead part of a much wider programme of (palliative) care that maximises the needs of frail older people to live well at the end of their lives.

8.5.5. Researcher reflexivity and reflections

Undertaking research for the first time in an environment that was so familiar to me clinically was more difficult than I had expected. Looking back at the first few interviews, it was clear that I was at the very

beginning of a transformative phase between experienced nurse and nurse researcher. Initially, I found myself assessing the participants in the study as hospital patients, and interviews took a more question-and-answer format rather than a conversational process.

Reflexivity, however, is not just about the moment-to-moment interactions between the researcher and participants (Doyle, 2013). Acknowledging it as part of the wider ontological and epistemological frame of the research study is essential. The interviews were designed to provide a platform for understanding the experiences, understandings and expectations of planning future care. I presented myself as a nurse researcher and took an active role in co-constructing, interpreting and setting out the findings (Riessman, 2008).

As well as learning about the research process during the study, increasing my understanding of the lived world of frailty in such depth has also had an impact on my nursing practice. As a clinician, I worry about the practice of discussing 'do not attempt cardiopulmonary resuscitation' and end-of-life decisions in a bid to be more transparent. I acknowledge that changes are needed but believe that as a profession we have a duty of care to learn more and understand about the impact these discussions can have on frail older people. Since taking on this research study, my confidence has increased and I am more likely to follow up on these conversations. However, my experience puts me in a good position to do this, and I believe that as a profession, nurses cannot be expected to hold these difficult discussions without training to do so.

Furthermore, listening to stories from those who are frail has made me realise that, although I have spent many years communicating with older people, I have never really listened to their personal stories. Doing so as part of the research process has had a profound effect on me both personally and professionally. I now realise that the richness of these stories can offer a multi-dimensional view of the lived world of patients. Frank (2000) asserts that storytelling is the elaboration of the relationship between those sharing the story. If this is the case, then there may be ways in which encouraging patient stories through assessment and implementation of care can enhance the nurse–patient relationship.

Previous research has identified that patient stories can be used in an education field to change perceptions and improve care (Overcash, 2010, Tweedie, 2012). In the future, I am interested in looking more closely at how liberating the voice of frail older people can be used to develop clinical care practice for this group across a wide range of healthcare disciplines.

8.6.   CONCLUSION

The aim of this thesis was to explore the expectations, experiences and understandings of frail older people and their significant others of planning for future care and to examine the implications of this for the practice of advance care planning. The impetus behind it came from a desire to understand how frail older people with cognitive impairment and their significant others might be more prepared to make difficult decisions relating to end-of-life care in acute care environments. However, findings suggest that ACP in its current conceptualisation holds little relevance to the lives of those living with frailty and their significant others.

What emerged from the findings was a complex and dynamic story of living with frailty that has implications for future planning and the practice of ACP. Participants in the study described a process of change, disruption and loss which presented a sustained threat to their identities. This continuous state of flux and imbalance brought about a need to redirect attention to one day at a time, with concentration on health-strengthening behaviours and the positive aspects of their lives.

For those facing increasing dependency on care and care services, lack of autonomy in day-to-day decision making is a reality. The liberal ideal of autonomy as self-determination and self-interest presented by the legalistic and ideologically driven policy of ACP is out of step with the lived worlds of frail older people. The frail older people in this study recognised that their lives will change and as a result so will the care decisions they need to make.

Although calls for a more relational approach to ACP and care of frail older people are not new, this empirical work reinforces the importance of relationships when living with frailty. It also demonstrates the dependent and interdependent nature of frailty within the care system. It raises

questions as to whether asking frail older people to make autonomous decisions regarding their future, when they have little control over day-to-day decisions, is a realistic expectation.

For those with frailty, frameworks that acknowledge a more relational approach when planning future care will be needed in order to engage them. These frameworks will need to concentrate on what helps those with frailty to live well. Frail older people themselves will need to be consulted in order to understand how to address the tensions that are present when making healthcare decisions.

This thesis is significant because it provides a voice to a small group of frail older people who have not been previously well represented in this area. These insights provide some empirical evidence of what may enable or constrain the process of ACP with frail older people and their significant others. The findings highlight and promote the importance of helping those with frailty to live well and concentrate on the positive aspects of life, despite their proximity to death.

The end-of-life orientation of current ACP policy and best-practice guidance in the UK has the potential to undermine the health-strengthening behaviours and needs of frail older people to live well. As a result, frail older people may find themselves marginalised from the more positive benefits of a broader approach to ACP that is emerging from the international literature. Rather than pursuing conversations with a purpose based on anticipating end-of-life care, ACP with frail older people needs to part of an ongoing wider programme of palliative care. This programme of care must focus predominantly on living well and consider the physical, social, psychological and relational aspects of their lives.

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Appendix A: Interview aide memoires

The University of Nottingham

Aide Memoire

Planning Future Care Study 1st Interview

These are the main themes of the initial interview.

The questions below will act as prompts for the interviewer as opposed to a list of questions that will be asked in turn. It is anticipated the interviewee will be given the opportunity to talk at length about these issues.

Purpose: To build a rapport with the participants, gain understanding of their current situation and healthcare needs.

Topic	Potential questions	Objectives
Introductory: Understanding of diagnosis and prognosis (developing/recognition of health problems)	• Can you tell me about being admitted to hospital and your illness? • Has your health been deteriorating for a while? • How has being admitted to hospital made you feel about your health?	2
Reflection of care Needs and impact of hospital admission	• What are the challenges you face because of your health? • Have your health needs changed? • How do you feel about that?	2

Level of communication: With health professionals and close persons/relatives	• Has anybody spoken to you about your health whilst in hospital?
	  • Anybody else?
	  • If so what about
	  • How do you feel about that?
	• Who do you usually/like speak to?
	• Is there anybody else you would like to speak to?
	• Have you thought about future care?
	• Have you talked about this with your family?
		2/3

Decision making about current care	• Have you had to make any decisions about your health or healthcare needs? • Who helps you make decisions? • How do you let others know about these decisions?	2/3
Is there anything that we have talked about that you wish to say more about, or anything else you would like to say?		
General Prompts:	• Can you tell me more about that? • How do you feel about that? • Are you worried about that? • What happened then? Or ... And then? • Why do you think that happened	

In addition to the above, field notes and a reflective diary will be kept.

1st memew AIDE MEMOIRE The Planning Your Future Care Study V1.0 26/11/2013

The University of Nottingham

Aide Memoire
Planning Future Care Study 2nd Interview

These are the main themes of the initial interview.

The questions below will act as prompts for the interviewer as opposed to a list of questions that will be asked in turn. It is anticipated the interviewees will be given the opportunity to talk at length about these issues.

Purpose: To reflect on the hospital admission and time at home since the last interview. To understand expectations for future care and the hospital's role in this

Topic	Potential questions	Objectives
Health status since last interview	• Can you tell me about how things have been for you since being discharged from hospital? • Is your health different from before the admission? • What challenges do you face now and how has this been since you were discharged? • Where these challenges addressed in hospital or since then? If not... Why do you think this is? What would you have liked to talk about? And with who?	2/3
Wishes and preferences for future care	• Has being in hospital made you think about your future healthcare? • Have you ever thought about what might happen if you were admitted to hospital and were unable to make you own decisions? • How do you feel about discussing these issues? • Have you ever talked to anyone about this? Who?	2/3
Level of communication: With health professionals and close persons/relatives	• Since leaving hospital is there any information that you needed but did not get? • How and when would be a good time to receive this? • Who would you have liked to give you this information? • Why do you think this is? • How do you feel about this?	2/3
Is there anything that we have talked about that you wish to say more about, or anything else you would like to say?		
General Prompts:	• Can you tell me more about that? • How do you feel about that? • Are you worried about that? • What happened then? Or ... And then? • Why do you think that happened	

In addition to the above, field notes and a reflective diary will be kept.

2nd Interview Aide Memoire The Planning Your Future Care Study V1.0 26/11/2013

Appendix B: Approvals

NHS
Health Research Authority

NRES Committee East Midlands - Nottingham 1
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839525

06 February 2014

Professor Jane Seymour
Sue Ryder Care Professor of Palliative and End of Life Studies
University of Nottingham
Sue Ryder Care Centre for the study of supportive, palliative and end of life care
School of health Sciences, University of Nottingham
Queen's Medical Centre, Nottingham
NG7 2UH

Dear Professor Seymour

Study title:	Advance Care Planning Towards the End of Life in Frail Older People: Implications for Acute Hospital Care.
REC reference:	14/EM/0004
Protocol number:	13144
IRAS project ID:	135608

Thank you for your letter of 31 January 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Helen Wakefield, nrescommittee.westmidlands-edgbaston@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

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

Non-NHS sites

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.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study 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 a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

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

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the 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 final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		27 November 2013
Evidence of insurance or indemnity	Henderson Corporate	31 July 2013
GP/Consultant Information Sheets	1.0	26 November 2013
Investigator CV	Professor Jane Seymore	25 April 2013
Letter from Sponsor	University of Nottm	27 November 2013
Other: Investigator's CV	Karen Cox	27 November 2013
Other: Investigator's CV - Student	Louise Bramley	27 November 2013
Other: 1st Interview Aide Memoire	1.0	26 November 2013
Other: 2nd Interview Aide Memoire	1.0	26 November 2013
Other: Capacity Assessment Tool	1.0	26 November 2013
Other: Condolence Letter	1.0	26 November 2013
Participant Consent Form: Relative/Carer	2.0	31 January 2014
Participant Consent Form: Patient	2.0	31 January 2014
Participant Consent Form: Advice Form Consultee	2.0	31 January 2014
Participant Consent Form: Follow Up Patient Consent Form 2	1.0	31 January 2014
Participant Information Sheet: Summary Sheet	1.0	26 November 2013
Participant Information Sheet: Patient Information Sheet	2.0	31 January 2014

Participant Information Sheet: Consultee Advice Sheet	2.0	31 January 2014
Participant Information Sheet: Relative/Carer Acting as a Consultee Information Sheet	1.0	31 January 2014
Participant Information Sheet: Relative/Carer Information Sheet	2.0	31 January 2014
Participant Information Sheet: Follow Up Patient Information Sheet	1.0	31 January 2014
Participant Information Sheet: Follow Up Summary Patient Information Sheet	1.0	31 January 2014
Protocol	1.0	26 November 2013
REC application	135608/533297/1/646	27 November 2013
Referees or other scientific critique report	University of Nottm	05 July 2013
Response to Request for Further Information	Letter	31 January 2014

Statement of compliance

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

After ethical review

Reporting requirements

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
- Notification of serious breaches of the protocol
- 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.

Feedback

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.

Further information is available at National Research Ethics Service website > After Review

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

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

Yours sincerely

PP

Mr Robert Johnson
Chair

Email:nrescommittee.westmidlands-edgbaston@nhs.net

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Copy to: *Paul Cartledge, University of Nottingham*
       Mrs Alison Steel, Nottingham University NHS Trust

Research & Innovation
Nottingham Integrated Clinical Research
Centre

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Tel: 0115 9249924 ext 70659
www.nuhrise.org

Ms Maria Bentley
EENT Building
Queens Campus
Nottingham University Hospitals NHS Trust
Derby road
Nottingham
NG7 2UH

7th February 2014

Dear   **Ms Maria Bentley**

Re: **13PC006**

CSP

REC   **14/EM/0004**
The Planning Your Future Care Study

The R&I Department have reviewed the following documents and NHS permission for the above research has been granted on the basis described in the application form, protocol, and supporting documentation. The documents reviewed were:

Participant Consent Form: Relative/Carer v2.0 dated 31 Jan 2014
Participant Consent Form: Patient v2.0 dated 31 Jan 2014
Participant Consent Form: Advice form Consultee v2.0 dated 31 Jan 2014
Participant Consent Form: Follow up patient consent form 2 v1.0 dated 31 Jan 2014
PIS: Summary Sheet v1.0 dated 26 Nov 2013
PIS: PIS v2.0 dated 31 Jan 2014
PIS: Consultee Advice Sheet v2.0 dated 31 Jan 2014

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PIS: Relative/carer acting as a consultee information sheet v1.0 31 Jan 2014
PIS: Relative/Carer information sheet v2.0 dated 31 Jan 2014
PIS: Follow up PIS v1.0 dated 31 Jan 2014
PIS: Follow up summary PIS v1.0 dated 31 Jan 2014
Consultant/GP letter v1.0 dated 26.11.2013
Condolence Letter v1.0 dated 26.11.2013
Capacity Assessment Tool v1.0 dated 26.11.2013
1st Interview aide memoire v1.0 dated 26.11.2013
2nd Interview Aide Memoire v1.0 dated 26.11.2013
Protocol v1.0 dated 26 November 2013

Your study now has NHS permission , on the understanding and provision that you will follow the conditions set out below.

Conditions of Approval

The Principal Investigator is responsible for

1. Compliance with all relevant laws, regulations and codes of practice applicable to the trial including but not limited to, the UK Clinical Trials Regulations, Medicines for Human Use (Clinical Trial) Regulations 2004, principles of Good Clinical Practice, the World Medical Association Declaration of Helsinki entitled 'Ethical Principles for Medical Research Involving Human Subjects' (1996 version), the Human Rights Act 1998, the Data Protection Act 1998 the Medicines Act 1968, the NHS Research Governance Framework for Health and Social Care (version 2 April 2005). Should any of these be revised and reissued this will apply. Copies of the up-to-date regulations are available from the R&I Office or via the R&I website http://nuhrise.org

2. Submission of study amendments to the Ethics committee and MHRA in accordance with the IRAS guidelines. Amendments and information with regards to changes in study status must be sent to R&I, (this includes changes to the local study team). Within 35 days from the receipt of a valid amendment submission, NUH will inform you if may not locally implement the amendment. If no objections are raised NHS permission is valid and the amendment may be implemented.

   When submitting documents for studies adopted into the NIHR portfolio please send the information to NUHNT.TRENTCLRN@nhs.net
   When submitting documents for all other studies please use the email address rdamend@nuh.nhs.uk

3. Ensuring all study personnel, not employed by the Nottingham University Hospitals NHS Trust hold either honorary contracts/letters of access with this Trust, before they have access to any patients or staff, their data, tissue or organs or any NUH facilities.

4. In accordance with the Department of Health's Plan for Growth, for initialising and delivering research

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within the NHS the 'first patient, first visit should occur 70 days from receipt of a valid submission in R&I. Therefore for all research where :

- The sponsor is a commercial partner
- NUH holds a funding contract with the National Institute for Health Research (NIHR)
- The research is classed as a "clinical trial "on the IRAS filter page.

The research team is expected to collaborate with the department of R&I in reporting recruitment data to rdmon@nuh.nhs.uk.

1. For GTAC-approved studies, the NHS permission should be forwarded to GTAC via the sponsor. GTAC should then issue a site authorisation letter which must be received by each site prior to recruitment commencing. A copy of this letter must be forwarded to R&I.

2. Comply with requests from NUH R&I to allow monitoring of research to comply with the Research Governance framework.

3. Record _all_ types of adverse events (including Suspected Unexpected Serious Adverse Drug Reaction - SUSARS) in the patient medical records and study documentation and report to the sponsor as required by the protocol. Further guidance can be found in R&I SOP 11 - "Adverse Event Monitoring, Recording and Reporting for investigators".

4. Report any Serious Breach of the UK Clinical Trial regulations in connection with the trial or Serious Breach of the protocol, immediately after becoming aware of the breach to the study sponsor.

For NUH sponsored studies only, the Chief Investigator is responsible for:

i. All duties as detailed in the "Clinical Trial Delegation of Sponsorship responsibilities to Chief Investigator" agreement.

ii. Contacting the sponsor for review of all amendment documentation prior to submission to NRES and MHRA. Please note that according to NRES and MHRA regulations, all submissions of amendments need to be signed by the authorised sponsor's representative. All relevant documentation should be emailed to **rdappl@nuh.nhs**.

iii. Send copies of the completed Annual Safety, Progress reports and End of Study reports required by the Ethics Committee and the MHRA (if appropriate) to the Quality Assurance manager at NUH R&I.

iv. Notify NUH R&I of all SAEs by completing and sending the *"Serious Adverse Event reporting form"* to R&I **(only via fax, e-mail or by hand),** within 24hrs of becoming aware of the event. If the event is defined as a SUSAR then a follow up report must also be submitted to R&I, via the above channels-**no longer than 7 days after the original report was submitted**

v. Reporting any Serious Breach of the UK Clinical Trial regulations in connection with the trial or Serious Breach of the protocol, immediately after becoming aware of the breach to NUH R&I as sponsor. Further guidance can be found in R&I SOP 12 "Protocol Violation and Serious Breach Reporting"

We are here for you

This approval letter constitutes a favourable Site Specific Assessment (SSA) for this site.

Please note that the R&I department maintains a database containing study related information, and personal information about individual investigators e.g. name, address, contact details etc. This information will be managed according to the principles established in the Data Protection Act.

Yours sincerely,

Dr Brian Thomson / Dr Maria Koufali
Director of Research and Innovation / Deputy Director Research and Innovation

cc Nottingham Research Ethics Committee

We are here for you

Appendix C: Patient participant information sheet

The University of Nottingham

PATIENT INFORMATION SHEET

Title of Study: The Planning Your Future Care Study

Name of Researcher: Louise Bramley

I would like to invite you to take part in my research study alongside your relative or the person who helps care for you. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Please ask if there is anything that is not clear.

What is the purpose of the study?
People are living longer and it is important to understand what impact the ageing process has on our future lives. Sometimes, after being ill in hospital, older patients' needs change. Health professionals are expected to talk to patients and their relatives or carers about their needs and to help them to make plans to meet them now and in the future. This may include expressing wishes and preferences which can guide future care planning and treatment decisions in case at any time patients are no longer able to express their own needs. It may also include patients and their relatives talking about planning future care together. We already know that there is a range of opinions about future care planning. The purpose of this study is to talk to older people who have been hospitalised and their relatives/carers so that we can understand their views about future care planning and to find out whether this is something they had the opportunity to do while in hospital or after discharge and how this felt.

Why have I been invited?
You have been invited to take part because you have been admitted to hospital and as a result may have first-hand experience of planning future care. You may also have expectations of what future care you may need or want. I am inviting up to 20 other people like you to be involved.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights or the standard of care you receive during your stay in hospital.

What will happen to me if I take part?
If you and your relative or the person that cares for agree to take part:

- You will have a confidential interview together (or separately if you wish) lasting about one hour. I will ask you and your relative or the person that cares for you questions about you being in hospital and any experiences of planning future care you may have. I will also ask what expectations if any, you may have about this process. This will not delay discharge from hospital or affect the care you receive if you decide not to take part.

- You will also be asked to take part in a follow up confidential interview at home or that of your relative or the person caring for you. This will be about 4-6 weeks following your discharge from hospital. I will ask you and your relative or person that cares for you, to reflect on your hospital admission and how this may have affected the care that you would wish to receive in the event of future illness and hospital admission.

- Prior to this interview, I will contact you 24-48 hours before to make sure you are happy with the interview time and place and still wish to be part of the study.

Will I be paid to take part in the study?
Participants will not be paid to participate in the study.

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What are the possible disadvantages and risks of taking part?
I do not think there is any risk to taking part in this study; all I need is the time to complete the interviews from you. As the subject of the interviews will reflect the hospital admission and views and any experiences you have had of planning any future care, you may find this upsetting. However, many people find it helps to talk about things. I have experience of nursing older patients and dealing with relevant issues should they arise during the interview.

What are the possible benefits of taking part?
I cannot promise the study will help you, but the information from this study may help hospital staff to understand the types of information that patients and their relatives/carers need to plan their future care during and following an admission to hospital.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to me - Louise Bramley - the researcher, and I will do my best to answer your questions. My contact details are at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by writing to PALS at the address at the end of this leaflet.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of your electronic medical records and the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Should there be any reason to believe that the care you have received from individual staff members whilst in hospital has been contrary to hospital policy, I will report it to the appropriate people e.g. the nurse in charge of the ward or Matron.

What will happen if I don't want to carry on with the study?
This will not affect any of the care you receive in hospital. Your participation is voluntary and you are free to withdraw at any time, without giving any reason and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

Involvement of the General Practitioner/Family doctor (GP)
With your permission, your hospital consultant and GP will be informed of your participation in the study. They will be told that you have participated in interviews about planning future care and that some of the information discussed may have been upsetting. This means that should you require any information or wish to discuss any of the issues raised further with them they will be aware of the study. The contents of the interview will remain confidential.

What will happen to the results of the research study?

Planning future care study Patient Information Sheet Draft 1.0

The findings of the study are to be written up as part of a Higher Degree at the University of Nottingham to be submitted no later than September 2016. The results may be used in publications and presentations and to inform future research, policy and hospital practice.

Who is organising and funding the research?
This research is being organised by the University of Nottingham as part of a higher degree.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Committee.

Further information and contact details
Thank you for reading this information sheet, and for considering taking part in the study. For further information in the first instance please contact:

Researcher: Information removed for confidentiality purposes

Chief Investigator: Information removed for confidentiality purposes

Complaints can be addressed to: Information removed for confidentiality purposes

Further independent advice can be sought from: Information removed for confidentiality purposes

Planning future care study Patient Information Sheet Draft 1.0

Appendix D: Significant other participant information sheet

The University of Nottingham

RELATIVE/CARER INFORMATION SHEET

Title of Study: The Planning Your Future Care Study

Name of Researcher: Louise Bramley

I would like to invite you to take part in my research study alongside your relative or the person you care for. Before you decide I would like you to understand why the research is being done and what it would involve for you. I will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Please ask if there is anything that is not clear.

What is the purpose of the study?

People are living longer and it is important to understand what impact the ageing process has on our future lives. Sometimes, after being ill in hospital, older patients' needs change. Health professionals are expected to talk to patients and their relatives or carers about their needs and to help them to make plans to meet them now and in the future. This may include expressing wishes and preferences which can guide future care planning and treatment decisions in case at any time patients are no longer able to express their own needs. It may also include patients and their relatives talking about planning future care together. We already know that there is a range of opinions about future care planning. The purpose of this study is to talk to older people who have been hospitalised and their relatives/carers so that we can understand their views about future care planning and to find out whether this is something they had the opportunity to do while in hospital or after discharge and how this felt.

Why have I been invited?

You have been invited to take part because your relative or the person you care for has been admitted to hospital and as a result may have first-hand experience of planning future care. You may also have expectations of what future care your relative or the person you care for may need or want. I am inviting up to 20 other people like you to be involved.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

If you and your relative or the person you care for agree to take part:

- You will have a confidential interview together (or separately if you wish) lasting about one hour. During the interview I will ask you and your relative or the person you care for questions and need you to give your opinion or fill in the gaps if he/she is unable. I will ask questions about being in hospital and any experiences of planning future care you may have. I will also ask what expectations if any, you may have about this process. This will not delay discharge from hospital or affect the care your relative or the person you care for receives if you decide not to take part.

- You will also be asked to take part in a follow up confidential interview at home or that of your relative or the person you care for. This will be about 4-6 weeks following discharge from hospital. I will ask you both to reflect on the recent hospital admission and how this may have affected the care he/she would wish to receive in the event of future illness and hospital admission.

- Prior to this interview, I will contact you 24-48 hours before to make sure you are happy with the interview time and place and still wish to be part of the study.

Will I be paid to take part in the study?

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Participants will not be paid to participate in the study

What are the possible disadvantages and risks of taking part?
I do not think there is any risk to taking part in this study; all I need is the time to complete the interviews from you. As the subject of the interviews will reflect the hospital admission and views and any experiences you have had of planning any future care for your relative or the person you care for, you may find this upsetting. However, many people find it helps to talk about things. I have experience of nursing older patients and dealing with relevant issues should they arise during the interview.

What are the possible benefits of taking part?
I cannot promise the study will help you but the information we get from this study may help hospital staff to understand the types of information that patients and their relatives / carers need to plan their future care during and following admission to hospital.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to me Louise Bramley - the researcher, and I will do my best to answer your questions. My contact details are at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by writing to PALS at the address at the end of this leaflet.

Will my taking part in the study be kept confidential?
We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, data collected for the study will be looked at by authorised persons from the University of Nottingham. All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Should there be any reason to believe that the care your relative or the person you care for has received from individual staff members whilst in hospital has been contrary to hospital policy, I will report it to the appropriate people e.g. the nurse in charge of the ward or Matron.

What will happen if I don't want to carry on with the study?
Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?
The findings of the study are to be written up as part of a Higher Degree at the University of Nottingham to be submitted no later than September 2016. The results may be used in publications and presentations and to inform future research, policy and practice.

Who is organising and funding the research?
This research is being organised by the University of Nottingham as part of a higher degree.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Committee.

Further information and contact details
Thank you for reading this information sheet, and for considering taking part in the study. For further information in the first instance please contact:

Researcher: Removed for confidentiality purposes

Chief Investigator: Removed for confidentiality purposes

Complaints can be addressed to: Removed for confidentiality purposes

Further independent advice can be sought from: Removed for confidentiality purposes

Appendix E: Participants summary sheet

The University of Nottingham

Planning Future Care Study
Summary Patient Information

I would like to invite you and your relative/carer to take part in a research study.

People are living longer and it is important to understand what impact the ageing process has on our future lives. Sometimes, after being ill in hospital older patients' care needs change. Health professionals are expected to talk to patients and their families/carers to help plan, reflect and prepare for future care. This may include expressing wishes which can guide future care planning in case they are unable to express their own needs. We already know a range of opinions on this subject but not from patients and their relatives/carers in hospital. The purpose of this study is to find out how you feel about this before and after an admission to hospital.

If you take part:
- You will have a confidential interview together (or separately if you wish) lasting about one hour. I will ask you and your relative/carer questions about you being in hospital and any experiences of planning future care you may have. I will also ask what expectations if any, you may have about this process. This will not delay discharge from hospital or affect the care you receive if you decide not to take part.

- You will also be asked to take part in a follow up confidential interview at home or that of the person caring for you. This will be about 4-6 weeks following your discharge from hospital. I will ask you and your relative/carer to reflect on your hospital admission and how this may have affected the care that you would wish to receive in the event of future illness and hospital admission.

- Prior to this interview, I will contact you 24-48 hours before to make sure you are happy with the interview time and place and still wish to be part of the study.

You do not have to take part if you do not want to.
Please ask if you need more time to make up your mind or if you need to know any more information. You can stop taking part at any time without giving a reason and your care will not be affected in any way.

There should be no risks from the study
An independent ethics committee has looked at the study and is happy to let me carry it out. Please let me know if you are worried about this study.

Any information we collect will be kept strictly private.
The results may be used in publications and presentation to other hospital staff. It will be written up as part of a higher degree at the University of Nottingham but your name will never be mentioned.

Researcher details removed for confidentiality purposes

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Patient Summary Sheet The Planning Future Your Future Care Study V1.0 26/11/13

Appendix F: Condolence letter

Date

Dear

I am writing to say how sorry I am to hear of your (relationship to relative/carer) recent death. I would like to offer you my sincere condolences.

You kindly took part in an interview recently and at the time you agreed to talk to me again. I realise that you will have much to attend to at the moment. However, if you are willing to do so, I would still like to talk to you about the care your (relationship) received during his/her (delete as appropriate) illness and I will phone you in a few weeks to see if you are still interested in taking part in an interview.

In the meantime, if you would like to get in touch with me I can be contacted by phone on: removed for confidentiality purposes.

Yours Sincerely

Louise Bramley

Condolence Letter The Planning Your Future Care Study V1.0 26/11/13

Appendix G: Two-stage capacity test

Capacity assessment tool

Planning future care for frail older people

Patient Name:

Researcher Name: Louise Bramley

Date of assessment:

Two stage capacity assessment:

Stage 1: Is there an impairment of, or disturbance in the functioning of a person's mind or brain? If so,

Stage 2: Is the impairment or disturbance sufficient that the person lacks the capacity to make a particular decision?

Can the person (free from undue pressure):	Yes	No
Understand information about the study?		
Retain the information (for long enough to make a decision)?		
Use it to make a decision?		
Communicate the decision?		

If yes to all – patient has capacity.
If no to any – patient lacks capacity

Patient has capacity?		

If **yes,** ask patient if they are willing to take part and nominate a carer. Seek written informed consent from participant and carer.

If **no,** await carer before approaching patient; seek consultee consent and carer-participant consent.

Capacity Tool The Planning Future Your Future Care Study V1.0 26/11/13

Appendix H: Consultee advice sheet

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

CONSULTEE ADVICE SHEET

Title of Study: The Planning Your Future Care Study

Name of Researcher: Louise Bramley

Your relative (it could also be a friend or someone you care for, but for brevity this document will use the term 'relative') is being invited, alongside you to take part in a research study.

Before you decide whether you agree to their participation it is important for you to understand why the research is being done and what it will involve. I will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask me if there is anything that is not clear or if you would like more information.

Who can act as a consultee?
Where people cannot take the decision to consent to be involved in a research project then a consultee must be appointed. A personal consultee is someone unconnected with the research who knows the potential research participant in a personal capacity and is able to advise on the person's wishes or feelings. This can be a friend, family member or court appointee.

What is the role of the consultee?
The consultee advises the researcher on what the participant's wishes and feelings would be if they were able to consent for themselves, and on whether they should take part. The consultee does not give consent, only advice. The responsibility to decide whether the participant should be entered into the research lies ultimately with the researcher. Consultees will be provided with information about the research project and will be given the opportunity to discuss it and their role as consultee. All consultees must be able to understand their role and be willing to undertake it.

What is the purpose of the study?
People are living longer and it is important to understand what impact the ageing process has on our future lives. Sometimes, after being ill in hospital older patients' care needs change and healthcare professionals are expected to help patients and their families or people that care for them to plan, reflect and prepare for future care. The purpose of this study is to talk to older people who have been hospitalised and their relatives/carers so that we can understand their views about future care planning and to find out whether this is something they had the opportunity to do while in hospital or after discharge and how this felt.

Why has my relative been chosen?
Your relative alongside you is being invited to take part because he/she has been admitted to hospital and as a result may have first-hand experience of planning future care. He/she may also have expectations of what future care may be needed or wanted. I am inviting up to 20 other similar people to be involved.

Does my relative have to take part?
We would like you to think very carefully about whether or not your relative would have wanted to join the study. If your opinion is that he/she would have decided to take part, you would be given this information sheet to keep and be asked to sign a declaration form indicating your view allowing you're relative to participate in the study. If you later decide that he/she no longer wishes to take part, please inform us and he/she will be withdrawn from the study. You do not need to give a reason and **it will not affect the standard of care your relative receives.**

What will happen to my relative if they take part?

- Your relative will have a confidential interview alongside you lasting about one hour. During the interview I will ask you and your relative questions and need you to give your opinion or fill in the gaps if he/she is unable to do so. I will ask you both questions about being in hospital and any experiences of planning future care you may both have. I will also ask what

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expectations if any, you both may have about this process. This will not delay discharge from hospital or affect future care you receive if a decision is made not to take part.

- I will also ask you both to take part in a follow up confidential interview at home. This will be about 4-6 weeks following discharge from hospital. During this interview, I will ask you both to reflect on the recent hospital admission and how this may have affected the care that he/she would wish to receive in the event of future illness and hospital admission.

- Prior to this interview, I will contact you 24-48 hours before to make sure you are happy with the interview time and place and that you and your relative still wish to be part of the study.

Will my relative be paid to take part in the study?
Participants will not be paid to participate in the study.

What are the possible disadvantages or risks of taking part?
I do not think there is any risk to taking part in this study; all I need is the time to complete the interviews from you and your relative. As the subject of the interviews will reflect the hospital admission and views and any experiences you have had planning any future care for your relative, you or they may find this upsetting. However, many people find it helps to talk about things. I have experience of nursing older patients and dealing with relevant issues should they arise during the interview.

If during the interviews you or your relative becomes upset, distressed or tired, the interview can be stopped until you feel able to continue. If you no longer wish to continue the interview but want to remain part of the study, an alternative time to continue the interview can be arranged that is convenient to you. If you do not wish to continue you are free to withdraw from the study at any time.

What are the advantages of taking part?
I cannot promise the study will help your relative, but the information from this study may help hospital staff to understand the type of information that patients and their relatives or people that are caring for them need to plan future care during and following an admission to hospital.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to me the researcher Louise Bramley, and I will do my best to answer your questions. My contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by writing to PALS at the address at the end of this leaflet.

Will information gained whilst taking part in this study be kept confidential?
We will follow ethical and legal practice and all information about your relative will be handled in confidence.

If your relative joins the study, some parts of their electronic medical records and the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to your relative as a research participant and we will do our best to meet this duty.

All information which is collected about your relative during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about your relative which leaves the hospital will have your relative's name and address removed (anonymised) and a unique code will be used so that he/she cannot be recognised from it.

Your relative's personal data (address, telephone number) will be kept for 6 months after the end of the study. All other data (research data) will be kept securely for 7 years. After this time your relative's data will be disposed of securely. During this time all precautions will be taken by all those

The Planning Your Future Care Study Consultee Information Sheet V2.0 31/01/14

involved to maintain your relative's confidentiality, only members of the research team will have access to their personal data.

The only exception to this this confidentiality will be if you disclose information which raises concerns about the safety of the person you care for or about care they have received either within the hospital or your own home. If any serious concerns arise, I will discuss these with you where possible and if necessary report them to the appropriate person. I will always make every effort to contact you and discuss with you any need to break confidentiality in this way before contacting anyone else.

What will happen if I do not want my relative to carry on with the study?
This will not affect any of the care your relative will receive in hospital. Your relative's participation is voluntary and you are free to withdraw at any time, without giving any reason and without yours or their legal rights being affected. If you withdraw then the information collected so will be used in the project analysis unless you specifically state otherwise.

Involvement of the General Practitioner/Family doctor (GP)
With your permission, your relative's hospital Consultant and GP will be informed of their participation in the study. They will be told that your relative has participated in interviews about planning future care and that some of the information discussed may have been upsetting. This means that should you require any information or wish to discuss any of the issues raised further with them they will be aware of the study. The contents of the interview will remain confidential.

What will happen to the results of the study?
The findings of the study are to be written up as part of a Higher Degree at the University of Nottingham to be submitted no later than September 2016. The results may be used in publications and presentations and to inform future research, policy and hospital practice.

Who is organising and funding the research?
This research is being organised by the University of Nottingham as part of a higher degree.

Who has reviewed this study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by (information removed for confidentiality purposes).

Further information and contact details
Thank you for reading this information sheet. For further information in the first instance please contact:

Researcher: Information removed for confidentiality purposes.

Chief Investigator: Information removed for confidentiality purposes.

Complaints can be addressed to: Information removed for confidentiality purposes.

Further independent advice can be sought from: Information removed for confidentiality purposes.

The University of Nottingham

ADVICE FORM CONSULTEE

Title of Study: The Planning Your Future Care Study

REC ref: 14/EM/0004

Name of Researcher: Louise Bramley

Name of Consultee:

Name of Participant: **Please initial box**

1. I the above named consultee have been consulted about the above named participant's participation in this research project. I have read and understand the consultee information sheet version number 2.0 dated 31/01/14 for the above study and have had the opportunity to ask questions. ☐

2. I understand that I can request he/she is withdrawn from the study at any time, without giving any reason, and without their medical care or legal rights being affected. I understand that should I withdraw then any information collected so far will be used in the project analysis unless I specifically state otherwise ☐

3. I understand that relevant sections of their medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to their taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from their participation in this study. I understand that all personal details will be kept confidential. ☐

4. I agree to their GP and Consultant being informed of participation in this study. ☐

5. In my opinion he/she would have no objection to taking part in the above study. ☐

_____   _____   _____
Name of Consultee   Date   Signature

_____   _____   _____
Name of Person taking advice   Date   Signature
on behalf of the chief investigator

3 copies: 1 for consultee, 1 for the project notes and 1 for the medical notes of the participant

Consultee Advice Form The Planning Your Future Care Study V 2.0 31/01/14

Appendix I: Consultant/GP letter

The University of Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

(details removed for confidentiality purposes)

[Insert GP/Consultant address]

Dear Doctor

Re:

I am writing to inform you that [patient name] has agreed to take part in an interview based research study about advance care planning in frail older people. I have attached a participant information sheet for your information.

Participants for this study have been recruited following an acute hospital admission and will be interviewed post discharge. Due to the nature of the topic, the interviews may touch on sensitive and emotive issues regarding end of life care and specifically advance care planning for end of life care. Every effort will be made to ensure that participants are debriefed following participation in the study and will be provided with any information they require regarding end of life care.

Should you require any further information regarding the study, please do not hesitate to contact me at any time.

Yours Sincerely

Louise Bramley

CONSULTANT/GP LETTER The Planning Your Future Care Study V1.0 26/11/13