'AM I STILL HERE?':
A LONGITUDINAL, ETHNOGRAPHIC
STUDY OF LIVING WITH FRAILTY

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Abstract

Purpose: To explore how older people with complex problems experience and make sense of frailty in their daily lives.

Relevance: Frail older people have complex care and support needs that are currently challenging the health and social care system. There is a need for more appropriate models of service provision that can deliver personalised care for frail older people. Although there is an increasing body of literature that has explored the concept of frailty from a biomedical and functional perspective, there is a lack of research-based evidence exploring the personal experience of frailty from an older person's perspective.

Study design: A prospective, longitudinal, ethnographic case study design was adopted. Ten cases were studied over a period of two and a half years. Each case comprised an older person, a community matron and a significant other, such as a daughter. Cases were followed up monthly for a minimum of six months or until death. In total, 56 care visits between an older participant and their community matron were observed and 54 interviews were conducted with older people. Medical and nursing documents were reviewed for each case. A narrative approach to data analysis was undertaken, with identification of common themes within and across cases.

Findings: Three themes illuminated the experience of living with frailty. '*Transitions in health and illness'* details how the older people in this study experienced transitions in health and illness in later life. '*Dimensions of frailty'* reports perceptions of frailty in later life and accounts of how feeling frail relate to episodes of uncertainty. '*The provision of health and social care – rhetoric and reality'* explores the inter-relationship between the older person's world of declining health and the episodic interactions with health professionals.

Conclusions: This study offers a number of original contributions to the body of knowledge pertaining to the personal experience of frailty. First, new insights into the interrelationship between frailty and transitions in health and illness have been revealed, particularly how transitions in health and illness contribute to and shape the experience of frailty. Second, frail older people experience temporary moments of 'liminality' which are expressed as uncertainty and/or feeling frail. It is in these situations where there is real therapeutic potential in exploring the emotional experiences linked to a frail older person's interpretation of events. Third, there are challenges to engaging in partnership working with frail older people. In some circumstances frail older people can exercise autonomy and make decisions that are relevant to their own situation. However, often community matrons' work is framed by a policy of clinical assessment and therefore at times assumptions underpinning the label of frailty can challenge partnership working. These competing demands need to be considered by policy makers, commissioners and providers of community services and practitioners alike. Only then can effective supportive care services be delivered to frail older people.

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Glossary of terms

COPD   Chronic Obstructive Pulmonary Disease

CPAP   Continuous Positive Airway Pressure

LREC   Local Research Ethics Committee

LRGC   Local Research Governance Consortium

LTC   Long Term Condition

PCT   Primary Care Trust

PPOC   Preferred Priorities of Care

Key to extracts of observational, interview and case account data

Italics   Participant interview extracts

Non-italic   Field note/field journal/observations

Boxes   Case account extracts

Chapter 1: Introduction

1.1 Introduction

The aim of this study was to contribute to the knowledge base relating to frailty in later life. It was intended that the findings would inform the development of current and future nursing and health care practice, as well as health and social policy. Although there is an increasing body of literature that has explored the concept of frailty from a biomedical perspective, there is a lack of research based evidence exploring the experience of frailty from an older person's perspective. This was the focus of the study.

The introduction to this thesis is in two sections. In the first section I outline the rationale for this study, illuminating the importance of the enquiry. I also describe my professional background and interests that led to the study. In the second section I provide an overview of the thesis, detailing the research questions and methodology and the content of each chapter.

1.2 The relevance of this study

1.2.1 Demographic trends

It is now widely acknowledged that the proportion of older people in the United Kingdom (UK) is growing. In 2010 20% of the total population were over the age of 65, with almost half of these being over the age of 75 (Office for National Statistics (ONS) 2010). In twenty-five years it is anticipated that those over the age of 65 will account for 23% of the total population. It is also expected that by 2035 the numbers of people aged at least 85 will be more than double what they were in 2010, reaching 3.5 million (ONS 2010). Whilst it is recognised that many older people will continue to experience good health, for many the experience of growing into advanced old age will be associated with multiple health problems and co-morbidity. The experience of ill-health is more likely to occur in the 'fourth age', after the age of 75 years (Laslett 1989), and may be further compounded by situational constraints, including poverty, social isolation and increased dependency (Grenier 2012). Furthermore, the 'fourth age' is often associated with a period of decline and infirmity which ultimately leads to the end of life (Laslett 1989; Gilleard and Higgs 2010). This has implications for the use of health and social services in

that as people age and experience poor health and co-morbidities the need for in-patient and community services is likely to increase. For example, Tadd et al (2011) identified that the mean age of patients in hospital in England was eighty. Furthermore, in England of the 500,000 people who received care in their own home over three quarters were aged 75 and over. Similarly, over half the case load of community nurses was found to comprise older people (Department of Health 2004).

1.2.2 Frailty as a description of old age

Within contemporary society the term frail is frequently used to describe those older people who are experiencing complex health problems and are in receipt of health and social care services (Browne and Markle-Reid 2003; Levers, Estabrooks and Ross Kerr 2006). Furthermore, it is often associated with an inability to maintain autonomy and independence in daily living (Gilleard and Higgs 2010; Van Campen 2011). In the UK these defining features of frailty underpin government policy that addresses the health and social requirements of older people (Department of Health (DOH) 2001; DOH 2011). Moreover, they often determine access to a range of health and social services, including end of life care (Nicholson et al 2012b). It is important that current health and social care services are able to support older people with complex requirements, particularly at the end of their lives; however there are difficulties inherent in accessing such services. Although the term frail is commonly used in practice and aspects of frailty can be observed by those who work with older people it remains difficult to define.

In an early literature review Browne and Markle-Reid (2003) identified that older people were considered to be frail when there were indications of one or more of the following: functional impairment and dependence on others; poor physical health; disability; vulnerability; poor mental health functioning; requiring informal/formal or long term care to meet basic needs; and simply old age in chronological terms. In the context of an ageing population it has been recognised that the development of indicators that can identify those who are frail, or at risk of becoming frail, are necessary in order to ensure that older people receive appropriate supportive care (Poltawski et al 2011; Sourdet et al 2012). However, such criteria appear to be inconsistently and

inappropriately used in health and social care practice and therefore older people are often labelled as frail without a comprehensive assessment.

As Browne and Markle-Reid (2003) pointed out, labelling in this way without clear assessment could be potentially problematic as it classifies frail older people as a homogenous group and implies that the experience of frailty is uniform. In doing so there is the danger that health and social care service provision is underpinned by the assumption that one service 'fits all'. Clearly this is problematic, considering the wide range of characteristics that may indicate frailty and the likelihood that one person will experience them all. Accessing care is compounded by the fact that frail older people receive services from both health and social care agencies, in a mixed economy of care. Where differing assessments and interpretations are made, across care boundaries, regarding the features of frailty it may mean some older people are negotiating highly complex models of service delivery with the potential for overlaps or inappropriate service delivery. Conversely, it could lead to frail older people falling in 'between the spaces' of these services (Seymour et al 2005a; Heath 2012).

1.2.3 Frailty: current issues in policy and practice

Frail older people have complex care and support needs that are currently challenging the health and social care system. The last decade has seen a huge shift in the way that health and social services for older people have been organised and delivered, with the aim of modernising services to meet the demand of an ageing, and increasingly frail, population and subsequent care requirements (DOH 2001; DOH 2005a; CSCI 2006a; CSCI 2006b; DOH 2008; NHS England 2014a). This has led to an increasing number of provider organisations delivering services to frail older people across care boundaries (Cornwell 2012). A key focus has been to enable the frail older person to remain at home where possible and with appropriate support; even if this entails the older person taking some risks in order to maintain their independence (CSCI, 2006b; NHS England 2014a). Moreover, the onus has been on health and particularly social care organisations to deliver services that are more personalised, and that suit the lives that frail older people live. Here personalisation involved a strategic shift to ensure that all older people

across the spectrum of need have choice and control over the nature of support, even where significant assistance is required (DOH 2008).

However, Cornwell (2012) argued that health and social care policy has been slow to adapt to the requirements of an ageing, and increasingly frail population. More recently the Ready for Ageing report (House of Lords 2013, p1) stated that the nation and government are 'woefully unprepared' to address the implications that an ageing population will have on individuals and society. The report made it clear that the current model of health and social care is inappropriate and unable to cope with changing patterns of ill-health in the context of an ageing population; particularly the split between health and social care is unsustainable. Furthermore, the document highlights that the dominance of hospital-based care is a poor fit with the needs of an ageing population.

It is now generally acknowledge that in spite of the myriad of policy documents and guidance there is more of a gap than ever between the written policy and its implementation in practice (Lloyd 2012b). In particular, the exposure of poor standards of care provided to frail older people, particularly in the hospital setting, has been a feature of some service provision within the UK (Parliamentary and Health Service Ombudsman 2011; Local Government Association et al 2012; Francis 2013). All these reports have highlighted instances where older people were treated in an undignified manner, as well as illustrating aspects of sub-standard care. These included lack of nutritional support, lack of attention to personal hygiene and elimination, poor pain control and lack of communication. These are some of the very issues that were of concern leading to the introduction of the National Service Framework for Older People in 2001 (DOH 2001), suggesting the system is still falling short for frail older people in certain circumstances. As Cornwell (2012, p1) stated, it is time 'to turn the rhetoric of personalised care into the reality of everyday care and practice in relation to frail older people'.

In response to this calls to action have been made to improve the quality of care for frail older people with a specific focus in practice on dignity, compassion and good clinical assessment (Smith et al 2010; Lloyd et al

2012a; Bridges et al 2012). Furthermore, guidance on best practice in caring for older people in the acute setting has been developed (Bridges et al 2009). Although this guidance focused specifically on caring for older people in hospital, the best practice statements are clearly transferable to other contexts, taking into consideration that caring for frail older people is a core component of nursing work in every setting (NMC 2008). This present study is timely in that it will further develop an understanding of how older people experience and make sense of frailty in daily living. In doing so, it will inform policy and practice by contributing to the development of more appropriate models of service provision that can deliver personalised care to frail older people in the context of everyday health and social care practice, including nursing.

1.2.4   Approaches to nursing in caring for frail older people

In light of the challenges in providing care to frail older people it is important to consider in more detail the current approaches to caring for frail older people and how these frame nursing practice.

Within gerontological nursing the concepts of 'person' and 'relationship-centred care' are viewed as the cornerstone of good practice when providing supportive care to older people (Eliopoulos 2013). The person-centred approach to care respects and acknowledges that an older person can make decisions regarding their own health and wellbeing. Key to person-centred practice is 'knowing the person' (Dewing 2004); this recognises that each older person brings to the care situation knowledge and experience that can contribute to decision making that will best serve their health and wellbeing (McCormack 2003). Furthermore, it is recognised that including a biographical account in the assessment and on-going management of health problems, as well as establishing how older people make sense of changes to their health and wellbeing, are central to this process (McCormack 2004). In this context, understanding the meanings that older people ascribe to their own experience of frailty is important.

Relationship-centered care is a framework of care that recognizes that the nature and quality of relationships are central to the delivery of nursing and health care (Nolan, Davies and Brown 2006; Smith et al 2010). A key

component is the acknowledgement that all participants appreciate the importance of their relationships with one another, in conjunction with a person-centered approach. The relationship between the older person and the nurse is central; however the relationship of staff to themselves, with others and the clinical environment is also emphasized (Nolan, Aveyard and Keady 2001).

It has been suggested that the relationship between the nurse and older person is the vehicle through which person-centred care is enacted and is built on mutual trust, understanding and a sharing of knowledge (McCormack 2003). However, Dewing (2004) suggested that in order to develop a relationship-centred approach to care a high level of interpersonal competence and capability is required. Dewar and Nolan (2013) highlighted the complex skills required to engage in conversations (relationship-centred) that enable older people to reveal their feelings, emotions, wants and desires (person-centred). At the time of writing, as previously noted, there are current challenges to creating therapeutic relationships with older people in order to provide compassionate and dignified care, particularly with those who are frail. A number of reports have exposed the poor standard of care provided to frail older people, particularly in the hospital setting (Parliamentary and Health Service Ombudsman 2011; Local Government Association, NHS Federation and Age UK 2012; Francis 2013). All these reports have highlighted instances where older people were treated in an undignified manner, as well as illustrating aspects of sub-standard care. It is timely therefore, to examine how relationships are developed and enacted between frail older people and nurses in order to provide person-centred care.

1.2.5 Personal background and interest in this enquiry

Within the context of this study it is important to acknowledge that my role as researcher is likely to have influenced every stage of the research process, as well as the findings of the research (Dowling 2006). My professional and personal background has provided a lens through which I interpret the world, and therefore these have influenced the study from the development of the research question and methods, through to data collection and analysis and finally the write-up. Reflexivity is demonstrated throughout the thesis (Elliot, Ryan and Holloway 2012) however at this point it is important to detail the

professional and personal influences that led to my initial interest and continuing relationship regarding the issue of frailty in later life.

I am a Registered Nurse currently working as an adult branch lecturer in a School of Nursing, in a University in the north of England. I am responsible for delivering teaching to undergraduate and post graduate students with a focus on palliative and end of life care and the care of older people. Back in 2005, it was through exploring issues in providing appropriate end of life care to older people in later life that I first started to contemplate the use of the term 'frailty'. This is what Malinowski (1922, cited in Hammersley and Atkinson 2007, p21) referred to as the 'foreshadowed problem', where preconceived ideas are challenged through the deliberation of ideas and evidence. Within the field of palliative care at that time illness trajectory frameworks were being mooted as one way of considering service delivery to older people at the end of life (Lynn and Adamson 2003; Murray et al 2005). In particular, a trajectory that proposed 'frailty' as its focus was highlighted as a means to consider palliative care for older people with general decline, with the implication that this was likely to become an increasingly common route to death (Murray et al 2005). At this point I was interested in examining the appropriateness of such a trajectory to guide palliative care services, specifically the management of nursing support.

However, during initial explorations of the literature questions were raised about my understanding of the term 'frail'. I had made the assumption that I would be able to easily define what it meant to be 'frail' in older age, and in doing so would therefore be able to examine the usefulness of an illness trajectory to guide care for older people at the end of their lives; this was not the case. Furthermore, on reflection I began to realise that in nursing and health care frailty was a term that was used to describe many older people, without an assessment of frailty being made. Moreover, I considered that there was a limited understanding by health and social care professionals of what frailty meant to the older person. I contemplated the possibility that in labelling someone as frail, without a comprehensive assessment or a person-centred approach to care, it could compromise the care given to patients. On further scrutiny I realised that I had probably used this term in relation to older people myself and this was a strong motivating force in pursuing this line of enquiry further. Consequently, the focus of my study changed at a

very early stage. I felt that it was important to explore how older people understand and experience frailty in order to enhance the approaches to working with older people in later life.

Another influencing factor that focused my interest in exploring frailty links to my personal family situation. Both my parents have complex health problems and it was during a conversation with my father's general practitioner in 2007 that he mentioned that my father was frail. I have never considered either of my parents to be frail and I realised that my father in particular was being labelled thus, possibly because of the way he looked and his current health problems. This prompted a further development in the focus of my study; I wanted to contribute to the development of the knowledge base, relating to frailty and older people, which would influence the attitudes of health care professionals. On reflection, I think that there was another personal reason for exploring frailty in older age. As a woman approaching her 51st birthday I look to the future to the type of care that I wish to receive myself and would hope that if I require health and social care, including nursing, that it is from people who understand what frailty might mean to an older person.

1.3 Overview of the thesis

1.3.1 Research questions

The study set out to answer the following research questions:-

- What do older people understand by frailty generally and in relation to themselves?
- How do relationships with significant others and care staff influence an older person's experience of frailty?
- How do wider societal influences affect the experience of frailty?

1.3.2 Methodology

I adopted an ethnographic case study design to examine how older people living at home, and considered to be frail, experienced and attributed meaning to their daily life. The methods of data collection included: participant observation, interviews and documentary review. I observed the care visits by community matrons to ten older people once a month for six months. Alongside the observations, interviews with the older participants,

community matrons and significant others were undertaken. The period of data collection lasted for two and a half years, from September 2008 until March 2011. Generating knowledge about personal experiences of older age in this study required an epistemological approach that acknowledged the individual nature of experience, as well as the wider societal influences that contribute to the experience of frailty.

1.3.3 Structure of thesis

This thesis comprises nine chapters, including this introductory chapter. This section briefly outlines the focus of each of the subsequent chapters.

1.3.3.1 Chapter 2: Literature Review

This chapter provides a context for the study by presenting a review of the literature pertaining to frailty in later life. It consists of two sections and presents an illustration of key issues associated with current conceptualisations of frailty in the context of ageing. The first section of the chapter details the approach to the review of the literature undertaken in this study. The second section presents a review of theoretical and research based literature, as well as an overview of health and social policy developments, which underpin current understandings of frailty in later life.

1.3.3.2 Chapter 3: Research Methodology

This chapter explores the relationship between the methodology and the epistemological stance taken in this study, providing a rationale for the chosen research design and methods of data collection. First, an overview of the study design is provided in order to provide a context for the ensuing discussion. The chapter is then divided into the following sections: epistemology; ethnography; research design; access to the research setting; recruitment of participants; and ethical approval. A reflexive approach is demonstrated in relation to field access and recruitment of participants.

1.3.3.3 Chapter 4: Study field work

This chapter presents the methods of data collection and the process of data analysis undertaken in the field. It is divided into the following sections: participant observation; interviews and conversations; documentary review;

withdrawal from the field; and data analysis. Ethical issues encountered during the period of field work are explored. A reflexive approach to the collection of data is demonstrated.

1.3.3.4 Chapter 5: The study findings: Transitions in health and illness in later life

This chapter presents the ten case studies and the participants that comprise each case. It also reports the first of three key findings that illuminate the experiences of frailty in later life, based on the analysis of the observational, interview and documentary data from the case studies. The first key finding relates to how older people in this study experienced transitions in health and illness. Four themes arose from the analysis of the data which characterise transitions in health and illness in later life. *The nature of transition* examines the types and patterns of transition relating to health and illness and the impact these have on daily living. *Managing transitions in health and illness* details the extent to which older people are able to actively engage in the process of transition. Such an examination reveals how transitions often lead to periods of heightened vulnerability where older people encounter difficulties in managing their daily lives. *Making sense of deterioration* demonstrates how older people contemplate their future lives in the context of transition. *Support Networks* explores how formal and informal networks support an older person in managing their daily routines in the context of ill-health.

1.3.3.5 Chapter 6: Study Findings - Dimensions of frailty in later life

This chapter reports the perceptions and experiences of frailty in later life, in the context of fluctuating ill-health. Four themes illuminate how frailty in later life is represented. *Frailty as decline* examines the extent to which changes to physical and mental capacity contribute to the experience of frailty. *Frailty as confinement* details a social dimension to frailty, where older people become increasingly housebound and socially isolated. F*railty as vulnerability* explores how older people struggle to live with the uncertainty of fluctuating ill-health. Accounts of feeling frail illustrate how episodes of uncertainty challenge identity, as well as providing insights into how sense is made of such uncertainty. Finally, *frailty as a label* examines professional and lay constructs of frailty. Furthermore, it reveals the mismatch between

lay and professional accounts of frailty which in many instances leads to rejection of the label by the older person.

1.3.3.6 Chapter 7: Study Findings: Health and social care provision - rhetoric and reality

This final findings chapter provides insights into the inter-relationship between the older person's world of declining health and the episodic interactions they have with health and social care professionals. Particular emphasis is placed on the interactions that occur between older people and a number of professional caregivers, within the context of deteriorating health. Two themes arose from the analysis of the data which characterise the degree to which participants engaged with health and social care agencies, as well as informal support, whilst employing their own strategies to adapt to the disruption that transition brought. *The nature of participation* examines the extent to which older people are able to participate in their care. In particular, it reveals the ways in which partnership working is constituted, negotiated and enacted in the context of a clinical encounter. *Revelations and discoveries* details an analysis of how issues of relevance are introduced, discussed and subsequently dealt with between older people and care providers. Such an examination reveals the complexities inherent in such interactions as well as illuminating the importance of the therapeutic relationship within the context of the encounter.

1.3.3.7 Chapter 8: Establishing and maintaining trustworthiness

This chapter is concerned with the quality and trustworthiness of the study. The concepts of credibility, dependability and transferability have been drawn upon as they have been consistently used to describe and support various aspects of trustworthiness in qualitative research. A summary of my reflexive analysis throughout the study is presented.

1.3.3.8 Chapter 9: Discussion and conclusion

This chapter presents a critical examination of the three key findings and how they informed and influenced the experience of frailty of the older people in this study. In doing so, I contribute to the development of the knowledge base pertaining to frailty in later life, as well as to existing theoretical perspectives. The implications of the findings are explained and recommendations for

future practice, policy and research made. The methodological strengths and weaknesses of the study are outlined and reflections on the process of conducting the study are described.

1.4 Chapter summary

This chapter presented the rationale for the study as well as an introduction to the professional and personal influences that have shaped the development of the study. The research questions were introduced along with an overview of the methodological approach adopted. Finally, the structure and content of the thesis was summarised. The next chapter presents the literature that has provided the context for this study.

Chapter 2: Review of the literature

The aim of this chapter is to provide a context for the study by presenting a review of the literature pertaining to frailty in later life. This review enabled me to develop my thinking around the topic of frailty in order to focus the development of the research questions, aim and objectives. In the first section of this chapter I describe the approach to the review of the literature that was undertaken in this study. In the second section I present a review of theoretical and research based literature, as well as health and social policy, which underpins the current knowledge base regarding the concept of frailty in later life. In doing, so I provide a rationale for the development of this study.

2.1   Strategy for identifying literature for narrative literature review

The aim of this literature review was to describe and critique the body of evidence relating to frailty and older people, in order to shape my research questions, aim and objectives. I adopted a comprehensive narrative approach to the literature review as this enabled me to critique and summarise the literature relating to frailty, enabling the identification of gaps and inconsistencies in the current body of knowledge (Cronin, Ryan and Coughlan 2008). This approach also provided a comprehensive background to my understanding of frailty by enabling source materials other than empirical studies, such as theoretical debates, unpublished work and clinical commentaries, to be accessed. This provided evidence relating to the experience of frailty within the context of informed debate (Hawker et al 2002; Greenhalgh and Peacock 2005). Within this approach I adopted a systematic search strategy to identify the most relevant literature to inform the development of my research questions and frame my inquiry (Aveyard 2010).

The initial search for literature involved the pragmatic and inclusive approach to the use of four databases: CINAHL (Ebsco); ASSIA; PsycINFO; MEDLINE/PUBMED. These databases comprise the principal sources used to identify theoretical and research literature, policy documents, discussion and opinion pieces and news items relevant to health and social care. The

key words included: Frail; Frailty; Old* People; Old* Adults; Elder*, used in conjunction with Boolean operators 'AND'; 'OR' (Ely and Scott 2007).

Initial scoping with the key word 'frail' revealed that in the majority of literature the term frail was used to describe the population of frailty but not the concept of frailty. In reality this meant that much of the research was not about the experience of frailty and contained no substantive discussion. Green, Johnson and Adams (2006) identified that it is not reasonable to review every paper that has even the most minute relation to the topic of study. Also, frailty appeared to be viewed mainly from one perspective, that of biomedicine. Whilst this was an important aspect of frailty I did not feel that it enabled me to consider frailty fully. In order to inform the review further I deemed it necessary to consider frailty in the context of the ageing process in later life, Therefore, the search was expanded by including the key words 'advanced old age' and 'later life'. Combinations of these key words were used across all the electronic databases. The following inclusion criteria were applied:

- Date of publication 1980 – 2013 inclusive (a wide time frame was adopted to ensure that seminal works were identified (Paniagua 2002; Cronin, Ryan and Coughlan 2008).
- English Language Literature

Table 1 presents the number of articles located when undertaking the initial searches.

Table 1: Search strategy using main databases

Information sources	Keywords	Search limits	No. of results
CINAHL (Ebsco)	Frail*; and/or Old* people; and/or Old* adults; and/or Elder; and/or Later Life; and/or Advanced Old Age	1980 to 2013 English language	2944
ASSIA	Frail*; and/or Old*	1980 to 2013	56

	people; and/or Old* adults; and/or Elder; and/or Later Life; and/or Advanced Old Age	English language	
MEDLINE/ PUBMED	Frail*; and/or Old* people; and/or Old* adults; and/or Elder; and/or Later Life; and/or Advanced Old Age	1980 to 2013 English language	3562
PsycINFO	Frail*; and/or Old* people; and/or Old* adults; and/or Elder; and/or Later Life; and/or Advanced Old Age	1980 to 2013 English language	123

Hawker et al (2002) and Greenalgh and Peacock (2005) acknowledged that searching via electronic databases is the principal method of locating relevant literature. However, they go onto state that this method will not identify all relevant published studies and articles. To facilitate the search further the content of relevant on-line journals, available via the University of Nottingham and Sheffield Hallam University, were scrutinised. These included: *Health and Social Care in the Community; Age and Ageing; Ageing and Society; Journal of Ageing; Sociology of Health and Illness; Social Science and Medicine; Sociology*. Finally, citations and particular authors found in journal articles were followed-up. This was to ensure as far as possible that all relevant research and literature would be identified, including unpublished or 'grey' literature. Hand searching was undertaken when appropriate (Hawker et al 2002). Following removal of those articles that did not explore the concept of frailty, the subsequent level of scrutiny was determined by the nature of the articles and its relevance to the topic under consideration (Aveyard 2010).

2.1.1 Appraisal of the literature

Cronin, Ryan and Coughlin (2008) highlighted the importance of adopting an appropriate strategy for analysis and synthesis of appropriate literature in order to focus and shape research aims and objectives. Initially I read the abstract or summary of each text to determine whether they were worthy of further reading and inclusion within the review. Following this I categorised the literature according to their source, such as primary research (n=150), integrative literature review (n=12), conceptual/theoretical/policy (n=72). I read each literature source and entered details systematically onto the Refworks data base accessed via Sheffield Hallam University. The details included a short summary of each article. For research papers and integrative literature reviews I used a checklist adapted from Hawker et al (2002) in order to extract and appraise data on: abstract and title; introduction and aims; research design and methods; sampling; data analysis; findings; transferability or generalizability; and implications for practice. For conceptual and theoretical texts I extracted and appraised data on: theories of ageing; context; policy (Green, Johnson and Adams 2006). As I read and re-read the articles I used an iterative approach to synthesise the literature, initially identifying sub-themes and finally major themes in order to integrate the empirical and theoretical literature (Burns and Grove 2009). In doing so I was able to provide a background and context for the development of my study. The subthemes and major themes were tagged on Refworks for ease of retrieval. During the study period I continued to review relevant literature in order to shape the analysis of the findings (Burns, Grove and Gray 2011). The literature is now presented using the thematic framework, thus providing a background and context for the development of my study.

2.2 Frailty: an examination of the literature

This part of the chapter presents the themes that emerged from the analysis and synthesis of the literature identified within the review. It is subdivided into five main themes: frailty as a clinical syndrome; the social production of frailty; the experience of frailty; ageing and society; and UK policy and frailty.

2.2.1 Frailty as a clinical syndrome

Within the literature the concept of frailty has been firmly rooted within a biomedical and functional framework. Furthermore, there has been a focus

on age related physical ill-health and disability. Within this context, therefore, frailty is understood as a mismatch between an older person's physiological reserve and their capacity to withstand stress, with ensuing disability and reduced levels of functional ability (Buchner and Wagner 1992; Bortz 1993; Rockwood et al 1994; Fried and Walston 1999; Lipsitz 2002; Fulop et al 2010; Mitnitski et al 2011; Clegg et al 2013). This was initially encapsulated by Campbell and Buchner (1997, p315) who defined frailty as,

> 'a condition or syndrome that best results from a multi-system reduction in reserve capacity to the extent that a number of physiological systems are close to, or past, the threshold of symptomatic clinical failure. As a consequence the frail person is at increased risk of disability and death from minor external stresses'.

They went onto state that this definition included loss of reserve, feebleness and vulnerability and the presence of abnormalities of physiological function without there being obvious disease present. Many authors supported the view that changes in reserve capacity caused functional losses that influenced the capacity for independence and linked the loss of biological function with the ability to carry out daily living activities (Fried 1994; Walston and Fried 1999; Abellan van Kan et al 2008; Sourdet, Rouge-Bugat and Forette 2012). The essential reserve capacities for interaction with the environment have been identified as musculoskeletal function, aerobic capacity, cognitive and integrative neurological function and nutritional reserve. 'Unstable disability' occurs when function fluctuates greatly with minor external events, producing deterioration in performance thus challenging independence (Clegg et al 2013).

2.2.1.1 *'Markers' to identify and predict outcomes of frailty*

The conceptualisation of frailty as a physical syndrome has driven most of the research activity to date. One of the main themes in the empirical literature was the identification of physical markers of frailty in later life. These markers were used predominantly to determine whether an older person can be classified or assessed as frail (Brown et al 2000; Fried et al 2001; Briggs et al 2003; Abellan van Kan et al 2009; Fulop et al 2010; Cruz-Jentoft et al 2010).

In this body of literature the main single markers for frailty have been identified as muscle strength (Briggs et al 2003; Bautmans et al 2007), walking speed (Abellan van Kan et al 2009), malnutrition (Bales and Ritchie 2002; Cruz-Jentoft et al 2010), fatigue (Wong et al 2010) and endocrine abnormalities (Leng et al 2003; Gale et al 2013). It has been argued (Rockwood 2005; Rockwood and Bergman 2012) however, that a single marker is not enough to capture the clinical complexity of 'frailty', especially one that focuses on a single physical factor. Within a number of studies, combinations of factors have been used to characterise frailty (Fried et al 2001; Jones et al 2004; Rockwood et al 2006; Fulop et al 2010).

In this seminal cohort study, Fried et al (2001) aimed to develop and operationalise a phenotype of frailty in older adults. Frailty was defined as a clinical syndrome in which three or more of the following criteria were present: unintentional weight loss (10 lbs in past year), self-reported exhaustion, weakness (grip strength), slow walking speed, and low physical activity. Within this community-dwelling population the overall prevalence of frailty was 6.9%. It increased with age, was greater in women than men and was associated with being African American, having lower education and income, poorer health, and higher rates of co-morbid chronic diseases and disability. Other combinations considered as markers are mild cognitive impairment and gait speed (Abellan van Kan et al 2009), osteoporosis and malnutrition (Fulop et al 2010), dermatoporosis and fatigue (Kaya and Saurat 2007), and falls, functional impairment, and cognitive decline (Maly 1997, Black and Rush 2002, Ottenbacher et al 2005).

Markers of frailty have also been used to predict a variety of health and adverse outcomes for older people, such as, health related quality of life (HRQoL), hospital admission and length of stay, and morbidity and mortality (Fried et al 2001; Covinsky et al 2003; Jones et al 2004; Rockwood et al 2006; Song, Mitnitski and Rockwood 2010; Ravindarajah et al 2013). Where markers have been used to identify health outcomes this can be seen at the population level, where demographic research centred on using markers of frailty to predict longevity and mortality rates; and also at the individual patient level, where the focus has been the development of clinical interventions and appropriate services (Grenier 2007).

A key theme to emerge in relation to individual patients is self-reporting of poor overall health when frailty is identified. For example, building on the work of Briggs et al (2003) Sayer et al (2006) investigated whether grip strength was associated with Health Related Quality of Life. The findings from this cross-sectional survey, within a cohort study design, indicated that men and women with lower grip strength were significantly more likely to report poor as opposed to excellent to fair overall opinion of their general health. Following adjustments for age, size, physical activity and known co-morbidity, decreased grip strength was associated with poor scores for physical functioning. It was concluded that lower grip strength is associated with reduced HRQoL and may reflect the link between sarcopenia and generalised frailty. The relationship between fitness, frailty and long term health outcomes was also the focus of a retrospective cohort study by Rockwood et al (2006). The findings indicated that worst frailty was associated with worse survival, and a higher risk of institutionalisation. For any given level of frailty men died younger than women. Masel et al (2009) reported that there was a statistically significant association between the presence of frailty and lower health related quality of life in older male Hispanic Americans with a mean age of 82.

Over the last decade the dominance of a physical and functional approach to frailty has been challenged (Brown and Markle-Reid 2003; Levers, Estabrooks and Kerr Ross 2006; De Lepeleire et al 2009). Rockwood (2005) proposed that a successful definition of frailty should be multi-factorial and represent the many factors in a way that takes their interactions into account. This has led to the recognition that other factors can be used to identify frailty, including cognitive and psychological elements (Abellan van Kan et al 2010; Comijis 2011) and social factors (Nourashemi et al 2001; Schuurmans et al 2004). Lack of social support, particularly in relation to regular contact with family or friends, has been identified as a key factor contributing to frailty (Brown et al 1995, Strawbridge et al 1998, Nourhashemi et al 2001). For example, Nourashemi et al (2001) found that certain types of social activities could have a positive and negative relationship to frailty. Participating in senior citizen's clubs and older people's holidays were more likely to have a negative relationship with frailty whereas regular family contact and support was seen to be positively linked to frailty. Lang et al (2009) reported that the

presence of frailty increased when older people lived in the most deprived areas and had the least support from social networks.

Instruments that encompass the multiple domains that link to frailty have been developed to assist with geriatric assessment, care planning and decision making for individuals, as well as evaluating health outcomes at a group and organisational level (Studenski et al 2004; Puts et al 2005; Rolf et al 2006, Abellan van Kan et al 2010; De Vries et al 2011). Although such models are welcomed criticisms are levelled at the diversity found in the components of frailty that have been adopted within the models (Abellan van Kan 2010), suggesting that it makes it difficult to truly assess frailty in a consistent manner. The early dominance of physical and functional markers is being challenged Poltawski et al (2011) argued that new models still have a bias towards a physical focus. Furthermore, what is required is an inter-professional and integrated approach to the assessment of frailty (Poltawski et al 2011). This will continue to be challenging as the concept of frailty is complex and remains difficult to define (Abellan van Kan et al 2010).

2.2.1.2 *The incidence of frailty*

The difficulty in defining frailty and the diversity identified in the components of frailty models means that determining the actual prevalence of frailty is problematic (Abellan van Kan 2010). Within the literature there has been a huge variation in the prevalence of frailty across a number of cohort studies. The landmark study by Fried et al (2001) in the United States reported that, of the sample aged 65 and over, 7.3% of women and 4.9% of men were frail.

Similar prevalence rates were identified in European studies (Cesari et al 2006; Cawthon et al 2007; Endsrud et al 2007). In particular, the findings from the Hertfordshire, UK, cohort study reported that the prevalence of frailty was 8.5% among women and 4.1% among men (Syddall et al 2010).

However, other studies have found higher estimates. Lunney et al (2007) stated that 20% of older people in the last year of their life were categorised as frail. Similar figures were reported in a study identifying disability in the last year of life by Thomas et al (2010). In the Hispanic Established Populations for the Epidemiological Studies of the Elderly study Ottenbacher et al (2005) reported that 20% of older people aged over 70 were frail. Mohr

et al (2007) concluded that of the men in the Massachusetts Male Aging study, aged between 70 and 79, 11% were frail, increasing to 36.5% in those aged between 80 and 86. Higher estimates were also reported by Santos-Eggiman et al (2009) in the Swiss cohort study.

The differences in prevalence rates have been attributed to differing methodological approaches across studies that make it difficult to make direct comparisons, especially where different frailty assessment scales have been used (Abellan van Kan 2010). Another issue relates to the differences in study protocols particularly whether individuals were included or excluded on the basis of selected disease and disability (Santos-Eggiman et al 2009). These differences are highlighted where different frailty assessment models have been used with the same population. In a study by Ensrud et al (2008) the prevalence of frailty ranged between 33% and 88% depending on the frailty tool used. It is unlikely therefore that the exact prevalence of frailty will ever be known whilst there is such heterogeneity in frailty tools.

2.2.2   The social production of frailty

There is a small body of literature that has explored how frailty is socially produced and constructed through the interaction of older individuals, their caregivers, institutions and wider society (Gadow 1986; Kaufman 1994; Kaufman & Becker 1996; Lustbader 2000; Grenier 2005, 2007). Considering 'frailty' as a social construct, that is, as a phenomenon "invented" or "constructed" by participants within a particular culture or society, may offer further insights into this complex phenomenon (Berger and Luckman 1966). From a social constructionist perspective of frailty there is a social dimension to human life which cannot be reduced to a set of bodily imperatives. In general this literature has been critical of the dominance of the biomedical perspective within health and social care practice, suggesting that frailty is used as a label to justify and allocate services based on clinical and social need. Although this could be considered to be an appropriate use of the term frail these authors indicate that once the label is applied it becomes difficult to see the older person beyond their medical and functional problems.

For example, Kaufman (1994) conducted an anthropological study of one hundred community living elders over the age of eighty. Over the period of a year, observations of geriatric assessment team meetings were undertaken

where the cases of 43 older people whose conditions had deteriorated were discussed. From 25 family conferences 10 older people, or their carers, were invited to participate in an interview. In discussing her findings Kaufman (1994) suggested that frailty is socially produced and constructed through the interaction of older individuals, their caregivers, health providers and wider society. Frailty, therefore, became more fully articulated within the discourse of surveillance, safety, risk and care. She acknowledged that although older adults may come willingly to a health or social care provider or service they do not come with the expectation that behaviours, habits and patterns of a lifetime will be scrutinised along with the symptoms they choose to reveal. Kaufman (1994) went onto suggest that the 'lived experience' of older people was transformed into a problem list that encompassed personal and social behaviours as well as psychological disorders. Similarly, Lustbader's (2000) reflections on what it means to be frail also identified how consigning an older adult to a category, 'the frail', potentially turned that person into needs, around which a health care professional performed a task. She suggested that it is then difficult to remove the label and the behaviours and attitudes of the health care professionals that could follow.

More recently Grenier (2005) undertook a qualitative study using narrative interviews to explore how twelve older women made sense of frailty, impairment and decline in their everyday life. From the accounts of the older women she concluded that understandings of frailty seemed to focus on the bodies and function of older people, which tended to be an age-based concept judged through medical criteria and/or functional limitations of the body. 'Frailty' then became a discursive representation of risk, which structured eligibility and guided interventions within health and social care. In later work Grenier (2007) developed her ideas relating to frailty and older people. She examined the dominant notions of frailty, suggesting that 'frailty' functions as a 'dividing practice' through the classification of those who are eligible for care. Furthermore, this concept of frailty, that Grenier is critical of, represents and orders the context, organisational practices, social representations and lived experiences of care for older people.

2.2.3 The older person's experience of frailty

There is a small but emerging body of literature that has focused upon the experience of frailty from the perspective of the older person. The findings from this empirical literature have demonstrated that older people experience frailty as decline in health as well as physical, psychological and social functioning (Becker 1994; Grenier 2006; Puts et al 2009; Nicholson 2012a). Furthermore, a sense of loss associated with the decline in overall health and wellbeing has been identified, although older people endeavour to remain in control of their daily lives and make their own decisions where possible. For example, Becker (1994) reported findings from a three year qualitative investigation of the transition from independence to dependence amongst the oldest old, defined as aged 80 years and older. Over the period of a year semi-structured interviews were conducted with 28 older people (16 women and 12 men) focusing on their daily lives and routines, health, family and friends; of these 19 were considered to be frail by health professionals. The findings revealed how older people experienced differing levels of impairment, which were categorised as: new to impairment; impaired but stable and increasingly impaired. Becker (1994) concluded that in spite of differing levels of impairment older people continued to attempt to remain in control of their lives, no matter how daunting such endeavours became. There are a number of issues with Becker's (1994) study. Firstly, there is no indication of the age of the participants. Secondly, older participants were recruited from a number of sources, which included a geriatric assessment service and community and inpatient services for older people. Also, some older people had been recruited from an earlier study, five years previously, focusing on the experience of stroke. Thirdly, there is minimal detail regarding the methods of data collection. The lack of methodological detail makes it difficult to transfer the findings to other settings and client groups (reference).

Grenier (2006) conducted narrative interviews with a diverse group of 12 older women who were receiving urban public services in Canada. The women were recruited using current service eligibility guidelines: 6 were perceived to be frail through service use. Six were not in receipt of services therefore were categorised as non-frail. The aim of the study was to explore how older women understand, make meaning, and negotiate the concept of

frailty in relation to their everyday lives. Grenier (2006) concluded that the individual accounts of the older women reveal how they make meaning of their life events in relation to their diverse experiences and identities, rather than as a frail person. Furthermore, these identities and the older women's interpretations are key to their negotiation of life and health and social care needs. A limitation of this study is that the time frame for conducting the interviews was not made explicit, as well as the number of interviews per participant. Also, the age range of the participants was never revealed.

Puts et al (2009) undertook a cross-sectional qualitative study, using semi-structured interviews, to describe the meaning of frailty to older people. The data was collected as part the Longitudinal Aging Study Amsterdam (LASA), which is an ongoing multidisciplinary study on predictors and consequences of change in physical, cognitive, emotional and social functioning in older people in the Netherlands (Smit, De Vries and Poppelaars 1998). Participants were recruited randomly from population registers and allocated frailty markers during an interview cycle three years prior to the current arm of the study. Participants were defined as frail if they scored three or more frailty markers and non-frail if they scored zero frailty markers. Thirty two respondents were approached to take part in the study, twenty five participated. Of the twenty five older people who took part 14 were categorised as non-frail and 11 as frail. The mean age was 78 and there were 14 men and 11 women. Key areas of questioning included the meaning of frailty, and appraisal of the person's own situation in relation to frailty. They found that older people were able to identify frailty, linking it to reduced health, and psychological and social problems, in which the person was not able to do what they enjoyed. This led to the experience of loss. Furthermore, older people were not always able to control the process of decline associated with frailty. However, an issue in transferring this knowledge to other contexts is that there is no term in the Dutch language that directly translates to frailty. Therefore alternative terms were used, which included vulnerability and fragility. Although this is acknowledged by the authors this is problematic in terms of transferability of the findings. Moreover, there were large time delays between the application of the frailty score and participation in an interview therefore it was difficult to establish the relationship between the label of frailty and personal experience.

More recently Nicholson et al (2012a) undertook a longitudinal qualitative study, combining psychosocial narrative approaches and psycho-dynamically informed observations, in order to understand the experience of home-dwelling older people deemed frail. Fifteen older people, age range from 86 to 102, were recruited to the study from an older person's intermediate community care team. The sample comprised five men and ten women. A purposive approach to recruitment was adopted focusing on those older people who lived at home, either alone or with family members, and who were regarded as frail by the health and social care team. A common theme within the findings was the experience of loss associated with physical decline. In light of such losses, negotiating and maintaining a balance between autonomy and independence was complex, and involved participants employing strategies that reconnected them to their bodies creating anchorage in their daily lives. However, the findings suggested that there were also opportunities for the older people to relate to their bodies in new ways, thus creating new connections. The authors concluded that the experience of frailty is a delicate balance between integrating previous, present and future realities (Nicholson et al 2012a). However, older people are not always able to remain in control of the decline in their health and wellbeing. A qualitative study by Puts et al (2009) highlighted that although older people were able to identify frailty and the ensuing losses, they were not always able to control the process of decline.

Another developing theme in this body of literature relates to whether older people consider themselves to be frail or not. Participants in Becker's (1994) study did not use the term frail to describe themselves, although they were defined by health professionals in this way. Similarly, in Grenier's (2006) study the older women did not consider themselves to be frail; however there were instances where they experienced 'feeling' frail. When the women reported 'feeling' frail it did not necessarily correspond with the experience of impairment or disability. Three main issues appeared to be linked to when the older women 'felt' frail. These included: the emotions or feelings related to the physical functioning of the body; feelings about traumatic events; and uncertainty related to a perceived threat to self, or loss of continuity. In her explorations of frailty Grenier (2006, p299) concluded that 'older women's identities and strategies were at least partly negotiated in relation to the

experience of 'feeling' frail, and that the identity, and the self, served as a protective mechanism from 'becoming' frail'. In contrast, the participants in Puts et al's (2009) study identified that those older people who were labelled as frail by health care professionals, following the application of a validated assessment scale, also considered themselves to be frail. Furthermore, they often referred to personal features when describing general characteristics of frailty.

2.3 Ageing and Society

It is argued that 'ageing' is not simply a matter of organic maturation and decay, but is influenced by cultural variability. Moreover, social divisions order and regulate the ageing process over the life course (Hockey and James 2003). It is useful to consider the stereotypical images of old age, frailty in particular, and how this may influence attitudes to older people. Biological signs, such as grey hair, changing skin texture, failing eyesight, reduced muscular strength, reduction in stature are considered to be the defining features of old age (Westerhof and Tulle 2007; Grenier 2012). For those considered frail, predominantly women, images of using Zimmer frames or other mobility aids, or being confined to bed or chair come to mind (Bytheway 2011; Hurd Clark 2010). Furthermore, these signs are linked with frail health, being unproductive and requiring support (Bond and Rodrigues Cabrero 2007; Gilleard and Higgs 2010). This somewhat negative perspective on ageing, and frailty in particular, appears to be the norm, and reflects the link to biological and therefore natural processes of ageing (Westerhof and Tulle 2007; Richards, Warren and Gott 2012).

However, within the context of the life course perspective ageing is an individualised, unique process involving changes in many aspects of life. It is suggested, therefore, that the inevitable association of ageing with bodily decline does not reflect the diversity of experience relating to old age (Marcoen et al 2007; Grenier 2012). Featherstone and Hepworth (1989, p148) argued that there is a view of ageing that assumes that old age is a mask, which 'conceals the essential identity of the person beneath'. This highlights the tension between powerful, popular stereotypes of ageing and the way this informs attitudes and behaviours towards older people, and the diversity of actual personal experience (Featherstone and Hepworth 1991).

Another difficulty is that older people who are generally labelled as 'elderly' do not self-identify as old (Itzin 1990, Bury and Holme 1991, Thompson 1992, Heikkenen 2000, Degnen 2007; Andrews 2012). Therefore, assumptions about how an older person who may look frail will experience their daily lives, may be very different to the actual experience of the older person. This highlights the continuing pervasive ageism that affects the lives of everyone, in particular older people (Peace and Bond 2007; Walker 2012).

2.3.1 The Third and Fourth Age

Within the gerontological literature there has been much debate as to the nature of ageing (Grenier 2012). Successful ageing has been linked to a 'third age' (Laslett 1989). This has generally been associated with the age range of fifty to seventy as well as conceptualised as a time of life where older people generally experience good health and are able to exercise autonomy and choice (Gilleard and Higgs 2000; 2010). Furthermore, it is posited as a time of extended consumerism, opportunity and activity. It has been recognised that in the third age there is resistance to the label of old age, and it continues to be supported by expanding markets for anti-ageing products and active lifestyles (Gilleard and Higgs 2000; Hurd Clark and Griffin 2007; Lumme-Sandt 2011).

In contrast the 'fourth age' (Laslett 1989) was characterised as a period of debility and decline, one that Laslett (1989) suggested should be delayed for as long as possible. Gilleard and Higgs (2000) described how the creation of the fourth age has been considered to mark the end of the third age. Similarly, Twigg (2006) highlighted the contrasting elements of the third and fourth age, namely the fourth age could be seen to be what the third age was not. Therefore, the fourth age is a phase of life characterised by decreasing decline and reduced autonomy in the period before death (Gilleard and Higgs 2010; Lloyd et al 2012a). It is at this point that it could be suggested that the concept of frailty becomes prominent, and linked to deterioration and decline. Gilleard and Higgs (2010, p125) have likened the experience of the fourth age to that of a 'metaphorical black hole'. Here they suggest that being in the fourth age is synonymous with being sucked into a black hole. Those in later life, possibly frail, are held in this 'space', one which is both unknowable and where there is no return.

The closeness of the fourth age to death has been noted (Twigg 2006; Gilleard and Higgs 2011; Lloyd 2012b). According to Twigg (2006) the period prior to death has been emptied of meaning and linked to a period of decline as a consequence of the lack of meaning surrounding death in secular society. Gilleard and Higgs (2010, p125) identified the fear of the fourth age, one that they suggested linked to 'passing beyond any possibility of agency, human intimacy or social exchange'; one that ultimately leads to death. Although this is an extreme argument it is never-the-less important to develop an understanding of how frail older people experience health and illness, independence and dependence in later life.

2.3.2 The experience of ageing in later life

Similar to the biomedical and functional literature older people in later life do articulate their experience of ageing in relation to bodily and functional decline. This is expressed by older people as: loss of memory, immobility, general weakness and fatigue, ill health, altered body image, loss of sexual activity and sensory impairment. (Bury and Holme 1991; Becker 1994; Heikkinen 2000, 2004; Easley and Schaller 2003; Jones 2006; Degnen 2007; Nilsson et al 2007; Janssen, Abma and Regenmortel 2012; Lloyd et al 2012a). Such experiences appear to find expression in the meanings that people attach and ascribe to the process of ageing within the context of their own lives, not just the functional limitation in isolation. Both positive and negative meanings appear to be attributed to this process.

2.3.2.1 The process of ageing later life

Continuing to live 'engaged' lives in spite of functional decline and illness, whether that is enacted in terms of routines or relationships, is seen to be a positive aspect of ageing (Heikkinen 2000, 2004; Easley and Schaller 2003; Torres and Hammerstrom 2006). Such 'engagement' in life, whether this was playing group games, participating in a community group, or engaging in work activities, was identified as an important aspect of the experience of being aged 85 and over in a cross sectional qualitative study by Easley and Schaller (2003). Engaging in such activities enabled the older women to feel active and gave a sense of control in their lives, in spite of health problems.

The ability to engage in life is also linked to a strong family support network and a positive attitude and outlook towards life (Bury and Holme 1994; Heikkinen 2004; Clarke and Warren 2007; Janssen, Abma and Regenmortel 2012). Clark and Warren (2007) reported that having a positive outlook towards life enabled older people to consider future hopes. These related to maintaining health, further developing positive relationships, optimising limited functional ability to achieve small goals, as well as preparing for the end of life. In Janssen, Abma and Regenmortel's (2012) qualitative narrative study even where participants were severely limited by their ill-health and disability a positive outlook enabled the adaptation of small tasks to their current capabilities, enabling them to continue to engage with their daily life.

Dependence on others to participate in activities that enable engagement can lead to a decrease in wellbeing and therefore can be seen as a negative aspect of the ageing process (Bury and Holme 1991; Easley and Schaller 2003; Janssen, Abma and Regenmortel 2012; Lloyd et al 2012). In the seminal study by Bury and Holme (1991), a longitudinal mixed methods study exploring the experience of living over the age of ninety, they identified that increasing dependence was a source of distress to some older people, linked to the loss of capacity and reliance on others to perform basic tasks associated with daily living. More recently studies have also illustrated how dependence on others is considered to be a negative aspect of ageing (Hammarstrom and Torres 2009; Breheny and Stephens 2012). In the qualitative study by Breheny and Stephens (2012) they demonstrated how older people constructed dependence on others as burdensome. Likewise, Lloyd et al (2012a) reported how some older participants in this qualitative study found it difficult to accept help as it challenged their sense of selves as an independent person.

Although there is generally an assumption that dependency is a negative aspect of the ageing process Secker (2003) argued that older adults who may be highly reliant on others for support in the maintenance of activities of daily living can still experience positive well-being. She suggested that this is linked to the older adult's ability to maintain high levels of subjective independence. Similarly, Fine and Glendinning (2005) highlighted that it is not uncommon for those who live with limitations to continue to regard themselves as autonomous individuals despite requiring assistance on a

regular basis. More recently, in a qualitative study by Hammarstrom and Torres (2012) participants who were receiving assistance from social care did not experience a loss of capability or agency. The authors concluded that multiple factors determine whether or not receiving help brings about the feeling of dependence and loss of capability for being autonomous.

This is considered to be influenced by how much the older person can match their lived experience to their desired level of choice, social usefulness and autonomy (Becker 1994, Secker 2003). This in turn can depend on the older person's psychological make-up and sense of identity, biography, social context and cultural heritage (Secker 2003; Clarke and Warren 2007; Hammerstrom and Torres 2012). Furthermore, the relationship between the older person and the care worker can influence whether an older person experiences loss of agency as a result of receiving care (Barret. Hale and Gauld 2012). Janssen, Abma and Regenmortel (2012) identified that promoting and maintaining independence was linked to the nature of social support that was available. They concluded that it was not just the type of support but also the way that it was introduced, and the reciprocity within the relationship.

2.3.2.2   *Making sense of ageing in later life*

The way in which older people make sense of the ageing process can influence their attitudes towards the changes experienced as well as how they regard support. Taking one day at a time or 'living for now' is one way in which older people manage the effects of ageing and unpredictability in later life (Nilssen et al 2000, Heikkenen 2004, Clarke and Warren 2007). Adaptation of well-established routines and expectations related to the process of ageing also appear to shape how an older person makes sense of their own ageing (Heikkenen 2004; Torres and Hammarstrom 2006; Clarke and Warren 2007; Lloyd et al 2012a). For example, in a longitudinal qualitative study exploring the ageing process of participants aged between 80 and 90, Heikkenen (2004) found that older people adapted situations to their limitations in order to maintain a sense of wellbeing. For example, the identity of one participant was closely linked to her ability to play the violin, which she had done all her life. She could no longer bend her arm sufficiently therefore had exchanged the violin for a mouth organ. Clark and Warren

(2007) discovered that the activity driven goals of previous years were often replaced by the accomplishment of simple, everyday activities; these could be actively chosen thus maintaining a sense of autonomy. Furthermore, 'active ageing' could be experienced within the ordinary, everyday needs and relationships that older people experienced.

The experience of uncertainty relating to the present and future can challenge an older person's ability to adapt and make sense of changes as a result of ageing. Torres and Hammarstrom (2006) demonstrated how personality and biography influenced how an older person managed their experience of uncertainty within the context of decline and ageing. Where decline in everyday competence was interpreted as a fact of life there was acceptance of problems that arose, in particular accepting help was not seen to be problematic. Older people who regarded decline in everyday competence as burdensome and arduous, however not to be accepted without 'putting up a fight', found the uncertainty challenging but found ways to work round the limitations. Where decline in competence was perceived as irreversible the uncertainty led to worry and anxiety. This was compounded further when there was a reluctance to ask for or receive help. Lloyd et al (2012a) demonstrated how older participant's accounts often encapsulated a sense of precariousness about the present and great uncertainty about the future. During these challenging times participants had to work hard physically, mentally and emotionally to enable them to manage the changes in their lives. However, giving up was not an option and being determined was confirmation of an individual's will to continue living.

2.3.2.3   *Being old and feeling old in later life*

Research literature suggests that older people generally do not consider themselves to be old (Itzin 1990, Bury and Holme 1991, Cremin 1992, Thompson 1992, Becker 1994, Heikkenen 2000, Grenier 2005, Degnen 2007; Andrews 2012; Lloyd et al 2012). Moreover, distinctions are made between 'being old and feeling old' (Cremin 1992, Kaufman 1996, Degnen 2007). Cremin (1992) conducted an ethnographic study to explore the experience of ageing in relation to older people and the underlying assumption within health and social care that frailty and dependence are 'natural' characteristics of chronological age. The findings highlighted

differences in the ways that older participants and their children constructed the experience of older people's aging. The older adults experienced 'feeling' old as a temporary and sporadic phenomenon, triggered by different kinds of trouble; in fact none of the older adult participants considered themselves to be old. In contrast, the children identified their parents as 'being' old. Holding conflicting views about 'being' and 'feeling' old had an impact on the ways that participants defined trouble. For the older adults circumstances were seen as troublesome when they threatened specific skills or attitudes which they highly valued and had helped them take a particular stance on the world throughout their lives. In contrast the children labelled those situations as troublesome when it threatened their perception of their parent.

This is supported in part by Nilsson et al (2000) who found that for participants aged 85 and over feeling old was characterised by fear of helplessness and not being able to manage one's life situation. In an ethnographic study Degnen (2007) identified how older people also made distinctions about who was old and what oldness comprised, in some circumstances more than the majority of younger people. In contrast to the dominant biomedical perspective, when assessing their peers in relation to old age the older people in the study did not emphasise chronological age or physical ability. Instead mental acuity and social comportment were more important indicators of whether someone was deemed to be old. Oldness then became attributed to the person and written onto them through interpretations of their behaviour, speech and appearance. The study identified that the process of attributing oldness to others was not fixed. For example, when a person, identified as old by the group, interacted with a person who they deemed to be old, they no longer 'appeared' old to the group.

2.4 UK Policy and frailty

The last decade has seen a huge shift in the way that health and social services for older people have been organised and delivered, with the aim of modernising them to meet the demand of an ageing population and subsequent care requirements. The National Service Framework (NSF) for Older People (Department of Health (DOH) 2001) was heralded as an important policy development as it would empower stakeholders to develop

better services for older people across the interface of health and social care (Philp 2002). At this time there were concerns that services were often unacceptable, and did not meet the needs of those using the services. More specifically there were concerns about the loss of dignity suffered by older people, particularly in hospital; the ageist attitudes towards the provision of care; the lack of integration of services to meet individual needs; the lack of choice and inequity of access to services; organisational structures that provided barriers to assessment of need and access to care; and lack of evidence based practice in some clinical areas (NSF 2001; Philp 2002).

Following implementation of the NSF for Older People (DOH 2001) there have been significant developments in government policy in relation to adult health and social care (DOH 2005; 2005b; 2006, 2007; 2010). Central themes of these policies have been to promote health, wellbeing and active ageing; improve quality of life; enhance choice; personalise services; and free users from discrimination. In particular, 'putting individual citizens as consumers or 'co-producers' in control of designing the services that can best deliver for them signalled a different sort of relationship between the state and the individual (Local Government Association et al 2012). The onus was on health and particularly social care organisations delivering services to ensure that they were more personalised, and that they suited the lives that people live. Here personalisation involved a strategic shift to ensure that all older people across the spectrum of need had choice and control over the nature of support, even where significant assistance was required (DOH 2008).

A key focus of UK policy has been to enable the older person to remain at home where possible, with appropriate formal home-care provision (Timonen 2008), even if this entails the older person taking some risks in order to maintain their independence (Department of Health 2001, Department for Work and Pensions (DWP) 2004, Commission for Social Care Inspection 2006a). However, what an older person may consider as a risk to their independence and how health and care professionals identify a 'frail' older person at risk may be two different things. There is a possibility that health and social care professionals define the 'frail' older person using a biomedical/functional framework within a culture where ageing is clearly linked to bodily decline, thus dependency. It has been argued that a focus on

'risk', and levels of surveillance through assessment, has dominated health and social care policy and practice relating to older people within the UK. Criticisms of such policies have highlighted how they have focused predominantly on functional decline and ageing, in particular increasing dependency and decreasing productivity (Westerhof and Tulle 2007; Lloyd 2012b). This may lead to conflict in relation to whether an older person is able to remain at home or not.

Although it is acknowledged that older people may have some 'dependency needs', it is argued that loss of social roles invites a view of the older person in terms of biological or physiological age terms alone (Katz et al 2011).Therefore, within this context old people are viewed as returning to the dependency of childhood; older people then become treated as children (Bury and Holme 1991). There is the suggestion that dependency should be seen as a feature of life at any age, involving 'complex dynamics of choice and constraint' (Bury and Holme 1991, p132). This would move away from the assumption that dependency must always be overcome; under some circumstances it may bring some advantages to the individual.

In spite of the myriad of policy developments there is still a gap between the written policy and its implementation in practice. Cornwell (2012) argued that health and social care policy has been slow to adapt to the requirements of an ageing, and increasingly frail population. More recently the Ready for Ageing report (House of Lords 2013, p1) stated that the nation and government are 'woefully unprepared' to address the implications that an ageing population will have on individuals and society. The report made it clear that the current model of health and social care is inappropriate and unable to cope with changing patterns of ill-health in the context of an ageing population; particularly the split between health and social care is unsustainable. Furthermore, rather than an emphasis on individual choice, there needs to be a sharing of responsibility between the individual and the state.

There is clearly a gap between the policy rhetoric and its implementation in practice (Lloyd 2012b). The exposure of poor standards of care provided to frail older people, particularly in the hospital setting, is becoming a common occurrence across the UK (Parliamentary and Health Service Ombudsman

2011; Local Government Association et al 2012; Francis 2013). All these reports have highlighted instances where older people were treated in an undignified manner, as well as illustrating aspects of sub-standard care. These included lack of nutritional support, lack of attention to personal hygiene and elimination, poor pain control and lack of communication. These are some of the very issues that were of concern leading to the introduction of the NSF (DOH 2001) for older people suggesting the system is still failing older people in certain circumstances. As Cornwell (2012, p1) stated, it is time 'to turn the rhetoric of personalised care into the reality of everyday care and practice in relation to frail older people'. The interface between policy and practice requires further exploration.

2.5 Reflecting on the literature

Following this review it is reasonable to assume that the way in which frailty is conceptualised and interpreted has implications for how health and social care practices are organised and delivered; how therapeutic relationships are developed and maintained; and the personal experience of care. The majority of the literature is located within a biomedical, functional framework that describes frailty in terms of functional losses that influence a person's capacity for independence in activities of daily living. Specifically, the classification and measurement of markers, to assess for and identify potential outcomes of frailty, dominate the literature. Although this instrumental and reductionist approach may be useful to clinicians, there is a claim that it may not reflect the complexity and uniqueness of the experience of frailty at the level of the individual (Brown and Markle-Reid 2003; Levers et al 2006). Moreover, that on the whole these aspects have been mostly viewed in isolation from each other and in general these approaches do not address how the combination of physical, psychological, social and environmental factors may influence frailty. Thus, the role of the broader environment and other factors such as poverty and isolation, which are often out of the control of the older person, are ignored (De Lepeleire et al 2009).

It could be argued, however, that this approach was never designed to explore the unique experience of frailty and that for some older adults identifying and managing aspects of functioning in relation to their daily lives could be highly beneficial. Moreover, targeting clinical interventions in a

focused way to prevent adverse outcomes could help to target scarce resources. As a counterpoint to these critiques, in the last decade assessment instruments that address the multiple dimensions of frailty have been developed. However, these continue to be in the early stages of development and it has been recognised that further meta-analysis and meta-synthesis of different frailty instruments need to be undertaken to assess their effectiveness.

A further criticism of the dominant medical approach is the way in which it has influenced health and social care policy; to the extent that 'frail' older people are monitored to ascertain levels of independence in functional activities. Dependence is considered to impact on an older person's ability to manage their daily lives and is therefore equated with risk. This overarching perspective can also been seen at the micro level, where older people, through surveillance, are constructing old age and 'capacity' through interactions amongst their peers.

Although there is an emerging body of work there is little research that relates specifically to the subjective experience of frailty in later life. The current literature identifies that older people can experience frailty as loss, which appears to be experienced in physical, psychological and social domains. There is conflicting evidence in relation to whether older people consider themselves to be frail or whether they just feel frail. Drawing on individual experiences of ageing in later life can help illuminate some of the issues that may be pertinent to those who are considered frail. Interestingly older people are able to articulate their experiences of ageing in later life, which does in part relate to ill health and functional decline. However, this is not always perceived to be negative by the older person. Moreover, some older people are still able to maintain a positive sense of wellbeing. This appears to be related to their sense of self or identity, and the many components that contribute to this, such as level of autonomy, ability to engage in an 'active' life, social networks as well as wider societal influences. Importantly active ageing can still be achieved with decreasing ability. Another issue is that older people do not always think of themselves as old, although they may feel old at times. These aspects of ageing certainly challenge assumptions of what it means to be old and frail.

2.6 Exploring frailty: where my study is situated

This study is informed by a wide-ranging review and analysis of the literature on frailty and ageing. Although my study is clearly informed by the wider body of literature it is the limited body of evidence that informs the personal experience of frailty in later life upon which my study is situated and builds. The findings from this empirical literature have demonstrated that older people experience frailty as decline in health as well as physical, psychological and social functioning (Becker 1994; Grenier 2006; Puts et al 2009; Nicholson 2012a). Furthermore, a sense of loss associated with the decline in overall health and wellbeing has been identified, although older people endeavour to remain in control of their daily lives and make their own decisions where possible. It is still pertinent to explore how frail older people experience and make sense of frailty in later life as there are methodological issues in some of the studies reviewed that make it difficult to transfer some of the findings and theoretical insights to the UK context. Therefore my study will contribute to this body of knowledge. However, I recognised that I was required to develop and make a unique contribution to the current knowledge base.

On that basis in my opinion what was lacking in the literature was evidence relating to the personal experience of frailty in the context of living with complex health problems. The review has clearly highlighted the importance of adopting a comprehensive approach to the assessment of frailty and efforts to develop appropriate models of assessment continue. However, in my view what was needed was an exploration of how frail older people with complex health problems experience and make sense of frailty. This is timely in the context of the increasing number of older people living with co-morbidity and Long Term Conditions (LTC), developing the knowledge base required to facilitate a person-centred approach to the assessment and management of care for frail older people with complex problems. Also, a key policy driver in the UK is to enable frail older people to remain at home with appropriate support for as long as possible, therefore my study will focus on frail older people, with complex health problems, who live alone at home. This sets my study apart from the current evidence base as all the studies focusing on the personal experience of frailty have predominantly recruited older people who live with others as well as alone.

My analysis of the literature also identified that on the whole older people do not label themselves as old, and there are differing opinions in the small body of literature pertaining to the personal experience of frailty as to whether older people consider themselves to be frail or not. However, in the context of health and social care policy labels of frailty are frequently attached to older people, often in the absence of the application of a frailty assessment tool. It is likely that in labelling older people as frail health and social care professionals contribute to how frailty is experienced by an older person. None of the current studies reviewed have actually explored how interactions between health and social care professionals and frail older people contribute to an older person's experience of frailty. Therefore, my study intends to address this gap by exploring how older people's experience of frailty is constructed by those who provide care to them, including wider societal influences, and how older people make sense of it.

Overall this study therefore aims to address the gaps identified in the literature and expand the existing knowledge base relating to the personal experience of frailty in later life. The following research questions were developed and operationalised as an aim and objectives:

- What do older people understand by frailty generally and in relation to themselves?
- How do relationships with significant others and care staff influence an older adult's experience of frailty?
- How do wider societal influences affect the experience of frailty?

Aim

To explore how older adults with complex problems experience and make sense of frailty in their daily lives.

Objectives

- To examine how older adults with complex problems construct and communicate their own accounts of frailty.
- To investigate how older adults with complex problems make sense of frailty in the context of their ageing process.

- To explore how an older adult with complex problems is constructed as frail through social interaction with health care staff involved in their care.
- To consider how an older adult's experience and expression of frailty are shaped by their social world.
- To contribute to the development of nursing and health care policy and practice.

2.7   Chapter Summary

This chapter has explored the current literature and debates that have informed the development of my research questions, aim and objectives. The next two chapters will describe the research methodology that underpinned the study.

Chapter 3: Research Methodology

The previous chapter presented a review of the literature which led to the development of an aim and objectives focused on developing an understanding of how older people experience and make sense of frailty in their daily life. The following two chapters present the qualitative research methodology that was employed to answer the aforementioned aim and objectives. This chapter explores the relationship between the methodology and the epistemological stance taken in this study, providing a rationale for the chosen research design and the methods of data collection. First, an overview of the study design is provided in order to provide a context for the ensuing discussion. The chapter is then divided into the following sections: epistemology; ethnography; case study design; access to the research setting; recruitment of participants; and ethical approval. A reflexive approach is demonstrated in relation to field access and recruitment of participants.

3.1 Overview of the study design

I adopted a prospective, longitudinal, ethnographic case study design in order to undertake a focused and intensive analysis of how of an older person, considered to be frail and living at home, experienced and attributed meaning to their daily life. The methods of data collection included: participant observation, informal conversations and interviews and documentary review. The study took place in a city situated in the north of England. Ten participants aged 75 and over, receiving care from a community matron service, were recruited to the study; a case comprised an older person, a community matron and significant others where appropriate. I observed care visits by a community matron to an older person's home at monthly intervals for six months or until death; in total 56 care visits by community matrons were observed. Following each visit I conducted interviews with the older participant in their own home; 54 interviews were conducted in total. I also undertook interviews with the community matrons and significant others at the beginning and end of the observation period for each case. I conducted 16 interviews with four community matrons and four interviews with three significant others. Nursing, medical and social care documentation was reviewed for the ten cases. In total I was in the field for two and a half years from September 2008 until March 2011.

The analysis of the data was an iterative process and began prior to the fieldwork and continued during the writing of the thesis. Data analysis comprised thematic narrative analysis within and across cases. Three themes emerged from the analysis to illuminate the experience of living with frailty. *Transitions in health and illness* details the types and patterns of transition and the subsequent impact on daily life. *Dimensions of frailty* reports perceptions of frailty in later life; accounts of feeling frail relate to episodes of uncertainty. *Health and social care provision: rhetoric and reality* provides insights into the inter-relationship between the older person's world of declining health and the episodic interactions with health professionals.

3.2 Epistemology

Given that this empirical study aimed to develop an understanding of how older people with complex problems experienced and made sense of frailty, the underpinning epistemology needed to reflect personal views, perceptions, beliefs and behaviours associated with individual experiences. To this end it was important that my understanding of the nature of reality and the nature of knowledge underpinning the social world was made explicit. This informed the development of an appropriate research methodology as well as providing a framework to assess the 'validity' of the social knowledge established within the chosen research design (Pope and Mays 2007).

Epistemology refers to claims as to how knowledge of 'reality' may be gained; it considers the nature and forms of knowledge and reflects the relationship between the 'knower' and what may be known (Avis 2005). Within the literature it is acknowledged that researchers must give thought to the epistemological considerations underpinning the nature and purpose of research (Carter and Little 2007; Denzin and Lincoln 2011). Guba and Lincoln (2005) argued that an epistemology that can recognise and deal with the "insider's" view of a socially constructed reality will be radically different from an epistemology that supports scientific knowledge based on an assumption that there is an objective single reality that can be standardised and measured.

Generating knowledge about personal experiences of older age in this study required an epistemological approach that acknowledged the individual nature of experience. In order to facilitate an exploration of the experiences of older people in later life I first drew on the work of symbolic interactionism (Blumer 1986) and the concept that social interaction at the individual level provides subjective meaning in human behaviour and the social process; thus contributing to experience. There are three basic premises that underpin the concept. First, humans act toward things on the basis of the meanings they ascribe to those things. Second, the meaning of such things is derived from, or arises out of, the social interaction that one has with others and society. Third, these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters (Blumer 1986). In essence people construct the social world, both through their interpretations of it and through actions based on those interpretations. Therefore, the behaviour of individuals and the roles they adopt are determined by how they interpret, perceive and give meaning to symbols (Bluff 2005). Furthermore, those interpretations sometimes reflect different cultures so that there is a sense in which, through their actions, people create distinct social worlds (Blumer 1986).

Therefore, drawing on their personal beliefs, values and emotions an older person will appraise and judge their experience of ageing in many situations. Consequently, their behaviour may be influenced by symbols associated with the experience of ageing, such as transitions in health status, attitudes of health and social care staff, introduction of aids and appliances for personal use, levels of independence and contexts of care provision. Furthermore, the behaviour of older people during a particular experience may be in response to changing situations associated with external events, such as the introduction of care services within their own home, as well as personal experience of such care. In turn this informs their personal interpretation of a particular experience within their social world (Hammersley and Atkinson 2007). Similarly, health, illness and the experience of hospitalisation are recognised as social events that may be interpreted differently by older people (Bowling 2002; Giddens 2009).

What I acknowledged here is that older people will have diverse experiences of ageing, thus the presence and experience of frailty will be different for

each older person based on their unique understandings of the world. In this sense 'reality' for each older person is subjective and therefore this required consideration when developing the research methodology. For this reason I rejected the notion that there is a single reality that exists for all older people in relation to their experience of frailty; that there is an objective truth that all older people who are frail will have the same characteristics, features and experiences which are quantifiable in the tradition of positivism (Ashworth 2003). I did not consider older people to be passive recipients therefore it was unlikely that the experience of ageing would be the same for all older people. In essence I was not seeking to identify the one reality of ageing and frailty, but many realities.

I did not make the assumption that experience is straightforwardly owned. Morgan (2008, p66) referred to 'an immediate, pre-reflective, affective experience of everyday life' and highlighted the tension between the immediacy of this experience and the narrative account of such experiences. He went onto explain that there will always be a gap between experience and the reconstruction of experience, in that giving an account of experiences will involve both conscious and unconscious omissions. Therefore, I did not take for granted that the experience of frail older people was transparent and self-evident or straightforwardly narratable.

Whilst these perspectives assisted in developing a research methodology to gain an insight into the individual meanings that are ascribed to the experience of frailty and ageing it does not fully capture the role of society in the development of knowledge and thus 'reality'. For example, it is likely that societal attitudes towards older people within contemporary British society may have some influence on an individual's experience. Therefore, generating knowledge about personal experiences of older age in this study also demanded an epistemological approach that acknowledged socially constructed interpretations of reality (Berger and Luckman 1969). The central concept underpinning this is that over time individuals and groups interacting in a social system form concepts or representations of each other's actions. These concepts eventually become habituated into reciprocal roles and are played out in social situations. When these roles are made available to other members of society to enter into and play out, the reciprocal interactions are said to be institutionalised. Furthermore, they become accepted as the norm

and this process of institutionalisation leads to meaning being embedded in society. This in turn influences the meanings that people attach to things and thus their interpretation of them.

As highlighted earlier there is a stereotypical image of a frail old person, usually female and wrinkled, who has a degree of physical disability and is dependent on others for personal care (Hurd Clark 2010). Thus, people's knowledge and belief of what reality is becomes embedded in the institutional fabric of society and therefore reality is said to be socially constructed; the image of a frail older person described above becomes accepted as the norm and is shaped by the cultural, historical, political and social norms operating within British society. In the context of frailty, linked to the stereotypical image are certain attitudes and behaviours that are enacted within the daily lives of older people. However, acknowledging the socially constructed nature of society does not mean that it is a fixed and unchanging entity external and independent of older adults, whom respond in a simplistic way to factors that may influence their experience of frailty (Brewer 2000). The structures that pre-exist us do not occur independently of human agency, but are reproduced and transformed by our action and everyday activities (Gergen 2009). Therefore, although frailty could be considered to be socially constructed, it is in itself replicated and changed by the action of older people and those who interact with them, through personal and professional relationships.

In light of this discussion it became apparent that the research methodology needed to consider how to ascertain the subjective views of older people, whilst at the same time acknowledging the influence that context and wider societal values exert on individual experiences, and vice versa (Ritchie and Lewis 2009). It also needed to consider the nature of the research question that had been formulated. Thus, I recognised the complexity of the relationship between epistemology, methodology, research design and methods (Carter and Little 2007). To this end an ethnographic case study design was selected.

3.3 Ethnography

In keeping with the epistemological underpinnings of this study the principles of ethnography have been drawn upon to support the study inquiry. I

understood ethnography as a philosophical paradigm rather than just a set of data collection methods (Atkinson 2001). The aim of ethnography is to describe and investigate the social world (Hardin and Clarke 2012) and in doing so the meanings, functions and consequences of human actions and institutional practices (Hammersley and Atkinson 2007). Furthermore, a central tenet of ethnography is that individuals' experiences are socially organised, and as such, the researcher begins by examining the individuals' experiences but then proceeds to explore how broader social relations have shaped them (Brewer 2000). Thus, by exploring small scale events in everyday life there is the opportunity to identify the common features within a broader social world. Brewer (2000) went onto suggest that general processes permeate down to and are in part reproduced at the level of people's everyday lives. Thus, in this study I intended to describe how a frail older person living at home experienced their daily life. Furthermore, I would be able to explore the interaction between older people, significant others and nurses, in particular how this shaped the older person's experience of frailty. Finally, I would be able to examine ways in which wider social issues influenced the experience of frailty in the daily life of older people.

Within the context of ethnography I did not subscribe to the idea that by getting close to older people and accessing ethnographic accounts that I would be able to represent reality in a straight forward, naturalistic way. Drawing on modern approaches to ethnography I acknowledged that I was part of the social world that I intended to study and that my personal biography, including my values and beliefs, would influence the knowledge produced pertaining to frailty. As Hammersley and Atkinson (2007) pointed out ethnographers construct the social world through their interpretation of it, therefore I was not seeking to uncover an 'objective truth' about the experience of frailty.

I recognised that my interpretations of the data and my presence in the field enabled at best a partial, selective and autobiographical account of the experience of older people with complex health and social problems (Brewer 2000). However, they still offered an interpretation and representation of frailty. To clarify this interpretation and enhance the quality of the research I drew upon the concept of reflexivity (Hammersley and Atkinson 2007); in order to understand how my position as researcher affected all stages of the

research process. This involved continuous reflection upon my values and preconceptions and the effect of my presence and behaviour, as well as others, in the field. Continually evaluating my actions, responses and relationships in the field contributed to an understanding of how knowledge regarding frailty was constructed in this study (Jootun et al 2009). Reflexivity is demonstrated throughout the thesis.

3.4 Case Study Design

A case study design was selected to shape the ethnographic approach to data collection. Within healthcare and nursing the use of case study methodology is gaining increasing credibility (Thompson 2004); in particular it provides nurses with a form of inquiry that is holistic and one that is akin to the concepts underpinning nursing that includes person, environment, health and nursing (McGloin 2008). Also, one of the aims of the study was to contribute to practice development; Corcoran et al (2004) suggested that one of the purposes of case studies is to provide a critical analysis that may contribute to the transformation of practice in others.

The use of case studies as a research design is not unproblematic. Within the literature there are criticisms aimed at whether it is 'methodology', 'methods' of data collection or the outcome of a process of study (Stake 1995;Yin 2009). There is agreement however that the methods of data collection can incorporate quantitative or qualitative methods, or a combination of both, to collect multiple sources of data; this enables a more complete picture of the topic of interest to be formed. There are a number of definitions underpinning the design, although there are considered to be two major approaches to case study research.

Yin (2012, p4) defines case study research as,

> 'An empirical inquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident and in which multiple sources of evidence are used'.

Whereas Stake (1995, pxi) defines case study as,

> 'The study of the particularity and complexity of a single case, coming to understand its activity within important circumstances'.

In spite of the many definitions the main feature of the case study appears to be an intensive analysis of a specific and contemporary phenomenon of interest within a real life setting; where an attempt is made to explore and understand the features which are important in determining the dynamics of the phenomenon (Appleton 2002). This is particularly so when little is known about an issue, as is the case regarding the personal experience of frailty in old age. The literature review highlighted the diversity of experience of older people, as well as how interpretations of frailty may influence the organisation of health and social care and thus the person's experience. Therefore, using a case study design enabled me to organise and collect in-depth and varied data about detailed aspects of an individual's experience of frailty and their meaning pertaining to this, as well as examining all variables that might have an impact on the experience of frailty in older age (Burns and Groves 2009). It also took into account the history and social context of the case (Platt 2007). This was in keeping with the ethnographic approach (Hammersley and Atkinson 2007). It also facilitated a holistic explanation of the factors that contribute to the experience of frailty in older age which may offer suggestions for practice development (Vallis and Tierney 2000; Hewitt-Taylor 2002).

3.4.1 Case Study Approach

I adopted the case study design proposed by Stake (1995) as it appeared to be influenced by an epistemology that closely mirrors that underpinning this study; the understanding that knowledge is constructed rather than discovered, as well as the impact of unique contexts and their influence in shaping individual cases (Hammersley and Atkinson 2007). Woods (1997 cited in Appleton 2002) demonstrated the importance of considering the researcher's own philosophical view point when considering the particular approach to case study. In contrast Yin's (2009) case design appears to have emerged from a positivist view point, focusing on the development of a scientific framework, including hypothesis development, using criteria such

as reliability and validity to evaluate the quality of a case and explanation of causal relationships.

3.4.2 Constituting the case

In the literature articulating what is 'the case' has been identified as problematic, particularly when there is little guidance or clarity as to what can constitute a case. In fact it has been suggested that it may be impossible to identify all aspects of the case at the beginning of a study and that this is likely to unfold as the study progresses (Appleton 2002). However, it has been acknowledged that a focused definition of the case will inform the methods of data collection as well as guiding the outcomes of the study (Stake 2005); therefore it was important that I gave detailed thought as to what a case would 'look like', both the phenomena of interest and the context.

I was attempting to develop an understanding of how a person experiences frailty in older age therefore a case would certainly comprise an older adult. However, not all older people are 'labelled' as frail therefore characteristics that made it more likely for this to occur also constituted the case, such as, number of health problems, in receipt of care services. Clearly depicting the 'boundaries' of the case in this way ensured, to some extent, that I kept the experience of frailty in focus (Stake 1995). I was also interested in how relationships with nursing staff and significant others influenced an older person's experience of frailty and therefore a case would also comprise nurses as well as significant others.

Clarifying the context that constitutes the case was equally important. Locating the older person who is labelled as frail within context enabled an exploration of the many factors that may influence their experience of frailty (Denzin, Norman and Lincoln 2007). The main context in this case involved the person's own home; however contexts at the periphery of the case were considered, such as, the hospital setting and intermediate care facilities (Cresswell 2012). Apart from the physical context which situates the case, it was important to describe the wider context within which the case was located. In my study the contextual factors included, health and social policy, community nursing policy/protocols and guidance, voluntary and statutory organisations and services, professional practice issues, attitudes towards

older people. In recognising these contextual factors I was able to describe the boundaries, here I mean the blurred edges (Appleton 2000), between the experience of frailty and wider influencing factors.

3.4.3 Type of case study

There is often an expectation for case studies to be categorised according to their function. However, it is recognised that this may not always be possible and it may limit the process of analysis of the case (Stake 1995). Stake (1995) described three types of case study design: intrinsic, instrumental and collective. The 'intrinsic' case study focuses on seeking clarity and understanding of a particular case; it is the unique case which is of interest. Within the 'instrumental' case study the case is not the primary focus; it is used to explore and comprehend an issue. In this study I adopted elements of intrinsic and instrumental case design. I intended to examine how an older person experienced frailty, as well as developing insights into the concept of frailty. I also undertook a collective case study, as I was exploring a number of cases to explore the experience of frailty in older age (Stake 1995). This enabled me to capture the many factors that may influence an older person's experience of frailty, such as, gender, range of health problems, service provision, and family support. A longitudinal case study was chosen as it enabled an exploration of frailty in the context of an individual's ageing process (Jamieson and Victor 2000).

3.5 Selecting the field setting

Selecting an appropriate setting that enabled the investigation of the research questions was the first step in the process of data collection (Hammersley and Atkinson 2007). A multi-stage sampling frame was used to define and select the study population (Bower, House and Owens 2011). The target population comprised older people with complex health problems living at home receiving care from health and social care workers. First, I identified the organisations that provided health and social care to older people in their own homes, followed by consideration of the categories of nursing staff who worked within them. This involved a review of potential research sites to identify their suitability to take part in the study as well as the likelihood of gaining access (Hammersley and Atkinson 2007). The choice of setting was also influenced by pragmatic considerations such as the ability to make

contact with relevant personnel and the scale of travel time and costs incurred within the setting. At this point there was uncertainty in determining which type of nursing staff would be included in the study until the nature of the organisation was clarified. However as Ritchie, Lewis and Elam (2009) suggested careful consideration was given to identify those organisations and categories of staff that would be most likely to answer the research aim and objectives.

I made the decision to negotiate access to the local community matron service. This service was chosen as these nurses provide one of the main services to older adults with complex problems at home (DOH 2005c). The community matron role was first introduced in 2004 as part of the Government's strategy to improve the management of care for people with Long Term Conditions (LTC). The NHS Improvement Plan (DOH 2004b) outlined the complex problems that people with LTCs face, especially those who are older. These included a range of disabling symptoms, decreased quality of life, and functional dependence alongside loss of family and work roles. For many people, living with the complexities of a LTC means numerous unplanned admissions to secondary care services, such as hospitals and intermediate care. Within the context of the NHS and Social Care Long Term Conditions Model (DOH 2004b) case management was proposed as an effective delivery system to manage the complex health and social care problems associated with LTCs. Community matrons were introduced to apply this case management approach with the main remit of improving care for people, as well as reducing the use of emergency bed days.

This particular community matron service, established in 2005, was situated within a Primary Care Trust (PCT) in a post-industrial city in the North of England. This northern city has a population of 555,500; at the time of the study there were approximately 40,122 people aged over 75. Of these 7,206 were aged between 85 and 89 years and 3,433 were aged over 90 (Sheffield City Council (SCC) 2014). There were more men than women across all the age groups. Eighty two percent of the residents were White British, living across 28 wards. Residents from Black and Ethnic Minority (BME) groups comprised 18% of the total population, with the majority living in the central wards of the city and many of whom were under the age of 50 and likely to

be students (SCC 2014). Eight community matrons were employed to provide services to people with LTCs across the locality. Each community matron was located within a geographical region of the PCT and linked to a cluster of general practices. The community matrons were managed by team leaders who were responsible for leading a team of community nurses within that geographical region.

I was aware that by focusing on cases in a particular setting this made it inherently difficult to transfer the findings of this study to a wider population (McGloin 2008; Simons 2009). Due to pragmatic reasons I only focused on one setting. I acknowledged the uniqueness of the case setting in this study, as described in the previous paragraph, and recognised that the findings may not reflect the experience of frail older people located in different cultural and demographic contexts, including place; making it difficult to transfer the findings of this study to a broader population. However, it is anticipated that these findings will contribute to the development of theoretical knowledge and it is this knowledge that can be used by broader research and practice communities (Sangster-Gormley 2014).

3.5.1   Access to and preparation of the field setting

Negotiating access to the setting is essential; in particular Hammersley and Atkinson (2007) noted the importance of seeking permission from the appropriate member of an organisation to authorise access. Initially, I arranged a formal meeting with the manager of the community matron service to discuss the purpose of my research, and to ascertain whether the community matron team would be interested in participating in the study. During this meeting I realised that we had met before when she had been involved in a research project at a local research centre where I had previously worked. She was supportive of the study and provided consent to access the service; she also acted as gatekeeper to the management team.

Subsequently, I was invited to a meeting with key members of the line management team, where agreement in principle was given to support the study. It became clear during this meeting that the manager of the community matron service had already communicated her support of me undertaking the study to her team. This highlighted the value of relationships with

gatekeepers particularly where gatekeepers have close ties to a group (Sharkey et al 2010); in particular the more trust the group places in the gatekeeper, the more trust it extends to the researcher. It was clearly valuable that the manager of the community matron service was overtly supportive of my study. Moreover, the time that I spent preparing for these initial meetings had been crucial in order to facilitate the process of gaining access to potential participants (Bryman 2012).

Following the meeting with the line managers I was given permission to approach the community matrons at their next team meeting, in June 2008. Twelve community matrons were in post at that time; eight were present at the meeting. Prior to this team meeting I circulated a study information sheet via email to all community matrons (Appendix 1). During the meeting I delivered a Power Point presentation (Appendix 2) summarising the nature of the study and outlined what their involvement would be should they wish to take part in the study. It was kept brief and written avoiding the use of 'research jargon' (Ross 2012). Providing information in this way to the community matron team was important so that the main elements of the study were communicated, for example, access to participants, methods of data collection, process of informed consent; this was fundamental to the process of gaining co-operation of the team (Denscombe 2010; Hammersley and Atkinson 2007). Following the presentation a discussion took place where the community matrons were able to ask questions and clarify issues. Denscombe (2010) highlighted the importance of allowing 'key' personnel the opportunity to explore the impact of a study on themselves and others, in this instance older people on their case-load, in order to maximise access to the research field. The discussion was also useful in the following ways:-

1. The community matrons had the opportunity to discuss the study and ask further questions. Overall, this led to a clearer understanding of the study aims and how the findings would be used to enhance the care of older people, with complex problems, living at home.

2. The opportunity to raise concerns relating to the research process was provided. One concern raised by a community matron related to the additional burden that an older person could face, as an excerpt from the field notes illustrate:

Question noted: Many of the older people on our case loads have multiple health problems and are vulnerable, how will you make sure that you don't over burden them?

In response to this I clarified that the process of consent and participation was on going, therefore should an older person find the experience burdensome over time they would be free to withdraw from the study, without pressure to continue. The older people would be given verbal and written information that outlined this. Here I demonstrated that I was guided by the principle of non-maleficence – avoiding the causation of harm (Beauchamps and Childress 2013). I also clarified that the study had been awarded LREC/LRGC approval (Appendix 3) and that adopting criteria relating to the recruitment of vulnerable older people would safeguard against this. In particular, there would be no coercion to take part.

Another community matron asked a question that related to the observation of their practice:

Question noted: In the information sheet it mentions that you will be observing our practice but not making judgements, how would this work?

I explained that I would be observing the clinical care that they gave to their patients, as well as non-verbal communication; this would be documented in field notes that I would write at the time of the observation. I reinforced that the purpose of the observation was not to be critical of their role, but to observe how they carried out their work with older people. However, I made it clear that a requirement of LREC approval was to report episodes of 'poor practice'. I found this a difficult disclosure to make as I was aware that this information was potentially threatening to the community matrons. In particular I was mindful that the threat of sanction in relation to their nursing practice could influence whether or not they agreed to take part (Sheldon and Sargeant 2007); this would have a huge impact on recruitment. However, to my surprise the community matrons were not overly concerned about this; there was a general consensus that working within the context of the Nursing and Midwifery Code of Conduct (Nursing and Midwifery Council (NMC) 2008) would safeguard against this. This led to a useful discussion regarding what

constituted 'poor practice'. Moreover, it enabled me to highlight the tensions that I may encounter in my dual role as researcher and nurse, ones that I took seriously, and how such situations may be handled. On reflection, I considered that this useful dialogue provided a foundation for future discussions with the community matrons regarding care issues should they arise. On this basis I did not consider it appropriate to use a formal protocol outlining 'poor practice' as advocated by other nurse researchers (Casey 2007; Houghton et al 2010). In my opinion taking such an approach implies that nurses cannot undertake research because they can only agree to confidentiality if they observe flawless care.

3. A number of community matrons asked what benefit the study would have for them. The following question was noted in field notes:

   Do you think that taking part in this study will be useful for us?

   This enabled the community matrons to discuss the possible benefits of the study to the development of their role. First, they were engaged in a formal evaluation of their role and therefore there was an agreement that elements of the study could be used to inform this evaluation. The community matrons were keen to have their role revealed to a wider audience. However, I was mindful that although this may have its advantages in the context of their current evaluation I could not guarantee that the findings would always support aspects of their role. At this point I found this difficult to raise as I did not want to jeopardise access to the setting (Hammersley and Atkinson 2007).

   Second, participating in research was a key element of their specialist role and therefore participation would contribute to their professional development (NMC 2008). However, although participation in the study was clearly seen as an advantage to role development in this meeting, the possibility that findings could challenge the role of the community matron was not raised. Moreover, at this point I had not considered that potential findings could highlight aspects of their role that were not working and this would become a challenge later in the study.

4. It provided me with the opportunity to communicate my credentials as a researcher and nurse. Moreover, I was able to reassure the team that I had the relevant knowledge, skills and attitudes required to undertake such a study. This was crucial to developing a relationship with the community matrons; two agreed to take part immediately as a result of the meeting. This resulted in them signing-up for the study at a later date.

3.6 Gaining access to the research participants

After obtaining approval in principle from the community matrons to participate in the study I had to consider how to access them and the older people on their caseload (Hammersley and Atkinson 2007). Once a community matron expressed an interest in the study I contacted them by telephone to arrange an appointment at a time and place convenient to them; this was normally at the health centre where they were based. This initial contact enabled me to give further details of how the recruitment process would work, for the older person and themselves; I also arranged to spend a day visiting patients with them. The visits were very useful and enabled me to become familiar with the types of patients that they visited and the nature of the work within and surrounding the patient contact, within that locality (Hammersley and Atkinson 2007).

Showing interest in their work also enabled me to further develop my relationship with them. I was able to demonstrate empathy in relation to engaging with older people who were potentially vulnerable and on reflection this helped to put the community matrons at ease when I was present during patient visits. This also enhanced access to potential participants (Murphy 2005; McGarry 2007). The community matrons that I accompanied were keen to identify older people to take part in the study. In total I approached seven community matrons who had expressed an initial interest in the study; of these four took part in the study over the two and a half years of field work. The other three were not included for the following reasons: one had returned from maternity leave and had not built up her caseload of patients; one was new in post and therefore was developing her knowledge and skills in the role; one never returned my phone call.

3.6.1 Identification of research participants: sampling strategy

The sampling strategy used to select a 'case' was informed by the aim and objectives of the study and current gaps in the knowledge base pertaining to frailty (Stake 1995). This study aimed to explore how older people with complex problems experienced and made sense of frailty in their daily lives. Also, a key objective was to explore how interactions with health and social care staff influenced the experience of frailty. I adopted a purposive approach to sampling in order to choose participants who were likely to contribute to my understanding of frailty in later life. Within each case this was considered an appropriate method as it would enable the selection of participants who could provide rich information relevant to the research question (Hansen 2006; Bryman 2012).

The following inclusion criteria were used to guide recruitment of the purposive sample of older people (Box 1).

Box 1: Criteria used to recruit older participants

Inclusion criteria:

- Aged 75 and over
- Living at home
- Two or more health related problems
- Receiving a community matron service
- Perceived as frail
- English speaking
- In receipt of or eligible for care services

Within the sampling frame it was important that the inclusion criteria prioritised the most appropriate characteristics pertaining to frailty, including diversity where relevant (Ritchie, Lewis and Elam 2009). It was necessary to recruit older people who would have appropriate experiences that would illuminate and inform my understanding of frailty. The aforementioned criteria were developed and applied for the following reasons:

1. **Chronological Age**: Chronological age is considered to be the basis of powerful expectations and assumptions in relation to older age. Although I recognised that age in itself does not equate with frailty (Bytheway 2011) I

was interested in how perceptions of frailty were linked to older age; hence the lower age limit of 75.

2. **Living at home**: Of those aged 65 and above 95% live in their own home, alone or with others. Policy drivers have focused on the importance of keeping frail older adults in their own home where possible (CSCI 2006b).

3. **Health related problems**: The study focused on older adults with more than one health related problem, such as, breathlessness, pain, nausea and vomiting, constipation, anorexia, weakness, fatigue, depression. A number of studies have highlighted that a greater number of health problems increases the complexity of the older person's experience and situation and their classification as 'frail' (Barnes and Bennet 1998; Katz et al 2011).

4. **Receipt of or in need of health and care services**: The rationale for choosing older people on the community matron case load was based on DOH health policy (2004), as these services reflected key provision for older adults with complex problems. The rationale for choosing older people in receipt of social care services was based on studies that have recruited frail older people in receipt of home care services (Patmore 2001; Katz et al 2011); where older people, aged over 75 years, with complex needs, were successfully identified. After a discussion with the community matrons, older people who were not in receipt of care services were still considered for inclusion. This is because some older people would refuse services that they were assessed to be eligible for. This could potentially offer an alternative view point on the experience of ageing and frailty.

5. **English speaking**: A decision was made to only include patients who were able to understand English. Although the experience of frailty of non-English speaking older adults clearly warrants attention, there was good evidence that this would require a study in its own right (Moreno-John et al 2004).

6. **Cognitive impairment**: The study excluded those older adults with moderate to severe cognitive impairment. Matthews and Grant (2004) suggested that people without 'a voice' have as much right as anyone else to be involved in research. Similarly, it is acknowledged that older adults who lack decision making capacity should not be excluded from properly conducted research, as stated in the Mental Capacity Act

(Department for Constitutional Affairs (DCA) 2005). In fact, researchers should demonstrate that potential participants **do not** have the capacity to consent to involvement in a research study. However, this piece of research was being carried out as part of an educational qualification; therefore the time scale imposed on the study made it difficult to include those who lacked the ability to demonstrate understanding and provide informed consent. Also, it was very likely that there would be older adults who were able to provide informed consent to participate within the study (DCA 2005). Therefore, after discussion with my research supervisors a pragmatic decision was made to exclude those participants with moderate to severe cognitive impairment.

7. **Considered frail**: The literature review has highlighted that there is no common understanding relating to frailty, therefore, as well as meeting the other criteria, the community matrons were asked to consider whether the older adult that they were working with was 'frail'. In particular, words used to describe frailty in the literature were put forward with links made to older adults within the service, such as, vulnerable; fragile; dependent; at risk (Browne and Markle-Reid 2003).

In keeping with the principles of ethnography opportunistic sampling also informed the strategy (Ritchie, Lewis and Elam 2009), described by Hammersley and Atkinson (2007, p35) as 'sampling within cases'. This sampling strategy developed during the field work when I realised that I had not considered at the outset that other people would influence the experience of frailty within each case. Therefore, opportunistic sampling was important in identifying those potential participants involved in the daily lives of the older people, who would contribute to my understanding of frailty, for example, care workers, volunteers, hairdressers.

3.6.2   Recruitment of the sample

The process of recruitment was complex (see Figure 1). Once I had made contact with a community matron, I asked them to apply the above criteria and consider if they had patients on their caseload that would be suitable for participation within the study.

Once an older person had been identified in line with the recruitment criteria the community matron gave them some verbal information about myself and the study during a planned care visit. The older person was also asked whether I could attend the next clinical visit to give them further details of the study. Twelve older people were asked by the community matrons if I could visit them and they all agreed. By using the community matrons in this way, to distribute information regarding my study and gain verbal consent to possibly opt-in, I attempted to minimise the risk of coercion by removing myself from the consent process until the older participant was willing to meet me (Houghton et al 2010).

The community matrons contacted me by telephone once an older person had given verbal agreement to my visit. After gaining this verbal consent I accompanied the community matron during the next appropriate care visit. During this visit I introduced myself as a researcher and gave a short, jargon free outline of the study including what participation would mean for the older person (Ross 2012). This outline included a brief description of the focus of the study, the number of observation visits and interviews, the use of audio-equipment, involvement of significant others as well as the right to refuse to take part or withdraw from the study at any time. I acknowledged that it was not possible to provide information about everything that would take place. Hammersley and Atkinson (2007) highlighted that the ethnographer may not always know what the study completely entails or what all the consequences are likely to be. At this point I left an information sheet with the older person (see Appendix 4) and asked them to discuss it with family and friends where appropriate (Harris and Dyson 2001). I wondered whether the older people would discuss the study and share the information sheet with others, and in five cases this occurred. When required the information sheet was adapted to the needs of the individual person, for example, ensuring that the font size was large enough for the two older people with sight impairment (Josselson 2013).

It was important that potential participants were given time to consider the information given and what involvement in the study would mean for them; this increased the likelihood that consent was voluntary (Houghton et al

2010). For most of the older participants in this study this ranged from one to three weeks; four had involved members of their family within this process. Once the older person had communicated to the community matron that they would like to participate in the study, I accompanied the community matron on the next appropriate visit. Again, I was given time at the beginning of the consultation to ascertain that the older person had read the information sheet and understood what participation in the study involved. I also gave the older person the opportunity to ask any questions regarding concerns that they may have, as well as clarifying any misunderstandings. It was not always clear whether the older person had read the information sheet and therefore I had to ensure that I reiterated what involvement in the study would mean for them. As Sheldon and Sargeant (2007) highlighted I think that they had already decided that I, therefore the study, was 'trustworthy'. On reflection, this was because of my own interpersonal skills and also my association with the community matrons. There may have been other reasons that motivated the older people to participate. For example, older participants one, two and nine often mentioned that they were lonely and taking part in the study could have alleviated that to a certain extent (Pleschberger et al 2011).

Figure 1: Recruitment of Sample - older participant; community matron; significant other

Community matron (CM) given an information sheet.
Older participant (OP) identified from CM caseload as meeting inclusion criteria. Verbal information about study given to OP by CM at next visit.

Timescale 1-2 weeks

Verbal agreement given by older participant to CM for researcher visit. Researcher visit: clarified met inclusion criteria. Verbal information given regarding study; information sheet handed out and left for consideration.

Timescale 1-2 weeks

Verbal agreement of OP to participate/not participate given to CM.

Timescale 1-2 weeks

Verbal agreement not given.

Exit from study

Verbal agreement given.

At next visit written consent form completed with older participant by researcher.

At time of OP consent verbal agreement given to approach CM and significant other (SO) to participate in study.

Verbal consent obtained from CM at same time; written consent obtained on return to office same day.

1st observation undertaken at the same visit.

Letter of invitation (with reply slip) and information sheet for SO left with older person.

No/negative reply slip returned: exit from study.

Positive reply slip returned. Date/venue for interview arranged. Consent form completed with SO by researcher.

1st interview arranged

Once it was clear that the older person understood the study, I obtained written consent. In total 12 older adults were approached and 10 were recruited to the study. One older person decided to not participate after reading the information sheet; another person had not fully met the inclusion criteria as they were under the age of 75 (see Table 2 detailing the study participants).

Table 2: Participants in the study

Community Matron	Older participant	Nominated significant other	Significant other agreement
1	1	Yes: neighbour	Yes
	6	No	
	7	Yes: daughter	No
2	2	Yes: son	No
	3	No	
3	4	Yes	Yes but withdraw after relative's death
	5	Yes: daughter	Yes
4	8	Yes: daughter	Yes
	9	Yes: nephew	No
	10	Yes: daughter	Yes but became ill herself so withdrew

Once an older person had provided written consent (Appendix 5) to take part in the study, I asked their permission to approach the community matron involved in their care to also take part in the study. After obtaining the older person's agreement I asked the community matron for verbal consent to commence data collection at that visit; later on the same day, on return to the health centre, I obtained written consent from the community matron to take part in the study (Appendix 6). Overall, four community matrons participated in the study.

I also asked the older person to nominate a significant other to take part in the study should they wish, and asked their permission to approach that person. Where possible the older person was asked to give the nominated person an information package relating to the study. This included an information sheet (Appendix 7), my contact details should they require further information about the study, a reply slip indicating whether they would or would not like to take part in the study and a pre-paid envelope. Once an

affirmative reply slip was received I contacted the nominated person and arranged to meet them at a convenient time and place, where written informed consent was obtained (Appendix 8). Eight older people nominated a relative or neighbour to take part in the study (see Table 2). Four family members and one neighbour formally agreed to take part in the study. One family member agreed to participate however his mother died and therefore he felt unable to contribute; another became ill. One son and nephew would not be interviewed formally but were occasionally present at community matron visits and agreed verbally to participate in this way. On reflection, it is possible that they did not want to be involved in the bureaucracy of form filling, highlighting how the formal research process can inhibit participation (Seymour et al 2005).

I was required to continually ascertain whether a participant continued to give their consent to remain in the study, acknowledging that the participants were free to change their decision at any time (Sheldon and Sargeant 2007). As Norman (2010) highlighted the process of gaining informed consent was not a one-off process. I continued to gain consent at the beginning of each observation and interview. Where possible I also arranged the subsequent interview and observation visit date at the end of the previous session, thus in some ways giving the participants an extra opportunity to opt-in. None of the participants changed their mind and all continued to take part in the study.

3.6.2.2   Sample size

The sample size was relatively small in keeping with ethnography (Hammersley and Atkinson 2007) and the case study design (Stake 1995). The intention was to scrutinise a small number of cases in detail in order to understand the context and the complexities underpinning the experience of frailty in later life. Furthermore, the type of information collected would yield large amounts of data rich in detail therefore in pragmatic terms it was important to keep the sample size small. Also, the sample size was not used as the basis for generalization of the findings (Lewis and Ritchie 2009). Previous studies adopting a case study design and similar sampling strategies have recruited sample sizes ranging from three to twenty (Baxter and Jack 2008; Shibusawa and Padgett 2009;

Casey and Houghton 2010; Duner and Nordstrom 2010; Smebye, Kirkevold and Engedal 2012). In this study I recruited ten older people, constituting ten cases.

3.7 Ethical approval

In order to undertake research that involves service users and health and social care staff within any National Health Service (NHS) setting ethical approval must be sought. There is also a requirement to meet the Research Governance Framework for Health and Social Care (DOH 2008) in order to safe guard participants. Concurrent with the preparation of the research site approval was sought from the Local Research Ethics Committee (LREC) and the Local Research Governance Consortium (LRGC). It was important to manage site preparation, LREC and LRGC simultaneously, for example, the manager of the community matron service was required to sign approval in principle to take part in the study on the LREC application form.

I acknowledged that obtaining ethical approval for this ethnographic study was potentially problematic. In attempting to recruit frail older people I recognised that some potential participants would be vulnerable, raising issues around informed consent (Pleschberger et al 2011). Furthermore, I was aware that the methodology of ethical review is predicated on an anticipation that it is known how the research process will proceed. As Simpson (2011) argued it is difficult to completely anticipate all elements of the ethnographic research process in advance, for example, obtaining consent; who will participate in the study; the length of participation; and where the observation will take place. I had to acknowledge these tensions on the ethics application forms. I felt that it was important that I attended the LREC meeting so that I could answer any questions that issues such as these raised, demonstrating my integrity as a researcher. Approval was given by the LREC and LRGC following two minor amendments: an addition to the information sheet regarding where to access support; removal of the need to inform the older person's family doctor that they were participating in the study. Access to the clinical setting was approved from the end of February 2008.

3.8 Chapter summary

This chapter has explored the relationship between the methodology and the epistemological stance taken in this study, providing a rationale for the chosen ethnographic case study design. Access to the research setting and the strategy for recruitment of participants has been detailed. A reflexive approach to my engagement with these aspects has been demonstrated. The next chapter will describe the methods of data collection and data analysis. It will also detail the ethical issues encountered in the field.

Chapter 4: Study Field Work

The previous chapter explored the relationship between the methodology and the epistemological stance taken in this study. Access to the field and recruitment of participants was also detailed. This chapter presents the methods of data collection and the process of data analysis undertaken in the field. It is divided into the following sections: participant observation; interviews and conversations; documentary review; withdrawal from the field; and data analysis. Ethical issues encountered during the period of field work are explored. A reflexive approach to being in the field is demonstrated.

4.1 Ethnographic methods

In the context of ethnography there are three main approaches to the collection of data in order to illuminate the focus of the enquiry. These are: observation of people in their natural surroundings; pursuing lines of enquiry through informal and formal conversations; and review of documentation and artefacts (Hardin and Clarke 2012). Figure 2 illustrates the schedule for data collection, per case, during the study period.

4.2 Participant observation

Within this study a key element of data collection involved the observation of older people in their own homes for a sustained period of time (Hammersley and Atkinson 2007). Principally, I observed face-to-face contacts, and the 'interactions' surrounding these, between older participants and the community matrons, as well as significant others. Participant observation is considered to be a central tenet of ethnographic data collection methods. Through it, the researcher learns about cultural rules and expectations from the perspective of an insider (Brewer 2000; Atkinson 2001). Therefore, through participant observation I studied the actions and accounts of an older person, community matrons and significant others, in their everyday context. A closer view of the routines and practices of older people and their interactions with community matrons, and significant others, facilitated my exploration of factors that contribute to an understanding of the experience of frailty in later life.

Figure 2: Flow Chart to illustrate the methods of data collection in the field work per case
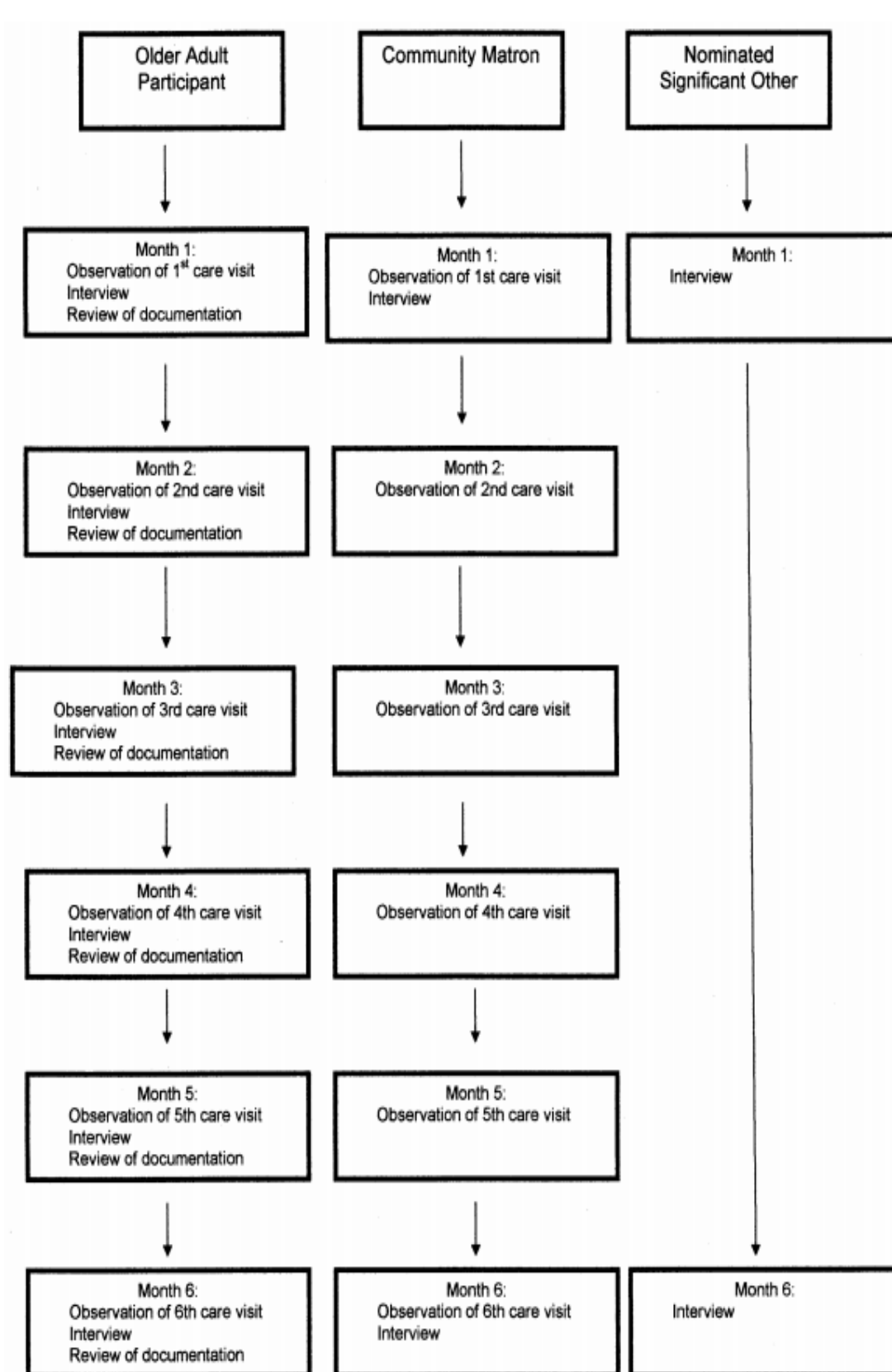
I observed up to six care encounters with each older participant and their community matron, at monthly intervals, over a period of time ranging from four to ten months. I considered these to be appropriate time-frames to enable a focus on how the older participants experienced their daily lives over the course of time (Polit and Tatano Beck 2010). This facilitated making links between earlier and later time points and context (Jamieson and Victor 2002). It also allowed me sufficient time to view the 'interaction' as part of a changing and on-going association between people, not as a one off occurrence isolated from previous and future encounters. I continued my observations when undertaking interviews with the older participants, following the earlier care visit by the community matron.

For some older participants the timing between the observations was longer than a month; this was for a number of reasons. Some were transferred in and out of other care services, including across care boundaries. On a number of occasions the community matrons did not make me aware of a planned visit, which I found frustrating; however, I had to accept that my study was not a priority for them. At times, the older participant was not well enough to take part or I was ill and could not attend the field. There were occasions where observations were planned to capture a particular event, such as a case conference as I felt that these gave an insight into the overall experience of the older person (Holloway and Wheeler 2010).

4.2.1   Structure of the observations

It was important that I considered what to observe and when to observe it. Hammersley and Atkinson (2007) revealed the importance of a structured approach when capturing the detail of the 'natural world' under scrutiny. First, I engaged in 'descriptive' observation where I observed everything, assuming that I knew nothing about what was going on or taking nothing for granted (Silverman 2011). This comprised the context within which the interactions took place, for example, the time of day that the care visit occurred. It also included the specific focus of the care visit, such as, annual long term condition checks, administering the flu jab and emergency call outs. I observed the physical lay-out of the home in order to get a sense of how the

space was managed. I listened to the interaction between, and observed the behaviours of the older participants, the community matrons and others present in the home (Polit and Tatano Beck 2010).

With increased exposure Hammersley and Atkinson (2007) suggested that the ethnographer should engage in more focused observation in which certain aspects defined as irrelevant are ignored. However, over the period of data collection per case I did not focus my observations in this way as I did not find it possible to define aspects as irrelevant. However, I did occasionally engage in selective observation (Hammersley and Atkinson 2007), for example, on occasion the community matrons would have a discussion with a care worker in a different room from the older participant. I attended these discussions as they illuminated how the community matron and care worker communicated issues relating to the older participant.

I was aware that by undertaking observations in an older participant's home I was accessing a private space. Therefore, I also needed to consider what spaces I could observe, for example, what was a public space and what was private. In the first instance I accessed the living space that a community matron was given permission to enter and this was the main area within which my observations occurred (Ceci and Purkis 2009). I made the decision that I would only enter the living spaces that I was given permission to do so throughout the period of study and I always checked that this was acceptable in any given situation. This took into account the possibility that an older participant's situation could change. In some instances I was given permission to enter an older participant's kitchen and bedroom, especially when they asked me to retrieve something for them.

4.2.2   My role of observer

It was important to consider my role of observer in the field as this would clearly influence the range and character of the data to be collected (Hammersley and Atkinson 2007). The role of the ethnographic observer has been considered along a continuum from complete participation to complete observation (Gold 1958; Junker 1960). In the former, the researcher's presence is concealed during immersion in the field as a 'member', whereas in the latter the researcher has no contact with those being observed. In this study I considered the impact that the differing roles would have on my ability

to collect data and develop relationships within the field. Hammersley and Atkinson (2007) acknowledged that both perspectives share similar advantages and disadvantages. From a positive perspective both minimise the response of individuals to the researcher. However, conversely both limit the nature of what can be observed and in some instances it may be difficult to question participants which could limit opportunities for data collection.

I initially adopted a mid-point position, that of observer-as-participant (Gold 1958). I consciously adopted a situational identity that enabled me to engage in day-to-day social interaction without becoming involved as a 'member' of the field. Thus, observer-as-participant was an acceptable compromise allowing me to interact casually and non-directively with participants. Also, adopting this role would not inhibit lines of enquiry as I did not have to adopt the remit of a specific hidden role (Hammersley and Atkinson 2007). Furthermore, it provided me with the opportunity to understand the perspective of the participants whilst at the same time maintaining the focus of the research. I considered it problematic to assume the role of participant-as-observer as there were few membership roles that I could take up in the field. The most obvious would be that of a care worker; however I felt that this could create tensions between my professional responsibilities as a Registered Nurse and those of a care worker. Furthermore, it would require an honorary clinical contract and a pragmatic decision around the study time scales further influenced the rejection of this approach.

During the first visit to all participants my role as observer-as-participant was made explicit and I was introduced as a colleague who was undertaking research. In acknowledging that my primary role as a researcher was to observe older people in their own homes I was able to minimise the risk of deception (Hammersley and Atkinson 2007). I sat quietly in a corner of the room, observing and recording in field notes the interactions and activities that took place. At this point I was not involved in any 'work' and was a participant because I was present in the setting.

4.2.3   Recording the observational data

When conducting participant observation it was important to consider how to write and record the details of the observations in the form of field notes (Hammersley and Atkinson 2007; Hardin and Clarke 2012). I was aware that

I needed to be unobtrusive so that I did not disrupt the interaction and behaviour under scrutiny (Ritchie 2009). It was also important that I created a rhythm to writing the field notes, taking into account the potential gap that could occur between the observation and the writing up of the field notes so that I could maximise my memory recall (Silverman 2011). To reduce the risk of forgetting information I made the decision to record verbal interaction during each care visit on a mini-disc recorder, therefore the field notes focused specifically on what I observed and not the verbal interaction (Casey 2007; Atkinson and Coffee 2011). The mini-disc recorder was placed near the older participant and the community matron, but in a position that was not considered to be obtrusive, such as a small table or chair arm.

I recognised that in recording the verbal interaction I could give this a higher status than the detail of the observations written in my field notes. Prior (2011) acknowledged that using technology to record has the potential to privilege what is captured through recording at the expense of the lived experience as the ethnographer has personally known it. However, I was able to concentrate on what was happening around the verbal interaction and write field notes of my observations.

There were periods when I experienced tensions in writing my field notes. On occasions it became difficult to concentrate on what was happening and simultaneously write notes therefore, at times I had to forfeit detail (Huxham and Vangen 2003). Although I endeavoured to write detailed notes, in such instances I recorded key words to enable concentration. For example, at times the community matron and the older participant moved into another room so that the older participant could be weighed; the scales needed to be on a solid surface. On these occasions I followed them through into the room with the mini-disc recorder, although it was difficult to record notes at this time. To maximize memory recall I paid particular attention to these situations when I wrote up my formal notes shortly after each visit, mostly on the same day (Eberle and Maeder 2011).

I also kept a fieldwork journal throughout the study, which complimented the field notes. In this I captured my impressions during an observation as well as links that I made within and across cases. This occurred as soon as possible after each visit, mostly in the same day; although some entries were

made within the week. The following extract from my journal regarding older participant two demonstrates how I made a comment regarding his loneliness and I was able to link this to other cases:

> Memo to self: OP2 seems lonely, so do OP1 and OP3.
> What does literature say? Look for this theme through other cases.

In my fieldwork journal I also kept notes about strategic methodological decisions as well as recording my thoughts and feelings about the activities that I observed and the people that I was involved with. In particular, it was an invaluable resource for examining my own emotional responses to situations, thus demonstrating reflexivity. Nicholson (2009) argued that in order to fully understand the experience of frailty it is necessary to explore the researcher's emotional experiences to situations and my fieldwork journal facilitated this. I also acknowledged that in working with older people in later life I was vulnerable to emotions that could blur my perceptions and interpretations of events (Valentine 2007; Woodthorpe 2009). Thus, by keeping the journal I was able to monitor the cumulative effects of continued emotional engagement and challenges in the field (Rolls and Relf 2006).

4.3 Accessing participant accounts

Accessing participants' oral accounts is considered important as it enables the ethnographer to gain an insight into the subjective experience pertaining to particular phenomena, as well as checking inferences made from observations in the field (Brewer 2000). Furthermore, participants' oral accounts provide insights into the context within which they were produced, illuminating the larger subculture and cultures that influence the experience of frailty (Hammersley and Atkinson 2007). Therefore, as well as watching and listening to what happened in the field it was important that I sought the participants' views regarding the situation. This was difficult during the care visit with the community matron therefore I decided to undertake a series of in-depth interviews with all the participants: older person, community matron and significant others. The use of interviews was justified for two main reasons. First, they would clarify issues that arose from the observations from the perspective of the participants as well as eliciting general understandings pertaining to the concept of frailty. Second, the data from the

interviews could be used to illuminate aspects within the observation (Millner and Glassner 2011).

I acknowledged that the knowledge regarding frailty inferred from the interviews would be generated by the interaction between myself and the participants, thus demonstrating resonance with the epistemological approach to the study (Millner and Glassner 2011). I did not subscribe to the view that knowledge is a 'given' in the sense that I was waiting to uncover the participants' experience through questioning alone. Thus, in my role as researcher I recognised that I would play an active part in the development of data and meaning alongside the participants.

4.3.1 Interviews with older participants

Where possible following each observation visit I conducted face to face qualitative interviews with the older participant. I considered the interviews to be a form of conversation (Lofland et al 2004). By engaging in such conversations the fundamental process through which knowledge about the social world is constructed in normal interaction was reproduced (Rorty 1980, cited in Ritchie and Lewis 2009). However, within this study the interviews would differ from a normal conversation and would become a conversation with a purpose as I endeavoured to explore the concept of frailty in later life (Legard, Keegan, Ward 2009). Therefore, I introduced an element of structure to the interviews in order to ensure a focus on issues relating to frailty and the older participant's experience of ageing in general (Holloway and Wheeler 2010). This led to the development of a loose interview guide which was developed from the literature as well as lines of enquiry that emerged from data gathered from subsequent observations and interviews (Britten 2007) (Appendix 9).

Using this guide, I asked open ended questions to access experience and meanings, ensuring that my focus remained on elucidating the older participants' perspective, based on observation in the field as well as general insights into the concept of frailty (Hansen 2006). The guide was continuously informed by the older participants' and my own experience, as well as the research literature, during the duration of the period of data collection (Silverman 2011). Thus, the interview guide changed overtime as new areas of enquiry relating to frailty developed, ensuring flexibility. This

ensured that all the older participants were asked the same general questions as well as enabling them to change the direction of the conversation.

I conducted the interviews with the older participants in their own home, at a convenient time, and with permission they were audio-recorded. They lasted from twenty minutes to one and a half hours. The length of interviews was determined by a number of factors, such as, the older participant's current health status, their willingness to talk about issues, and presence of others in the house. In the case of two participants interviews were consistently short. For example, older participant seven was always breathless due to her end-stage COPD and she often had to pause to use her CPAP non-invasive ventilation machine. I often felt unsure about whether or not to carry out these interviews. On many occasions I asked her if she would like to stop but she was insistent that she was able to continue. This placed a huge responsibility on me to manage the situation sensitively so that she could participate without it becoming overly distressing for her (Sheldon and Sargeant 2007). Management of this situation involved a number of strategies. First, I had to accept that on the whole older participant seven was unable to give lengthy responses to questions, as she would become too breathless if she spoke for long periods of time. Answering a thought provoking question would mean that she was more likely to use her CPAP mask; therefore I had to balance these with the use of closed questions and periods of silence so that she could calm her breathing. Second, she regularly needed to have a drink of water because the CPAP mask would make her mouth dry, which would make it difficult for her to speak. It could take five minutes to answer one question. I found these interviews draining because I was required to be constantly 'in the moment'.

It was not always the older participant's ill health that led to a short interview. When interviewing older participant six he often gave one word answers and when I asked for further detail to illuminate an account of a certain event, situation or experience he was often unable to explain what he meant by something he said, as illustrated in the third interview:

> OP6: That's the only time I go out, when I go to the luncheon club. I had to go to the optician, I was having some trouble with

my glasses. (Name of daughter) took me to Specsavers on (place). And that's the only time I get out if she takes me.

JS: How do you feel about not being able to get out so much?

OP6: Well it's just one of those things you have got to live with it haven't you?

JS: How do you live with it?

OP6: I just do (3rd interview: OP6)

I found myself working hard to get him to expand his responses, as I was mindful that I did not want to make assumptions about the meaning and implications of these responses (Gomm 2008).

I made the assumption that I would be able to facilitate participants to give me further detail of their experiences; this was the case with most of the older participants who had been very willing and able to share their experiences and thoughts but not older participant six (Horrocks and King 2010). The outcome of these interviews did not live up to the expectations that I had of them. As he progressed through the study I felt very uncomfortable about undertaking the interviews and I found them increasingly hard work. For some reason the dynamic in this relationship meant that I did not interact with him as a 'story teller'; he became someone who merely reported or answered specific questions (Horrocks and King 2010). On reflection, I wondered if he would not open up to me as a younger woman; also whether it was a feature of his personality that he did not elaborate his points with detail. Furthermore, it could have been how I came across and he may have felt uncomfortable talking to a younger female stranger with a non-Sheffield accent. I sometimes wondered whether he might have confused me with the community matron team as the format of their conversation was very much question and answer, matter of fact. In these situations I found it difficult to maintain interest in the conversations.

In spite of this experience one of the strengths of semi-structured interviews was that they gave the opportunity for older participants to talk freely about their experiences (Ballinger and Payne 2002; Britten 2007; Clarke and Warren 2007). This was the case with the majority of the older participants and I got the sense that they enjoyed talking about their experiences. We

also shared personal stories during the interviews; this enabled me to get a sense of who these older participants were and vice versa (Sheldon and Sargent 2007). Occasionally this became difficult to manage when they would go off at 'tangents' and I would have to work hard to bring the conversation back to the focus required. This was particularly the case with four older participants, whose interviews consistently lasted for over an hour.

I acknowledged that for some older participants my visits may have become important for other reasons, contributing to the length of interviews. A number of participants were lonely and therefore my visits provided company. During the third interview older participant two mentioned that if I had not come that day he would not have had any visitors for three days. Pleschberger et al (2011) highlighted how qualitative interviews provided companionship where participants lived alone with little social support and were lonely. I felt comfortable with this as it enabled me to demonstrate reciprocity.

4.3.2 Interviews with community matrons

I also conducted semi-structured interviews with the community matron involved in the delivery of care to the older participant. The intention had been to undertake two interviews, one at the beginning of the older participant's involvement in the study and the second towards the end of the study period. However, this proved to be difficult to arrange due to the busy nature of the community matrons' workload and therefore I had to be flexible in my approach to data collection. Where possible I still endeavoured to undertake a formal face-to-face interview at the two time points. These interviews took place at a convenient time for the community matron and in a variety of settings such as the local health centre, the community matron's office, outside the older participant's home and over the telephone; ranging from 20 to 45 minutes.

Within these interviews I established how long the community matron had been involved in the care of the older participant. I also pursued lines of enquiry as they emerged from the data gathered during the periods of observation; this enabled me to explore how they managed the care of the older person and any issues that arose (Britten 2007). I also introduced an element of structure in order to explore their understanding of frailty in relation to the older participant, and older people in general. Issues relating to

their role and managing care for older people were explored (Holloway and Wheeler 2010). A loose interview guide was developed from the literature as well as following themes that emerged from subsequent observations and interviews (Appendix 10). The interviews were recorded on a minidisc recorder and transcribed verbatim.

4.3.3 Interviews with significant others

Semi-structured interviews were also conducted with the nominated family member or significant other. Eight people were nominated; five agreed to be interviewed. Of the five who had agreed I was unable to interview older participant four's son as she died soon after he had decided to take part and it did not seem appropriate to engage him in an interview at that time. Also, older participant ten's daughter became ill herself and was unable to participate. Generally, the first interview took place at the beginning of the older participant's involvement in the study and the second towards the end of the study period. The interviews took place at a convenient time for the nominated person and in a variety of settings, which included their own, or the older person's home as well as university office space. I introduced an element of structure in order to explore their understanding of frailty in relation to the older participant, and older people in general (Appendix 11). Within these interviews I established how the significant other was involved in the care of the older participant. I also explored the impact of such caring activities and pursued lines of enquiry as they emerged within the interview (Britten 2007). The interviews were recorded on a minidisc recorder and transcribed verbatim. The interviews lasted between 20 minutes and one hour.

4.3.4 Conversations

Whilst in the field I listened to the interactions between the older participants, community matrons and others present in the field. Hammersley and Atkinson (2007) described how in daily life people continually provide accounts to one another to suit many purposes, such as making sense of situations and relaying information. In the context of this study the older participants, community matrons and significant others interacted in the context of a care visit or personal encounter in the older participant's home.

These encounters created accounts that provided evidence relating to the experience of frailty.

During the field work there were many situations where I engaged in conversation with the participants, outside of the formal interviews. I always engaged in conversation with the older participant on entering and leaving their home. A number of informal conversations occurred with the community matrons around the time of a visit, either just before entering or leaving the older participant's house, or in the health centre. These were useful for a number of reasons. They provided updates regarding the older participant's condition, as well as sharing insights into the older participant's situation.

On occasion, I found that during a care visit with the community matron the older participant would start a conversation with me. In these situations it was important to consider not only what was said but the context of these accounts. Often, they provided a counterpoint to my, or others, interpretation of a given situation, providing useful insights into differing perspectives regarding frailty. This was illustrated in the extract taken from the case account of older participant four:

On arriving at older participant four's house one day the community matron and I found that the social worker was already present and was engaged in a conversation with older participant four and her son. During the next half hour the social worker proceeded to comment on how she was not doing enough for herself on her return home from an intermediate care unit. Older participant four became increasingly silent during this encounter. When the social worker had left and the community matron was taking her pulse, older participant four turned to me and said, 'Am I still here?'

When she turned to me and said, 'am I still here' we all laughed at first. On reflection I think this comment also was a counterpoint to the fact that she felt ignored when the social worker was present (Case account: OP4).

4.4   Documentary review

I undertook a review of relevant documents alongside the participant observation and informal conversations and interviews (Hammersley and

Atkinson 2007). When approaching the study of documents to be reviewed it was important to recognise that that there were a number of ways in which the data within documents might be collected. First, I accessed relevant local and national policy guidance relevant to the care of older people. I also accessed and reviewed documents relevant to each case which included the older participant's health and social care records and community matron notes. This provided data relating to the personal details of the older participant in the context of health and social care provision including medical diagnoses and treatment; nursing assessment and care management; referral to health and social care services; other health and social care treatments and transfer to other services.

A key source of data was the content of these documents, which Prior (2008) described as documents as a resource. This data was used to identify what was going on generally in relation to the care of frail older people (policy) as well as the specific detail of care given to the older participants (case notes). Accessing case notes revealed details of care work. I scrutinised what was written in these documents and was able to identify issues relevant to each case. I was also able to detect absences or additions within documentation in comparison to my observations. This approach provided the context as to how health and social service provision framed the experience of the older person.

I was also interested in how written accounts were produced and subsequently utilised which added further insight into how community matrons structured their work with older people. As Prior (2008) noted, reviewing documentation cannot adequately rely on document content, it is also important to consider how the content came to assume the form that it did. Therefore, I looked at how the encounters and interactions between the older participant and community matron had been recorded in the case notes following a visit. This highlighted how documents were produced, who produced them and how the production process was socially organised.

It was also useful to review how documents were used during a visit between the health professional and the older person, which is described as 'documents in action' (Prior 2011). Therefore, I observed how the community matrons used the notes during a visit. Documents are considered to play an

active role in the configuration of the clinical encounter (Rosenbloom et al 2011). In particular, I observed whether the notes provided a framework for organising subsequent interaction during the visit, or whether they were used to exert an effect on the entire interactive sequence.

4.4.1 Challenges to accessing documentation

There were a number of challenges to accessing the older participant's records that had to be overcome. All the older participants had a set of nursing notes left in their home. Initially, I intended to access these notes during an observation visit; however, I realised that this would prove difficult as it would detract from the process of observation during the fieldwork. Also, not all health and social care professionals wrote in the nursing notes and therefore data would be missing. After a discussion the community matron negotiated with a health secretary at the specific health centre that I could access the older participant's notes. On a monthly basis I contacted the relevant secretary at the health centre and spent a morning looking at the participants' notes and recorded salient details, including documentation of the observed visit; the number of contacts made by the community matron; contacts and appointments by other health and social care staff; and admission to other care facilities. For two participants I was unable to access their records at the health centre and therefore I had to look at these when the opportunity arose, for example, during or following the care visit or after an interview.

Another challenge emerged during the period of field work as an electronic note system, System 1, was introduced across the PCT. The community matrons were given hand held note pads to use during patient visits; this data would then be transferred to the main database. Therefore, I could no longer access paper notes and had to use the community matron's work based computer to access participant information. As a result of this I had to access the system when the community matron was in the office; this became problematic at times for example, when the community matron had to leave the office unexpectedly. However, on the whole it worked as I would access the system twice a day, during their office based time.

4.5 Developing relationships in the field

I had to work hard to build and maintain relationships with all the participants

during the process of their initial recruitment to the study and the subsequent periods of data collection. At the start of my involvement with each case, upper most in my mind was the need to balance the presentation of myself, as someone personable, approachable and professional, with the need to 'fit in'. Here I attempted to reduce the amount of disruption caused by my presence in the older participant's home and at the health centre where the community matrons were based (Angrosini and Mays de Perez 2005). Sheldon and Sargeant (2007) likened the process of negotiating relationships in research to the everyday practice of establishing working relationships, particularly the development of trust. Here I drew on my skills developed over many years of nursing practice, both as a clinician and educator. I used and adapted appropriate verbal and non-verbal communication to demonstrate an interest in all the participants involved in a case. In relation to the older participants this involved getting to know them, which included asking them about their current and previous experiences. In the early stages of working with the community matrons I asked them questions about the care that they delivered to older people, showing a particular interest in new treatments. I also asked questions about their role, specifically in relation to patients that we had visited as well as more general questions; this included aspects of the role that worked well and the challenges they faced. At the beginning of a relationship I worked flexibly with the participants. For example, with the older participants I fitted interview visits around their other commitments. In relation to the community matrons I attended study afternoons, team meetings, or visits to other practices.

I found the 'work' of developing and maintaining relationships to be extremely tiring, particularly in the early stages of field work. This was as a result of always presenting an interested and personable front, as well as trying to be authentic and honest. I experienced the management and the regulation of my feelings, such as the day-to day responses to common situations, as emotional labour (Hayward and Tuckey 2011). However, my commitment and flexibility paid off and overtime, as I became accepted by the older participants and community matrons I did not have to work as hard to use different aspects of my personality, or professional skills, in the maintenance of these relationships.

4.6 Withdrawal from the field

With all the cases there was a time when the period of date collection came to an end and I had to prepare to leave the field (Hammersley and Atkinson 2007). I knew that this was going to be difficult as I had fostered a relationship with most of the older participants and community matrons over time. Moreover, I recognised that the quality of the relationship that I developed would make it harder to extricate myself from the field (Watt 2008). This became particularly difficult when I realised that for some older participants my visits had become an established part of their routine, and they looked forward to them. I was mindful that for some older participants I had become a friend and that the relationship would no longer continue; they would have to readjust to visits without me. Similarly, I had come to see some of the older participants and community matrons as friends (Dickson-Swift et al 2007).

In view of these issues I had to negotiate leaving the field and manage the subsequent expectations (Delamont 2004). To smooth the process of leaving, half way through the fieldwork I started to mention to the older participant the number of observation visits and interviews that were left and how many times I would be coming to see them. Specifically, I made it clear on the penultimate observation visit that the next visit with the community matron would be the last one. At the final care visit I explained to the older participant that I would no longer be accompanying the community matron, but that I would visit them for a final interview the following week.

On reflection, although it was hard to leave the older participants, and I felt very sad, my preparation to leave the field meant that their expectations beyond this were not raised. I did not arrange to meet them again. I had thought that I could continue to visit some older participants as a friend. However, I had to start new field work sites, as well as manage a busy home and work life, therefore this was not possible. I did leave a card with my contact details should the older participants wish to contact me with further information regarding their experiences. Leaving the field did not break the relationship with the community matrons in the same way, and it was easier to maintain contact with them after leaving the field. We agreed that I should

contact them monthly by telephone to gain updates regarding the older participants once I had left the field.

Two older participants died during the period of field work. Although I was aware that this was a possibility at the outset of the study I was still saddened by this news and found it difficult to cope with. This was particularly challenging in relation to participant four as she died in an intermediate care unit and she had not wanted to be admitted there. As Watt (2008) suggested, in these situations I accessed the support of my supervisors and found the safe space that this provided very useful in exploring my thoughts and feelings regarding these deaths.

4.7 Analysis of the data

In the context of ethnography the analysis of data is an iterative process and therefore not considered to be a distinct stage of the research process. Hammersley and Atkinson (2007) suggested that analysis begins in the stage prior to field work and continues into the writing of reports and publications. Furthermore, Sharkey and Larsen (2005) identified that data analysis is on-going and progressive, interlinked with and influenced by data generation. Therefore, I acknowledged that the process of analysis commenced before I started field work as I formulated my ideas pertaining to frailty in later life. It also comprised a dialectic movement between the collection of data and theory development, both being shaped and re-shaped as my knowledge regarding the experience of frailty in later life deepened and expanded during the fieldwork (Denzin and Lincoln 2012).

4.7.1 Narrative analysis

I drew upon the principles of narrative analysis, one component of the broader field of narrative inquiry, to focus the analysis of my ethnographic case-centred data (Hardy, Gregory and Ramjeet 2009). Narrative concepts and methods have increasingly informed ethnographic approaches to research (Riessman 2008). Narrative inquiry is based on a widely accepted definition of a narrative mode of thinking, namely, 'as engagement in sequential, action-orientated, detail-driven thought' (Bruner, cited in Sools 2013, p94). It is founded on the premise that individuals and groups construct identities overtime through story telling (Riessman 2008). Yuval-Davis (cited

in Riessman 2008, p8) mentioned that people tell stories to themselves and others about who they are, and who they are not, and therefore they become narratives of identity.

Although I had not intended to use a narrative approach to analysis at the outset of the study, during the process of longitudinal data collection I realised that in the interviews there was a mixture of both narrative and non-narrative elements. I acknowledged that I had not engaged in purely autobiographical interviews, however, the participants had been able to narrate autobiographical accounts. Sools (2013) referred to such accounts as 'big stories' where space is created in a research interview for the telling of autobiographical narratives. For example, overtime the older participants recounted stories about their lives combining retrospective and prospective detail, continually mixing the past, present and future. This also related to their on-going experiences relating to health and illness throughout their lives and into later life. Moreover, they disclosed what was important to them when recounting their experiences as well as making decisions about when and how to disclose information (Riessman 2008). I recognised that the older participants did not merely recount their experiences but arranged and communicated them in meaningful ways (Kleinman 1988).

I had also collected data that observed the interactions between the older participant and the community matrons. Drawing on the work of Mattingly (1998; 2012) I considered that not only did the older participants and the community matrons tell individual stories but they created story-like structures through their interactions. Mattingly (1998) referred to this as 'therapeutic emplotment', where the process of treatment encourages health care professionals to reason in a narrative mode. Here a balance is achieved between what a health care professional aims to achieve in the present with a patient with what they anticipate can be achieved in the future. This is obviously also influenced by the unfolding requirements and contributions of the patient. I considered the significance of an episode of care, between the older participant and the community matron, within the context of a larger therapeutic story; one that was in the process of being constructed. I also considered that these encounters created on-going conversations in everyday interaction in context and were akin to what Sools (2103) described as 'small' stories. This enabled me to emphasise the micro-processes

through which the community matrons and the older participants co-constructed meaning in the context of the care encounter.

Undertaking narrative analysis was clearly relevant to this study. In collecting what Sools (2013) referred to as 'big' and 'small stories' I was able to analyse personal experiences and how they contributed to the experience of ill-health and frailty in later life; whilst simultaneously analysing how interactions between the community matron and older participant shaped the content and structure of stories and the nature of stories pertaining to the experience of frailty. Riessman (2008) highlighted the importance of focusing on what the story is about ('big' stories) as well as how a story is told and why it is told in a particular way ('small' stories). Within my analysis I attempted to be flexible in my approach to the interpretation of the data, where appropriate combining the 'big' and 'small' stories (Georgakopoulou 2007).

4.7.2 Process of data analysis

Although data analysis is a continuous and iterative process it consists of two key components: data management and data interpretation (Lewis and Ritchie 2009). Data management is initially concerned with creating workable data sets in order to decide the themes or concepts under which the data will be coded, indexed and sorted. This is in contrast to interpretation of the data that is associated with the application of themes, and identification of meaning, relationships and explanatory theory. These stages do not occur independently or sequentially; however I found it useful to separate the two, for the purpose of discussing the process of analysis overall. As Ritchie, Spencer and O'Connor (2009) suggested, interpretation of the material and development of theoretical explanations can be problematic if the data is not sufficiently ordered and categorised. Furthermore, the rigour of the research was enhanced by enabling the process of analysis to be as transparent as possible (Denzin and Lincoln 2012).

4.7.3 Data management

In the first instance I had to manage the data to ensure anonymity of the participants (Richards 2005). I gave each case a number and labelled all the associated data with the aforementioned number, which included: the audio recordings, transcriptions of the audio recordings, documentary evidence and

field notes. I also labelled entries in my fieldwork journal with the relevant number. I stored my field notes, paper copies of transcripts and field work journal in a locked filing cabinet in my work place. I stored the information detailing each case's information and their case number in a separate locked box. Data in the form of audio-recordings and transcripts were stored on my research laptop which was password protected (Lewis 2009).

4.7.4 Confidentiality

In relation to confidentiality it was necessary to avoid the identification of participants and the case study sites through the attribution of comments either in reports or presentations. Houghton et al (2010) have highlighted the difficulties in maintaining confidentiality in qualitative research because of the level of description used in reporting the findings. This is increasingly problematic when the sample size is small, as in this study, and there is the potential to cause exposure if too much personal detail is disclosed (Stake 2005). Hansen (2006) noted it is possible for individuals to recognise themselves specifically where quotations are used as evidence to support findings. All the participants were given pseudonyms to ensure that identities would not be revealed (Polit and Tatano Beck 2006). However, I acknowledged that there would be circumstances where descriptions made to contextualise the case may compromise confidentiality. In these circumstances I made points in more general ways, and selected smaller extracts from the data to support the discussion. At the same time recognising that the contextual detail was compromised (Houghton et al 2010).

4.7.5 Transcribing the data

I paid attention to the process of transcribing the data as the use of a particular transcription method contributes to the interpretative process in narrative analysis (Riessman 2008). Moreover, I was aware that how I produced excerpts from the observations and interviews would contribute to producing 'big' and 'small' stories which would then further influence the analysis (Sools 2013). In the first instance I transcribed all the interview and observational data verbatim, including my own questions and responses as interviewer. I also stayed close to the spoken language of the conversations;

therefore I included repetition, dialect, sounds and pauses. This is illustrated in the transcript of the third observation of older participant three in Box 2.

Box 2 : Transcript Extract 1

CM: Ooh, have you got your oxygen in a mess, shall we do some unravelling? He said they are supposed to be doing your cleaning on a Wednesday but you say no?

E: No.

CM: Right let's unravel this (murmuring in background by CM). You seem to be getting through this moisturising cream for your legs, do you put it on or do the carers put it on?

E: The carers put it on.

CM: Right, so you'll be needing some more of that because you are running out, I'll have to get some more ordered. How have things been since I saw you?

E: Just the same as usual me breathing is worst, any exertion and I'm out of breath.

CM: Have you had to call the doctor out?

E: No there's nothing they can do about my breathing.

This highlighted the immediacy and dialogical nature of the interactions in context and enabled me to analyse the micro-processes involved ('small' stories). Moreover, at this stage by presenting the text as close to actual speech as possible I endeavoured to give voice to the older participants experiences rather than cleaning up text that was difficult to understand for the purposes of communication (Riessman 2008). As the data analysis evolved I also emphasised the flow of speech within the transcripts, particularly in relation to the older participants. Within the interviews this involved eliminating my participation in the conversation to highlight the content and direction of a particular story, thus contributing to 'big' story analysis. For example, Box 3 illustrates how removing my questions and comments from the transcript enabled the emphasis on Martha's worry regarding a number of current health problems to emerge.

Box 3 : Transcript Extract 2

When Martha was asked how she had been since I had seen her she replied:

> Not bad, but I've been having aches in my breast, those have gone but I started having them down there, those have gone and now I have them up there in that shoulder. I'm sure it's my bones because I have pain from my bones and I'm used to it, so, and I'm still having slight dizziness, so, I think, (name of community matron) came yesterday and she was going to have word with them to see, she was, and our (daughter) said I'm taking my mum to see the doctor at the (hospital) next week so she says I can mention it to him. So (name of community matron) said do that and see what he says. I have it all the time more or less. Osteoporosis, I've had it a long long time I'm used to it. When it hurts I cry out a lot, I breathe in and out to ease it a bit. I have two paracetamol, no cocodamol 4 times a day and sometimes I miss me one, I knock one off I think, if I'm going to bed I'll leave one off and then if I need them, you know need them extra at another time. Which I have done once or twice I can have them without having them at night, I'm not bad love, I know my walking is not so clever I know that I am not right sort of thing getting about.

4.7.6   Getting to know the data

In order to engage in the process of analysis I 'immersed' myself in the data (Denzin and Lincoln 2012). However, close reading of the data proved challenging as the process of data collection produced a number of different texts within the context of each case: transcripts of conversations during observations in the field; transcripts of informal conversations and interviews; observational field notes; documentary evidence; reflective field journal notes. Moreover, this was compounded by the longitudinal nature of the study as I had collected multiple sources of data over a number of time points. Rather than analyse individual data sources independently, such as interviews and including specific time points, I familiarised and analysed the multiple sources of data overtime within the context of each case (Baxter and Jack 2008). I combined the different data sets in order to enhance my interpretation and understanding of the features that influenced the experience of frailty in each case (Sangster-Gormley 2013).

On the first reading of the data I was able to get an overview of how an older participant experienced their daily life and the nature of their encounters with

community matrons. On closer, multiple readings I became thoroughly familiar with the data set which enabled me to identify concepts that helped me to make sense of an older participant's experience of frailty in later life. Avoiding what Hammersley and Atkinson (2007, p162) referred to as 'cherry picking', where cursory reading of and inadequate acquaintance with the data leads to unconvincing analysis.

To ensure that I gave equal weighting to each source of data I listened to the mini-disc recordings, alongside reading the transcript, and matched this to the field notes that I had written. As Casey (2007) claimed this would ensure that the verbal interactions would be considered within their context, facilitating a detailed exploration of factors that contributed to frailty. For example, during my first observation visit to older participant one a care worker was present preparing lunch. A discussion between older participant one, the community matron and the care worker, about what to have for lunch, had ensued. An extract from the case account illustrates this:

Care worker: What do you want for lunch today (name of older participant)?

OP1: I don't know love

Care worker: (turns to the community matron) This is happening a lot now, she doesn't know what she wants and then when she has decided she doesn't eat it. I don't know what to do. That's right isn't it (name of older participant)?

OP1: (silent)

At the same time I wrote in my field notes:

Discussion about lunch: care worker raising her voice speaking to OP1 as if deaf; she is not. Care worker talking about OP1 as if she was not in the room; turns her back to her. OP1 not responding; she has folded her arms. (Case account: OP1)

4.7.7 Recreating case accounts

A challenge in the process of analysis was to pay attention to the personal experiences of ageing and frailty, whilst at the same time considering the impact of context and interaction in shaping such experiences. Moreover, I was mindful that I had to balance the analysis of the 'big' and 'small' stories within the data (Sools 2013). To achieve this once I had immersed myself in

the data relating to a particular case I engaged in the analytic process of 're-storying' an account from the original raw data (see Appendix 12 for extracts from case four's re-storyed account). According to Ollerenshaw and Creswell (2002) re-storying is the process of gathering data, analysing them for key elements of the narrative, such as time, place, plot, and scene, and then rewriting the story to place it within a chronological sequence. Initially, this process involved further repeated readings of the transcripts, documents and field notes linked to an observation visit and/or interview. At times I listened to the original audio-recording alongside the transcript to enhance my interpretation of the text. This was a lengthy process but it enabled me to become more familiar with the data (Tuckett 2005).

Concurrently I engaged in careful textual analysis, noting main points such as, the nature of place and changes to physical space, specific events that had occurred, feelings experienced, recurring or different stories and conversations, patterns of interaction and timeframes. From this, I was able to detail the story line of a case overtime, including key episodes and turning points in the narrative, finally rewriting the story to place it within a chronological sequence (Riessman 2008). I accepted that in recreating such accounts it was my interpretation of events. As Ollerenshaw and Creswell (2002) noted often when individuals retell a story the sequencing is not logically developed therefore I used rich description about the setting and experiences, including verbatim quotes from all data types, to support my interpretation of events within and across the case accounts. I recognised that determining the boundaries of stories was difficult and ultimately it was down to my interpretation. However, I regularly emailed my supervisors extracts of case accounts with my interpretations in order to enhance the rigour of my analysis. These were discussed at subsequent supervision meetings (Thomas and Magilvy 2011). I produced a re-storyed account for each case (n=10).

4.7.8   Narrative analysis of the re-storyed case accounts

During and following the re-storying I examined the content communicated within each case account, identifying common patterns and sequences which led to the identification of themes (Riessman 2008). This involved searching for content that reappeared in a case account overtime, or in predictable

sequences, as well as content that differed. I was aware that interpretation of a significant event was a matter of subjective perception. Therefore to seek clarity I referred back to the original data, and listened to the audio-recordings, to further examine the content of an account. Here I listened for tone of voice and observed the structure of the speech as well as its content. Where appropriate I looked for detail of non-verbal behaviours and other comments in my field notes.

I also concentrated on the cultural context in which the narration of stories and interaction took place. Here, I examined the data in order to identify how the context influenced the way in which the older participants and the community matrons narrated and communicated their experiences. I scrutinised the data to examine how overtime identities were constituted in relationships and enacted with and for different audiences. Here I was able to focus on the interplay between stories, and how these were enacted in the observation visits and during interviews within each case. I also paid attention to small, everyday events, for example, how an older person mobilised around their living space. As Sools (2012) pointed out focusing on small events directs attention to taken for granted aspects of daily life, opening them up for scrutiny. Therefore, I was able to direct attention to how the older participants engaged with daily life in the context of frailty.

4.7.9   Development of themes

The on-going examination of the case accounts and original data to identify thematic content was in part guided by my prior theoretical knowledge. For example, in my initial reading of the literature I was aware that some older people articulated their experience of ageing as bodily decline (Lloyd et al 2012a). Therefore, I thought it likely that the older participants in this study would experience bodily decline as a result of ill-health and ageing. I also searched for novel theoretical insights from the data (Riessman 2008). For example, when collecting and analysing data in older participant one's case I noted that at times she appeared to be at 'cross purposes' in her interactions with a care worker. I began to look for other examples of this type of interaction within her case.

I also searched for patterns and sequences across all the case accounts. In this way I further developed the themes by analysing similarities and

divergences between the ten cases (Stake 2005; Sangster-Gormley 2013). Moreover, I looked for how an event was told or enacted, made sense of or commented upon. I considered this focus to be important as it enabled the refinement of the emerging themes in the light of new and existing data. For example, in the early stages of analysis I coded data extracts that demonstrated examples of bodily decline. However, as a later entry in my field work journal indicates I began to notice a pattern in how bodily decline was interpreted:

> I am beginning to realise that the older participants do not seem to talk about their bodily decline per se. They talk about what they can't do as a result of bodily decline. I am getting a sense of a routine broken. For some the breaking of routine seems to be experienced as a loss. Look/ask about this in future cases. Also, how do community matrons interpret bodily decline.

Thus, I started to refine how I coded and labelled the patterns and sequences emerging from the data. By constantly returning to the data when new patterns emerged I was able to compare them against the development of both previous and newly emerging data. The emerging themes were also influenced by my reading of relevant literature. In the early stages of analysis I engaged in describing the data, however as the themes developed I was able to make interpretive links within and across themes, thus leading to theoretical explanation (Green at al 2007). In Table 3 the development of the data patterns and sequences into themes is presented.

Table 3:   **Dominant narratives, themes and sub-themes within the findings**

Dominant narrative	Theme	Sub-theme
Transitions in health and illness in later life	The experience of transition	Disruption to daily life
		Getting used to disruption
		Ongoing disruption
		Stability and disruption
	Managing transitions in health and illness	Patterns of daily living
		Rethinking routines
		Acquiring new skills
		Keeping the routine going
	Making sense of deterioration	Relativism in later life
		New beginnings and endings
	Support Networks	Formal provision
		Informal support
Dimensions of frailty	Frailty as vulnerability	Positive approach
		Maintaining confidence
	Frailty as decline	
	Frailty as confinement	Attachment to home
		A life lived
		Social isolation
		Feeling isolated
	Frailty as a label	Older participant's perceptions
		Community matron's perceptions
		Resisting the label of frailty
Health and social care provision: rhetoric and reality	The nature of participation	Role boundaries
		Competing roles
		Roles as a position
		Frailty and partnership
	Revelations and discoveries	Sharing concerns
		Negotiation surrounding concerns
		Cross purpose interactions
		Relationships

Unlike the approach adopted in grounded theory (Charmaz 2006) I did not use the themes to separate segments of data. I was mindful that I had to keep each case account intact. 'Fracturing' the data by analysing segments would not preserve the sequential and structural features of each case. Therefore, I applied my thematic framework to the extended accounts rather than fragmenting them. I colour coded chunks of data for specific thematic content. 'Blocking' data in this way enabled me to keep them within the context of the interview or observation data, as well as the overall case (Grbrich 2012). I also marked the margins of each case account with memos to indicate insights and thoughts relating to a particular code (Tuckett 2005). This further facilitated an analysis of the variety of texts that I had collected within each case, such as, oral, written and visual (Riessman 2008), keeping the story intact for interpretive purposes.

I made the decision not to enter the data onto a qualitative data analysis package. I recognised that computer soft-ware could speed up the process of handling the large amount of data that I had collected in each case (Denzin and Lincoln 2012). However, it was important to keep the context of the data intact. Spencer, Ritchie and O'Connor (2009) highlighted how many soft-ware programmes encourage tagging and retrieval of segments of data, removing them from their context. Furthermore, current debates question whether the data can be produced in such a way that it is ready for analytic commentary (Denzin and Lincoln 2012). I acknowledged that I played a crucial role in the analytic process and considered that the use of a soft-ware package would possibly jeopardise this.

4.8 Ethical issues in the field

I encountered a number of ethical issues whilst accessing the research site and in my continued engagement in the field, particularly around informed consent. These ethical issues relate to the principles of autonomy, beneficence and non-maleficence (Beauchamps and Childress 2013).

4.8.1   Consent to participate

Informed consent in research has been defined as: 'A procedure for ensuring that research participants understand what is being done to them, the limits to their participation and awareness of any potential risks they incur' (Social

Research Association 2003, p28). Gaining informed consent from potential participants in health and social research is considered to be a central tenet of ethical research practice (Wiles et al 2007). Of paramount importance is the respect for individual autonomy and dignity, with the emphasis on the right of competent adults to make a free choice regarding participation based on accurate information regardless of risk of harm (Beauchamps and Childress 2013). This informed consent must include: detailed explanations of what the participant will or may experience in the study followed by checking of understanding; ascertaining the capacity of the person to make a decision without the pressure of coercion to take part (Moore and Savage 2002).

In this study I recruited older people, some in advanced old age, who had complex health and social care problems and were considered to be 'frail'. Jacobson (2005) and Pleschberger et al (2011) have highlighted the need to consider whether potential participants are vulnerable as this will raise ethical issues throughout the duration of a study, particularly in relation to consent. I acknowledged that for some older people in this study the experience of complex health and care problems could affect competence to consent to research (Gilhooly 2002; Griffiths 2006). Also, where older people suffered impairments to communication this could create difficulties in relation to the giving and understanding of information (Griffiths 2006). Moreover, some of the older people could be approaching the end of their lives. I acknowledged that there would be challenges in enabling older people at the end of their life to participate, for example, where the experience of complex symptoms was great, or where participation could lead to psychological distress (Seymour at al 2005b; Whiting and Vickers 2010; Pleschburger et al 2011).

Considering the vulnerability of potential older participants was not to exclude them from the study but to ensure ethical issues raised were addressed. This enabled participation where appropriate and also ensured that those who did want to participate were not overburdened by the consent process. Therefore, I endeavoured to achieve a balance between maximizing the involvement of older people in the study whilst at the same time protecting their right to refuse and safeguarding them from harm. I found the ethical issues inherent in this endeavour to be a constant challenge throughout my study. Moreover, at times I found these very difficult to manage. I had to think

'on my feet' and make decisions informed in part by an external ethical framework as well as my own active reflections about what appeared to be the 'right' course of action in a particular situation (Wiles 2012). As Seymour et al (2005b) and Pleschberger et al (2011) have pointed out obtaining LREC approval does not offer solutions to ethical issues in the field; this is the remit of the reflexive researcher and I found these to be constantly taxing. I spent a lot of time considering how to enable the older person to give meaningful, informed consent. The process of consent considered the initial approach to the older person, as well as explanations of the project with subsequent understanding and decision making around participation (Harris and Dyson 2001).

4.8.2 Initial approach to older participants

I used the community matrons to provide me with initial access to potential older participants, before I made contact with them myself. I did not find that this posed a barrier to recruitment; in fact it appeared to be the opposite. Although the community matrons were busy they all found time to give the older people information regarding the study, contrary to other researcher experiences in primary care (Ewing et al 2004; Almack et al 2012). I was mindful that the community matrons did gate keep access to the older people on their case load, for example, when they considered an older person too vulnerable to participate. This did provide a barrier to recruitment of older participants (Williams 2006; Kirchoff and Kehl 2007). However, on reflection these decisions were carefully considered and appropriately made, and I was still able to recruit older people who had complex problems. For example, one of the community matrons asked an older person who was critically ill and possibly at the end of her life if she was interested in participating; this older person agreed to my initial visit.

In the context of gate keeping I was aware that the power dynamic was in favour of the community matron and that it might be difficult for an older person to refuse to meet me. This became more of an issue when I realised early on in the field that some community matrons had introduced me as a colleague and not as a researcher. Reflecting upon this, I realised that I did not know how the community matrons actually described me to the potential participants or chose to deliver the information to the older person. Therefore,

this may have influenced the decision that an older person made to permit me entry to their home. I picked this up following a visit with the community matron to the fourth potential older participant and wrote in my field notes:

> 'After climbing the stairs we entered the living room, older participant four was sitting in a chair next to the door. The community matron greeted her and went onto mention that I was accompanying her, and as she was sitting down on the settee she went onto say, 'Do you remember (name of older participant), the colleague that I mentioned last week'. Older participant four nodded her agreement.
>
> Note to self: The CM introduced me as a colleague; I wonder how many other CMs have done this? Must get across my role as researcher.

Following this experience I ensured that I gave all the community matrons a small card, with details about myself and the study on it. This ensured that all the older people knew that I was a researcher and were given the same information about the study.

4.8.3   Older participant's understanding of the study

Assessing understanding is considered to be crucial to the process of informed consent (Wiles et al 2007) however I found this difficult to ascertain. It is suggested that understanding or lack of understanding can be demonstrated by the asking of questions (Harris and Dyson 2001), yet none of the older people asked questions about the study or what their involvement would be. This became a repeated concern for me in the initial phases of recruitment and I became acutely aware that I could never really know what the older person understood about the study or how they thought the study may affect them. What I had to accept was that they had the autonomy to make many decisions in relation to their daily lives and therefore were able to say yes or no to participate in the study. Furthermore, older people with high support needs have the right to have their voices heard and I did not want to make assumptions that they were unable to do so (Gott et al 2011; Katz 2011). However, I was careful to ensure that they were aware of the following:

- That they could withdraw from the study at any time without it influencing the care they were receiving from the community matron or other health and social care services.

- That at times some questions raised during interviews could be distressing to them, and that they could decline to answer. Also, that I was an experienced nurse and would be able to support them through this, but could also direct them to additional support if required. This issue is discussed later in this chapter.

- That they were aware that any information collected during the research would remain confidential and would only be shared with my research supervisors, unless the information disclosed raised issues of safety for the older person, or revealed poor practice.

- That the findings of the study would be used to help develop health and social care services for older people in the future.

4.8.4   Giving study information

At times I felt under pressure to communicate information about the study quickly as I was very aware that I was taking up time within the consultation. This could detract from the community matron's assessment and management of the older person's current health and social needs, as well as impacting upon other patient visits that day. This created a tension for me as I tried to ensure that the older person had been given adequate information, which at times meant rephrasing details of the study using language that the older person could understand. I may have communicated that I was rushed thus perhaps preventing the older person from asking questions at this point. Furthermore, I found it difficult to ensure that I had offered the same explanation to all the potential participants. It could be suggested that in terms of the principle of justice I should have offered the same explanation to all participants (Beauchamps and Childress 2013). However, I would argue that although I did not use the exact same words I did explain the key features of the study to all potential participants taking into account their differing communication needs based on a variety of attributes, such as, education, professional and work background, sensory impairment and gender.

There was an issue for one potential participant regarding the information sheet. Reading the information sheet was difficult for participant one as she had poor eyesight, even with her glasses on. Although she had a daughter who lived close by she asked me to read the information sheet to her. The following extract from my field notes illustrates this:

'The community matron had already told (participant one) at the previous visit that I would be accompanying her on this visit; (participant one) remembered. She seemed at ease with my presence, and asked me to sit down and asked if I would like a cup of tea and a biscuit. I sat on the settee which was situated at a right angle to her chair, and due to the community matron's busy schedule declined the cup of tea. I ensured that I was facing (participant one) and at her level to make her feel at ease. I introduced myself as a student undertaking research into older people with health problems and outlined the study and what her involvement would be. I then informed her that I would leave her the information sheet so that she could have a look at it in her own time and discuss it with a family member should she wish to. (Participant one) informed me that she would be unable to read the information sheet due to her poor eyesight, even with her glasses on, and would I go through it with her there and then. I showed her the large font but she was still reluctant to read it herself so after checking with the community matron that we had time to do this, I agreed. We went through the information sheet page by page, and as we did this I checked that she understood and whether she had any questions' (Field note 1: OP1).

Whilst reading I became very conscious of the length of the information sheet, and wondered if this had been one of the reasons why this participant had also been reluctant to read it. This raised an issue as to whether the process of recruitment itself can over burden those who want to contribute; paradoxically the people who are considered to be frail and are relevant to the research are potentially not able to participate because of the over whelming nature of the information. Pleschberger et al (2011) highlighted the importance of ensuring that written information is not overly complex. Similarly, Brown-Wilson (2011) identified that it is often the case that

research participants are presented with more information than they can cope with, as a result of LREC demands. Jamieson and Victor (2000) suggested that older people expend a great deal of energy in managing activities of living, and energy reserves can be used up very quickly. This particular participant became tired very easily, and therefore reading such a lengthy information sheet was perhaps considered to be onerous.

4.8.5 Timeframe for recruitment

I endeavoured to ensure that all the participants had enough to time to think about the study and their potential inclusion. However, one participant wished to consent to take part during the first introductory visit; this followed on from reading out the information sheet. The following extract is taken from my field notes:

> I said that I would come back with the community matron on her next visit to gain her consent, giving her time to consider the information that I had given her. However, (participant three) expressed a wish to participate there and then. I felt awkward about this; I had not anticipated that a potential participant would agree to take part immediately. I felt under pressure to make a decision as to whether to recruit or not on this first visit. She was adamant that she wanted to take part; therefore, even though I felt stressed, I went through each individual item on the consent form with her and asked her if she agreed to these, she did. (Participant three) said that she had difficulty writing as her hand shook and would I sign the boxes for her; I ticked them after she had agreed a statement. After this I asked her if she would be able to sign the consent form. I rested the form on my observation book and although shaky she was able to write her signature. I was careful throughout this process to reinforce that her participation was entirely voluntary and that even though she agreed now she could withdraw from the study at any time. The community matron was present throughout the whole process. Having gained consent from (participant three) I agreed with her and the community matron that I would attend at the next planned home visit (Field note 1: OP3).

In this situation I doubted my integrity as a researcher because I was unable to follow the protocol when obtaining consent. I was concerned that she did not have the time to make a considered decision about whether to take part or not, and I felt under intense pressure to ensure that she had not felt coerced to participate (McCann and Clark 2005). However, I recognised here that I had a responsibility to create an environment where participant three could exert her control and choice and make a decision whether to participate or not (Bowers, House and Owens 2009; Ryen 2011; Katz et al 2011); she chose to make that decision within a small time frame. I ensured that I clarified what she understood about the study and what involvement would mean for her. This included ensuring that she was engaged in listening to what I was saying by checking out her non-verbal signs. Also, by checking that she answered my questions appropriately (Harris and Dyson 2001; Duckett et al 2010). At the end of this process I respected the decision that participant three made to participate within the study. I felt more confident about this decision due to the presence of the community matron and the fact that she had known participant three for a few years and therefore had a good insight into her understanding of issues.

4.8.6 Providing written consent

Physically signing the consent form was a problem for some of the older people as they found it difficult to hold a pen and coordinate their writing, especially for the two participants who were extremely breathless. They were required to initial each item on the consent form as well as sign the bottom of the form. Five older participants asked if I would do this for them. Therefore, I asked them about each item and then ticked the boxes on the consent form as they agreed to them. I then held the consent form in a position that they were able to write on to sign their name. Once the form was signed I explained to them that it was not a binding contract but a record of the decision that they had taken to participate in the study on that day (Harris and Dyson 2001).

4.8.7 Process of on-going consent

As previously discussed, throughout the process of data collection all the participants were made aware at the beginning of each observation and interview visit that they were still being observed and that their conversations were audio-recorded. They were provided with the opportunity to give

continued consent and the opportunity to withdraw from the study should they wish to (Moore and Savage 2002).

I acknowledged that for some older people changes in their health condition could make it difficult for them to continue with the study, for example, extreme breathlessness, urinary and chest infections, low mood (Poythress 2007). Furthermore, I could not assume that an older person who had encountered a major life transition, such as a fall, was necessarily the same person who had originally given consent. In a study of hospice patients Lawton (2000) highlighted that consent could not be taken for granted because of the loss of self, due to progression of the disease. Therefore, I had to be mindful of situations where an older person's capacity or situation was altered. I found myself in challenging situations in relation to on-going consent on a number of occasions. They highlight the dynamic moral choices that researchers face during the research process (Seymour et al 2005b).

For example, over a period of time participant two's mood became low culminating in an admission to a respite unit because he was beginning to neglect his personal care. At this point he had participated in the study for five months. I had received a phone call from the community matron to inform me that her visit to participant two had been brought forward as they were in the process of arranging a care package, and could I get there earlier. As I neared the house his son was standing in the window and beckoned me in. I made the following note in my field notes:

> When I entered the room I greeted (participant 2). He was sat in his chair, bent over, holding a cup in his hand; he looked grey. He raised his head and greeted me; his voice sounded flatter than usual. He said he was pleased to see me and apologised for being in a 'sorry state'. The community matron was sitting on the settee and the social worker was on the telephone in the kitchen. The community matron began to fill me in with the situation and asked if I was going to turn on the audio-recorder. This raised a dilemma because I needed to ensure that (participant 2) was still able to give informed consent; it was clear that his mood was very different to how it had been two weeks before and I did not

want to ignore signs that he may not have the capacity to consent to me being there, observing and recording (Field note 5: OP2).

I felt that I was really put on the spot in this situation and it made me feel very uncomfortable. I had entered a context where important inter-professional decisions were being made about participant two's immediate care needs. I was aware of the need to 'fit in' so that the process of decision making could continue however I needed to draw participant two's attention to my study and his continued participation (Sheldon and Sargeant 2007). Immediately I was mindful that it was possible that participant two's low mood could impact on his ability to provide on-going consent (Poythress 2007). As soon as I could I sat next to participant two and reminded him that I was still undertaking my research study. I asked him whether he still wished to take part; I made it clear that I realised that he was having a difficult time at the moment and that he could refuse to continue with the study at this moment, without any consequences to himself or subsequent care. He was clear that he wanted to continue to participate and that he was happy for me to be there, observing and recording, via notes and audiotape; I recorded in my field notes that verbal consent was given.

It could be argued that I should have taken the decision to exclude participant two myself and I did consider this course of action. However, Bamford and Bruce (2000) argued that exclusionary ethics may limit the opportunity for individuals to engage in a process that might be experienced in a therapeutic way. Also, over the last five months I had developed a positive relationship with participant two, one that respected his personhood, and by putting participant two at the centre of this relationship ensured that I kept him central to the process of informed consent (Poythress 2007).

However, it could be suggested that older participant two was a captive audience and that there was the potential to exploit the situation because I had developed such a good relationship with him over the last few months; to the point that the on-going research study was forgotten about (Sheldon and Sargent 2007). What I did not do here was blend into the background but brought the research study into the conversation, ensuring that participant two remembered my role as researcher (Brown-Wilson 2011; Pleschberger et al 2011). I also considered whether I would be causing him harm by

observing and recording the visit. The tensions in this situation could never be completely resolved and I had to make a decision in a short time frame. Combining my active reflections upon the right course of action with the ethical principles of autonomy and non-maleficence (Wheeler 2011; Beauchamps and Childress 2013) enabled me to accept participant two's consent to continue participating in the study at this particular point in time.

There was one occasion when I made the decision not to undertake an interview because an older participant was not well enough to give informed consent. On arriving at participant seven's house she was more breathless than usual and had been using her CPAP machine all morning. She looked blue around the lips. When I asked her whether she was able to take part in an interview today she just shrugged her shoulders. Based on my knowledge of the effects of low oxygen levels I made the decision that the lack of oxygen was likely to impact on participant seven's ability to make a decision to take part in the study on that day (Nickel 2006). She also clearly did not have the energy to give me a verbal response. I was also aware that talking to me about her recent experiences would be likely to do her harm as she would not be able to keep her CPAP machine on, thus, lowering her oxygen levels even further. I arranged to contact her the following week with a view to rescheduling the interview.

Enabling on-going consent was also an issue in relation to the interviews. This concerned providing enough information regarding what I would ask all the participants during the interviews, so that they could provide informed consent; whilst at the same time enabling fluidity of content within the interview (Horrocks and King 2010). In reality some of the discussion topics changed each time depending on what had happened during a previous observational visit or if there had been any changes in the older participant's situation, such as, transfer across care boundaries, ill health, and new service provision. Therefore, this required me to achieve a balance between giving enough detail of the areas to be covered, so that older participants in particular could make an informed choice to participate and know what to expect in the interview, without inhibiting the nature of what would be discussed (Wiles 2012). However, this was easier said than done. It became a particular issue in the case of two older participants where it became apparent to myself and the community matron, during observation visits, that

the care workers were not always providing an adequate service; either through direct care provision or in their communication with these older participants. I wrote in the field notes following a visit to older participant three:

> Today's visit has been very difficult for all of us. On arriving at the house we found older participant three's commode to have been left in a disgusting state, it is clear that the carers have not cleaned it properly for a lengthy period of time. I have found this whole situation very upsetting. Participant three is totally reliant on the carers to ensure that her living environment is clean and safe and they obviously have not done this. I feel that her care has been neglected and this has put her in a position that is degrading and embarrassing for her. She looked really forlorn during this whole episode. It is important that I ask her about this at the next interview although I need to consider how best to do this (4th field note: OP3).

Prior to the subsequent interview a week later I felt nervous as I was aware I needed to let older participant three know that I wanted to ask her about the issue with the commode, yet at the same time I did not want to inhibit her talking about this. In order to stay in her own home she was totally reliant on the carers and therefore I realised that she may not reveal too much for fear of reprisals (Horrocks and King 2010). Before I engaged in this interview I mentioned to older participant three, as usual, that I would be asking her about the last visit that I had made with the community matron and was she happy to talk about this. I was not specific in mentioning the issue with the commode immediately and was aware that I had avoided the issue for fear of losing data, which made me feel more uncomfortable with myself. Therefore, I paid attention to how I raised the topic further on in the interview. I framed the question thus,

> *'(Name), I hope you don't mind but I would like to ask you a couple of questions about the issue with the commode that last week?'* (4th interview; OP3).

By introducing the topic sensitively in this way I was able to renegotiate the boundaries of the interview, providing older participant three with the opportunity to say yes or no.

4.8.8   Consent of others in the field

During the study it became apparent that during the planned visits with the community matron other people would be present in the older participant's home, such as, care personnel; hair-dressers; doctors; cleaners and other nursing staff. This raised a real tension as I was aware that these individuals had not given consent to take part in the study. Murphy and Dingwall (2007) highlighted the difficulties in controlling access to the research field during participant observation, particularly for those who have not given consent to take part in the study. Initially, I turned off the tape recorder and stopped writing notes whilst these individuals were present, however this led to a disjointed observation.

I realised very quickly that these individuals were an important part of the older participant's daily life and therefore it was important that they were included in the field work. Initially, I decided to hand out information sheets at subsequent visits and follow the recruitment protocol. However, I realised that I did not have the time to hand out information sheets and wait for consent; also not all potential participants were always present in the field. Therefore, every time I encountered a new person I alerted them to the fact that I was undertaking a research project and gave a concise verbal account of the research that was currently taking place, specifically alerting the person to the audio-recording of the situation. Following this I gained verbal consent from that person to continue with the observation, note taking and recording. In this situation a prescriptive approach to obtaining informed consent was not appropriate, and I had to think carefully about how to solve the complex ethical issues that arose in this situation (Seymour et al 2005b).

4.8.9   Confidentiality in the field

I had a moral obligation to ensure the participant's anonymity (Wiles 2012). I had to ensure that the identity of those taking part was not known outside the research team (Crow and Wiles 2008; Kaiser 2009) and measures to achieve this were put in place as access to the field was negotiated. I acknowledged that in the context of ethnography and the case study design absolute guarantees of anonymity could not be given, due to the nature of the structural linkage between participants (Lewis 2009). This was specifically in relation to the nurse participants as I would be spending time in their place of

work; therefore I ensured that I communicated to them that others may know of their participation. I ensured that I never discussed an older participant with the community matron in the shared office space to protect the anonymity of the older participant (Brown Wilson 2011). The community matrons also never verbally revealed who I was visiting with them. Furthermore, I always met the community matron at the older participant's home so no-one else in the nursing team knew I was attending a visit.

4.9 Minimising distress in the field

4.9.1 Participant distress

Engaging in observation of others had the potential to lead to harmful consequences (Watt 2008). It was likely that some older participants would be experiencing stress and anxiety as a result of their health and wellbeing, therefore being observed could potentially heighten such anxiety. Here, I had to consider the benefits and the risks to the older participant, drawing on the principles of beneficence and non-maleficence (Beauchamp and Childress 2013). I drew on my professional skills and knowledge, and those of the community matron, in order to make a decision whether to start or continue with an observation or not. This guarded to a certain extent against situations which would put the older participant in a vulnerable position. I observed all the clinical visits by the community matrons to the older participants.

I was conscientious in my attempts to manage the observations to minimise distress and found this to be hard work. What I did not consider prior to the start of the study was how the recalling of current and past experiences could provoke the experience of loss (Watt 2008). This was brought to the fore early on in the study during my first observation visit to older participant one when I asked what I thought was a seemingly innocuous question. Whilst the community matron was in the kitchen I commented upon a photograph on the wall, which portrayed a young man and woman. The following extract is taken from my field notes:

> Whilst the care worker and CM went back in the kitchen at one point I pointed at a picture of (OP1), when she was young, with a sailor, I presumed this was her husband, older participant one clarified this. I noted that (OP1) became very emotional when talking about her husband; I wished that I had not made a reference to the picture and

felt uncomfortable that I had made her tearful. I apologised for making her upset and drawing her attention to her husband; she told me not to worry as she always got tearful and still wanted to talk about her husband. I made a note in my reflective journal that I would not ask about personal photographs on a first visit, but would introduce these as I became more familiar with and developed a relationship with the participants (1st field note: OP1).

This felt like a salutary lesson; one that focused my attention on how I would introduce topics of conversation that could be sensitive and thus intrude on feelings that would never have been knowingly disclosed (Dickson-Swift et al 2007). I learnt very quickly that there were certain areas that I would never ask about, on the first visit in particular, unless the participant introduced it first, such as, how many children they had.

Developing a rapport with participants invites disclosure of sensitive and emotional experiences, specifically in interviews (Houghton et al 2010). I recognised that the experience of emotional distress is an integral part, not a by-product, of the interview process (Mackintosh and Morse 2009) therefore I was mindful that situations where participants became upset would occur. Moreover, it was important that I gave attention to some of these issues before I commenced the interviews. At the beginning of the field work I was aware that for many of the older participants and significant others, conversations about ageing and reaching the end of life may be difficult, and that for some it would be an unwelcome topic; one that I would have to handle carefully. I was cautious in making the decision to broach this with the older participants.

A number of participants talked freely about their own life and death and I was able to follow their lead on this. For others, the community matron had discussed end of life care options during an observation visit and therefore I would discuss this at the subsequent interview. However, not all participants mentioned it or did not pick up cues around care options in the face of deteriorating ill-health therefore I did not probe further. Two family members also talked openly about the possibility that their relative would die and the impact that this had on them. For example, Martha's daughter described in her first interview how the last few months had been emotionally and

physically tiring and that how on many occasions she had thought her mother would not survive the multiple heart attacks and fall, as she stated:

> 'You go through, it's not quite choosing funeral music but you're nearly there and you think I've got to prepare myself, I've got to prepare myself. I've done that, it started at Christmas when she had a bout of colitis; she was really, really ill with it. I thought then I couldn't believe that she had survived. Then that started the frailty really, and then she was, although we were still going out shopping and to the garden centre, having a cup of coffee that sort of thing she was really quite frail and then she had a heart attack. She did have a heart attack 5 years ago, the latest series the one in March. And I thought this is it and you go through all the emotional preparation and then she gets better and then she has a cataract operation and she comes through that and five days later she's back in hospital and I'm going through it all again. So it's like a roller coaster of emotions preparing yourself and then it not happening and you think I can get back to where we before, my mum's not going to die. And then she has another one and you think she can't possibly come round after this and then the fall and I know exactly what happens with falls that's it, but not with me mum'
> (1st interview: SO5).

I was also mindful that there would be situations where the community matrons could be asked questions relating to the death of an older participant, or where care situations were challenging.

As I developed relationships with the participants this increased the potential for discussing sensitive topics as they disclosed their life experiences. Here, reminiscing for some older participants was difficult but it was something that they wanted to do; it appeared to reaffirm their identity (Lloyd et al 2012). For example, older participant nine recalled his experience of landing on the beaches of Normandy at the age of 18. Older participant three recalled how she had married late in life and then later in the conversation disclosed details regarding the death of her husband and step-daughter. Older participant ten always became upset when thinking about her past but it did not stop her recollections of how her life had changed following the death of her father in a road traffic accident when she was nine.

I ensured that I attended to any distress so that participants were given the opportunity to compose themselves and then decide whether to continue or not with the interview. Furthermore, I gave them the opportunity to decide whether to stop participating in the study. However, in these situations I felt a tension as I felt simultaneously guilty and excited about the data that was being generated. This unease in the collection of sensitive data has been highlighted by Dickson-Swift et al (2007). On reflection, I did not really want the participants to withdraw yet I did not want to upset them further.

I felt that I had the necessary communication skills to manage such emotional distress, in particular I responded empathically to participant's immediate distress. Here I drew upon my professional code of conduct (NMC 2008). On reflection, at times I responded to participants with therapeutic skills, particularly in the presence of strong emotional reactions from the participants. Knox and Burkhard (2009) pointed out the dilemmas for health care professionals in using therapeutic skills suggesting that it can cause role confusion for participants, perhaps leaving them uncertain whether they participated in a therapeutic or research interview. This was clearly a tension for me. In using therapeutic skills in response to such situations, I acknowledged that I may have influenced participants' interpretations of such events, perhaps compromising the integrity of the data collected during an interview (Haverkamp 2005). However, I recognised that I could not switch off my caring approach to the participants and that I automatically gave something of myself, in these situations therapeutic skills, and I felt comfortable doing so (Dickson-Swift et al 2007).

4.9.2   Researcher distress

It was important that I also considered the impact of the research on my own health and wellbeing (Dickson-Swift et al 2007). I experienced many situations, especially during the interviews, where the older participants disclosed sensitive and personal information to me. Furthermore, I was exposed to complex situations whilst undertaking the care visits with the community matrons. This often led to me witnessing difficult and distressing circumstances for the older participants. Over time, I did not become de-sensitised to these situations, as has been illustrated in other studies (Morgan and Krone 2001). On reflection, at times I became overly immersed

in these situations and this effected how I interpreted the experience of the older participant in subsequent observations. As Warr (2004) suggested I became emotionally vulnerable. Furthermore, I was exposed to situations that gave me a heightened sense of my own mortality and vulnerability and how this might be acted out in later life. This was compounded by the nature and length of the field work. Over the two and a half years in the field I became intermittently physically and emotionally exhausted; this often influenced my interpretation of a given situation (Dickson-Swift et al 2007).

Early on in the field work I made arrangements to meet with my supervisors, or make telephone contact, on a regular basis to discuss any situations or feelings that the experience of being in the field triggered. This provided me with the necessary social and emotional support when undertaking this challenging work (Hayward and Tuckey 2011). For example, over a period of two weeks in the first year of data collection I was exposed to two difficult situations. I found these to be demanding and the cumulative effects led me to feel upset and drained. This prompted me to make a phone call to my supervisor to discuss my feelings surrounding these. In the first situation it became apparent that the care workers had not been cleaning older participant three's commode over a long period of time, and it was encrusted with faeces. The following week when entering older participant one's house with a care worker we found her on the floor following a fall in the middle of the night. I wrote the following in my fieldwork journal:

> This has been another difficult week. Today older participant one was found on the floor of her bedroom; she had fallen out of bed at 2am in the morning and lay there all night. I found this situation really upsetting; older participant one was in a really vulnerable position. The care workers stated that they were not allowed to help her up. I feel a mixture of emotions: anger, frustration, sadness, distress. Combined with the commode situation, that I experienced with older participant three last week, I feel really drained emotionally; I have had to draw on inner reserves to be able to cope with this. Must contact supervisor.

On occasions I felt that I was unable to maintain a position that provided access to the participants' experience without becoming overly involved and influenced. Whilst it could be argued that this introduced bias to the fieldwork

(Brewer 2000) I considered that this was not detrimental to the experiences that I endeavoured to explore. Nicholson (2009) suggested that research that attempts to examine the complexity of ageing must connect with the ambiguities and emotions that this raises for the researcher. Therefore, I ensured that within my fieldwork journal I illuminated my actions, feelings and thoughts regarding a particular situation and how they influenced that situation.

4.10   Presence in the field

It is important to acknowledge that my role of researcher and my presence as observer-as-participant in the field clearly influenced the 'social action' that I observed and listened to. Although I did not claim to be capturing 'what is there' as reality, but one interpretation of reality (Atkinson et al 2007) it was still necessary to consider my influence on the situation. Blackwood (1995, p53, cited in Hobbs and Wright 2006) concluded that 'identities in the field' are never stable, never simply defined'. I realised that how I was perceived by others would influence the data I collected, for example, in terms of being a researcher, a professional, a woman and middle-aged.

During the process of observation I acknowledged that I could make the participants feel uncomfortable which may have altered the interaction between the community matron and the older participant, some care activities and also possibly some of the outcomes. This was in part influenced by how the participants viewed me, in particular how I was perceived within the context of the visit. For example, the community matrons were always nervous during the first observation visit within a case, possibly because they felt that their clinical practice was under scrutiny. I was in a powerful professional position as a nurse researcher from an external organisation and it is likely that the perceived threat of sanction impacted upon their clinical performance (Sheldon and Sargeant 2007). On reflection, this could have been an issue for the care workers involved in the care of some older participants. Only two out of fifteen agreed that I could observe them during a visit, and none of them would agree to take part in an interview. During the early part of the field work local authority care provision was undergoing a major organisational review and it is likely that the personnel I encountered felt threatened by my study. In particular, they may

have been concerned that it could have a negative impact on their future employment.

4.10.1 Personal front

It was also important to consider other personal characteristics that influenced the context of the observations and the relationships that developed. Hammersley and Atkinson (2007) highlighted the importance of recognising aspects of 'personal front' as they may limit the negotiation of 'identities' and relationships in the field. Moreover, they are less open to management. On the whole I felt that my gender positively enhanced the development of relationships with the community matrons and the older participants. During the visits I observed many intimate care activities and I think that this may have been more difficult if I had been a male researcher. On reflection this was also bound up with my professional background as a nurse, which is still a female dominated workforce. Therefore, I think that the participants generally found it acceptable for me to be there.

As well as social categories participants' response is further influenced by whether membership of a group is shared. Miller and Glassner (2011) suggested that where the researcher does not share membership of the group social difference can lead to mistrust or misunderstanding between the researcher and participant. This can influence the response of participants and the ability of the researcher to ask the right questions. It was likely that I shared some attributes, thus membership, with the community matron participants, in terms of my age, gender and professional qualification. As a middle-aged woman I was a similar age to them. Alongside my gender, I think that this made us more able to relate to each other and share common experiences, which in turn positively enhanced the relationship and development of the field work. This was also the case with two of the family caregivers as they were both middle-aged and female. Furthermore, I started to care for an ageing parent half way through the period of field work. It was less likely that I shared membership with the older participants therefore I acknowledged that the meaning systems of older adults would be different to mine. I did not assume an understanding of ageing in later life just because of my own experiences of ageing up to that point.

One aspect of my personal front that I could manage consistently was my appearance and dress code. I paid attention to how I presented myself to all the participants, particularly during the first visits in the field. During observation visits I adopted a smart dress code that I felt to be acceptable within the context of the professional encounter; this was different to the corporate suits worn by the community matrons. I hoped to avoid confusion for the older participants that I was there as a clinical colleague whilst at the same time communicating my professional attitude towards my researcher role (Hobbs and Wright 2006; Atkinson et al 2007). Another aspect of personal front was the use of language and I ensured that I introduced myself in the same manner to all participants. Although I acknowledged that this could be different with male and female older participants, and those with different roles. It could also change as I developed relationships with participants.

4.10.2 Observer role: 'insider' and/or 'outsider'

Hammersley and Atkinson (2007, p112) described how the researcher needs to be 'intellectually poised' between the familiarity and strangeness of a given situation, therefore I had to consider whether I was approaching the field as an insider or outsider. Breen (2007) recognised that the participant observation role is on a continuum between insider and outsider and that this can offer constraints as well as insights into the situation being observed. Furthermore, these positions are not absolute and may change overtime. Hammersley and Atkinson (2007) referred to the researchers 'marginal' position, trying to balance the 'outsider' and 'insider' views.

At the point of entry to the field I considered myself to be an 'outsider' because I did not work for the organisation and also I was a new person within the context of the care relationship between the community matron and the older participant. I was able to use this status positively to explore situations from a less subjective perspective. For example, in the case of older participant three I noted at the second observation she had been very unhappy with the conduct of her general practitioner towards her during a recent home visit. She continued to mention this episode at subsequent visits and I recorded in the fourth observation field notes:

(OP3) has mentioned again how she was made to feel during the visit by GP about her breathing, this is the third time. It seems as if this incident has really rattled her as well as having a real impact on her ability to manage her episodes of breathlessness and panic. The CM does not seem to be picking this up and is focusing on her inhaler technique again. Note to self: explore this with (OP3) at the next interview (4th field note: OP3).

Being an outsider meant that I could ask more 'naïve' questions to explore and clarify issues. For example, during the field work I observed that there were a number of role tensions between the community matrons and other organisations involved in the care of the older person. The following extract from case four illustrates this:

When the community matron and I arrived at older participant four's house unbeknown to us the social worker was already there. The following extract from the interview illustrates how I was able to ask about her inter-professional working and challenges to her role:

> JS: At the last visit the SW was already there, you seemed surprised at this?
>
> CM: I was very unhappy about that. The social worker had had no contact with me, so she obviously didn't know that I had been involved with (OP4) and this has an impact on care not knowing what is going on. I think when you have got a patient and you are talking to each other, social services and health, you can actually sort things out and have a conversation around that patient….. if I'd got that SWs name I could have rung her up and said can we do a joint visit, it works much better that way'.
>
> JS: Do you find it difficult to work with social services?
>
> CM: Yes when there is no communication. (Case account: OP4)

However, at the start of the study I also considered myself to be an 'insider' and therefore I had to balance these competing perspectives in the field. I was an insider because of my professional nursing registration and I was able to use my nursing knowledge and clinical insights positively within the observations. For example, I had an understanding of most of the health conditions and their subsequent care requirements and was also familiar with some of the terminology and the equipment that was used. This meant that I

was able to maintain focus during the observations without worrying that I had misunderstood something. However, I also felt an 'outsider' to some extent in relation to my professional status as I was not currently practicing as a nurse. Moreover, my area of clinical expertise had been within the intensive care environment in a teaching hospital. I perceived this to be a strength as I had very little experience of the community matron role or working professionally in a person's home; therefore I would not be familiar with work 'routines' or 'language'. I was able to distance myself to some extent from events and not take issues for granted.

An example from the field notes taken during an observation with older participant one and the community matron highlighted this:

> On driving back to the Medical Centre in the community matron's car I commented on how the care worker had talked as if OP1 was not in the room. The first response from the community matron was 'I didn't do that did I?' In this instance I was able to respond that she had not, although I thought that it was interesting that she had not noticed that the care worker was doing this. The community matron then went onto mention that (name of older participant) did not like this particular member of staff and that there were always tensions at meal times. We discussed how it must feel being ignored and this was possibly making the situation worse (2nd field note: OP1).

Here, being an 'outsider' had clearly enabled me to consider how the care worker had spoken to older participant one. The community matron had not picked this up, possibly because she was familiar with the situation and the member of staff and also she was busy trying to manage older participant one's medications at the same time. What this also demonstrates is that the relationship between 'insider' and 'outsider' is dynamic and not necessarily one or the other at any given time (Murphy 2005). As the extract above shows I also used my 'insider' status to raise a professional issue in a positive way. This then enabled a discussion of the community matron's own communication skills as well as the relationship between older participant one and the care worker.

4.10.3 Role fluctuation

As my role of participant observer evolved and I developed relationships with all the participants I accepted that in some contexts I became more of an 'insider' to the situation; furthermore my role of observer-as-participant altered and fluctuated. This positively enhanced the collection of data as well as creating difficult challenges.

Over time, the development of a relationship between all the participants enabled me to become accepted as a member of the situation; this meant that increasingly my role became that of participant-as-observer. This was dependent on my ability to develop a trusting relationship with the participants and was enhanced by the following: honesty; friendliness, openness. In particular, I paid attention to pursue 'normal' social intercourse alongside my research interests; this enabled the participants to feel at ease (Hammersley and Atkinson 2007). Consequently, over the course of their involvement with the study all of the older and community matron participants called me by first name. In relation to the community matrons when based in the various health centres, my opinion would be sought on general issues relating to clinical practice. This often led to frequent discussions regarding their views on providing end-of-life care to older people and the challenges they faced.

With permission I started to engage in a number of basic care duties in the older participants' home, such as making cups of tea, emptying commodes, and running a bath. Occasionally, I would assist the community matron to weigh a participant; one particular participant was unsteady on her feet and it became common place for the community matron to weigh her when I was present. On the whole I felt comfortable undertaking these activities and felt that this reciprocity assisted in maintaining the trust of the community matrons and the older participants in my role as researcher (Seymour et al 2005b). However, it was more than that; I actually wanted to give something back to the older people that I was getting to know.

On reflection a real strength of becoming an intermittent participant-as-observer was that it enabled me to access experiences that further illuminated how the older participants managed their daily lives; these would have been inaccessible had I remained purely an observer-as-participant.

For example, on the penultimate visit to older participant one she expressed her unhappiness with the carers as she had not had a bath for six weeks because they were always too busy. The community matron suggested that she had a bath whilst we were there; I offered to run the bath. The following extract from my field notes illustrates this:

> Older participant one mentions that she might have a bath that afternoon. The community matron asks why she doesn't wait until carers are here. She says that they always say that they are too busy so she tells them to get off then, 'I'm not stopping you'. The community matron suggests that she has one whilst we are there, even though she has a busy day with some extra visits; I offer to run the bath. When I get upstairs I notice that there is a second Zimmer frame at the top of the stairs. There is quite a distance from the bathroom to the bedroom and I note to myself to ask older participant one how she manages with the distance (extract from 6th field note: OP1).

By going upstairs to run the bath I was able to get a sense of the physical space that older participant one had to manage and I asked her about this at the next interview.

However, becoming a participant-as-observer made the task of observation difficult as I still had to observe what was happening and write down the observations, even whilst engaging in some basic care activities. This became especially difficult if I had left the room and I had to rely on the audio-recordings to give me an idea of what had been happening during that part of the consultation. In these situations I listened to the audio-tape the same day and matched this with my field notes, noting when I had left the room.

I also became more visible and at times during an observation visit the older person would turn to me and ask me personal questions. For example, how had my holiday been, how were my children; particularly when the community matron was writing in the notes. I would respond to these questions however often felt uncomfortable as I did not want to 'take over' the consultation, but at the same time did not want to appear abrupt in my

response. Furthermore, by giving the older person my attention during these conversations meant that I was not as attentive to the situation as a whole.

I realised that such rapport could also have negative effects and introduce bias to the process of data collection and analysis (Brewer 2000). For example, where I became familiar with the routine of visits I considered myself to have 'gone native' (Hammersley and Atkinson 2007). I noticed that my field notes became less detailed the longer I remained in the field with a community matron and older participant. On reflection it is likely that the familiarity of the situation led me to miss things, for example, around the routine monitoring of vital signs such as blood pressure, pulse and temperature. Another consequence of 'going native' was that at times, during visits, I asked questions about something that had been happening to the participant which influenced the direction of the consultation. For example, during the third observation visit to older participant four she was complaining of pain and I found myself asking her where the pain was before the community matron had the chance to pick up this cue.

4.10.4 Role of researcher versus nurse

In this study my intention was to bring the role of researcher to the fore. In doing so I acknowledged that situations could arise that created challenges for my professional responsibility as a nurse. Murphy (2005) and Brown Wilson (2011) have highlighted the tensions that are created between a long established nursing identity and the emerging identity as a field worker.

Occasionally my 'duty of care' as a nurse (NMC 2008) came to the fore and I made the decision to assist the community matron in managing a difficult situation; as described earlier in the case of participant three and cleaning the commode. During the interviews I encountered situations where there had been deterioration in an older participant's health condition. Here, I faced a dilemma regarding what role to adopt in such circumstances. I found that I could never ignore a clinical issue however my response would vary depending on my interpretation of the severity of the situation. For example, on visiting older participant one for her third interview it was clear that her breathing was worse and both her ankles were more swollen than normal; she commented upon this herself. Her community matron was on holiday and older participant one was worried that she would get worse before she

returned. I suggested to her that I ought to contact another community matron and she agreed to this. Consequently, older participant one's water tablets were increased following a visit from the community matron's colleague.

Similarly older participant three complained that her breathing was worse during the third interview. I noted in the care notes that an emergency practitioner had been called out at the weekend, although older participant three had refused to be admitted to hospital. I considered that older participant three's breathing had been the same as the previous visit; however I still asked whether she wanted me to call the community matron. She declined and mentioned that she would wait until the community matron's next visit in a couple of days' time. I did mention this issue to the community matron over the phone following the interview and she stated that she was visiting in a couple of days' time and that this was not an unusual experience for older participant three.

4.10.5 Developing attachments

The blurring of boundaries during interaction between the researcher and participants was not unproblematic, and I did develop strong relationships with some of the older participants and the community matrons (Dickson-Swift et al 2006). I had intended to develop a rapport with the participants whilst remaining inside the formal role of the researcher. However, this became harder as I got to know the participants over time and where the field work became more intense. To develop the rapport I felt that it was important to maintain a warm and interested approach with all the participants. Over time this meant revealing my personal life experiences, and emotions, when appropriate, in order to develop an appropriate rapport with the different participants. I also demonstrated reciprocity by running small errands, for example, older participant one had run out of milk during an interview visit and her neighbour did not shop until the following day. I was mindful that such reciprocity overtime could lead to the development of other relationships such as friend and colleague, which it did. However, I considered it a privilege to be allowed access into the older participant's homes and to see them in potentially vulnerable situations; as well as observing the work of community matrons. I felt that it was important to give something back to the participants.

4.11　　Chapter Summary

This chapter presented the methods of data collection and the process of data analysis undertaken in the field. Ethical issues encountered during the period of field work were explored and a reflexive approach to being in the field was demonstrated. The next chapter will introduce the ten case studies. It will also detail the first of three key findings.

Chapter 5: The study findings

This chapter presents the ten case studies and the participants that comprise each case. It also reports the first of three key findings that illuminate the experience of frailty in later life, based on the analysis of the observational, interview and documentary data from the case studies. Extended case study examples are sometimes used to further illuminate the nuances relating to the experience of frailty, particularly over time.

5.1 Case study participants

A case comprised an older person, a community matron, and sometimes a significant other, such as, daughter, neighbour (See Table 4). The age of the ten older people ranged from 77 to 91 years, with a median age of 84 years; seven were women and three were men. All of them lived alone at home and all were receiving care from the community matron service. The four community matrons who took part were all female and aged between 40 and 55. The number of years they had been qualified as a nurse ranged from 20 to 37 years. All had been in post as a community matron since the service commenced in 2005. Prior to this three had worked as district nurses; one had been a practice nurse. Table 4 presents details of each case and the involvement of the participants in the study; the older people have been given pseudonyms.

Case 1: Vera

Vera had been on the community matron's case load for three years, following referral from another specialist nurse. She had been widowed for a number of years and had a married daughter who lived locally. She lived in a three bedroom house. In the past she had worked as a cleaner and home help. Her past medical history was complex, including, coronary heart disease; congestive cardiac failure; COPD. At the time of referral to the community matron service Vera's main problems were: oedematous legs; social isolation; unstable blood pressure; and risk of falls. She received carer visits four times a day and a neighbour supported her with shopping. She had recently had a respite placement in a local care home and she had a city wide alarm system in place.

Table 4:   Details of the cases including the number of observations and interviews undertaken and the time frame in study

Case Study	Ethno-graphic Observ-ations (n)	Inter-views with Older Person (n)	Documentation review	Supplementary Interviews Participant (n)	Status at end of study period	Time in study (months)
Vera	6	6	Yes	CM (2) Neighbour (1)	Died	10
Keith	6	6	Yes	CM (2)	Alive	10
Esther	6	6	Yes	CM (1)	Died	11
Grace	3	1	Yes	CM (1)	Died	4
Martha	6	6	Yes	CM (2) Daughter (2)	Alive	9
Derek	6	6	Yes	CM (2)	Died	8
Amelia	5	5	Yes	CM (1)	Died	6
Christine	6	6	Yes	CM (2) Daughter (1)	Alive	7
Stephen	6	6	Yes	CM (2)	Died	8
Eve	6	6	Yes	CM (2)	Alive	6
Total	**56**	**54**		**20 CM (17) Other (4)**		

Case 2: Keith

Keith had been receiving care from the community matron for almost two years, following a referral from his family doctor. He had been widowed in the last five years, and shortly after this his daughter had died. He had two married sons who lived in the region. He lived in a one bedroomed bungalow. He had been a driver for a local steel works firm. He had numerous health problems, including diabetes, coronary heart disease and COPD. He was referred to the community matron service for assistance with symptom and

medication management. At the time of recruitment to the study he received an evening call from carers to prepare an evening meal.

Case 3: Esther

Esther lived on her own in a three bedroomed semi-detached house. She had been widowed for many years and had no contact with any living relatives; she had no children of her own. She worked in the steel works as a young woman. She had been referred to the community matron service by social work services and had been on the community matron's caseload for a couple of years. Esther was receiving care services three times a day. She had supportive neighbours who helped her with shopping and washing. Esther's main health problems were COPD, hypertension and angina. She had a history of falls and was in possession of a city wide alarm. She had previously had two episodes of respite care in two separate local nursing homes.

Case 4: Grace

Grace lived on her own in a one bedroom upstairs flat. Her husband had died many years ago. She had one married son who lived locally. Grace had been a child minder all her working life. She had been recently referred to the community matron service by a local community nursing team. She had numerous health problems which included: asthma, diabetes and stroke. She paid a private carer for two hours twice a week to assist with daily living activities.

Case 5: Martha

Martha had been widowed for many years and lived on her own in a three bedroomed semi-detached house. She had two married children who lived in the city. Martha had worked as a dinner lady. Martha had been recently referred to the community matron service following two heart attacks. She had been referred by a specialist nurse. Martha had a number of health problems which included ischaemic heart disease, irritable bowel syndrome, and cervical spondylitis. She received no support from care workers.

Case 6: Derek

Derek lived alone in a two bedroomed part-owned council house. He had been widowed for several years. He had three children, two sons and one daughter; one lived outside the region. He had worked in the steel industry in the Rolling Mills, and had seen active service as a soldier during the Second World War. Derek had been recently referred to the community matron team by his family doctor. He had a number of medical conditions, these included: COPD; heart failure; and diabetes. He received no support from carers.

Case 7: Amelia

Amelia was divorced and lived on her own in social housing. She had lived in the area all her life. She had two daughters who lived locally and offered her support as and when it was needed. She had worked as a home carer all her life. Amelia had been on the community matron's caseload for a year and had been referred by her family doctor. She was suffering from end-stage COPD, osteoporosis and hypertension. She received visits from carers three times a day.

Case 8: Christine

Christine had been receiving care from the community matron for several years, following a referral from the family doctor. She lived on her own and had been widowed for nearly a decade. She had two daughters who lived in the vicinity and who supported her with various activities of living. She had been receiving visits from care workers four times a day for many years; she also had access to a personal alarm system in case of emergencies. Her main health problems included coronary heart disease, irritable bowel syndrome and osteoporosis.

Case 9: Stephen

Stephen was a single man who lived alone in a one bedroomed flat. He was supported at home by a nephew and other members of his extended family. He had worked for the water board all his life and had seen active service in the Second World War. He had been receiving visits from the community matron service for just over a year, following a referral from the hospital. His

main health problems were COPD and coronary heart disease. He received no support from carers, however did have a city wide alarm.

Case 10: Eve

Eve lived alone in a three bedroomed terrace house. She had been widowed for many years. She had three married children, all who lived out of the area; although her daughter visited every week. She had worked in her husband's business all her working life. She had been on the community matron's case load for a number of years following a referral from her family doctor. She received visits from carers four times a day. Her main health problems were coronary heart disease, epilepsy and arthritis.

5.2 Transitions in health and illness in later life

This section reports the findings related to transitions in health and illness that the older people in this study experienced in later life. The lives of these older people were shaped by the nature and process of their transition experiences; yet my widely held assumptions about the experience of transition were challenged. Of particular interest is the meaning that older people ascribe to such experiences in the context of their life course. These findings provide an opportunity to develop a critical understanding of the diversity and complexities within transition experiences in order to enhance the way that health and social care professionals engage with, and provide supportive care for, frail older people.

Four themes arose from the analysis of the data, which characterise transitions in health and illness in later life. *The experience of transition* examines the types and patterns of transition relating to health and illness and the impact these have on daily living. *Managing transitions in health and illness* details the extent to which older people are able to actively engage in the process of transition. Such an examination reveals how transitions often lead to periods of heightened vulnerability where older people encounter difficulties in managing their daily lives. *Making sense of deterioration* demonstrates how future lives are shaped by the experience of transition in the context of ageing. *Support networks* explores how formal and informal networks support an older person in managing their daily routines in the context of ill-health.

5.2.1 The experience of transition in health and illness

5.2.1.1   Disruption to daily life

It was apparent from listening to the majority of the older participant's accounts that over time, transitions in health and illness had led to the experience of physical decline, with subsequent disruption to daily routines. On the whole disruption of such routines was expressed as losses and the older participants in this study were able to articulate those losses, although these were expressed in different ways depending on the degree of decline and individual circumstances. Not being able to go out was a key loss associated with physical decline and ill-health. Moreover, a combination of physical immobility and fluctuations in health influenced the ability to sustain wider social relationships. For example, Esther described how she used to regularly go out for lunch and shopping with a friend**:**

> *'My friend had a car. She hasn't got it now, but she had a car. She used to be able to come and take me and we'd go for a meal, twice a week perhaps, but it got to the point that I couldn't walk to the car. I could only walk around the house with that (points to mobility trolley). I needed the support. When I got to the door I'd be lost, I'd need something to help me. But she hasn't got the car now so all that's dropped off. She's the same as me, she's in her eighties. She's like me she can't do what she used to do' (1st interview: OP3).*

Similarly Martha described how part of her daily routine had been to talk to her neighbour over the garden fence and she missed that:

> *'(Name) would knock on the window and I would go out and stand at the privy and chat with her. I haven't been able to do that all year. I've come out of my routine and I'm all upset' (2nd interview: OP5).*

Not being able to manage the home environment was another outcome of physical decline. For the women in particular not being able to keep the house clean was an intermittent cause of frustration. Vera recalled how she was no longer able to do her housework:

> *'I can't clean anymore. I used to be right active and it's gone. I used to stand on the steps and clean the windows. I used to run up and down (pause) it*

annoys you. I'm always looking around for something to clean' (1st interview: OP1).

The loss of physical capacity was expressed in other ways. Christine often mentioned that she could not read books anymore because of her failing eyesight. This was a great source of distress to her as reading had been a passion all her life and was the one activity that compensated for not being able to go out. Eve was hard of hearing and she commented on how this made it difficult to engage in conversations especially when she attended a weekly luncheon club.

For some older participants in the study deterioration in their mental health and wellbeing intensified the effects of physical decline. Over a period of a few months both Vera and Keith experienced episodes of low mood and at times this compromised their ability to manage their daily living and further disrupted their daily routines. For example, as Keith's mood deteriorated he began to have problems managing his diet and this impacted upon the control of his diabetes. Furthermore, towards the end of the study period I observed how he was less interested in his physical appearance and personal hygiene to the extent that he began to neglect himself and forget to take his medications.

5.2.1.2   Getting used to disruption

Although all the older participants talked about the losses and limitations to daily living brought about by illness and physical impairment it appeared that some had adjusted to the problems expressed. In fact, some commented that they had been in their current position for a number of years. This suggests that for some older people an end point to a particular transition in health and illness can be achieved, with subsequent stability. For example, Esther had not been outside the house for four years and Vera had employed a cleaner for ten years. In these situations the effects of illness and physical impairment, and its associated losses, appeared to have been accepted and a new level of lower overall ability was accommodated. Moreover, the physical impairment appeared to have been redefined so that it became part of the background of daily life and therefore, in the context of daily living, did not seem to be a current issue. So, although Esther was not able to go out, she was able to mobilise within the home so that she could manage her daily

routine. Thus, even though the impairment shaped life it was possible for an older person to redefine their ill-health and physical impairment and adapt to the disruption.

On further examination accommodating disruption was a complex process which required an older person to achieve a sense of balance in their lives. This involved the management of the loss experienced, as a result of ill-health and disability, whilst at the same time securing continuity in daily activities. For example, Martha experienced a major transition in her health after suffering two heart attacks within quick succession. This was followed three weeks later by a fall where she fractured her femur, prompting a lengthy stay both in hospital and an intermediate care unit. At the beginning of the study it was clear that Martha's health problems and physical disability appeared to have led to a disruption of her previous life style. What came across very strongly was the sense of loss she was experiencing as a result of not being able to go out. Martha consistently described how she had been fit and active, managing to get into town on public transport a couple of times a week, as she recalled during the first interview:

> *'I just miss going out, I miss it awful. Because I always went into town, well a couple of days, I had been going into town Tuesdays and Fridays by myself'* *(1st interview: OP5).*

Early on in the study I also observed the changes to her mobility. During the second observation visit, following the fall, Martha did not get up from her chair at all. This had been different to the visit four months previously where she readily, and with relative ease, got up to collect items for the community matron. Furthermore, I observed how difficult she found it to get out of her chair and walk to the scales so that the community matron could weigh her.

Over time Martha showed signs of recovery and at each successive interview she spoke of new accomplishments. Initially she had been unable to manage her personal hygiene or cooking, but as time passed she could manage some activities sitting down, as she recalled in the third interview:

> *'I can sit and do little things; I sat and sewed a button on here. My peg bag was coming apart so I sat and sewed that. Just sat in the kitchen and done some vegetables, to do some broth another day'* *(3rd interview: OP5).*

Two months later she was able to undertake many daily living activities, including personal washing and dressing, cooking and hanging out washing, adopting new strategies and techniques where appropriate. However, she was left with a permanent disability due to the shortness in her leg following the fracture. Over time she made fewer references to the period before the heart attacks and fall and her desire to get out and walk, but instead focused on managing daily routines at home and engaging with the family. In particular spending time with her great grandchildren and wanting to be around for the birth of two new great grandchildren appeared to be a motivating force. I considered that as Martha came to terms with and managed the losses associated with her ill-health and disability she was able to contemplate new ways of engaging with daily living that in my opinion enabled her to successfully redefine her impairments. Recovery for Martha had been a simultaneous process of achieving some sense of continuity with aspects of life before and adjusting to the constraints imposed by her ill-health and disability.

5.2.1.3   On-going disruption

For some older participants the redefining of the impairment and accommodation of disability and adjustment to the changes became problematic. The disruption experienced appeared to be influenced by the nature of the transition in health in illness. For a number of older participants I observed that a transition in health and illness was experienced as a constant process characterised by gradual decline over a lengthy period of time. I noticed how such a gradual and persistent deterioration, challenged the ability to maintain daily living activities and routines. For example, over four months I observed how Stephen became increasingly breathless. Initially, on first visiting his home Stephen would open the door when the community matron and I arrived. However, later on he was unable to do this as he became too breathless to walk the distance. Moreover, Stephen noticed that his breathing was deteriorating, and he started to describe how every day was becoming a struggle. During the fifth interview he mentioned how:

> 'I felt terrible last night really breathless. I think I had a trying day. Well first thing in the morning I was having a wash and a shave, and then I was

caught short and I had to dash in there (toilet) with the frame and it went all over the seat. Well that knocked me back trying to clean that. And when I went to bed I felt terrible. In the morning I am breathless too, first thing. I can feel myself getting worse' (5th interview: OP5).

A week after this interview Stephen was admitted to hospital with a chest infection, in spite of having antibiotics for two weeks prior to this at home. Likewise, I observed how Keith's mood deteriorated over a number of months which coincided with a decline in his general health and wellbeing. In between two observation visits I noted how he was less able to manage his daily routine and I documented in my field notes:

> Keith took a long time to answer the door today, which is unusual. When he opened the door he was still in his pyjamas. I was surprised at this as he was normally dressed at this time in the morning (10am). He mentioned to me that he was still in bed and made his way back to the bedroom. I noticed that he shuffled. He appeared dishevelled and he looked to have a few days growth of a beard; he had always prided himself on shaving daily.

Where continuous transition experiences were punctuated with significant health crises, such as falls or infections, further disruption to daily routines was encountered. Here, the difficulties in balancing the losses attached to such deterioration and the desire to manage routines were brought to the fore. For example, over a period of ten months I noticed how Vera's health and wellbeing slowly deteriorated, presenting her with numerous challenges to maintaining her daily routine. When I first met Vera she was experiencing a number of health problems. The community matron recalled these problems when I interviewed her prior to the first observational visit:

> *'Sometimes there are problems with her heart failure, if we are not careful she can get really oedematous legs, we have to alter her diuretic medication, she doesn't really get out of the house so we've tried to sort getting her out to luncheon clubs and things like that, she is also at risks of falls, she hasn't fallen for quite a while, and now I'm worried about her eating and this weight loss, she has lost 1.5kg in 5 weeks, she now only weighs 41.5kg …… so it's mainly her blood pressure problems, weight loss and these oedematous legs'* (1st interview: CM1).

This range of health problems provided the backdrop to my first meeting with Vera. It became clear to me from hearing Vera talk to the community matron on that day that her ill-health was affecting her. When the community matron asked how she had been since her previous visit seven days earlier Vera replied that she had not been very well at the weekend; using the phrase 'off it'. At this point Vera was upset and she went on to describe how not being able to go out with her daughter because she felt unwell had made her feel fed up. She said that she did not feel particularly poorly but that she was tired. This feeling of tiredness was compounded by her poor mobility and Vera described during the first interview a week later that it was not only the tiredness that was stopping her from doing things but her mobility was also getting worse because of her swollen legs:

> *'I'm worried about my swollen legs and feet because they're beginning to affect how I get up and down the stairs. I like to rise early in the morning and go downstairs but in the last week I have had to sit on the edge of the bed and wait for the carers to help me because I've not been able to get down the stairs myself.......I get really mad with myself' (*1st interview: OP1*).*

The manner in which Vera articulated her concerns demonstrated to me that the changes to her health were beginning to limit her ability to manage and take control of her current daily routine, in this instance getting down the stairs unaided. Over the next three months further challenges to the daily routine were evident to me. During the third interview she mentioned how once she got downstairs she would try and get a cup of tea, although on a few mornings that week she had not been able to accomplish this. The combination of decreasing mobility and tiredness were frustrating, as she said:

> *'I try and make myself a cup of tea, if I can walk in the kitchen……..but this morning I couldn't manage to go in the kitchen as me feet were right swollen. And you know when I'm walking I count a lot, to keep me going, I thought if I count I might keep going me self, but I couldn't this morning I was just too tired after getting downstairs' (*3rd interview: OP1*).*

Over the next two months my examination of the community matron's notes revealed that Vera's health continued to deteriorate. Vera entered a period of

upheaval that further challenged her capabilities and led to uncertain times. Her gradual decline in health, punctuated by low blood pressure, a number of falls, arthritic pain, constipation and a urine infection, exacerbated her loss of appetite and mobility. I observed Vera's general decline and noted during the fourth visit with the community matron that she was becoming increasingly unsteady on her feet. At this point Vera was beginning to lose her confidence as her mobility decreased.

On closer scrutiny it seemed that Vera was finding it increasingly difficult to balance her daily routine with her increasing disability. This was compounded further by a transition from home to hospital as she was admitted to hospital for three weeks following a fall. At this time these changes confronted Vera with the reality of her decline and her inability to cope. In particular I think that she recognised that her ability to exercise control over her personal daily routines was diminishing. For the first time during the study she began to express that she was frightened about everything that was happening and that her future was uncertain. In this situation, I considered that her increasing disability and fluctuating ill-health were very much in the foreground and she had no capacity to redefine these in order to manage her daily routine.

5.2.1.4   Stability and disruption

In contrast, for two older participants I observed that there were no significant transitions in health and illness during the study period. In these cases I thought that there was a period of stability in relation to their health and wellbeing. Although these older participants did experience health problems they appeared to be able to accommodate those problems without upheaval and uncertainty, with no real disruption to daily routines. Moreover, where management of health issues was well established I considered that accounts of accommodation were more prominent than disruption. For example, although Derek experienced a chest infection and raised blood pressure during the period of the study he demonstrated that he was able to manage these effectively and take them in his stride, even when the introduction of a water tablet meant that he had to frequently go to the toilet. Similarly, Eve had frequent episodes of nausea which she was able to

manage through decreasing her intake of fatty food and altering the dose of her pain killers for arthritis.

5.2.2   Managing transitions in health and illness

5.2.2.1   Patterns of daily living

In order to manage the effects of physical ill-health and impairment maintaining a daily routine was important. Engaging with such routines appeared to be significant as it enabled the older participant to sustain their sense of self as an independent person through the control of habitual routines. Furthermore, a degree of continuity with important aspects of life was maintained. I observed how patterns of the day were structured and adhered to. For example, Stephen routinely had an early lunch and then retired to his bedroom so that he could lie down and watch television; this also conserved his energy for his bedtime routine. Similarly, Esther would lie down after breakfast to read and then after lunch would watch a series of television programmes up to bedtime. Keith visited his son weekly to have a cooked family meal. When routines were easily accommodated the impairment seemed to go out of focus thus enabling the older participant to get on with their routine.

In contrast, I observed that for many older participants' patterns of daily living could be easily interrupted. This was more likely to be the case where transitions in health and illness were experienced as a crisis event, or were enduring in nature. Here impairments were brought into sharp focus and became part of the foreground of daily life, challenging the ability to control daily routines and independence. Furthermore, a sense of self and continuity of personhood were called into question. On a number of occasions Amelia had been unable to eat her breakfast because she was so breathless. This affected her energy levels and made it difficult for her to subsequently engage in other daily activities, such as walking to the kitchen to make a drink or reading a book. Both Vera and Grace suffered a number of falls as a result of deteriorating mobility and weight loss. For Grace, this meant that she could no longer manage her own routine of personal hygiene and dressing. In Vera's case, she found it difficult to walk into the kitchen to get a new packet of cigarettes. The inability to take control was expressed as frustration and Amelia's exasperation in not being able to wash a cup

captured the annoyance experienced by many of the older participants in this study:

> *'I am so annoyed and frustrated with myself. I mean I can't even wash up a few pots and a cup. I never would have thought that I would ever be like this. But by the time I come out of the living room into the kitchen I'm good for nothing. I don't like leaving everything to the carers' (4th interview: OP7).*

5.2.2.2 Rethinking routines: 'You have to find ways for yourself'

Regardless of where an older participant was situated in relation to their transition in health and illness it became apparent that they 'worked' to maintain their daily routine. This involved managing new episodes of, or deteriorating, ill-health, and the subsequent challenges that these brought to maintaining independence. I observed how on-going and increasing impairments and constraints were re-thought. This involved employing strategies that would enable engagement with the process of transition in order to accomplish daily routines. For some these strategies involved making more concessions in the organisation of daily routines and the range of strategies appeared to reflect their current level of impairment. Furthermore, whether an older participant was restricted to the home, or not, influenced the nature of the strategies employed. For example Vera, Christine, Esther and Stephen were generally house-bound, whereas Derek, Keith and Eve were still able to get out of the house around their local neighbourhood with minimal or no support. Therefore the strategies employed reflected the current situation.

For example, over a period of five months Vera's mobility decreased and she found it increasingly difficult to walk from the living room to the kitchen to eat her meals at the table. To manage this she began to eat her meals on a tray on her lap in the living room. Similarly, as Amelia's condition deteriorated, activities previously taken for granted tired her out to the extent that she was then unable to continue with others. She described how she was unable to go back upstairs to the toilet after getting washed and dressed:

> *'I was coming downstairs after the carers had helped me wash and dress, but I was needing the toilet straightaway. I couldn't get up the stairs again, I was all done in. So that's why I've got a commode downstairs now' (3rd interview: OP7).*

For some, concessions involved making the decision not to pursue activities outside the home. This suggested a degree of disengagement with former routines. When I first met Keith he was regularly driving in the local area as he recalled during an early interview:

> *'I go to the (supermarket) in the car, to the health clinic and once a week I drive to (name of son) for an evening meal. If I didn't go in the car to the shops I'd be in a real mess with my breathing. My daughter-in-law does a big shop but I can't carry any weight, so the car is really helpful. And sometimes I drive to my sister in (name of place)' (2nd interview: OP2).*

Over a period of three months his health and mood started to deteriorate and I noted that he was not going out as much and was using his car less. When asked about this he mentioned:

> *'I've decided not to drive anymore…(pause)…I'm not bothered about driving anymore really I've had enough. I mean, what, 40 odd years I was driving on the road with (name of firm) and then steel works with the artics. I feel safe if I can go at my own pace, those that want to fly by me let them go. I'm confident but I'm not bothered now, I've had enough. But I miss going out I get stalled by staying in and I end up talking to myself. If you hadn't come today I wouldn't see anyone from teatime the previous day. I won't get to see my sister anymore either' (5th interview: OP2).*

Taking additional time to complete tasks was another approach used to manage daily routines. For example, over the study period Esther's breathlessness as a result of her chronic obstructive pulmonary disease became worse and this reduced her ability to walk through to the kitchen from her downstairs bedroom to make a cup of tea. She still continued to walk to the kitchen but she had to rest for longer periods so that she could get her breath back before continuing. She also combined this with changing activities as she described:

> *'I no longer make a cup of tea; I only take my pots through on the trolley for the carer to wash. They make me a flask of tea at lunchtime so that I can drink that for the rest of the day' (4th interview: OP2).*

On occasion omitting daily tasks altogether was the only strategy that the older participant could employ in order to manage their symptoms. This was the case for Amelia, who was experiencing an intense and enduring

transition. During the last three months of her life she was consistently unable to have a daily bath or wash, and she did not persist in achieving this. This enabled her to have the energy to interact with her daughter and grandchildren when they visited.

5.2.2.3   Acquiring new skills

The acquisition of new skills enabled the older participants in the study to manage the effects of deteriorating health and impairment in order to engage in daily routines. For many older participants this involved gaining new knowledge and learning new techniques for the purpose of monitoring and interpreting symptoms, managing medication and using equipment. For example, Keith had to master the use of a new blood glucose monitoring machine. Similarly, the physiotherapist introduced Stephen to a new inhaler that facilitated the expectoration of phlegm to try and reduce the chance of him developing a chest infection.

Through observation and listening to older participants I considered that in order to adapt to the transition new skills and behaviours had to be mastered. I perceived that many older participants had already mastered skills and behaviours and therefore had been able to accommodate the changes brought about by transition. This was particularly the case in relation to using aids and appliances for mobility as a result of falls or increasing unsteadiness. For example, to assist Vera around the home she used a Zimmer frame, she had one upstairs and downstairs. She had also installed a stair lift and she was able to use this alone to get downstairs before the carers arrived in the morning to help her with washing, dressing and preparing breakfast. Likewise, Eve got around her home using two sticks and a stair lift and was able to manage the majority of her daily activities. Once Christine had mastered the use of her Zimmer frame she adapted it so that she could carry items on it, such as her knitting, so that she could transfer it upstairs.

Being able to practice new skills over time was important, but at the same time these had to be adapted to changing levels of disability, whether these continued to decline or improve. Also, having a purpose appeared to encourage and facilitate the mastery of a new skill. For example, following discharge from hospital Martha was referred to the community

physiotherapist. Various strategies and plans were implemented by the physiotherapist to improve her mobility. This involved initially using a Zimmer frame but progressed to using two and then one stick. Over a period of 5 months I observed Martha practising the strategies that she was shown. As her abilities grew she was able to build on what she was taught and blend these with her own capabilities, which often meant using furniture and the walls. She was also able to refuse appliances offered by care staff:

> *'Somebody has mentioned a stair lift. I don't want one. I'm managing. I've been told and shown by the physio to put both feet on the same step when I come up and down. He's happy and I'm happy I know what is best for me'* (3rd interview: OP5).

In contrast the mastery of new skills was not always possible. During transition the ability to master new skills was complex and challenging and this affected an older participant's ability to maintain independence through the management of their condition and therefore their routine. I observed situations where it was difficult to develop the new skills required to manage deterioration in health. This was more likely to occur at the beginning of a transition, or where there was a crisis during enduring transition. One of the reasons appeared to be that the older participant did not have the physical strength or manual dexterity to actually use the equipment. For example, Esther's breathlessness became worse over a period of a few weeks and on two occasions she had called for an ambulance; although she refused to be admitted to hospital. The community matron was concerned that Esther was not able to use her inhalers and therefore introduced a new device to assist with this. Over the period of data collection Esther was never able to master the technique and therefore it became difficult for her to take her medication. Moreover, her inability to control her breathlessness affected her mobility.

Similarly, over a period of a month Keith became increasingly unsteady on his feet. Subsequently a referral was made to the community assessment and rehabilitation team where he was given a Zimmer frame to use around his home, to prevent falls whilst he engaged in his daily routines. I observed how he found the Zimmer frame difficult to manipulate and often when I visited he would not use it to walk around his flat. As he said,

'I just can't get used to it, it seems to be more trouble than it's worth' (4th interview: OP4).

In contrast some older participants made a decision not to acquire new skills or behaviours in the process of managing their routine in the context of deteriorating health. This may be influenced by how they perceived the change because it implied a challenge to their independence. For example, Stephen had recently fallen against the wall in the hallway. He had been carrying a cup of tea whilst walking to his bedroom from the kitchen with his Zimmer frame. This had prompted a referral to the community equipment department. On the subsequent observation visit I noticed that next to the Zimmer frame was a mobility trolley with a tray. Stephen was adamant that he was not going to use it. Here resistance could be due to the fact that for Stephen the use of mobility aids signified vulnerability and being an 'old person'.

5.2.2.4   Keeping the routine going: 'It gets tough some times'.

There were occasions where the work required to manage daily routines pushed the capabilities of some older participants to the limit, interfering with routines that had previously been taken for granted. In these situations older participants often struggled to cope. Maintaining daily routines became a fine balance, juggling additional constraints imposed by deteriorating and fluctuating ill-health and existing limitations. In these circumstances it often became difficult for the older participant to control their routines and retain their independence, challenging their sense of personhood. Extra resources were drawn upon to continue managing and adjusting to 'deterioration'. Here, a feature of these circumstances was the experience of uncertainty and being in a precarious position.

For example, Christine had to balance her limited mobility and low weight, whilst managing the changes to her health after undergoing major dental surgery. Although the surgical procedure had gone well, a sinus had developed from her mouth through to her nasal passage. She was constantly worried about this as it was creating problems for her when eating and as a result of this she was losing weight. I considered that this created uncertainty for Christine; whether the sinus would heal or not and the consequences for

her if it did not. During the fourth interview, a month later, she stated that she was '*not well at all*' and went on to say:

> '*I have had lots of trouble. I had the Doctor here yesterday (name of CM) is worried about me. That is the top and bottom of it. She asked the Doctor to come and have a look, because I have lost so much weight and I am still losing it. I am not eating properly, the trouble with my mouth and of course. I have to go back and have some more surgery, the stitching has broken away. My gums were stitched together and it has come apart and the bones have come back through. It's dreadful; it is painful but not unbearable. It's really frightening, I am really scared, you see the bone is dead*' (4th interview: OP8).

During this time it was decided that Christine required further surgery and she was prescribed prophylactic antibiotics. However, these resulted in the side effect of diarrhoea and as a result of her poor mobility managing this had been distressing:

> '*I was in a terrible state this time last Wednesday. It was awful. I had been up to the bathroom. I got downstairs and I thought oh no I have got to get back again. But I couldn't get right back, got as far as the bathroom door. Oh dear I was in such a state. It took me ages and ages to clean myself up in the bathroom, because I have got to hang on to something when I am doing anything. So it was a long, oh I did feel ill. I was poorly for a couple of days*' (4th interview: OP8).

Similarly, over a period of two weeks Amelia began to experience pain in her ribs which made her breathlessness worse. She had to balance the increasing breathlessness with her engagement in all activities of daily living. During a visit by the community matron it became apparent that Amelia had broken a rib. Amelia recalled how she had felt something crack the week before when she coughed. Here I considered Amelia's situation to be increasingly precarious as she had to manage taking painkillers that would be strong enough to reduce the pain, without making her drowsy and her breathing worse.

At times the work to maintain daily routines became arduous and was not enough to overcome the constraints imposed by deteriorating and fluctuating ill-health and existing limitations. Here the balance was tipped in the favour of

the disruption and the older participant could no longer cope. In these situations the older participant was typically transferred across care boundaries to either hospital or intermediate care. For Grace and Martha it was a combination of both. Here, these individuals experienced transition in health and illness and transition in place simultaneously which often compounded the ability to adjust.

However, in spite of the decline in health the older participants did not stop trying to engage with activities that contributed to their daily routines. They continued to attempt to take control by being realistic about what they could or could not do, at any given time and in any given situation. Disengaging completely from these activities did not appear to be an option. Their approach at times demonstrated resilience in order to exert some control and maintain continuity of routine in increasingly difficult circumstances. Regardless of the challenges faced the emphasis appeared to be on 'keeping going' and I observed how small accomplishments were viewed as important in order to enable daily routines to continue. A comment by Christine during her transition in health summed up the resilience many older participants exhibited:

> 'If I can carry on and cope one way or another, I will' (5th interview: OP8).

5.2.3   Making sense of deterioration

5.2.3.1   Relativism in later life

Reappraisal of deteriorating health and disruption to personal routines in relation to an ageing self, appeared to enable the older participants in this study to further redefine their problems and accommodate changes to daily routines. For example Esther, commented on how she had come to terms with not being able to go out by clearly linking it to age related expectations:

> *'I'm not worried about all that now. I'm quite content to sit here and watch the world go by, watch my telly and read, that's all really. I've accepted that I'm 88 and a half. They can't do anything about that, nobody can. So I shake myself, I think pull myself together. There's nothing I can do about my age. There's nothing I can do about me breathing. So I've accepted it all' (4th interview: OP3).*

She constantly described herself as being '*past my sell by date'*, which she went on to explain:

> '*I know I am old but it's only my condition that makes me feel that I am past my sell by date. I just accept things as they are. I realise that there's nothing I can do about my age and nothing the doctor can do about my breathing, so just accept things that's all there is to do. And I watch telly and I watch hospital programmes and I'm better off than them (laughs). I think about someone that's blind and I think that I'm better off than them and I am, for my age I don't do bad really' (4th interview: OP3).*

Here not only was age used as a barometer but comparisons were made between herself and others who she perceived to be in worse situations than herself.

Similarly, when contemplating his rapidly deteriorating health Stephen considered that he had had a good innings. He also mentioned that he was better off than some other people. In particular he commented that at least he still had all his faculties. Making comparisons to older people who were less able was a common feature of the data, particularly issues linked to mental capacity. These comparisons seemed to be used as a benchmark for being able to positively reshape their ideas of independence in the face of disruption. In addition, comparisons were made with older people who were perceived to be in better shape and this appeared to motivate some older participants to do more for themselves. For example, Stephen went on to mention that his ninety-four year old neighbour had offered to cook his meal the previous day but he had refused and stated that:

> '*I must do it myself. If she can I can'*, even though he described '*everyday as a struggle' (3rd interview: OP9).*

Even where I observed periods of stability in relation to health and illness older participants still contemplated age in a way that normalised their experience and the management of their limitations. For example, although Derek felt as if there was nothing in particular that he felt unable to do as result of ageing and ill-health, he did miss going out but was pragmatic about this:

*'Well it's just one of those things, you have to live with it, haven't you? I feel the same as I did at 60 really, except that I'm a bit older. I think I'm not as healthy. I get a bit more breathless easier than what I did then, but what do you expect at 92. Mind you I've got these inhalers they are easy to use. No, I'm getting set in here, in this chair (laughs). It's nice to get out that one day (to luncheon club) it's a break. I like my reading, crosswords and what not; I was doing the crossword before you came'. (*2nd interview: OP6*).*

However, awareness of becoming 'old' was a complex process and on occasions caused conflict with the expectations that an older participant had for their own recovery. For example, as Martha's recovery continued it became evident that she would be left with a degree of permanent disability due to the shortening of her right leg following her fractured femur. The following extract from the fourth interview illustrates how Martha began to negatively interpret the permanent disability that remained in the context of her old age. For the first time, she began to acknowledge her disability and linked this to ageing. When I asked her how she had been since my last visit the following conversation ensued:

M: I'm not bad love, but I know my walking is not so clever. I know that I am not right sort of thing getting about. You can see how my leg, when I am sat at a dining room chair this foot is lower than that.

JS: So you have ended up with a shorter leg?
M: I've ended up with a shorter leg. So I was told to use my stick in the left hand away from that so it supports and it's better on that one. But it's hard.

JS: What is hard?

M: Well, I mean, I have to bend down to put my pants on in a morning and then I have to bend my leg up sort of thing, to get in (daughters) car I have to pick that leg up and put it in the car whilst this one goes in quite easily. I am grumbling but I shouldn't be (long pause).

JS: It's alright you can grumble sometimes.

M: I know you can but…..(voice tails off).

JS: It isn't doing quite what you want it to?

M: That's right it isn't. And I always said I don't need a stick. Our (name of daughter) for the last couple of years has been trying to get me to use a stick. I said, 'I'll use one when I need one', and now I need one. It doesn't look as though I'm going to get rid of it, does it?

JS: It's become part of you?

*M: It has love, and every now and again I try not to use it. Sometimes I put it down and walk round holding the furniture, but make sure I don't do that when our (daughter) is here. She'd have a do. They don't realise you have lived your life in a routine sort of thing, to go out of that it's annoying. It sounds as if you are mardy sort of thing. I suppose sometimes I wobble walking you know, or put my foot wrong; I'm not a spring chicken am I? (*4th interview: OP5*).*

Martha had never considered herself to be old, and I think one of the reasons that she resisted the offer of a stick is because to her this represented getting older. As she said in the same interview: *'I didn't want a stick, because old people have sticks';* she went on to mention: '*I don't feel any different in myself I don't feel old'.*

The above extract suggests that Martha began to realise that it was likely that she would have to use a stick for the rest of her life; therefore in her eyes she was becoming old. However it was difficult for her to come to terms with this and she struggled to acknowledge her dependency on the stick, a symbol of ageing to her.

Where the experience of transition appeared to be sudden and chaotic an awareness of becoming old and what this meant also challenged a sense of self as autonomous. For example, as Grace recognised that her ability to manage her daily routine was diminishing her accounts increasingly referred to her past. Here a temporal dimension appeared to enable her to position different accounts of herself, although she never referred to herself as old at this time. For example, in the following extract Grace refers back to herself as a younger woman. In referring to the past she possibly used this as a counterpoint to the older self that she was currently experiencing, lacking autonomy, and the present that she does not want:

'I was always on the go. I was a child minder for 40 years. I would take babies as young as two weeks old. I never had to ask for work, my new families came on recommendation from those on my books. It was a job I liked. I liked it too because if anything went wrong with anyone they'd say,

send for Grace'. And I was a keen gardener; nobody could grow long carrots
like me. I miss my garden, I had some lovely plants in there, 40 rose trees,
carnations, marrows; all sorts' (1st interview: OP4).

5.2.3.2   New beginnings and endings

When ill-health and impairments severely disrupted the equilibrium of daily
life, the older participants in this study were able to think about the
implications of these changes for themselves. Awareness of the transition
appeared to enable choices to be considered that may shape future lives. For
some, challenges to their independence and ability to maintain control of their
routine at home prompted them to consider whether the time had come to
move into a care home. For example, as Vera's health declined she
appeared to be in a state of liminality, where she was becoming increasingly
unable to influence the organisation of her daily life. Furthermore she had to
deal with the possible implications of her declining health for her future.
Vera's greatest fear was being admitted to a care home and she would return
to this topic of conversation frequently during this period of upheaval. For
example, during the fifth interview she recalled again how she had spent a
few weeks in a care home the previous year and she was adamant that she
would not return:

> *'I'll never go in that home no more (adamant tone of voice). I was sent in for*
> *5 weeks and oh the food was disgusting. I couldn't eat it and I think that's*
> *reason that I lost a lot of weight. I mean I was bonny on there (points to a*
> *photograph). I told them (family) at the time I can't stand it in here, I can't*
> *stand it. She (care home worker) says, 'are you going in the back room*
> *where they all sit and watch television'. I says no I've got one in my bedroom*
> *I'll watch it in there. I wouldn't go in there because they were crying and they*
> *were moaning. Oh I didn't like it, I'd never go in again' (5th interview: OP1).*

The new beginnings associated with moving into a care home as a
consequence of deteriorating health were seen as negative by Vera in this
instance. It would appear that the thought of moving challenged Vera's
current and customary way of life and that she was grappling with her sense
of self as an ageing person, particularly as a result of her failing body. In this
extract she referred to the fact that the older people in the care home were
'*crying and moaning*'. She distanced herself from this behaviour and felt that

being able to remain at home would enable her to maintain her autonomy, identity and dignity, even if it was a struggle.

Although Esther contemplated moving into a care home as her breathlessness increased it was not perceived in such negative terms. Early on in the study she acknowledged that without the support of the home carers she would be unable to manage at home and would have to go into a care home at some point, although at that time she was sure that the time was not right:

> *'I'm not ready yet. When the time comes I won't mind. I have been to respite to (home), and I dare say I'll go again because it was very nice, it was very good. I will go to (name of home) again when the time comes, but I'm not ready yet' (2nd interview: OP3).*

I asked her how she would know when she was ready to go into a home and she replied:

> *'That I couldn't walk at all, or that I was really helpless. Then I'd think well I do need looking after I can't cope, but at the moment I can cope with help' (2nd interview: OP3).*

Over a two month period Esther's breathlessness deteriorated, and she started to consider whether it was time for her to move to a care home, as she mentioned during the fourth interview:

> *'I've been seriously wondering about going in a home. I don't want to. Then I think no I wouldn't be any better in a home. But then I think well I will. Because they are always there the Doctors, nurses and things. And then I don't want to go in a home, that's how I am. But I think that time is getting nearer, nobody can do anything about my breathing now' (4th interview: OP3).*

Here Esther continued to express doubt and the final relinquishing of control was hard. She continued to have good days and bad days which contributed to the dilemma.

For some older participants the experience of bodily decline and deteriorating health led them to contemplate the end of their lives. Stephen, Amelia and Martha were able to talk openly about their death. Moreover, Stephen and

Amelia both expressed the desire for their lives to end. For example, over two months Amelia experienced a number of near death experiences, which she described during her third interview:

> 'I had me tablets and things. I went and had me nebuliser. I walked in to the kitchen, I usually count, something to take me mind off it, I can't remember if I got to 25 and 50. I couldn't breathe so I went back into there on the machine. I started panicking couldn't breathe and (name of care worker) came in and I must have been drifting in and out of consciousness, so it's a good job she came. Depending which way you look at it, it isn't my time to go, but I wish it was. I'm tired. I'm weary' (3rd interview: OP7).

In contrast, although Martha began to consider her own mortality she was not ready to die. She clearly described how she had first contemplated this during the penultimate interview:

> 'Having these problems, it does make me realise that I am on my way out. I'm getting older so you don't live forever do you? No you don't. I hope it's quick, the quicker the better. I never thought I was on my way out before the heart attack, no never, I knew I were getting old. If I ever thought about it I just hoped I wasn't. But having a heart attack it makes you think about these things. And folks will say oh you don't want to think that way, but you do, you can think that way without being morbid. You can that's my opinion' (5th interview: OP5).

However, in the final interview she alluded to a motivating force that was keeping her going:

> 'I've two more great grandchildren due and (name) is in April 1st because I said, oh fool what baby. Our (name) my youngest granddaughter and I think the world of her. I do of them all, but I have a little favourite. She's expecting around the 3rd May. I want to see that baby so that's what I want to live for, to see that baby' (6th interview: OP5).

Vera did not talk about the end of her life. However, she was able to consider how she would like to be cared for if she became very unwell. In contrast Esther was clear that she was not dying, she was just old:

> 'Because I know I'm not dying I know that, as I say it's old age, I'm 88 and a half, nearly 89, it's old age' (4th interview: OP3).

Yet she had made clear plans for her funeral. For the two older participants who I considered to be experiencing stable health no reference to the end of their life was made.

5.2.4   Support Networks

The majority of the older participants in this study had established networks of support which contributed to the maintenance of their personal routine in the context of deteriorating health and disability.

5.2.4.1   Formal provision

For many this involved carers coming into their homes, up to four times a day, to provide assistance with personal washing and dressing, meal preparation and domestic duties, such as cleaning and clothes washing. Although, for some the level of support focused upon specific activities, for example, Keith received one daily visit to prepare his evening meal. Similarly, Grace paid a personal carer to take her out to access local amenities.

From my observations and listening to older participants' accounts of the experience of receiving help and support from home care staff it was evident that these physical caring activities were important. They enabled the older participant to manage the effects of declining and fluctuating ill health and remain in their own home. On the whole satisfaction was expressed with the services provided and it was not uncommon to hear praise of the carers themselves. Undoubtedly the physical caring activities were essential; however I recognised that the relationship between the older participant and their carers, was as equally important in providing support. It was clear that over time emotional connections had been created through the process of physical care-giving. In the following extract, Christine's account of her favourite carer being unable to visit due to illness demonstrates the depth of the relationship that has developed between them over time:

> *'(Name) hasn't been able to come today. She's got that flu bug that's going round. I do hope she looks after herself. She's been working really hard recently. She walked here when we had that really bad snow so I didn't miss out' (3rd interview: OP9).*

Similarly, I frequently witnessed how Vera and her carers talked generally about what had been happening in any given week. Conversations were light hearted and jovial, and being listened to seemed to lift Vera's spirits, even during those periods where her health and wellbeing were declining. For Vera, this supportive relationship ended when a new care agency took over the provision of care. I noticed how conversations with the new carers were very much focused on the task in hand.

These examples appear to illustrate that through the act of physical caring a relationship can be developed which enables the older participant to express who they are and to preserve their identity as a person other than someone who is just sick. Therefore these care-giving opportunities are not just about physical support during deteriorating health; they may provide emotional support that can contribute to how an older participant can subsequently manage periods of transition.

The importance of these relationships was further revealed during situations where the community matron was concerned about care that was being delivered by the home care staff. For example, Vera's weight loss was of concern. However, on a number of occasions the carers had prepared white bread marmalade sandwiches for her lunch. When I asked Vera about this in a subsequent interview it was clear that she had a good rapport with this particular carer and was prepared to overlook these inappropriate meals, as she mentioned,

'She's a good girl, she will do anything for me' (4th interview: OP1).

Similarly, as part of Esther's care package she received one hour's cleaning per week. It became apparent that she was prepared to overlook situations where standards of cleanliness in her main living space had declined. During the third observation visit to Esther on entering her home she was sitting on the settee holding a blood-stained towel against her leg. She explained how she had caught it whilst getting off the commode. My field notes illustrate the community matron's concerns with the standard of hygiene:

> As the community matron moved the commode to the side she noticed that is was caked in dried faeces, under the commode seat and on the legs; it was obvious to her that it had been there for a while. Whilst the community matron was kneeling on

the floor she noticed that the floor was covered in dust and crumbs, and she asked Esther when the carers last did some cleaning Esther mentioned that she had not got a proper cleaner and that her neighbour sometimes does it. The community matron was concerned that it would attract mice; she then also noticed that the trolley was caked in dirt and had also not been cleaned. The community matron looks very concerned about the general level of cleanliness in Esther's house. When I looked at the trolley I noticed that the bottom tray was caked in dust and crumbs, as well as being stained and littered with crisp fragments. On the top tray water had spilt from a glass and there was a pot for her teeth which had dirty water in it.

The concern about the level of cleanliness prompted the community matron to contact the care agency to complain, with Esther's permission, although Esther commented: '*It isn't really dirty'.*

As with Vera it was clear that Esther had a good relationship with her carers. During the following interview I asked how she had felt when they had not cleaned her commode properly. She replied:

> *'I think they should have known. I'm not going to tell them their job. They should know their job. I'm not going to say, when they say, 'we're going to leave you now', I'm not going to say,' no you can't you've got to do the commode'. I'm not going to do that, they should know, but it's not really essential that. I'm quite satisfied with the care I get' (3rd interview: OP3).*

Although Esther had been unhappy with the level of cleanliness of the commode she rationalised it as not being essential, as overall she was satisfied with the care that she was receiving. Esther acknowledged that if the carers did not come to support her she would be unable to cook her own meals or manage the housework therefore she would have to go into a home. Clearly, there was a concern here that by raising the issue, or 'complaining', it could jeopardise her relationship with the carers and therefore her ability to manage and stay at home.

Although on the whole the care received was well evaluated as it enabled the older participant to maintain their daily routine, there were times when the delivery of the service disrupted these patterns. This was particularly the case when carers did not arrive at the time that they were meant to; for the older participant this did not fit in with the significant timings of their day. For example, I frequently observed how the carers would arrive late at Vera's, around ten o'clock, for her morning call. As a result she would be finishing her breakfast as carers arrived to make her lunch. Similarly, Keith often made himself a cold tea because the carer arrived late, which was a problem to him in view of his diabetes. For Grace, once home carers were introduced there was a conflict regarding her bed-time as the carers arrived at seven o'clock at night, whereas she liked to watch the news before she went to bed. In these situations the service was inconsistent and unreliable, causing anxiety and frustration. Furthermore, it did not always meet the requirements of the person when they were experiencing further disruption to their health.

At the start of the study period, three older participants did not receive home care services. Derek constantly refused support to cook him a meal at lunch time. He was satisfied with the support that was provided by his sons and daughters. Although the community matron often asked about this he was always determined that he could manage on his own. As Stephen's health continued to deteriorate, resulting in a hospital admission, he agreed to have a home care visit once a day to assist with personal washing and dressing, and preparing breakfast. Following her fall, which resulted in a fractured femur, Martha should have had home care on discharge from hospital but the referral was never made.

5.2.4.2   Informal support

The majority of the older participants in this study received combinations of help from families, friends and neighbours. Practical assistance was a key feature of the support that was offered, and this included: personal care, shopping and preparing meals, clothes washing, house work, medicine management and accompanying to hospital or other health related appointments. For example, Stephen's nephew and his wife visited three times a week to bring shopping, manage his laundry and clean his flat. He also relied on a number of friends and neighbours to run errands when

required. Likewise, Vera relied on her daughter and neighbour to support her in managing her daily routine at home. However, Esther had no living relatives in the country and therefore was reliant upon a neighbour to do her shopping and run errands. For example, during the fourth interview she recalled how the telephone had stopped working and her neighbour had bought a replacement.

The nature of the practical assistance provided by family and neighbours was influenced by a number of factors. Obviously, the provision of home care services shaped the nature of support. Christine, Vera, Eve and Amelia received comprehensive home care packages; therefore the practical help from family and neighbours focused less on personal care and more on domestic activities and food shopping. In contrast, following Martha's return home from the intermediate care unit she received no home care services and therefore her daughter, Janine, engaged in personal care tasks as well as other domestic duties. This involved moving in with her mother for two weeks and then sustaining daily visits for a subsequent six weeks. Over time, as Martha's condition improved Janine's daily visits reduced and by the end of the study she was visiting twice weekly. During the later visits she would carry out some light housework but the majority of the time they played scrabble and did jigsaws.

As with formal care provision the emotional connections, sustained through the relationships with family and neighbours, were also important in helping the older participant cope with their daily routines, especially in the context of fluctuating ill-health and disability. On the whole, accounts of the older participants revealed that they perceived their family and neighbour relationships, and subsequent support, as positive. Furthermore, there was a gratitude for the support that was given, even when it was hard for the older participant to accept it. It seemed that in order to prevent their situation from worsening and to remain at home, help had to be accepted. For Stephen, Martha and Derek help from family was preferable to formal home care provision.

However, the older participants in this study did not always accept the help from relatives, or would not always ask for help if their health deteriorated. During conversations with them it became apparent that most of them did not

want to be considered a burden. For example, Christine was reluctant to ask for her daughter's help when she was struggling to manage following her dental surgery. Martha became concerned about the amount of time that her daughter was spending with her following her episodes of ill-health and she began to indicate that she was becoming a burden to her family. She mentioned during the fifth interview that,

> *'I don't want to be a burden to anyone and I've been a burden all last year'*
> *(5th interview: OP5).*

Although she realised that her daughter would not really perceive her to be a burden it made her feel guilty that she was coming backwards and forwards to support her.

On occasion there were mixed feelings when the older participant thought that their relative should have been doing more. In these situations relationships appeared strained. For example, Keith was unhappy that his son did not come round as often as he should, although he did acknowledge that he worked away and his job was busy. He seemed to expect more, for example, he wanted to go and visit his wife's and daughter's graves. Also, Vera would often mention that she wished her daughter would visit more, or invite her to her house, whilst at the same time acknowledging that her daughter was good to her. In contrast, some older participants revealed that they thought their relatives did too much. Martha was grateful for the support that was given but thought that it was too much, as she stated:

> *'She does far too much for me. She's wearing herself out, so I'm worried about her. But, she did say once, 'Mum you shut up', you did exactly the same for me when the kids were young', which I did' (4th interview: OP5).*

Amelia described how her daughters worried too much about her when they had their own lives and families to deal with.

Although the majority of older participants were willing to accept support from family and neighbours it was important for them to show that they were able and keen to give something back. I observed examples of such reciprocal relationships. Stephen always offered callers a cup of tea and as they left would ask them to take sweets from the jar in the kitchen. Similarly, Vera

would always ask the community matron and myself if we would like a cake with our hot drink.

5.3 Chapter Summary

This chapter has reported the types and patterns of transition that the older participants in my study experienced in relation to their health and illness. It has revealed how the nature and process of such transitions is diverse and unique to individual circumstances at any given time. Furthermore, older people have to work hard to engage with the disruption that such transition brings in order to maintain daily routines. Such work also enables older people to maintain independence and continuity of personhood. However the chapter also reveals how transitions in health and illness lead to heightened vulnerability where difficulties in managing daily lives are experienced. The importance of both informal and formal networks in supporting the older person to manage their daily lives is revealed. The next chapter reports findings that relate to the experience of frailty in the context of ill-health.

Chapter 6: Study Findings - Dimensions of frailty

The previous chapter presented findings that explored how the older participants experienced transitions in health and illness. This chapter reports findings that relate to perceptions and experiences of frailty in later life, in the context of fluctuating ill-health. Although the accounts of the older participants highlight comparable characteristics of frailty, they reveal individual differences in the way that frailty is understood and experienced. They also illustrate the complexities that older people face whilst trying to retain the capacity to manage their daily lives.

Four themes arose from the analysis of the data which illuminate how frailty in later life is represented. *Frailty as decline* examines the extent to which changes to physical and mental capacity contribute to the experience of frailty. *Frailty as confinement* details a social dimension to frailty, where older people become increasingly housebound and socially isolated. F*railty as vulnerability* explores how older people struggle to live with the uncertainty of fluctuating ill-health. Accounts of feeling frail illustrate how episodes of uncertainty challenge identity, as well as providing insights into how sense is made of such uncertainty. Finally, *frailty as a label* examines professional and lay constructs of frailty. Furthermore, it reveals the mismatch between lay and professional accounts of frailty which in many instances leads to rejection of the label by the older person.

6.1 Frailty as decline

All of the older participants experienced physical decline as a result of deteriorating ill-health and the general process of ageing, resulting in impairment and incapacity. Two of the participants, Vera and Keith, also suffered episodes of low mood alongside their physical disability. However, although the older participants were able to describe the multiple limitations to their health and wellbeing the majority of them did not consider themselves to be frail. Where the notion of being frail was rejected it became clear that ill-health or altered physical ability alone did not constitute frailty. In the context of fluctuating ill-health and impairment maintaining a level of independence in the management of daily routines was seen to act as a counterpoint to being frail. A focus on functional health, linked to the ability to autonomously enact daily routines and tasks, was a dominant theme in the accounts of the older

participants. I also observed situations where attempts were made to engage in daily living activities even when it was difficult. Furthermore, a resilience was demonstrated which appeared to motivate the older person to keep going in spite of the challenges brought on by physical decline. For example, Esther did not consider herself to be frail as she was able to get about downstairs with the aid of her mobility walker and could if required manage her daily activities unaided by others, as she described in her first interview:

> *'Well I don't consider myself to be frail, because I am able to, if I knew no-one was coming for dinner today I've got some microwave meals. I'm quite easily able to pop one in the microwave and it's ready in a few minutes. I'm able with the aid of this (mobility frame), I couldn't walk without that, I'm able to get in the kitchen. I'm not able to get in the bathroom it (frame) won't go in so I have to have a commode. I consider myself lucky really. You have to keep trying. All old people I know will try' (1st interview: OP3).*

Similarly, Eve did not consider herself to be frail because she was still able to cope with her daily routine, as she described:

> *'I can cope with most things. I can handle the washing machine. I can make myself a cup of tea. I can make myself anything in that way. Just sometimes it's work that annoys me that I can't just put the cleaner on. I could I suppose if a pushed myself' (1st interview: OP10).*

I think by presenting themselves in this way there was an attempt to portray a self as independent in the context of ill-health and ageing, one that was able to use initiative and be self-reliant in spite of limitations. Moreover, there was a sense of maintaining a continuity of self and therefore identifying themselves as a frail person did not fit with their opinion of themselves.

In contrast, two older people did consider themselves to be frail and for both of them this was linked to their physical ill-health and ensuing disability. Here I considered that there had been a degree of accommodation of the changes brought on by physical impairment and that these physical changes were interpreted as representing frailty. Vera thought of herself as frail because of her physical ill-health, including her recent weight loss, swollen feet and falls. There were also issues with her energy levels as she recalled how she became easily tired, especially when she went to her daughters for Sunday lunch:

'I had a right job last week getting into my daughter's house. Both of them, me son-in-law and me daughter, and he got hold of one arm. He said, 'We ought to have brought the wheelchair, we will do next time', and he says, 'We'll bring the commode down next time, save you going up them stairs'. Cos he says, 'It knocks you out' and I says, 'It does love'. I get knocked out easily and that's why I bought that other chair. I like it to go right to the top; it goes right to the top. It's a lot better for me. I turn it round then, get hold of me frame and they get at the back of me, carers, to make sure that I don't fall' (2nd interview: OP1).

Likewise, Stephen considered himself to be frail because of his numerous health problems, as he described:

'I think of myself as frail. I do with my legs and my eyesight. Of course if I have a shave I can't see properly where my side burns are. And there's my arthritis' (1st interview: OP9).

In describing some of his health problems Stephen's reference to his image suggested that his inability to shave himself adequately presented a frail person to the external world.

Most of the older participants had to come to terms with the fact that their bodies would not always enable them to engage in taken for granted activities. Nevertheless, changes to the body provoked concern in relation to daily living. Where there was a loss of or challenge to an older participant's autonomy, managing established routines and personal care became difficult. In these situations the concern with the functioning of the body led to some older participants to express that they felt frail. Here feeling frail was directly linked to changes in the body that provoked self-doubt concerning daily living. In the case of Amelia she was finding it increasingly difficult to walk into the kitchen to make a cup of tea, finding that it was not only her breathlessness that affected her but she was losing the bodily strength to pick up the kettle. She described this during the third interview:

'It's getting harder to walk into the kitchen to make a cup of tea. I get really breathless and kind of wobbly when I am walking sometimes. Last week I wasn't able to pick up the kettle when I wanted. I felt like throwing the kettle through the window. I felt like that. Then I think, 'You should get a smaller kettle', so I bought one' (3rd interview: OP7).

Here the feeling of frailty was temporary. She was able to re-evaluate her ill-health, and her inability to manage what she considered to be a basic task, and persevered in finding a solution.

Likewise, as Christine lost weight, following major dental surgery, she began to notice how her body was less able to cope with her daily activities, such as pushing her mobility trolley through to the kitchen to get the sandwiches her carers had prepared for tea time. She described how she felt during the fourth interview:

> *'It's terrible at the moment. Because any exertion and my heart pounds and I feel tired. I want to sit down. I feel so weak, it's either weak or frail, whatever you like to call it. Normally I would be up and about and forget about it, any aches and pains, but I can't at the moment. But knowing that you are on your own you have to get on and do what you want to do. But it's difficult at the moment; it doesn't take much to overdo it. I'm hoping it doesn't bring on a bad attack' (4th interview: OP8).*

Although older people described how bodily changes affected their ability to control their routine, on the whole these difficulties were overcome or worked round. Therefore, control was maintained and the feeling of frailty was temporary. In contrast I observed how Grace found it increasingly difficult to accommodate the changes to her body following a series of falls and further functional decline. Over a few weeks I noticed how the changes to her body greatly challenged her autonomy in daily living and I began to think she was becoming frail. For example, following her return home from a three week stay in an intermediate care unit Grace described how she had been unable to get up from the toilet:

> *G: I've had a high seat toilet put in today; I couldn't get off the toilet yesterday when I came home. And I thought, 'Oh lord'. Anyway I sat and sat. I'd been sat there an hour and I couldn't get off and I thought, Oh don't panic someone will come this afternoon'.*
>
> *JS: And you were sat on the toilet for 1 hour?*
>
> *G: Yes.*
>
> *JS: Oh Grace.*
>
> *G: That's what I thought, but I just couldn't move you see to get out of the way. I tried and tried but then gave it up as a bad job.*

JS: So how did you get off?

G: Well I'm just trying to think. I know my daughter in law came and sent for somebody. But I thought to myself, 'Well somebody's sure to come', but they never do when you want them to. I'm finding it rather hard at the moment, adjusting' (1st interview: OP4).

Over the following month I observed how Grace's mounting level of disability became increasingly problematic and she found it difficult to recreate a structure to her day in order to establish a sense of control. New problems emerged daily, for example, on the morning of the third observation she had been unable to get out of bed. This seemed to be one of the final issues that indicated to her that she was finding it increasing difficult to exert control over her daily living. At this point I think that Grace was starting to consider whether she was becoming frail. She began to talk about how the changes to her body were making her feel:

> 'I don't like this falling asleep business. I am not used to it. But like I say you get some older people and they seem to go right frail, but sometimes it's a bit put on. But that bothered me this morning when I can't get myself up. On the back of my neck, all across me shoulders, all across me shoulder blades. It's all stiffened up'. (4th Observation: OP4)

For the first time she drew upon characteristics linked to frailty to compare with her own situation. Here Grace's bodily changes were challenging her sense of self as an autonomous individual; yet, she did not want to acknowledge that she might be becoming frail. She continued to protect herself from the idea of becoming frail by drawing on her personal characteristics that from her perspective did not link to frailty, as she stated: '*I know I have a lot on my plate at the moment, but I'm determined'.* Grace never articulated that she felt frail and I wondered if she recognised that his situation was becoming permanent, posing a huge threat to her continuity of personhood.

6.2   Frailty as confinement

Most of the older participants were unable to independently leave their homes as a result of physical impairment and poor mobility. Here the loss of agency of the body generally confined them to a space that they could manage on a daily basis. Consequently, two of the older participants had

chosen to remain permanently in their homes. For example, Stephen lived on the top floor of a block of flats and had made the decision that he would no longer go outside as negotiating the lifts was complex. Likewise, Esther had concluded that the effort required to leave her home far outweighed the benefits of attending the luncheon club that had been suggested by the community matron. Others were able to leave their homes but only when they were provided with transport and assistance. For example, Derek and Eve attended luncheon clubs in their local area. Eve, Christine and Vera were taken out by family members for shopping trips and celebratory events, such as birthday meals. Derek, Keith and Martha were the only participants who were able to go outside their homes alone. Derek walked to the corner shop every morning to buy a newspaper. Keith was able to drive to the local shops on a regular basis, as well as attending a fortnightly Rotary club meeting, although towards the end of the study period he was no longer able to manage this. By the end of the study period Martha was able to walk into her garden herself to hang washing out.

6.2.1 Attachment to home

On further scrutiny I considered that being confined to the home did not necessarily equate to the experience of being frail. From my observations it was clear that the home was important in sustaining and creating a positive sense of self and identity. All the older participants demonstrated an attachment to their homes, in that they wanted to stay at home. Here attachment to place appeared to be important as it enabled the older participants to express their independence and on-going capability. However the desire to stay at home was evident even when situations occurred that challenged independence, which at times contributed to the older participants feeling unsafe. For example, Vera fell during the night after getting up to use the commode and lay on the floor for 8 hours before the carers arrived to get her up but she did not want to move to a care home. Similarly, in spite of worsening breathlessness and difficulties in coping with daily living Esther also continued to refuse to go into a care home. Therefore attachment to home was more than demonstrating independence and it became clear that personal meanings were connected to the home.

6.2.2 A life lived

Most of the older participants had lived in their homes for a lengthy period; for eight they were still living in their marital home where many had brought up families. Therefore, attachment to home was connected with personal meanings related to a life lived, as well as family and social ties. All of the participants talked about their lives in the context of their home. Keith and Derek, both widowed, frequently referred to the care that they had given their wives at home, during the last years of their lives. Christine, Vera and Eve often mentioned their experiences of bringing up their children in the home. I also observed how, in spite of external aids and appliances and changes to downstairs living space, most of the older participants were still surrounded by objects and materials of their choice. These items appeared to be important in maintaining and contributing to an on-going identity. For example, Eve had been a keen crafts woman all her life. She could still knit although she could no longer manage the fine detail of embroidery. Around her living room she had a large number of screens that she had made over the years, which she was proud of. Similarly, Grace had been a keen gardener. Although she could no longer tend to the garden she had placed plants on all the window ledges so that she could grow flowers and herbs inside.

Photographs in particular were another way that identity, a life lived, was maintained and these were often used as talking points by the older participant. I noted how in moments of difficulty photographs were used to put forward an alternative to the current experience. For example, when Vera was losing a lot of weight she showed me a photograph of herself in her forties where she had been bigger, as she put it '*bonny'.* Likewise, when Esther was experiencing problems with the carers she showed me a photograph of herself when she was married and working in her husband's pub. Here aspects of life from the past were kept alive enabling a sense of continuity as well as fostering a positive self-image.

6.2.3 Social isolation

Confinement to the home made it difficult for the older participants to maintain their social connections. This was a source of frustration to many older participants as they could no longer visit family and friends when they

wanted to. Not being able to go out also limited daily social contact and the ability to engage in small talk. For example, Vera recalled how she used to sit on the doorstep and '*watch the world go by, chatting to people as they passed'.* She often referred to the fact that now she just sat in the same position every day, illustrated from an extract from the first interview:

> *'It's very rare that I get out of this chair, even to open the door, in fact I leave it open for (neighbour). She's a good friend'. (1st interview: OP1)*

Martha and Esther could no longer chat to their neighbours on a regular basis and they both missed the opportunity for sharing day to day experiences. Esther joked one day that they were probably both sitting in the living rooms alone with the television on and that perhaps they should knock the dividing wall down.

Here a social dimension to frailty was revealed demonstrating that not being able to engage in external social activities, because of confinement to the home, could contribute to being frail. On closer examination I considered that it was not just about being able to go out, but the lack of meaningful social contact that could contribute to being frail. In support of this although Stephen no longer went out, a combination of friends, neighbours and family visited every day and this appeared to provide him with the significant interaction and support that he needed. In this sense he did not appear to be frail. In contrast Vera often talked about being lonely and during some of the community matron's visits and interviews would cry. Here the decrease in social contact seemed to be a source of great loss to Vera and contributed to her frailty. I observed how she appeared to be in her element when there were a lot of visitors and activity within the home. For example, on a number of occasions when I arrived at Vera's house there would be a number of people present, such as, the care workers, hairdresser, neighbour and community matron. I interpreted these situations to be chaotic, with a whirlwind of activity happening over a short period of time. The following extract from my field notes during the second observation visit illustrates this:

> When I entered the house after knocking Vera was in the kitchen with the community matron and the hairdresser. Vera was having rollers put in her hair. The community matron was making a cup of tea and getting biscuits. There was a general chit chat and banter going on

between the three of them. Vera and the community matron were joking about the community matron's figure and biscuits. The hairdresser then put on the portable dryer, which is very noisy, and goes into the living room. The carers arrive – Vera's house becomes a whirlwind of activity. What strikes me is that Vera is in the middle of all this with no real control of the situation – she has the drier on and cannot hear what is going on. The community matron and carers have a discussion about the change to Vera's medications. The carers then talk to Vera and they all have a joke at how strange she looks with the portable drier on – Vera joins in this – she has a good sense of humour (4th field note: OP1).

I considered that although Vera was at the centre of the activity she seemed out of control of the situation. However, Vera did not experience these situations in the same way and she enjoyed the frenetic level of activity, as she stated:

> 'I like the company; it's great to have a laugh and a joke with people'. (4th interview: OP1)

This was different to the days where she saw few people and on these occasions she was glad when the carers came to put her to bed at night.

6.2.4 'Feeling' isolated – 'a hole in the programme'

Changes to valued support networks highlighted the important role that these played in maintaining health and wellbeing, when confined to the home permanently or for long periods. In some situations concern about these changes led some older participants to express that they felt frail. For example, Keith mentioned feeling frail following the recent death of a close friend who had visited on a weekly basis. The loss he experienced appeared to reinforce his social isolation. As he stated during the third interview when I asked him why he felt frail that particular day:

> 'Because I'm stuck here. There's too much time to think, too much is going through your head. I used to have a friend who used to come regularly, he was really good. His wife knew my wife since she was a child. Well he died two weeks ago and that's knocked me back because I could sit and talk to him, have a laugh. Remember things as they used to be. It's made a hole in

the programme now, because there's nobody. I have a sister in (place) who is 86. I talk to her on the phone but I can't meet face to face. I did drive over once last summer but it's too much now, I don't like the driving. And it's even worse with all the roads having been diverted, with the road works because of the road collapse. She's on her own as well, her husband died. I talk to her three times a week. She's older than me. We didn't always get on as kids but we do now' (3rd interview: OP2).

The loss of his friend not only challenged the continuation of social relationships but also brought to the surface the multiple losses Keith had experienced. His wife had died three years ago, followed a year later by the death of his daughter at a young age from cancer. He now had no contact with his granddaughter who had ceased visiting after the death of her mother. Over a month Keith's mood deteriorated further and it began to affect how he managed his daily routine, prompting a referral by the community matron to the community mental health team for support.

The importance of maintaining valued relationships was also experienced by Eve. Her anxiety was heightened when her daughter broke her ankle and was unable to maintain her weekly visit which Eve relied on for both practical and emotional support, as she mentioned during the fourth interview:

'There are odd days when I feel a bit down. Mostly I get by, I don't worry, although (daughter) has not been too well this week. She fell and broke her ankle. And she's still trying to get over that problem with her teeth. One thing that worries me is that (daughter) won't be able to continue with doing it. She's nearly 70 herself so I don't know what will happen then. I shall have to get someone in to clean eventually; (daughter) does it at the moment. I'm not going to give way, I know I feel sorry for myself but I shouldn't. I used to have some lovely neighbours but they have all gone one at a time. And now I am surrounded by students. I worry more as I get older. I'm glad you've come. I cry sometimes when I go to bed and cry myself to sleep. We were together for 70 years. I don't cry, my family don't want me to. We've all got to get old. You don't expect young ones to know. I'm quite content, I've had a good life. It's just that I miss my husband' (4th interview: OP10).

Eve's account reveals that it was not only the reduced support from her daughter that was causing her anxiety. Thinking about it raised awareness of the loss of her husband, clearly an important relationship for her.

A decrease in contact with existing friends also contributed to the experience of social isolation and some of the older participants articulated that they missed the camaraderie of their friends. Many commented that their friendship groups were decreasing either through death or because their friends had also become ill and were unable to leave their homes. For example, until a year ago Esther had been visited regularly by a couple that she and her husband had gone dancing with. However, following the death of her friend's husband she was no longer visited by her friend as she could not drive. In some instances contact with peer groups was maintained by attending events such as luncheon clubs; however, for many this did not replace the companionship of friends and some became reluctant to attend.

On closer analysis the lack of social contact did not bother everyone to the same extent. I considered that this appeared to depend on the individual's character and personal circumstances. For example, Esther appeared to be relatively self-sufficient and did not appear to require a lot of company and on the whole she seemed content to be on her own. At a young age she had worked in the steel industry during the war. Also, she had not married until she was in her forties and I got the impression that she had always been fiercely independent. In contrast, Vera appeared to need many people around. It may have been linked to the fact that she had always been protected; she recalled one day that she had rheumatic fever as a child and that for four years her father had carried her everywhere. She married at a young age and she indicated that her husband had looked after her well.

6.3 Frailty as vulnerability

There were episodes where many of the older participants stated that they felt frail. Although circumstances where the older participants expressed feeling frail were unique to each individual a feature of these situations was that they provoked anxiety and fear. Moreover, the emotional expression of feeling frail appeared to signal a threat to their sense of self, which appeared to lead to feelings of heightened vulnerability. For some older people episodes of feeling frail were accommodated and therefore became a temporary feature of their experience. For others the situations became more permanent and in these circumstances I considered that an older person could be becoming frail.

For a number of people feeling frail referred to the way that managing daily living activities sometimes became precarious. Where bodily changes made it difficult to negotiate taken for granted activities these were perceived as risky, which led to feelings of anxiety and fear. For example, following Martha's fall, resulting in a broken leg, she became frightened of falling again and sustaining further injury. Two months following her return home from hospital she mentioned:

> *'I do feel frail sometimes. There have been times when I have been walking with my stick and I've felt as though I'm going to trip you know. I'm frightened of tripping. I don't want to go somewhere like that again. Because I'll end up having Morphia again and having the hysterics. A nightmare it was. Yes, I'm frightened of falling again. I've always been a dare devil even as a child. It has bigger consequences; well I found out that myself' (3rd interview: OP5).*

In spite of feeling frail it did not stop Martha taking risks with her mobility during her recovery. As she recovered I observed how she appeared to feel less frail and began to take risks with her daily activities. During the fourth interview she recalled how she was waiting for the better weather so that she could go up and down the garden alone. Although she was walking to the black bin she was reluctant to go any further because the paving stones were uneven. Martha was taking greater risks at the end of the study period which included climbing a step-ladder to get rid of the streaks on the windows after her daughter had cleaned them. Her attitude to risk taking appeared to change as she regained control of her body.

Where it had appeared to be her responsibility for falling she now linked the possibility of falling to chance, as an accident, as she stated in the final interview:

> *'I don't feel frail now. I just know it is possible to slip up accidentally. So, I just have to watch it. Mind you there's no point in watching it; if it's going to happen it's going to happen' (6th interview: OP5).*

Here she had accommodated a change to her mobility and integrated it into her identity to maintain continuity of personhood. Similarly, Vera experienced a number of falls and this contributed to a level of uncertainty as to whether she could manage at home. She was becoming increasingly worried as to

whether she could stand up to use the commode in the day, which was placed at the side of her chair. At this point in the trajectory of her condition she articulated that she felt frail, and she linked this to being frightened about the future. However, for Vera feeling frail also became a temporary experience. Towards the end of the study, following an inpatient stay in hospital, I observed how she had more energy and with support she was able to do a lot more for herself. This also appeared to lift her mood. She mentioned during the final interview:

> 'I don't feel frail anymore; I can do a lot more. I was able to make myself a cup of tea this morning and I had a bath yesterday. The carers helped me in with the bath chair but I was able to wash myself. And I was singing, and they said, 'Who's that singing?' I said, 'It's me, haven't you heard me sing before?' And they said, 'No'. I sing those modern songs; I can't remember the old ones. Although I should because my father used to say, 'She's at it again. Vera's at it again, she'll wake all the neighbours up' (6th interview: OP1).

During challenging situations not all the older participants articulated that they felt frail, however they recounted experiences where they expressed fear and anxiety regarding their situation. Where there was an awareness of a change in bodily health and the risks the change imposed, some older participants gave the impression of being vulnerable as their continuity of self was threatened. For example, Christine experienced an episode of severe chest pain during the night, which came out of the blue to her and had not been linked to overdoing activities during the day. She described this during the third interview:

> 'I had a really bad angina attack last week. It woke me up in the night; the pain woke me up in the night. I thought, 'What's wrong with me at this time in the morning?' I was really scared. Mind you I have to get up to go to the loo, a couple of times, so I eventually realised what it was. I was groping for my puffer on the bedside cabinet. I couldn't find the button to press and then I couldn't get it to work. Anyway I finally managed to use my spray and then I just lay still, had another spray until it eventually went off. When they are bad they are pretty frightening. I knew if I was quiet it would go but this one lasted 20 minutes. I think I panicked because I didn't know what was happening. And I'm worried now what it means; I shouldn't be getting pain when I

haven't done anything out of the ordinary in the day. I'm a bit scared to move at the moment' (3rd interview: OP10).

On return home from the intermediate care unit Grace was worried how she was going to physically manoeuvre around her home without falling. During a conversation with the community matron she kept referring to the personal alarm that she was now wearing around her neck. The pace of change, in relation to her deteriorating health and movement across care boundaries, had been rapid which appeared to contribute to her vulnerability. This extract illustrates how her return home from the intermediate care unit had been rushed:

> *'I came home earlier than they thought I was coming, yesterday, because what happened. They came early before one o'clock, before I'd had me dinner and then somebody said to me, 'Grace you've got a couple of visitors'. I says,' Oh that'll be nice'. When I looked it was two ambulance men, what they called, with cars and I said, 'Oh'. And of course it was all rush, rush, rush. Same when I was coming home. I keep thinking. Oh well I've got my alarm now'. (2nd observation: OP4)*

The precariousness of her current situation is reflected in her reference to the personal alarm around her neck. Furthermore, the reference to personal safety demonstrated her vulnerability, particularly in relation to her feeling of security. It seemed that Grace had to balance on the one hand her desire to be at home, with the possible realisation that she did not have the ability to be in control of daily living, which made her feel unsafe.

In both these situations I considered that the older participant's sense of self was being threatened and compromised. For Grace, this was linked to her ability to negotiate and manage her home. For Christine, it was related to her ability to control worsening of her symptoms.

6.3.1 Positive approach

Expressing a positive outlook to life was apparent in the older participant's accounts and appeared to act as a counterpoint to situations where they experienced feeling vulnerable. In describing how he was still finding it difficult to manage his leg cramps, Derek mentioned the importance of *'keeping in good spirits'.* Martha tried not to dwell on the impairment to her

ability after her fall, by making light of her situation in relation to others, as she mentioned:

> 'Worse things happen at sea as they say. I'm keeping my feet on terra firma' (5th interview: OP5).

Pushing negative thoughts to the background was also a strategy that enabled older people to maintain a positive outlook. When Amelia experienced worsening symptoms she mentioned how:

> 'I just push thoughts of not being able to cope to the back of my mind' (3rd interview: OP7).

Similarly, Esther and Christine on the whole tried not to think about the periodic difficulties that they faced. I also observed how many of the older people used humour and this appeared to contribute to the maintenance of a positive outlook in demanding situations by making light of a situation. Christine would frequently make humorous comments regarding her situation when it was difficult or when she was experiencing a challenging moment. For example, when she struggled to stand up so that the community matron could put cream on her sacral pressure sore she commented, '*Not a pretty sight I should think'.* Stephen often used humour to lighten the atmosphere when his current problems were troublesome. For example, during the third visit it became apparent that he had recently fallen. Alongside this his urinary catheter required changing and he was developing a chest infection. He mentioned that everything always happened at once and that he did not like to be a burden to which the community matron replied he was not. When the community matron asked when he had last completed a course of antibiotics the following conversation ensued:

> CM: When did you finish your last antibiotics?
>
> S: Yesterday (starts to sing the Beatles song).
>
> CM: Oh yesterday (laughs). All my troubles seemed so far away.
>
> S: (still singing) Now it looks like she's in the family way. I haven't lost my sense of humour. (We all laugh) (4th interview: OP9).

Here humour was used to deflect from the current situation as well as indicating a previous life where he did not experience such problems.

Humour was also used to reassert a positive sense of self. Following a fall and an in-patient stay at an intermediate care unit, Grace was visited by a social worker. During this encounter I observed how Grace was often spoken over as if she was not in the room. When the social worker left she asked, '*Am I still here?',* as the community matron counted her pulse.

It became apparent that it was not always possible for the older participants to adopt a positive outlook to their current situation, especially where there was deterioration in their condition. Vera started to become very tearful during the observations and interviews towards the end of the study as she was becoming increasingly overwhelmed and distressed by the changes to her health and the ensuing loneliness. She often mentioned that she did not know what was wrong with her, '*I don't know why I am like this'.* At one point Esther's conversation started to be dominated by her anger and frustration at her increasing breathlessness as it indicated to her that her condition was getting worse. She was beginning to feel fed up and she did not know how to improve her situation. Grace's use of language also revealed how she was becoming agitated and troubled by the deterioration in her health during later visits. I noticed that she constantly repeated the phrases, '*when I adjust'* or '*when I adjust I will be alright'.* This behaviour demonstrated to me the level of uncertainty that she was experiencing as she was confronted with the reality of her declining independence, thus her ability to manage her daily routine.

6.3.2 Maintaining confidence

Where older participant's experienced episodes of feeling frail the ability to maintain confidence in their own capability was important. It appeared to enable them to manage periods of uncertainty and take control of the situation. Although, Martha, Eve and Christine experienced episodes of vulnerability they never lost confidence in their ability to manage the periods of uncertainty. This seemed to be because the challenges were relatively short lived. In contrast, where changes to health and wellbeing took on a more permanent feature a loss of confidence ensued. For Esther this related to her inability to control her breathlessness. As she became worse she lost her confidence in her ability to manage these episodes alone. At times in conversations she debated with herself revealing the tension she

experienced in trying to maintain her confidence to manage her breathlessness:

> 'My breathing was really bad yesterday, I couldn't get my breath and it made me panic. But what do I expect; I'm not ill it's just my breathing. I just need to take my time more, I know it will pass. Just take my inhaler' (4th observation: OP3).

Similarly, Grace lost her confidence and this was heightened as she recognised that what had appeared to be a temporary situation was becoming a permanent feature of her life and the loss of confidence in her physical functioning compounded her ability to organise her daily life. I got a sense that her diminishing confidence was linked to the fact that she was becoming detached from her living space, daily routine and social world. The uncertainty that was experienced as a result of her bodily changes intensified her disconnectedness from self, the home and her broader community. I noted how the loss of power to influence her daily life was articulated in vague terms. For example, she persistently mentioned that she was '*being off*' and when asked what she meant by this she replied, '*I know I'm not doing what I should do*.' Although she found it difficult to articulate what was happening she was able to clearly link it to her lack of confidence:

> '*I have lost a lot of confidence, for one thing, you can see that I don't move very often, and then different things….I've been wanting to go out there for some weeks now (points to the window). Ever since I've came from (name of care home). And like they were saying, ok I needn't go to bed when the carers come at 7pm, but then I'm worrying, when am I going to get in bed? I will struggle, I've got two bad arms which are hurting every day, a bad behind' (1st interview: OP4).*

Keith was able to continue and to some extent to manage his daily routines; however he seemed to have lost the motivation to do so. This enhanced his loss of confidence. Within a period of two months the community physiotherapist had been concerned that Keith's mobility was deteriorating, with the subsequent impact on his ability to manage at home. Consequently, following two falls Keith was admitted to hospital, followed by a referral to an intermediate care unit. On return home he was awaiting to hear the outcome

of the referral to the community mental health team. He sounded in a low mood in his final interview as he recalled:

> *'I've got really low. Nothing was happening, right up until last Friday I did not know what was happening and I was getting really down. They couldn't tell me whether I was going to (mental health clinic). I am getting really worried about myself because I am not eating, I have got to have something, I have no appetite. The carer could tell that I wasn't myself and she brought something into the bedroom. I stay in bed unless I eat, I'm too tired. Since before Christmas it's been a toll. I've lost my confidence. I've gone downhill, I know that. I've been trying to pull myself round but I've no interest' (6th interview: OP2).*

6.4 Frailty as a label

6.4.1 Older participant's perceptions

When asked to describe frailty one of the central themes emerging from the older participant's accounts was a physical dimension. This physical dimension incorporated physical appearance, physical decline and physical ill-health. For example, in detailing the characteristics of a frail person Stephen mentioned:

> *'Well I should think they'd be a bit unsteady on their legs and look a bit pale. Old in the face I should think' (1st interview: OP9).*

Similarly, Martha, Derek and Keith all linked frailty to problems with mobility in relation to not being able to get about, specifically mentioning the use of aids and appliances to assist with mobility as markers of frailty. Both Esther and Christine associated a decline in senses, such as hearing and sight, with frailty. Grace made direct reference to falls and ill-health when recalling older people who she had considered to be frail in the intermediate care unit:

> *'Well I've seen one or two that's frail. They were sending us home like (from the unit) and getting new carers in and out. Of the four that were going home, those two both finished back in. They had falls; made a right mess of themselves, broken arms and allsorts' (1st interview: OP4).*

Likewise, Eve referred to the older women that she met at her weekly visit to the blind club as being '*wobbly on their legs and poor at walking'.* Implicit

within these descriptions was a connection between the degree of physical decline and ill-health and the functional ability to manage daily routine.

Further analysis revealed that these older participants did not regard physical decline and ill-health as the only indicator of frailty. To a lesser extent links were made to a cognitive dimension where being able to cope with daily activities was important. In this dimension not being able to make decisions because of a lack of mental capacity was perceived as contributing to frailty. A number of older participants referred to a frail older person as '*losing their marbles*' and '*not having all their faculties*'.

6.4.2 Community Matrons' perceptions

The community matrons were asked to identify older people on their caseload who they considered to be frail. Although their descriptions of frailty incorporated a physical dimension this was not the only characteristic of frailty that they attributed to the older participants. In contrast to the older participant's accounts the community matron's representations were more holistic, incorporating a range of dimensions. Alongside physical ill-health and functional limitations a psychological and social dimension was also assigned. For example, during the first interview the community matron described Esther as frail for the following reasons:

> '*She was very vulnerable; I thought she was very anxious. I attributed her alcohol and inhaler use to her anxiety, a lot of call outs for breathlessness, which I again attributed to anxiety. So I thought, she's dependent on the oxygen, without the oxygen she wouldn't be alive. Also, her needs and her dependency, she had two carers a day, this then increased to three, and in effect she could really do with four now, it's only because of the vacuum flask in the afternoon she manages with the drink. There's going to come a point where she won't even be able to go and get her tea from the fridge possibly, it's going to be a struggle for her. Her dependency on carers. And I just thought with the oxygen and everything, and the carers in place, she's quite well in some ways for her age but without the oxygen and carers in place, she's very frail' (1st interview: CM2).*

This extract illustrates how Esther's physical ill-health and limited functional ability, combined with her dependency on external support and anxiety about her situation all contributed to the community matron's perception of her as

frail. Similarly, a combination of physical and social dimensions contributed to Martha being described as frail during the first interview with the CM:

> *'The fact that she has had the cardiac episodes. She is also vulnerable because she lives on her own. I know her daughter visits regularly but they don't even live nearby and that's what worries me with Martha, is the fact that her daughter doesn't live on the doorstep. I know she's in the same city but it still seems a distance to me, you know she's not that near. I think it's her vulnerability too, she's a little bit unsteady at times' (1st interview: CM3).*

On closer examination there were occasions where age and physical appearance were used as markers to indicate frailty. Here I considered that the community matrons' first impressions guided their opinions on what constituted frailty and led to a label being applied. For example, Vera was initially described by the community matron as 'a *little, wrinkly old lady'.* Likewise, frailty was linked to Martha and Grace's age and the fact that they were both thin. However, these initial labels were generally supported by reference to other dimensions of frailty and not used in isolation. In the case of Vera, the community matron commented upon her lack of independence and emotional instability, as she described during the first interview:

> *'I also thought she was frail because she was still getting very upset, even on the first meeting she was tearful about the loss of her husband, she was a very sad little lady' (1st interview: CM1).*

Similarly, although reference was made to Grace's age and appearance in the first instance the community matron expanded her description of why she considered Grace to be frail to include functional and social dimensions:

> *'She'd had falls as well and she obviously needed walking aids. The fact that she lived on her own. She'd got some family support, she weren't having any care company, but the family were paying a carer that was visiting Grace a couple of times a week. That was doing other things like taking her shopping and things like that, not just getting her meals because at that time she was able to get her own meals most of the time. I was also a bit concerned about the stairs up to the flat' (1st interview: CM3).*

A central theme within the community matrons' accounts was a link between frailty and vulnerability, and this was linked to the older participant's specific circumstances and experience of ill-health. In many instances vulnerability

appeared to be linked to being in a precarious position, where the older participants were perceived to be at risk from harm. Furthermore, these situations were often linked to a combination of decreasing functional ability and ill-health. For example, Christine, Vera, Martha and Esther were considered to be vulnerable because they were at risk of falls as a result of poor mobility and unsteadiness on their feet. This risk was often compounded when it was perceived by the community matrons that the older participant was engaging in activities that potentially put them more at risk, such as drinking alcohol. Stephen was considered vulnerable because of his poor eye-sight which meant it was difficult for him to manage his medications. I observed during the final visit with the community matron how he had started taking the medications from his Nomad system on the wrong day and this had concerned the community matron as she mentioned during her final interview:

> '*I was worried about Stephen on that last visit. He had just come out of hospital. He had started taking his medications from the Nomad from the Wednesday night compartment, instead of the Saturday. It put him all out of sync and I thought he was vulnerable at that point because he couldn't manage his medicines properly because his eyesight was getting worse. But he is such a stoical man; he won't have anyone giving him his medicines'* (2nd interview: CM4).

On closer analysis it became apparent that the community matrons also linked being in a precarious position to emotional well-being. In some instances this concerned the inability to manage emotions in certain situations. Throughout the study Vera and Eve were often tearful regarding the loss of their husbands. Here emotional fragility was frequently linked to low mood by the community matrons and from their perspective heightened the older participant's vulnerability. In other situations it related to the inability to cope with changing situations. In the case of Keith, the community matron described how he was '*emotionally wobbly*', as he was intermittently unable to make decisions about the management of his daily living. These situations were made more difficult when he was physically unwell. The following extract from the first interview with the community matron illustrates this:

> '*He is easily thrown, just one thing totally throws him and he can't just form a normal day. He then can't keep the day going without ending in crisis.*

Without emotional support he isn't functioning and I also know there are days physically when he is not well and he is lacking energy when he couldn't consider going out. Whilst he is quite capable of physically picking up the phone, emotionally etc I don't think he is capable of actually advocating for himself' (1st interview: CM2).

The accounts of the community matrons revealed that they perceived frailty to have a temporal dimension, in that the degree of frailty could change over time. This was particularly prominent where there was deterioration in an older participant's condition with challenges to their independence in daily living. Here a physical and functional dimension to frailty often came to the fore. In the case of Vera the community matron recalled how she had seen a decline in her health over the previous year and in her opinion she had become frailer. She recalled this during a conversation:

'She's obviously got more frail, she's losing her independence. I used to come and sometimes she'd be stood at the sink scrubbing the pots out. She'd say, 'The carers don't do this properly'. Now more or less she has to stay in that chair. She's got a commode downstairs. She used to be able to potter when the carers had gone, quite often she got herself in the bath sorted herself out, even though she knew she had to wait for them. I think that she has been quite a feisty lady. She loves it when the family come round. Before she was able to get to the door, she's always had different people coming to the house. She could get up and do that herself. She used to love going to the daughter's caravan, but those trips have got less as she becomes older and more poorly. It's the loss of activities of daily living that she can do herself, it has got worse'. (2nd interview: CM1)

Likewise, the community matron articulated how she had seen Grace become frailer over time. As well as attributing this to her general condition she linked her increasing frailty to losing confidence in her ability to manage her daily living. Moreover, towards the end of Grace's life the community matron considered that she began to give up trying. Losing confidence was also an issue for Keith and towards the end of the study period the community matron was concerned that his low mood and loss of motivation to care for himself contributed to his lack of confidence in moving about his home and making decisions about his own care.

The accounts of the community matrons revealed that not all the older participants became frailer over time. Furthermore, in some cases where symptoms were well managed they recognised that there were periods of stability in relation to health and wellbeing. However, even when an older person's condition was relatively stable the majority of the community matrons continued to use the label of frailty. On reflecting upon Martha at the end of the study period the community matron mentioned:

> *'I still think she is frail and vulnerable, but I think things are on an even keel at the moment. Dr (name) has discharged her from the hospital and referred her back to the GP now, so I think as far as her heart disease goes she's on optimum treatment. So it's just a matter of monitoring that and looking for signs worsening but I still think there's the vulnerability and frailty there but she is stable at the moment' (2nd interview: CM3).*

Likewise, the community matron still considered Christine to be frail even though her visits had reduced to monthly and she was in the process of handing her care to the district nursing service for case management. Here there was a reluctance to remove the label of frailty, even in the context of reasonable health. In contrast, one of the community matrons did reconsider whether one of the participants on her caseload should have been labelled as frail:

> *'I do think, sometimes because of his age and living on his own you think, oh he's frail. You can't get your head round that how can someone of that age live on their own at home and manage, does that make them frail? It's quite hard to put your finger on it and describe frail. I'm sure if you asked Derek he doesn't think he is. There's a worry about, the hospital staff whether he should have come out of hospital at the moment, whether he could manage but he's managed for years and I wondered if I was at fault because I labelled him as frail, when I took him on. Like when you were asking if I had any patients that were frail over the age of 75. I could say that 99% of my caseload is frail in my opinion, but 95% of them would probably say I'm not. We automatically think people are frail because of their age, health problems and the fact that they walk with a stick. I think we have preconceived ideas about people at the time we get the referral because of their health problems and age. I'm not sure now whether Derek was ever really frail, maybe vulnerable at times, but does that make him frail?' (2nd interview: CM1).*

Through reflection this community matron was beginning to challenge her own professional judgement regarding the labelling of older people as frail, and the subsequent implications this may have for care and support at home.

6.4.3 Resisting the label of frailty

Although all the older people were able to describe the physical and cognitive characteristics that in their opinion indicated frailty the majority of them did not consider themselves to be frail. In fact, on the whole they vehemently resisted the label when asked if they considered themselves to be frail. This was in contrast to the community matrons' perceptions, who had labelled all the older participants to be frail. Only Vera and Stephen thought of themselves as frail when asked, interestingly Vera replied, '*They'd be like me'.*

On closer examination, I considered that in rejecting the notion of being frail the older participants were attempting to maintain their self-respect and feelings of self-worth, in the context of disability and restricted autonomy. It was through the accounts of why they did not think themselves as frail that an alternative identity as an autonomous person was revealed; challenging the physical and psychological dimensions that they themselves offered as representing frailty. I perceived that they attributed negative connotations to being labelled as frail. Moreover, being labelled in this way had the potential to deprive them of their dignity.

The biography of the older person offered some insights into how the label of frailty was interpreted. In listening to older participants accounts of their lives it became apparent that many had encountered periods of hardship throughout their life which had been managed and overcome, illustrating strength of character. On reflection this resilience and independence came through in their attempts to manage daily living in the context of fluctuating ill-health and in my opinion this contributed to the rejection of being frail. For example, at the age of eighteen Stephen had landed on the beaches of Normandy during World War Two. Likewise, Esther and Martha had worked in the ammunition factories during the war. A number of older participants had lived in poverty and experienced deprivation through living in the slums in the city centre. Once the slums were cleared all had been moved to new areas across the city. For some the experience of loss and bereavement had

occurred at a young age, which again led to difficult circumstances. In the case of Eve her father had been killed, aged thirty five, when he was crossing the road to work. Consequently her family had to move away from the local area. Following the move, in order to manage financially, her mother had taken in lodgers; Eve herself had to do extra laundry to supplement the income. Esther's sister had suffered three miscarriages and then committed suicide.

In listening to older people's accounts it became apparent that they did not consider dependence on others for support as contributing to being frail. Moreover, on many occasions it was recognised that the different levels of formal and informal support were important in enabling them to maintain their independence and remain in their own home. For example, Esther, Vera, Christine and Eve realised that the support of carers was crucial in assisting them to continue with their daily routine. This was particularly important for Esther as she had no living relatives nearby; she had been receiving formal support for two years. The following extract from the first interview illustrates the nature of support she received as well the value she placed on it:

> 'They come for breakfast in a morning between 8 and 9. I try to get dressed myself but they help me wash. Then they're here for lunch about 12. They make me some sandwiches and put them in the fridge for tea, you see. And then they'll come at night, about 7, give me a cup of Horlicks and see that I'm alright and able to get to bed. They'll even shop if you need them to, bring something from the shop. In fact one of the carers who comes for my breakfast, she's fetching me something back this dinner. They do things like that. They'll do anything you want. They're very good, they really are. I always think this. My mother never had carers. If she hadn't had us children she wouldn't have had anybody, like I haven't. But I've no children so we're very lucky at our age to have carers' (1st interview: OP3)

On closer analysis where the label of frailty was denied it could also imply a resistance to acknowledge the changes that were taking place. This could be the case when the changes challenged the older participant's sense of self, in the 'here and now' and for the future. For example, it was difficult for Esther to think of herself as frail even though it was becoming more difficult for her to control her breathlessness; one of the physical markers that she thought linked to frailty. It would challenge her ability to stay at home and for

her this was more difficult than others because she had no family in the country. I observed how Grace was confronted over a short space of time with increasing impairment and disability. In the chaos of the situation she was overwhelmed by the experience of changing care arrangements and the inability of her body to engage in daily living. In this context I considered that denying the label of frailty was the only way that she could attempt to maintain her dignity.

6.5 Chapter summary

This chapter has reported findings that relate to the perceptions and experiences of frailty in later life in the context of fluctuating ill-health. The analysis of the findings has revealed how frailty can be experienced in different dimensions. However, there is a mismatch between lay and professional accounts of frailty. Professional interpretations of frailty were holistic and to some extent encapsulated the situation of the older participant. However, the older participants did not consider themselves to be frail; here they used mainly physical representations of frailty to compare against themselves in order to reject the label of frailty. Being able to manage the effects of ill-health and disability provided a counterpoint to being frail. The maintenance of dignity and a positive sense of self were central to the resistance of the label. Yet there were situations where an older person felt frail and this appeared to be related to vulnerability. Moreover, a common strand across lay and professional accounts was the concept of vulnerability. It is perhaps in the emotional expression of feeling frail that there was the greatest fit between lay and professional accounts and interpretations of frailty. The next chapter reports findings that explore how the older participants engaged with health and social care agencies, as well as informal support, in order to adapt to the disruption that the experience of transition brings.

Chapter 7: Study Findings - Health and social care provision rhetoric and reality

This final findings chapter provides insights into the inter-relationship between an older person's world of declining health and the episodic interactions they have with health and social care professionals and care workers. Particular emphasis is placed on the interactions that occur between older people and a number of caregivers, within the context of deteriorating health. In doing so the analysis illuminates the degree to which participants engaged with health and social care agencies, as well as informal support, whilst employing their own strategies to adapt to the disruption that transition brought. Hitherto, the way that older people participate in their health and social care has been presented as a form of partnership. These findings provide a critical perspective on the policy and practice rhetoric that surrounds the ideas relating to partnership working between older participants and health and social care agencies.

Two themes arose from the analysis of the data which characterise how health and social care is provided to frail older people in later life. *The nature of participation* examines the extent to which older people are able to participate in their care. In particular it reveals the ways in which partnership working is constituted, negotiated and enacted in the context of a care encounter. *Revelations and discoveries* details an analysis of how issues of relevance are introduced, discussed and subsequently dealt with between older people and providers of care. Such an examination reveals the complexities inherent in such interactions as well as illuminating the importance of the therapeutic relationship within the context of the encounter.

7.1   The nature of participation

At first sight, observation of care work around older people living at home gives the impression of health and social care staff and older people working together. I observed participants enacting roles which appeared to enable joint working, in order to help with the management of the older participant's health conditions. Moreover, there seemed to be an implicit assumption held by the older participants and community matrons that these roles were important and had to be fulfilled.

For example, within the context of the care encounters between the community matrons and the older participants I perceived that a key focus of the interaction was to monitor the older participant's health status and well-being. Monitoring was an expected and important activity that guided the professional and lay management of the health condition; it occurred at every clinical visit. Participating in this aspect of health care was seen to be a given by both parties; both had a role to play in the monitoring of health status and I observed both the community matron and the older participant enact that role.

My observations over time revealed further detail of the monitoring, the outcome of which was to maintain existing treatment plans, making changes when appropriate, as well as initiating new treatment plans when required. I noted that the community matrons conducted regular physical assessments and recorded vital signs, such as blood pressure, pulse, temperature, oxygen saturations, weight, listening to chest sounds and measuring leg oedema. The following extract from the second observation visit with Eve is one of many examples of monitoring vital signs within the context of a care visit:

> CM: Do you mind if I take your blood pressure?
>
> E: No love, that's fine.
>
> CM: (putting blood pressure cuff around Eve's arm) You look as if you have lost a little weight, are you eating enough for your meals?
>
> E: Yes.
>
> CM: (silence for 2 minutes) That's fine. I notice that you've got your leg bandaged Eve?
>
> E: I knocked it; the district nurse took a swab the other day.
>
> CM: Right, let's take your temperature after this; we don't want you getting an infection. I'll look at your ankles too. I'll chase up that swab result.
> (2nd observation: OP10).

Enquiries were also regularly made by the community matron about the older participant's bowel habits, diet, sleep patterns and whether they were experiencing any pain. The older participant also contributed by sharing details of any recordings that they had been asked to monitor themselves. For example, Keith was regularly asked to monitor and record his blood

sugar readings over a number of days. He shared these readings so that the community matron could make a decision regarding the insulin prescription, as well as monitor his dietary intake around this. Martha consistently updated the community matron regarding her leg oedema and the extent of it during the week. Based on the outcomes of the monitoring, an action plan was devised and subsequently discussed and agreed with the older participant towards the end of the care encounter.

Over time, these procedures became an established routine within the clinical visits; one that I perceived to focus the interaction between the community matron and the older participant at various points within the consultation. I became aware that the community matron and the older participant enacted their roles in order to facilitate this monitoring, which gave the impression of working in partnership. For instance, the community matrons had the appropriate equipment to hand and I observed them using their knowledge and skills to undertake and interpret the results of the monitoring; the older participants participated in the activities by giving consent for the community matron to utilise the equipment and assessment techniques. In particular, some older participants pre-empted the process by being ready for the next procedure without prompting. For example, Stephen and Esther often rolled up their sleeve before the community matron had mentioned taking their blood pressure. Similarly, Martha frequently took off her socks in readiness for the community matron to look at the level of oedema in her legs. This prompt from the older participant, that communicated they were ready for the procedure, appeared to contribute to the smooth running of the monitoring within the visit.

7.1.1   Role boundaries

Closer examination of the data demonstrates that the roles enacted by the older participant and the community matron can be constituted quite differently, thus questioning the nature of partnership working. Ultimately, this affected how an older participant made decisions about their care, including whether they undertook certain activities. I noticed that some older participants found it difficult to engage with certain aspects of the monitoring, however they endeavoured to fulfil their responsibility even when it led to discomfort. In these situations I wondered why they participated. It appeared

that the older participant was being positioned within the partnership, rather than being actively involved in contributing to how the partnership should be organised and enacted. There was an expectation that the older participant would be involved in the process of monitoring; a role that was directed by the community matrons.

For example, having their weight recorded was particularly difficult for Vera and Esther. They had to walk into the kitchen to stand on the scales because the carpet surface in the living room was not suitable for the electric scales. Both of them had poor mobility and used a walking aid; as well as becoming breathless on exertion due to their COPD. Also, Esther was on long term oxygen therapy therefore the oxygen tubing had to be managed whilst she walked through to the kitchen. Both of them found this process very challenging and anxiety provoking yet always agreed to have their weight recorded. I watched Esther as she stopped frequently to steady her breathing, with the encouragement and support of the community matron. Similarly, I noted that Vera always counted out loud to focus her attention on walking longer distances as I recorded in the field notes:

> Vera walks into the kitchen using her Zimmer frame; (name of CM) is to the rear of her in case she falls backwards. As she is walking she counts 1; 2; 3; 4; 5 over and over again; she seems to be willing herself to get to the scales and is using the counting to focus her attention (3rd field note: OP1).

In being positioned in this way I considered that Vera and Esther were able to participate in their care rather than working in partnership. In these instances their participation occurred within certain boundaries, which appeared to be determined by the clinical assessment framework used by the community matron to monitor their condition. Here I observed that the community matrons exerted their professional power, albeit unknowingly, to determine the parameters of the partnership, therefore shaping the older participant's role. Rather than being able to say no, Vera and Esther continued to enact their role in relation to the monitoring of their health condition set within the professional frame; even when it was a struggle for them. I never heard them question whether being weighed was absolutely necessary; they seemed to accept the monitoring parameters that had been set by the community

matron. It looked as if they enacted the role that was expected of them even when it was an effort to do so. However, overtime I realised that the older participants respected the knowledge and skills of the community matron in contributing to the management of their health; therefore it appeared that it was important for them to fulfil their obligations. On the whole, participating in monitoring was seen as a necessary requirement yet this data illuminates the extent to which routinisation of care can negatively influence the level of partnership working by ascribing certain roles which can be difficult for community matrons and older participants to step outside of.

7.1.2 Competing roles

Partnership working was complex and the work of the community matrons was shaped by multiple frameworks at any one time. Working within each of these frameworks comprised different roles. The data illustrates how the enactment of these differing roles in any given situation influenced the extent to which an older participant was able to participate in and make decisions about their care. As previously illustrated the community matrons monitored the older participants' health status in relation to their LTC and on the whole this clinical imperative directed and constrained the older participant's participation within the monitoring. However, the community matrons were also positioned in the partnership by their professional nursing responsibilities, as well as working within a number of other national and local policy guidelines. I became aware that at times the community matrons managed the competing demands of their roles, which appeared to influence the level of participation by the older participant. The complexities inherent in the minutiae of managing care situations are illuminated when a community matron made a decision not to perform clinical observations.

For example, Amelia's COPD was worsening and following a case conference, with Amelia present, the decision was made that she was to receive a palliative approach to care; this included a Do Not Attempt Resuscitation order being put in place and Amelia's Preferred Priorities Of Care being discussed. She made the decision that she wanted to remain at home to die. During the third observation visit, on entering Amelia's house it was obvious to me that she looked more breathless than usual. The previous day she had been found in a collapsed state by the carer and it was clear

that her condition had deteriorated since the last visit by the community matron. I observed the community matron communicate to Amelia that she did not want to disturb her by taking her vital signs that day. The following extract from an observation with Amelia illustrates this:

> CM: How are you today?
> A: Okay…….I think, had a bad one yesterday.
> CM: I heard. Have you had any more funny turns since yesterday?
> A: No (shakes her head).
> CM: (long pause) I'm not going to take your blood pressure today, I don't want to tire you out even further.
> A: (shrugs her shoulders) (3rd observation: OP7).

This situation gave me an insight into how the community matron combined a compassionate and ethical approach to caring for Amelia, within the competing policy frameworks that informed her particular approach to care that day. She stepped outside the role of monitoring Amelia's LTC within the context of case management. Within an end of life care framework she made the decision that it was not appropriate to monitor vital signs which would potentially cause discomfort. In this encounter it appeared appropriate that the community matron took control of the situation and managed Amelia's expectation and requirement to participate in the monitoring of her health status, thus maintaining her comfort and dignity.

7.1.3 Roles as a position

Older participants can be located in the partnership in a position that is determined by others; this enabled them to participate in activities that were prescribed by the community matron. There is the implication here that the older participant was a passive recipient of care. However, this was not always the case and I noted that older participants were able to position themselves as an active partner in order to make decisions regarding their own care. This often meant stepping outside others' expectations of them in a given situation. Within the care visits I observed older participants moving in and out of the roles of being an active partner and participant. I observed many occasions where older participants were able to make the decision to decline a service proposed by the community matron.

Esther continued to participate in the monitoring of her weight even though it was challenging, yet she was able to assert her opinion on other matters and make decisions that were contrary to what the community matron suggested. For example, there was concern that Esther spent many hours on her own, particularly as she experienced episodes of panic in relation to her breathlessness. This had been one of the reasons why she had been referred to the community matron's caseload in the first instance. The community matron asked whether she would consider re-instating the visiting service, to which Esther replied:

> E: No, thanks, I'm not that sort of person; I don't need a stranger to chat to me about what their grandson did yesterday or anything like that. I'd rather talk about going to the moon or something like that (laughs).
>
> CM: More factual, you like information?
>
> E: Yes.
>
> CM: Okay then, right, let's think about the next visit' (2nd observation: OP3).

This was also illustrated in Stephen's case. As a result of his COPD he was finding it difficult to wash and dress himself in a morning because of his breathlessness. The community matron on a number of occasions suggested to him that he might benefit from a personal care visit from a care agency. Stephen was adamant that he could manage and that he had a good support network of family and friends to help him.

Within their roles the community matrons were in the position of linking current services to current health issues. Here they provided information regarding services, with suggestions as to why they thought it may be beneficial to the older participant. They also demonstrated that they listened and took on board the older participant's view points, perspectives and experiences. Although I perceived it was difficult at times for the community matrons to do this, ultimately they demonstrated respect for the older participants' opinions and on the whole they accepted the decisions they made to decline services.

On reflection, how the community matron and older participants were positioned in relation to each other in these situations appeared to be

different from how they were positioned in relation to each other in the context of monitoring. Whereas I considered the routine nature of monitoring enabled participation in care on the community matron's terms, making decisions about some services enabled the older participant to exert some power and control. This suggests that the balance of power did not always lie with the community matron and that some older participants were able to position themselves within the encounter to actively participate. Where the community matrons adopted a person-centred approach to case management it was more likely to influence the extent to which the older participant could actively participate. Whereas monitoring was routine, here was something that was considered to be more individual perhaps, taking in to account what the older participant wanted for themselves; demonstrating a person-centred approach to care. On reflection, I considered that it was not simply the case that the community matron had power and that the older participant did not. It appeared they were positioned in relation to one another and sometimes this meant that they worked in partnership but at other times the older participants could only participate in their care.

7.1.4 Frailty and partnership

In some situations it was difficult for the older participant to position themselves as an active partner in the relationship. I observed that this was more likely to occur if an older participant had experienced deterioration in their health status, for example, a fall or a chest infection. Furthermore, the subsequent disruption in health status often led to changes in an older participant's existing routine. During these encounters I perceived that the older participant was labelled as frail, albeit unintentionally, with subsequent assumptions made about an older participant's level of independence and ability. Being labelled in this way appeared to make it more difficult for the older participant to position themselves in the partnership in order to make decisions about managing their daily lives.

A clear example of the way in which labelling an older participant as frail challenged their active role within the partnership was observed in the case of Grace. She had recently fallen and had been admitted to an intermediate care unit. After three weeks she had returned home, where many adjustments to her daily routine had taken place. For example, changes had

been made to her medications during the inpatient stay and the use of a NOMAD system had been instigated; also carers had been introduced at home and were given the responsibility for giving Grace her medications, amongst other duties. The community matron visited Grace the day after her return home. I observed her catching up with the sequence of events leading up to Grace's admission to the respite unit. Following this the community matron began to establish the involvement of the carers in the administration of her medicines. The following extract from the case account illustrates how Grace was no longer able to get her own medications ready, this responsibility had been given to the carers, but she asserted her position as being able to self-administer her inhaler:

CM: Did she give you your medication this morning Grace?

G: Yes love, you see I've been so used to taking my own medication for years and I've only got to look at a tablet and I know what it is.

CM: Have you used your inhaler this morning?

G: Yes, I don't have Ventolin, just Serotide, one in an evening, well at night.

CM: Good.

G: And of course I'm still on a water tablet, ooh they're deadly, you've no sooner been and then you want to go again. And they've put me a thing at the side of me bed.

CM: I might give them a ring then, (to herself)…..(turns to Grace) I might give the carers a ring and ask them if they are happy to give you your inhalers.

G: She gave it to me and I know what to do with it (silence).

CM: That's fine then…

G: I mean I've been taking my own tablets for years and I can look and think that's so and so (Case account: OP4).

During the period of data collection it became apparent that older participants were 'susceptible' to changes in medication. Therefore, it seemed high on the community matrons' agenda to ensure compliance with medication, in order to enable optimum treatment and minimise side effects. In this situation I considered that Grace and the community matron took different positions regarding medication administration. I observed how a process of negotiation

ensued comprising the defence of these different positions. In the first instance, the community matron assumed that the carers would administer all the medications because of Grace's deterioration in physical independence. However, Grace very quickly asserted her position regarding her inhaler use. When faced with such a change Grace took control and communicated to the community matron that she was able to manage as she always had. In a direct way she questioned what was being offered, thus contributed actively to the partnership. This was underpinned by demonstrating knowledge of her medications and previous autonomy in self-medication assuaging any doubt that the community matron had about the situation causing problems.

In labelling older participants as frail their actions were considered in terms of posing risk to themselves. At times, this led to interactions that appeared to be in conflict, rather than demonstrating negotiation. I observed situations where the older participant, in attempting to maintain a sense of order through managing their daily routines, was considered to be putting themselves at risk. This often led to a gentle rebuke, where the older participant was reminded how they should manage the situation. For example, Vera was unsteady on her feet and required support from care staff to assist with getting up in the morning and back to bed at night; she used a Zimmer frame and a stair lift. The care staff frequently reported to the community matron that Vera used the stair lift on her own in a morning to come downstairs. Vera was adamant that she could manage and she did not want to wait upstairs until ten 'o'clock until the carers came. Here, once the label of frailty was synonymously linked with risk it appeared difficult for health and social care staff to see outside of that label, and therefore Vera's behaviour was subsequently always judged in that frame. This communicated a narrow understanding by the carers of the factors that influenced Vera's experience of frailty. As the previous findings chapters have illustrated maintaining autonomy in daily activities in older age is more likely to be a continuous and fluctuating process that will be shaped by the level of health and wellbeing at any given time. This analysis suggests that the older participants and carers weighed up the risk in a different way.

There were some encounters where being positioned as frail and at risk the older participant was less likely to be able to maintain control of the situation. Again, this appeared to be more common during a transition in health; the

outcome here would be influenced by the level of risk that the community matron judged the situation to hold. I observed how this led to interactions that appeared to demonstrate conflict. For example, following the conversation between Grace and the community matron regarding Grace's inhaler use I observed and listened to an interaction at the close of the visit that became more like a 'battle ground' situation. Here, a verbal tussle took place regarding what Grace would have for lunch and both of them attempted to take control of the situation. The following extract from the case account illustrates this:

> The conversation changes focus to lunchtime, as it is coming up to 12md. The community matron is standing next to Grace with a hand on her shoulder. Grace asks where the marmalade sandwich that was on the coffee table has gone. The community matron had taken this through to the kitchen. As Grace wants this I go into the kitchen to retrieve it and bring it back through. The sandwich looked dry and there appeared to be a small amount of regurgitated bread on the edge of the plate. The community matron suggests that she should have something else, but Grace is adamant and says in a low, quiet but defiant voice, 'Shan't have anything else love'. The community matron makes it clear that it would be more appropriate for the carers to make something fresh as the sandwich has been out for too long and may give her an upset stomach. The conversation moves on to medications and the community matron takes the sandwich back into the kitchen. About 5 minutes later asks where the bread has gone. I go back and get it, the community matron mentioning again to Grace that there may be germs on the sandwich and that the carers will make her a fresh lunch. Grace reluctantly agrees with this. I write in the field notes,
>
> *'The issue with food has become another battle ground between the community matron and Grace, similar to the management of the medicines three weeks ago. Grace is adamant that she is going to eat the sandwich, against the advice of the community matron. This has been an uncomfortable incident; I feel that Grace is trying to exert some control over her situation however in this instance the sandwich raises issues about risk and Grace's safety. In the end the community matron ensures that she has a fresh meal'.*

> *I considered that the community matron judged the situation to pose a serious risk to Grace's health and therefore she took control of the situation. The outcome was that Grace appeared to be disempowered (Case account: OP4).*

During these lengthier 'battles' the outcome could go either way. Where an outcome went in favour of the community matron it appeared to be influenced by the 'level of risk' that the community matron perceived the situation to hold – they appeared to hold the power in this context. Grace won the 'battle' relating to the medicines but not the 'battle' relating to her meal.

During periods of transition in health and illness not all the older participants wanted to be autonomous and make independent decisions. For example, Keith had complex medical problems and suffered from depression, and over a period of three months he became less able to manage daily activities in the home. His wife had died four years earlier and a year later his only daughter had died. His wife and daughter had made all the day to day decisions and he now struggled to manage these for himself. Therefore, the community matron spent a lot of time focusing on strategies for self-management. Although he had two sons he would not ask them for help. Over time as his health deteriorated the community matron became concerned that he was becoming too dependent on her; in particular she felt that he considered her to be fulfilling a daughter role. He would frequently reply, '*Whatever you think (name)'* or '*I'll do what you say, you know best'* when asked for his opinion on changes to his daily routine. Here, the community matron was clearly concerned about this when following a consultation she mentioned that she was, '*becoming worried that Keith was over reliant on her and not managing things for himself',* and she went onto state, '*I am starting to think that this relationship is not working'.*

It appeared that during these periods Keith did not want to make decisions about his health and this challenged how the community matron perceived their working relationship; the community matron's expectation of her role was to enable Keith to manage himself. This example illustrates how power sharing was a cornerstone of working together. It could be suggested that Keith had lost his ability to use his personal power within the relationship, which had left the community matron feeling that she must be in control of the situation. He felt comfortable with this current situation however the

community matron clearly felt uncomfortable adopting a role that she appeared to experience as exerting power over Keith. Furthermore, she interpreted this as contributing to his increasing dependence.

A similar situation was experienced by Vera. Over a period of a month her mood appeared to be getting lower and she would become very tearful during the encounters with the community matron. During this period the community matron suggested to Vera that she may benefit from referral to a unit where they could assess her low mood. Initially Vera agreed to think about it, but eventually she decided not to accept the referral. During the third observation Vera was particularly upset and the community matron asked:

> CM: What's been happening this weekend then if you say you've not been, you've been off it?
>
> V: I've been off a bit yeah, crying all time.
>
> CM: This is another reason why I think it would be beneficial to be referred Vera, because you are getting quite low aren't you?
>
> V: Yes (very softly, started to cry). I've been like it a bit now. I says to me self, community matron is coming round today, I says she'll sort me out'.
>
> CM: I wish I had a magic wand to sort you out….(gentle laughter) (3rd observation: OP1).

During these changes in personal health and wellbeing it appeared that Keith and Vera positioned themselves in a certain way that looked to the community matron to manage the situation. The older participant's perspective of the nature of the relationship challenged the community matron's expectations of their role.

7.2 Revelations and discoveries

The second part of this chapter focuses on the ways in which older participants and health and social care staff interacted to identify, discuss and manage issues of concern that pertain to health issues and daily living. It also examines the extent to which communication strategies influence the nature of partnership working.

7.2.1 Sharing concerns

Conversations around concerns were a feature of the interactions between older participants and social health and care professionals and care workers. I considered these to be important as they enabled the sharing of information regarding the concern, which for some older participants enabled them to participate in their care. I observed and listened to the sharing of information from both the professional and lay perspective within conversations; this appeared to facilitate the identification of possible causes of an issue, forming the basis for joint planning of care, as well as establishing whether current management strategies were effective. This included a range of physical and psychological problems, such as breathlessness, pain, low mood and fatigue, as well as some domestic concerns.

Appropriate communication strategies were important in enhancing the participation of older participants in their care by enabling the sharing of information. I observed how the eliciting of concerns was a feature of the interactions. During visits by the community matrons the older participants were always asked how they had been since the last visit creating an opportunity to bring up areas of concern. A characteristic of the community matrons' interaction was the appropriate use of questioning techniques. For example, when asked '*how have you been since I last saw you*?' Christine replied '*not good*'. She had recently undergone major dental surgery as an outpatient and had been prescribed antibiotics which were now giving her diarrhoea. Similarly, when asked, Grace mentioned that she had fallen against the wall whilst walking into the kitchen a couple of days before and had hurt her arm. A range of other strategies were then used interchangeably to elicit and pursue concerns and to seek further detail and clarification, which included the use of open and closed questions, paraphrasing, observation, listening techniques and touch.

On closer examination the sharing of concerns was not always guided by the older participant. During the observations it also became apparent that the older participant shared information following a specific enquiry from the health and social care professional. For example, during the visits I noted that the community matrons routinely enquired about a number of health related topics, including, bowels, urine output, sleep, pain and appetite.

These concerns did not always seem to be of relevance to the older participant and seemed to reflect the clinical assessment framework, almost a check list, used by the community matron. However, the older participant always responded to this line of questioning; as highlighted in the previous section it seemed to be an expected element of the routine of the care encounter.

7.2.2 Negotiation surrounding concerns

Once an issue had been raised, regardless of how this had happened, conversations around concerns appeared to enable the building of consensus and goal setting between the older participant and the community matron. Negotiation appeared to be the main communication strategy; this was fostered by further sharing of information and questioning, and the giving of relevant information and advice by the community matron. On many occasions this led to the development of an action plan at the end of the visit, which enabled the older participant to be actively involved in managing their own care.

For example, it became apparent that Derek was not eating enough in the day to keep his diabetes under control. The following extract from the case account illustrates how, after finding out that Derek was not eating enough in the day, a plan regarding his meals was developed jointly:

CM: What do you have for breakfast?
D: Right, a bowl of cornflakes, a tea cake with a pot of tea, and then for dinner I have a banana and some tinned fruit and ice cream. And then for my tea I have a plate dinner.
CM: Do you have anything at supper time?
D: I might have a tea cake. It all depends I might do but not regular.
CM:: Right, what about lunch time, you say you have a banana and tinned fruit, do you have anything else?
D: No, but I might have a teacake after, I have my dinner at 11.30am.
CM: You have your lunch early don't you?
D: Yes and about 2.30pm I might have a tea cake, but not always not regular.
CM: Right, you could do with a sandwich, or soup and a roll or beans on toast. It's not much to have a banana and fruit, when you are only having a bowl of cornflakes and teacake for breakfast, to last you right through to tea time. What time are you having your tea?

> *D: About 4pm.*
> *CM: And so you are going from 4pm until, what time do you have your breakfast?*
> *D: 7am in morning.*
> *CM: So that's 15 hours without anything to eat, that's too long, you need some supper don't you? Let's see what you have in the cupboards, we need to get this sorted.*
>
> At this point Derek and the community matron went into the kitchen and looked together at the food in the kitchen cupboards. Whilst they were doing this the community matron asked Derek what meals he liked to eat. After walking back into the living room the community matron made suggestions for a weekly menu and Derek made some notes. (Case account: OP6)

During an interview the following week it became apparent that Derek had acted upon the discussion with the community matron and had written a shopping list so that his son could then buy the appropriate foods. Here effective participation was based on a merger of his experience and information with the specific knowledge and guidance of the community matron. Furthermore, the community matron ensured that she discovered information that was relevant to Derek's situation before offering further guidance. In particular, she avoided making assumptions about his situation. The negotiation that occurred enabled Derek to have greater control and more responsibility in decision making around this issue.

Similarly, Christine had lost weight following major dental surgery; this was a concern to her and the community matron as she was already under weight. Although nutritional supplements had been prescribed in drink form by the community dietician, Christine was finding them difficult to consume as they altered her bowel habit. Over a period of four weeks there was a continual discussion and negotiation about how to increase Christine's calorific intake. This involved increasing the number of meals in a day, as well as decreasing the intake of nutritional supplements to every other day; overall this had the mutually desired outcome and Christine's weight increased.

Within the context of the conversations I observed strategies for encouraging and rewarding participation. On the whole the community matrons consistently praised older participants when something was going well or to reinforce progress. It appeared that participation seemed to be enhanced

when this happened, especially when the issue was challenging. An example of this is illustrated by an extract taken from the case account of Vera.

Vera had not been eating and had been losing weight and there was concern that she would be admitted to hospital; she was reluctant for this to happen. Following a referral to the community dietician and discussion with the care agency providing her meals there was an overall improvement. During the fourth observational visit she had put on 2lbs to which the community matron responded:

CM: *'All this that I have been telling you that you'll waste away if you don't eat, do you believe me now? Because that's proof of the pudding now'.*

V: *Yes it is.*

CM: *You've put weight on and you're feeling better?*

V: *I am feeling better love yes. I feel more myself you know?*

CM: *Good.*

V: *I am I'm more myself and I have those home care laughing when they come.*

CM: *That's absolutely fantastic Vera, that is.*

V: *Yes, I'll have to carry on eating.*

(Case account: OP1).

Similarly, over time Keith became unsteady on his feet and was worried about falling when he went outside. However, he still managed to get into his car and drive to the local shops once a week to buy a few groceries. As Keith talked about this the community matron made positive remarks about his ability to continue driving and how important it was. It was particularly significant for Keith as he had driven all his life. He had worked as a driver in the local steel works and therefore continuing to drive now enabled some continuity of self.

7.2.3 Cross purpose interactions

I identified that negotiation was a key communication strategy in the context of partnership working. I noted that there were situations where negotiation regarding an issue was restricted thus limiting the extent to which older participants were able to be involved in their own care and make decisions about their daily life. It would appear that the framing of a concern within the context of a professional agenda influenced how that concern was subsequently discussed and managed. During some observations it became

apparent that the community matrons did not pursue all concerns raised by the older participant; therefore these concerns could not be explored and the negotiation of care outcomes became limited.

For example, when Grace mentioned that she had been falling asleep a lot and that this was unusual for her, the following conversation ensued:

> G: And I've been falling asleep.
>
> CM: Have you?
>
> G: Couldn't keep awake.
>
> CM: Couldn't you, have you been sleeping at night?
>
> G: Yes mostly but I have had some terrible days and nights this week. I mean I'd only just had my cereal yesterday morning, sat here and that was it, an hour and a half after I came too.
>
> CM: That's alright.
>
> G: Ah, but it's not it's not me.
>
> CM: So, what about this arm is it any better? (1st observation: OP4)

Here the community matron initially acknowledged the concern however the conversation very quickly became focused on sleep patterns at night. When Grace reported that she had experienced some '*terrible days and nights'* this was not picked up, and when she communicated that it was out of character for her the community matron moved onto another unrelated issue. This did not demonstrate 'active' listening and therefore no real exploration of the concerns that had been expressed. Similarly, following a discussion regarding a mobility aid to support Stephen after a fall he mentioned that his '*arm was weaker'* to which the community matron replied, '*yes….how's your breathlessness at the moment?'*

Although the issues raised here were initially acknowledged by the community matrons, the cues were not pursued. The opportunity to negotiate meaning was lost and therefore the purpose of the on-going conversation appeared to be different for each participant. In fact, it could be suggested that the conversations appeared to be at cross purposes. One interpretation is that if the older participant's concern was not considered to be professionally relevant it was relegated to the margins of the conversation and/or excluded. In these encounters I felt that Grace and Stephen were disempowered as a result of the community matrons' dismissal of their

information. Consequently, the concerns in these situations were not addressed which appeared to limit the older participant's participation in their care. The analysis also suggests that simply listening to the older participant's concerns was not enough. Here, partnership working did not become a reality as the older participant's perspective was not heard and was not brought to the fore within a conversation.

To an observer not picking up an older participant's concerns could seem 'unfeeling' however in the context of the community matron's focused agenda and time constraints within the consultation this may be appropriate. It may have been enough to ascertain that the concern was not a feature of some wider clinical syndrome, such as, depression. In Grace's case this could have been the situation with the issue of sleep which is something the community matron was able to screen for and subsequently manage. In these circumstances the community matrons made clinical decisions about the stability of the participants' condition, choosing not to pursue cues. However, I considered that the issues raised, which seemed small to the community matron and not of significance, were representing the experience of 'transition' in relation to ageing. Therefore, they were of huge concern. It was apparent from observing these situations and listening to the older participants' accounts that it was difficult for them to articulate what was happening during these periods of transition. This limited the opportunities to explore these concerns further. Challenges to partnership working are demonstrated, particularly when an older participant is trying to articulate something that is not easy to put into words, for example, non-specific general changes that occur with ageing. These findings appear to suggest that the opportunity to have a voice became limited when concerns were viewed in a particular way, for example, in this instance using a biomedical approach.

I considered that being at 'cross purposes' was a feature of other interactions between the older participants and the community matrons, particularly when a professionally led issue was raised. During the conversations with some older participants an issue was raised by a community matron, the focus of which was not made explicit to the older participant. In this situation the older participant would try to work out the cue, whilst in the process of trying to participate within the conversation.

Subsequently, there was an inadequate discussion of the topic that was raised. On a number of occasions this occurred when a community matron focused the conversation on end of life care.

For example, I observed the community matron ask Esther what she would like to do if she became unwell:

> CM: Esther, at some point we need to talk about what your wishes would be if you weren't very well regarding where you would want to be looked after, you know if you got very very poorly, have you ever thought about that?

> E: Well if it got as I couldn't cope then I would have to go into the (name of care home) to be looked after, that's all I can say (3rd observation:OP3).

Esther appeared to interpret this line of discussion and question as not being able to cope in general, and she had a clear idea as to what she would do in this situation. This prompted the community matron to rephrase the question, asking specifically about hospital care and mentioning that she had to fill in some official documentation about care preferences, to which Esther replied, '*But I'm not ready yet, am I*?

Consequently the community matron was left with an inadequate end of life care discussion. It could be suggested that the 'cross purpose' in this situation was the result of using language that did not clearly communicate to the older participant the focus of the enquiry. It is also possibly reflected the clear policy directive that the community matron was following, to enquire about Preferred Priorities of Care. However, it was not easy to raise this with Esther and therefore euphemisms were used. In this instance the community matron was led down a blind alley and the conversation tailed off because it did not follow the intended direction.

Raising end of life concerns and preferences was difficult at the best of times however I wonder if it was made more difficult in this situation because contrary to the community matron's judgement, Esther did not consider herself to be at the end of life; she appeared to be getting on with living.

On reflection, I noted that some of these interactions seemed to be at odds with the notion of person-centred care when working together with the older participants. By not exploring the older participants concerns, or initiating what were considered to be irrelevant topics, I considered that a person-centred focus was not maintained; thus it could be argued limiting autonomy and independence. However, these potentially difficult encounters did not seem to be perceived as negative by the older participant or the community matron. During the observations it became apparent that the process of the relationship, the specific way in which the community matrons and older participants worked and interacted together, was underpinned by the quality of the relationship; one that was based on trust.

7.2.4 Relationships

During the observation visits it was apparent to me that positive relationships had developed between the older participants and the community matrons; this seemed to be irrespective of the length of time that the relationship had been established. For example, Grace and Martha had only been on the community matron's caseload for one month prior to their recruitment to the study; however the rapport between them indicated a lengthier relationship. I listened to the reciprocal sharing of personal information and experiences and noted that this was a common feature of all the conversations. It appeared to provide an important back drop to the monitoring activities, care interventions and discussions regarding the older participants' health and social problems. Furthermore, it enabled all the participants to recount their personal narratives which conveyed an interest in their situation; this could either be initiated by the older participant or the community matron. I perceived that this type of conversation was important as it appeared to weave together the discussions about various issues during a visit.

Much of this conversation was of a general nature and included talk about the weather, who else had visited that week, what had been on television, plans for a specific time of year. Talking about family was also a prominent topic of conversation that was shared between the participants and the community matrons. For example, Grace's grand-daughter had recently won a prize by entering her dog into a national competition and it was clear that Grace was very proud of her. As she showed the photographs she also

recalled how she had done this herself in the past. Christine had recently been to stay with her son and his family; he lived out of the area and this trip had involved months of planning. At the subsequent visit following the trip the community matron asked her how it had been to which she replied:

> 'Oh marvellous, it was great to catch up with the family, particularly the grandchildren, they had grown so much. And we had some lovely meals out, I was really spoilt' (4th observation visit: OP8).

During Keith's participation in the study he had been on a week's holiday and the community matron was very keen to hear about his experiences.

During the observations it became apparent that there was reciprocal sharing of information and the community matrons shared their own personal experiences, for example, holidays, weekend activities, birthday celebrations and this again enhanced the relationship. In some situations the strength of the relationship enabled the older participant to ask personal questions, for example, during one visit Vera asked the community matron if she had lost weight recently and this led to a conversation about strategies for dieting. Keith asked the community matron if she had changed her car prompting a reminiscence of his job as a heavy goods vehicle driver. In these situations the quality of the relationships appeared to enable the older participant to contribute to and direct the conversation. Furthermore, it communicated respect for the participants' personhood.

The positive relationship also appeared to be enhanced by the personal style of the community matrons, particularly the demonstration of empathy. The community matrons used a range of positive non-verbal and verbal communication strategies including: acknowledging remarks, closed questions, supportive/reassuring statements, positive tone of voice, eye contact, position, touch, facial expressions. Although, it could be argued that an approachable manner and good communication skills within the context of the relationship are not enough when it limits the nature of partnership and the ability of older participants to be actively involved in decisions about their care. Yet, even though some of the concerns raised by the older participants were not really addressed it appeared that it was enough for the older participants to be able to express some of their concerns, problems or feelings to another person instead of internalising it; this released some of

the worry that the older participant was experiencing in relation to a specific issue and helped in the process of 'making sense' of what was happening. It allowed the concern to be legitimised; perhaps even enabled the older participant to have a voice.

Overall I observed that the community matrons demonstrated respect for personhood and this appeared to underpin the relationship that had developed between them and the older participant. There were isolated occasions where I feel that respect for personhood was not maintained and these encounters were more likely to inhibit the development of partnership working. Interestingly, these situations did not involve the community matrons, but other health and social care professionals. Their relationships with the older participant appeared less well developed. These difficult encounters also seemed to be fuelled by differing role expectations but were executed differently to the community matrons.

This was an issue in the case of Grace which arose during an encounter that I observed during the third care visit. The social worker was already present in Grace's flat when the community matron and I arrived.

We were immediately brought into a difficult situation where it felt as if Grace was being reprimanded for not being more actively involved in her care at home, illustrated by an extract from the case account:

As we enter the social worker and Grace's son are already present (the son is sitting in the chair near the TV; the social worker is sitting on the end of settee nearest to Grace); we introduce ourselves and sit down on the settee at the other end to the social worker – who proceeds to update us regarding the issues with Grace, mainly her poor mobility, and that she was 'doing better in the day care at (name of care home)'. The social worker goes onto say that before we arrived she had been 'telling her off' for not doing as much for herself. Her son mentions that he used to walk her up the street but now she is shuffling and not picking her feet up. All this time Grace has not said a word to anyone or participated in the conversation. She has a resigned, but defiant, look on her face, and is looking out of the window during these conversations. I feel very uncomfortable about this and feel that Grace is being ignored and spoken

to as if she was either not there or a child. It feels as if she is on trial. Finally, Grace speaks for the first time since we arrived asking why she is falling asleep, but she is interrupted here as social worker goes onto say that they have been discussing care homes but that Grace is not at the stage to go into a care home. A general discussion ensues, directed by the social worker, as to what Grace is able or unable to do for herself at home and the support offered by the care package (carers 4 times a day); comparisons are frequently made between what Grace can do at home and what she did at (name of care home) before discharge. This is a difficult time as the woman often uses a patronising tone of voice towards Grace when making these comparisons:

> *'I don't understand why you can't now, I think you can do it here. It's about motivation because you can do it…….you've got your trolley, smaller kettle' (Case account: OP4).*

In this situation I perceived that Grace was not fulfilling the role that was expected of her by the social worker, which led to a communication strategy that the community matron recalled as bullying in a subsequent interview:

> *'She was loud, bullying really, 'well you could do this when you were in (name of care home)' and it wasn't going through her mind, 'oh yes, that was when she got support and other people were around, she's back here on her own now' (2nd interview: CM3).*

It was clear that the community matron recognised the social worker's lack of attention to Grace's circumstances, particularly the vulnerability created by increased incapacity, and how this challenged Grace's sense of autonomy and dignity. In this context it appeared to demonstrate that the social worker was inflexible in relation to what was expected of each other's roles in a given situation. She did not seem to take into account how Grace was coping with the situation as it unfolded. It was not enough to set roles at the beginning of the relationship and expect them to remain static; this situation illustrated the extent to which role change needs to be accommodated as different issues emerge. So here Grace was not doing enough in the opinion of the social worker and this frustration was communicated insensitively; ultimately partnership working was affected.

I became aware of other situations where communication with an older participant appeared to negatively influence the relationship. For example, Esther wanted help to manage the panic associated with acute breathlessness which led to her arranging a home visit from the general practitioner. Although I never witnessed the encounter she recalled this incident at all of the visits that I made hinting that he had dismissed her concerns in a negative way, as she recalled:

> *'I had the doctor and he said, 'What can I do for you?' and I said, 'Well I can't breathe'. 'Can't breathe for you' he said, and I know he can't and there's no medication for it either. So I won't have him anymore I don't think, I just thought there could be some medication that could relieve you but there isn't'* (2nd interview: OP3).

From the general practitioner's perspective it may be that he considered himself to have been called out unnecessarily; Esther felt that he had been dismissive and communicated his exasperation to her. As a result of this she appeared to lose confidence in managing these acute situations, and subsequently called out the emergency care practitioners; which led to an increase in the contact of the very agencies that were known not to be able to offer help. On the three occasions that she contacted the 999 service during the study period she always refused to be admitted to hospital. This seemed to undermine all the work that the community matron had done in supporting her to manage the episodes herself. Furthermore, she indicated that there had been a negative impact on her relationship with her general practitioner, and it was unlikely that she would call him out again in the future.

7.3 Chapter Summary

This chapter has reported findings that relate to the provision of health and social care to frail older people, enabling a consideration of partnership working. Exploration of the nature of partnership working with the older participants revealed a complex relationship between the roles that participants are given and are able to enact and the positioning of these roles in the context of a care encounter. At one level the older participants were offered roles and were able to participate in care, although this did not necessarily imply partnership working. On another level older participants were able to exercise autonomy and made decisions that were relevant to

their own situation. All this happened in one care encounter highlighting the contextualised and fluid nature of working in partnership. In particular this reflects the way in which participants are constantly positioned and repositioned in relation to one another at any given time. It was challenging for the older participant to continue to position themselves as an active partner, and it was equally challenging for the community matron to manage their competing role demands and not exert power. Where an older participant was considered to be frail, especially during a period of transition, partnership working was challenged.

The findings also examined the processes involved in discussing and managing relevant concerns and highlighted situations where older participants were enabled to work with community matrons to negotiate care outcomes. The importance of the relationship and demonstrating empathy was illuminated. Furthermore, the characteristics of the relationship between older participants and care staff are posited as a central element in the creation and sustaining of partnership working.

The next chapter is concerned with positioning my attempts to ensure the rigour of the study.

Chapter 8: Establishing rigour

Throughout this thesis I have endeavoured to establish the quality and trustworthiness of the knowledge claims that are being made within the study. This has been achieved by presenting a rationale for all decisions made throughout the process of the research as well as providing a critical stance on my position as researcher. Prior to the discussion of the findings this penultimate chapter further strengthens these claims by providing the framework within which the rigour of this study has been considered and addressed. In particular the following aspects of rigour are detailed and explained: credibility; transferability; dependability; and reflexivity.

8.1 Establishing trustworthiness

Research findings should be as trustworthy as possible (Graneheim and Lundman 2004; Houghton 2013); therefore it is important to judge the quality of this study using appropriate criteria to establish its validity and reliability. Within the literature there have been debates as to the correct terminology that should be used when considering the quality and trustworthiness of qualitative research (Long and Johnson 2000; Lewis and Ritchie 2003; Rolfe; Porter 2007). These on-going debates consider that the terms reliability and validity mean essentially the same thing in a given research paradigm, irrespective of research tradition, and that nothing is gained by changing a label. In the context of qualitative research Avis (2005, p12) described validity as 'the quality and strength of the argument that researchers put forward to substantiate claims about the reliability of their evidence and the credibility of their conclusions'. Researchers must still convince their audience that their evidence is credible and supports their inferences. For this reason I drew upon the concepts of credibility, dependability and transferability as they have been consistently used to describe and support various aspects of trustworthiness in qualitative research (Guba and Lincoln 2005; 1985; Holloway and Wheeler 2010; Polit and Tatano Beck 2010).

8.2 Credibility

Credibility is concerned with the focus of the research, referring to confidence in how well data and processes of analysis address the intended focus of the study (Polit and Tatano Beck 2010). Credibility was considered early on in

the study when I made decisions about the context of the study, the selection of participants and the approach to gathering data (Graneheim and Lundman 2004); as described in detail in this and previous chapters. These were all driven by the focus of the study, itself refined by the review of the literature, and more specifically the research aim and objectives.

Credibility can be further demonstrated through prolonged involvement and persistent observation in the field, triangulation, peer debriefing and member checks (Holloway and Wheeler 2010).

8.2.1 Prolonged involvement and persistent observation

I enhanced the credibility of the research through prolonged engagement and persistent observation in the field (Guba and Lincoln 2005). The engagement commenced when I first made contact with the managers of the nursing service in order to access the clinical setting and this was seen as integral to the success and credibility of the findings. Prior to commencement of the field work a meeting was held in the clinical setting. This provided a forum for discussion around a number of identified issues, for example, relating to the role of nursing staff in the process of patient recruitment. My engagement in the field continued until the final observation and interviews with the last participants. In total the period of field work lasted two and a half years, therefore spending this amount of time in the field enabled me to develop a detailed understanding of the factors that contributed to and influenced the experience of frailty in later life. The length of time in the field enhanced the ethnographic validity (Walker 2012). This added depth to data collection and afforded me the opportunity to observe experiences and participants to describe their experiences (Hammersley and Atkinson 2007).

In relation to developing a comprehensive understanding Houghton et al (2013) suggested that during fieldwork and the process of on-going analysis the lack of new emerging data is evidence that saturation has been achieved, further enhancing the credibility of the research. Within this study to a certain extent data saturation was achieved as I began to notice repetition in the data (Bowen 2008, Green et al 2010; Kuper 2010). It was harder to achieve theoretical saturation as the time frame for the study limited the ability to continue sampling until there were no new themes, particularly in relation to deviant cases (Bowen 2008).

8.2.2 Triangulation

Credibility was also strengthened through the use of triangulation, a common strategy used to demonstrate validity and in turn trustworthiness in a research study (Tuckett 2005; Polit and Tatano Beck 2010). Within this study the use of ethnography enabled method triangulation (Cruz and Higginbottom 2013). As a result the data gathered from observations, interviews and documents were compared to explore the extent to which findings could be verified. For example, my observations of interactions between older people and health care professionals identified factors that contributed to the experience of frailty. During subsequent interviews participants were asked to discuss their perceptions of the situation that influenced the experience of frailty. Through using different methods I was able to find consistencies and inconsistencies in the data thus enhancing credibility (Casey and Houghton 2010; Cruz and Higginbottom 2013).

8.2.3 Peer debriefing

I engaged in peer debriefing in a number of ways in order to enhance the credibility of the study (Casey 2007). First, my supervisors were asked to look at extracts from the case studies and the key themes to see if they agreed with the data labels and the thought processes that had led me to label the data in that way. This created many fruitful discussions during supervision as my data analysis was developed through their agreement and further questioning, thus enhancing credibility. It was not the intention to ask my supervisors to independently analyse the data. I acknowledged that qualitative data analysis was an individual process and therefore it was unlikely that my supervisors would arrive at the exact same thematic structure as myself (Graneheim and Lundham 2004). Peer debriefing also involved the presentation of preliminary findings from this study to a professional multi-disciplinary health care audience at a national palliative care conference. Comments from the audience validated the findings as they resonated with their clinical practice and research experiences.

8.2.4 Member checking

Member-checking as a means of establishing credibility involves allowing participants to read the findings of the research and the content of any transcripts involving their spoken word (Thomas and Magilvy 2012). There

were a number of challenges to undertaking member checking in this study. The decision was made not to ask participants for feedback on the reported data following analysis as it was unlikely that individual participants would be able to recognise themselves and particular experiences following my interpretation of the data. Houghton et al (2013) suggested that member checking should not occur after analysis for this reason however could take place following transcription. I asked the community matrons if they wanted to read the transcripts. All of them stated that they were too busy. It was not possible to ask the older participants to read the transcripts of observations, conversations and interviews. I considered that it was unethical to expect older participants, many of who were experiencing fluctuating ill-health, to read often lengthy transcripts. Moreover, two older participants died during the study and therefore it was important to be consistent across all participants and therefore the decision was made not to use member checking as means to further establish credibility.

8.3 Transferability

Transferability in qualitative research refers to whether or not particular findings can be transferred to another similar context or situation, whilst at the same preserving the meaning and inferences from the completed study (Holloway and Wheeler 2010). In this study transferability of findings to other areas was limited, largely due to the subjective nature of the judgements made in keeping with the ethnography (Cruz and Higginbottom 2013). Furthermore, in the social world of older people living at home receiving support from community matrons, contextual and structural differences in home settings and case management provision means the resulting transference of experiences across settings and to other older people receiving case management may not be possible. However, although findings cannot be generalised to other groups of older people or settings in the UK, findings in this study do offer some insights into the experiences of some older people that may be useful to current and future health and social care practice and policy development. It is these insights that may be transferable.

Considering that inferential generalisation is a matter of judgement my role was to provide rich description to allow others to assess transferability (Lewis 2003). Therefore, in order to enable transferability of such insights I

endeavoured to describe the original context of the research and provide sufficient detail of the original observations and interviews, as well as the environment in which they occurred. By providing detailed descriptions the reader of this thesis and future publications will be able to make an informed decision about the transferability of the findings to their specific context (Lewis 2009). To this end I ensured that I created 'thick' description of the context and the research methods. I also presented examples of the raw data within the context of data collection and the findings so that readers could consider their interpretations. Findings were presented with appropriate exerts from field notes, observations, interviews and case accounts.

8.4 Dependability

Dependability refers to the stability of the data and is determined by the process by which the end product is achieved, which must be robust and dependable. The way to do this is by outlining the decisions that have been made throughout the research process to provide a rationale for the methodological and interpretative judgements of the researcher. Holloway and Wheeler (2010) suggested that dependability is linked to the researcher's transparent use of research based procedures that are recognised and confirmed by other researchers in the field. Silverman (2011) insisted that dependability is fundamental to the ethical nature of the study and the research process. Readers of research must be able to identify how the researcher identified, developed and explored issues relating to the theoretical, methodological and analytical choices made throughout the study (Avis 2005). I endeavoured to be as transparent as possible about the process of research and achieved this by leaving an audit trail of all methodological and interpretative decisions made at each stage of the research process. Even with such an audit trail I acknowledged that it would be impossible to exactly replicate the findings of this study due to the subjective nature of the interpretations I have made throughout (Hammersley and Atkinson 2007). To counter this I have endeavoured to enhance dependability, therefore trustworthiness of this study, through reflexivity (Elliot, Ryan and Holloway 2012). This has been achieved by making explicit and transparent my interactions with the methodology, the context and the participants, throughout the study.

8.5 Reflexivity

In keeping with the epistemological perspectives underpinning this inquiry and the principles of ethnography it was important to consider my position as researcher and the influence this had on the development and process of this study. I acknowledged that my presence in the field influenced the interaction and culture which I sought to scrutinise (Elliot, Ryan and Holloway 2012). Through the use of reflexivity I worked hard to become perceptive to my influence on the study as a whole, particularly the methods of data collection and analysis, thus capitalising on what was revealed about the experience of frailty during this process (Hammersley and Atkinson 2007; Jootun, McGhee and Marland 2009). By providing reflexive detail I demonstrated how I came to terms with the complexities of my presence in a systematic way. In doing so I did not attempt to eradicate the effects of my presence, I sought to gain an understanding of them, acknowledging that by being in the field I became an active research instrument. However, the use of reflexivity in the construction of the findings does not imply the findings do not or cannot represent social phenomenon. Hammersley and Atkinson (2007) recognised that in working with what we currently take to be knowledge, through interactions with others based on meanings, descriptions of phenomena can be made through systematic enquiry and by reflecting on what seems to be problematic. I accounted for my subjectivity, presence of researcher, whenever possible throughout the thesis, paying particular attention to: the rationale and background to the study; issues relating to research methodology; the explanation of the data collection methods and data analysis, and interpretation of findings.

8.6 Chapter Summary

This chapter presented the approach to establishing the quality and trustworthiness of the study, paying attention to aspects of rigour. The next chapter presents a discussion of the findings. The implications of the study are detailed and recommendations for future practice, education and research are made.

Chapter 9: Discussion

The aim of this study was to explore how older people with complex problems experienced and made sense of frailty in their daily lives. At the outset of the study the following research questions were posed:

- What do older people understand by frailty generally and in relation to themselves?
- How do relationships with significant others and care staff influence an older person's experience of frailty?
- How do wider societal influences affect the experience of frailty?

The study adopted an ethnographic case study design to answer the research questions. Ten cases were studied over a period of two and a half years; each case comprised an older person, a community matron and a significant other. This chapter presents a critical examination of the findings and summarises the contribution of the study to the development of the knowledge base pertaining to frailty in later life, as well as to existing theoretical perspectives. It will also detail the unique contribution of my work to the body of knowledge relating to the personal experience of frailty in later life. In addition, the implications of the findings are explained and recommendations made for future practice, policy and research. The methodological strengths and weaknesses of the study are outlined and my reflections on the overall process of conducting the study are described.

This study provides insight into three areas of interest relevant to how older people experience frailty in later life. First, how older people struggle to achieve balance in daily living as their health changes and the diversity of experience attached to this. Second, frailty experienced as periods of uncertainty. Third, the provision of health care services in supporting older people as they encounter transitions in health and illness and fluctuating frailty in later life.

9.1 Explanation of thesis title

Before I discuss the findings it is important to explain the quote that I have used within the title of my thesis. 'Am I still here?' was a phrase used by an older participant who experienced a major transition in their health and illness

during the course of the study, resulting in a three week stay in an intermediate care unit for rehabilitation. On return home the older participant found it difficult to manage daily living as a consequence of their increasing frailty. During a research visit a social worker was already present in the older participant's home; a difficult encounter ensued as the social worker challenged the older participant's concerns about her own ability to manage at home. Gradually the older participant disengaged from the encounter by becoming silent, folding her arms and looking out of the window.

Once the social worker had left the flat the community matron commenced with her routine clinical assessment and prepared to take the older participant's pulse. The older participant spoke for the first time in twenty five minutes and asked, 'Am I still here?' On reflection I felt that the older participant was reaffirming not only her physical self, but her personal identity after feeling out of control of the previous discussion with the social worker. This quote became more meaningful as the study developed. All the older participants worked hard to maintain their daily routine, and in doing so presented a strong sense of self, one that engaged in daily living. Yet, at the same time many experienced being ignored or not taken seriously in light of their frailty. To me this quote summed up the dichotomy in the personal experience of living with frailty.

9.2   Transitions in health and illness in later life

In this study frail older people experienced, and were more susceptible to, transitions triggered by ill-health, as a consequence of living with long term conditions and co-morbidities in later life. This resonates with observations made by Grenier (2012) in a qualitative study highlighting the influence of ill-health on the experience of transition. Disruption to daily living, as a result of transitions in health and illness, was a common occurrence in the lives of the older people in the present study. The frail older adults in my study encountered and expressed loss and disruptions to routine in a variety of ways, depending on their particular circumstances; an observation also made by Nicholson et al (2012a). For example, Martha's experience of ill-health was a sudden-onset event and she initially found it difficult to manage the disruption to daily living brought about by the loss of her mobility. However, eventually she experienced recovery from her heart attacks and fall as

progressive and upward. In contrast, for the majority of the older people in this study transitions in health and illness were enduring and encountered as gradual deterioration over a period of time. Frail older people's attempts to accommodate the transitions were on-going, but led for some to periods of relative recovery and stability, and for others decline or death. These particular patterns to some extent resonate with studies that have identified how a particular 'frailty' trajectory is a common route to death in later life (Lunney et al 2007; Godfrey and Townsend 2008; Thomas et al 2010). These findings also concur with previous studies that show that the nature and experience of disruption is diverse and is dependent on the onset, nature and pattern of the transition trajectory (Becker 1994; Nilsson et al 2000; Godfrey and Townsend 2008).

As Grenier (2012) pointed out, existing perspectives on transitions in health and illness in later life often portray them as single, marked events. She argued that by failing to recognise that older people often experience multiple and embedded transitions assumptions are made regarding the process of adjustment. My study suggests that frail older people's experiences of transition are neither single events, in contrast to findings indicated in previous studies (Torres and Hammarstrom et al 2006; Godfrey and Townsend 2008), nor do they neatly fit into a given category at any one time. Rather than experiencing transition in a linear fashion, with fixed moments that determine the arrival and exit points within a given transition, my study findings suggest that the process of transition for frail older people is more convoluted. The findings indicate that frail older people are more likely to experience transitions in health and illness as a continual process of change over a lengthy period of time, where sudden on-set of events, general decline and periods of relative stability frequently intersect. As such it is difficult to ascertain a beginning and an end. In these fluctuating circumstances for many frail older people a minor, albeit sudden, on-set event can trigger a major transition. Frail older people with uncertain and deteriorating health experience loss and challenges to their identity; these are exaggerated when they move from one care setting to another or their relationships with others change. This is compounded further by the timing of an event, for example, when an event is unexpected which can lead to a frail older person seeming out of control of their situation. Overall, these findings illustrate the complexity

of disruption and how accommodation to change by the frail older person is compromised by many factors. These include the nature and impact of the illness on the older person, their existing health problems, available personal and social resources, as well as the threat to them of further untoward events (Godfrey and Townsend 2008).

9.2.1 Transition as disruption?

These findings provide evidence that some frail older people will experience biographical disruption, where a person's anticipated life trajectory is interrupted, interfering with taken for granted assumptions, behaviours and normal ways of managing daily living (Bury 1982; Godfrey and Townsend 2008; Levealahti, Tishelman and Ohlen 2007). In the present study searching for meaning by the frail older person was a key element in repairing the disruption that had occurred, by linking the changes to daily living and biography. The frail older people achieved this by drawing upon inner and external resources. For some older people this became difficult when the transition became overwhelming, and their physical body could not be trusted, or when their taken for granted activities shaping their personal identity were strongly challenged. This demonstrates how particular meanings attributed to the changes can shape the experience of biographical disruption in later life, enabling or preventing the accommodation of changes (Hockey and James 2003; Lloyd et al 2012a).

This study also builds on theoretical perspectives that recognise that the experience of transitions in health in later life can lead to biographical continuity and reinforcement (Williams 2000, Faircloth 2004). My findings illuminate how, in later life, the work of accepting, managing and integrating the constant effects of ill-health and impairment contributes to continuity of personhood as an autonomous and independent person. This aligns with the concept of biographical flow (Levealahti, Tishelman and Ohlen 2007). Acceptance of being old appears to facilitate the assimilation of declining health into an ongoing life. The frail older people in this study generally had a strong sense of being old. They largely accepted it and this appeared to provide legitimacy for putting up with the effects of ill-health and impairment, thus, further contributing to continuity of self. This is in contrast to others' findings that have mainly outlined how older people do not generally consider

themselves to be old (Degnen 2007; Andrews 2012; Lloyd et al 2012a). However, it builds on the understanding developed by Heikkenen (2004) who observed that in advanced old age, perceptions of age change in the context of impairment and chronological age. For the frail older people in this study it seemed to be that being old was the least of their worries.

In my study frail older people's perceptions of age appeared to be linked to physical and social changes. They demonstrated a more mature understanding of self in the context of age and this contributed to the acceptance of their situation (Biggs 1999). Time was also a critical factor in enabling frail older people to understand and accept the significance and consequences of their ill-health and disability. Where the older participants had been given time to adjust it afforded them a view of ill-health and impairment in terms of ageing and being old, which enabled acceptance to a certain extent, a finding echoed by Grenier (2012).

9.2.2 Frailty and working with disruption

Grenier (2012) identified how living with transitions in health and illness in later life is challenging and requires frail older people to achieve a balance between the level of acquired disability and impairment and the ability to manage daily routines. The 'hard work' associated with achieving this balance is clearly illustrated in my study. The degree of physical, psychological and emotional labour that frail older people engaged in to manage the disruption and subsequent losses was enormous. Regardless of the nature and complexity of the transition my findings provide further evidence that frail older people experiencing transitions in health engage in managing and accommodating the changes (Lloyd et al 2012a). This occurred even when transitions were enduring and multifaceted in nature, pushing an older person's adaptation to the limit in order to survive. The older people's engagement was predominantly achieved through the creating and sustaining of everyday routines and in spite of the hard work was attempted at all costs. Their engagement was influenced by familial, social and cultural contexts as well as their previous life experiences, further illustrating the diversity of frail older people's experiences. On the whole frail older people made the most of what they had and accepted the realities of their lives, although this was challenging at times. These findings build upon theoretical

perspectives that illuminate the capability that frail older people retain in order to work with the challenges that disruption to daily living and accumulated loss brings. The findings of studies by Hicks et al (2012), Lloyd et al (2012a), Janssen, Regenmortel and Abma (2012) and Nicholson et al (2012a) all identified that maintaining routines enabled older people to sustain equilibrium in daily life.

9.3 Dimensions of frailty in later life

A key insight that has emerged from my study is the understanding that in striving to craft and sustain daily routines, older people create a counterpoint to becoming frail. In particular, the present study expands the knowledge base regarding how frail older people exercise personal agency (Becker 1994; Grenier 2008; Hammarstrom and Torres 2010; Breitholtz A, Snellman and Fagerberg 2013). My findings demonstrate that older people have a determination to fiercely resist dependence and in doing so the importance of maintaining personal autonomy comes to the fore. This is evidenced through the many decisions that were made in relation to sustaining the minutiae of daily routines, for example, through the rethinking and prioritising of activities, negotiating the physical environment, learning new skills and accepting support from informal and formal networks. Such determination was even expressed in those older people who received assistance from care agencies. These findings build on existing knowledge that has identified that reliance on others for support with daily living activities does not inevitably lead to loss of capability or agency in making decisions relating to daily life (Hammarstrom and Torres 2010). In addition, my study highlights the large amounts of time that older people spent at home alone in between visits from family and friends and formal service provision; during this time they will have made many decisions regarding daily living although these were not visible in the study.

In examining day to day experiences where autonomy was exercised findings from my study illuminate how frail older people maintain, what Nordenfelt (2004) referred to as the 'dignity of identify'. In continuing to make decisions the older people demonstrated their dignity as 'integrated and autonomous persons with a history and a future', even when that future was short (Nordenfelt 2004, p33). Anchorage in daily routines, as previously mentioned,

is key to enabling frail older people to exercise autonomy. Nicholson et al (2012a, p1431) described how frail older people constructed 'their own habitual routines or personal scripts'. In my study similarly, living day to day and the existence of routines not only enabled the assimilation into an on-going life of declining health and disruption to daily living, but it afforded a way of maintaining dignity of identity, even in situations that compromised and threatened it.

In demonstrating how frail older people exercise their personal autonomy these findings provide further evidence that older people attempt to resist the process of objectification that comes with the stereotyping of the ageing process and in particular frailty. As in other studies the majority of older people rejected the idea of being considered frail (Van Campen 2011; Nicholson et al 2012a). Within the context of my study the label of frailty had been applied to all the older participants by the community matrons; however, they managed to contain or resist their frailty by persevering with daily routines. This was also the case for those older people who saw themselves as frail. Here, the body was seen to mediate the relationship between an older person's self-identity and their social identity (Goffman 1990); displaying what Gilleard and Higgs (2011) referred to as socially recognised intent.

These findings thus offer some insights into the current debates regarding frailty and the fourth age, a period that is often depicted as one of decline, including loss of agency over the body, and lack of meaning (Twigg 2006; Gilleard and Higgs 2010). Clearly, the older people in this study experienced bodily changes which were exacerbated by ill-health, and where their agency over their bodies was challenged. However, although older people found caring for themselves to be problematic, my study has demonstrated that they were able to engage in meaningful daily living; as well as accommodating changes to their customary way of life, albeit with support. Although some frail older people made fleeting reference to the end of life and/or move to a care home, this study illustrates how making choices in day to day living enabled a continued engagement with life; rather than the withdrawal from successful body maintenance described by Higgs and Rees-Jones (2009). Gilleard and Higgs (2010) argue that the fourth age cannot be understood exclusively from personal experience, and that the fourth age is

shaped by institutional practices. However, this study illustrates the counterpoint that frail older people provide to the notion of the black hole scenario depicted by Gilleard and Higgs (2010); the frail older people who took part in my study clearly still had things to look forward to in their lives.

9.3.1 Resilience and frailty

Older people expressed a variety of responses to the challenges faced in daily living, which included: anger, anxiety, frustration, bewilderment, sadness as well as the expression of humour and display of a positive attitude. It is through exploring such expressions in the context of daily life that the notion of resilience emerges as a contributing factor to how older people reject the idea of being frail. The findings of my study illustrate how high risk situations were encountered as a result of fluctuating ill-health and disability, challenging capacity for independence. There was diversity in the types of behaviours that the older people drew upon to respond to and adapt to difficult situations supporting the view of Fitzpatrick and Vacha-Haasa (2010) that resilience, as a response to adversity, links to personality characteristics. As I listened to the older people's life stories it also became apparent that their resilience had been developed overtime as a result of successfully coping with adversity throughout their lives, echoing the findings of studies by Wagnild and Collins (2009) and Wiles et al (2012). For example, most of the older people in this study had lived and worked through the Second World War, and the majority had subsequently worked and brought up families. A substantial number had lived in the slums and had been rehoused. All of them had experienced the death of a close relative. To some extent, the many examples of shared experienced that my study highlights also reflects a cohort effect (Chandola et al 2007). In this study, as well as life experience and biography resilience was also inextricably linked to relationships with others and the environment, supporting the findings of Wiles et al (2012) that resilience is also embedded in social contexts.

9.3.2 Frailty as uncertainty

In demonstrating how older people exercise their personal autonomy and resilience, these findings provide further evidence that the work involved in maintaining daily living does not match up to the stereotypical views of frail older people, similar to the studies of Van Campen (2011) and Nicholson et

al (2012a). However, although older people often reject being seen as frail, the present study illustrates how older people experience moments of 'feeling' frail. As found in other studies (Lloyd et al 2012; Portacolone 2013) these episodic moments of frailty in daily lives were experienced by the older people as uncertainty, where daily living became precarious and resilience was threatened. This led to periods of anxiety and vulnerability. Some older people were able to articulate this although some were not.

In this study, older people predominantly experienced 'feeling' frail when they were unable to engage in daily living activities and keep their routine going. Furthermore, my findings suggest that where older people were able to maintain equilibrium in daily living it was often a fragile balance between what had to be done and the ability to do it. Consistent with the literature the balance was for the most part tipped by bodily decline (Grenier 2007), although my findings also suggest that for some older people deterioration in mental health and wellbeing further exacerbates physical decline (Hurd Clark 2010). This was more likely to happen where transitions in health and illness were complex. For example, if the onset of a transition was sudden resulting in new chronic illness and impairment, or multifactorial and intersected in the context of enduring ill-health. Movement across care boundaries compounded this further. Older people's feelings of frailty were also linked to anxiety regarding social support networks, and being alone, contributing to the experience of frailty as multi-factorial in nature (Nicholson et al 2012a). There was diversity of experience highlighting the individual nature of illness transitions and trajectories and the unique dynamic between physical, social and psychological factors that influence such experiences.

Overall, these findings suggest that such an embodied experience forces older people to anticipate a situation where independence may decrease and the ability to exercise personal agency is reduced, similar to what Grenier (2006, p1) described as 'rupture of self'. 'Feeling' frail also reflected an attempt to make sense of the change brought on by transitions in health and illness, actual or anticipated, whilst integrating the change in the context of a person's sense of self (Twigg 2006). In this study, 'rupture of self' led older people to contemplate their ability to continue living at home, their own ageing and mortality. These findings expand the current thinking regarding the way that changes in the body render the negotiation of the everyday

difficult and how these are interpreted by frail older people in the context of an ongoing life.

9.3.3 Frailty and liminality

These findings also add to contemporary perspectives regarding the passage of transition, in particular the concept of liminality. In the context of transitions in health and illness, 'feeling' frail in this study can be likened to being in a liminal state. Turner (1967) first described a liminal state as 'being betwixt and between' a point of change, in the context of rites of passage (Van Gennep 1961). Barrett, Hale and Gauld (2012) described how rites of passage models are widely employed to explain life-stage transitions and are particularly useful in understanding change in old age. At times in my study, older people were positioned 'betwixt and between' a point of change, due to fluctuating ill-health, when they were unable to manage daily routine. These situations were characterised by ambiguity and feeling unsettled. Here, increasing impairment and change in circumstances upset the previous equilibrium and threatened an older person's identity as an independent person. This focused the older people's thoughts towards their ability to stay at home and their own mortality. Similar to observations noted in a study by Janlov, Hallberg and Petersson (2006) my study provides evidence that older people do experience periods of instability and discontinuity that can be likened to a liminal state.

However, for the majority of the frail older people in this study being in a liminal state was transient, in contrast to the recent observation by Nicolson et al (2012b) that frailty brings with it a persistent state of liminality. My findings suggest that, over time, the experience of frailty, as a liminal state, becomes a temporary feature in a given life story, more in keeping with the observations of Grenier (2006; 2012). Therefore, my findings suggest that the experience of frailty and its relationship to liminality is more complex and fluid. Furthermore, they support the view that the emotional work of frailty is central to understanding the experience of being frail (Grenier 2006; Nicholson 2012a).

9.4 Health and social care provision - rhetoric and reality

As illustrated in this study the lives of frail older people were complex, and they could be described as having high support needs (Blood and Bamford 2010; Katz et al 2011). Many were receiving a combination of services from statutory health and social care agencies, as well as informal networks, to support independent living. These findings offer insights into the way that frail older people engage with and are supported by health, and to some extent, social care services. Furthermore, they challenge the policy rhetoric which, as Lloyd (2012b) suggested, presents a seemingly uncomplicated view of the nature of partnership working between older people with high support needs and those who provide care for them.

Similar to previous studies (Lyttle and Ryan 2010), frail older people in this study experienced varying levels of involvement within their care. The findings of my study illustrate that the degree to which an older person was involved was influenced by their fluctuating ill-health and disability and their understanding and expectations, as well as the structure and organisation of the services, including attitudes of health and social care staff. This has highlighted that it is unrealistic to expect frail older people to be involved in their care to the same extent all the time, highlighting the complexities and challenges in creating and sustaining partnerships.

At one level the participation of frail older people in their care was clearly evident, although it was enacted in different ways. This was dependent on an older person's individual circumstances and capabilities as well as how care was delivered to them by care staff. In this study, participating in care mainly involved older people sharing information and opinions with the community matron. This contributed to decisions that were made about their care and treatments, similar to findings in studies by Wellard et al (2003) and Eldh, Ekman and Ehnfors (2006). It also comprised engagement in monitoring activities during and outside of the consultation visits. In line with current understandings (Ellins and Coulter 2005; Penny and Wellard 2007) participating in care also promoted concordance with treatment plans, which in turn contributed to independence in daily living. However, where there was deterioration in physical and mental health and wellbeing it became more

challenging for frail older people to participate in their care, although they endeavoured to do so.

9.4.1   Partnership working and relationships

The nature of the relationship between frail older people and health and social care staff was integral to enabling participation in care. In this study all the older people had developed a strong relationship with the community matron and this appeared to create a platform for their participation in care within the care encounter. This was supported by the interpersonal skills of the community matron and the extent to which they were able to adopt an approach that demonstrated respect for personhood and dignity as well as maintaining an emotional connection (Hubbard, Tester and Downs 2003). This resonates with findings from other studies that recognised the advanced interpersonal skills that community matrons utilise in providing psychosocial support (Savage 2012); in my study they were integral to creating and sustaining participation in care.

However, the findings from my study also illustrate the circumstances where relationships negatively influenced participation in care, thus inhibiting decision making. Within the case studies I saw isolated examples where I concluded that the older person was not treated with dignity and respect. In a small number of instances where the relationship between an older person and care worker was less established opportunities for identifying the wishes of the older person were limited. In this study such experiences were sometimes linked with the way that care was organised and have to be considered in the context of the wider issues in care meaning that staff are often under skilled and poorly paid and have to meet targets set by the company employing them (Barrett, Hale and Gauld 2013). However, in the context of the ten cases I observed these situations infrequently. It is important to acknowledge here that the nature of my study, predominantly the recruitment of community matrons, means that at times the lens through which I observed the cases may have been more closely aligned with the community matrons than other care staff.

The structured opportunities for interaction and participation were also important for the older people in this study in sustaining social well-being, building upon a developing body of knowledge that recognises the

importance of social interaction for older people who are isolated (Cloutier-Fisher, Kobayashi and Smith 2011; Katz, Holland and Peace 2013). Here the meaningful relationships that were developed with the community matrons and the care workers enabled the older people to feel part of a social world as well as contributing to feelings of self-worth. The importance of such relationships goes some way to explain how a positive sense of self was retained in circumstances where care standards were below what was expected, similar to findings described by Lloyd et al (2012a).

9.4.2   Partnership and decision making

Although participating in care was clearly evident and important for the older people, this study illuminates that participation in itself does not constitute working in partnership. Respect for autonomy in decision making is emphasised as a crucial element of partnership working (Cheek 2003). This study highlights how, within the context of a care encounter, a frail older person's ability and desire to exercise autonomy in decision making fluctuates. Maintaining autonomy and the right to independent decision making was difficult for older people when their functional independence and mental health and wellbeing was challenged, particularly in the context of transition (Morgan et al 2006). Lack of mental capacity was not an issue in this study but clearly will be for some older people and will further influence their ability to exercise autonomy (Lloyd 2012). How an older person is positioned within a partnership can also affect the extent to which autonomy in decision making is achieved.

The study has highlighted the risk of 'cross purpose' interactions between the community matrons and carers and the older person, illustrating the tensions older people may face when trying to be autonomous and make decisions about their own care. Similar to other studies, making decisions regarding 'risky' behaviours was problematic, for both the older person and the community matrons, and limited the degree of partnership working (Hughes and Goldie 2009; Modig et al 2012). In my study, frail older people engaged in what the community matrons perceived to be 'risky behaviours' linked to life style choices, mobility and food. Where community matrons took control of a situation to minimise the risk they perceived to the frail older person it appeared to be influenced by their sense of professional responsibility, as

well as the requirement to practice within the context of national and local policy protocols. Furthermore, frail older people were often steered towards what the community matron thought was the 'right' choice (Lyttle and Ryan 2010). Cheek (2003) and Ceci and Purkis (2009) have described how the home can become a site of professional knowledge and action. In situations where cross purpose interactions were evident I felt that the older person's home was dominated by professional knowledge and this inhibited the older person's decision making ability. The irony is that these encounters took place within a small time frame in the daily life of the frail older person; for the rest of the time the frail older person would make their own decisions and act on them, taking appropriate risks for themselves.

Frail older people were able to reposition themselves and challenge decisions made by the community matrons to take charge of a situation. This was another way of resisting being defined as incapable and dependent. This study illuminates intermittent situations where frail older people were able to exercise autonomy indicating that there can be power sharing within the care encounter. This is congruent with what Cheek (2003) identified as the cornerstone of a sharing and enabling partnership. Conversely, in certain situations some frail older people relinquished their ability to engage in decision making and invested their trust in the community matrons (Morgan et al 2006). In line with Ceci and Purkis (2009) these findings provide further evidence that for some frail older people how risk is professionally conceptualised and operationalised can lead to the limited choices of withdrawal, refusal or imposition of services. These challenges to partnership working appeared more prominent during the experience of transition and when the older person was experiencing uncertainty or feeling frail.

9.4.3 Frailty and end-of-life care

The findings of this study demonstrate that frail older people do think about their own mortality in the context of fluctuating ill health and decline. However, the older people in this study appeared to be concentrating on living rather than dying. Furthermore, they were concerned with where they would live and how, particularly when they experienced further losses to their independence. Consequently, it was difficult for the community matrons to initiate and pursue end of life conversations with frail older people. This study

presents the tensions that working within policy frameworks that separate out living from dying brings and in particular it identifies the significance of identifying the frail older person's experience and perspective (Lloyd and Cameron 2005). Consistent with the findings of Nicholson et al (2012b) my study reveals how the links between dying and frailty in old age are not clear cut, requiring much greater exploration and development.

9.5 Strengths and limitations of the study

One of the strengths of this ethnographic study is that it enabled older people, generally confined to their home, to express their views and opinions about living with ill-health, impairment and frailty. Older people, who would otherwise have been invisible, were given the opportunity to contribute to understandings of frailty in later life. These older people did not have a high profile and as Katz, Holland and Peace (2013) have described, lacked a collective voice. I acknowledge that I have interpreted and analysed the accounts offered by the participants (Denzin and Lincoln 2012), however I endeavoured to use extracts from the data to support my analysis and in this way the voice of the older person is retained. Of course what is missing is the voice of the older person who is unable to communicate easily, for example, those with conditions such as dementia or stroke. A pragmatic decision was made at the beginning of the study not to recruit frail older people with severe cognitive impairment or communication difficulties. Therefore, these findings do not capture their experiences and this can be seen as a limitation of the study, although some of the findings will clearly be intensified in light of such issues.

There were methodological challenges to ensuring that older people were given the opportunity to express their views, particularly when I interviewed them. Given that the aim of the interviews was to encourage older people to share their personal views and experiences, it was important to foster a relationship that enabled this. I drew upon feminist approaches to in-depth interviewing, being aware that the interviews would become a collaborative venture, between me and the older person. Feminist approaches to interviewing advocate a more reflexive and interactive style, suggesting the interview is a reciprocal exchange where it is equally important that the researcher expresses feelings and discloses personal information (De Vault

and Gross 2012). In expecting the researcher to do the same as the participant an attempt is made to shift power away from the researcher; this avoids objectifying the participant fostering a non-hierarchical approach and respect for personhood (Lewis 2009).

However, I found that it was difficult to ascertain whether I shared power with the older participants to give them some control over what they wanted to talk about. At times it felt as though I held the power, because they did not refuse to answer any of my questions. However, on reflection the older participants did not always answer the questions that I asked directly. In these situations I considered that they had directed the focus of the discussion to one that they felt more comfortable with; this to some extent demonstrates that they had some control over the content of the interview. I also endeavoured to pick up non-verbal cues which indicated that an older participant may not wish to pursue a topic, but the fact that they were experiencing major disruption meant that this was sometimes easier said than done, highlighting the challenges in conducting such interviews.

This study aimed to explore how experiences of frailty changed overtime, therefore the longitudinal approach to data collection was used to capture important aspects of change for most participants. In this study most participants were followed up for a minimum of six months. This is in contrast to previous studies where time frames of 17 months were considered insufficient to capture changes in how frailty was experienced over time (Nicholson et al 2012a). However, in the present study the time frame was enhanced by the use of ethnographic methods of data collection. Data was drawn from multiple sources enabling the individual experience and the context to be richly described further enhancing the capture of experience over time. However, caution is required when considering the transferability of the findings. First, the sample size was relatively small in this study although in the context of ethnography I was concerned with information richness and exploring ideas from the data which illuminated the individual's perspective in the context of wider factors (Hammersley and Atkinson 2007; Hardin and Clark 2012). Furthermore, great attention was given to establishing the trustworthiness of the findings through researcher reflexivity, and methods for ensuring rigour which have been addressed throughout the thesis.

Older people were recruited to the study through the community matron teams and therefore I did not capture the experience of frail older people who were not in receipt of these services; this is a further limitation of the study. The community matrons were asked to select participants using a number of criteria, one of which included the question, 'do you think this older person is frail?' On reflection, a frailty scale, such as that developed by Rolfson et al (2006), could have been used although this would have meant asking the community matrons to apply this to their patients in the context of a busy workload. This may have influenced their decision to take part in the study. This does limit the findings to some degree but captures the complexity inherent in contemplating frailty. Using an operational definition that was clinically operationalised by the community matron did allow for a wider multi-factorial understanding of frailty to emerge.

The study also had limitations with regard to the mix of the participants. One of the aims of this study was to capture a diverse range of experiences and I had intended to recruit older people taking into account their age, gender, cultural and social background. However, the small sample recruited was white, from the UK and predominantly from a working class background therefore caution is required when considering these findings. Also, all these older people were keen to be involved in the study and therefore could represent a group of people who were keen to share their stories and experiences. Therefore, I acknowledge that this study excludes older people who did not wish to share their experience in this way, thus limiting the findings.

At the outset of the study I had intended to recruit family carers and significant others to take part in interviews, to further illuminate the experience of frailty in older people. Clearly, informal and formal care networks were integral to the support of the older person at home. However, few agreed to be formally interviewed as part of the research and therefore the carers remained in the background, limiting the understanding of the factors that influence an older person's experience of frailty.

9.6 Contribution to scholarship and the body of knowledge relating to frailty

Although there are limitations to this study, as acknowledged and discussed in the previous section, I suggest that the substantive findings of this thesis make an original contribution to the growing knowledge base of frailty in later life in three main areas. These relate to frailty and transitions in health and illness; the experience of frailty as a persistent 'liminal' state; and how interactions with health and social care staff shape the experience of frailty.

First, my study has revealed new insights into the interrelationship between frailty and transitions in health and illness. To the best of my knowledge this is the first study to present empirical findings that challenge the current understandings of how frail older people with complex problems experience transitions in health and illness. Existing literature has focused on transitions in health and illness as single, marked events (Godfrey 2008). Findings from this study reveal that for many frail older people with complex problems, transitions in health and illness are enduring and complex, where sudden on-set of events and general decline frequently intersect. The constant and embedded nature of the transitions in health and illness influence how a frail older person manages and adjusts their daily living routines. This is complicated further when multiple transitions occur, such as movement across care boundaries and bereavement. The findings suggest that frail older people demonstrate resilience in the face of complex transitions in health and illness. Here resilience was multi-dimensional, combining personality traits, personal experience, social and contextual factors. Therefore, this study adds to the framework for considering the relationship between frailty, transitions in health and illness and resilience and the consequences for daily living and subsequent health and social care support.

Second, my findings offer an alternative perspective to published work that has illuminated how frailty brings with it a persistent state of liminality (Nicholson 2012b). On the basis of the analysis of the data collected in this study I have argued that frailty as a liminal state is a temporary feature in the context of transitions in health and illness. Furthermore, findings from this study concern how frail older people, in the context of transitions in health

and illness, experience such temporary moments of liminality as uncertainty and feeling frail. In previous work the experience of feeling frail has not been linked to physical impairment (Grenier 2006), whereas in my study feeling frail was often linked to disability and impairment.

Third, I have identified no studies that have examined how frail older people, living at home, interact with health and social care professionals in the context of clinical encounters. Thus, as far as I know this is the first study to present findings based on the direct observations of such encounters, in particular how they are both shaped by, and contribute to, frailty. The study findings have the potential to contribute to enabling partnership working between frail older people and those who provide care. I have argued that these findings challenge the rhetoric of partnership working with frail older people. There is a tendency to underestimate the ability of frail older people to participate in their care. In many circumstances frail older people can exercise autonomy and make decisions that are relevant to their own situation. However, the findings from this study suggest that it is difficult for frail older people to be constantly engaged as an active partner in their care, and nor is it constantly desirable. I would argue that the contextualised and fluid nature of partnership working needs to be reflected in policy and practice.

9.7 Study implications

Findings from this study raise a number of implications for clinical practice and health and social care policy.

These findings contribute to the body of knowledge that health and social professionals, particularly nurses, require when engaging in supportive care for frail older people. In doing so they also enhance the models of care that are currently being developed for frail older people with complex health problems in health and social care practice (Coulter, Roberts and Dixon 2013; NHS England 2014a). A key remit of such models and guidance is to develop a more focused approach to personalised care planning, with the aim of ensuring that an older person's values and concerns shape the way they are supported to manage their health and wellbeing. This also includes a shift towards care that is co-ordinated around the full range of an

individual's needs rather than a disease based focus; as well as enabling older people to work collaboratively with health and social care professionals to support effective self-management, including that of complex problems.

My study illuminates the personal and lived experience of frailty and therefore contributes to the body of knowledge that is required to engage in personalised care planning with frail older people. In particular, health and social care staff must develop an understanding of the complex patterns and enduring nature of transitions in health and illness that frail older people can experience. It is also important that health and social care staff understand how frail older people attempt to manage and make sense of the disruption that occurs in order to maintain continuity of self, so that they can be supported to sustain daily routines and manage their health and wellbeing. Furthermore, the resilience that frail older people draw upon must be acknowledged. This involves developing an awareness of the importance that frail older people attach to maintaining daily routines and how they make sense of and attach meaning to the disruption and changes experienced. Thus, health and social care staff must enable older people to express their experience of transitions in health and illness. This could enable a more proactive approach to the care of frail older people, rather than a reactive approach to ill-health and decline. To do this the current emphasis placed on the burden of frailty needs to be balanced by a greater focus on the capacity of frail older people in conducting their daily lives.

My findings have identified that frail older people are not always able to articulate their concerns, or make sense of what is happening to them. In these circumstances it becomes difficult to identify the frail older person's perspective, particularly in relation to the meaning that they attribute to a changing situation; therefore the opportunities to adopt a personalised approach to assessment and care planning can be lost. There are a number of implications for clinical practice here. I suggest that there is real therapeutic potential in exploring the emotional experiences linked to a frail older person's interpretation of events when they state they feel frail, or appear to be living with uncertainty. Here I suggest that there is scope to develop clinical practice, specifically nursing, in relation to advanced communication skills and interventions that will enable the expressions and

identification of the emotional requirements of frail older people. This will further enhance the engagement of frail older people in their care, a key element that underpins personalised care planning (Coulter, Roberts and Dixon 2013; NHS England 2014a). Taking all these factors into account, an approach to care that establishes and values the meaning that a frail older person ascribes to their ill-health must be more widely adopted in main stream health and social provision.

Working within a partnership model of care is considered to be fundamental to personalised care planning for frail older people (Coulter, Roberts and Dixon 2013; NHS England 2014a). Specifically, a partnership approach is considered to support shared decision making around support needs, goals and interventions. My study offers some useful insights into the nature of partnership working with frail older people and health and social care staff. They challenge the assumption that there is a shared understanding of what partnership working means and subsequently entails for both parties. These insights have the potential to contribute to future policy guidance relating to partnership working with frail older people, in particular the nature of the roles required to facilitate partnership.

First, my study shows that the ability of frail older people to make decisions about their care fluctuates; maintaining autonomy and the right to independent decision making is difficult in the context of complex transitions in health and illness. The findings have highlighted that it is unrealistic to expect frail older people to be involved in their care to the same extent all the time. Therefore, policy guidance regarding partnership working needs to reflect the dynamic and fluid nature of partnerships when older people are experiencing complex transitions in their health and illness. Partnership working needs to be considered as a continuum from participation to collaborative practice and this approach needs to be reflected in policy guidance.

Second, the findings have illustrated how a focus on clinical and medical assessment, including risk, can inhibit partnership working leading to some of the wider care requirements of frail older people not being addressed. This is particularly the case in those moments when an older person is feeling frail or

experiencing uncertainty. Findings from this study would suggest that there is the potential to enable older people to have greater participation in decisions regarding their care. This is particularly true in areas relating to managing risk to personal safety, where, in spite of good intentions of the health and social care professionals involved, they have often been excluded. Health and social care professionals need to be able to recognise situations that lead to conflict so that supportive negotiation can take place and appropriate solutions identified. In light of this, an awareness of their own practice needs to be developed and how their actions and behaviours can positively or negatively influence an older person's autonomy and dignity.

However, there are wider implications for considering the approach to partnership working and service delivery for frail older people, particularly the development of specialist roles. Case management is still being promoted as an appropriate model of care for working with frail older people (NHS England 2014a). In light of this study, the case management role has the potential to provide support that links the physical, social and psychological requirements of a frail older person with complex health problems. The findings have identified a number of ways in which community matrons, as case managers, worked positively with frail older with complex health needs. In particular, the community matrons worked with frail older people in a way that maintained respect for personhood and dignity and in some instances shared decision making was evident, elements that Bridges et al (2009) identified as best practice for older people. In particular they were able to provide psychosocial support as well as acting as an advocate in the context of working with other agencies.

However, the findings also identified constraints to partnership working within the role, where the focus on clinical and risk assessment prevented partnership working with frail older people, specifically a personalised approach to care. Community matrons as case managers are already functioning as advanced practitioners. However, in relation to working with frail older people the role needs developing to include the knowledge and skill base required to care for frail older people, for example, a person and relationship centred approach, comprehensive geriatric assessment. This is

in line with the development of advanced practice skills for frail older people in hospital (Goldberg, Cooper and Russell 2014). In particular, there is scope to expand the role further in conjunction with developing approaches and models of care for older people (NMC 2009; Bridges et al 2009; Katz 2011). For example, Katz et al (2011) created a model that puts the older person at the centre and distinguishes between the things that older people want and value and the factors that hinder or help them to access these things.

Furthermore, it focuses attention on what can be done differently to help older people with high support needs achieve and retain the things they value in life, rather than simply assuming that their individual social and/or medical conditions will inevitably place many experiences out of reach. As Branfield and Beresford (2010) suggested improving frail older people's quality of life is not just about re-designing services, but focusing on what works and in which situations. Working with frail older people with high support needs in any setting requires a broad set of skills and these can be developed within the context of the case management role further.

Any expansion of this model of service delivery will have financial implications (NHS England 2014b). However, the role of community matrons, as case managers, is well established. Therefore any additional costs are likely to be restricted to the development of educational programmes and targeted clinical interventions, such as the application of comprehensive geriatric assessment frameworks. Also, major drivers and incentives are currently being put into place to bring the management of frailty to the forefront of clinical practice (NHS England 2014a). Commissioners of services are being encouraged to make focused use of the Better Care Fund in transforming the care of frail older people and developing the role of the community matron could be part of this remit.

9.8 Recommendations

Overall, I achieved the study aim and have examined how older people with complex problems experienced and made sense of frailty, thus contributing to the knowledge base pertaining to the personal experience of frailty. Through exploring the implications of the findings further questions and

opportunities have been raised in relation to practice, education and research. My recommendations are as follows:

Clinical practice

- Frail older people experience complex transitions in health and illness. In the context of personalised care planning (NHS England 2014a) it is important that health and social care professionals understand how frail older people make sense of such transitions, in particular how resilience is affected. Information regarding personal experiences will ensure that frail older people are effectively supported to manage their ill-health and well-being and continue to engage in daily living. There are situations when it is difficult for the frail older person to articulate their experience especially when they are feeling frail or uncertain. Consequently, it would be useful to develop focused interventions on the emotional requirements of frail older people in the context of transitions in health and illness, for example, the 'emotional touch' technique (Dewar et al 2009). This would contribute to personalised care planning.

Education

- The study findings have raised many implications for the development of the knowledge base that health and social care staff require in providing supportive and person-centred care for frail older people, including how frail older people experience complex transitions in health and illness, how older people respond emotionally to the experience of frailty and how partnership working is influenced by the experience of frailty. Clearly, there is scope to contribute to undergraduate and post-graduate curriculum development across a range of courses for nursing and allied health and social care professionals. In doing so the knowledge, skills and attitudes required in caring for frail older people will be enhanced. However, I acknowledge that many frail older people's services are provided by unqualified health and social care assistants therefore it is also important to influence the development of curricula in colleges of further education.

Policy

- Recent policy directives and guidance emphasise the need for getting services right for older people living with frailty (House of Lords 2013; NHS England 2014a). Clinical examples of how models of care can be implemented for frail older people are embryonic and currently tend to be focused on the needs of acute hospital patients, for example, the

emergence of frailty units and the development of hospital-based advanced practitioner roles. Whilst these are clearly important, concurrent developments need to occur to ensure that comprehensive and co-ordinated services are being delivered across all health and social care services, including those delivered within the voluntary sector. I recommend that the case management role, currently delivered by community matrons, is developed and expanded to reflect the flexible and person centred approach that is required when working with frail older people. Policy guidance needs to reflect a less rigid approach to clinical assessment in the context of frailty. Developing the existing case management service in this way would help resource and embed service redesign.

Research

- The personal experience of frailty is under explored. This research focused on frail older people from mainly white British backgrounds. Subsequently, to reflect diversity of experience further research is needed to investigate the experience of frailty of older people from other cultural backgrounds and more specifically those with communication difficulties, including dementia and stroke.

- Since the start of my study policy guidance has increasingly focused on identifying individual levels of frailty so that appropriate pathways of care and interventions can be organised according to need. There is a range of frailty screening and assessment tools available to use. However, at this stage it is important to ensure that within these tools the personal experience of frailty is not overlooked. At the moment this appears to be limited to cognitive experience relating to mood (Rolfson et al 2006). Therefore it would be useful to devise mixed methods studies to investigate the relationship between the use of formal frailty assessment scales and the personal experience of frailty.

9.9 Conclusion

The aim of this thesis was to develop an understanding of frailty in later life. The original impetus behind this empirical study came from a professional and personal interest in developing an understanding of the personal experience of frailty. This was in the midst of an expanding knowledge base with a predominant focus on frailty from a bio-medical and functional perspective. In doing so, my intention was to contribute to the developing body of knowledge around the personal experience of frailty in later life, in order to enhance the care of frail older people. Adopting a prospective, longitudinal, ethnographic case study design I endeavoured to undertake a

focused and intensive analysis of how of an older person with complex problems experienced and made sense of frailty in their daily life.

After two and a half years of fieldwork the study findings illustrate a complex picture. Frail older people work hard to craft and sustain daily routines in the context of complicated and enduring transitions in health and illness. Maintaining independence, dignity and continuity of personhood provide a counterpoint to becoming, or being seen as, frail. In doing so frail older people present a determination to fiercely resist dependence and in doing so the importance of maintaining personal autonomy comes to the fore. It is through exploring such expressions in the context of daily life that the notion of resilience emerges as a contributing factor to how older people reject the idea of being frail. In this study frail older people experienced episodic moments of frailty in their daily lives, which were often articulated as uncertainty, where daily living became precarious and resilience was threatened; akin to a temporary period of liminality. These findings raised implications for clinical practice, education and research.

It is this backdrop against which community matrons attempt to work in partnership with frail older people. Frail older people are involved in decisions about their own care but this involvement is influenced by their fluctuating ill-health and disability, their understanding and expectations, as well as the structure and organisation of the services, including attitudes of health and social care staff. Thus, it is unrealistic to expect frail older people to be involved in their care to the same extent all the time, highlighting the complexities and challenges faced in enabling partnership working. Frail older people can and do develop strong relationships with community matrons and this appears to create a platform for their participation in care within the care encounter. However, the role of case management in working with frail older people with complex problems work is framed by a policy of clinical and risk assessment. Therefore at times, assumptions underpinning the label of frailty can be at odds with the frail older person's experience. As a result, the situations where frail older people experience uncertainty and feel frail are often overlooked. These competing demands have implications for policy development and need to be considered by policy makers, commissioners and providers of community services and practitioners alike.

Only then can effective supportive care services be delivered to frail older people.

When I embarked upon this study seven years ago I had no idea of the journey of discovery that I would undertake. At the outset I had already begun to question the nature of frailty in my own area of clinical practice and in relation to my own personal life. My own thoughts regarding frailty have moved on. I have had the privilege to meet ten older people whose capacity for engaging with life constantly amazed me, even in the most difficult and taxing circumstances. The work of exploring the personal experience of frailty must continue in order to develop a comprehensive approach to working with frail older people in later life.

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Appendix 1   Community Matron Information Sheet

The University of Nottingham

Please quote ref no:

Research Participant Information Sheet: Community Matron Version 2: April 2008

Study Title: **A study to explore how older adults experience old age**

Researcher: Julie Skilbeck

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. 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. Take time to decide whether or not you wish to take part. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Thank you for reading this.

What is the purpose of the study?
I am interested in exploring how people, aged 75 and over, with health problems living at home think and talk about the experience of getting older. Also, I would like to find out more about how community matrons carry out their work with older people. I hope that the study will provide information about the experience of growing older. This will help to identify the types of help that older people require to help them manage at home, as well as the training requirements for care staff who work with older people.

Why have I been invited?
You are a community matron who works with older adults aged 75 and over. Would you be able to help me by answering some questions about the experience of caring for an older person? I hope to contact between 10 and 14 older people, and their community matrons, for my study.

Do I have to take part?
No, your taking part is voluntary. It is up to you to decide. I will describe the study and go through this information sheet with you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect your work situation in any way.

What will be involved if we agree to take part in the study?
You will be asked if I can observe what happens when you visit and provide care for an older person in their own home. If you agree I would like to work with you whilst you visit the same client once a month for 6 months. You will also be asked to take part in 2 short interviews. In the interviews you will be asked questions about your work with the older

person. Each interview should last no longer than half an hour. The visits and the interviews will be recorded on a minidisk recorder with your permission.

Will anyone else be involved in the study?
I will be asking one of your clients and their family members if they would like to take part in the study.
What are the possible risks of taking part?
For some carers certain questions could raise issues about the experience of growing older that might be upsetting for them. I am an experienced nurse researcher and am able to talk to people in these types of situation. I will be aware of sensitive or difficult issues that you may experience. Support would be available following the research interview if required.

You may feel that there will be the opportunity for criticisms to be made about your work. The researcher will not intend to be critical of your work and notes taken during the period of the observations will be available at your request. I will discuss any concerns that you may have should they arise. However, should you reveal practice that may be harmful to the older person this will be managed according you to your work code of conduct. Where appropriate, therefore, confidentiality may have to be breached in the public interest.

What are the possible benefits of taking part?
The information that we get from the study will help me gain knowledge about the experiences of being an older person with health problems, as well as how community matrons work with older people. I cannot promise the study will help you but the information I get from this study may help develop future services.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have any concerns or other questions about this study or the way it has been carried out, you should contact Julie Skilbeck on 0114 2255613, or you may contact the University of Nottingham complaints department. The detailed information on this is given in Part 2.

Will my taking part in this study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?
You are free to withdraw from the study at anytime. Any information that has been collected during the time that you gave consent to be in the study will be used to write a report.

What if there is a problem?
If you have a concern about any aspect of this study you should ask to speak to Julie Skilbeck (Chief Investigator) or Professor Jane Seymour (Research Supervisor); contact details for both are below. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the study, the (*name*) complaints procedures should be available to you. This does not affect your right to legal action in the unlikely event that such a situation should arise.

Will my taking part in the study be kept confidential?
All information that is collected about you during the study will be kept strictly confidential. The only people to see that information will be myself and my research supervisors. Any information about you will have your name and address removed so that you cannot be recognised from it. You will be allocated a study number, which will be given by myself and held at my place of work, in a locked cabinet, during and after the study as a record. All data held on computer will be password protected, and all minidisks will be destroyed following transcription. Transcriptions will be kept until the end of the study and then destroyed.

What will happen to the results of the research study?
The findings from the study will be written up as a thesis and kept in the library at the University of Nottingham. Some of the study findings will be written up as an article which will appear in an academic journal, or as a conference presentation. All the information you give will be strictly confidential and it will be impossible to identify you in the report. I will provide you with a summary of your own input, and invite you to make comment before I write the final report.

Who is organising and funding the research?
The study is being undertaken as part of a course of study (part-time) leading to the award of a PhD at the University of Nottingham. The study is funded by the University of Nottingham.

Who has reviewed the study?
All research in the NHS and Social Services is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by North Sheffield Research Ethics Committee.

What if I have other concerns?
If you have a concern about any aspect of this study you should ask to speak to Julie Skilbeck (Chief Investigator) or Professor Jane Seymour (Research Supervisor), contact details for both are below. If you have any complaints about the way the researcher carries out the study, you may contact (who is the person at Nottingham?)

Thank you for taking the time to read the information sheet.

Contact details

Julie Skilbeck	Professor Jane Seymour
Sheffield Hallam University	Sue Ryder Centre for Palliative and End of Life Studies
Q103 Parkholme	B Floor, Medical School
30 Collegiate Crescent	Queens Medical Centre
Sheffield S1 1WB	Nottingham NG7 2UH
Tel: 0114 2252203	Tel: 0115 8230890

Appendix 2   Community Matron Presentation

Understanding Frailty in Adults with Complex Problems Receiving Health and Social Care:
An Ethnographic Study

Julie Skilbeck
PhD student, University of Nottingham

Background

- 16% of the total population are aged 65 and over
- Of these almost half are 75 and over
- By 2031 numbers of people aged 85 are expected to double
- Advanced old age can be associated with multiple health problems and co-morbidity, situational constraints, including poverty and social isolation, increased dependency, and end of life issues

Old age and frailty

- With advancing old age there is recognition that some older people will experience frailty
- In the literature frailty mainly defined as:
  - Health and functional loss
  - Dependence
- Generally there are no clear criteria relating to frailty, people are 'labelled' as frail with no clear criteria

Research question

- 'How do older adults with complex problems living at home, who are considered to be 'frail', experience their daily life?'

Research Objectives

- To explore how older adults with complex problems understand the concept of frailty.
- To explore how older adults with complex problems construct and communicate their own accounts of frailty.
- To explore how an older adult with complex problems is constructed as frail through social interaction with care staff involved in their care.
- To examine how older adults and those involved in their care, make sense of frailty in relation to the ageing process towards the end-of-life.
- To consider how an older adult's experience and expression of frailty are shaped by their social world.

Study design

- Longitudinal ethnographic design
  - Participant observation
  - Interviews
  - Documentary review
  - Diaries

Target population

- Adults aged 75 and over (n=10-14)
- Living at home, not an institutional setting
- 2 or more health related problems
- Receipt of personal care services
- Considered to be 'frail' by those providing care

Other participants

- Paid care worker
- Nominated family member
- Health and social care professionals involved in the care of the older adult

What will this study add?

- It will develop an understanding of frailty in relation to older adults with complex problems from their perspective.
- Factors which may result in differentiated experiences of frailty in later life will be illuminated, with the potential to identify aspects of health and social care practice that may positively influence the experience of the older person.

What will this study add?

- Issues relating to end-of-life care and the experience of 'frailty' will be raised which will enable the beginnings of a critique of illness trajectory frameworks at the end-of-life.
- Through exploring how health and social care workers interact with older people with complex problems it may be possible to identify areas of good practice, also highlighting educational and support needs for care staff.

Ethical issues

- Working with vulnerable older adults
- Capacity to give informed consent
- Bringing up sensitive topics
- Development of a relationship with the participants
- Care staff may feel under pressure to take part
- Judgements about care given

- Why am I talking to you today?

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Levels of support: 'Kaiser Permanente Triangle'

Level 3: Case Management

Level 2: Disease Management

Level 1: Supported self care

Level 3: Case Management

Complex needs, high intensity service users
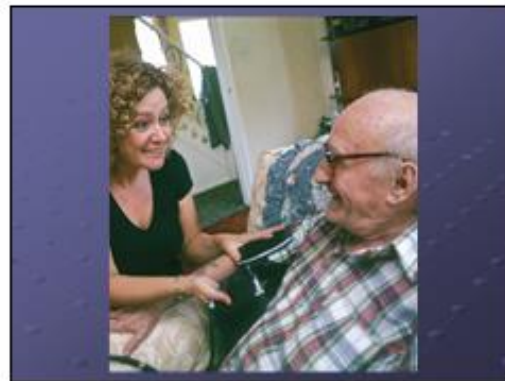
Appendix 3   Ethics Approval

North Sheffield Local Research Ethics Committee
1st Floor Vickers Corridor
Northern General Hospital
Herries Road
Sheffield
S5 7AU

Telephone: 0114 271 4011
Facsimile: 0114 256 2469

19 February 2008

Ms Julie Skilbeck
PhD student
Q103 Parkholme
Collegiate Crescent
Sheffield
S1 1WB

Dear Ms Skilbeck

Full title of study:	**Understanding Frailty in Older Adults with Complex Problems Receiving Social Care: An Ethnographic Study**
REC reference number:	07/H1308/162

Thank you for your letter of 23 January 2008, 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.

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].

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

- *The protocol submitted (Version 2) has been altered in places not requested by the Committee. This version is not approved. Please make the requested change to version 1 of the protocol (Check paperwork to ensure no mention is made of the diaries). No other changes should be made without the submission of a substantial amendment. The next version of the protocol should be version 3.*

- *Statement 6 on the consent forms does not make sense. The statement should be as in the standard guides i.e. "I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust where it is relevant to my taking part in this research" The consent form for older people should say 'medical notes/social care notes and data….'*

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		03 December 2007
Investigator CV	Supervisor	03 December 2007
Investigator CV		03 December 2007
Protocol	1	30 September 2007
Summary/Synopsis	1	02 December 2007
Letter from Sponsor		27 November 2007
Peer Review		04 October 2007
Letter of invitation to participant	1	29 November 2007
Participant Information Sheet: Older Adult	2	15 January 2008
Participant Information Sheet: Family member	2	15 January 2008
Participant Information Sheet: Paid Carer	2	15 January 2008
Participant Consent Form: Older Adult	2	15 January 2008
Participant Consent Form: Family Member	2	15 January 2008
Participant Consent Form: Paid Carer	2	15 January 2008
Response to Request for Further Information		23 January 2008
Interview Themes	1	30 October 2007
Interview Themes Family Member	1	30 October 2007
Interview Themes Paid Carer	1	30 October 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from http://www.rdforum.nhs.uk/rdform.htm.

Statement of compliance

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

1.2.1

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After ethical review

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

Here you will find links to the following
  a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
  b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
  c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
  d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
  e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk .

07/H1308/162	Please quote this number on all correspondence

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

Yours sincerely

Dr C A Moore
Chair

Email: april.dagnall@sth.nhs.uk

Enclosures: Standard approval conditions [SL-AC1 for CTIMPs, SL-AC2 for other studies]

Copy to: Mr Roger Brooks

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Sheffield Health and Social Research Consortium

PROJECT RESPONSE FORM (NON-COMMERCIAL)

CONSORTIUM REFERENCE: ZJ59a
(To be quoted in all correspondence)

PROJECT TITLE: Understanding Frailty in Older Adults with Complex Problems Receiving Social Care: An Ethnographic Study (SCC component)

Principal Investigator Details	
Name: Ms Julie Skilbeck	Email: J.Skilbeck@shu.ac.uk

ITEM	DATE RECEIVED (dd.mm.yy)	ATTACHED TO ACCOMPANYING EMAIL MESSAGE?		
		YES	NO	FILE REF
Sheffield City Council Research Application Form	14.12.07	Yes		14.12.2007C0
Honorary Contract Request Form	14.12.07	Yes		14.12.2007Cb

Action Messages :	ACTION Message:
To PI: Ms Skilbeck	Thank you for you valid application which was received on 14/12/07 • **NHS Research Ethics Opinion:** All Principal Investigators requiring a NHS research ethics opinion must provide a copy of a letter from a NHS Research Ethics Committee giving a 'favourable opinion' before Research Governance Approval is granted, unless otherwise indicated here. • **Funding:** we note that this is an unfunded study for the purposes of obtaining a PhD • **Negligent Indemnity:** University of Nottingham, dated 27/11/07 • **Sponsor:** University of Nottingham, dated 27/11/07
To Research Lead(s): • John Randall, Sheffield City Council	• **Requests for NHS Management approval to Research Lead of Each Consortium Partner or other organisation in which the researcher(s) wish to work:** Please inform this Consortium alone of the decision on whether or not NHS/SSS Management Approval is being granted. This approval will be communicated to the researcher only through the Consortium Research Governance Approval letter. Once management approval is given, please endorse the Consortium's request for an honorary contract to be drawn up, by emailing Sue

1.2.2

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	Palfreyman and copying this email to the Consortium.
	• **Brief description of why each Consortium Partner is being asked to give approval:**
	The research will involve non-participant observation, face to face interviews with patients, carers and staff of the City Council
To HR Contact: • **Sue Palfreyman, Sheffield City Council**	**Honorary contract:** Please draw up an honorary contract for the following (whose names and addresses are listed): Ms Julie Skilbeck, 186 Walkley Crescent Road, Sheffield S6 5BB Note that the honorary contract will be issued through the Consortium Office at the time of Research Governance Approval
To: Consortium Projects Administrator	• Please log this screen

ADVICE TO ALL PRINCIPAL INVESTIGATORS

Health and Safety. The Research Governance Framework requires that all researchers are aware of their obligations under Health and Safety regulations. 'The safety of participants, and of research and other staff must be given priority at all times, and health and safety regulations must be strictly observed.' Useful links can be found on the DoH's Research Governance web site (<<<www.doh.gov.uk/research/rd3/nhsrandd/researchgovernance/h_and_s/h_and_s.htm>>>) including a Code of Practice for the Safety of Social Researchers.

Confidentiality: If you want to use patient data for your research project then it must be completely anonymised or else you must get explicit consent from every patient whose data you intend to use in your project. Further details may be found in Issue 6 of REACH, the Consortium's newsletter: http: <<www.shef.ac.uk/~scharr/shsrc/news.htm#newsletter>> <<<<<<http://www.shef.ac.uk/~scharr/shsrc/news.htm#newsletter >>>>>.

Research Governance Approval Letter. Please note that Consortium Research Governance Approval, if granted, will be issued by a signed letter and not by e-mail message. Research on staff, patients, users or carers in any of the NHS/SS partner organisations may not commence until then.

Appendix 4   Older person information sheet

Please quote ref no: JS/09/08

Research Participant Information Sheet (Older adult): Version 2: 15th January 2008

Study Title: Understanding Frailty in Older Adults with Complex Problems Receiving Social Care: An Ethnographic Study

Researcher: Julie Skilbeck

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. 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. Take time to decide whether or not you wish to take part. Part 1 tells you the purpose of this study and what taking part involves. Part 2 gives you more detailed information about the conduct of the study

Thank you for reading this

Part 1

What is the purpose of the study?
I am interested in older people's experiences of ageing and health problems. Also, I would like to find out more about how paid care workers carry out their work with older people. I hope that the study will provide information about the experience of growing older. This will help to identify the types of help that older people need to help them manage at home, as well as the training needs of care staff working with older people.

Why have I been invited?
I am contacting older people, aged 75 and over with health related problems, who are receiving care from the Community Matron Team and asking them if they could help me by answering some questions about the experience of growing old. I hope to contact between 10 and 14 older people for my study.

Do I have to take part?
It is up to you to decide. I will describe the study and go through this information sheet with you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen if I take part?
I would like to come into your home with your Community Matron. I will ask if I can do this once a month for 6 months. During the visits I will note how the Matron works with you to meet your needs. I will also ask you some questions in a short interview about how you experience your daily life, and about your view of the visits by the Matron. Each interview should last no longer than half an hour. The conversations that take place will be recorded on a minidisk recorder with

your permission. I will also ask you if I can view your medical and social care records.

Will anyone receive payment for taking part in the research?
Yes. Julie Skilbeck will receive a bursary as a PhD student at the University of Nottingham

Will anyone else be involved in the study?
With your permission I will ask you if your paid carer and a family member would like to take part in the study.

What are the possible risks of taking part?
For some older people certain questions about later life could raise issues that might be upsetting for them. I am an experienced nurse researcher and am able to talk to people in this situation. I will be aware of sensitive or difficult issues that you may experience. Support would be available following the research interview if required.

What are the possible benefits of taking part?
The information that we get from the study will help me gain knowledge about the experiences of being an older person with health problems, as well as how paid carers work with older people. I cannot promise the study will help you but the information I get from this study may help develop future services.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have any concerns or other questions about this study or the way it has been carried out, you should contact Julie Skilbeck on 0114 2252203, or you may contact the complaints department at the University of Nottingham. The detailed information on this is given in Part 2.

Will my taking part in this study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?
You are free to withdraw from the study at anytime. Any information that has been collected during the time that you gave consent to be in the study will be used to write a report.

What if there is a problem?
If you have a concern about any aspect of this study you should ask to speak to Julie Skilbeck (Chief Investigator) or Professor Jane Seymour, contact details for both are below. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the study, the Normal National Health Service complaints procedures should be available to you. This

does not affect your right to legal action in the unlikely event that such a situation should arise.

Will my taking part in the study be kept confidential?
All information that is collected about you during the study will be kept strictly confidential. The only people to see that information will be myself and my research supervisors. Any information about you will have your name and address removed so that you cannot be recognised from it. You will be allocated a study number, which will be given by myself and held at my place of work, in a locked cabinet, during and after the study as a record. All data held on computer will be password protected, and all minidisks will be destroyed following transcription. Transcriptions will be kept until the end of the study and then destroyed. Confidentiality would only be broken if I felt your paid carer was putting you in a situation where you were at risk of harm.

What will happen to the results of the research study?
The findings from the study will be written up as a thesis and kept in the library at the University of Nottingham. Some of the study findings will be written up as an article which will appear in an academic journal, or as a conference presentation. All the information you give will be strictly confidential and it will be impossible to identify you in the report. I will provide you with a summary of your own input, and invite you to make comment before I write the final report.

Who is organising and funding the research?
The study is being undertaken as part of a course of study (part-time) leading to the award of a PhD at the University of Nottingham. The study is funded by the University of Nottingham.

Who has reviewed the study?
All research in the NHS and Social Services is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by North Sheffield Research Ethics Committee.

What if I have other concerns?
If you have a concern about any aspect of this study you should ask to speak to Julie Skilbeck (Chief Investigator) or Professor Jane Seymour (Research Supervisor), contact details for both are below. If you have any complaints about the way the researcher carries out the study, you may contact Professor Jane Seymour.

Thank you for taking the time to read the information sheet.

Contact details

Julie Skilbeck	Professor Jane Seymour
Sheffield Hallam University	Sue Ryder Centre for Palliative Care Studies
Q103 Parkholme	B Floor Medical School
30 Collegiate Crescent	Queens Medical Centre
Sheffield S1 1WB	Nottingham NG7 2UH
Tel: 0114 2252203	0115 8230890

Appendix 5   Older person consent form

Please quote ref no:

Centre Number:
Study Number:
Patient Identification Number for this study:

CONSENT FORM: OLDER ADULT (Version 2 January 2008)

Title of Project: Understanding Frailty in Adults with Complex Problems Receiving Social Care: An Ethnographic Study

Name of Researchers: Ms Julie Skilbeck

Please initial box

1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected. ☐

3. I agree to the interviews being tape-recorded. ☐

4. I agree to researcher accessing my medical and social care records. ☐

5. I understand that my confidentiality will be broken should I be at risk of harm. ☐

6. I understand that relevant sections of my medical/social care notes and data collected during the study may be looked at by your research supervisor at the University of Nottingham, or personnel from Sheffield PCT. I give permission for these individuals to have access to my records. ☐

7. I am happy for my Matron to be observed and my family member to be interviewed. ☐

8. I agree to take part in the above study. ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

1 for participant; 1 for researcher; 1 to be kept with social care notes

Appendix 6   Community Matron Consent Form

The University of
Nottingham

Centre Number:
Study Number:
Patient Identification Number for this study:

CONSENT FORM: Community Matron (Version 2 January 2008)

Title of Project: **Understanding Frailty in Adults with Complex Problems Receiving Social Care: An Ethnographic Study**

Name of Researchers: Ms Julie Skilbeck

Please initial box

1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐

3. I agree to the interviews being tape-recorded. ☐
☐

4. I understand that the researcher will access my client's medical and social care records. ☐

5. I understand that my confidentiality will be broken should there be at risk of harm to my client or myself. ☐

6. I understand that relevant sections of the medical/social care notes and data collected during the study may be looked at by your research supervisor at the University of Nottingham. I give permission for these individuals to have access to my records. ☐

7. I am happy for my client to be observed and a family member to be interviewed. ☐

8. I agree to take part in the above study. ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

1 for participant; 1 for researcher

Appendix 7   Family Member Information Sheet

The University of
Nottingham

Study Title: A study to explore how older adults experience old age

Researcher: Julie Skilbeck

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. 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. Take time to decide whether or not you wish to take part. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Thank you for reading this.

What is the purpose of the study?
I am interested in exploring how older people with health problems living at home think and talk about the experience of getting old. Also, I would like to find out more about how paid care workers carry out their work with older people. I hope that the study will provide information about the experience of growing old. This will help to identify the types of help that older people require to help them manage at home, as well as the training for care staff who will be working with older people.

Why have I been invited?
You have a relative/friend aged 75 and over with health related problems who is receiving care from a paid carer. Would you be able to help me by answering some questions about the experience of knowing an older person with health problems? I hope to contact between 10 and 14 older people for my study.

Do I have to take part?
No, your taking part is voluntary. It is up to you to decide. I will describe the study and go through this information sheet with you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care your relative/friend would receive.

What will happen if I take part?
If you agree to take part you will be asked to take part in 2 short interviews. In the interviews you will be asked questions about how your relative/friend and ways in which you support them at home. Each interview should last no longer than half an hour. The visit and the interview will be recorded on a minidisk recorder with your permission.

Will anyone receive payment for taking part in the research?
Yes. Julie Skilbeck will receive a bursary as a PhD student at the University of Nottingham

Will anyone else be involved in the study?
Your family member/friend and their paid carer will be taking part the study.

What are the possible risks of taking part?
For some family members certain questions could raise issues that might be upsetting for them. I am an experienced nurse researcher and am able to talk to people in these situations. Support would be available following the research interview if required.

What are the possible benefits of taking part?
The information that we get from the study will help me gain knowledge about the experiences of being an older person with health problems, as well as how paid carers work with older people. I cannot promise the study will help you but the information I get from this study may help develop future services.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have any concerns or other questions about this study or the way it has been carried out, you should contact Julie Skilbeck on 0114 2255613, or you may contact the University of Nottingham complaints department. The detailed information on this is given in Part 2.

Will my taking part in this study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?
You are free to withdraw from the study at anytime. Any information that has been collected during the time that you gave consent to be in the study will be used to write a report.

What if there is a problem?
If you have a concern about any aspect of this study you should ask to speak to Julie Skilbeck (Chief Investigator) or Professor Jane Seymour (Research Supervisor); contact details for both are below. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the study, the Normal National Health Service complaints procedures should be available to you. This does not affect your right to legal action in the unlikely event that such a situation should arise.

Will my taking part in the study be kept confidential?
All information that is collected about you during the study will be kept strictly confidential. The only people to see that information will be myself and my research supervisors. Any information about you will have your name and address removed so that you cannot be recognised from it. You will be allocated a study number, which will be given by myself and held at my place of work, in a locked cabinet, during and after the study as a record. All data held on computer will be password protected, and all minidisks will be destroyed following transcription. Transcriptions will be kept until the end of the study and then destroyed. Confidentiality would only be broken if I felt the paid carer delivering care to your relative was putting them, or others, in a situation where they were at risk of harm.

What will happen to the results of the research study?
The findings from the study will be written up as a thesis and kept in the library at the University of Nottingham. Some of the study findings will be written up as an article which will appear in an academic journal, or as a conference presentation. All the information you give will be strictly confidential and it will be impossible to identify you in the report. I will provide you with a summary of your own input, and invite you to make comment before I write the final report.

Who is organising and funding the research?
The study is being undertaken as part of a course of study (part-time) leading to the award of a PhD at the University of Nottingham. The study is funded by the University of Nottingham.

Who has reviewed the study?
All research in the NHS and Social Services is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by North Sheffield Research Ethics Committee.
What if I have other concerns?
If you have a concern about any aspect of this study you should ask to speak to Julie Skilbeck (Chief Investigator) or Professor Jane Seymour (Research Supervisor), contact details for both are below.

Thank you for taking the time to read the information sheet.

Contact details

Julie Skilbeck
Sheffield Hallam University
Tel: 0114 2252203

Professor Jane Seymour Tel: 0115 8230890

Appendix 8   Family Member Consent Form

Centre Number:
Study Number:
Patient Identification Number for this study:

CONSENT FORM: Significant other (Version 2 January 2008)

Title of Project: Understanding Frailty in Adults with Complex Problems Receiving Social Care: An Ethnographic Study
Name of Researchers: Ms Julie Skilbeck

Please initial box

1. I confirm that I have read and understand the information sheet dated for the above study and have

had the opportunity to ask questions.   ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time,   ☐
     without giving any reason, without my care or legal rights being affected.

3. I agree to the interviews being tape-recorded.   ☐

4. I understand that the researcher will access my relative's medical and social care records.   ☐

5. I understand that my confidentiality will be broken should there be at risk of harm to my   ☐
     relative, the Community Matron, or myself.

6. I understand that relevant sections of data collected during the study may be looked at by your
     research supervisor at the University of Nottingham.
     I give permission for these individuals to have access to my data.

7. I am happy for my relative, and their paid carer, to be observed and interviewed.   ☐

8. I agree to take part in the above study.   ·   ☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

        1 for participant; 1 for researcher

Appendix 9   Interview Themes for the Older Adult: Version 1 October 2007

1. Life story in relation to the current situation, therefore opening question will be:
    *   Could you tell me something about yourself?

2. Insight into their daily experiences:
    *   Could you describe to me a typical day?
    *   What makes daily life difficult for you at this moment and why?
    *   What impact do these difficulties have on your daily life?
    *   What makes daily life a positive experience for you at the moment and why?
    *   How do you try to resolve the difficulties or maintain the positive times?

3. Family/Health and social care support:
    *   Who is involved in helping you with aspects of your daily life and why?
    *   How did these agencies/individuals become involved in your daily lives?
    *   How does the involvement impact on your daily life?
    *   How do you feel about the problem/help with the problem?
    *   What are other peoples attitudes towards your problems?

4. What is understood by 'frailty':
    *   What do you understand by the term 'frail'?
    *   If you had to describe an older person as frail what would that description include?
    *   In your opinion what has influenced your description of frailty?
    *   In considering this description would you consider yourself to be frail?

As the study progresses the interview themes will develop according to data collection, especially data collected during periods of observation and the diaries.

Appendix 10 Interview themes for the community matron: Version 1 October 2007

1. Establish their relationship with older the person:
   - How long have you been working with …?
   - How did you become involved in providing care to …?

2. Insight into their daily work:
   - Could you describe to me a typical day working with ….?
   - What does working with ….. involve?
   - Are there any problems working with …. at the moment?
   - What are the good things about working with ….. at the moment?
   - What difference to ….. daily life do you think that you make?
   - How do you find working with older people generally?

3. What is understood by 'frailty':
   - What do you understand by the term 'frail'?
   - If you had to describe an older person as frail what would that description include?
   - In your opinion what has influenced your description of frailty?
   - In considering this description would you consider the person you are caring for to be frail?

As the study progresses the interview themes will develop according to data collection, especially data collected during periods of observation and the diaries.

Appendix 11 Interview Themes for nominated significant other: Version 1 October 2007

1. Life story in relation to the current situation, therefore opening question will be:
   - What is your relationship to …. ?
   - When did your relative first receive home care?
   - What was the reason for this?
   - How did these agencies/individuals become involved in their daily life?
   - How important is the support received by the paid carer?

2. Family support:
   - How do you help support …. with their daily life?
   - How does this involvement impact on your daily life?
   - What are the good things about supporting ….?
   - What are the difficulties in supporting …..?

3. What is understood by 'frailty':
   - What do you understand by the term 'frail'?
   - If you had to describe an older person as frail what would that description include?
   - In your opinion what has influenced your description of frailty?
   - In considering this description would you consider your relative to be frail?

As the study progresses the interview themes will develop according to data collection, especially data collected during periods of observation and the diaries.

Appendix 12 Extracts from the re-storyed account of Case 4

I was first introduced to older participant 4 as I accompanied her Community Matron (CM) on some routine visits to patients. Prior to the visit I had discussed the inclusion criteria with the CM and established that this patient may be suitable for inclusion within the study: she was aged over 75, lived alone, received support from a private carer and the CM considered her to be frail.

The visit took place at 10am for 30 minutes. On arrival at the patient's house I was introduced as a nursing colleague who was undertaking some research into the health of older people. On seeing Grace I felt that she would be suitable, and recorded my first impressions in my field notes:

> She was sitting on the settee and was neatly dressed in a matching velour track suit top and jogging bottoms. She was a tall woman with a slight frame; I thought she looked extremely thin and underweight. She had white hair; her facial skin was olive in tone and dark, although underlying this she looked pale. She looked as if she would 'break' and my immediate thoughts were that she appeared frail! During that visit the CM asked Grace to stand up so that she could assess the skin condition on her bottom. She found it difficult to get up from the settee without assistance. When some of her clothing was removed I noted that she there was no extra fat on her body and that her bones were prominent.

The CM had already told Grace at the previous visit that I would be accompanying her on this visit and Grace remembered; she seemed at ease with my presence. I sat on a chair which was on the other side of the room to the settee whilst the CM chatted to Grace about how she had been that week. When the opportunity arose to discuss my study and her possible inclusion I sat on the settee next to her. I re-introduced myself as a student undertaking research into older people with health problems and outlined the study and what her involvement would be. I then informed her that I would leave her the information sheet so that she could have a look at it in her own time and discuss it with a family member should she wish to. Grace expressed an interest in the study and said that she would discuss it with her son and daughter-in-law that week. We agreed that she would let the CM know whether she was happy to participate and if she was I would accompany the CM on the next visit to obtain consent and commence the study. I was contacted by the CM two weeks later to say that Grace wanted to take part in the study and we agreed that I would accompany her when she visited Grace the next day.

Biographical and medical information

Grace was in her mid-eighties and lived on her own in a council owned 1 bedroom upstairs flat. Grace had one married son who lived locally. She paid for a private carer for two hours twice a week; this person was responsible for assisting Grace to visit the local post office to collect her pension, and other outdoor activities. Grace's past medical history included: Asthma; Type II diabetes – diet controlled; Stroke and angina.

Grace had been referred to the CM by the Community Nursing Team (CNT) on a month earlier. She had been receiving visits by the CNT and was having her legs dressed as they were swollen and leaking. The CNT had felt that Grace's care required case management which had prompted the referral. The CM recalls the referral:

> *'She had been referred to me by the District Nurses (DN); the DNs had been going in, she had had a spell in hospital, she had had a fall. The DNs had been going in to see to her legs, they were quite oedematous her legs and they asked me to get involved from that point of view. She had Diabetes and a bit of Heart Failure. So it was earlier last year when I first started seeing her it wasn't very long; really to go in and do some long term planning reviews and giving her support (*Interview with CM).

At the point of referral Grace had been concerned about her mobility since the stroke, as were the family. The first contact assessment by the CM was undertaken on the 16 days after referral; the following extract was recorded in the notes by the CM that,

> Grace is unsteady; using furniture to mobilise around the flat…she says she is unable to use walking aids due to the loss of power in her hands.

This prompted a referral to the Community Physiotherapy team for mobility assessment. Other current problems included: pain from arthritis; oedematous and leaking legs; weight loss; urinary incontinence; toe callus and problem with feet generally. Her clinical observations were recorded as BP 100/60; Oxygen saturations 98%; weight 37.7kgs.The CM summed up the main issues at that time:

> '*The fact that she lived on her own, she'd got some family support, she weren't having any care company but the family were paying a carer that was visiting Grace a couple of times a week that was doing other things like taking her shopping and things like that, not just getting her her meals because at that time she was able to get her own meals most of the time. I was a bit concerned about the stairs up to the flat, but other than that I think she managed quite well'* (1st interview CM).

She had also noted that in her opinion she was frail at that time:

> *'Well she was very thin and she'd had falls as well and she obviously needed walking aids and her age obviously'* (1st interview CM)..

The next visit is 3 weeks later; this is the first visit that I made to Grace to start the process of recruitment. My contact with Grace is right at the beginning of her relationship with the CM – although I got the impression that the CM had known Grace for a long time; I think this was a result of the way that the CM engaged with Grace at the beginning of the relationship (person centred care).

1st observation of care visit

On arrival at Grace's flat we enter using the key safe facility. The CM calls hello to Grace as we are climbing the stairs to the first floor. Grace was in the living room sitting on the settee holding a pot of medicine. She immediately said that,

> *'She was glad to see the CM as she had been having a bad week'*

and went on to say that she was concerned about her sore bottom as she had been going to the toilet all the time after putting the cream on, and also that she had kept dropping things in the kitchen. After greeting Grace the CM sits down on the chair next to the television; from this position she is unable to give Grace eye contact; once she put her bag down and gets Grace's notes from the unit she turns to face Grace.

I had negotiated with the CM at the health centre that I would gain consent before commencing the consultation. As Grace had raised some concerns so soon on arrival I was conscious that I did not want to take up too much time obtaining consent; although I need to make sure that Grace had understood what the process of the study would entail for her. I felt uncomfortable about this. I sat on the settee next to her and asked about her thoughts about the study. Grace made it clear that she had read the information sheet and discussed it with her family and that she was happy to take part in the study. I asked her if there were any questions that she wanted to ask and she said no. I handed her the consent form to sign, however she asked if I would go through each point. After doing this I asked her if she would be able to sign the consent form; she said that she had difficulty writing due to her arthritis and would I sign the boxes for her; I ticked them after she had agreed a statement. I then rested the form on my observation book and although shaky she was able to write her signature. I was careful throughout this process to reinforce that her participation was entirely voluntary and that even though she agreed now she could withdraw from the study at any time. The CM was present throughout the whole process.

A soon as she form had been signed the CM began to discuss Grace's concerns and I turned on the audio-tape with every ones agreement; it is placed on the coffee table in front of the settee. The CM moved over to the settee and begins to talk about looking at Grace's bottom:

> CM: So do you want me to have a look at your bottom Grace?
> G: You can do love…..
> CM: See if it's getting any better….
> G: Not a pleasant sight I shouldn't think (both laugh)

At this point the CM changes the conversation to the meals that Grace is going to have delivered. Grace informs the CM that they have already started to be delivered and that she had one for tea last night. These meals were discussed last week at the previous visit, the CM had brought a brochure from a company that provides meals and Grace had agreed that she would order them, as they looked appetising. During this the CM turns to me and says:

> 'She'd actually put a little bit of weight on last time I weighed her…'

and then turns to Grace:

> didn't you, you'd put on a bit of weight, your weight the other day when I weighed you was a little bit **more** than before, when I weighed you a few weeks ago wasn't it Grace?'

Grace points out that she knows that but that she had not had hot meals until yesterday. The CM replies that she knows that (sounds a little exasperated) and then Grace changes the subject to her medication:

> 'Well anyway I'll tell you what, that water tablet will be the death of me'.

She goes onto explain that every time she takes the tablets she gets violent stomach pains, which makes her think that she needs the toilet and then she doesn't. The CM has remained sitting on the settee and looking at Grace throughout this conversation. She clarified where the stomach pain is and how many tablets she is taking a day, which is one; although Grace does not feel it is doing her any good, she tries to take it every day but her ankles are not improving. The response from the CM is that she will pass that information to the GP, with a reply from Grace that the Dr had said that he was coming but that he had not said which year - generating laughter from all of us.

At this point the CM suggests that she has a look at Grace's bottom, 10 minutes after it was first mentioned. Grace shuffles to the edge of the settee and then stands up with difficulty; the CM assists her by allowing Grace to use her arm as a support; Grace mentions here that she always needs to

have a free arm, implying that she cannot put both her arms down on the settee to push herself up. In response to this the CM mentions that she has sent in the request for a physiotherapy referral and that the physiotherapist should be ringing her soon. Grace makes it clear that she is anxious about her mobility and any assistance that she might get,

> 'What I'm anxious about is that aid that I'm having to help me do a bit of walking…
>
> CM: Yes that's what I'm saying the physio…'

At this point the CM does not seem to be responding to what Grace is concerned about, she appears to be focussed upon the fact that the physiotherapist referral will manage the mobility problems; Grace appears to be worried about the aid itself. The conversation does not expand as Grace calls out in some discomfort and communicates to the CM that she can manage, she demonstrates by holding on to the edge of the settee. Again whilst Grace is still trying to stand up the CM brings in a different topic of conversation by asking if her daughter-in-law is coming that day. Grace replies that she's supposed to although they have had a busy week, but she is sure that they said they were coming today. At this point in the visit I start to get the impression that the CM has an agenda that she is using to guide the consultation; aspects that she has to cover within the visit – this seemed to be happening whilst undertaking the physical examination of her bottom.

The examination of Grace's bottom reveals that she has a red area on her sacrum but no broken areas. A conversation ensues regarding the cause of this; Grace thinks that it is the result of the pressure relieving cushion and mattress that she has been using. The CM mentions that they will see how they will get on with the others, which implies that alternative devices have been ordered. There is a lull in the conversation whilst the CM writes in the notes after the physical examination; she is sitting back in the chair next to the television to do this. Whilst the CM is writing in the notes Grace initiates a change in conversation, again reflecting a concern that she currently has. The following dialogue ensues:

> G: And I've been falling asleep.
> CM: Have you?
> G: Couldn't keep awake.
> CM: Couldn't you, have you been sleeping at night?
> G: Yes mostly but I have had some terrible days and nights this week, I mean I'd only just had my cereal yesterday morning, sat here and that was it, an hour and a half after I came too.
> CM: That's alright.
> G: Ah but it's not it's not me.
> CM: So what about this arm is it any better?

Here Grace is communicating about an issue that is troubling her; although the CM initially acknowledges this the conversation very quickly becomes focused on sleep patterns at night. When Grace reports that she has had some terrible days and nights this is not picked up, and when she communicates that it is out of character for her the CM moves onto another unrelated issue; at this point the CM is still writing in the notes and therefore possibly not really able to listen to Grace's conversation. Following documentation in the notes I observe the CM as she undertook a physical assessment of Grace, which included: BP; Pulse; temperature. During this process Grace returns to the topic of the terrible night that she has had last night; this developed from a conversation focusing on getting Grace's legs elevated which prompted Grace to mention her displeasure again regarding the water tablets – she is of the opinion that the water tablets are not doing her any good:

CM: *Yes you need to get those legs up missus.*

G: *And then I sit there when I'm having a meal, more than likely, well when I'm having a sandwich, (laughs), but you see water tablets aren't doing a bit of good, they never did…..only thing they are doing is making me feel bad round the bottom.*

CM: *Well we need to have a chat with the Dr about that Grace, alright.*

G: *They'll be sick of me (laughter), more often talking about something that's gone wrong….I keep promising myself that I'll stitch that hole in my (talking about slipper) …..but I've a job to manage things but oh dear come on…let's see….I don't know…..I had a terrible night last night.*

CM: *What was that with?*

G: *I could not settle at all…I was in bed before 10 to 11, I usually am, twenty to one I got woke up again (indignant) that's every night, twenty to one…*

CM: *What with?*

G: *I don't know, anyway, I were all muddled up and couldn't settle, and I thought shall I get up and go and sit in chair and then I thought no I shan't it'll be too cold (laughter)…so….but somehow this week I'm fed up with it I really am because I haven't been out this week at all, mind you I could've gone, my carer would have taken me.*

CM: *It's not been very good weather though this week.*

G: *No but there's one thing about me carer he'll go and pay me rent for me and do anything I want but he can't be up there and*

doing in here can he? I do what I can which lately has not been much (laughter)……long pause.

A couple of issues are pertinent here. First the CM changes the subject to the weather rather than picking up the cue about Grace being really fed up. Second, the CM speaks on behalf of Grace suggesting the pain is the cause of her bad week; however Grace continues to talk about her concerns which are very different to the suggestion put forward by the CM. She tells us that everything that could have gone wrong that weekend did, starting with dropping everything. She went onto explain that she even dropped the clothes washing tablet, which crumbled all over the floor; she then decided to hoover it up so that it didn't trail all over the house. It became apparent that whilst Grace was hoovering she knocked her arm; she now starts to link this to other problems that she has experienced. She generally appears to be unhappy with the weekend; whilst in this mood everything that is not happening as she would wish is becoming an issue for her:

> *'I hurt me arm, and of course I've got a bad back, that's usual, only I remembered I fractured this shoulder a while back, a few years ago, and everything seems to fly back there, it's that blood that she took here and here, and what with blood tests and scans and x-rays…..I don't know…. And I want my hair trimming and I don't know when I can fit her in, they come to the house you see…..'*

Overall, Grace is starting to feel fed up because she is unable to get out, although this seems to be dependent on how she is feeling. As she talks about that she also starts to disclose another reason that may stop her from going out, that is waiting for people to come, whether it be the hairdresser, person dropping her medications off, her daughter-in-law; it seems to bother her that she does not know when they are coming. During this general conversation the CM asks her if she can carry the medicines in to the flat that have just recently been delivered and left at the bottom of the stairs. Grace is unable to therefore the CM gets them and puts them on the dressing table in Grace's bedroom. Once again the CM does not seem to be 'actively listening' to Grace and focusing on issues that are part of her agenda.

The consultation is wrapped up with the CM arranging the next visit – June 1st 2009; I also arrange to visit her to undertake the first face to face interview on Thursday June 11th. Grace gives me permission to access her flat using the key safe facility. Following this visit the CM sends a fax to the GP practice informing them that she has prescribed Cavilon Barrier Cream for Grace's sore sacral area. I note in field notes that *'there is no mention of Grace's wider concerns'.*

As planned I visit Grace a week later to undertake the first interview. When I arrive I was surprised that the key safe had already been opened; this made

me think that there was already someone there. I knocked on the door 5 times but there was no answer; I looked up at the first floor window and it appeared dark. I concluded that Grace was not there, which was worrying. I contacted the CM to let her know; she was also confused as to what is happening. We arranged that she would contact me once she knew what had happened. Later on at the next observation Grace tells me about the key safe:

> 'I'll tell you what happened there, Cheryl (granddaughter) had got the key safe, and when I went into hospital Pam says, I said to Pam rather I didn't fancy leaving it in there because anybody could walk in so she took it'.

Following the last visit the CM does not have contact with Grace for 6 weeks; this period involves detective work to piece together what has happened to Grace during this time frame. The CM was not involved in any of the care decisions that were made during this period, and was not aware when Grace was transferred to different care settings or when different care packages were introduced. The CM indicates that not knowing about changes to care undervalues her role with Grace,

> 'Well you feel a bit as though, you know you think, 'how important your involvement has been really', because the family didn't think to let you know even though they'd got a contact number, but I'm not surprised at the GPs really as they don't do things like that (laughs), but that is a good practice where she is registered with and one doctor does let me know about any changes with patients, but this particular time it wasn't'.

In the following three weeks Grace has four falls; the first fall leads to a hospital admission via A&E but only for the day:

> G: 'The only time I went in hospital was when I bashed all my face and that and I went in on that Saturday morning. They patched me all up I was in a right mess, bleeding and anyway I managed to, I think I pressed me buzzer for some help and then I rang me son but you see the fault here is you see I was in the bedroom and it comes through the phone so I couldn't hear what they were saying but the paramedics came out and they were absolutely marvellous and there was a young lady with the driver and she never left me and er I think if I remember rightly (name of daughter-in-law) went with me'.

This prompts a referral to the Community Assessment and Rehabilitation Team (CART). The CART service is a rapid response service providing short term care in a person's own home; in Grace's case three visits were made at 11am; 16.40; 'bedtime' by Assistant Practitioners (AP). During the first visit Grace was already up, washed and dressed, and had already eaten her breakfast. At the second visit, she was not feeling 'too good'; a meal was

prepared for her. She was advised to use the Zimmer frame in the kitchen (this is new she did not have this when we last visited her); it was then placed in the living room so that Grace could use it. There is also a note that Grace asked them to look at the back of her leg; information will be passed onto the DN team to look at this. The last visit that day is a joint visit to help Grace to bed; again she is already in her nightdress. She is made a hot drink but does not have any supper; the curtains are drawn and lights out. It is unclear what time 'bedtime' is as there is no record of the actual time; this does become an issue for Grace over the next couple of months as she did not like to go to bed too early.

The next day when the AP arrived, an Emergency Care Practitioner (ECP) was already present as Grace had fallen again. The AP *'prompted with food'*. The DN was called; once she arrived the ECP left. The DN wrote in the notes:

> *'Mechanical fall this a.m. Injury to left elbow. Four falls in past week. Bandage applied by ECP. UTI diagnosed. Discussed resource bed but refused. ? has cancelled their input. To discuss with son and care agency.*

Later that day at 14.15 the community physiotherapist visits and writes in notes:

> *Mobilising with Zimmer frame, swapped to rotator frame. Still requires supervision. Required assistance to stand from toilet. High risk of falls. Grace agreed to resource bed to maintain safety.*

There are no detailed records of how the decision was made to admit Grace to the resource bed; Grace's initial recollections were *'I think it was the Dr….or paramedics…. I don't really know',* and later she would say:

> *'I didn't have a choice love, they put us in there like, it was through the Dr that I went in there… they took me all that way out there, so no-one could come, it took us three hours to get there, there was a hold up on*
>
> *the motorway or something and I was beginning to feel right off before we got where we were going……but…..I never thought I'd come to this love.*

This raises the issue of 'voice' and 'choice', particularly in a crisis situation, where health and social care professionals are using the Risk Assessment process to guide decisions. The impact on Grace's sense of self is enormous.

Three further visits are made that day by members of the CART team, one at 15.35 by a Registered Nurse (RN) where it is noted that Grace is to be

admitted to a resource centre when a bed is available; also an assessment is made of her left leg where there is leaking from blisters. At 18.00 an AP visits and changes are made to the living room furniture to accommodate a commode. The settee is moved along closer to the window so that the commode is against the wall next to the settee. A microwave meal is cooked. A further visit is made at 20.40 where Grace is '*persuaded to go to bed but she is more comfortable in chair, adamant not to move*'. The next day Grace has two visits from the AP. The timing of the first is not clear but it is apparent that Grace has had an '*uncomfortable night, finding it difficult to mobilise*'. She is given breakfast, and it is noted that she has a place at (a nursing home) and that the ambulance is booked and her son and daughter-in-law informed. The final visit at 9.45 by an AP is to help Grace with washing and dressing and to '*pack medication and clothing for Grace to take with her*'. When I asked how she had felt about going into the home, Grace just said, 'ooh', with a wry laugh and a shake of her head although she went onto say that, '*they were marvellous, honestly*'.

Grace returned home a month later. In the notes a CART team member (AP) has made an assessment and fitted a bed lever and a raised toilet seat. It is unclear whether Grace was present or not.