

THE EXPERIENCE OF FALLING OF  
OLDER PEOPLE WITH DEMENTIA  
AND THEIR CARERS

A thesis submitted for the degree of

Doctor of Philosophy

by

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November 2012

## **Abstract**

Falling by older people is of significant global concern as the population ages, because of subsequent injury, disability, admission to long-term care and mortality. Older people experiencing dementia are twice as likely to fall with more severe consequences. Unsurprisingly, carer-burden increases when a care-recipient falls. Older people are rarely asked about their falls experiences and those with dementia less so.

The studies presented in this thesis explore the experiences of falling of older people with dementia and memory problems, and their carers. The studies were informed by contextualism and the primary study used interpretative phenomenological analysis to explore the experiences of nine older people with dementia and their 10 carers, using one-to-one and joint interviews, and three focus groups with nine older people experiencing memory problems and 12 carers from a branch of the Alzheimer's society.

Analysis of the data considered the falls experience itself and the perceived consequences of falls within two higher level themes: 'Falling as a malevolent force' as two themes - 'Going back to the experience', 'Reactions, responses and coming to terms with events', and 'Falling as the manifestation of dementia' as two themes - 'Self, identity and falling', 'The caring relationship'.

The secondary study elaborated upon primary study data using an inductive interpretative approach unaligned to any tradition. Older people recently diagnosed with dementia and carers from another Alzheimer's Society branch participated in two focus groups. Participants discussed stimulus cards with quotations from primary study participants.

Thematic analysis suggested four major themes: Making sense of falls, The personal and social significance of falling, Falling, self and identity and Struggling to care.

The findings demonstrate how falling and dementia are enmeshed and embodied experiences for participants. Spouse-carers' discussion of their own falls emphasise the need for joint assessment and intervention to reduce carer-burden and preserve couplehood.

## **Acknowledgements**

I am indebted to my supervisor Dr Frances Reynolds, for her commitment and support. I have learned so much from you, and I never fail to admire and appreciate your expertise, hard work and patience. I will miss my supervision sessions with you, as I have valued them tremendously. I would also like to thank Professor Lorraine De Souza for wise words and insightful feedback.

I would like to thank my husband Michael, and my children Elizabeth and David for accompanying me on this academic journey without complaint and with great patience. I can never really thank you enough. To my family, my friends and colleagues – I thank you for your understanding, emotional and practical support.

I would like to thank Diane Everett, Head of Physical Therapies, for your commitment and sharing of the first part of this journey and Dr Mary Morley, Director of Therapies, South West London and St George's Mental Health NHS Trust for your support.

I would like to thank all the participants, staff and organisations that were involved in the research, for their generosity in taking part in the studies, and sharing their experiences with me.

To my fellow IPA'ers – Betty, Chris, Elena and Alison, and to Virge – I continue to learn so much from you all.

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## Chapter 1 - Introduction to the thesis

In this introductory chapter, I will present my research question and my interest in the topic. These sections are followed by a brief summary of what the reader can expect from the subsequent chapters in the thesis.

### 1.1 The research question

The purpose of the research presented in this thesis was to gain a deeper understanding of the experiences of older people with dementia who fall and their carers. To this end the thesis presents a primary study and a smaller secondary study. The research question for the **primary study** is:

- **What is the lived experience of falls among older people with dementia and their carers?**

The aims of the primary study were to explore the lived experiences of falling and the consequences for older people with dementia and their carers.

The research question for the smaller **secondary study** is:

- **What are the elaborations and illuminations of older people with dementia and carers of the falls experiences of others?**

The aims of the second study were to explore whether other older people with dementia and carers found that the findings from the primary study resonated with their own experience.

### 1.2 My interest in the topic

My experience as a practising occupational therapist was to help my older clients to regain or maintain those everyday activities that they wanted or needed to do, in order to enhance their health and wellbeing. These professional beliefs reflect the theoretical basis of occupational therapy, namely occupational science, where the form, function and meaning of everyday

occupations are explored (College of Occupational Therapists [COT] 2003). In order to enable my clients' health and wellbeing, I wanted to find out more about their everyday lives, and the meanings and values these everyday experiences held for them. Because my clients did not live in a vacuum or sterile environment, I also wanted to know more about their relationships with others, as I was aware that these also shaped their everyday lives. This allowed me to offer interventions that were meaningful and therapeutic.

Falls in older people are considered as one of the "giants" in health and social care not only because of the consequent high rate of physical trauma, disability, admission to hospital or residential care, and mortality, but also because the cause and management of falls are often problematic (Close 2005). With the increase in the average age of the global population, falls and their consequences are predicted as an increasing burden on health and social care (Rubenstein et al 2006, Gilbert et al 2009). Falls management is therefore perceived to be an important part of health care provision for older people. In my own clinical practice I worked to prevent falls amongst my older clients, and when they had already fallen, I attempted to address and limit the consequences.

I followed a bio-psycho-social model of health and functioning in my service provision; namely the International Classification of Functioning, Disability and Health [ICF] (World Health Organisation [WHO] 2001). This model not only fits within my professional philosophy, but I felt (and still feel) that this was a more holistic way of considering the lived experience of falling. I was very aware that the experiences of falling were very different for the individual, their partners, families and carers. In addition, the meaning of these experiences differed between individuals. This meant that these older people accepted and responded differently to the interventions that my colleagues and I provided.

When I started my PhD in 2003, the review of the literature identified that older people had rarely been asked about their experiences of falling. Furthermore, there was little evidence that older people with dementia were being asked about this. As a clinician, and subsequently as an academic and researcher, I

was dissatisfied with both of these observations as they clashed with my profession's code of ethics and professional conduct, which advocates client centred practice at the heart of intervention (COT 2010).

To this end, I wanted to capture and understand the experiences of falling by older people with dementia, and the people that care for them, more fully. I also wanted to gain insights into the meanings that these older people and carers attributed to their experiences of falling and the potential influence of this on their everyday lives.

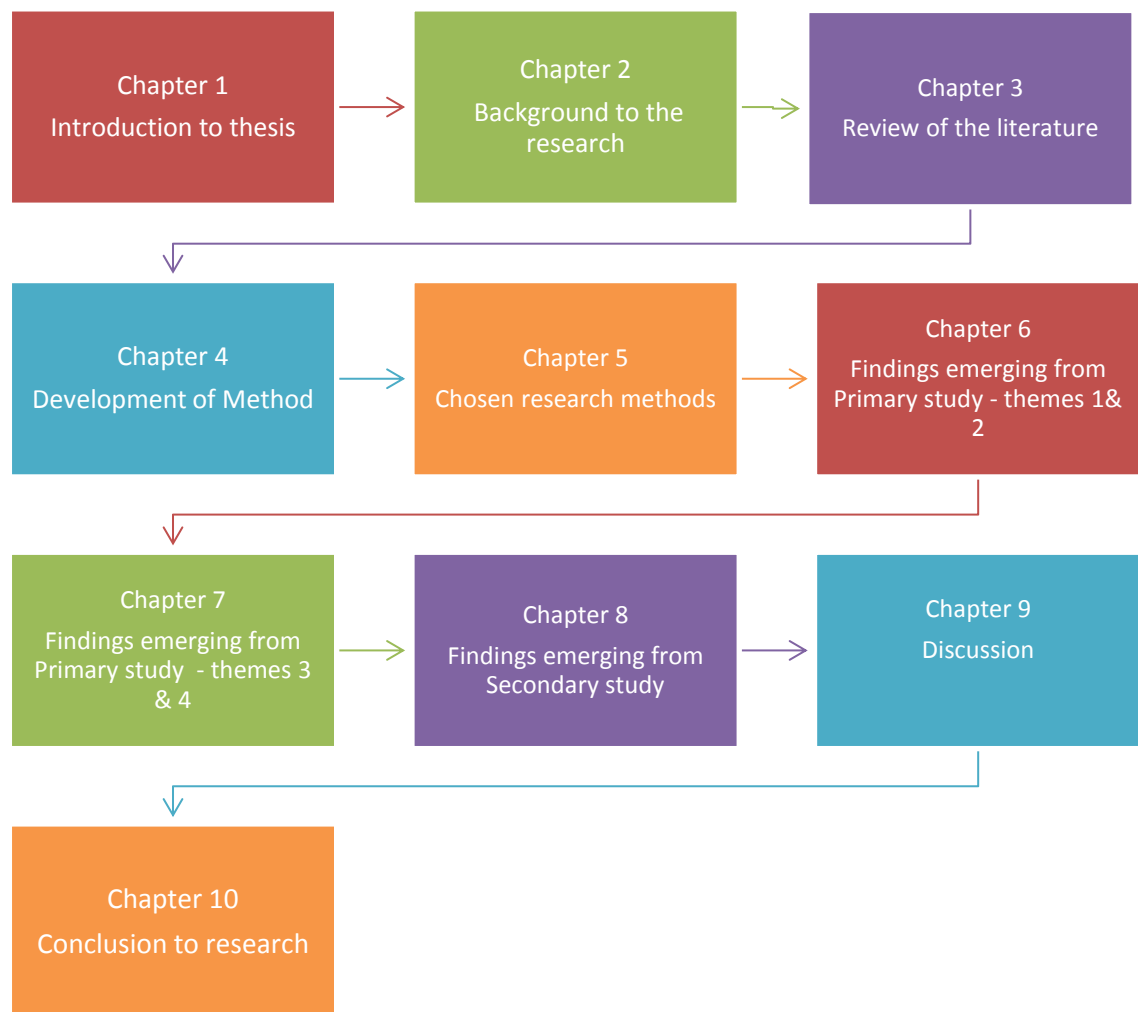
### 1.3 Overview of thesis

The chapters subsequent to this introduction are briefly described here, along with a diagram, which also shows the structure of the thesis (figure 1.1).

**Chapter 2** provides a background to the studies. The literature is reviewed to present the current understanding of the incidence of falling, dementia and caring amongst older people. Also national and international policies, legislation, reports and strategies of relevance are discussed to place the study in context.

**Chapter 3** provides a more critical review of the literature appertaining to dementia and the experience of falling both for the older person themselves and also their carers. The chapter is divided into two main sections. The first section starts with a general overview of the experience of dementia before critically examining the literature on falls and dementia, and more specifically, the subjective experience of falling by older people with dementia.

The second section of chapter 3 starts with an overview of the literature relating to the subjective experience of caring and dementia. The literature relating to the subjective experience of caring for an older person with dementia who falls, is then critically reviewed.



**Figure 1.1 Overview of the thesis**

**Chapter 4** provides the reader with an understanding of the chosen methodology for both the primary and secondary research studies. My epistemological position is justified along with a justification for the chosen approaches for both studies. The chapter also debates the issues to be considered when involving older people in research.

**Chapter 5** provides a detailed description of the specific methods chosen to answer both research questions. Issues of collecting data within the changing National Health Service [NHS] are presented. Being a therapist-researcher is also considered. Ethical considerations and processes are discussed;

participant information and recruitment, retention and data collection and methods of analysis are discussed and justified.

**Chapters 6** and **7** present the findings from the primary research question. In particular, chapter 6 presents findings relating more specifically to the participants' experiences of falling. Chapter 7 presents the findings that relate to the wider ramifications of a fall experienced by both the older people with dementia and their carers.

**Chapter 8** presents the findings from the secondary research question, where the experiences of falling, shared from the primary study, are elaborated upon by a second group of participants. In this chapter, the experiences common to both the older people with dementia and the carers, and those experiences specific to each group are presented.

**Chapter 9** provides a discussion of the findings from both studies, and highlights the unique contribution of these findings to knowledge. The relevance of the findings to existing literature and policy will also be considered.

**Chapter 10** is the concluding chapter where the research will be critiqued and reflected upon, for its quality and its relevance to health and social care practice.



## **Chapter Two: Background to the research**

This chapter provides a background to the thesis, to place the research in an epidemiological context and to consider the national and international policies and guidance on falls, dementia and caring that have informed the research both in its inception, conduct and interpretation of findings. Firstly, the incidence of falls, dementia and caring amongst older people will be presented. The incidence of falling amongst older people with dementia will then be discussed, along with the reported consequences and common interventions. Finally, pertinent legislation, policies and guidance will be considered from a UK and international context.

The World Health Organisation (WHO) in their Active Ageing policy document identifies that there is an expansion in the global population of those people aged over 60 years of age; with this age group predicted to make up 29.4% of the UK population in 2025 from 20.8% in 2002 (WHO 2002). Moreover, the population in England of those aged over 80 is also predicted to rise by 50% and those over 90 by 100% during the same time (from 2002 to 2025) (Department of Health (DH) 2001). The increase in the average age of the population is pertinent to both the incidence of falls and of dementia amongst older people, as both of these are said to increase with age (Ferri et al 2005, Logan et al 2010).

### **2.1 Falls and older people**

The current estimation is that 25% of people aged 70, and 50% of those aged 80 years and over, fall annually (Logan et al 2010). However, this is perhaps a conservative estimate as many falls go unreported (Martin 2009). Falls are also the fifth leading cause of death in older people (Rubenstein 2006). It is recognised within the literature that multiple risk factors increase the likelihood of falls. These factors include poly-pharmacy, mobility problems (as a result of poor balance and or muscle weakness), chronic health conditions (such as stroke or Parkinson's disease), sensory impairments such as visual or

proprioceptive loss), reduced independence and performance of activities of daily living, environmental hazards, or incorrect use of assistive devices (National Institute for Health and Clinical Excellence [NICE] 2004). Whereas the greater the number and prevalence of these risk factors is considered to increase the risk of falling (Close et al 2003, United States of America Centres for Disease Control and Prevention [USA CDC] 2008, American Geriatric Society and British Geriatric Society [AGS &BGS] 2009), it is acknowledged that some individual factors, such as cognitive impairment, also significantly increase the risk of falling (Tinetti and Williams 1998).

It is also interesting to note that there are many definitions of falling within the research literature and may mean that falls have been poorly reported (McIntyre 1999, Hauer et al 2006). Hauer et al (2006), in their systematic review, also suggest that a universally accepted definition of falling also needs to be simple enough for lay people to understand and report when necessary. Indeed Ballinger and Payne (2002) suggest that older people and health professionals differ in their perceptions of what constitutes a fall.

In this study, the chosen definition of falling was one that was most universally accepted by practitioners at the time the study commenced in 2003. This definition was that used in the falls audit pack produced by the Chartered Society of Physiotherapists (CSP) and College of Occupational Therapists (COT) in 2002. This was based upon the definition of Tinetti et al (1988) which was that a fall has occurred “when a subject unintentionally comes to rest on the ground or at some other lower level, not as a result of a major intrinsic event (e.g. stroke or syncope)” (CSP and COT 2002:5). More recently, an international consensus of falls experts agreed the most current definition of a fall, which is “an unexpected event in which the participants come to rest on the ground, floor, or lower level.” (Lamb et al 2005:1619), which is very similar to that of Tinetti et al (1988).

## 2.2 Dementia

It is said that there are 24.3 million people globally with dementia (Ferri et al 2005), with approximately 700,000 people affected by dementia in the UK (DH 2009). As previously stated, the incidence of dementia increases with age, and as the average age of the population increases (both in the UK and globally) there are concerns about the potential increase of people with dementia in the years to come. Indeed, the prediction is that the number of people with dementia in the UK will double to 1.4 million in the next thirty years (DH 2009).

There are different types of dementia, with the most common being Alzheimer's disease (approximately 50-70% of the population with dementia), followed by vascular dementia (10-30%), and dementia with Lewy Bodies (15-25%) (Feldman and O'Brien 1999). Even though these diagnoses are often not differentiated by services, they differ in their onset and how they affect the individual. It has also been more recently acknowledged that the different types of dementia can frequently occur together and this can currently only be determined post-mortem. Indeed the diagnosis of dementia can be difficult to make, even with internationally agreed signs and symptoms of the different types of dementia (Gow and Gilhooly 2003). Therefore, it is more common for people to be diagnosed by their predominant form of dementia (Feldman and O'Brien 1999), for example, in this study; people with predominantly Alzheimer's disease were the main study participants.

Knapp and Prince (2007) define dementia as "a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain as a result of physical diseases such as Alzheimer's disease" (p.xi). Whereas Alzheimer's disease is associated with a gradual and progressive worsening of memory, cognitive functioning (such as language or motor skills or perception) and changes in behaviour, vascular dementia tends to have a sudden onset with "step-wise" decline with transient or residual neurological signs (such as from frontal lobe damage or upper motor neurone signs). Dementia with Lewy Bodies also has a progressive onset but causes fluctuating cognitive impairment, Parkinsonism

and psychosis, including visual hallucinations and delusions (Feldman and O'Brien 1999, Gow and Gilhooly 2003).

### 2.3 Caring and carers

Many older people with dementia are cared for at home by informal carers, for example, by their spouse, family or friends (Edgell et al 2010). The National Audit Office [NAO] (2007) survey of dementia services identified that there are 560,000 people with dementia in England, cared for by 460,000 unpaid/informal carers. However the incidence of caring is not always easy to determine. Many people do not perceive themselves as carers; seeing the care they give as an extension of, or part of, their role of spouse, child, sibling, parent or friend. For others, the perceived stigma of the health condition experienced by the care recipient means that many carers do not explicitly acknowledge their role (DH 2010). It is also difficult to determine what constitutes caring, with different definitions and concepts. Even within surveys organised by the UK government there exist different definitions, as can be seen by the English Longitudinal Survey of Ageing [ELSA] (wave 1) in 2002 (Hyde and Janevic 2004) and the UK Census in 2001 (Office for National Statistics 2006) (see box 2.1)

#### Box 2.1 Definitions of caring

- Providing active support to another in the preceding week of the survey (Hyde and Janevic 2004)
- Provide unpaid care for family members, neighbours, or others who are sick, disabled or elderly (ONS 2006)

Data from these two surveys have been analysed by several research groups. Dahlberg et al (2007) examined the UK Census (2001) data and identified that ten per cent of the UK population are carers, which equates to 5.9 million people, however they acknowledge the lack of consensus of what “caring” is. Studies by Ross et al (2008) and Vlachantoni (2010) explored the ELSA data collected in 2004 and 2006 and identified that ten per cent of the population

aged over 52 years are carers, 39% of whom care for their spouse and 34% care for their parents/in laws (Ross et al 2008).

Whereas it has been traditionally considered that the majority of informal carers are women, the studies by Dahlberg et al (2007), Ross et al (2008) and Vlachantoni (2010) all identify that the gender profile of carers differs from age group to age group. Indeed the majority of carers in the peak age group for caring (45-59 year olds) are mainly women. However, from the age of 70 onwards, the majority of carers are men. This age group is most likely to consist of spouse carers, who have the greatest care burden (Ross et al 2008), and less likely to receive help from others (Baker and Robertson 2008). Dahlberg et al (2007) also identify from the UK census (2001) that the older the carer, the more hours of care given, with those carers (especially men), aged 80-89 years, providing 50 or more hours of care a week. A recent survey by The Princess Royal Trust for Carers (2011) also identified that two thirds of older carers have their own long-term health problems, such as musculo-skeletal problems, heart disease, cancer and depression. There is also evidence that carers neglect their own health, by cancelling hospital appointments and routine checks because of the burden of care (DH 2010, The Princess Royal Trust for Carers 2011).

Whereas the ELSA in 2002 was able to capture data about carers based upon its own criteria (rather than being declared by the participants themselves), it meant that the characteristics and health condition of the care-recipient were not captured. In some instances, the spouse care-recipient was also interviewed in the ELSA, and therefore some of the data from both spouses could be correlated (Ross et al 2008). Whereas care-recipient health, independence in personal activities of daily living (PADL) and experience of pain did not seem to impact on the spouse-carer's quality of life, there were significant correlations between the care-recipients' reduced independence in instrumental activities of daily living (IADL) (mainly community living and integration) and memory function, on the spouse-carers' quality of life. It would seem that impaired memory function had the most significant impact on the carers' quality of life (Ross et al 2008). One could also suggest that those people with more severe cognitive impairment, would also have been excluded

from the survey because of their limited capacity to consent to participate, therefore a correlation between their ability to carry out personal and instrumental activities of daily living, their mental function and the carers' quality of life or burden of care could not be explored. Moreover, Baker and Robertson (2008) and Vikström et al (2008) suggest that subjective and objective carer burden, carer strain, reduced health and wellbeing, and restricted activity and participation for the carer, all increase as the severity of the dementia develops in the older person.

## **2.4 Falls and dementia**

This section will consider the incidence and consequences of falls and evidence for falls interventions with older people with dementia.

### **2.4.1 The incidence of falls**

Morris et al (1987) explored the occurrence of falling in community living older people with dementia during a four-year period and identified that 36% fell during this time. Like Morris et al (1987), Allan et al (2009) studied the incidence of falls amongst people with dementia living in the community. Allan et al (2009)'s prospective study also explored the incidence and prevalence of falls amongst community living older people with the four most common forms of dementia (Alzheimer's disease, Vascular dementia, dementia with Lewy Bodies and Parkinson's disease with dementia). This research group identified that whereas 65.7% of the participants with all types of dementia had fallen at least once during the twelve months of the study, the incidence of falls in older people with Alzheimer's type dementia was 47% compared with a 35.9% incidence in the cognitively normal group. The study by Allan et al (2009) suggest a higher incidence of falling amongst community living older people with dementia than those in the study by Morris et al (1987). Allan et al (2009) also specifically identify for the first time, that the rate of falls for those older people with Alzheimer's disease, living in the community, was twice that of their cognitively normal counterparts.

It would seem that older people living in residential and nursing home care fall more frequently, with van Dijk et al (1993) finding that 75% of older people with dementia had fallen within a year of being admitted to a nursing home and 25% of these had a mean falls rate of 4 falls per year during a two-year period. A more recent study by van Doorn et al (2003) also ascertained that older people with dementia living in residential and nursing care had a similar falls rate to the study by van Dijk et al (1993) of 4.05, compared to that of 2.33 per year, for cognitively normal older people.

#### 2.4.2 The consequences of falling

The consequences of falling such as serious injury (e.g. hip fracture), lying on the floor for a long period, decline in everyday activity, admission to long term care and mortality are all more likely for older people with dementia and cognitive impairment (Kallin et al 2005, Oude Voshaar et al 2006, Fleming and Brayne 2008). Falling is one of the major causes of hip fracture in older people (Morris et al 1987); with older people with dementia being two or three times more likely to sustain a hip fracture than an older person who is cognitively normal (Friedman et al 2010, Baker et al 2011). Hip fractures are considered a major cause of disability in older people, especially for those with dementia or cognitive impairment (Baker et al 2011). Poorer recovery following hip fracture, admission to residential or nursing home care, with poorer response to rehabilitation, are also suggested by researchers (Holmes and House 2000, Oude Voshaar et al 2006, Baker et al 2011). However Moncada et al (2006) identified that there is some evidence for positive outcome from hip fracture for older people with cognitive impairment, even though this may not be to the same level as, and may require a longer rehabilitation period than, cognitively normal older people. Oude Voshaar (et al 2006) also explored older people's recovery after a hip fracture, and associated a less favourable outcome with fear of falling, cognitive impairment and depression. The psychological impact of falls such as loss of self-efficacy, autonomy and fear of further falls are acknowledged in cognitively normal older people (Lord et al 2007); with Cree (2004) identifying that functional recovery following hip fracture has a significant

impact on a positive perception of health status by older people with cognitive impairment.

It is also of relevance to consider that falls and hip fractures have consequences for the carers of older people. Two correlational studies by Kuzuya et al (2006) and Saltz et al (1999) identified that carer burden and carer strain correlated with the incidence of falls and hip fracture in older people without cognitive impairment. Whereas Kuzuya et al (2006) could not identify why carer strain increased, they surmised that this was associated with increased fear or stress of the care-recipient falling (rather than increased help with everyday activity) and Saltz et al (1999) suggested that an increase in physical burden, as well as fear of further falls, increased carer strain. If one extrapolates these findings with the findings by Baker and Robertson (2008) and Vikström et al (2008), one can suggest that one of the consequences of falls in older people with dementia is likely to be an increase in carer burden and carer strain.

### **2.4.3 Falls interventions for older people with dementia**

In the motivation to carry out falls prevention with older people with dementia, many initial studies have attempted to identify why older people with dementia are at greater risk of falling than cognitively normal older people. Evidence suggests that risk factors for cognitively impaired older people (including dementia) are increased impairments in gait and balance, reduced reaction times, impaired dual tasking, visual impairments, medication (especially psychotropic medication), orthostatic hypotension, the type and severity of dementia and reduced ability in activities of daily living (Shaw 2002, Hauer et al 2003, Allan et al 2009, Harlëin et al 2009).

Whereas multifactorial interventions, (involving exercise, knowledge provision, medication, environmental, vision, bone health interventions and foot-care) are commonly provided and seen to be effective in cognitively normal older people (Lamb et al 2005, Gillespie et al 2009), there is little evidence to support these interventions with older people with cognitive impairment (Jensen et al 2003,



Shaw et al 2003, Hauer et al 2006). There are said to be methodological issues with these studies, with Shaw et al (2003) including older people from residential homes in their randomised control study. Other suggested criticisms of these studies were that the sample sizes were too small to show sensitivity to change, and that there was a lack of specificity of the type and severity of cognitive impairment (AGS & BGS 2009). However, the study by Jensen et al (2003) did involve separation of their intervention groups into those participants with higher or lower cognitive function, determined by an Mini Mental State Examination [MMSE] (Folstein et al 1975) score of 19, and ascertained that the group with higher cognitive functioning had statistically significant improvement in incidence of falls after the intervention, which the group with lower cognitive functioning did not. However, this study was carried out in nine residential care homes, with a lack of randomisation and blinding of staff to group allocation. Although this study lacks generalisability and was not carried out with community living older people with dementia, the response to intervention by the different groups is of interest. Indeed, Shaw (2007), AGS & BGS (2009) and Gillespie et al (2009) recommend that intervention (and therefore intervention research) should specifically target the needs of people with different types of dementia and degrees of cognitive impairment, to increase the evidence base. What has also been identified is that few of the measures recommended in falls research and intervention have been validated for older people with cognitive impairment or dementia (Hauer et al 2010).

Both Shaw et al (2003) and Jensen et al (2003) are rare examples of randomised control trials of falls interventions with older people affected by dementia. However, all of the participants in the study by Jensen et al (2003) lived in residential or nursing home care and some of the participants in the study by Shaw et al (2003) also lived in residential care. A recent systematic review by Jensen and Padilla (2011) identified only two other research studies by Mackintosh and Sheppard (2005) and Ries et al (2010), of falls programmes for older people with dementia which were carried out with community living participants. However, both of these were very small quasi-experimental single group designs reporting no significant findings for the efficacy of their interventions. The intensity, approach and type of interventions varied between

studies, with only Shaw et al (2003) providing home-based interventions. Whereas Shaw et al (2003) took a multi-factorial approach, but provided individualised programmes, Mackintosh and Sheppard (2005) and Ries et al (2010) were mainly group interventions focussing on exercise and balance. Moreover, it would seem that none of these involved the family carers, with only Mackintosh and Sheppard (2005) stating that liaison with family members took place where necessary.

Therefore, very few studies of falls interventions have been carried out with community living older people with dementia, and yet these people are the most likely to fall and have more severe consequences than their cognitively normal counterparts (Kallin et al 2005, Oude Voshaar et al 2006, Fleming and Brayne 2008). Unfortunately the studies carried out have been of varying quality, and the findings have lacked significance, with none of these studies seemingly involving the carers or families of the older participants with dementia.

## **2.5 General Policies and Guidance relating to Older People**

Much of recent national and international policy and guidance relating to older people have been informed by activity by the United Nations (UN) or the World Health Organisation (WHO). The Universal Declaration of Human Rights (UN 1948), the Declaration of Alma Alta (WHO 1978), the Ottawa Charter for Health Promotion (WHO 1986), Proclamation on Ageing (UN 2002), Madrid International Plan of Action on ageing (UN 2002), Active Ageing: a Policy Framework (WHO 2002) have all influenced the health and social care provision in the late 20<sup>th</sup> and early 21<sup>st</sup> century. These policies highlighted not only the universal right of individuals to good health and dignity in care, but also that the families caring for these individuals have the right to support. The policies and declarations also advocate that all people should be empowered, involved and listened to, either as individuals or communities, in the planning and implementation of health care provision, and that older people in particular, should be viewed as contributors and not as burdens to society (UN 1992, 2002, WHO 1978, 1986, 2002).

These aspirations can be seen in many national policies pertinent to older people, those with dementia, those who fall, and their carers, especially in the English National Service Framework for Older People [NSFOP] (Department of Health [DH] 2001). It is also worth placing this study in a historical context of these many documents. As already stated, this research started in 2003 and the data collection ended in 2008. During this time period, other pertinent policies and guidance documents have been published, however not all of them were available at the time that data were collected, therefore how they have informed the study is often in hindsight and at the final analysis and writing of the thesis.

This research project was informed by targets set by the Department of Health for England in the NSFOP (DH 2001) for health and social care services. The NSFOP (DH 2001) was preceded and informed by the NHS Plan (DH 2000), which identified a need for national standards of care and services, along with service user involvement in local NHS provision and also the Health of the Nation (DH 1998) which highlighted five key areas (including mental health) central to health care policy in the 1990's. Support for carers was also identified with the NHS Plan, along with the provision of intermediate care and partnership working between health and social care services.

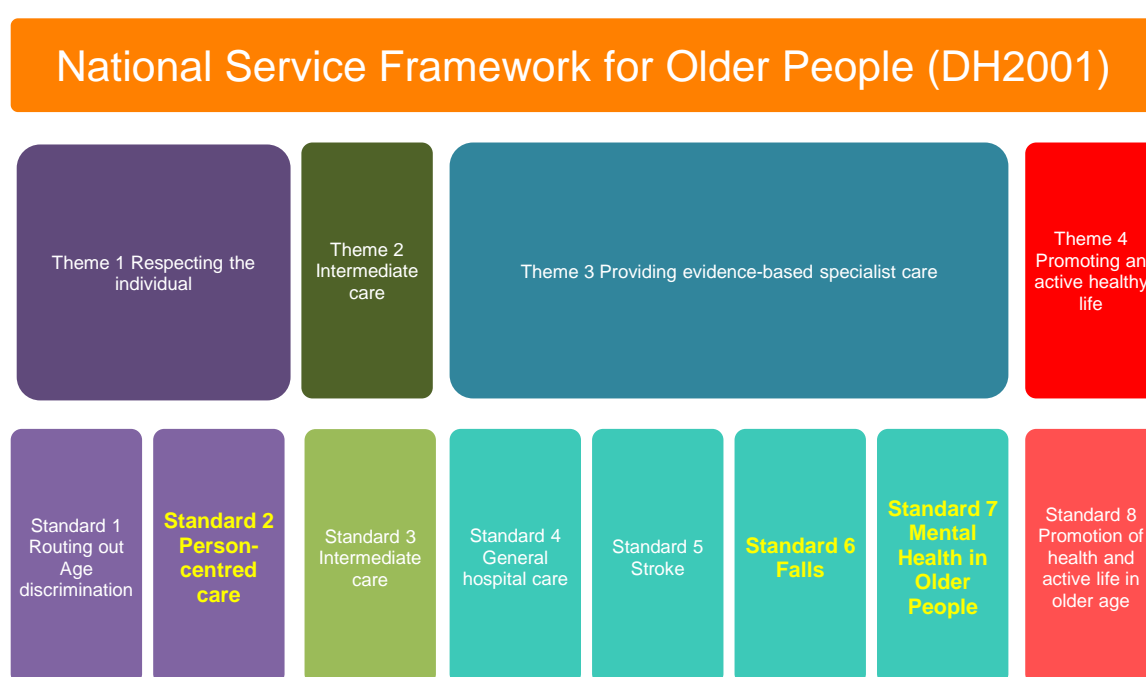
The NSFOP was the first strategy to provide targets for both health and social care provision for older people in the UK, and within the NHS Plan (DH 2000), and it was stated that the NSFOP would ensure dignity and security in old age.

A total of eight standards were set by the Department of Health (2001) who specified targets to be completed within a ten-year period by all health and social care services for England to meet and address for older people. This meant, for example, that not only did acute and community physical health services have to develop a falls strategy, plan and implement this, but so also did older people's mental health services along with local authorities and other social care agencies.

The standards from the NSFOP that mainly informed this study are standard two (Person centred care), standard six (Falls) and standard seven (Mental Health in Older People). In standard two, the NSFOP identified that older

people and their carers should receive person-centred care and services, with carers being partners in care provision, and both members of the dyad being supported and provided with appropriate information. Standard six relates to the provision of evidence-based and specialist care to all those older people that had fallen and the provision of services to prevent falls. The targets for this standard involved the identification of risk through regular screening and provision of interventions targeting these risk factors.

**Table 2.1 Themes and standards of the NSF Older People (DH 2001)**



The setting up of specialist-run falls services (for assessment and/or intervention) was stipulated within the NSFOP (DH 2001), along with every health and social care service having a falls care pathway to ensure that the appropriate assessment and intervention is available to all older people. Standard seven sets targets for all health and local authority services to provide integrated care to older people in order to promote good mental health, speedily diagnose those with mental health problems, provide access to specialist care and to provide informal carers with advice, information and practical support.

A subsequent audit of NHS services found that not all targets were achieved within the specified time (Audit Commission 2006). For example, the dignity and human rights of many older people, especially those with mental health problems were still of an unacceptable standard. Not all NHS trusts had a falls service and many mental health services did not provide equitable service provision for older people. As a result, a second document was produced with updated and revised targets for older people's services in the document "New Ambition for Old Age" (DH 2006). What was also acknowledged was that many older people have complex needs because of having one or more long term conditions (for example, dementia and cardio-vascular disease) and therefore they (and their carers) need integrated services (DH 2006). Interestingly, because of the complexity of some of the themes; standard or theme specific documents and targets were produced – especially those relating to older people who fall, those with dementia and for carers. It could be said that as a result of these "independent" documents and policies, the integration of these targets have not yet been explicitly carried out. Some of these documents, pertinent to older people who fall, those with dementia and carers will now be presented.

## **2.6 Policies and guidance relating to falls prevention for older people**

Within the UK, there has been a drive to reduce accidents caused by falls in older people since the early 1990's (Health Education Authority 1999, Department of Trade and Industry [DTI], 2001). However, since 2001 the main driver for falls prevention and reduction for older people in England has been the targets set within standard six of the NSFOP (DH 2001). The main essence of standard six was that changes to service provision needed to be made. These changes were to address prevention of falls through identification and management of risk factors, and prevention of serious consequences of falls, such as fracture. It was considered that this would occur through identification and intervention for those people with (or at risk of) osteoporosis, through appropriate care, medical treatment, rehabilitation, education and long-term support. The DH (2003) also stated that falls and their negative impact could be

reduced by 30% with effective local working between health and social care agencies. The National Institute for Clinical Excellence [NICE] produced guidelines in 2004 in support of standard six of the NSFOP (DH 2001), with principles of practice for falls service provision for all community living older people. These guidelines were based on international evidence published up until 2003, such as a Cochrane review by Gillespie et al (2003) (now updated to Gillespie et al 2010), joint guidance produced by AGS and BGS (2001), epidemiological studies and systematic reviews of assessment, intervention and psychological consequences of falls (NICE 2004). Not only did NICE (2004) aim to provide evidence-based guidance on risk assessment and falls prevention for older people, but it recognised that there were many barriers to older people either taking up or adhering to falls advice. Therefore, it recommended that psychological factors (such as fear of falling) should be included in risk assessment, and that older people should be involved in service development, provision and evaluation, to enhance take-up. The NICE (2004) guidance stated that multi-factorial interventions should be offered to all older people who had fallen, and that these should include strength and balance training, assessment and intervention of hazards within the home, assessment of cognitive function, assessment of vision, review and modification of medication. NICE (2004) recommended that all health and social care professionals working with client groups known to be at high risk of falling (e.g. older people with dementia) should have (and maintain) competency in falls assessment and prevention. It also identified that more research into effective strategies for older people with cognitive impairment (such as dementia) was needed, as there was insufficient evidence at that time. A recent review of the NICE guidance for falls in 2011 identified that these 2004 guidelines still were relevant, and the recommendations (including more research required on falls interventions for people with dementia) are still valid (NICE 2011).

More recent guidance by the WHO (2007), Centre for Disease Control and Prevention [CDC] (2010) in the US, Australian Commission on Safety and Quality in Health Care [ACSQHC] (2009), AGS & BGS (2010) and a Cochrane review by Gillespie et al (2010) have considered that there is insufficient evidence for falls intervention with older people with cognitive impairment or

dementia. Even though the CDC (2010) suggests that people with cognitive impairment should be given equal opportunity; it is the ACSQHC (2009) document that gives more pro-active guidance for this client group. The guidelines recommend that older people with cognitive impairment (or dementia) should not be excluded from falls interventions because of lack of evidence, but that the interventions may need greater modification or supervision. The rationale given by the ACSQHC (2009) is that many successful falls intervention studies that explicitly excluded older people with cognitive impairment may not, in reality, have excluded them. They suggested that differing definitions of cognitive impairment are used in research, and that some studies of more frail older people (e.g. Lord et al 2003, Wolf et al 2003), used a MMSE (Folstein et al 1975) score of 20 as their inclusion criteria, thus including older people with mild to moderate cognitive impairment/ dementia as participants.

Disappointingly, recent audits of falls service provision in the UK (Health Care Commission 2008, Royal College of Physicians [RCP

] 2011) have identified that many health and social care services have not met the targets set by the NSFOP (DH 2001) or the NICE (2004) guidance, especially in relation to identification of those older people with cognitive impairment or dementia. The RCP (2011) audit of falls provision also highlighted that 6% of all falls services have been routinely and explicitly excluding older people with dementia from falls service provision. Like the ACSQHC (2009), the RCP (2011) stated that service providers should not discriminate against older people with dementia, nor can they assume that this group of older people would not benefit from falls assessment or intervention.

What is also of interest is that although standard two of the NSFOP (DH 2001), the NHS Plan (DH 2000), the Audit Commission (2002) and the WHO (2007) all advocated that older people should be involved in service delivery, from inception to evaluation, very few reports document this. Disappointingly, the RCP (2011) audit of falls services found that only 60% of services that they audited used a patient evaluation questionnaire, and that many older people felt that communication about, to and from falls services was poor. It is perhaps

only in the Public Health Agency of Canada (2005) and Health Scotland (1999) documents that older people have been listened to, for their opinion and their experiences of falls.

In conclusion, the last ten years have seen both global and UK aspiration for falls prevention and intervention for older people. Since this study commenced, evidence for falls intervention and assessment has identified their efficacy for different groups at high, medium or low risk of falling. However, there is still little evidence or recommendations for service provision for older people with cognitive impairment and/or dementia (who have been highlighted as a high-risk population for falls), and in some instances in the UK, they are still excluded from falls services (RCP 2011).

The involvement of older people and their carers in service development and evaluation also seems to be limited. However, their involvement in falls management development and evaluation is especially pertinent when one considers that there is limited uptake of, and adherence to, these evidence-based falls interventions (aa, 2006b, Nyman and Victor 2011). There is also criticism that interventions are not tailored to the individual's needs (Hill et al 2009), or delivered in the most favourable way for older people (Yardley et al 2008). Therefore the consultation and involvement of older people with dementia and those that care for them, is of great importance to ascertain their opinion and views of falls experiences and interventions. Furthermore, it is of great importance to reduce the risk and incidence of falls in older people with dementia who are a group of older adults at high risk of falling.

## **2.7 Policies and Guidance relating to people with dementia and their carers**

Many of the current and most recent documents appertaining to people with dementia, also address the needs of their carers, as it is recognised that the majority of this client group are supported to a lesser or greater degree by their spouses or families in the community. It is therefore pertinent to consider how these documents influence the provision of services for both members of the



dyad, in this section, with a separate section that will present pertinent policies and legislation that relate solely to carers.

The last ten to fifteen years have seen an increasing concern by UK and international governments about the potential increase in older people with mental health conditions, alongside the increase in the ageing population. The increase in the population of the oldest-old in the UK is of particular concern, when the estimate is that one in four of the population aged over 85, has a mental health condition (Audit Commission 2000) and that over 12% of people over the age of 82 have dementia (NAO 2007). In response to these predictions, and the survey carried out by the Audit Commission (2000), the UK government has produced several key documents that relate to the mental health needs of older people. Key documents other than those already discussed and appertaining to older people with dementia, that were available when this research started was the “Forget Me NOT” report by the Audit Commission (2000).

It could be argued that the “Forget Me Not” report (Audit Commission 2000) was produced in response to the concerns about the ageing population. However the “Forget Me Not” report (Audit Commission 2000), the NSFOP (DH 2001) and the later service development guide “Everybody’s Business” (DH/ Care Services Improvement Partnership [CSIP] 2005) were the start of a strategy of care and service provision for older people with mental health problems. The Audit Commission (2000) report indicated a wide variation in health and social care service provision, available resources and integrated working in England and Wales. The survey also showed that the speed of identification and diagnosis of mental health problems (especially dementia) by General Practitioners [GP] varied. What arose out of the survey findings were that the identification of a mental health problem often occurred only when the carer asked for help from their GP, and that GPs had differing attitudes to diagnosis. Approximately 50% of GP respondents considered that early diagnosis of dementia was unnecessary, or inappropriate, or they felt that they lacked the skills and training not only to diagnose but also to manage dementia (Audit Commission 2000). What arose out of this report was the recommendation for

early diagnosis (and communication of that diagnosis) to support people with dementia and particularly carers to plan for the future and also to reduce stress of the unknown (Audit Commission 2000).

A review by the DH (2004) identified that many mental health services were still discriminating against older people on grounds of age. In response to these findings, the DH and CSIP (2005) provided a development guide for older people's mental health services. This document reiterated the targets set within the NSFOP (DH 2001), but also identified that older people with mental health problems may have an increased requirement for care and that services should involve a "whole systems approach" (DH/CSIP 2005 p8) to match the complexity of the needs of this client group. This document also acknowledged the importance of gaining the perspectives of both the older person and their carer, as their views and needs might differ.

During this time, legislation relevant to older people with dementia came onto the statute books in England and informed subsequent policy and guidance. The Mental Capacity Act (HMSO 2005) stated that there had to be an assumption that an individual has capacity to consent to decisions, unless it could be proven otherwise. The Act also stated that all practicable steps had to be taken to facilitate decision-making, so that obtaining consent from individuals should take place in a more person-centred way. Subsequently, the involvement of people who would have previously considered lacking capacity to take part in decision making and informing processes has changed.

Since 2005, the UK governments have produced documents specifically related to people with dementia. Social Care Institute for Excellence [SCIE]/NICE (2006) published the first jointly produced guidelines by health and social care disciplines in England, which involved people with dementia and carers in the decision making (Iliffe and Manthorpe 2007). The guidance emphasised the need for person-centred practice, in terms of no discrimination in service provision on grounds of age or diagnosis, and that valid consent must be sought about available options. Like the DH/CSIP (2005) document, it was acknowledged that the needs of the person with dementia should be taken into account in conjunction with their carers and families. Not only did the

SCIE/NICE (2006) guidance address pharmacological interventions, but also identified that people with dementia should be able to access interventions that would promote and maintain their functional independence (such as self care and mobility) and those that would maintain cognitive functioning appropriate to the stage of dementia.

Also of relevance were the acknowledged needs of carers of people with dementia, with identification of the provision of support and interventions to educate, to address psychological distress and the psycho-social impact of the person with dementia's diagnosis on themselves, as well as practical support mechanisms for both the carer and the person with dementia (such as respite and short break services).

In 2007, two reports appertaining to dementia were published, one by Knapp and Prince (2007), on behalf of the Alzheimer's Society in the UK and the second by the NAO (2007). Both of these reports provided more accurate numbers of people diagnosed with dementia and also more research evidence for practice. The NAO (2007) identified that very little had changed since the Audit Commission (2000) survey in terms of diagnosis of dementia, even though early diagnosis and intervention were deemed to be cost effective for both the person with dementia and the carer. Identified barriers to timely diagnosis were still the attitudes of older people and their families (in terms of fear, ignorance and social stigma) and attitudes of GPs (limited perception that anything can be done, lack of urgency or lack of confidence in making diagnosis). Other barriers to diagnosis and routine mental health screening (as recommended in the NSFOP) were apparent in acute health care services, where it was perceived that identification of dementia would impede discharge. Findings also showed that in some circumstances, people with dementia were inappropriately admitted to hospital with a condition that did not require acute care (e.g. fall or infection) because of a lack of appropriate community support.

The most recent key document in the UK is the DH (2009) "Living well with Dementia": National Dementia strategy for England, which aspires for better health and well-being for older people with dementia and their carers. This strategy provided 17 key objectives for health and social care services based

around three main aims which relate to increasing public and professional awareness of dementia, earlier diagnosis and intervention and improved quality of care. This document identified the need for on-going peer support and learning networks; improved intermediate care and that carers' rights and needs should be assessed, addressed and monitored.

The targets and recommendations within these strategies and guidance documents have been mirrored in other countries within the UK. Interestingly some of the Scottish documentation (Scottish Intercollegiate Guidelines Network [SIGN] 2007, Scottish Government 2011) have specifically mentioned management of physical conditions, such as visual impairment and falls, with one of the research recommendations being to establish effective interventions to reduce and prevent falls in people with dementia. Like the Department of Health in England (DH 2010, 2011), the Scottish Government (2011) followed up the publication of their dementia strategy (Scottish Government 2010) with recommendations for core competencies for health and social care staff when working with people with dementia. Whereas the DH (2010) briefly mentions falls risk, the Scottish Government (2010) document provides more explicit required competencies and knowledge of falls management for differing staff groups, according to their involvement with people with dementia.

## **2.8 Policies and Guidance relating to carers of people with dementia**

It has been suggested that informal carers save the UK taxpayer £87 billion per year in carrying out unpaid care (Carers UK 2009), but it is only in the last ten to fifteen years that carers have been given increasing rights independent of those people that they care for. More pro-active laws and policies in England, such as the Carers Equal Opportunities Act (2004), "Carers at the heart of the 21<sup>st</sup> century" (HM Government 2008) and "Recognised, valued and supported: Next steps for the Carers strategy" (DH 2010) have been mirrored by similar legislation and strategies in other UK countries and have been produced since the NSFOP (DH 2001). These later laws and strategies have identified carers' needs for respect and dignity (independent to those of the care-recipient), advocated recognition of carers as expert partners by health and social care

practitioners, financial and employment security and good health and well-being. There is little difference between the policies of the UK countries, but international differences do occur, mainly because of the presence (or absence) of delivery of statutory health and social care (Audit Commission 2004). However the principles of support for carers are the same – including respect for human rights, dignity, security and optimal health and well-being (Ministry of Social Development [New Zealand] 2008, Canadian Caregiver Coalition 2008, National Alliance for Caregiving [US] 2009, Australian Government 2011).

Interestingly, even though the NSFOP (DH 2001) and the DH (2009) national dementia strategy acknowledge the needs of both the older person (as care-recipient) and their carer, it is the Australian national carer strategy that explicitly highlights that caring occurs as an inter-relationship, between the carer and the care-recipient. This strategy suggests that even though the individual needs should be addressed, it is important to understand that the needs of either member of the relationship can change because of their interdependence on each other and changing life circumstances (Australian Government 2011).

## 2.9 Summary

This chapter has presented a background discussion for the research studies presented in subsequent chapters. It has highlighted the incidence and consequences of falling, dementia and caring in older people. Even though many national and international policies and guidance documents (along with the research evidence), have been produced to assist health and social care provision of effective falls assessment and management, the provision of these services for older people with dementia lack an evidence base and coherent or explicit guidance.

Whereas the NSFOP (DH 2001) proposed targets for health and social care services in England for all older people, subsequent policies and guidance documents have been published focussing on the needs of specific groups of older people, such as those with dementia (DH 2009), carers (DH 2010) and those who fall (NICE 2004, 2011, WHO 2007). It is suggested that this can often

lead to the needs of older people with more complex problems such as dementia and falls being overlooked, because of a lack of explicit guidance for their care and intervention. Other governments have produced documents where the needs of older people with dementia are explicitly considered within falls management guidelines (ACSQHC 2009) or the needs of older people who fall within dementia care guidelines (Scottish Government 2011). Although the National Dementia strategy (DH 2009) acknowledges the needs of both the person with dementia and the carer, it is perhaps in the Australian National Carer strategy that acknowledges the inter-relationship between carers and care-recipients and their joint needs (Australian Government 2011).

In conclusion, it would seem that many of the UK policies and guidance have aspired to improve the experiences of older people who fall, have dementia or who are carers. Unfortunately, many of the targets set by government for service providers have not been met. Furthermore, the involvement and understanding of the experiences of these groups of older people to inform service development and provision has not been universally carried out by health and social care services. In many instances this has led to older people declining to participate in interventions or take up offered care. One could suggest that the prioritising of the opinion of health and social care “experts” has led to the perspective of the older person being lost or never explored, and therefore the service provided failing to meet their needs.

### Chapter 3 – Literature Review

In this chapter, the research literature of the experiences of older people with dementia and their carers about falling are reviewed and critiqued. As already stated in the first and second chapters of the thesis, the importance of listening to, and understanding the experiences of older people and their families, have been informed by my own practice when working with clients, by the tenets of client centred practice, and by international and national policy (WHO 1986, DH 2001). Moreover, it is not only proper to listen to clients as this allows for their experiences, circumstances and opinions to be understood, (Rapport et al 2005). Therefore, the overall focus of this literature review is on the experiences of older people with dementia and their carers.

It is important to explore the existing and relevant literature to identify what it contributes, to consider potential gaps and to provide a rationale for one's own research (Smith et al 2009, Finlay 2011). As is quite common practice in qualitative research (especially phenomenological research), an initial and orientating review of the literature took place in 2003 to explore the available evidence at that time (Holloway 2005, Smith et al 2009). This initial review provided a rationale for the research and informed the research ethics application (Frankel 1999, Finlay, 2011). Phenomenological research (and IPA in particular) aims to bracket off pre-suppositions or preconceptions when exploring the life-world of the participants during data collection and analysis (Smith et al 2009). Therefore, a more comprehensive review of the literature took place after data collection and analysis, with the final literature review occurring in October and November 2011.

The chapter is divided into two parts. The first part (section 3.1) reviews the literature of the experiences of older people with dementia and the experiences of carers of people with dementia. The second part (section 3.2) relates more to the experiences of older people with dementia in relation to falls and the experiences of carers of older people with dementia in relation to falls.

The literature review in part one (section 3.1) could be considered a more traditional review (Pope et al 2007) where the literature discussed provides an

overview or broader context to the research by reviewing key theories and ideas, as well as a synthesis of relevant research evidence (Steward 2006, Haverkamp and Young 2007). Part two (section 3.2) provides what Pope et al (2007) suggest as a “second generation review’ (p6), where both qualitative and quantitative literature is reviewed to identify the gaps within the existing research, the contribution that different research approaches make and to establish their quality (Baumeister and Leary 1997, Pope et al 2007).

### **3.1 Part One: The experience of dementia – a traditional review of the literature**

#### **3.1.1 Introduction**

The literature reviewed in this part explores the experiences of older people with dementia in section 3.1.1 and then explores the experiences of carers of older people with dementia in section 3.1.2, to provide a background to the main review in part two of this chapter (section 3.2).

Although search terms have been used to identify relevant literature, the chosen literature was prioritised because of its contribution to existing knowledge rather than methodological quality (Baumeister and Leary 1997, Pope et al 2007). A process of “berry-picking” described by Walsh and Downe (2005 p206) was also used as a means of literature retrieval, where divergent strategies were used to identify relevant literature ‘along the way’, as the research proceeded. Indeed Greenhalgh and Peacock (2005) suggest that “serendipitous discovery” (p1065) of the literature can provide a better yield for even a systematic review rather than relying solely on pre-defined search terms, criteria and protocols.

#### **3.1.2 Search strategy**

The databases that were searched for the literature in both sections of this traditional review of the literature in part one, were Scopus, Medline and Web of Science (combined through Web of Knowledge), CINAHL plus, PsychINFO and Academic Search Complete (combined through EBSCOhost).



The search terms for the literature reviewed in section 3.1.3 were:

“lived experience” OR “personal experience” OR “subjective experience”  
AND Dementia,

with similar search terms for the literature reviewed in section 3.1.4:

“lived experience” OR “personal experience” OR “subjective experience”  
AND carer AND Dementia OR caregiv\* AND dementia.

### **3.1.3 Dementia as experienced by older people**

Hydén (1997) suggested that when the focus in medicine shifted from disease to illness in the latter half of the twentieth century, the voice of the patient became important. He also identified that whereas acute illness temporarily disrupts an individual’s life, chronic health conditions permanently alter the individual’s sense of who they are and what their future may be. This confirms research by both Bury (1982) and Charmaz (1983) who discussed that people with rheumatoid arthritis found their everyday lives disrupted not only by their bodily impairments, but also through loss of activity and consequential social isolation because of the disease. Both authors considered that the consequential disability could lead to loss of role, increasing dependency on others, restrictions in lifestyle, and therefore lack of opportunity for self-validation and being valued by others. Whereas Bury (1982) termed this biographical disruption, Charmaz (1983) described a loss of self.

Alzheimer’s disease has often been associated with an unravelling of self and identity, with Fontana and Smith (1989) describing a gradual “unbecoming of self” (p.35), occurring as part of the disease process. Other researchers have debated that the social consequences of chronic and progressive conditions can be more disabling to self and identity than the actual impairments of the disease. This is demonstrated in Kitwood’s (1989) social-psychological model of dementia. Kitwood and Bredin (1992) suggested that the degree to which an individual is disabled by their dementia is determined by interplay between their neurological impairments, their personal sense of self and how they are perceived and treated by those in their social environment. Kitwood (1990)

described a “malignant social psychology” (p.181), where interactions with, and the actions of others, can depersonalise, harm the individual’s sense of self (which he termed “personhood”) and exacerbate their symptoms, through treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, invalidation, outpacing, objectification and banishment. Kitwood (1997) advocated for person-centred dementia care, where the individual and their personhood (or sense of self) are foregrounded, rather than focussing on the disease process.

Bender and Cheston (1997) developed a social constructionist model of dementia, which similarly to Kitwood and Bredin (1992), considered that the emotional awareness and behaviour of the person with dementia is not only dependent upon their degree of impairment but also their social context. Bender and Cheston (1997) suggested that many of the emotional behaviours portrayed by people with dementia had been accepted as part of the disease process, rather than being explored or questioned more fully. These researchers regarded that normal reactions (such as anxiety and fear), to suspicion of, or identification of memory problems, are often exacerbated in dementia by malignant social psychology (as described by Kitwood 1990), especially when the individual’s diagnosis is withheld from them, leading to a lack of trust in others or paranoia. Early feelings of grief and depression, loss or terror, perhaps as a reaction to actual or anticipated loss of role and self-esteem, or a sense of emptiness and impending destruction of a loss of self or identity were all identified by Bender and Cheston (1997). These researchers considered that people with dementia protect themselves by using denial of any problems, living in the past, attachment (parent fixation), apathy or withdrawal, as coping mechanisms (Bender and Cheston 1997).

The involvement of people with dementia in research to explore their subjective experience has been advocated by Downs (1997), Woods (1997) and Wilkinson (2003), amongst many others. The main objective of this body of research has not only been to more fully understand the impact of dementia, but also to privilege the voices of the individuals experiencing it. Indeed, much of the early research used a vicarious route into the experiences of people with dementia, by interviewing their carers and families, or by observation, as it was assumed

that people with dementia would not be able to fully cooperate with the process (Bamford and Bruce 2000). Much of the research exploring awareness and coping styles revealed evidence for a wide range of responses to living with dementia. Whereas the majority of the participants in studies by Pearce et al (2002), Clare (2003, 2005), Clare et al (2006), and van Dijkhuizen et al (2006) acknowledged their memory problems, the reason given by participants for these problems were normal ageing or lifelong difficulties, previously stressful lives, or a traumatic injury such as a head injury or fall. Only a small number of participants in the studies attributed their memory problems to their diagnosis of dementia (or Alzheimer's disease). These researchers also highlighted that the participants experienced a sense of uncertainty, concern and some confusion about their abilities (Clare et al 2005, van Dijkhuizen et al 2006). Moniz-Cook et al (2006) interviewed older people prior to their assessment at a memory clinic and their diagnosis of dementia. Even though these individuals had not been formally diagnosed with dementia at the time the data were collected, they voiced feelings of fear about the future in terms of potential loss of mind, self, body functioning, social identity and relationships, pleasure and independence. Moreover, they were concerned about the impact of their memory problems on their spouses and family.

Although these studies were concerned with awareness of dementia, the coping strategies used by participants all focussed on preservation of self and identity. Clare (2002) describes a continuum of self-adjustment and self-maintenance strategies by older people in early stage dementia, to preserve a sense of self and identity, and these strategies are evident in the findings of other researchers, such as Harman and Clare (2006). Strategies such as persevering to maintain activities through sticking to routines, practical strategies (such as diaries, memos), a sense of discipline and reliance on spouses or families to facilitate, protect or rescue them, were all apparent in studies by Clare (2002, 2003), Clare et al (2005), van Dijkhuizen et al (2006), Pearce et al (2002) and Preston et al (2007). Other strategies showed a level of adjustment to coping with dementia (mainly Alzheimer's disease), by participants acknowledging that they needed to re-appraise and perhaps downgrade their expectations. Other adjustments included gaining more knowledge of Alzheimer's disease,

involvement in support groups and being able to make a contribution (such as being a research participant) was seen to be empowering and assisted them to be more prepared for the future (Clare 2002, 2003, Clare et al 2005, van Dijkhuizen et al 2006, Pearce et al 2002 and Preston et al 2007).

Research by Menne et al (2002), and Phinney et al (2007) identified that the desire of participants to continue their accustomed lifestyle could be fulfilled through meaningful activity. Whereas some participants in the study by Menne et al (2002) wanted to maintain previous activities (such as driving and helping others), but felt powerless in whether these continued or not, others made their own decisions, and willingly refined or adjusted what they did in a desire to carry out activities safely and appropriately. Phinney et al (2007) found that activities that promoted feelings of autonomy and identity, connection and belonging or enjoyment and pleasure, were those activities that had been meaningful for participants over the years. Even though participants modified and adjusted some of these activities, they still felt that they were able to successfully complete them. In both of these studies, it could be suggested that the social and physical environment facilitated the successful and meaningful carrying out of activity (either through family support and facilitation, or familiarity of equipment or the environment), as well as continuity of pre-diagnosis activity to maintain a sense of self (Menne et al 2002, Phinney et al 2007).

Most of these studies have explored through interview the experiences of people with mild or moderate dementia in their ability to maintain their sense of self. However, research by Kontos (2004, 2005), used observation of older people with more severe dementia to gain a more embodied understanding of how these individuals still maintain a sense of self and identity with limited verbal communication. Kontos (2004, 2005) used a social constructionist model of selfhood, first described by Sabat and Harré (1992) and refined by Sabat (2002). Kontos (2004, 2005) observed that even in severe dementia, when individuals were not able to verbally communicate a sense of identity or selfhood, the participants were able to demonstrate not only a personal sense of self (self 1), but also a social sense of self (self 2) through gesture and expression. Examples given were the ability to comfort others, the desire to

maintain a visual presence (through the wearing of make-up or jewellery) and the expression of disgust at the behaviour of others.

Whereas the majority of the studies discussed here focus on the experiences of older people with dementia in coping with diagnosis and maintaining their selfhood or identity, research by Phinney and Chesla (2003) had a more embodied focus. Phinney and Chesla (2003) interviewed older people with mild or moderate dementia to explore the lived experience of dementia through bodily manifestation. Phinney and Chesla (2003) drew upon the phenomenological philosophies of Heidegger and Merleau-Ponty to emphasise that although dementia is primarily a health condition with cognitive impairments, these are experienced in a bodily manner. Their participants expressed feelings of being slow; whether this was being more hesitant when walking, or those other tasks such as fastening buttons, ironing or even conversation became more laboured, requiring effort and attention. Other findings from this study were the physical sensation of being lost; not only in their own locality, but also misplacing items in their own home or losing track or sequence within an activity. Phinney and Chesla (2003) considered how the bodily experiences of participants were fore-grounded when they lacked fluency when carrying out tasks or activities, and also in the absence of activity, because of an increasingly limited involvement in the world in a physical or bodily way. Phinney and Chesla (2003) concluded that like other health conditions, with more physical impairments, the once transparent and taken for granted body becomes obtrusive and problematic in dementia.

This section has highlighted pertinent literature that explores the personal or lived experience of older people with dementia. Most of the participants in these relatively small qualitative studies had mild or moderate dementia at the time of data collection (Clare 2002, Menne et al 2002, Pearce et al 2002, Clare 2003, Phinney and Chesla 2003, Clare et al 2005, van Dijkhuizen et al 2006, Harman and Clare 2006, Phinney et al 2007, Preston et al 2007); therefore, the lack of generalisability to the wider population of older people with dementia cannot take place, (nor indeed was suggested). However, these studies have provided insights into the experiences of the participants in their attempt to both maintain

their personal sense of self and identity, as well as a more socially acceptable self; and adjustment to the progressive nature of the disease.

#### **3.1.4 The experience of caring for an older person with dementia**

The role of informal carers such as spouses, family members or friends is crucial to enable an older person with dementia to live in their own home for as long as possible. It is suggested that over 80% of people with dementia are supported by spouses or families, in the community (NAO 2007).

In response to supporting carers of older people with dementia, early research focussed on the burden and stress of caring, with Etters et al (2007) identifying that 80% of carers of people with dementia frequently experienced caregiver burden. Carer burden is said to lead to health problems such as depression and cardiovascular problems for the carer (O'Rourke and Tuokko 2000, Li et al 2011) and admission to long term care for the care-recipient with dementia (Etters et al 2007). Morgan and Laing (1991) suggested that burden could be considered in subjective and objective terms where subjective burden relates to the feelings, attitudes and emotional reactions of the carer and the objective burden relating to concrete events (e.g. the older person with dementia falling) and activities. However, Morgan and Laing (1991) suggested that subjective burden is not exclusively determined by objective burden, and in their grounded theory study proposed that subjective burden was associated with the quality of the previous relationship between the carer and care-recipient with dementia and their understanding and acceptance of the diagnosis of Alzheimer's disease.

Different aspects of burden and stress have been explored. Indeed, an early correlational study by Zarit et al (1980) identified that carers' feelings of burden were not associated with the behavioural problems of the person with dementia that they were caring for, but with the available social support provided. Carer burden has been considered as a multi-dimensional concept (Etters et al 2007). The study by Zarit et al (1980) did not specify how long their participants had been diagnosed with dementia, whereas the participants in the study by Morgan and Laing (1991) had been diagnosed within the previous six months when

recruited. It could therefore be said that the carers in the study by Morgan and Laing (1991) were not yet involved in many caring tasks that might cause objective burden, however it is of interest that the carers' sense of subjective burden was also influenced by their understanding of the diagnosis of Alzheimer's disease. These findings are similar to those reported by Quinn et al (2008) who explored the caring experiences of spouse and partners of those in early stages of dementia. Similarly, to Morgan and Laing (1991), some of their participants did not fully understand the consequences of dementia, and either minimised the problems they encountered or denied the presence of Alzheimer's disease. The findings intimated a change in carer roles, with more responsibility and control for household tasks. Other changes that seemed to be more difficult for some carers were always being with the person with dementia, giving up their own interests outside the home and loss of friends when they felt they needed them most. Carers voiced a fear of the future and an increase in emotional distress. Quinn et al (2008) suggested that the lack of understanding and uncertainty about dementia and the consequential changes in their partners were major contributors to the feelings of distress experienced by these carers.

A meta-analysis by Li et al (2011) identified that those carers who used dysfunctional ways of coping (such as uncontrolled expression of emotion, behavioural and psychological disengagement) were more likely to suffer anxiety and depression as a result of caring. The exploration of the long-term effects of caring on carers' health and wellbeing, was carried out by Skaff and Pearlin (1992) from a less positivist perspective (1992). These researchers considered the engulfment of identity and roles through the activity of caring. This study identified that even though some carers felt they had grown and developed because of caring, they still experienced loss of identity. Women, spouses or younger carers more commonly reported loss of self. Loss of self was associated with surveillance and control of behaviours, greater caring demands, less contact with friends (more so than family contacts), lack of outside employment and loss of an intimate relationship, especially if there was a "couple identity". Blum (1991) also considered how carers of family members with dementia managed the stigma of diagnosis. In their longitudinal study of carers using interviews and participant observation, Blum (1991) considered

that carer-participants managed the stigma of dementia initially by colluding with the person with dementia and ultimately colluding with others to avoid being stigmatised themselves through association. Blum (1991) considered that this transference of collusion was initially to seek verification from others of the difficulties they were experiencing and then to preserve their own perceived competence and sense of self.

Like Skaff and Pearlin (1992), Karner and Bobbitt-Zeher (2006) explored how the identities of carers became transformed and reconstructed through caring for someone with more severe dementia. These researchers took a symbolic interactionist stance in their study and suggested that the carer participants found the “emotional labour” (p564) of being a carer more demanding than the more physical daily tasks. These participants not only expressed a loss of the familiar person to dementia, but also considered that there was a loss and consequential renegotiation of their relationship. For some carers there was a clinging to earlier memories of their care-recipient in order to try to maintain both the identity of the care-recipient and the couple identity. They also voiced a transformation of their sense of self and identity into that of a carer. Whereas some were happy to identify themselves as “carer”, others struggled with the loss of their previous identity as spouse or child, as they had to reconfigure to a new identity as carer (Karner and Bobbitt-Zeher 2006).

Not all research has considered the negative aspects of caring. Netto et al (2009) described the personal growth gains in their grounded theory study of carers of older people with dementia in Singapore, in terms of practical and emotional skills and spirituality. Moreover, research by Graham and Bassett (2006) in Canada considered how caring can be empowering and enabling, with a two-way interaction. Even though they suggested that a lack of understanding about dementia could lead to declining relationships as the carer’s expectations of the care-recipient was based on previous behaviours, they also observed that those carers who had gained knowledge and understanding of dementia were more positive and supportive of the person with dementia. Graham and Bassett (2006) suggested that more positive experiences of caring were based on the carer’s expectations of themselves and not the care-recipient. They also suggested that where the carer lacked understanding of how the care-recipient



was affected by their dementia, they cared for, but not about, the care-recipient as the disease progressed.

More recent research has taken a more holistic approach to considering both the positive and negative aspects of caring and has considered the relationship between the person with dementia and their carer (Hellström et al 2007). Factors such as gender differences, spouse or child-parent relationships, have all been explored by researchers. The experiences of spouse carers have been explored within the research literature, with Sanders and Powers (2009) and Sandberg and Eriksson (2007) exploring the experiences of husbands looking after their wives. Recent surveys show that it is more common for older carers to be men, whereas younger carers tend to be women (Baker and Robertson 2008). Sandberg and Eriksson (2007) carried out a small qualitative study of 3 older husbands who cared for their wives. Even though these participants found themselves in a new and unfamiliar role they perceived this as taking on a new job, or “working role” (p8), with goals to fulfil. Even though these husbands struggled with taking on a changed role, they tried to maintain their marital role, mainly through being together even though they were aware that their wives were not always getting enjoyment from this. Sandberg and Eriksson (2007) suggested that their participants used their happy memories of past events and their loyalty to, and wedding vows with their wives, to cope with the present. They also focussed on goal setting and problem solving as a way to cope with the daily challenges, approaching these with optimism that they hoped to manage better the next day. These experiences are similar to those 17 participants in the study by Sanders and Power (2009), who similarly acknowledged taking on a new role and the changes in their relationships. These husbands expressed that their care-giving was part of their role as husband, to protect their wives, to preserve their self-esteem, to provide personal care and to be planners of activity and socialisation. Like the study by Sandberg and Eriksson (2007), they acknowledged the change in their relationship with their wives, with some voicing guilt that they had previously been unhelpful but also expressing how they cared for their wives still through a sense of intimacy and affection and because of the vows that they had made.

Like Sandberg and Eriksson (2007) and Sanders and Power (2009), the study by Perry and O'Connor (2002) suggested that spouse carers perceived caring as an extension of the marital relationship, by trying to maintain their past lives together, by supporting their spouse in what they were able to do and protecting them from what they were unable to do. Perry and O'Connor (2002) suggested that whereas husband carers concentrated more on presenting a sense of normality, wife carers were more anxious to protect their husbands from recognising their deterioration, with Perry (2002) describing their wife-carer participants as constructing new identities for their husbands. The study by Walters et al (2010) had converging and diverging findings of the experiences of wives caring for their husbands with dementia. Those wife-carers who were able to accept the changes within their husbands and relationships, were more able to adapt to the changes, care and empathise with their spouse, similarly to those participants in the studies by Perry (2002) and Perry and O'Connor (2002). However, Walters et al (2010) suggested that the wife carers who had difficulty in perceiving their husband as the same person, went through great relational change and found caring for their husbands more stressful and constricting. Walters et al (2010) suggested that none of their participants reported that their pre-morbid relationships were poor. One wonders if these participants were more able to discuss their caring role because they had more positive sense of selves and role as carer, as a consequence of previous positive relationships with the person with dementia.

Other studies of carers for family members presented findings of isolation and conflict (Parsons 1997, Russell, 2001). Both son and daughter carers faced conflict with their siblings, who although reluctant to share the care of their parent, were opposed to the care-recipient being admitted to long term care, as there seemed to be a lack of understanding of their parent's needs (Guberman et al 1992, Parsons 1997). Sons found it more difficult to carry out personal care for their parents, as it threatened their perception of the acceptable child-parent relationship (Parsons 1997). The sense of loss of a parent caused by the increasing deterioration of the care-recipients' abilities and loss of identity, were expressed by both son and daughter-carers (Parsons 1997, Butcher et al 2001).

Much of the literature discussed here considers how the identity (or personhood) of the person with dementia is preserved by the carer, and more importantly, by the pre-existing relationship (Whitlach 2001). Whereas many studies have explored the individual experiences of dementia by the older people themselves, or their carers, it is only in the last ten years that the experiences of the dyad or couple relationship have been explored. However, Robinson et al (2005) interviewed nine couples where one partner had a recent diagnosis of dementia. The findings from this study suggested that couples were continually trying to make sense of the diagnosis of dementia and the changes that were happening, as well as dealing and coping with the difficulties and losses that occurred because of the dementia. These findings confirm the recommendations of Hellström et al (2005a) to consider the needs of the couple (or dyad) because of their interdependence and interrelationships, which they termed couplehood. Hellström et al (2005a) described a growing understanding of the relationships between the couple sustaining the sense of personhood (or self) of the person with dementia. Indeed Phinney (2002) stated that in dementia the "...self is constituted through its being in relation to others..." (p342). Much of the research by Hellström et al (2005a, 2005b, 2007) was based on the theory of Keady (1999) and Keady and Nolan (2003) who described how couples work together to maintain the personhood of the person with dementia. Keady and Nolan (2003) described a framework of "working together, working alone, working apart and working separately" (p.19) to maintain personhood of the person with dementia. Even though, in this framework, the carer works to maintain a sense of identity or self-esteem in the care-recipient, it is increasingly recognised that many carers experience satisfaction, a sense of wellbeing, continuity in their relationship, maintenance of their own activity and their sense of self (Forbat 2003, Perry and O'Connor 2002, Phinney 2006, Hellström et al 2007). However these researchers acknowledge that much of the "doing things together" is dependent upon the relationship the spouses or family members had prior to the onset of dementia.

In this section, research that has considered differing aspects of caring have been considered. Early emphasis within the literature seemed to focus on the negative consequences of caring, within a more quantitative tradition. More

recent research has taken a more qualitative and inductive approach. Some studies such as those by Robinson et al (2005), Perry and O'Connor (2002) and Phinney (2006), Walter et al (2010) have all used more interpretative approaches in their research (such as phenomenology). Although these studies have used relatively small sample sizes and do not purport to offer generalisations to larger populations, these studies offer important insights into the life-worlds of the participants, with some resonance and congruence between studies.

### **3.1.5 Summary of literature reviewed on the experiences of dementia**

The literature reviewed in sections 3.1.3 and 3.1.4 have contributed to an understanding of the experiences of older people and their carers about their dementia. The majority of the literature reviewed in both sections was qualitative in nature, using relatively small sample sizes, and as already discussed, their findings cannot be generalised to other populations. However the literature reviewed provides a useful (but not exhaustive) overview of the experiences of older people with dementia and their carers.

The literature appertaining to older people with dementia focussed more on the ability of these individuals to maintain their sense of self and identity (Bender and Cheston 1997, Clare 2002). The literature identified that threats to the sense of self came not only from the impairments associated with the diagnosis, but also from contextual factors such as the social environment, which Kitwood and Bredin (1992) termed as malignant social psychology. The literature also suggested that the participants from some studies preserved their sense of self through denial or a lack of awareness of their diagnosis, or through the maintenance of valued activities and routines, a sense of discipline and increasing reliance on their spouse (Pearce et al 2002, Clare 2003, 2005, Clare et al 2006, and van Dijkhuizen et al 2006).

The literature reviewed in section 3.1.4 considered both positive and negative aspects of caring for an older person with dementia. A focus on carer burden within the quantitative literature (O'Rourke and Tuokko 2000, Eters et al 2007, Li et al 2011), has considered the health issues and delaying the importance of

relationships in carers' experiences. Subjective burden not only related to a poor understanding of the diagnosis of dementia and the consequences, but also their own loss of self and identity through changing roles and relationships (Skaff and Pearlin 1992, Quinn et al 2008). However the literature also identified positive aspects of caring, especially for those with more knowledge about dementia and its progression (Graham and Bassett 2006, Netto et al 2009). Gender differences in the role expectations of caring have also been explored (Perry and O'Connor 2002, Sanders and Power 2009). The concept of 'couplehood' in terms of the interrelationships and reciprocity between the carer and care-recipient has also highlighted that the sense of self, health and well-being of both the care-recipient and carer could be interdependent (Keady and Nolan 2003, Hellström et al 2005a).

### **3.2 Part Two - The experiences of falling**

This second part to the chapter provides the main review of literature relating to older people with dementia and carers' experiences of falling. The literature is reviewed under two main sections. A critical review of the literature appertaining to older people's experiences of falling follows (section 3.2.3), before exploring the literature that specifically relates to older people with dementia's experiences and perspectives of falling. The literature relating to carers' experiences of falling by older people is then critically reviewed before finally reviewing the literature that appertains to caring for an older person with dementia who falls (see section 3.2.5). It was considered relevant to review the literature of falls experiences of cognitively normal older people before reviewing that literature appertaining to those older people with dementia, because there may be some similarities, including issues of frailty, for example. Moreover, it has already been highlighted by the document on falls prevention by the Australian Commission on Safety and Quality in Health Care [ACSQHC] (2009) (see chapter two, section 2.6) that many studies have used differing definitions of cognitive impairment in their research so that people with mild/moderate cognitive impairment or dementia may have been included in the falls research by default.

At the beginning of this chapter the literature review in this section was described as a “second generation” review, as termed by Pope et al (2007). Second generation reviews follow a more formal and transparent protocol to select and critically appraise both qualitative and quantitative literature, and tend to provide a qualitative summary of the research evidence reviewed (Cook et al 1997, Pope et al 2007). These reviews are often known as narrative reviews, however in many instances this can belie the systematic nature of the review process (Baumeister and Leary 1997, Pope et al 2007). Such reviews can be used in what Pope et al (2007) describe as “knowledge support” (p.15) where research evidence can be synthesised to identify gaps for further research. Knowledge support reviews summarise and synthesise research evidence, and a common method of doing this is through thematic analysis, where the focus is to present “the main ideas and conclusions across a body of evidence, looking for what is prominent rather than developing ‘higher order’ new explanations...” (Pope et al 2007 p96). The process of selection and appraising the literature is now described in sections 3.2.1 and 3.2.2.

### 3.2.1 Literature search strategy for falls experiences of older people

This section describes the search strategy used to identify pertinent literature that has been reviewed and critiqued in section 3.2.3. Search terms and databases were determined by exploratory understanding from the literature. The following databases were searched, from their inception date until the final search date of October 2011:

- CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) ) *A combined search*
- PsycINFO ) *via EBSCOhost*
- Academic Search Complete
  
- Medline ) *A combined search*
- Web of Science ) *through Web of Knowledge*
- Scopus

The search terms to identify literature appertaining to older people’s experiences of falling were:

experience OR attitude OR belief OR perception OR understanding OR identity

AND fall\*

AND old\* OR eld\*

*(The symbol \* indicates truncation of the associated word).*

The databases were chosen as they access a wide range of journals, including those from health and social care, psychology, sociology and anthropology disciplines. Papers were limited to research papers and reviews in peer reviewed journals, written in English. Each database has its own options to maximise the sensitivity of the search strategy, and the specific search strategy for each database can be seen in table 3.1 below.

**Table 3.1 Limiters for search of databases described in sections 3.2.1 and 3.2.2**

<p style="text-align: center;"><b>EBSCOhost</b></p> <p style="text-align: center;">(CINAHLplus, PsycINFO, Academic Premier)</p>	<p style="text-align: center;"><b>Scopus</b></p>	<p style="text-align: center;"><b>Web of Knowledge</b></p> <p style="text-align: center;">(Medline, Web of Science)</p>
<ul style="list-style-type: none"> <li>• Peer reviewed journals</li> <li>• Abstract available</li> <li>• English language</li> <li>• Research article</li> <li>• Aged 65+ years</li> <li>• Human</li> <li>• Audience – psychology, professional &amp; research</li> <li>• Exclude dissertations</li> </ul>	<ul style="list-style-type: none"> <li>• Article or review</li> <li>• Subject areas - Medicine, nursing, health, social sciences, psychology</li> <li>• Aged</li> <li>• Human</li> <li>• Falling</li> <li>• Accidental falls</li> <li>• English language</li> </ul>	<ul style="list-style-type: none"> <li>• Article</li> <li>• Subject areas- health care sciences, rehabilitation, geriatrics, gerontology, social issues, psychology, behavioural sciences, social work, general internal medicine, nursing, sociology, psychiatry, anthropology</li> <li>• English language</li> </ul>

A total of 743 papers were initially identified, however the final number of papers reviewed was 22. Papers were discarded for the following reasons:

- Older people were not the focus of the study
- Older people were not the participants in the study
- The experiences of older people were not considered
- Falling was not the focus of the paper
- Duplication of papers between databases

A hand search was carried out; based upon relevant literature referenced in other identified papers, relevant policy and guidance documents. The hand search yielded nine further papers.

The same databases and search strategies were then utilised to establish the available literature relating to older people with dementia and their experiences of falling.

The search terms to identify literature appertaining to older people with dementia's experiences of falling were:

experience OR attitude OR belief OR perception OR understanding OR identity

AND fall\*

AND Dementia OR "cognitive impairment"

(The symbol \* indicates truncation of the associated word).

The previous exploratory review of the literature in the early stage of this study indicated that there would be very little research on falling in older people with dementia. It was therefore considered appropriate to include "cognitive impairment" as a search term as this is often perceived as a "preclinical" stage to Alzheimer's disease (Jones and Ferris 1999), and therefore leads to potentially more papers of relevance being identified.

172 papers were initially identified but 171 were discarded because of similar reasons stated above, and/or because carers of older people with dementia or cognitive impairment were the participants within the study. Three papers that were discarded for this latter reason have been included in section 3.2.2. The



sole paper identified that explored the experience of older people with dementia or cognitive impairment also had carers as participants and therefore this paper will be addressed both in section 3.1.3 and in section 3.2.3.

Therefore, a total of 32 papers are reviewed in section 3.2.3. The flowchart in figure 3.1 provides details of the number of papers identified and rejected in the database and hand searches. Most (but not all) of the literature reviewed were qualitative studies. Therefore the review of the literature followed the criteria provided by Elliot et al (1999) (see figure 3.1) which although mainly discusses establishing the quality of qualitative research, also provides guidance of criteria common to both qualitative and quantitative research.

- Explicit scientific context and purpose
- Appropriate methods
- Respect for participants
- Specification of methods
- Appropriate discussion
- Clarity of presentation
- Contribution to knowledge

**Box 3.1 Criteria for establishing the quality of both qualitative and quantitative research (Elliott et al 1999:220)**

A table of the all the papers included in the review can be seen in table 3.2, along with details of methodology, theoretical basis, design, sample size and whether older people with cognitive impairment or dementia were included in the research. The table has been divided up chronologically, so it can be seen which papers had been published prior to this research study commencing in 2003, those that were published whilst data collection took place (2003-2007), those that were published during the data analysis (2008-2010), and finally those that were published after the findings had been completed and this final review of the literature carried out (late 2010-2011).

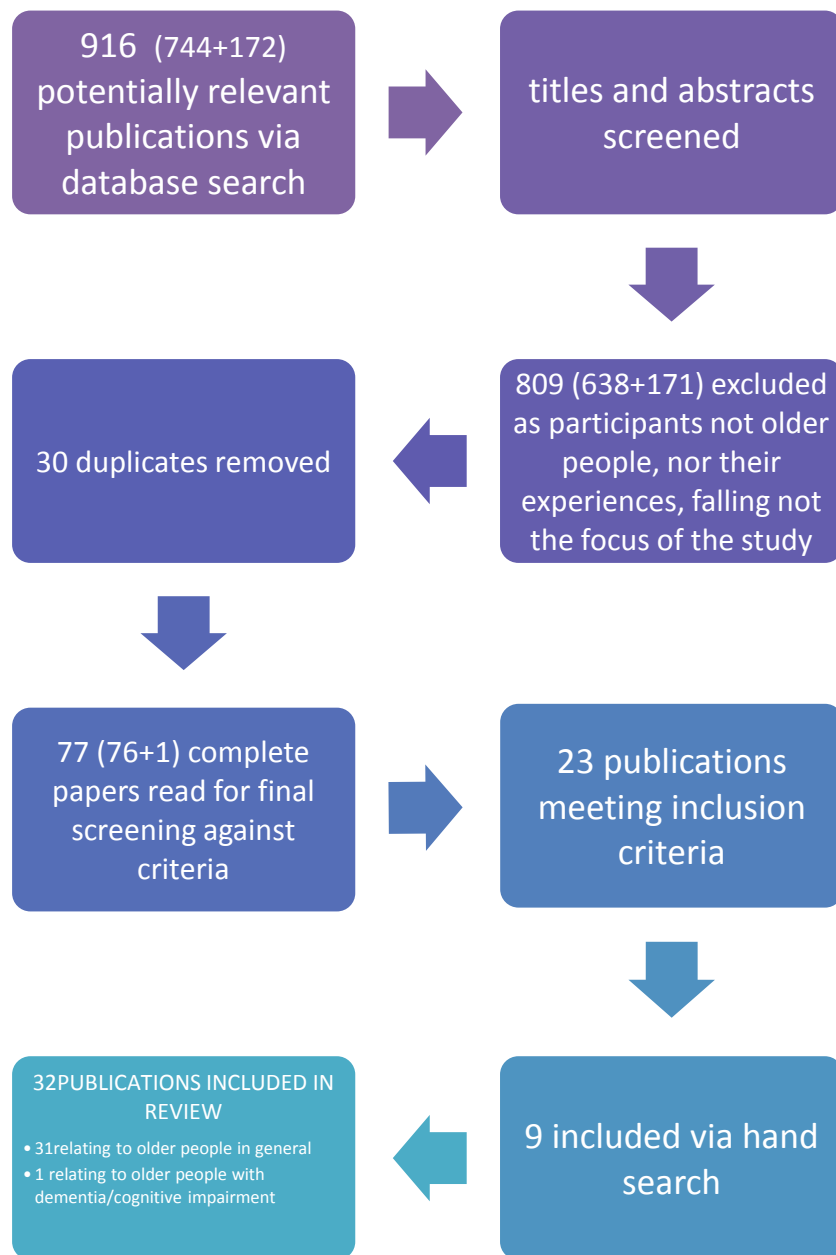


Figure 3.1 Flow chart of literature search process

### 3.2.2 Literature search strategy for carers' experiences of falling

The search strategy used to identify relevant literature to be presented and critiqued in the following section (3.2.3) is described here. The same databases were used here, as those searched in section 3.1.2, as it was considered that these databases included journals from a wide range of disciplines that were considered of relevance to the following review. Therefore, the following databases were searched, from their inception until October 2011:

- CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) ) *A combined search*
- PsychINFO ) *via EBSCOhost*
- Academic Search Complete )
  
- Medline ) *A combined search*
- Web of Science ) *through Web of Knowledge*
- Scopus

The search terms to identify literature relating to carers' experiences of falling were:

Care\* OR caregiv\*

AND fall\*

AND experience OR attitude OR belief OR perception OR understanding OR identity

*(The symbol \* indicates truncation of the associated word).*

The same limiters were used as in section 3.1.2. Six hundred and sixty six papers were initially identified; and after the titles and abstracts were read, the final number of papers identified for review was seven. Papers were discarded for the following reasons:

- Informal carers were not the focus of the study
- Informal carers were not the participants in the study
- The experiences of informal carers were not considered

- Falling was not the focus of the paper
- Duplication of papers between databases

A second search as carried out using the same databases, same search limiters and this time with an extra search term:

Care\* OR caregiv\*

AND fall\*

AND experience OR attitude OR belief OR perception OR understanding OR identity

AND Dementia OR “cognitive impairment”

*(The symbol \* indicates truncation of the associated word).*

In this instance, 165 papers were identified, but only four were included for further scrutiny after the titles and abstracts were read. Papers were discarded because people with dementia or cognitive impairment were not the care-recipients and for the same reasons as above. A hand search did not reveal any papers not already identified in the database searches. The three papers identified in the search for literature relating to older people with dementia and falls (but at that stage identified as being more relevant to carers) were also added here. However, one of these was a duplicate paper. Therefore, 13 full papers were then read using the same criteria and another five more papers were discarded, because falls were one of many variables in the paper and not specifically discussed (in four papers) and because professional or formal and not informal carers were the focus of the study. Therefore, eight papers were critically reviewed; and once again, the criteria provided by Elliot et al (1999) for reviewing quantitative and qualitative research papers were followed.

A table of the eight papers included in the review can be seen in table 3.3, along with details of methodology, theoretical basis, design, sample size and any details about the care-recipients in the research. The table has been set out chronologically, and it can be seen that only two papers were published prior to this study commencing in 2003, a further four were published whilst data

collection took place (2003-2007), and two at the final stages of data analysis and writing up of the findings.

Table 3.2 Articles reviewed in section 3.2.3 presented in chronological order

Research published prior to 2003						
Authors & Country of origin of study	Research issue	Research methodology	Theoretical basis	Design	Sample information	Inclusion of older people with cognitive impairment
<b>Bhala et al (1982) USA</b>	Fear of falling	Not described	None described	Not stated but a case study observation of patients	3 in & out patients	Not specified
<b>Murphy &amp; Isaacs (1982) UK</b>	Post-fall syndrome	Not described	None described	Not stated but a case study observation of patients	36 in-patients	Not specified
<b>Vellas et al (1987) France</b>	Restriction of activity post fall	Not stated but a quantitative study	None described	Prospective longitudinal survey completed by medical practitioner	89 older fallers and 89 controls Nursing home residents & own home	Not specified
<b>Tinetti et al (1988) USA</b>	Identification of risk factors for falls	Not stated but a quantitative study	None described	Prospective longitudinal survey completed by nurse researcher	336 community living	Yes

Research published prior to 2003 (continued)						
<b>Tinetti et al (1990) USA</b>	Falls related self-efficacy	Not stated but a quantitative study	Bandura's theory of self-efficacy (1979)	Study to test psychometric properties of outcome measure	18 in first stage, 56 in second stage - community living	Excluded
<b>Borkan et al (1991) USA</b>	Psycho-social consequences of falls	Narrative analysis and Quantitative rating scale	Explanatory model of Illness	In-depth interview with 2 follow up interviews using open ended questions and standardised scales,	80 community living	Excluded
<b>Howland et al (1993) USA</b>	Fear of falling	Not stated but a quantitative study	None described	Closed question survey completed by interviewer	196 community living	Excluded
<b>Arfken et al (1994) USA</b>	Fear of falling	Not stated but a quantitative study	None described	Random selection from existing cohort study, using closed question survey	890 community living	Those with a MMSE of 18< excluded
<b>Braun (1998) USA</b>	Knowledge of fall risk factors by older people	Not stated but a quantitative study	None given	Survey – self administered with closed questions	120 community living	Not specified
<b>McKee et al (1999) UK</b>	Causal attributions of falls	Not stated but a quantitative study	Attribution theory	Survey – self administered with closed questions	40 in-patients	People excluded if considered too confused by Dr.

<b>Research published prior to 2003 (continued)</b>						
<b>Authors &amp; Country of origin of study</b>	<b>Research issue</b>	<b>Research methodology</b>	<b>Theoretical basis</b>	<b>Design</b>	<b>Sample information</b>	<b>Inclusion of older people with cognitive impairment</b>
<b>Ballinger &amp; Payne (2000) UK</b>	Meaning & interpretation of a fall	Qualitative - Discourse analysis	Social constructionism	Semi-structured interview	8 day hospital patients	Ability to give informed consent required.
<b>Salkeld et al (2000) Australia</b>	Fear of falling & quality of life with hip fracture	Not stated but part of a large quantitative RCT	None stated	Quality of life survey with time trade off technique	194 community living	Ability to give informed consent required.
<b>Kong et al (2002) Hong Kong, China</b>	Psycho-social consequences of falling	Qualitative, no tradition stated	None stated	Semi-structured interviews	20 community living & in-patient	Not stated
<b>Yardley &amp; Smith (2002) UK</b>	Fear of falling and activity avoidance	Not stated, but quantitative	None stated	Prospective survey, existing and modified outcome measures in a questionnaire	224 at baseline, 166 at 6 months community living	Not stated



Research published 2003 - 2007						
Authors & Country of origin of study	Research issue	Research methodology	Theoretical basis	Design	Sample information	Inclusion of older people with cognitive impairment
Simpson et al (2003) UK	Uptake of intervention to prevent falls	Qualitative	None stated	Semi-structured interviews	32 community living	Not stated
Ward-Griffin et al 2004 Canada	Fear of falling	Qualitative	Phenomenology	Semi-structured interviews	9 community living	Not stated
Tischler & Hobson (2005) Canada	Fear of falling	Qualitative	None stated	Semi-structured interviews	7 community living	Not stated
Yardley et al (2005) UK	Validation of Falls efficacy scale	Quantitative	None stated	Cross sectional survey, postal or structured interview	704 community living	Not stated

<b>Research published 2003 - 2007</b>						
<b>Authors &amp; Country of origin of study</b>	<b>Research issue</b>	<b>Research methodology</b>	<b>Theoretical basis</b>	<b>Design</b>	<b>Sample information</b>	<b>Inclusion of older people with cognitive impairment</b>
<b>Yardley et al (2006a) UK</b>	Perceptions of falls prevention advice	Qualitative	None stated	Focus groups and interviews	66 community living	Not stated
<b>Yardley et al (2006b) Europe</b>	Perceptions of falls prevention advice	Qualitative	None stated	Semi-structured interviews	69 community living	Not stated
<b>Horton (2007) UK</b>	Social constructions of risk of falling	Qualitative, Grounded theory	Social constructionism	In depth interviews	40 community living	Not stated
<b>Ruthig et al (2007) Canada</b>	Falls, global control & optimism	Not stated but a quantitative study	None stated	Face to face structured interview, existing outcome measures, closed questions, using scales	231 community living	Older people with cognitive impairment excluded.
<b>Zijlstra et al (2007) Netherlands</b>	Fear of falling & activity avoidance	Not stated but a quantitative study	None stated	Cross sectional study, short closed question postal survey	4031 community living	Not stated

Research published 2008 - 2011						
Authors & Country of origin of study	Research issue	Research methodology	Theoretical basis	Design	Sample information	Inclusion of older people with cognitive impairment
<b>Bertera &amp; Bertera (2008) USA</b>	Fear of falling & activity avoidance	Not stated but a quantitative study	Health Belief Model	Structured interview with closed questions	3474 community living	Not stated
<b>Lee et al (2008) Australia</b>	Fear of falling	Qualitative	Phenomenology	In depth interviews	9 community living	Not stated
<b>Roe et al (2008) UK</b>	Understanding of falls	Qualitative	Not stated	Semi-structured interviews	27 in-patient, residential care & community	Not stated
<b>Berlin Hallrup et al (2009) Sweden</b>	The lived experience of falling	Qualitative	Phenomenology, Merleau-Ponty	In depth interviews	13 community living	Those with obvious memory problems excluded
<b>Hill et al (2010) Australia</b>	Fear of falling	Not stated but a quantitative study	Not stated	Sub analysis of RCT of a falls prevention programme	712 Accident & Emergency patients	Not stated

Research published from late 2010 - 2011						
Authors & Country of origin of study	Research issue	Research methodology	Theoretical basis	Design	Sample information	Inclusion of older people with cognitive impairment
<b>Faes et al (2010) Netherlands</b>	Impact of falling	Qualitative, Grounded theory	Not stated	Semi-structured interviews	10 (incl. 4 with Mild Cognitive Impairment, 3 with dementia) out-patients and 10 carers	People with cognitive impairment & dementia recruited
<b>Lim et al (2011) Korea</b>	Fear of falling	Not stated but a quantitative study	Not stated	Structured telephone interviews	828 community living	Not stated
<b>Walker et al (2011) UK</b>	Identity in falls prevention	Qualitative	Not explicit – but Social constructionism	Observation and semi-structured interviews	11 community living	Not stated

### 3.2.3 The experience of falling

The experiences of older people that fall have been observed and documented by researchers for many years, with an interest in the more psychological and social aspects of falling developing from the 1980's. Cwikel et al (1990) suggested that psychological impairments were one of three outcomes of falling, alongside physical injury and limitation in everyday activity, which impact on subjective health. This review will concentrate on the psychological and social factors that are associated with falling in older people within the research literature. One of the earliest and largest areas of scrutiny by researchers, fear of falling, will be critically discussed. This will then be followed by a review and critique of other psychological and social factors that occur because of falling, and those factors that influence adherence and uptake of advice and intervention. Finally, the literature that specifically considers the personal experiences of falling of older people with dementia and cognitive impairment will be reviewed and critiqued.

#### 3.2.3.1 Fear of falling

Early reporting in the literature of fear of falling, was carried out by Murphy and Isaacs (1982), Bhala et al (1982) and Tinetti et al (1990). However these early papers report on quantitative research studies where the views and experiences of older people were not considered; but based on clinical observations of behaviour by clinicians and medical researchers, or surveys of older people where the content was determined by the research team or health-care professional opinion (Vellas et al 1987, Arfken et al 1994). Murphy and Isaacs (1982) described a post-fall syndrome which they observed in 26 older inpatients which involved difficulty walking without support, including a tendency to grab at nearby support, and Bhala et al (1982)'s observed three older inpatients who had a self-imposed restriction on activity because of excessive fear of falling, which resulted in the term "ptophobia" (p.180). Many subsequent studies also associated fear of falling with activity restriction, and identified that approximately 25% of older people who fall not only fear falling again and restrict activity as a consequence (Tinetti et al 1988, 1990, Arfken et al 1994, Zijlstra et al 2007, Bertera and Bertera 2008, Lim et al 2011). Interestingly,

Tinetti et al (1990) highlighted that it was important to ascertain which older people developed fear of falling and why, but this was not explored further and they suggested that asking older people if they were afraid of falling was insufficient and unreliable, because of the subjectivity of responses. They also considered that self-perception of fear of falling would be a poor predictor of actual behaviour. Instead they devised a measure of fear of falling based on Bandura (1977)'s model of self-efficacy, as it was considered that it was more appropriate to ask about fear of falling in relation to specific situations. Bandura (1977) defined self-efficacy as the belief in one's capabilities to perform an activity, which then influences future performance. Tinetti et al (1990) named their measure the Falls Efficacy Scale (FES), which assesses the amount of self-efficacy older people have for ten everyday activities in the home environment. All of the items included in the FES were ascertained by an expert panel of health care professionals, rather than involving older people themselves. This measure has become a popular outcome measure of fear of falling, with good psychometric properties reported, and with subsequent modifications to enhance its ecological validity for a wider range of older people and countries (Yardley et al 2005), including reliability studies for its use with older people with moderate cognitive impairment (Hauer et al 2010).

The concern about fear of falling in the research literature not only relates to an increasing risk of further falls, but also their impact on older people's quality of life and social interaction. Howland et al (1993) and Hill et al (2010) identified that older people did not go out alone (or at all), either for walks or social events because of fear of falling. Both of these studies used structured interview surveys, with predetermined items collecting quantitative data, with Hill et al (2010) using a modified version of the FES (Tinetti et al 1990). The advantages of the designs chosen in these studies are that they provided an opportunity to collect data from large numbers of participants, which can be generalisable to other populations (Robson 2002), to consider prevalence of fear of falling and also which pre-determined factor this fear was associated with (Howland et al 1993). However, by using fixed and pre-determined questions, no new knowledge can be ascertained (Robson 2002). Indeed Lee et al (2008) cautioned against attributing reduction in activity only to fear of falling. In their phenomenological study of nine people, fear of falling was one of many factors

that led some of their older participants to restrict their activity, along with personal or spouse's health status or perception of increasing age (Lee et al 2008).

### **3.2.3.2 What are older people fearful of, following a fall?**

Whereas the studies reviewed above associated fear of falling with restriction in activity, these arguably reflect a more positivist notion of cause and effect, with fear of falling being associated with carrying out of everyday activity. None of the studies reviewed above (apart from Lee et al 2008), identified or explored what their older participants were fearful of, and why. However, other studies have attempted to explore and identify why older people are frightened following a fall. Salkeld et al (2000) initially carried out in-depth interviews with 16 older women to gain an understanding of their quality of life after a hip fracture. Four case vignettes were devised from this interview data representing four different health states from worst to best-case scenarios. Subsequently 203 older women (aged 75+) were interviewed, who had been identified as having fallen within the previous year, and at risk of hip fracture. These 203 women were asked to rank the four vignettes representing full health, fear of falling, 'good' hip fracture and 'bad' hip fracture to consider a time trade off between longevity and quality of life. The participants were asked to rank the four vignettes from worst to best case scenarios and then asked whether they would trade living longer in poorer health or living for a shorter period in full health. Salkeld et al (2000) concluded that quality of life was an important factor, as the older women were prepared to (hypothetically) trade off a longer life for a better quality of living, with 80% saying that they would rather be dead than be admitted to a nursing home. It would seem that these participants were more threatened by loss of independence, dignity and possessions, which they felt would accompany nursing home admission, than death. Other studies also revealed fear of being admitted to residential or nursing care, loss of independence, personal freedom, as well as fear of physical harm or feelings of pain following their fall (Kong et al 2002, Yardley and Smith 2002, Tischler and Hobson 2005, Lee et al 2008). Interestingly, the average age of participants in these studies was above 75, and one could suggest that their fears were also

age-related, when interpreting these findings alongside those of Ruthig et al (2007) who correlated reduced optimism with older age.

### **3.2.3.3 Falling as a threat to identity and autonomy**

Yardley and Smith (2002) identified other psychological consequences of falling, such as threats to identity and functional independence, and suggested from their findings that damage to identity was as strong a consequence of falls as loss of independence in everyday activity. They based these conclusions on a questionnaire devised by themselves and constructed from several measures, including falls history, general fear of falling, perceived consequences of falling and fear of falling in activity restriction (including social and physical activity). The data was collected using a rating scale and collected at two points, once at the beginning of the study from 224 participants when they attended their GP practice as part of a larger trial and secondly six months later as a postal questionnaire, with 166 responses. It could be said that the findings of Salkeld et al (2000) and Yardley and Smith (2002) were limited in their understanding of the experiences of older people, because they were mainly quantitative surveys, using structured interviews with closed questions that collected numerical data. However, both of these studies are of interest, as their data collection tools mostly came from qualitative and more inductive methods. What is of interest, is that whereas Salkeld et al (2000) base their vignettes for data collection on the interviews of 16 older women and suggest generalisability of their findings, Yardley and Smith (2002) base some of their data collection items on focus groups with 35 older people, and suggest that their study is a “tentative exploration” (p.22).

Threats to identity manifested as fear of social embarrassment and indignity were found not only in Yardley and Smith (2002)’s study but also in studies with qualitative methodologies by Ward-Griffin et al (2004) and Lee et al (2008) with the supposition being that potential damage to identity through social embarrassment was the reason for avoidance of social and more public activity by many older people. In these studies, reducing and avoiding social activities were suggested as the main strategies to prevent both social embarrassment and risk of admission to residential care (Ward-Griffin et al 2004, Lee et al 2008). Interestingly, a qualitative study by Roe et al (2008) reported that some



of the participants' fears of falling outdoors were related more to feelings of vulnerability, such as accusations of being intoxicated, being amongst strangers, or being totally alone and in danger. The study by Kong et al (2002) noted that their older Hong Kong Chinese participants, voiced concerns of being a burden to others because of their fall. Conversely, these participants expressed happiness at receiving increased attention and emotional support from their families because of their fall, perhaps as a reinforcement of the emotional support available to them, whilst maintaining their sense of identity and autonomy. Interestingly, Kong et al (2002) noted that limited visiting times in Hong Kong hospitals would contribute to these older in-patients feelings of isolation that would have been ameliorated by the extra attention given to them as a result of their fall. Accounts from the study by Borkan et al (1991) also reveal a feeling of loss of identity and belonging amongst those participants who never received visitors.

Other studies have explored a range of responses by older people that are considered to influence the psychosocial outcome of their falls. The findings from these qualitative studies consider the impact of denial, minimisation, powerlessness as well as a sense of agency, and the body as a machine. Perceiving the body as flawed after a fall was considered by Borkan et al (1991) and Berlin Hallrup et al (2009). In these studies a narrative and inductive approach was taken in data collection and analysis, which allowed for the meanings of falls experiences to be articulated by older participants. Borkan et al (1991) suggested that those older people who considered their body and hip fracture (post fall) in a more mechanistic way were more likely to recover and regain previous activities. They described these older participants as having a more physiological and linear view of "fall → break → fix → repaired (good as new)". Furthermore, those who perceived their fall and hip fracture in terms of disability and illness did less well and had a view of "degenerate → break → treat → rehabilitated (still flawed)" (Borkan et al 1991 p954). In contrast, those who had a less mechanistic view and had greater self-esteem and social participation were more likely to not only regain mobility but also to accommodate to any residual physical impairment and regain autonomy and social interaction and participation. The study by Borkan et al (1991) involved collection of narrative data, alongside the use of a formal functional status scale

and observation of treatment and rehabilitation. The transcripts of ten participants were analysed for emergent and recurrent themes to produce a coding sheet with bipolar scales to quantitatively rate the subsequent 70 narratives. Correlational statistics were then carried out on this data with outcome measures of functional status and demographic data, so that as Borkan et al (1991) stated, the data could be reduced. Therefore only the narratives of ten of the 80 participants were heard and presented with the remaining 70 being “reduced”, thus preventing any other potential themes to emerge from the data. However, the strengths of this approach were that it enabled typologies of different fall-reactions to be gathered, which might have been difficult to infer from a small sample.

Conversely Berlin Hallrup et al (2009) in their smaller study of 13 older women, used a lifeworld approach as described by Dahlberg et al (2008) and based their study on the phenomenology of Merleau-Ponty, which they describe as focussing on the “body as lived” (p.380). Berlin Hallrup et al (2009) explored their transcribed interviews for the everyday experiences of falls risk for the participants. The themes that emerged from this data proposed that the older women considered themselves alienated from their bodies and their lives because of their fall, resulting in a sense of fear and no longer being able to take the body for granted. Like the participants in the study by Borkan et al (1991), these participants communicated a lack of trust and reliance in the body’s physical and social function, leading to a loss of autonomy and an impaired sense of self. Interestingly, although a reflective lifeworld approach (Dahlberg et al 2008) was chosen for this study of 13 older women, Berlin Hallrup et al (2009) state that saturation of the data was realised, which is not a concept usually applied to this approach where variation in the sample is privileged over the size to obtain rich variations in the data.

Some of Borkan et al (1991)’s participants suggested that their fall and subsequent hip fracture were a spiritual lesson (e.g. pride coming before a fall). Ballinger and Payne (2000), Kong et al (2002), Simpson et al (2003) and Ruthig et al (2007) also reported perceptions of powerlessness, or attributing falls to bad luck, or old age. Some cultural influences in these findings are more explicit than others, with Kong et al (2002) identifying that feelings of fatalism and external locus of control are dominant in Chinese culture, and therefore

influenced their participants' feelings of powerlessness. Kong et al (2002) also reported that some of their older participants either ignored the interviewer when asked about their fall, or denied having fallen. Kong et al (2002)'s suggestion for the denial of falls in their participants was that the participants were attempting to maintain an intact sense of self and autonomy, rather than a lack of understanding of the risks. In the study by Braun (1998), participants perceived falling to be a major health problem for the general population but minimised their own potential risks of falling. Braun (1998) considered that these results were due to participants having a lack of understanding of their falls risks, however it would seem that only ten per cent of the sample (N=12) had fallen in the previous month of the study, with no other history of falls recorded. Therefore one could suggest that the experience of falling was limited within the sample population so that the older participants were not able to personalise the information given to them. Moreover, the use of a closed question survey did not perhaps allow Braun (1998) to explore idiographic reasons for why these older people minimised their risk of falling. It could be that Kong et al (2002)'s suggestion for the denial of falls in their participants would be the same reason older people minimised their risks in the study by Braun (1998), with the participants attempting to maintain an intact sense of self and autonomy, rather than a lack of understanding of the risks.

Maintaining a sense of autonomy through attributing blame for falling to external events emerged in several studies. Older people (and older men in particular, in the study by Horton 2007) who attributed their fall to extrinsic or environmental reasons seemed to make a better recovery and regained their independence following their fall as they retained a sense of agency in being able to prevent future falls (McKee et al 1999, Horton 2007). Indeed Roe et al (2008) suggested that those participants, who reflected upon their fall and had an understanding of how it may have occurred, seemed to confront their fear of falling, and maintained their sense of control, choice and autonomy. Whereas the studies by Horton (2007) and Roe et al (2008) were qualitative studies, the study by McKee et al (1999) involved the administration of a quantitative questionnaire to 40 older people whilst in hospital, as a result of the fall and a subsequent postal questionnaire two months later. Although differing methodologies, these studies provide interesting insights into the perceptions of their participants in relation to

how they maintained their sense of autonomy. Another quantitative study, by Ruthig et al (2007) observed other factors that impact upon older peoples self-beliefs. Whereas Horton (2007) observed gender differences in their qualitative study, Ruthig et al (2007) identified that older participants in their study (aged 85+) were more affected by a sense of powerlessness and reduced optimism than the younger participants (79-84) following their falls. Ruthig et al (2007) suggested that this might be because the older-old participants might not recover as easily from their fall or fall-related injuries than the younger-old participants. This study was relatively large, with 231 participants being drawn from a representative sample of the population and the researchers suggested that their findings had generalisability to cognitively normal community living older adults. The study by Ruthig et al (2007) provides interesting findings, which would be enhanced by a deeper exploration of this phenomenon.

The study by Horton (2007) mainly explored the gender differences in risk perception of falls by their older participants. They noted gender differences in perception and intention to modify risk-taking behaviours. Interestingly, although their older male participants voiced terms such as 'risk', 'unsafe' and 'liability', only one of the older women voiced 'risk', and yet their women participants seemed less aware of their risk taking behaviours, with men twice more likely to modify their risk taking. The study by Berlin Hallrup et al (2009), which explored older women's experiences of falls risk, indicated convergences and divergences in their data, in relation to risk. Whereas some of the older women's accounts acknowledged the frailty of their bodies, they also relayed a sense of defiance in their desire to continue carrying out relatively high-risk behaviours. Conversely, it would seem that most of the participants lived with a sense of precaution and reduced their activity outside of their home. Berlin Hallrup et al (2009) surmised that these older women's changed awareness of their bodies as unreliable and alien led them to live more careful and restricted lives, with fewer excursions into the outside world. Berlin Hallrup et al (2009) suggested that these strategies conveyed a paradoxical situation of home turning from being a haven to becoming a prison.

Another phenomenological study by Ward-Griffin et al (2004) described a similar paradox. The overarching themes from their study involving nine older people were described as "two opposing life forces" (p.307) – exercising

precaution and striving for independence. Like Berlin Hallrup et al (2009), Ward-Griffin et al (2004) considered how both of these motivations (or life forces) simultaneously facilitated and hampered the participants' independence, sense of autonomy and overcoming their fear of falling. Similarly to other studies, the participants in the study by Ward-Griffin et al (2004) conveyed a sense of the world outside the home being a threatening place (whether they had fallen or not). These feelings of caution and fear of falling were influenced by the concerns of their families, friends and health professionals, who encouraged them to be more careful. These older people avoided social activities or physical environments outside the home, as well as eliminating hazards to create a safe environment within the home. Their strategies also meant an increasing dependence on others, where the needs of the individual may not have been prioritised, but also provided an opportunity for interdependence on others, where the support was mutually beneficial. Ward-Griffin et al (2004) suggested that the contrasting behaviours emerged from the narratives in a variety of ways, including the minimisation of the impact of the fall by using terms such as "trip" or "slip" rather than "fall". Another emerging theme related to a resistance to confinement within the home, by participants taking risks, and living with the fear of falling in order to stay socially active, and is similar to the findings of Roe et al (2008). Ward-Griffin et al (2004) suggested that both of the themes – exercising precaution and striving for independence emerged in all of the participants stories, but that exercising precaution was the stronger theme and more likely to be selected as a strategy when potentially embarrassing or high risk situations were experienced. Although Ward-Griffin et al (2004) stated that this qualitative study used an interpretive phenomenological approach; this is not clear from their paper, with the philosophical basis of the research not stated.

#### **3.2.3.4 Influences on adherence and uptake of falls interventions**

Older people's perceptions of identity and autonomy have emerged in studies as influencing adherence and uptake of falls interventions. Simpson et al (2003) explored older people's strategies to prevent falls through their willingness to take part in physical exercise and have home modifications and safety checks. It could be said that the participants in the study by Simpson et al (2003)

maintained their identity and autonomy by avoiding potentially risky situations or by generally taking care. However some acknowledged that taking care required effort and was not always possible, especially when distracted by more interesting things. Exercise was perceived as too much effort or not of relevance, and not age appropriate. They saw home safety checks as intrusive and patronising, with some resentment at changes made against their own agreement or consultation. Although an interesting qualitative study, as it offered a glimpse as to why older people reject falls advice or intervention, methodological issues restricted the credibility of the study. These included a lack of recording of the semi-structured interviews with the 32 participants, which meant that verbatim accounts were not available for analysis and the poorly described descriptive thematic analysis, which closely reflected the topics, addressed in the interviews.

A more recent qualitative study carried out in the UK by Yardley et al (2006a), followed by a European study by Yardley et al (2006b) explored in a more inductive way, why older people did not take up falls interventions. This group of researchers were aware that the uptake by community living older people of falls advice or prevention had varied by 30-70% (Yardley et al 2006a, 2006b). Interestingly, in the first study, commissioned by Help the Aged in 2005, Yardley et al (2006a) had recruitment difficulties, especially for younger older people, until they altered the research information for potential participants to reflect health promotion and balance training for retired people rather than older people's views of falls prevention, which infers that falls carry stigma of frailty and ageing. The emerging findings from both Yardley et al (2006a, 2006b) were that older people found much of the available falls advice irrelevant, interfering and patronising. It would seem that the participants in both the UK and European studies found falls prevention advice stigmatising and threatening to their identity (Yardley et al 2006a, 2006b). Even though these two qualitative studies did not purport to generalise their findings, they are of interest. The findings are also more credible as both studies had more than 60 participants and the findings were similar across both studies, and across all six countries involved in the study by Yardley et al (2006b).

A more recent study by Walker et al (2011) explored older peoples' experiences and the importance of identity in falls intervention. Although Walker et al (2011)

suggested that falling and recognised risk of falling are threats to identity and independence, they wanted to explore the importance of identity in falls prevention programmes in their qualitative study of 11 older people. The findings presented themes relating to the collective identity of the group programme and especially the preservation of personal identity of the participants. Even though all the participants had a history of falling, they perceived themselves as 'non-fallers', attending not because they saw the need to, but because a respected professional advised them to do so. Indeed such compliance extended to participating in the programme out of politeness, rather than perceived need. However, a few accounts revealed threats to identity because of the group composition within the intervention programme, such as older people in their sixties not wanting to be associated with being old, like the other group members in their eighties, and feelings of isolation by individual men being in groups with women. Although a very small qualitative study with poorly described methods of data analysis, this study perhaps provides some insights as to why older people do not take up falls interventions.

Although the studies by Simpson et al (2003) and Walker et al (2011) have methodological flaws, they add to the findings in the studies by Yardley et al (2006a, 2006b), who suggest that not only does the falls event itself impact on self and identity amongst older people, but the type and presentation of falls prevention programmes also impinge on older people's preferred identities (Kingston 2000).

These papers have developed the understanding of fear of falling in older people and considered other psychosocial factors. Issues of self, identity, autonomy and relationships with others have emerged from the findings of the studies reviewed. Whereas earlier studies explored fear of falling, especially in relation to reduction in activity, later studies explored in more detail what older people are fearful of, such as loss of autonomy and admission to nursing home or residential care. Differences in the reactions to falling have been noted within the research literature, between young-old and old-old people and also gender differences. More recent studies have not only identified that falling threatens older people's sense of identity and autonomy, but the interventions offered to them to prevent further falls also seem to threaten the participant's identity. The majority of the studies reviewed here have been small qualitative studies of

varying quality. The quantitative studies reviewed have used correlational designs and therefore the generalisability of their results is also limited. Also of relevance to the studies in this thesis, is that older people with cognitive impairment (or dementia) were either excluded or their involvement was not stated.

### **3.2.3.5 The experience of falling by older people with cognitive impairment and dementia**

As already stated in section 3.2.1, the databases were searched for pertinent literature that related to the personal experiences of older people with cognitive impairment or dementia. Those that were shortlisted either did not consider the experiences of older people with cognitive impairment or focussed on the carer's experience, which were retained for the review of the literature in the following section (3.2). Only one study by Faes et al (2010) was found that matched to criteria applied in the previous section. The study by Faes et al (2010) has explored the views of older people with cognitive impairment and dementia about their falls experiences, along with the views of cognitively normal older people and their carers. Therefore, the findings and issues arising from the study appertaining to carers are discussed in section 3.2 and those that relate to the older people with cognitive impairment and dementia are discussed here.

The paper by Faes et al (2010) stated that its primary aim was to explore the impact of falls for frail community living older people in terms of their views, needs, emotions and experiences, and had a secondary aim of suggesting components for a future falls prevention programme. The chosen qualitative methodology was appropriate for the research question and aims, as it allowed for an in-depth exploration of the participants' views. However, the research approach (grounded theory) was only mentioned in relation to the method of data analysis. The initial rationale for the research was to gain an understanding of the experiences of frail older people, and Faes et al (2010) perhaps misinterpret Hauer et al (2010) in their inference that all older people with cognitive impairment are frail. The researchers also stated that potential frail participants were identified using criteria published by Fried et al (2001), however the procedure for identification, (and by whom) was not explained.



These participants were attendees at a local older people's hospital outpatient clinic in the Netherlands, and the other inclusion criterion was that the participants had had a fall within the previous month of attending the clinic. Seemingly, there were no other inclusion or exclusion criteria for the older participants. Carers were also recruited and were eligible to take part in the study if they were the primary family carer for a frail older person who had fallen and provided help with at least one everyday activity and monitored the older person. As already stated, the researchers chose to interview cognitively normal older people, those with mild cognitive impairment and those with dementia as one group of participants, but the rationale for this is unclear. Faes et al (2010) stated that they used purposive sampling to recruit ten older people (three with no cognitive impairment, four with mild cognitive impairment (MCI), two with Alzheimer's disease and one with vascular dementia) and ten carers, five of whom were carers to participants in the older peoples' group. Even though purposive sampling and small sample sizes are appropriate for qualitative research (but less so for grounded theory, where sample sizes are often >20), sample size is also determined by the homogeneity of the sample (Bluff 2005), which does not seem to have been appropriate here. Although not recorded in their paper, it is possible that Faes et al (2010) had recruitment difficulties with such hard to reach groups as older people with dementia and with MCI. Although the homogeneity and sample size may have been potentially compromised, it is also of great relevance that these groups of older people be included in research. It is unclear how Faes et al (2010) differentiated between those with MCI and those with dementia. The researchers stated that the MMSE (Folstein et al 1975) was used to identify participants as having mild cognitive impairment, no impairment or dementia, but did not state how it was used.

As already stated, the research approach, grounded theory, was mentioned in the data analysis section, but was not justified, and one could suggest that this was perceived as a method of data analysis rather than as an appropriate research approach for the whole study. The ethical approval was stated and the method of seeking consent described, with capacity to give informed consent determined by the geriatrician and the researchers (who would have had a vested interest in the study). The researchers did not state how many older

people were approached to take part, only providing the final number of participants within the results section. The topic guide was clearly explained within the paper, for both the older people and carers, and related to the research aims. The method of data analysis was appropriate for the chosen approach and the sample size, but it is questionable that data saturation was reached with the heterogeneous sample, as stated by Faes et al (2010).

The findings from the study were clearly introduced, and the demographic information about the participants was clearly presented, and assisted in identifying the origin of the quotations presented in the findings. Even though Faes et al (2010) stated that all participants were able to participate fully in the interviews and respond to the topics, there was a lack of clarity about the response of groups of individuals. At times the term "older people with cognitive impairment" was used (for example, some were unable to describe their falls in detail), but it is unclear if this term relates specifically to those with mild cognitive impairment or also includes those with dementia. In some respects, the themes presented seem to follow the aims of the research and the topic guide and therefore potentially limited other themes that could have arisen from the data. The themes presented were emotions, attributions, social consequences, coping, and expectations of a falls prevention programme. Another theme specific to carers - burdens and rewards of caring, is discussed in section 3.2. Even though (identified) quotations were provided from more than one participant, so that the reader can ascertain what some of the older people with mild cognitive impairment or dementia said, the findings are presented from the whole group of older frail participants. Therefore, there is little indication of the potential differences in experiences between the three groups. The prevalence of these themes amongst participants was also not indicated, so it is difficult to ascertain if most of the participants' experiences were being represented in the themes. Interestingly, participants used some quite emotive language to describe their experiences, which were not explored in the findings or the discussion, and has been advocated in grounded theory by Charmaz (2008). As many of the findings were similar to those from other studies of cognitively normal older people, it would have been useful for the researchers to have differentiated between the three groups of participants to ascertain which group (or even individual) the findings could be attributed to.

In the discussion, some generalisations about the findings were made to older people with cognitive impairment and yet not all the participants had cognitive impairment. Faes et al (2010) stated that their findings suggested that the barriers to falls intervention identified by the older participants with cognitive impairment were different to those seen in the literature, such as inability to prevent falls or reduce fear of falling. However it is suggested that the researchers used selective referencing to substantiate their argument as other papers published prior to Faes et al (2010) have identified fatalistic views in older people who fall (Borkan et al 1991, Ballinger and Payne (2000), Kong et al (2002), Ruthig et al (2007), Simpson et al 2003 Yardley et al 2007). It would also have been interesting for Faes et al (2010) to explore the cultural differences of their participants as Horton and Dickinson (2011) and Kong et al (2002) identified that many older Chinese people both in the UK and Hong Kong have feelings of powerlessness and fatalistic views of falling and falls prevention.

Faes et al (2010) highlighted their methodological strengths in their paper, citing purposive sampling, triangulation of the data and member checking as examples. The concerns with the purposive sampling have already been discussed earlier in this section; however the use of triangulation of the data (between that of older people and their carers) was not described earlier in the paper. The rationale for interviewing the carers was stated as to gain a “view of their personal experience with their care-recipient’s falling” (p.835) rather than for triangulation purposes. The use of member checking was also not described in the methods section, and this is debated within the literature as an appropriate quality tool in qualitative research (Holloway and Wheeler 2010). Faes et al (2010) acknowledged their small sample size, but stated they reached data saturation, and as a result of what they considered the methodological strengths of the study, suggested that their findings could be generalised to other similar outpatient populations and they made recommendations for practice, based on their findings.

The study by Faes et al (2010) has several methodological flaws – especially in the sampling strategy and presentation of the findings. It is suggested that these researchers missed the opportunity to have presented and compared more explicitly the views of older people with mild cognitive impairment and those

with dementia within the findings and discussion. However, it should be commended in that it appears to be the first published research study to have explored the experiences of older people with cognitive impairment about falling.

### **3.2.4 Summary of the literature on experiences of falling among older people with and without dementia**

The papers in this section have considered the falls experiences of older people. Sadly, none of the studies have specifically considered the experiences of older people with dementia or cognitive impairment, as the Faes et al (2010) study presented shared themes from their participants without regard to their level of cognitive impairment. What was not always clear was the process of recruitment of older people with cognitive impairment or dementia in the studies, and it is likely that in some instances older people with cognitive impairment (but not dementia) were included in the studies, perhaps by default, along with other older participants, potentially due to under-diagnosis (NAO 2007). Indeed, many papers did not state that older people with cognitive impairment or dementia were explicitly excluded or included in their studies (see table 3.2). Faes et al (2010) did attempt to recruit older people with dementia and cognitive impairment; however, this was alongside cognitively normal older people. This study showed an inclusive approach and respect for the views of older people with dementia; however, the opportunity was lost in most of the reporting of their findings to report any convergences or divergences in the data between these three different groups of participants.

Few of the qualitative studies have stated their epistemological approach, with even fewer providing a theoretical or philosophical basis for their research. Whereas studies by Ward-Griffin et al (2004), Berlin Hallrup et al (2009) and Yardley et al (2006a, 2006b) clearly described their method of data collection and analysis, others have not been so clear in their description of procedure. Therefore, their findings, although interesting, should be treated with caution. Some of the quantitative studies (for example, Borkan et al 1991, Salkeld et al 2000, Yardley and Smith 2002) used small preliminary in-depth and semi structured interviews or focus groups to collect more qualitative data to inform the content of the main quantitative and reductionist studies. However, many of

the quantitative studies were based upon the researcher's observations, deductions or previous similar quantitative studies that have provided information about the incidence, prevalence or causal relationships within the falls experience.

When reviewing the research literature of the falls experiences of older people it was interesting to take a quasi-historical look at the studies reviewed. This also assists to justify the research presented in this thesis. Prior to 2003, when this study commenced, few researchers had considered asking older people themselves about their falls experiences. Researchers such as Bhala et al (1982), Murphy and Isaacs (1982) reported on their clinical observations of older people and their perceived reticence to mobilise, which they identified as fear of falling. In response to this, many researchers studied the phenomenon of fear of falling which they associated with activity limitation (e.g. Tinetti et al 1990). However it was only later that a few (mainly qualitative studies) asked older people themselves what they were fearful of and how they perceived themselves after their fall (Ballinger and Payne 2000, Borkan et al 1991, Salkeld et al 2000, Kong et al 2002, Yardley and Smith 2002). Papers after 2003 (when this study commenced), began to explore more what the personal, social fears and consequences of falls were for older people (Ward-Griffin et al 2004, Tischler & Hobson 2005). Researchers began to explore the differences in attitudes and coping mechanisms between different age groups, genders or cultures (Horton 2007, Ruthig et al 2007). More recently, researchers have developed these findings further and explored older people's experiences of falls prevention and intervention programmes and the psychosocial factors that influence their uptake and adherence (Yardley et al 2006a, 2006b).

Although increasing, research that has explored the experiences of older people with cognitive impairment or dementia is extremely limited and yet people in this category have the highest incidence of falls and more severe consequences (Allan et al 2009, Fleming and Brayne 2008). Indeed, when this study commenced in 2003, there was little research exploring the experiences of cognitively normal older people about their falls, and no phenomenological study had been published at that time. Furthermore, until 2010, after the data had been collected and analysed in the studies presented in this thesis, no research had been carried out exploring the experiences of older people with

dementia that fall. To date, there have been no published studies carried out in the UK with community living older people with dementia. Only one study by Faes et al (2010) has attempted to explore the experience of falling of older people with dementia living in the Netherlands, however this study also explored the experiences of frail cognitively normal older people and those with MCI. It would therefore seem pertinent to explore the everyday (or lived) experiences of falling directly with older people with dementia, and also to gain an understanding of the consequences of a fall for them.

### **3.2.5 The experiences of falling by carers of older people with dementia**

This second section to the literature review chapter explores the research pertaining to the experiences of carers of older people with dementia about falls.

As can be seen in table 3.3, there were fewer research papers that explored the carers' experiences than the experiences of older people who fall, and the issues explored mostly differed from those research studies reviewed and critiqued in section 3.2.3. Many of the studies were more exploratory in nature, with more general research questions and aims.

Why or how falls of the care-recipient occurred were discussed by participants in three studies. Buri and Dawson (2000), Davey et al (2004), and Faes et al (2010) presented carer participants' discussions of the reasons for the falls of the older person that they cared for. The 14 participants in the study by Davey et al (2004) suggested in their semi-structured interviews that a range of factors could have led to their care-recipient with Parkinson's disease falling, however most of these related to the signs and symptoms of Parkinson's disease, such as poverty of movement and posture, freezing of movement, low blood pressure and side effects of medication, so have limited relevance for understanding the issues of people with dementia. Similarly the carers in the study by Faes et al (2010), when interviewed, suggested that the falls experienced by their care-recipient were caused by ageing or intrinsic factors identified at the recruiting out-patient clinic, but only blood pressure was suggested here.

**Table 3.3 Articles reviewed in section 3.2.5 presented in chronological order**

<b>Carer's experiences of falling</b>						
<b>Authors &amp; Country of origin of study</b>	<b>Research issue</b>	<b>Research methodology</b>	<b>Theoretical basis</b>	<b>Design</b>	<b>Sample information</b>	<b>Profile of care recipients</b>
<b>Liddle &amp; Gilleard (1995) UK</b>	Prevalence of fear in older people and their carers following a fall	Not stated	None stated	Structured survey using interviews on hospital admission & 1 month post discharge	69 older people – in-patients 42 informal carers	Older people admitted to acute wards following a fall. Older people with cognitive impairment or dementia excluded
<b>Buri &amp; Dawson (2000) UK</b>	The meaning of risk of falls to carers of older people with dementia	Qualitative study	Social constructionism  Grounded theory	In depth, unstructured Pre-pilot focus group, one to one semi structured interviews	7 in 1 focus group 6 interviews community living	Older people with moderate or severe dementia
<b>Davey et al (2004) UK</b>	Impact of falling in Parkinson's disease on carers	Qualitative study	None stated	In-depth semi-structured interviews	14 carers – community living	Mainly older people but all with Parkinson's disease
<b>Horton &amp; Arber (2004) UK</b>	Gender influences on support to older people who fall	Qualitative	Symbolic Interactionism Grounded Theory	In depth individual interviews of dyad	35 older people 35 carers community living	Older people with recurrent falls

<b>Carer's experiences of falling (continued)</b>						
<b>Authors &amp; Country of origin of study</b>	<b>Research issue</b>	<b>Research methodology</b>	<b>Theoretical basis</b>	<b>Design</b>	<b>Sample information</b>	<b>Profile of care recipients</b>
<b>Kuzuya et al (2006) Japan</b>	Are falls of care recipient associated with carer burden?	Not stated	None stated	Cross sectional analysis of baseline data from parent study	1478 older people and their carers community living	Frail older people, including those with cognitive impairment
<b>Mackintosh et al (2007) Australia</b>	Assess older carers' perceptions of falls	Not stated	None stated	Survey – self administered with closed questions	121 older carers community living	Not specifically stated
<b>Faes et al (2010) Netherlands</b>	Impact of falling	Qualitative, Grounded theory	Not stated	Semi-structured interviews with older people and carers	10 older people – out-patients 10 carers	Frail older people & those with cognitive impairment or dementia
<b>Kelley et al (2010) USA</b>	Lived experiences of carers of older people with stroke	Qualitative study	None stated	Secondary analysis of previously collected interview data	133 community living	Older people with stroke



Interestingly, in the interviews and focus groups, in the study by Buri and Dawson (2000), even though the participants did not suggest any possible contributory factors for falls, they seemed to still try to hypothesise why the older person with dementia had fallen, so they could try and prevent these in the future. Both Buri and Dawson (2000) and Faes et al (2010) used a grounded theory approach, however the study by Buri and Dawson (2000) provided a more cohesive understanding of how their carer participants coped with falls risk of their care-recipient with dementia.

How carers responded to falls by their care-recipient was explored by several researchers. In their quantitative survey of older people who had fallen and their carers, Liddle and Gilleard (1995) (the earliest study found of this kind) identified that carers experienced greater fear of falling than the older person themselves (58% as opposed to 25%), and that this fear increased after discharge to 66%, as opposed to 19% of the older people. This study used structured interviews to administer self-rating scales of fear of falling, emotional state, self-care activities and mobility, which were carried out before discharge and one month after discharge, with both the older person and their carer. Although this was the first study to explore and identify carers' fears of their care-recipient falling, Liddle and Gilleard (1995) did not explore what the carers were fearful of, other than further falls, and by using correlational statistical analysis were not able to infer a relationship between these differences. However, they provided two possibilities for the discrepancies in the findings between carers and their care-recipients, firstly that carers were more fearful, or secondly, that they were more able to express their fears. Researchers who took a qualitative approach and also identified that some of their carer-participants experienced fear of falls by their care-recipients were Davey et al (2004) and Kelley et al (2010). Unlike Liddle and Gilleard (1995), these studies were able to explore more what the carers were fearful of. Interestingly, the participants in these studies voiced that they were fearful of not being able to physically manage the care recipients with Parkinson's disease or stroke, if they had fallen; especially trying to get the care-recipient up from the floor. Many of these carers were wives, who commented on the physical challenges of being much smaller than their care-recipients, with most of them being older people

themselves. Other fears expressed by carers in the study by Davey et al (2004) and also Buri and Dawson (2000) was the fear of the care-recipient dying because of the consequences of severe physical injury (such as a hip fracture) following a fall, for example from a chest infection or during an operation.

Even though participants in the studies considered that falls were unpredictable and uncontrollable, many attempted to try to control, or as Buri and Dawson (2000) suggested, manage the chaos. Many of the researchers described how carers tried to prevent falls from happening by constant vigilance and monitoring (Buri and Dawson 2000, Davey et al 2004, Horton and Arber 2004). Whereas Davey et al (2004) described how their participants adapted the home environment or suggested that the care-recipient used assistive equipment, participants in the studies by Buri and Dawson (2000) and Horton and Arber (2004) took a more controlling approach. The findings from these studies presented instances of physical restraint or changing the environment without any consultation with the care-recipient (Buri and Dawson 2000, Horton and Arber 2004). Horton and Arber (2004) focussed their study on influences of gender in caring for older people who had fallen, and their findings suggested that sons looking after their mothers took a more controlling and vigilant approach, whereas the daughters in their study tended to negotiate and engage with the care recipient to consider how falls could be minimised or prevented. These studies were small grounded theory studies, and their aim was not to provide generalisable findings. However their findings provide interesting insights of the potential differences in caring, not only because of gender but also because of relationship between carer-participants and their care-recipient, by men and women carers.

Other emotional consequences of the care-recipients' falls were explored by all of the researchers (except for Liddle and Gillear 1995). Kuzuya et al (2006) identified that their participants experienced carer-burden following the care-recipients' falls. In this quantitative correlational study, the health status of the care recipient (including dementia) or their ability to carry out activities of daily living (ADLs) were independent predictors of carer-burden, however other variables were correlated with carer-burden when the confounding variables of health and ADL status were removed from the analysis. A previous fall history

for the care-recipient (within the previous six months) lead to psychological distress by the carer and depressed mood experienced by the care-recipient was significantly associated with carer burden. This study has many strengths, in that it used a culturally sensitive and standardised carer burden scale, and had a large number of carer-participants (N = 567). Kuzuya et al (2006) also explored the limitations in their study, such as omitting variables such as care-recipient incontinence and levels of social support, which may have provided significant findings. Interestingly, they identified that a limitation of their study was that the care-recipients were more frail older people, which they felt would not be representative of the general population of older people who fall. However, these findings are of relevance to the research presented in this thesis, as 39.9% of the care-recipients in the study by Kuzuya et al (2006) were diagnosed with dementia.

Many carer participants experienced social isolation and reduction in their own social activity, and the researchers suggested that this was associated with the carers' concern to be vigilant and monitor the care-recipients at all times in their attempt to reduce falls (Davey et al 2004, Faes et al 2010). More physical consequences of caring for an older person who was at risk of falling were expressed by participants in studies by Davey et al (2004), Faes et al (2010) and Kelley et al (2010), who all presented findings of carers feelings of fatigue, experiences of sleep deprivation and physical injury in their concern to monitor and assist the care-recipient. However not all carer experiences were negative ones, with some participants in the study by Faes et al (2010) voicing a heightened self-esteem from caring and trying to prevent the care-recipients from falling again.

A change in the relationship between the carer and the care-recipient was seemingly precipitated by the carers trying to prevent the care-recipient from falling, in the studies by Buri and Dawson (2000) and Horton and Arber (2004). A role reversal of the parent-child relationship was presented in both of these studies, especially where older women were being cared for by their sons.

The study by Mackintosh et al (2007) provided a different aspect of falls research. Here the researchers explored the actual and perceived risk of falls of

older carers themselves. In their self-administered survey with closed questions, these researchers found that older carers were falling more than the general population, with 42% of carers falling within a six month period, when it is considered that 25% of older people fall annually (Logan et al 2010). Approximately a third of the participants identified that they had a medical condition they felt contributed to their own falls and they recognised that falls were a problem for their age group. Although the participants rated environmental factors such as poor quality pavements and poor balance as predisposing factors for their own falls, they lacked awareness of high risk behaviours as contributory factors to their own falls risk. Even though Mackintosh et al (2006) identify that the minimisation or denial of risks by carers was of interest, their closed question survey did not allow them to pursue this issue further. The survey tool was also not a validated measure, even though it was based upon one used in a previous study (by Braun 1998) to identify falls risk. Moreover, the data collection tool did not seem to incorporate any items relating to the participants' caring role, in terms of what and how much care they gave, which may have impacted upon their findings. However, this study appears to be the first study to explore the falls' risks of older carers.

The role of health professionals in falls prevention was discussed in some of the studies. Participants in the study by Davey et al (2004) voiced that they had not been shown how to get the care-recipient up from the floor, even when the provision of hoisting equipment was not appropriate. They also observed how health professionals seemed to expect them to be able to manage these situations without any training, whereas health professionals received moving and handling training themselves. The accounts of participants in the study by Buri and Dawson (2000) also suggested that health professionals played a peripheral role in helping the carers manage falls. But it would seem that in the study by Buri and Dawson (2000), the carer participants were selective in accepting the advice they were given, especially if it did not coincide with their own values and preferences. In the study by Faes et al (2010), it would seem that most carers considered that formally provided falls prevention would not be of any benefit to their care recipient. It could therefore be inferred that like Buri

and Dawson (2000), carers in the study by Faes et al (2010) were selective about accepting any advice or intervention offered.

Of the eight papers reviewed in this section, only Buri and Dawson (2000) specifically explored the experiences of carers of older people with dementia who had fallen. Even though Faes et al (2010) included carers of older people with cognitive impairment and dementia, and individual quotations from carers of older people with dementia and cognitive impairment were provided, the prevalence of themes for this group of carers was not stated. It is interesting to compare the similarities in the findings from Buri and Dawson (2000) and Davey et al (2004). Even though these researchers used different research approaches, namely social constructionist grounded theory and one independent of any tradition and also had participants who cared for different client groups (dementia and Parkinson's disease), they both used qualitative and in-depth data collection methods, which allowed for greater exploration of the topic. In both studies, the carers both voiced fear of their care recipient dying as a consequence of falling and used strategies to prevent further falls, to avoid this. One could suggest that as the care-recipients in both studies were suffering from progressive neurological conditions, their carers were aware of their progressive deterioration and expectations of dependency, but were trying to manage, or "decelerate the illness trajectory", as suggested by Buri and Dawson (2000 p290).

#### **3.2.5.1 Summary of the literature on the carers' experiences of falling**

The majority of the papers reviewed in this section were qualitative in their approach, with Liddle and Gilleard (1995), Kuyuzza et al (2006) and Mackintosh et al (2007) having a quantitative approach and using self-report surveys. The studies by Liddle and Gilleard (1995) and Kuyuzza et al (2006) were similar in that they correlated the data they collected from validated rating scales, (for example, measuring self-care, and emotional status of care-recipients and carer burden and general health of carers) to answer their research questions, which they both achieved. Whereas Kuyuzza et al (2006) were able to collect data from a large sample of participants that could enhance the generalisability of their

findings, Liddle and Gilleard (1995) collected survey data from a much smaller number of carers, which potentially could have been collected in a more qualitative and exploratory way. However, it is worth considering that qualitative research was less common in 1995, when this study took place. The question that was unanswered in the study by Liddle and Gilleard (1995) was why do carers of older people fear falls in their care-recipient? Again in the study by Kuyuzza et al (2006) the use of their carer burden scale specifically focussed on objective burden and did not allow them to explore more subjective aspects of carer burden. As a survey, the study by Mackintosh et al (2007) was of interest as it considered the falls risks of the carers themselves, but there were limitations with the data collection tool as already discussed and the researchers acknowledged that their 20% response rate was a limitation to their study and generalisability of their findings.

The advantages of the qualitative studies reviewed here are that to a lesser or greater degree they explore more inductively the experiences of carers. However, the study by Kelley et al (2010) is limited in that it involved secondary analysis of interview data from people with stroke and their carers. The researchers acknowledged that the data they analysed came from brief interviews with a large sample (133) of participants. The purpose of their study was to explore the lived experience of falling by carers and people with stroke, however the comparatively large numbers of data items meant that data analysis was more reductionist and descriptive, using key word searches in their content analysis. It is suggested that more in-depth interviewing and analysis of a smaller data set would have enabled these researchers to carry out more inductive analysis and potentially enabled them to have answered their research question more credibly.

The study by Faes et al (2010) has already been critiqued in section 3.2.3 in terms of methodology and findings relating to older people who have fallen. The carer findings discussed in section 3.2.5 did not differentiate between those carers of cognitively normal older people, those with cognitive impairment and those with dementia. It is therefore argued that an opportunity was lost here to discuss or explore the possible divergences or convergences in the data between these three different groups of carers. Buri and Dawson (2000), Davey

et al (2004) and Horton and Arber (2004) potentially provide the richest findings. All of these researchers clearly explained their research methods, with Buri and Dawson (2000) and Horton and Arber (2004) stating the philosophical basis of their research, which was inherent throughout their methods and presentation of findings. These three studies had an obviously more inductive approach, with Buri and Dawson (2000) and Horton and Arber (2004) being more interpretative in their analysis and findings, and Davey et al (2004) being more descriptive. Although Buri and Dawson (2000) and Horton and Arber (2004) examined different concepts (construction of risk and gender influences), their data and findings are complementary. Whereas Buri and Dawson (2000) describe the status of the recipients of care of the participants in their study, Horton and Arber (2004) provide very little information about the older people being cared for by their participants. More demographic information (such as that provided by Faes et al 2010) would have been of interest. This would have allowed comparisons to take place with the findings of Buri and Dawson (2000) to have seen if the accounts of carers in both studies related to carers of older people in general or to more frail or cognitively impaired older people specifically.

In conclusion, the studies reviewed in section 3.2.3 have shown that little research has explored the lived experiences of carers with dementia or cognitive impairment in relation to their experiences and self-management of falls.

### **3.3 Summary of the review of the literature**

The research studies reviewed and critiqued in this chapter have indicated that older people who fall, experience a range of psychological and social consequences. However the consequences of falls of older people for their carers have not been fully explored. Even though fear of falling has been explored in both cognitively normal older people who fall and their carers, it has not been explored in older people with dementia. Interestingly, the research papers reviewed in sections 3.2.3 and 3.2.5 indicate that older people who fall and their carers are fearful of different consequences, with older people themselves being afraid of loss of independence, identity, autonomy and

admission to residential care, and carers being afraid of the older person dying, but not necessarily about the risks to their own health. Issues of threatened identity and autonomy as a consequence of falls have not been explicitly explored in older people with dementia or cognitive impairment, nor have these concepts been explored with their carers, although they arise with cognitively normal older people.

Even though older people with or without dementia and their carers have been both interviewed in some studies, the inter-relationship (or couplehood) of these dyads have not been explored to gain the perspectives of both members of the dyad about their shared or distinct experiences of falling.

Many of these papers were published after this study commenced, and clearly there has been a growing interest among other researchers in the lived experiences of older people who fall. Even so, there is still a gap in the research literature for greater exploration and understanding of the experiences of older people with dementia and their carers about their falls. Whereas the quantitative studies reviewed in this chapter have identified different issues and experiences for those older people that fall and their carers, their reductionist and deductive nature limit their studies. They ask “what” but do not always ask “why”, “what does this mean?” or “what is the everyday experience?” for their older participants. As an occupational therapist interested in providing evidence-based intervention, understanding the lived experience of older people with dementia who fall and the experiences of their carers is highly important to provide the most appropriate support and intervention for them. It is suggested that the most appropriate route into understanding the lived and everyday experiences of falling for older people with dementia and their carers is through a qualitative and inductive approach, so that the researcher holds no presuppositions about the potential findings. Issues of carrying out research with older people will be addressed in the next chapter, where a qualitative approach is justified.

Therefore the primary research question for the study presented in this thesis is both exploratory and inductive in nature, and is:

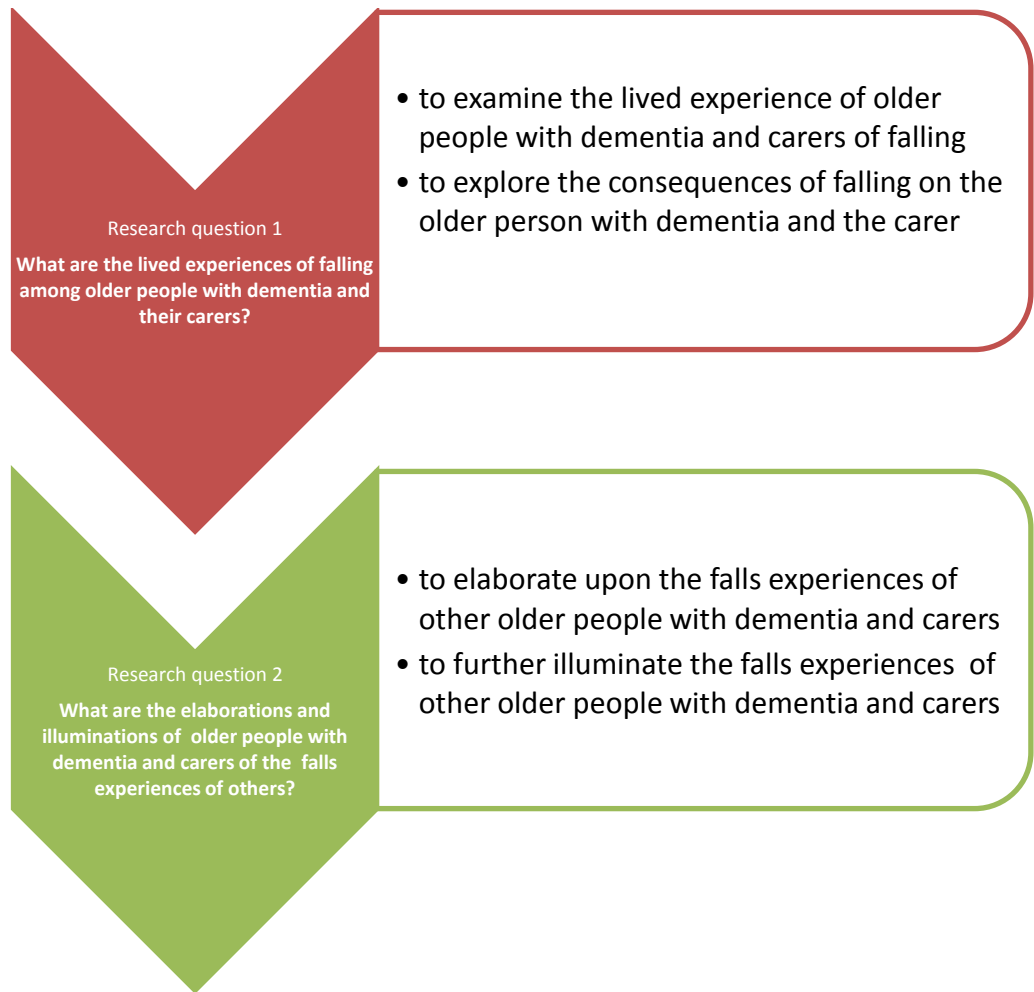


- **What are the lived experiences of falling among older people with dementia and their carers?**

Interestingly within the quantitative paradigm (and with some of the studies reviewed in this chapter) it is not unusual for studies to be repeated and developed further with different client groups and in different contexts, to gain a fuller understanding of the concept under scrutiny. It was therefore decided to carry out a secondary study where some of the accounts (from the primary study) would be taken to another group of older people with dementia and their carers for their thoughts and illumination of the data and elaboration of the data through the exploration of their own experiences of falls. Therefore the research question for the secondary study presented in this thesis is:

- **What are the elaborations and illuminations of older people with dementia and carers of the falls experiences of others?**

The aims for each study can be seen in figure 3.2 below



**Figure 3.2 The research questions and aims of the research study**

## Chapter 4 – Development of method

The primary research question identified at the end of chapter three indicates that the lived experiences of falling by older people with dementia, and their carers should be explored. The secondary research question proposes that an exploration and elaboration of these falls experiences by other older people with dementia and their carers could provide further insights into the experience of falling. The research questions are:

- **What is the lived experience of falls among older people with dementia and their carers?**
- **What are the elaborations and illuminations of older people with dementia and carers of the falls experiences of others?**

This chapter will initially discuss the involvement of older people in research, to provide supportive evidence for the methodological choice of the research. A justification of the ontological and epistemological basis of the research project will then be made to identify this as the most appropriate means of addressing the research question and aims. The research questions will be considered in turn, with a justification for the chosen methodological approach and the methods used to answer the research questions. As already stated in Chapter One, the findings for each of the research questions will be presented in separate chapters.

### 4.1 Older people and research

Older people have been increasingly involved in research in the UK in the last 10-15 years, probably because of the UK government promotion of user involvement in developing, delivering and evaluating services (DH 2001, Fudge et al 2007). However McMurdo et al (2005) suggest that there is a widespread exclusion of older people from research studies. It has been observed that older people are excluded from research for no apparent reason (Bugeja et al 1997), because obtaining consent can be too time-consuming (Bayer and Todd 2000),

or because inclusion in research is deterred by others (Zermansky et al 2005). Older people may be perceived as too vulnerable or frail by researchers (DH 2001, McMurdo et al 2005) or may be excluded specifically if they have dementia or cognitive impairment (Wilkinson 2002).

As older people can have multiple health conditions, researchers are often deterred from enrolling participants with co-morbidities and multiple medications in clinical trials in their desire to reduce confounding variables, and to avoid attrition and high mortality rates (McMurdo et al 2005, Zermansky et al 2005). It is observed that older people require longer explanation about a study or may wish to consult their families before deciding whether to participate (Harris and Dyson 2001, Davies et al 2010). It has also been reported that screening for selection may take longer with the oldest-old (often defined as above 85 years) as they may fatigue more easily and may have more difficulties with transportation and mobility (McMurdo et al 2005, Zermansky et al 2005, Davies et al 2010).

McMurdo et al (2005, 2011) suggest that the danger of not recruiting older people to clinical trials is a loss of autonomy, poor scientific outcome and the paradox of the people at greatest need being excluded by social isolation and ill- health.

The choice of design can often influence the reliability of the data collected from older people. Atwal and Caldwell (2005) identified that older people are often reluctant to express criticism of services during face to face interviews, and yet may have difficulty reading and completing potentially less intrusive postal questionnaires because of small font size or language barriers. More frail older people may also have difficulty in sustaining their participation in interviews or questionnaire-based surveys because of fatigue (Davies et al 2010). Cross-sectional and matched pair designs are often thwarted by the heterogeneity of an older sample population, but yet longitudinal cohort studies commonly suffer from participant attrition (Matthews et al 2004, McMurdo et al 2005). Indeed in a review of randomised control trials, McMurdo et al (2011) identified an attrition rate of up to 37% of older participants within the studies reviewed, often due to declining cognitive functioning, admission to long term care or mortality.

It is acknowledged that researching with older people as participants requires more time, planning and expertise (Owen 2001, McMurdo et al 2011) and an understanding of, and flexibility within, the consent process for both quantitative and qualitative research studies. Harris and Dyson (2001) and Davies et al (2010) identified that the initial approach to older people by using “gatekeepers” such as familiar and trusted health professionals, or by family members, enhanced recruitment. The personal contact with the researcher to gain information about the study, either face to face or by telephone also enhanced recruitment (Harris and Dyson 2001, Davies et al 2010). Researching with older people with dementia is also said to be enhanced by the use of qualitative methodologies, a flexible interview schedule (i.e. finding the right time), allowing the participant to return to the topic, being supportive and alert to non-verbal signals, as well as being willing to accept the person’s narrative as truth (Bond and Corner 2001, Wilkinson 2002, Hubbard et al 2003). The use of one-to-one or focus group interviews in qualitative research are said to be especially appropriate when involving older participants. The use of a semi (or unstructured) interview process following a conversational style, is also advocated to facilitate an older participant to reconstruct past experiences in a relatively free and unprompted way (Gearing and Dant 1990, Montazeri et al 1996),

It would seem that recruitment of older people to quantitative and clinical research studies is thwarted by many methodological difficulties. Even though the same barriers of recruitment, consent, and retention exist in qualitative methodologies, the use of more flexible designs and methods of data collection make qualitative methodology an advantageous choice when wishing to research with older people.

#### **4.2 Choosing the research methods to answer the research questions**

*“Qualitative research illuminates the less tangible meanings and intricacies of our social world. Applied to the therapy field it offers the possibility of hearing the perceptions and experience of service users.”*  
(Finlay 2011p8)

The review of the literature in chapter three identified that little research has been carried out into the experiences of falling described by older people with dementia, or their carers. However, the review of the literature in chapter three did identify how the use of a qualitative approach provided greater understanding of older people's perceptions and uptake of falls interventions. Evidence from the literature provided in section 4.1 also indicates the advantages of using a qualitative methodology with older people, in terms of recruitment and data collection. In conclusion, it is said that qualitative research allows the researcher to understand the everyday experiences of their participants, offers a brief glimpse of their daily lives, and may challenge assumptions of others (Pope and Mays 2000, Finlay 2011).

In both the primary and secondary studies presented in this thesis, the lived experiences of older people with dementia and their carers of falling are explored. Therefore, a qualitative methodology is the approach of choice within this thesis. The exploration of the participants' subjective or lived experience (or lifeworlds) of falling are compatible with phenomenological research methods (Langdrige 2007, Holloway and Wheeler 2010, Finlay 2011). Both the primary and secondary studies will be placed within an ontological and epistemological position and the methods of choice will be justified.

#### **4.2.1 Stating the ontological and epistemological position**

Choosing an appropriate research method within health and social care research, like any other, is determined by the research question and the ontological beliefs (i.e. views about the nature of the world) that the researcher holds (Finlay 2006). Research has traditionally been considered as residing in two opposing paradigms, and this has been termed as the paradigm or epistemological 'war' (Robson 2002 p43). These two paradigms have been classified in differing ways, for example, by methodology as qualitative and quantitative, or by epistemology such as positivist and interpretivist perspectives, or by ontology as realist or relativist (Bhaskar 1979, Finlay 2006).

Whereas quantitative research is said to take place in a positivist or post-positivist paradigm (where the researcher strives for objectivity, impartiality and

truth), qualitative research takes a more interpretivist-constructionist stance where the subjective experiences and meanings of the world are understood to be multiple and contextual and influenced by the researcher's involvement (Finlay 2006, 2011). Interpretivists are said to trace their roots back to phenomenology and hermeneutics, and focus on how people interpret and make sense of reality (Miller and Crabtree 1999). Interpretivists consider that experiences are contextual, temporal and subjective (Holloway 2008), with "our situatedness determining our understanding" (Finlay 2006 p19). Constructionists believe that social reality is constructed out of different social perspectives (Avis 2005) and doubt "in the existence of 'objective' knowledge" (Holloway 2008 p48), considering that all knowledge is relative to who and where the knowledge is held. Interpretivists believe in pluralism rather than relativism, so that it is considered that there are multiple and subjective realities and understandings (e.g. of health conditions), with constructionists believing that all social facts (including medical diagnoses) are discovered and created through the application of social norms, which may differ from one social group to another (e.g. dementia, schizophrenia, bipolar disorder) (Avis 2005).

These epistemological beliefs are also informed by the ontological position of the researcher and it is this view of the world that also influences the research approach taken. The ontological stances of realism and relativism are said to be at opposing poles of the ontological debate in research (Finlay 2006). Researchers that hold a realist position believe that reality exists independently of what we as human beings believe and perceive it to be, and therefore tend to adopt a quantitative approach to research, which links to the view that variables exist independently of human beings and can therefore be measured objectively (Finlay 2011). Whereas relativists consider there are multiple realities that are always open to variation and are socially constructed (Holloway 2008). Whereas qualitative researchers tend not to adopt a realist position, many do not adopt a relativist position either, and more recently, some researchers have considered that there is a paradigm continuum (Finlay 2011) and have adopted a middle ground in their approaches. Some may have a realist ontological perspective but an interpretivist epistemological perspective. Such researchers would identify themselves as contextualists (Henwood and Pidgeon 1994,

Madill et al 2000, Larkin et al 2006). Madill et al (2000) suggests that contextualist research acknowledges that all knowledge is local, provisional and dependent upon the situation; which varies depending on the context of both data collection and analysis. However, contextualism also accepts that there is a desire for some underlying logical understanding of the phenomenon under scrutiny (Madill et al 2000). For example, there is an acceptance that falls are real events, however how they are experienced are determined by the meanings the individual attributes to their fall and also how they make sense of what has happened. The middle ground perspective has been adopted in this study, and more specifically, contextualism has been adopted as the epistemological basis for this research.

Contextualism could be perceived to be more compatible with health care research, and especially bio-psycho-social models of health and illness such as the ICF (WHO 2001), where it is considered that the experiences of a health condition is determined by who the individual is, what they do, who they have relationships with and where they live. This model is pertinent to the more recent approaches to dementia care (O'Connor et al 2007), and also in falls management where the uptake and adherence of individuals to falls interventions are influenced by their attitudes, their sense of identity and autonomy (Yardley et al 2006a, 2006b).

### **4.3 Justification of research approach**

The primary and secondary research questions both aim to explore the individual and subjective experiences of the rarely privileged group of older people with dementia and their carers about their experiences of falls. Interpretative phenomenological analysis (IPA) has been chosen for the primary study and an interpretative approach independent of any tradition, but influenced by phenomenology, has been chosen for the secondary study.

#### **4.3.1 Phenomenology**

Phenomenology has become more recently popular in health care research because the focus on the insider's perspective or lived experience of individuals



fits comfortably within health care policy and remit of client centred practice, service user involvement and also professional traditions (Finlay 1999, Wilding and Whiteford 2005). As a research approach, phenomenology is a useful way to systematically explore the experiences of individuals, which may be difficult to observe or measure (Wilding and Whiteford 2005). Phenomenological research differs from many other qualitative approaches such as ethnography, grounded theory and discourse analysis, in that it does not make claims about the world itself (in terms of a social or cultural agenda) from a relativist perspective but focuses on the perspectives of individuals who have experienced the phenomenon under scrutiny (Wilding and Whiteford 2005, Holloway 2008, Willig 2008). Phenomenological researchers also resist the subject-object divide of positivism or realism by studying the individual's experience in their world (Langdrige 2007). The research paradigm of phenomenology is not often stated, however phenomenological researchers are agreed that an interpretive rather than a constructivist stance is taken because of the focus on the personal/individual rather than the social/cultural (Giorgi 1992, Smith et al 2009). Finlay (2006, 2009) considers that phenomenological research takes a middle ground stance, which is reflected in the emphasis of the person (or self) and the world, where our experience is always contextual, termed by Heidegger as *Dasein* or being- in- the- world (Larkin et al 2011).

Phenomenology attempts to “get at the truth” of a phenomenon in whatever form it appears or has meaning for the individual experiencing it, with the aim being to see the phenomenon with new or fresh eyes (Moran 2000). Consequently, phenomenology, as a research methodology, is popular in psychology and psychotherapy (Giorgi and Giorgi 2008, Holloway 2008) and is increasingly used in nursing (Benner 1994, Reed 1994) and the allied health professions (Finlay 1999, Dean et al 2005, Wilding and Whiteford 2005). Phenomenological research is based upon the philosophical movement of phenomenology, of which there are several different stances and beliefs (Moran 2000). These philosophies were not developed with research as a primary motive and controversies exist about how philosophical phenomenology can be, and is used, in research (Todres and Wheeler 2001). Until recently, few phenomenological researchers have described their research methods in any

detail in their desire to avoid a prescriptive “recipe following” approach, but considered that the philosophical influence of the research should be explicit (Finlay 1999, Giorgi 2006, Holloway 2008). Indeed there are criticisms that research is carried out and labelled as phenomenology, which lacks any philosophical basis (Paley 1997, Finlay 1999). However more recent research literature pertinent to health care does describe research methods for their approaches as well as their philosophical foundations, for example the Sheffield School of analysis described by Ashworth (2003) with several fractions (or fragments) of the lifeworld, arising from the philosophy of Husserl, Heidegger, Merleau-Ponty and Sartre and Lifeworld research described by Dahlberg et al (2008), influenced by Gadamer.

Phenomenological research can be split into different ‘factions’ and these divisions are based upon the beliefs and work of different phenomenological philosophers such as Husserl, Heidegger, Merleau-Ponty, Sartre, Gadamer and Ricœur. Some consider two splits into descriptive or transcendental, and interpretive phenomenology (Giorgi 1992, Lopez and Willis 2004), and others described three major divisions into descriptive, existentialist and hermeneutic phenomenology (Langdrige 2007, Holloway and Wheeler 2010). However there is on-going debate about the distinctions and overlaps between approaches (Holloway and Wheeler 2010). Indeed Finlay (2009) suggests that it is difficult to ascertain where description ends and interpretation begins. Whereas descriptive/transcendental phenomenological research is based upon the philosophy of Husserl and focuses on the description of the structure of experiences (or essences) as advocated by Giorgi (1992), Heidegger provides the basis for both existential and hermeneutic phenomenological research. Existential research is also informed by Merleau-Ponty and Sartre, with the focus on our experience of the world as we live it (Langdrige 2007), with hermeneutic research also being informed by the philosophies of Gadamer, Ricœur or Habermas where the understanding of an experience is always an interpreted one (Langdrige 2007, Finlay 2011). How these philosophers inform phenomenological research varies – with Giorgi (2000) remaining within a Husserlian philosophy and Benner (1994) being mainly influenced by Heidegger. Other researchers working within an existential framework are

influenced by Merleau-Ponty and Husserl (Ashworth 2003, Finlay 2003), and interpretative/hermeneutic researchers influenced mainly by Heidegger, also Gadamer, Ricœur and Sartre (van Manen 1998, Dahlberg et al 2008). Further exploration of the various phenomenological positions will follow.

#### 4.3.2 The founding fathers of phenomenological philosophy

Husserl is seen to be the founding phenomenological philosopher and as such emphasised the need to explore the taken-for-granted experience of an individual which he termed their “lifeworld” (*lebenswelt*) (Holloway 2008, Smith et al 2009). The lifeworld is a key concept for all phenomenological research including IPA; however, how this is explored varies amongst phenomenological philosophers. Whereas Husserl considered that the lifeworld in its purest form could only be accessed by rejecting pre-suppositions and a-priori knowledge, through bracketing and eidetic reduction, Heidegger and subsequent philosophers perceived that the lifeworld of an individual has to be considered in context. Heidegger’s emphasis is that an individual is a “being-in-the-world” (or in German, “*dasein*”). Heidegger considered that human action/experience has to be understood as part of the world and not separate from it; with our being-in-the-world having an intersubjectivity so that it is always coloured by who and what we are with, in the world and also when (e.g. our past, present and future) (Heidegger 1927/1962).

Heidegger transformed phenomenology away from Husserl’s transcendental approach (i.e. that our understanding of a phenomenon is by taking a “God’s eye view” - one that is external to the individual) to a more existential one where the focus is on the lived experience of the individual (Langdridge 2007) and it is perhaps Heidegger who provides the biggest influence on current IPA research. Heidegger criticised the transcendental emphasis of Husserl’s philosophy as being too Cartesian in the subject-object split of the experience from the individual (Heidegger 1927/1962).

The requirement in phenomenological research to involve people who have experienced the phenomena under scrutiny becomes much more obvious when considered in terms of authentic “being in-the-world”. Indeed the

intersubjectivity of our experiences are a crucial element of IPA (Eatough and Smith 2008) so that an IPA research study would seek to understand events or phenomena that are given meaning by the individuals that experience them. Therefore in this study it is important to acknowledge that the ownership of (or authenticity of) the phenomenon of falling differs for the person experiencing it (e.g. the person with dementia), the carer observing or being alongside, and the professional providing support and health care. By delving deeper into the experience by using less structured interviews allows the participant to speak in depth and in their own way, thus enabling their “being-in-the-world” (or *dasein*) to be revealed.

The concept of *dasein* was developed further by Heidegger to encompass the social nature of *dasein* – in that one is a being-in-the-world-with-others – termed “*mitsein*”. This concept of being-with-others is explored more by the existentialist philosopher Sartre who considered that one’s experience of a phenomenon is coloured by the people sharing it and therefore the memories and emotions of an experience are coloured by interpersonal contexts and relationships (Smith et al 2009). Therefore when exploring the experiences of couples or dyads these accounts will reveal “*mitsein*” through co-constructed stories and accounts.

Heidegger also considered that embodied nature of *dasein* in that he felt that individuals perceive themselves as whole human beings rather than with a person-body split. Whereas Heidegger considered the body as in the background and inconspicuous and Sartre described the body as “passed-over-in-silence” (van Manen 1998), Merleau-Ponty emphasised the embodied nature of *dasein*, with the body foregrounded in being (Inwood 1997). Although influenced by Heidegger, Merleau-Ponty was also influenced by Husserl in his belief of intentionality (i.e. we are always conscious of something) (Langdridge 2007). Merleau-Ponty considered that the physical body is enmeshed in *dasein* so that an individual is both object and subject. Merleau-Ponty emphasised the biological nature of the body and the demands that it makes on objects within the world and that perhaps give meaning to that individual. He therefore advocated that the physicality of the body comes first, so that living in the world is primary to being conscious about the world (Matthews 2006).

How much an individual is conscious of their embodied world is debatable but it is perhaps phenomenological research that explores the experiences of people with disability or health conditions where this is more obvious. Work by Toombs (1995) and Finlay (2003), who are existential phenomenological researchers, and IPA researchers such as Osborn and Smith (1998), Reynolds and Prior (2003) and Dickson et al (2008), have identified how a failing body becomes fore-grounded in everyday being for people with multiple sclerosis or spinal cord injury, for example. Where existential phenomenological research and IPA research differ is in their emphasis within the analysis, with the former perhaps concentrating on various fragments or “fractions” essential to the lifeworld, such as selfhood, sociality, and embodiment (Ashworth 2003) and the latter focussing on how the individual makes sense and gives meaning to their embodied experience in the context of their everyday lives (or lifeworlds) (Larkin et al 2011).

Heidegger’s later work developed the more interpretive focus of phenomenology to hermeneutics. He was heavily influenced by the nineteenth hermeneuticists Schleiermacher and Dilthey (Langdridge 2007). Whereas Schleiermacher advocated that hermeneutics (the interpretation of biblical texts) could be applied to all texts, Dilthey advocated that hermeneutics could be applied to the human sciences in general. Dilthey considered that the understanding and interpretation of human nature is also always subjective. Schleiermacher provided a slightly different emphasis, which Smith et al (2009) suggest is a key element of IPA research, in that when reading a text (or transcript), he proposed that the reader has the potential to understand the text better than the author themselves. Schleiermacher considered that the reader’s interpretation of the text involved exploring the language used to facilitate a deeper meaning of the text in order to reveal meanings not always apparent to the author (Schwandt 1998, Todres and Wheeler 2001). One can see the influence of Schleiermacher where metaphors used by research participants are explored and analysed in detail by IPA researchers (for example Smith 2004, Eatough and Smith 2006a). What is also pertinent to the research presented in this thesis (but not necessarily related to phenomenological philosophy) is the perceived importance of metaphor in some Dementia research and practice

where stories and metaphors of the past recounted by people with dementia can be interpreted, and related to their feelings and perceptions of their current experiences (Kitwood 1997a, 1997b).

Heidegger developed the concept of hermeneutics further by stating that interpretation is intrinsic to what a person is, as we always interpret experiences, either implicitly or explicitly from our own position or “facticity” (Todres and Wheeler 2001). Heidegger considered that things can show themselves in a variety of ways and rarely show themselves in their entirety; often having to be revealed or uncovered. For example, the consequences of an older person’s fall cannot be established just by observing their physical injuries, but are revealed more by considering their emotional, social responses and activity. It is also true to say that not all hidden objects are the treasure trove expected and therefore cannot be taken at face value but need to be explored and interpreted to understand their worth (Moran 2000). Heidegger suggested that discourse allows the object or experience to be revealed and brought out into the open. He emphasised the importance of language in revealing *dasein* (Moran 2000, Langdridge 2007). Again this focus on language reinforces how IPA research considers the use of language and metaphor by participants and digging beneath it to consider the interpretation of the individuals’ experiences. This is in contrast to discourse analysis, which has a social constructionist emphasis considering social or cultural concepts or interactions (Smith et al 2009). For example, Ballinger and Payne (2000) used discourse analysis to explore the perspectives of older people and therapists about falls. They suggested that older people used a moral discourse to explain their fall, portraying themselves as responsible, independent and blameless, whereas therapists used a risk discourse, perceiving the older people as vulnerable and putting themselves at risk of falling.

Heidegger also reiterated that one’s interpretation of the new is dependent upon our past – in terms of experience and knowledge. In the example of falling, one’s experience (or even anticipation) of a fall will relate to previous experiences of falling, in terms of the impact that it has on the individual. Indeed within the literature, there is evidence that the fear of future falls is based upon

the impact and consequences of past falls (Zijlstra et al 2007, Scheffer et al 2008).

Dowling (2007) suggested that an understanding of a phenomenon involves a reciprocal activity of pre-understanding and understanding, which Heidegger described as understanding developing through “circling back and forth through presumption and surprise” (Moran 2002 p18), known as the hermeneutic circle. Rapport (2005) described the hermeneutic circle as a continuous movement of “understanding, explication and interpretation” (p141). This circling within phenomenology is an analogy used by many phenomenologist philosophers, and the hermeneutic circle has been used to describe the relationship between the parts and the whole of an experience by Merleau-Ponty and Gadamer (Matthews 2006, Langdrige 2007). Heidegger considered that the new experience should always take precedence with the pre-understanding being acknowledged and set aside (or bracketed) to assist in revealing the new. However, Gadamer, considered as a prominent modern hermeneuticist, suggested that by momentarily bracketing our pre-understandings, new understandings become revealed that may help illuminate our preconceptions and pre-understandings, and that the new and the past, the reader and author are intertwined with a fusing of horizons (Langdrige 2007, Dahlberg et al 2008, Smith et al 2009). The fusing of horizons of past, present, interpreter and author in interpretation is a relevant issue in IPA research. Indeed Smith (1996) described a “double hermeneutic” in IPA research with the participant providing their interpretation of the experience and the researcher interpreting and making sense of the participants’ story. Smith et al (2009) acknowledged the influence of another hermeneutic philosopher, Ricœur, on IPA, in terms of a double hermeneutic in the use of Ricœur’s hermeneutics of empathy (or meaning recollection) and suspicion (or questioning) (Langdrige 2007, Smith et al 2009). Ricœur considered that empathy allows the reader to engage with the text and use their own pre-understandings and facticity to attempt to understand the meaning of the text (Smith and Osborn 2008). However the hermeneutics of suspicion could be said to involve the digging deeper for underlying meanings. Whereas Ricœur believed that the hermeneutics of empathy has a place within phenomenology, he felt that the latter was of more relevance to disciplines such

as psychoanalysis (Langdridge 2007). Smith et al (2009) consider that the double hermeneutic exists where the interpreter not only attempts to adopt the “insider’s perspective” but sometimes takes a questioning stance (perhaps a milder version of suspicion) to be alongside the participant to gain a different perspective and interpretation. For example, this thesis acknowledges that immersion in the data enabled the researcher to take a deeper interpretation of the participants’ accounts and experiences rather than make a description of their experiences and perceptions.

#### **4.3.3 Justification for Interpretative Phenomenological Analysis (IPA) as the chosen approach in the primary study**

Interpretative phenomenological analysis was chosen as the research approach for the primary research study, where the lived experience of falls among older people with dementia and their carers is explored. Interpretative phenomenological analysis (IPA) is a relatively recent hermeneutic phenomenological research approach of increasing popularity in the UK, especially in health care research. It was developed by Smith in the 1990’s as an alternative approach to quantitative research approaches in psychology (Smith 1996). Smith argued for the need to understand the micro-perspective rather than the macro-perspective of a phenomenon, so that the experiences of individuals and their perceptions of events/phenomena are explored rather than their social or cultural construction (Smith 1996).

Even though IPA is an approach developed within health psychology, it is attractive to allied health care professionals as it allows a deeper exploration and understanding of the perspectives of individual clients as well as complementing bio-psycho-social theories of health and functioning (Reid et al 2005, Biggerstaff and Thompson 2008, Clarke 2009). The adoption of IPA by “applied psychological” disciplines such as occupational therapy, is acknowledged by Smith et al (2009) as it is recognised that these disciplines have “a core interest in the human predicament” (Smith et al 2009 p5). As a hermeneutic research approach, interpretation in IPA is reliant upon the ability of participants to articulate their thoughts and experiences and also by the



researcher's ability to reflect, analyse and interpret these appropriately (Brocki and Wearden 2006). IPA also has a strong idiographic emphasis in that it aims for a detailed analysis of one case before attending to analysis of further cases analysed in the same detailed way. The aim is for "thick" interpretation of participants' accounts so that both the unique and the shared perspective is communicated, which Osborn and Smith (2008) consider of particular relevance where the topic under scrutiny is under-researched, multifaceted and contextual. The emphasis of IPA on trying to uncover or illuminate the unique and shared subjective experiences of individuals experiencing a phenomenon such as falls, dementia or caring has made IPA an appropriate approach to address the primary research question.

As an approach, IPA is continuously developing. Indeed since starting this study and collecting data, the corpus of IPA studies and literature has expanded considerably, the guidelines for sample size and data analysis have also changed subtly and a recent publication of quality criteria for IPA research has been proposed by Smith (2011). Initial publications focussed on the method of carrying out an IPA study (e.g. Smith 1996, Smith et al 1997, Smith et al 1999), and more recently the philosophical basis of IPA has been discussed within the literature (Smith 2004, Larkin et al 2006, Eatough and Smith 2008, Smith et al 2009). Consequently there are some studies published which emphasise IPA as a method of thematic data analysis (Chapman and Ogden 2009, May and Rugg 2010) with little evidence of the idiographic nature of an IPA study or a basis in a phenomenological research approach. Indeed Smith et al (2009) suggest that the data analysis method used is similar to that used in other approaches and is not specific to IPA. However, Smith and colleagues (2009) have more clearly defined the interpretive emphasis of IPA and along with this have developed their guidance on how and where to use IPA in research. Different methods of data analysis from the original description by Smith (1996) are now suggested alongside a recommendation for smaller numbers of participants. The method used in this primary study reflects the earlier recommended sample size and method of data analysis, because of the timescale of the project and the inter-relationship of this study with the secondary study (to be discussed in section 4.4). However, Smith et al (2009) emphasised that no one method of analysis is

preferable. Traditionally IPA research has used one to one (face to face) interviews with participants, and early IPA work using repeat interviews and focus groups could be seen to be exploratory in their design and undertaking (for example, Flowers et al 2003). As IPA research studies are published, so they evolve, with Smith and colleagues more recently advocating the single case and smaller numbers of participants to allow for a deeper and more idiographic and linguistic interpretation of the data (Eatough and Smith 2008, Smith et al 2009). These data collection methods will be discussed in more detail in both the methods and findings chapters.

Early IPA literature identifies Husserl, Heidegger, symbolic interactionism, social cognition and idiography as providing the theoretical basis for the approach (Smith 1996, 2004). Smith et al (1997) identified the influence of Bruner (1990), an early symbolic interactionist within IPA research on the meanings individuals make of, and what can be interpreted from their experiences. As already stated, the idiographic emphasis has been strengthened in more recent discussions of ways of carrying out IPA research, with smaller numbers of participants recommended and more in depth analysis of each case (Eatough and Smith 2008, Osborn and Smith 2008, Smith et al 2009, Smith 2011).

Larkin et al (2006) identified the theoretical underpinning of IPA as being mainly Heideggerian but state that this is not prescriptive. More recent literature also cites influences from Merleau-Ponty, Gadamer and Sartre (Smith et al 2009). Even though Smith (2004) considered IPA as part of a phenomenological research 'stable', many of these approaches differ from IPA in that they are based upon more specific phenomenological philosophies as already discussed in section 4.2.2. IPA draws from Husserl in his concern for the lifeworld and the importance of bracketing or *epoché*, even if this has different relevance in IPA research. Heidegger has perhaps provided the major influence to IPA (as he has to other hermeneutic phenomenological research approaches) in the contextual understanding of *dasein*, in proposing that we are beings in the world with others and therefore our experiences are always open to interpretation. Whereas Husserl and Heidegger are perhaps the crucial influences on how an IPA study is constructed, how participants are selected, the data collected and analysed; the influences of other philosophers may vary. For example an IPA

study that explores the experiences of relationships (being a daughter, carer, mother), may draw more on the philosophy of Sartre, whereas an IPA study carried out by a psychoanalytic researcher may be influenced by Ricœur. These philosophers, along with Gadamer also influence how an IPA study is carried out and especially how the hermeneutic circle influences how data are analysed. For IPA research that considers the embodied experience of living with a health condition such as dementia (Clare 2003), multiple sclerosis (Reynolds and Prior 2003) and back pain (Osborn and Smith 1998) the influence of Merleau-Ponty reminds the researcher that they can be empathic to the participant but never fully share their experience. Merleau-Ponty's philosophy enables the researcher to interpret and communicate the subjective and idiographic nature of the experience from an empathic perspective.

In conclusion, IPA has been chosen to answer research question one, where the experiences of falling by older people with dementia and their carers are to be explored. It is felt that IPA as a research approach enables a deeper understanding of individual and unique experiences as well as common themes of meaning. It also acknowledges the role of the researcher in the interpretation of the data presented. IPA, like other hermeneutic phenomenological approaches (and indeed other qualitative approaches), does not seek to generalise to other contexts but has been identified as a useful tool to "reflect upon and evaluate practice" (Taylor 2007 p90). It sits between the realist and idealist/relativist divide (Larkin et al 2006, Eatough and Smith 2008) and indeed is perceived as taking a contextualist position (Larkin et al 2006). Even though IPA research has an interest in language (like discourse analysis), the IPA researcher is more interested in understanding the meanings within the language used by participants when talking about their experiences rather than construction or social discourses of language (Flowers et al 2003). However, there could be considered to be many similarities between IPA and narrative analysis, as both consider the meaning making within a narrative or story. Conversely, narrative analysis differs from IPA in that it has many different forms of analysis including that which focuses on story, plot, and characters and therefore looks very different from an IPA study (Holloway 2010).

As someone more familiar to quantitative and positivist research prior to commencing the study, the clear guidance in carrying out a specific approach provided by qualitative researchers can be important, and both grounded theory and IPA provided this when this study was being planned and initiated. However, grounded theory attempts to generate a general and theoretical account of a topic and does not allow for the unique and individual converging and diverging experiences of individuals to be presented (Smith et al 2009). It is suggested that although there are similarities in the method of data analysis between IPA and grounded theory, IPA seeks to explore psychological questions through its interest in the nature of a phenomenon whereas grounded theory asks sociological questions and considers the social processes that create or are associated with a phenomena (Willig 2008).

This section has introduced interpretative phenomenological analysis (IPA) as the research approach of choice to answer the primary research question “What are the experiences of falls by older people with dementia and their carers?”

The processes involved in carrying out an IPA study will be discussed in the next chapter.

#### **4.4 Justification of methodology for secondary research question - “How do older people with dementia and carers interpret and elaborate upon the summarised falls experiences of others?”.**

In this section, the chosen research methodological approach will be debated in terms of its epistemological position. The most appropriate method of data collection to answer the research question and meet the aims will be discussed.

##### **4.4.1 Debating the methodological approach for secondary research question**

By taking a contextualist approach one can argue that a multi-faceted perspective, as suggested by Bhaskar (2008), can facilitate the exploration of the phenomena of falling for older people with dementia and their carers. Indeed, in the initial planning of the whole research project, the focus for this

stage was originally to validate the findings from the primary study, by carrying out focus groups with other older people with dementia and their carers, to enhance the generalisability of the research. However, greater understanding of the concept of validity and generalisability in qualitative research, and in contextualist and phenomenological research in particular, as well as further writings by Smith et al (2009), raised several issues about the place and role of validation and generalisability in this paradigm and research approach. Ballinger (2006) suggests that validity and generalisability are positivist concepts and that in middle ground epistemologies the trustworthiness of the data and study is a greater issue. Smith et al (2009) also suggest a theoretical transferability rather than generalisability is to be sought, and suggest “the reader makes links between the analysis in an IPA study, their own personal and professional experience, and claims in the extant literature” (Smith et al 2009, p.51).

However, Yardley (2000) discussed how a softer “triangulation” of data collection can enhance the rigour of a study by providing “a rounded, multi-layered understanding of the research topic” (p 222) through gathering data from different participants, such as that incorporated into this secondary research study. Madill et al (2000) also suggested that a triangulation within a contextualist perspective aims for “completeness and not convergence” (p10). Therefore, the aim of this secondary stage in the research is not to verify or validate the data already produced by recruiting and interviewing other older people with dementia and carers, but to gain further insight from a relatively hidden group to provide a multi-layered understanding of the experience of falling. It was hoped that these participants would be able to have an “embodied relational understanding” as described by Todres (2008) where the presentation of the data from the primary research study in the form of quotations, might resonate with their own experience and allow them to “be-with” or alongside the participants from the previous study. As the older people with dementia recruited in this secondary study had also experienced falls, it was hoped that the data presented to them from the primary research study, would prompt or facilitate their recollections of their own lived experiences of falling.

To date there has been no precedent for a study such as this where different participants with similar characteristics are asked to participate in another

qualitative study where elaboration of experience rather than verification is desired. However, there was a desire to stay true to the IPA core and not to carry out a study in this phase that would conflict with this approach and phenomenology in general. By acknowledging the phenomenological core of the research project this stage aims to stay true to the Heideggerian principles of uncovering and illumination (Moran 2000) and to elaborate on what has already been revealed in the primary research study. It was important to establish a complementary research method, and to maintain the experiential focus rather than theory generation (as in grounded theory) or observation (as in ethnography) and to maintain the thematic nature of the findings (unlike narrative analysis).

It is suggested that by presenting the descriptive data from the primary research study to the participants in the secondary study, that this might enable the researcher to enter the lifeworld of these participants. Therefore a qualitative inductive, interpretative approach with phenomenological influences and aligned to a contextualist perspective, was chosen to compliment the approach utilised in the primary research study, to further access these experiences and meanings.

#### **4.5 Being a reflexive researcher**

As has been discussed and justified in this chapter, an inductive and interpretative qualitative approach was taken to explore the lived experience of falling of older people with dementia and their carers. Like most qualitative approaches, interpretative research acknowledges and welcomes the subjectivity of the researcher (Smith et al 2009). However, it is advocated that this subjectivity within the research process needs to be acknowledged and not necessarily set aside or bracketed (Finlay 2011, Smith et al 2009). Therefore, the researcher has to identify and continually be aware of their previous understandings, assumptions, interests and experiences during the research process (Finlay 2011). Such reflexivity is considered to enhance the transparency of the research process, where the findings present interpretations and not 'truth' (Yardley 2008). Many of the chapters within this thesis contain

reflexive pieces including excerpts from my reflexive diary kept during the research process, including this chapter, in section 4.7.

#### **4.6 Summary**

In this chapter, the use of a qualitative methodology to answer both the primary and secondary research questions has been proposed and discussed. Taking a contextualist perspective has also been argued, in terms of personal and practice beliefs as well as its relevance to the considering the realities of falling for older people with dementia and their carers. The choice of an interpretative phenomenological approach, and IPA in particular has been justified, in terms of the acknowledgement that any data analysis involves interpretation and also its opportunity to explore the convergent and divergent experiences of participants. A pragmatic choice of IPA over other interpretative phenomenological approaches relates to the clearly described guidelines for carrying out IPA research that were available when this project started. The elaboration of these experiences by other older people with dementia and carers have also been discussed and related to the on-going debate of validity and generalisability of qualitative research. The next chapter, Chapter Five will present and justify the chosen research methods for both stages of this research.

#### **4.7 Reflection on the chosen methodology**

At the start of my PhD journey I had feelings of both clarity and confusion. The clarity quickly went and for a long time confusion reigned. I knew what I wanted to explore but was unsure of how I was going to go about this. As a practicing occupational therapist I had worked within a bio-medical model. My masters' research project used a quantitative design, and although challenging to carry out, I did not feel the need to question the positivist paradigm. I was aware that the quantitative approach was not appropriate for the research presented in this thesis and welcomed the challenge of qualitative research. In a positivistic mode I focused on the research approach, and then got confused by grounded theory, ethnography and phenomenology. I primarily explored grounded theory but felt that this would not have enabled me to explore the subjective

experiences of my potential participants. I then discovered IPA, and welcomed this because of the presented method in Smith and Osborn (2003). Thinking about the philosophical basis for IPA came later and I started to grapple with the phenomenological philosophies and this has continued until today.

At the same time I realised that I needed to consider the ontological and epistemological perspective for my research. Even though I considered myself as a (novice) qualitative researcher by this point, I was confused about what my epistemological position was, even after many months of reading. There came a heart-sinking moment when I realised that I was still in positivist mode and searching for *the* solution to my conundrum and getting very confused by differing terminology and concepts in the process. This was a turning point for me and I began to understand that variations in terms and concepts related to the different perspectives of the authors and also their disciplines. However, I was still unsure where I stood or what *the* answer was for IPA research. I carried on reading and began to realise that *my* worldview would inform my ontological and epistemological position. I was helped by reading papers by Yardley (1996) and Williams (1999), who related research paradigms to bio-psycho-social models of health, with which I could associate. I then found the paper by Madill et al (2000) and finally decided on contextualism as my epistemological position. What were also helpful were the debates within the IPA literature about the philosophical basis of IPA such as that by Larkin et al (2006), Eatough and Smith (2008) and Smith et al (2009).



## **Chapter 5 - Chosen Research Methods**

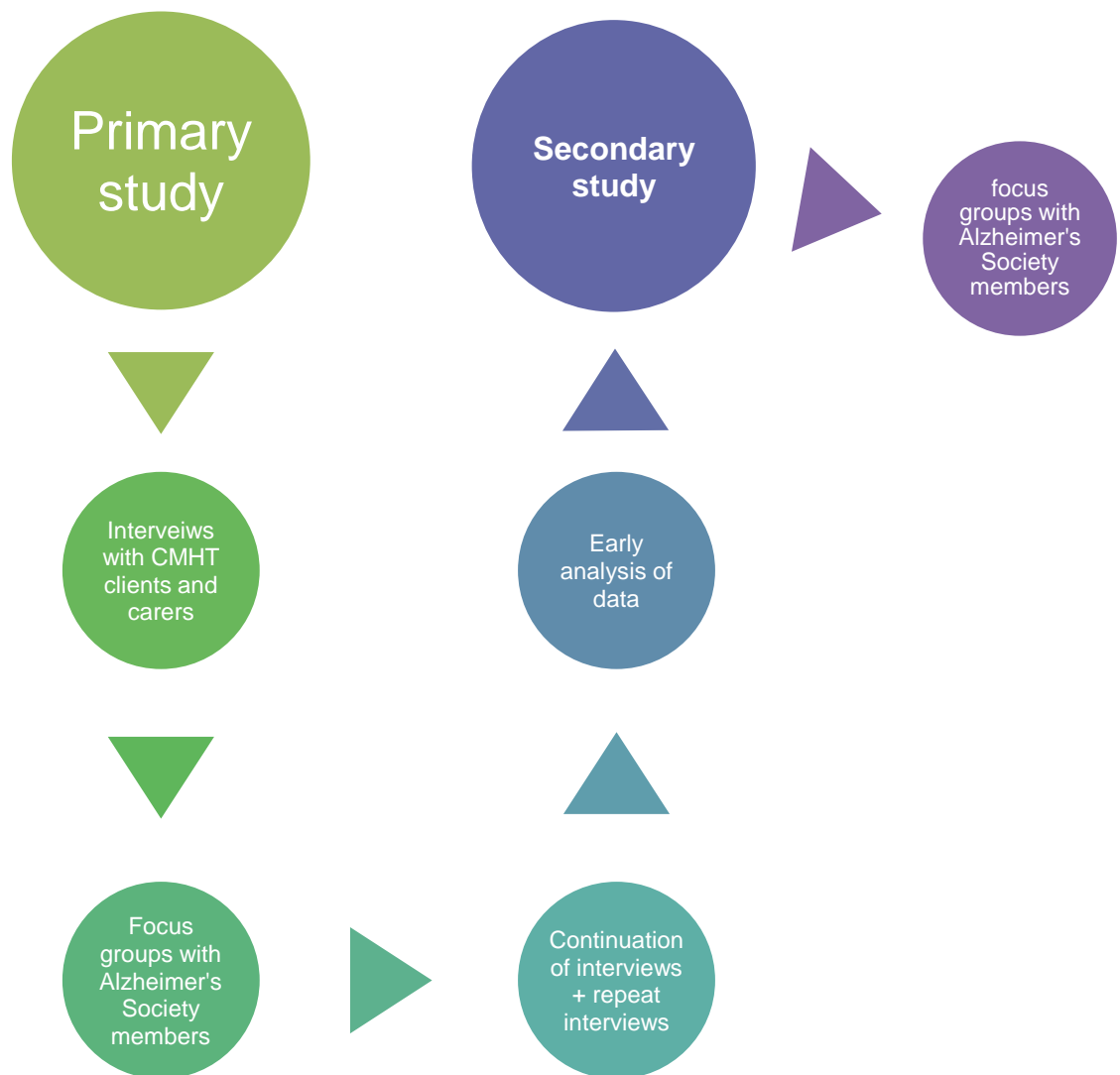
In this chapter, the methods chosen to answer the research questions in the study are presented. The method, issues and dilemmas of recruitment, data collection and analysis for the chosen participants, for both of the stages of the research will be considered in turn. Ethical considerations for both stages of the research will be presented first as these were an important issue in the methodological decisions made. Each of the research questions (stated in section 1.1. in Chapter One) are addressed in the two separate stages of the study.

### **5.1 Background to research**

It is essential to place the research in the context of where and how the data were collected, as these influenced the methods and processes of data collection in both studies. Even though the study commenced in late 2003, it took nearly twelve months to gain ethical approval, and so data collection started in 2004 and finished in 2007. The primary stage of the research was carried out in conjunction with a large London Mental Health NHS Trust, which partly funded the research from 2003 until 2005. They gave me an honorary post as a research occupational therapist within the Older Peoples Directorate from 2003 until 2007 so that I could carry out the research with the clients of this directorate.

### **5.2 Study design**

In chapter four, the choice of a qualitative and phenomenological approach in both stages of the research was discussed. As already stated, the primary research was an IPA study, where older people with dementia and their carers recruited from an NHS trust were interviewed, with focus groups being held with members of a local Alzheimer's Society branch. This primary study was then followed by a smaller secondary study where focus groups were carried out with members from two different groups from another Alzheimer's Society branch. Figure 5.1 provides an overview of the research process for both stages.



**Figure 5.1 Overview of research process**

### **5.3 Ethical considerations for primary and secondary stages of the research**

Many of the processes involved in gaining ethical approval were the same for both the primary and secondary studies, therefore they are discussed together here. The involvement of older people with dementia in this research meant that gaining informed consent had to be considered carefully, and again the principles of how consent was obtained in both stages of the research were the same, and therefore discussed here. However the procedures for both stages of the research differed because the route of access to the participants differed.

Therefore, these procedural considerations are discussed under the appropriate sections (5.4.3.2, 5.4.8.4 and 5.5.3).

Both the primary and secondary studies were scrutinised and approved by the local research ethics committees from the researcher's university, the NHS trust involved and their Research and Development (R and D) committee before commencing recruitment and data collection for both stages of the research (see appendix A). As is more clearly explained later, extracts of data from the primary stage of the research were used in the secondary stage of the research. This meant that although the secondary stage did not involve NHS patients, NHS ethical and R and D approval was required for this stage as data from NHS patients were being used.

Many of the procedures and rationale for decisions made apply to both the primary and secondary stages of the research. Giving informed consent to participate in the research was of obvious concern. As previously stated, different procedures to obtaining consent were utilised within the primary and secondary studies. However, the researcher was mindful of the ethical issues of obtaining consent from people with dementia who may have fluctuating capacity to consent to take part in research (Dewing 2002). A procedure for obtaining consent was similar to that described by Dewing (2007). Dewing (2007) describes this as process consent, as consent to participate is requested at several stages of the research. As participants in both stages were recruited by their key workers, guidance was given to these individuals about how capacity to consent was to be determined. At the beginning of the study the Mental Capacity Act had not been enacted, however this was in a draft form at the time of application for ethical clearance, so the key workers were guided to determine capacity for consent in accordance with section 3.1 of the Mental Capacity Act (HMSO 2005) (see box 5.1). This guidance was followed throughout the study.

### **Inability to make decisions**

(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

- (a) To understand the information relevant to the decision,
- (b) To retain that information,
- (c) To use or weigh that information as part of the process of making the decision, or
- (d) To communicate his decision (whether by talking, using sign language or any other means).

(2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).

(3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.

(4) The information relevant to a decision includes information about the reasonably foreseeable consequences of—

- (a) Deciding one way or another, or
- (b) Failing to make the decision.

**Box 5.1 Excerpt from the Mental Capacity Act (2005) section 3; page 2, indicating why or how someone may lack capacity to make a decision for themselves.**

#### **5.3.1 Issues of confidentiality**

Different issues relating to confidentiality were considered. Personal data about the participants were stored securely on a password protected PC. Each dyad or focus group was allotted a code, which again was stored separately, and password protected. This code was used to identify each interview or focus group recording and transcript. Transcripts were stored in a locked filing cabinet. Names of participants and places were replaced with pseudonyms throughout the study.

## **5.4 Chosen method to explore the lived experience of falls among older people with dementia and their carers – primary study**

The research question for this primary study is: What are the experiences of falls by older people with dementia and their carers? The aims of the study are stated below:

- To explore the lived experience of falls among older people with dementia and their carers
- To explore the experiential consequences of falling on the older person with dementia and the carer.

The methods chosen to answer the research question and meet the aims of the study are addressed below.

### **5.4.1 Background to this stage of the research**

As I was carrying this research out in conjunction with a large NHS Mental Health trust, I knew that I would have to consult and liaise with the relevant services during the period of my funding and contract. Various processes took place at the beginning of the study including on-going communication with the health care staff from the Older People's Mental Health Directorate. The consultation/activity was at its greatest in the first year of the research, where I attended meetings with the Falls Advisory Group for the Directorate to discuss and negotiate the focus of the research. I met with each of the consultant psychiatrists for older people and the clinical director to discuss the research aims and to obtain their support. I contacted the community mental health care teams; meeting with each of the five team leaders and where possible their teams in the Mental Health trust. I met with the local Alzheimer's' Society outreach workers to discuss the focus of the research. I also met with the chairperson of the NHS trust local research ethics committee to discuss and prepare my application for ethical approval and a member of the NHS trust Research and Development team. All of these meetings allowed me to gather information of how clients were referred and cared for. This was necessary, as there were still different procedures in place for each of the recently joined five services that made up the directorate. This then informed how I could collect the

data from the older people with dementia and carers in the most appropriate way.

Initially two members of the Older People's Mental Health directorate were involved in the primary study of the research as part of their professional development to be research active. These were one of the head occupational therapists and a head physiotherapist. Not long into the consultation stage the head occupational therapist took up another appointment elsewhere within the trust, however the head physiotherapist carried on her involvement for the primary stage of the project, including carrying out some of the interviews and also one of the focus groups. She had had no research experience at this point and so part of my role was to engage and train her in qualitative research techniques to ensure quality and consistency within this stage of the research. This will be returned to when discussing the piloting of the research.

#### **5.4.2 Research context**

Data collection for this stage of the research took place over a 20-month period, and started in 2005 and finished in 2006. At one point recruitment via the community mental health care team (CMHT) key workers was very slow and therefore I also approached a local Alzheimer's Society branch to collect data from participants. Data from the Older Peoples Directorate of the Mental Health NHS trust were collected using interviews and data were collected from the Alzheimer's Society branch using focus groups. The methods of participant recruitment and data collection are presented separately, along with the rationale for the chosen methods.

#### **5.4.3 Recruiting Participants from the Older Peoples Directorate of the Mental Health NHS Trust**

As stated in section 5.4.2, two different groups of participants were approached to take part in the research. This section addresses how service users of the Older Peoples Directorate of the Mental Health NHS trust and their carers, were identified and recruited. An early decision was made to interview older people with predominately Alzheimer's type dementia, who were service users of the

CMHTs within the London NHS trust and who had experienced a recent fall or “near fall” and their carer. Here a “near fall” was defined as “when you stop yourself from falling”. These people were to be living in the community, in their home setting with a permanent carer (ideally living in).

The decision to interview older people with predominately Alzheimer’s type dementia was made because this is the most common form of dementia and because the pre-dominant problems relate to cognitive and behavioural changes. Vascular dementia is often associated with upper motor neurone problems similar to stroke and Parkinsonism is commonly associated with Lewy Body dementia. It was considered that these individuals would have differing experiences of falling to those people with predominantly Alzheimer’s type dementia. However it should be acknowledged that approximately 30% of older people with predominantly Alzheimer’s type dementia have cerebrovascular lesions and 15 to 30% have the presence of Lewy bodies in their cerebral cortex on post mortem (Feldman and O’Brien 1999).

Purposive sampling was used to recruit and identify potential participants, and this is commonly used within qualitative research and IPA research in particular (Smith et al 2009). When this study was planned and data collection started, sample sizes in IPA studies varied between one and 48 (Brocki and Wearden 2006). However, more recently, sample sizes in IPA have become smaller in comparison to other qualitative methods (Smith and Osborn 2008), with sample sizes of between 4 and 10 for interviews being of common acceptance, to enable the researcher to explore the individual and personal accounts of participants (i.e. the idiographic) (Smith et al 2009). In this study, an initial decision was made to try to recruit participants with differing severity of dementia (determined by their Mini Mental State Examination [MMSE] score), to ascertain any differences in their experiences. However, very soon into the data collection (during the pilot interview stage) the researcher realised that this was not only unnecessary but also inappropriate for two main reasons. Firstly, that individualised accounts were appearing in the participant accounts and secondly, that a homogenous sample is usually desired within IPA research, so that there is a greater likelihood of participants sharing common experiences (Smith et al 2009). Even though the homogeneity of the sample varies from

study to study within IPA, a decision was made on completion of the pilot interviews that such stratification within the study appeared to add little to the answering of the research question and aims.

Participants were identified and recruited by their key workers from the CMHTs, who acted as gatekeepers for the study. The use of gatekeepers for recruitment of what are considered vulnerable groups of people (such as older people with dementia) is recommended within the research literature (Dewing 2007, Davies et al 2010). Therefore, the team members had to be cognisant of the study and the inclusion and exclusion criteria (please see next section). Consequently, meetings were set up with the team leaders of all five CMHTs to explain the study, and where possible attendance at team meetings was arranged, so that the study could be explained to the whole team. CMHT members were provided with an information leaflet explaining what the study was about (please see appendix B), the inclusion and exclusion criteria and also copies of a letter to give to potential participants.

Carers were recruited on the basis that they were the main person looking after the person with dementia, identified by the CMHT key worker. This included their partner or spouse, family member or friend, as it was considered that these people would have the greatest knowledge, understanding and sharing of experiences with the person with dementia that a formal carer would not. It was ideally preferred that these carers would live with the older person with dementia, however it was also considered that carers who did not live with the individual but provided daily care would be included.

Therefore, recruitment of the dyad was dependent upon both the person with dementia and the carer independently agreeing to take part in the study.

#### **5.4.3.1 Inclusion and exclusion criteria**

Inclusion and exclusion criteria were determined in relation to the aims of the study and the ethical issues appertaining to involving older people with dementia in research (Holloway and Wheeler 2010). The inclusion criteria for this group of participants were:



- People aged 65 and over, with dementia of pre-dominantly Alzheimer's type, who were patients of the Older Peoples Directorate of the Mental Health NHS Trust.
- These older people with dementia had to be living in the community with their permanent carer (e.g. partner, daughter, son, sibling or friend) or have regular and daily involvement with their carer.
- They had to have capacity to give consent to take part in the research and they also had to have a history of unsteadiness or a fall.
- Even though the diagnosis of dementia was not emphasised within the data collection stage of the study, older people with dementia who were not aware of their diagnosis of dementia were excluded from this arm of the study. It was the policy of the Older Peoples Directorate of the Mental Health NHS Trust to inform people of their diagnosis.

Other people excluded from the study were:

- Those people in long-term residential care,
- Older people with moderate or severe behavioural and / or communication problems.
- The decision was also made that any older person with dementia taking part in other research would be excluded, as there may have been some confusion between the studies and what their involvement might be.
- It was also considered that carers with cognitive or communication problems should be excluded from the research because they may have had difficulty supporting the person with dementia in expressing their falls experiences within the interviews.

People were not excluded on the grounds of English not being their first language as the NHS trust agreed that they would provide an interpreter if required. However, none of the people recruited to the study needed an interpreter present at their interview, even though English was not the first language for two of the carer participants.

#### **5.4.3.2 Procedure for obtaining consent for interviews**

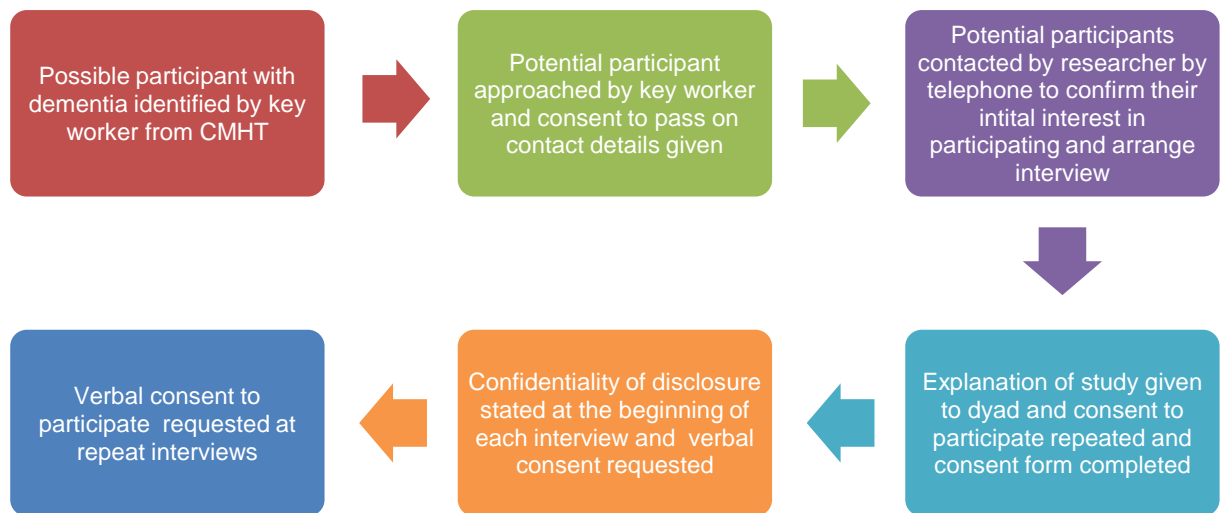
The ethical considerations for the whole study have been already discussed in section 5.3; however, the procedure for gaining consent for the interviews is

described here. In this primary stage of the research, consent to participate in the interviews was requested in three stages. Possible participants for interviews in the first stage of the research were identified by the community mental health care team (CMHT) key workers. The CMHT workers identified possible participants from their caseload, who met the study criteria and whom they considered had the capacity to give consent as already discussed in section 5.3.

The key worker approached potential participants to ask if they would be interested in participating and give permission for their details to be passed to the researcher. The researcher then contacted participants, when information about the study was given, to gain confirmation of their interest and to arrange the interview. At the beginning of the interview, information about the research was verbally repeated to both members of the dyad (person with dementia and carer) and also by the provision of a written information sheet for each participant (see appendix C). At this point participants were asked if they had any further questions about the study. The researcher reminded the participants that the interviews would be recorded and the participants' agreement to this was sought. Participants were asked again if they were willing to take part in the study and if amenable gave consent separately, with each participant witnessing the signing of the consent form for each other. Consent was obtained to access the case notes of the care-recipient for date of diagnosis, severity of dementia (often as a MMSE score) and age. Personal details of the carer were not requested.

It was decided that if any participant became restless or distressed during the interview that interviewing would stop until the participant became calmer. At this point, they would be asked if they wanted to continue or end the interview. It was also considered that if a participant left the room during the interview, the individual would be asked if they wanted to proceed, if and when they returned to the room.

In some instances participants agreed to take part in follow-up interviews. This option was included on the participant information letter, and at the interview people were asked if they were happy to participate again in the research.



**Figure 5.2 Process of consent with participants accessed via CMHTs**

Those people that agreed to take part in follow-up interviews were then asked if they were still willing to take part when contacted by telephone and before the repeat interviews commenced.

#### 5.4.3.3 The Sample

In total, thirteen people with dementia were invited and agreed to participate via their CMHT key worker. However, in two instances, when contacted by the researcher to confirm agreement of both the person with dementia and carer, the carer refused participation on behalf of the person with dementia. In both instances, the carers voluntarily stated that they considered that taking part in the research would be too upsetting for the person with dementia. The protective behaviour of family gatekeepers in this study mirrors that of other studies, where family members override the older persons' decision to participate (Davies et al 2010), or have conflicting opinion about participation, to that of the older person with dementia (Dewing 2002). Other reasons for attrition before commencing the study were further falls and subsequent injury. This happened in two other instances, where both the person with dementia and the carers were willing to take part in the study, but unfortunately the person with

dementia fell again prior to the interview taking place and was admitted to hospital with severe injuries and not expected to return home. Therefore, nine older people with mild, moderate, moderate/severe dementia of predominately Alzheimer's type and their ten carers participated in the interviews. The participants for the interviews were six women and three men experiencing dementia with two wife-carers, four husband-carers, two daughter-carers and two son carers (with one interview involving the husband and daughter). All of these participants were white European and none of the participants were in work at the time of the interviews.

All participants were invited to take part in follow-up interviews, as it was initially hoped to have a longitudinal arm to this study. Only three dyads agreed to be interviewed at approximately six monthly intervals. Once again, attrition had an impact on the follow-up interviews. One couple was interviewed on three separate occasions before moving out of the area. The other two dyads were interviewed twice. In one instance, the person with dementia had a stroke, was admitted to hospital and then transferred to residential care. In the other instance the person with dementia died suddenly at home before the third interview could take place. Chatfield et al (2004) identified that attrition in longitudinal studies was related to being older and having cognitive impairment, and indeed the two participants who died during the study were older but had mild to moderate dementia at the time of entering the study. (Please see table 5.1 for participant information for the interview participants).

#### **5.4.4 Method of Data Collection from Participants from the Older Peoples Directorate of the Mental Health NHS Trust**

Data were collected from the participants recruited via the CMHT using semi-structured interviews. Ideally, each member of the dyad took part in both a one to one and a joint interview with the researcher. The rationale for semi-structured interviews will be first discussed, followed by a discussion of the method (one to one and joint interviews) and then the process of data collection.

**Table 5.1 Demographic information for interview participants**

*(NB all names are pseudonyms)*

Person experiencing Dementia	Severity of Dementia *(MMSE score)	Age	Ethnicity	Carer	Relationship	Age of carer	Ethnicity
George	Mild (28)	84	White/UK	Vicki	Daughter	40-50	White/UK
Tony	Mild (28)	76	White/UK	Susan	Spouse	60+	White/UK
Wendy	Moderate (?)	84	White/UK	Bernard	Spouse	80+	White/ Swiss
Vera	Moderate /severe (14)	87	White/UK	Paul	Son	60+	White/UK
Rita	Moderate /severe (12)	84	White/UK	Neil	Son	50+	White/UK
Sheila	Mild/ moderate (23)	82	White/UK	Patrick	Spouse	82+	White/UK
Bob	Moderate /severe (14)	87	White/ Irish	Norma	Spouse	80+	White/Irish
Eileen	Mild/ Moderate (23)	79	White/UK	Karl	Spouse	85	White/ Polish
Bridget	Mild/ moderate (23)	83	White /Irish	Harry and Alison	Spouse And Daughter	80+	White/Irish And White/UK

IPA research, like other phenomenological research methods, commonly uses the semi-structured interview to explore the life experiences of the chosen participants. Kvale and Brinkmann (2009) state “Conversation is the basic mode of human interaction” (p.xvii) and therefore if one wants to understand another person’s lifeworld one should talk to them and listen to their stories. Indeed

Phinney (2006) suggests that most research exploring the experiences of people with dementia are based upon loosely structured interviews or conversations. Semi-structured interviews are said to provide this loose structure and perceived to be the middle ground “between consistency and flexibility” (Langdrige 2007, p.65), where a topic guide is used to inform the conversation, but not to control it, so that unforeseen topics can emerge.

#### **5.4.4.1 Planning the interviews**

When involving older people with dementia in non-therapeutic research such as this study, it was important to ensure non-maleficence (Holloway and Wheeler 2010). Therefore, various decisions were made to minimise any anxiety or burden to both the person with dementia and carer. These related to where the interviews would take place and how they would occur.

The decision to interview participants in their own homes was made for several reasons. It was considered that this would give them some control within the data collection and that they would feel more secure, comfortable and better orientated in the familiar environment of their own home. Other issues such as dealing with potential fatigue and discomfort could be more easily addressed in the home environment and transport difficulties for those potential participants with mobility problems could be avoided. These decisions mirror those made by Davies et al (2010), in their study of frail older people, and reflect recommendations, to provide a safe context for data collection with older people with dementia made by Pratt (2002).

How the interviews would take place, was also deliberated. It was decided to use a format similar to that used in practice within the NHS trust and the researcher’s own clinical practice. This entailed carrying out both individual interviews with each member of the dyad, followed by a joint interview with both the older person with dementia and the carer. The rationale for carrying out individual interviews with both the person with dementia and the carer, as well as a joint interview was that from a life-world perspective these individuals would have differing experiences of the same event(s), as well as collaborative

accounts. Therefore, the aim of the separate and joint interviews was not to privilege one account over another, neither was it to seek verification or 'truth'.

#### 5.4.4.2 Issues of confidentiality

Issues of comfort and confidentiality also needed to be considered when carrying out the interviews. As the individual and joint interviews for the dyad took place during one appointment, it was important to minimise fatigue for the participants. Therefore, it was planned that interviews should last approximately 30 minutes each, with a break in between these for the participants.

Whereas individual interviewing allows the participants to voice their own understanding and account of an experience such as their fall, the researcher was also aware that they could disclose information that they did not wish the other member of the dyad to know. Consequently, the researcher reminded participants at the beginning of each interview that they had the right to disclose only what they wished and that anything they discussed within the interview would be kept confidential to the research team. The aim of the joint interview was slightly different in that it allowed for a collaborative account of the falls experience, where the memory of one participant (usually the person with dementia) may have been prompted by the other member of the dyad, or where the experience may have been elaborated upon by either participant. However, the aim of the joint interview was for a co-construction of the falls experience and not verification of truth or facts by the carer.

Participants were also given the choice of whether they wanted to be interviewed individually and jointly. In two instances, carers declined taking part in an individual interview and reasons for this were environmental and concern for the person with dementia. For example, one person with dementia had mobility problems and there was nowhere else for the researcher and carer to sit for the individual interview. In another instance, it would seem that the carer was concerned at leaving the person with dementia unattended, during his or her own interview.

Other issues were of concern to the researcher and her clinical colleague. As experienced practitioners, they were unfortunately aware of the possibility of

older abuse amongst the participants. They therefore knew that if anything untoward was disclosed to them, that they would have to follow local policy to safeguard the individual concerned. Even though the researcher and physiotherapy colleague were not present in their capacity as the individuals' allocated health professional, they were still registrants with the Health Professions Council (HPC), and were bound by their professional code of ethics and professional conduct (HPC 2008). Therefore, this was made clear on the information letters given to both members of the dyad before the interview (see appendix C).

The head physiotherapist who carried out some of the interviews in the primary study was also seeing clients within the NHS trust in her professional capacity. It was agreed that she would only interview people who lived outside of her catchment area and therefore were not known to her in her capacity as a physiotherapist.

#### **5.4.4.3 How the interviews were carried out**

It was considered important that the interviews were arranged at the best time to suit the person with dementia and the carer, so that once again, the dyad had some control over the process and that they were not inconvenienced. The interview date and time were agreed by telephone, during the initial contact made by the researcher (see figure 5.2). Even though there was a brief explanation about the study on the initial consent form given to the participant by the key worker, the purpose of the study was given again and the approximate length of time required for the interviews. At this point, they were asked to identify a specific fall that they might want to discuss at the interview. This could have been their most recent fall or one they both identified that they wished to discuss. As the only contact the researcher or physiotherapy colleague had had with the dyad prior to the interview was by telephone, it was important to establish rapport with the dyad before starting the data collection. Clarke and Keady (2002) describe the use of a "lead-in" phase to establish rapport when interviewing people with dementia to reduce any anxiety or concerns. Therefore, the interview was always preceded by both members of



the dyad being seen together, with a general informal discussion (about the weather, garden, room) and an acceptance of offered cups of coffee before more complete information about the study and written consent were given. The fall that the dyad had decided to discuss was also confirmed at this point.

Permission to use the audio recorder was also asked at this point, and it was explained that by using this, the interviewer could concentrate on what the participant had to say. The recorder was left on during the whole of the interview and participants quickly forgot that this was being used. None of the participants asked for the recorder not to be used or turned off during the interview.

The same topic guide was used for the individual and joint interviews, and although this could be considered as repetitive, it allowed for further elaboration and collaboration within the joint interview (see appendix D). The use of general and more descriptive questions at the beginning of the interview were used to help the participants feel less anxious about talking. These questions included asking them their age, how long they had lived in their home, and how long they had been together. These quickly changed to prefixing these questions with “when” rather than “how long”, as these questions were easier for the majority of people with dementia to answer.

At the beginning of each interview, participants were asked to describe what they thought a fall was. This was asked in order to orientate the rest of the interview, as there are many perceptions and definitions of what a fall is (Hauer et al 2006). The main topics that the researcher wanted to explore were what participants were doing before their fall, the falls experience itself and the consequences and experiences following the fall. The topic guide in appendix D presents the overall topic areas and possible questions and prompts. It was hoped that these probes or prompts, or questioning by the interviewer would not all be necessary and that the initial questions would be open enough to facilitate the participant to talk (Smith et al 2009). However the researcher was also aware that for some participants more questioning or prompting would be required, because of concentration problems, short term memory or language difficulties and this was also observed by Kirkevold and Bergland (2007). It was

considered that some people with dementia might deny or not remember that they had had experienced a fall (even though this had been identified at the beginning of the interview); therefore, the interviewer would ask them their opinion of other people's falls experiences. This happened with one participant but in this instance, the participant then went on to discuss his/her own fall.

As already stated, the participants were reminded that they should only discuss what they wished to in the interviews, including the joint interview. This was aided by the use of open-ended questions or minimal prompts by the interviewer so that the participants mainly instigated the discussion.

At the end of the interview, the participants were thanked for their contribution to the research and given either a small gift of either some chocolates or biscuits as a thank you. In the same way that it was important to spend some time talking to the participants before the interview, it was also considered important to spend some time talking informally afterwards. A thank you card was also sent to the dyad after the interview.

#### **5.4.4.4 The pilot interviews**

As previously discussed, a physiotherapy colleague contributed to the data collection in this stage of the research. Even though she was an experienced practitioner and had expertise in interviewing people with dementia as part of her clinical practice, she had no research experience. My previous research experience was in quantitative research and so I had minimal qualitative research interviewing experience as well. It was therefore deemed important to prepare for and "rehearse" carrying out research interviews. Therefore, the two interviewers "interviewed" each other to rehearse the format and practice using the recording equipment, as well as trying to ensure that the style of interviewing was appropriate to encourage rich description and discussion by participants.

The decision was made that the first four interviews with the dyads would be pilot interviews, involving both the researcher and her physiotherapy colleague, with one observing the other during the interview. The aim of the pilot interviews was to observe the content and process of the interview and the technique of

the interviewer (Robson 2002). This was explained to the participants before the interview so that they could choose whether they wanted this to take place or not. It was also clarified that the observer was observing the person who was interviewing them and not the participants themselves.

As a result of the pilot interviews, some issues were confirmed and others needed slight modification. The content of the topic guide seemed to be appropriate, however as already stated some of the warm up questions needed a minor modification; so for example, if we had asked “*how long*” or “*how old*”, we replaced this with “*when* did you come to this house” and “*when* were you born”. These questions were not always necessary because of the general discussion before the interview. However, it was felt that it was quite useful to still ask for a definition or description of a fall at the beginning of each individual interview to “set the scene”. We also became more confident in allowing the participants to “travel and wander” a little more in their accounts, even if this seemed to be going “off topic” (Kvale and Brinkmann 2009). Other aspects of the process, such as not hurrying to start the interview and better positioning of the microphone nearer to the person with dementia were identified. Initially we gave the participants the choice of who would be interviewed first. However after one of the pilot interviews, the decision was made that if the participants did not have a preference, it was preferable to interview the person with dementia first. This gave them more of a rest period between their individual and the joint interview. It was also more difficult sometimes to bracket off what the carer had said in their interview, with a temptation to provide prompts to the person with dementia especially when they struggled to share their perspectives of events, which the carer had already shared with the interviewer.

The use of the joint interview was reinforced, as it was observed that by using the same topic guide, not only was the carer able to prompt and facilitate the memory of the person with dementia, but that the accounts of both were elaborated upon and different meanings and experiences were expressed.

As a consequence of the pilot interviews it was concluded that the topic guide provided appropriate prompts for the interviews, and that these four interviews could be included in the data analysis, which is acceptable in qualitative

research (Holloway 2008). It was also reinforced that the planned procedure could be followed, with a preference for interviewing the person with dementia first.

#### **5.4.5 Health care practitioner as researcher**

For both interviewers, maintaining the role of researcher and not occupational therapist and physiotherapist was challenging. The participants were aware of our professions, from our introductions, the information sheet provided to them and our identity badges, which the NHS trust obliged us to wear. So, in some instances professional advice was asked for. When this occurred the request was made that these questions could be repeated after the interview had finished. From a professional perspective, these participants were not our clients. One of the stipulations of both the university and NHS research ethics committees was that any concerns should be fed back to the key worker, and this was the process followed in these circumstances, whilst maintaining the confidentiality within the interview.

Holloway and Wheeler (2010) discuss the dual roles that health care professionals have when carrying out research. We were both experienced practitioners, used to interviewing our service users; however, we were fully aware of the differences in the nature and the reason for interviewing. As practitioners, we were used to asking specific questions to formulate and assess the service users experience and needs, however in a research interview we needed to ensure we facilitated the participants to tell us about their experiences so we could listen and gain an understanding of their lifeworld (Holloway and Wheeler 2010). Certainly as part of the pilot interviews, we were both aware that we were very tempted to ask leading questions so that we could find a reason or answer for the participants' falls. The strategies we put into place were verbal debriefing with each other and reflecting on our roles immediately following the interview. We also both kept a reflective journal, which enabled us to not only reflect on how the interview had proceeded but also to "bracket" our experiences as far as possible from one interview to the next.

#### **5.4.6 Researching in the real (and changing) world**

As already discussed in section 5.4.2, the study had some recruitment and attrition difficulties that are not uncommon in researching with older people. Recruitment to the study was slow and a year after data collection had started, six dyads had been interviewed, four potential participants were lost to attrition, and no more potential participants had been identified. Monthly phone calls and reminder letters to key workers, as well as attendance at team meetings had not provided any potential participants. During this time, the NHS trust went through a period of budgetary restraint which impacted upon the Older Peoples Mental Health service. Indeed two of the CMHTS changed the focus of their service; concentrating on clients with more severe mental health problems rather than on people with dementia with similar characteristics as the inclusion criteria for the study. Such recruitment difficulties, including reliance upon key workers not involved in the study as gatekeepers to potential participants, organisational restructuring and carers as gatekeepers to participation mirror those experienced by Miller et al (2003).

Therefore, a different recruitment strategy was explored, which was to approach service users of a local Alzheimer's Society branch. Ironically, after gaining the interest and approval in principle from the Alzheimer's Society branch and whilst waiting for ethical approval for amendment to the study, three more dyads agreed to participate and were interviewed.

#### **5.4.7 Recruitment of participants from local Alzheimer's Society branch**

The manager from a local Alzheimer's Society was approached to ascertain if their members would be interested in taking part in the study. The branch was identified because the researcher became aware that people with dementia with a history of falls were being referred to this, their local branch of the Alzheimer's Society after assessment rather than being seen by the CMHT. This branch had approximately 30 members who regularly attended a support group run jointly for both people with dementia and their carers. Discussion with the manager about the inclusion and exclusion criteria for the study revealed that the members of this support group would meet the criteria for the study. However

the manager requested that the term 'memory problems' be used as it appeared that many of the people attending the group were either not aware of their diagnosis of dementia, or had not been formally diagnosed. Therefore, the group run by the Alzheimer's Society was framed as for people with "memory problems" and their partners/family. Even though the membership of the group was not restricted to those people over the age of 65, the people attending the group at the time were all 65 years and over at the time of the study. Ethical approval had previously been given for the running of focus groups with service users of voluntary organisations such as the Alzheimer's Society. However, an amendment was requested acknowledging the issue of knowledge of dementia by participants. The term "memory problems" was subsequently used in all of the information leaflets, consent letters and topic guide and discussion with this group. Such decisions are not uncommon in dementia research, as discussed by Bartlett and Martin (2002) and Bartlett and O'Connor (2010).

#### **5.4.8 Method of data collection for participants from local Alzheimer's Society branch**

Even though the local branch manager considered that their members would be interested in participating in the research, she suggested that the preferred method of data collection would be as a group during their normal meeting. The service user group was asked by the local branch manager (who led this group) if they would be interested in taking part in the research at one of their meetings.

Using focus group methodology was an attractive proposition, as it is considered an advantageous method of data collection by some researchers (Cheston et al 2000, Bamford and Bruce 2000, Harmer and Orrell 2008) and these advantages are discussed in sections 5.4.8.1 and 5.4.8.3. The data collection took place at the branch group in the following month. It was arranged that the focus groups would take place towards the end of the usual meeting, so that those individuals that did not want to participate in the study would still benefit from their monthly group, but would not stay for the study. As members travelled to and from the group independently they were able to leave if they so

wished. The participant information sheet was circulated prior to the session identified for data collection. However, potential participants were also given a copy of the information sheet and a consent letter to complete prior to the study taking place.

#### **5.4.8.1 The use of focus groups**

As permission had been granted to approach these participants as a group, the most obvious method of data collection was the use of focus groups. There were many advantages to using this method. Firstly, the participants were a naturally occurring group, familiar with group activity and discussion with each other. Secondly, Wilkinson (2008) suggests that participants can be prompted to share their experiences, understandings and opinions in a more comprehensive way when focus groups are carried out. It is perceived that similarly to joint interviews, co-participants in focus groups can be supportive and also facilitate elaboration of accounts, or trigger memories through the discussion of their own experiences (Tomkins and Eatough 2010). It was also considered that the partner/family member also attending the focus group would also support and encourage the memories and accounts of the people with memory problems. However it was also acknowledged that the carer's contributions would have to be managed by the focus group facilitator to ensure that the voices of the people with memory problems were not overwhelmed.

#### **5.4.8.2 The role of focus groups in IPA**

Focus groups have been used as a method of data collection in IPA research (for example Dunn and Quayle 2001, Flowers et al 2003, de Visser and Smith 2007, Palmer et al 2010, Tomkins and Eatough 2010). However, their use is currently debated as there is concern that these limit the opportunity to gather idiographic data from group interviews, with less sharing of personal experiences and more socially desirable responses (Smith et al 2009). Palmer et al (2010) suggest that focus groups do present the opportunity to encourage sharing of experiences and accounts, especially in a naturally occurring group

that exists because of shared experiences and understandings, such as the Alzheimer's Society group.

#### **5.4.8.3 The role of focus groups with people with dementia or memory problems**

Therapeutic group work has been well established with people with dementia and as a consequence focus groups have been used as a method of data collection with this client group (Bamford and Bruce 2000, Cheston et al 2003, Mills 2003). Owen (2001) suggests that focus groups encourage participation of vulnerable clients who might be reluctant or hesitant to be singled out for interview on their own. Bamford and Bruce (2000) recommend the use of pre-existing groups, with the focus group being held in a familiar setting, such as the usual group venue. Whereas some researchers have carried out focus groups and one to one interviews with carers and staff in conjunction with focus groups with more frail older people (Reed et al 2008), only Zarit et al (2004) reported holding groups for people with dementia or memory problems and carers together. However Zarit et al (2004) ran these groups as a means of intervention, providing a memory club for people with dementia and their carers to empower both members of the dyad and to strengthen the dyadic relationships and understanding, and not as a focus group and a means of data collection in research.

#### **5.4.8.4 Procedure for obtaining consent for focus group participation**

In line with the Mental Capacity Act (2005), it was assumed that these participants had capacity to give consent. (The Alzheimer's Society worker was also aware of the issue of determinant of capacity for consent in the study). Potential participants were made aware of the study at their previous meeting and were given a participant information sheet (see appendix E). Before the data collection commenced people were advised of the study and asked if they would be happy to take part. Immediately before the data collection took place the participants were asked if they were happy to take part and at this stage completed and signed a consent form. As individuals were not recruited via their



health care provider, it was considered inappropriate to ask for their consent to access their medical records or request an MMSE score, as had been carried out for the service users of the CMHTs.

#### 5.4.8.5 Running the groups and collecting the data

Three concurrent focus groups were held at the usual group venue, involving 21 members of a local Alzheimer’s Society branch group session. These involved nine people with memory problems and 12 carers (see table 5.2 for details). The focus groups were facilitated by the researcher, her physiotherapy colleague, and another university colleague, experienced in research.

**Table 5.2 Details for focus group participants (*actual names replaced with pseudonyms*)**

<b>Focus group Participants</b>		
<b>Older Person with memory problems</b>	<b>Carer</b>	<b>Relationship</b>
<b><i>Focus group 1</i></b> David, Andrew, Bill, Edward	Kathryn, Diana, Christine	Spouses
<b><i>Focus group 2</i></b> Eamonn, Verity, Bill	Maggie, Sally, Marion, Derek,	Spouses ( <i>Maggie -daughter</i> )
<b><i>Focus group 3</i></b> Sarah, Rena	Joyce, Geoff, Peter, Deidre, Joe	Spouses

The researcher introduced the study to the whole group and then the participants split into three groups. As the group members were sitting at three separate tables for their group meeting these tables of people formed the focus groups. This meant that participants were sitting with their partner or family member and people that they already knew. Participants were able to ask questions about the study and were asked if the group discussion could be audio-recorded. They were also advised about the confidentiality of the

discussion between group members and their right to withdraw or not participate.

All the focus group facilitators followed the same protocol, and a topic guide similar to that used in the interviews informed the discussion (see appendix F). The groups lasted approximately 45 minutes and each group was audio-recorded. The facilitators tried to ensure that no one person dominated the discussion and that people did not “cross-talk”. At the end of the group, the participants were thanked for their participation, reminded of the need for confidentiality and were each given some chocolates as a thank you gift. Thank you cards were then sent to each participant or couple via the key worker in appreciation of their participation. The research team met after the focus groups to debrief and reflect on the method of data collection.

#### **5.4.9 Analysis of interview and focus group data**

All of the interviews and focus group recordings were transcribed verbatim and the transcripts of the joint and focus group interviews analysed so that the individual accounts could be identified (see appendix I). All names were replaced with pseudonyms.

The method of data analysis for this stage of the study was considered at great length. At the end of data collection, there were 33 transcripts from the interviews and three transcripts from the focus groups. It was therefore important to do justice to the accounts of the people with dementia, or memory problems and carers who had been interviewed. The aim was to carry out a “thick” interpretation of participants’ accounts so that both the unique and the shared perspectives were communicated, an aim which Osborn and Smith (2008) consider of particular relevance where the topic under scrutiny is under-researched, multifaceted and contextual.

As a relatively new research method IPA has developed since its inception, and since these data were collected. The use of fewer cases is now recommended to allow for a deeper analysis of the data. However Smith et al (2009) suggest that a study with larger numbers of cases might need to use a pragmatic

approach to data analysis, as they state that the method of data analysis is not prescriptive. Ultimately the data were analysed in 3 different phases with early analysis occurring in 2006/7 and the final analysis taking place in 2009/10.

At the time of the initial phase of analysis, preliminary findings were presented at the IPA annual conference (Surrey, 2006) and the audience asked for their opinion of how the transcripts from the people with dementia, carers and joint interviews should be analysed (the focus group interviews had not been carried out at this stage). Interestingly there were two different suggestions: one suggestion was to analyse the data as three different data sets and the other suggestion was to analyse the data from all the interviews as one data set (Virginia Eatough, Michael Larkin, Jonathan Smith, personal communication, IPA conference, September 2006).

Initially the data were analysed as three different data sets. The analysis started with the transcripts from the people with dementia and the first choice of analysis was to develop higher level (or major) themes for each of the first three transcripts from this data set using the process described in box 5.2, to inform the analysis of subsequent transcripts. However, it was felt that this did not enable a sufficient bracketing of previous cases when analysing the subsequent ones as recommended (Smith et al 2009).

The decision was then made to re-analyse the data by attending to each transcript and setting it aside before moving on to the next transcript and analysing this independently of the previous one. In an attempt to bracket off the previous case before moving on to the next one a reflexive diary was kept, with thoughts about the analysis I had carried out recorded and reflected upon, as discussed by Finlay (2003). My physiotherapy colleague was not involved in the data analysis.

1. Listen to the interview
2. Read and re-read to become familiar with the transcript
3. Identify meaningful elements, including paraphrasing of text, own thoughts, use of language etc.
4. Identify emerging patterns or themes
5. Form a preliminary list of themes
6. Cluster similar themes but keep close to transcript with identifiable quotations
7. Develop higher level/major themes from clusters

(Smith and Osborn 2008)

### **Box 5.2 Suggested steps for analysis of the case in IPA**

At this early stage of data analysis, more descriptive rather than interpretative themes were generated and provided the content for the focus groups carried out in the secondary study in this research (Please see section 5.5)

The analysis was carried out with all three data sets and an attempt was made to combine the higher level themes from all three data sets to provide one single set of higher level themes. At this point it was perceived that the individual accounts and experiences emerged from the data, whilst the dyadic relationship between the people with dementia and the carers did not. The decision was made to analyse the data again, this time treating all the transcripts from each dyad as one data item. However, in this instance the different accounts within the analysis were made apparent by colour coding the transcripts (blue for people with dementia and red for carers). This meant that where there were co-constructed accounts, convergence and divergence within the data, these could more easily be identified.

The method of analysis finally decided upon in 2009-10 was that advocated by Smith et al (2009) and described by Alexander and Clare (2004), who suggested that emergent themes could be identified from each transcript so that patterns and connections could be looked for at data set level. However, it was important to ensure that the analysis of the group was still illustrated by

idiographic quotations so that the individuals within the study were adequately portrayed. Smith et al (2009) also suggest that measuring recurrence of themes across cases is important in establishing higher level themes. Recurrence in this instance, means that the themes occur in a third, half, or all interviews. Therefore, recurrence of higher level and subthemes were recorded in tables (see findings chapter). When determining the higher level themes, Smith et al's (2009) recommendation for the use of broad higher level themes was followed as this allowed for exploration of convergence, divergence, commonality and contradiction between cases.

#### **5.4.9.1 Analysing follow-up interviews**

Other decisions about handling the follow-up interview data had to be made, as there was no precedent within the IPA literature at the time. Only three dyads agreed to be interviewed again. One dyad was interviewed three times before moving out of the area, and the remaining two dyads could only be interviewed on two occasions because of participants' ill health. It was then decided to follow the advice of Flowers (2008) who suggested that in these instances follow-up interviews are best combined with the previous interview transcripts into one data item to keep some consistency within the project. Extracts from follow-up interviews within the findings were identified, again as suggested by Flowers (2008).

#### **5.4.9.2 Analysing focus group data**

As already stated, there has been some contention within the IPA literature that the subjective experience of participants cannot be fully explored using focus groups. However, on analysis of the data, (using a similar method to the interview data), similarly to de Visser and Smith (2007), the themes that emerged from the focus group data were similar to those arising from the interview data. Indeed, where some novel themes emerged from the focus group data the interview data were returned to, in the iterative way expected within IPA (Smith et al 2009) and these themes were found to be present in some of these transcripts. Therefore, like de Visser and Smith (2007) and

Flowers et al (2003) the focus group data were integrated with the interview data, with each focus group transcript being treated as one data item. Once again, where focus group participant accounts have been used to support/illustrate findings, these have been indicated.

#### **5.4.10 Procedures to enhance the quality of the research**

Procedures were put in place to ensure the quality of the research. Validity of qualitative research is much debated, especially in hermeneutic phenomenological research where the study focuses on the researcher's interpretations of the subjective experiences of individual participants (Smith et al 2009). However, some guidance has been produced (Elliott et al 1999, Yardley 2008, Smith 2011), and the following procedures took place. With participants' permission, initial interviews carried out by the author and her physiotherapy colleague within the NHS trust, were observed and feedback given to enhance the rigour of the data collection without losing the flexible essence of in-depth interviewing. The first transcripts were independently analysed by the researcher's first PhD supervisor who is experienced in IPA research. The clustering of emerging themes was also discussed to consider and corroborate the analysis and interpretation. Data have been stored and recorded in such a way that an audit trail through the analysis is possible (see appendices I,J,K,L).

It was decided not to use member checking (or participant validation) as this is debated within qualitative research, especially interpretative research (Ashworth 1993, Langdrige 2007). Meyrick (2006) suggests that returning the transcripts or analysis back to participants, places higher value on their perception of themselves than the researcher's interpretation of the data. Other factors that were considered were that participants would not necessarily recognise the interpreted themes presented to them (Holloway 2008, Yardley 2008) or may have not remembered what they had said if presented with the transcripts, or not remembered the context and meaning attributed to the experience at the time of the data collection (Sandelowski 2002, Holloway and Wheeler 2010).

### **5.4.11 Summary**

In this section, the methods of data collection have been presented and justified. Sampling procedures for both the interviews and focus groups have been discussed. Choices of data collection methods were informed by the chosen method, IPA and in response to the needs of the participant groups. It was important to ensure that the wellbeing, rights and safety of the people with dementia in the study were upheld, especially as they would not directly reap any benefit from participation. Therefore, in the absence of evidence to support suitable methods of data collection to appropriately answer the research question and aims, some decisions appertaining to data collection were made to maintain dignity, feelings of security and ideally to facilitate the voices and experiences of people with dementia and memory problems to be heard.

## **5.5 Chosen method to answer Research Question Two**

The research question for this secondary stage of the research study is: “How do older people with dementia and carers interpret and elaborate upon the summarised falls experiences of others?” The aims of this secondary stage of the study are provided in section 1.1 in Chapter One.

### **5.5.1 Background to secondary stage**

In this secondary stage of the research, it was decided to approach a different group of older people with dementia and carers to participate in focus groups. Therefore, a different Alzheimer’s Society branch was approached to see if they would participate. These focus groups took place in late 2007. The method of recruitment and data collection are described below. As already discussed in Chapter Four (section 4.4.1), the use of triangulation within a contextualist approach aims for a more rounded or multi-layered understanding of experience, rather than convergence between studies (Yardley 2000, Madill et al 2000). Therefore it could be said that the data collection in this secondary study provides a ‘softer’ elaborative triangulation with the primary study findings.

### 5.5.2 Recruitment

For this stage of the research, the consideration of the perspectives of other older people with dementia and carers on the experiences of falling was an attractive prospect. As already discussed in section 5.5.1, the objective of this phase was to uncover and gain further illumination of the falls experience. It was therefore important to recruit potential participants with similar characteristics as those participants in stage one of the research. After running the focus groups in the primary stage of the research it was decided to use focus groups to collect the data and to recruit from local branches of the Alzheimer's Society once more. Reflection and critique of the involvement of older people with dementia (or memory problems) and carers in the same group, led to the decision to try and find existing groups, which were run separately for people with dementia and carers. Even though there were several carers groups running in South East England at the time (2007), there were very few groups being run for people with dementia. Indeed, it was only possible to identify one group in London that was run for people with dementia at that time. The same local branch of the Alzheimer's Society also ran a carers group and therefore the branch manager was approached for their permission to ask the members of these two groups to participate in the second stage of the research.

#### **Inclusion Criteria**

1. Clients with dementia of pre-dominantly Alzheimer's type over the age of 65
2. Clients will be living in the community with their permanent carer (e.g. partner, daughter, son, sibling or friend).
3. Clients will have a history of unsteadiness or a fall.

#### **Exclusion Criteria:**

1. Clients or carers who are not aware of the diagnosis of dementia.
2. Clients in long term residential care.
3. Clients with moderate / severe behavioural and / or communication problems.
4. Clients currently involved in other research.
5. Carers with cognitive impairment or severe communication problems

### **Box 5.3 Inclusion and exclusion criteria for stage two**



### 5.5.3 Ethical procedure for focus groups in secondary stage of research

A request was made to the university and NHS research ethics committees and NHS R and D committee for a minor amendment to the study to reflect a change in participant information letters, the sample population and the process of the data collection (see appendix A).

Consent was gained through a similar process as that described for the local Alzheimer's Society branch in the primary study. The branch manager was sent a letter explaining the study and the criteria for inclusion and gave permission in principle for the branch members to be approached. The outreach worker who facilitated both groups asked if the members would be willing to participate a few weeks before the session for data collection and the members were given information about the study. These information sheets were given out again before the data collection when written consent was obtained (see appendix G). It was considered that participants in both groups would have capacity to give consent. The people with dementia had been recently diagnosed and were living in their own homes at the time of the study. Consent was requested in two stages, once a few weeks before the arranged date for data collection and then after more detailed information about the study was verbally given and questions answered before data collection took place.

Participants were also asked for their permission for their discussion to be audio-recorded and advised that anything said within the focus group was to be confidential to the group members and the researcher.

### 5.5.4 The Sample

The group that ran for people with dementia had been specifically set up a few months previously for those older people who had been newly diagnosed with dementia, and so all of these members had been diagnosed within the previous year at the time the study took place.

No one in the carers' group was related to, or associated with, the members of the early dementia group. None of these people were connected in any way to participants from stage one of the research. Most of the members of the carers

group cared for spouses who had more severe dementia. Therefore, the profile of their care-recipient was different not only from that of the people in the early dementia group, but also the people with dementia in the primary study.

In total seven people (two women and five men) with a recent diagnosis of dementia initially agreed to participate in one focus group and all of these members had been diagnosed within the previous year at the time the study took place. However one woman left the group as it started and did not return, and the other woman did not want to sign the consent form but remained in the group, so her contributions have been excluded. There were seven carers who participated in a second focus group. (See table 5.3 for participant information). All of the people with dementia were over 65 years, with all except one carer, aged over 65. One carer (Christopher) had recently started caring for his mother and he was in his early forties.

**Table 5.3 Demographic information for secondary study participants**  
*(all names have been replaced with pseudonyms)*

People with Dementia Group		Carers' group	
Alan	Single, lived alone	Christopher	Single, lived with and cared for mother
Keith	Single, lived alone	Daniel	Husband carer - wife living in residential care
Trevor	Lived with wife	Felicity	Previously a carer, now widowed
Martin	Lived with wife	Mary	Previously a carer, now widowed
Stephen	Lived with wife	Iris	Wife carer
		Fiona	Wife carer
		Liz	Wife carer

### **5.5.5 Recruitment of participants**

As stated in the previous sections (5.5.3 and 5.5.4), participants were recruited via their Alzheimer's Society outreach worker and none of these were related to other participants in either the primary or secondary stages of the research.

### **5.5.6 Method of data collection for stage two**

Using focus groups as a method of data collection is not uncommon when researching with older people with dementia, or carers (Cheston et al 2000). As recommended by Bamford and Bruce (2000), the use of pre-existing groups for data collection, with these being held in their usual and familiar setting, facilitates participants to share their accounts, opinions and experiences. Another reason for not combining the two groups of participants was that their experiences of dementia seemed to be different. The carers mostly had experience of looking after someone with more severe dementia than that experienced by those people with a recent diagnosis. It was therefore decided that even though the carers or people with dementia may be able to share experiences and accounts within their own naturally occurring groups, they might not have been able to do this if the two existing groups of participants were combined for the research.

The objective for this stage of the research was to present these participants with early emerging and more descriptive data as verbatim and summarised quotations using stimulus cards, from the primary study, to consider if these resonated with their own experience. It was also hoped that these participants might be able to elaborate upon these themes and reveal more of the falls experiences for people with dementia and carers in order to gain a greater insight of their life-worlds.

#### **5.5.6.1 Preparation of stimulus cards**

The content of the stimulus cards for this stage were based on early analysis of the IPA data, at what Smith et al (2009) describes as the initial noting stage. This free textual analysis resulted in more descriptive data, which mainly

followed the topic guide from the primary study. Short quotations and summarised narratives were used, where there were several similar quotations from the primary study participants.

The decision to provide descriptive themes close to the topic guide from the primary study participants was made to ideally follow a similar format as in the previous focus groups. However the function of the stimulus cards was not only to provide memory prompts (as already discussed) and to stimulate discussion, but also to do as Bamford and Bruce (2000, p146) suggested – “to extend the discussion beyond personal experiences”. The use of short quotations, or linguistic comments (Smith et al 2009) involved the use of metaphors such as “time is a great healer” as well as more factual observations such as “having a urine infection”. It was hoped that these verbatim and summarised quotations would provide a richer and more authentic depiction of the falls experiences building on the accounts of the primary study participants, as suggested by Shenk et al (2008) and Kvale and Brinkmann (2009), thus facilitating their engagement with, and discussion of the data. To facilitate the resonance of the data provided on the stimulus cards, the verbatim and summarised quotations from the interviews of the older people with dementia from the primary study were presented to the people with dementia in the secondary study. The carers in this study were presented with the verbatim and summarised quotations from the carers in the primary study interviews. However, both focus groups were provided with the data from the joint interviews and focus groups from the primary study.

#### **5.5.6.2 Collecting the data**

Each focus group had the same format. The group started with some “ground rules” where participants were reminded of their right to withdraw at any time, to respect each other’s confidences and not to “cross talk”. Similarly, to stage one, the participants were initially asked to describe or define falling and also if they wanted, to share their own falls experiences. These warm up questions then lead into the main stage of the data collection. The decision was made to use stimulus cards (already discussed) for a “card-sorting” activity to facilitate the

earlier findings from the primary study, to not only stimulate discussion as suggested by Krueger and Casey (2000) but also to provide memory prompts for the topics and findings under discussion. (Please see appendix H for protocol and topic guide). Each focus group lasted 90 minutes approximately.

The stimulus cards were presented in a similar format as the topic guide for the primary study, in terms of what, why, where, when the consequences of falling. Cards were placed in the middle of the group so that each member could see them and the researcher read them out to the participants at the same time. Participants were initially asked if they felt the data on the cards resonated with their own experience, or were asked to rank in order of importance, in terms of matching to their own experience. Each set of cards finished with one with a large question mark to encourage participants to add their own experiences. However this task-driven aspect within the groups was very quickly abandoned because of the way the participants quickly engaged with and explored the data from their personal perspectives. Both groups of participants used the verbatim and summarised quotations as a vehicle to elaborate upon the experience, viewing and articulating about the experiences through a different lens.

As a summing up, participants were asked what they thought that they or others could do to prevent falls occurring or to better manage their consequences. They were also asked if they wanted to add anything to the discussion about falling. They were then thanked for their participation, offered a hot drink and each given biscuits as a gift for participating. After the focus group, each participant was sent a thank you card via the outreach worker, in acknowledgement of their participation.

### **5.5.7 Method of data analysis**

The focus group audio-recordings were transcribed verbatim, with the transcriptions parsed so that the accounts of individual participants could be identified (see appendix N). At this point the narrative of the person who had not consented to participate (but joined in the discussion) was removed. Thematic analysis was chosen as the method of data analysis, rather than carrying out an IPA analysis. Even though the lived experiences of these participants were

shared and discussed, this was prompted by the use of stimulus cards, which may have led to some lack of authenticity in their discussion. However, participants were clearly drawing on the emic perspective when evaluating and making meaning out of the summarised data that they were considering. The phenomenological status of this secondary study can be debated as it did not delve into the participants' personal experiences and it is difficult to ascertain how much influence the prompts (by using the stimulus cards) had on their accounts. Therefore, thematic analysis was undertaken, as participants did share their personal experiences but were influenced by the structure and content of the stimulus cards. Although a commonly used and reported method, thematic analysis is rarely described, however a method advocated by Braun and Clarke (2006) was utilised. Braun and Clarke describe both inductive and deductive methods. In this instance an inductive (or "bottom up") approach was taken where the analysis is driven by the data, rather than identifying data that fit with any preconceptions, questions or theories that the researcher may have had.

This method of analysis differs from IPA, where each transcript is read and analysed before moving on to the next (Smith et al 2009). The audio-recordings were listened to again by the researcher, to become more familiar with the accounts, before reading and rereading both of the transcripts. Repeated reading of the transcripts enabled the researcher to become more familiar with the data and allowed for patterns or units of meaning to be inferred within and across the transcripts. Data were analysed to allow for identification of what individual participants were saying, especially where they might repeat themselves to emphasise an opinion. At this point, initial codes and ideas were identified, especially relating to the participants' thoughts, opinions, feelings and own experiences. The codes were collated, along with the relevant passage, quotation or narrative that they related to. The researcher then searched for themes by clustering and re-clustering codes from both transcripts into subthemes, with subsequent arranging and re-arranging of subthemes into main themes (Harcourt and Frith 2008). At this stage the main themes were reviewed and refined. Braun and Clarke (2006) describe this refining of themes as happening at both a micro and a macro level, where the individual codes and

extracts are explored to consider if they “fit” or complement each other as well as looking at the themes themselves and examining if they reflect what the data set is conveying as a whole. What Braun and Clarke (2006) identify as the penultimate stage of the analysis before writing up the findings involved the writing of a brief account of the “story” to each theme.

#### **5.5.8 Strategies to enhance the quality of the data collection and analysis**

Similar strategies were put into place as those decided upon for the first stage of the research. The researcher debriefed with the outreach worker from the Alzheimer’s Society and reflected upon these focus groups in her fieldwork diary. Both of the transcripts were scrutinised by the researcher’s first supervisor and the initial analysis discussed. Member checking was decided again for the same reasons as before, that the participants may not have the same recollection of what they had said, and may have not recognised the interpretations of the researcher (Holloway and Wheeler 2010). Once again, data have been stored so that an audit trail through the analysis is possible (please see appendices N and O).

#### **5.5.9 Summary of methodology for secondary study – What are the elaborations and illuminations of older people with dementia and carers of the falls experiences of others?**

In this section the chosen method to address the research question “What are the elaborations and illuminations of older people with dementia and carers of the falls experiences of others?” have been described. The use of a method independent of any tradition has been justified, especially in the desire to complement the phenomenological core of the primary study of the research. The methods were chosen to allow for an elaboration and illumination of the data from participants in the primary study by participants in the secondary study. Here the method of data collection was determined to best allow the chosen participants, both older people with dementia and carers, to actively take part and contribute to the research. An inductive and interpretative analysis

of the data set was carried out resulting in a thematic presentation of the findings

## **5.6 Summary of methodology for primary and secondary studies**

In this chapter, the qualitative approaches and methods used to answer both research questions have been proposed and discussed. The methods of data collection have also been justified. In any research, the methods of data collection are determined not only by the research question and aims, but by the needs, characteristics and availability of the participants, and by the values of the researcher. The researcher was aware of the challenges of carrying out research with older people and especially those with dementia. Therefore, decisions were made to ensure that the research was carried out within an ethically sound framework and did not cause any harm to participants, whilst still enabling the research questions and aims to be addressed and the voices of a marginalised group to be heard. The taking of verbatim and summarised quotations from one group of people with dementia and carers was carried out to find resonance with another group. The aim of this was that they would build upon and further illuminate the falls experience as an elaborative triangulation within the research.

## **5.7 Reflecting on the research methods**

Much could be written here about the reflective process that has gone on during the design of the research, the data collection, analysis and writing up. Some of these reflections merge into the findings chapter as the iterative process of analysis has taken place.

One of the significant processes has been the understanding and interpretation of the concept of 'whole-part-whole' within this research. Therefore I include two extracts from my reflective diary about how I feel the concept of 'whole-part-whole' has informed my data analysis particularly.



24<sup>th</sup> August 2007

*I'm not sure if I have analysed these adequately – much is still very descriptive – is this lack of knowledge of the relevant theory or lack of interpretative skills or the type of data acquired. In some interviews the questions are quite leading so perhaps the data is much more closed. Also does the stage of the dementia have an input? I think I need to read more about autonomy, sense of self, control.*

*I feel that I have reflected and interpreted the transcripts as a whole rather than the individual segments to get my overarching themes. Does this help or hinder higher order analysis?*

*Later the same day:*

*Thinking of the overall story from the transcript. Bob speaks very little but the most he says is about how as a younger man he was more active and able to voice his thoughts and opinions. He identifies that he is older and has fewer thoughts and has to be more careful. It sounds like he dislikes how he is now and identifies his deterioration, and wishes he was younger - when he was active and carefree.*

5<sup>th</sup> May 2011

*Missed the IPA meeting in London where the paper by Smith (2007) relating to the hermeneutic circle and 'whole-part-whole' were discussed. It got me thinking about my w-p-w experiences. Certainly in my later analyses I got different interpretations from the transcripts by reflecting on the whole interview (this worked with some but not all) – so I began to see Tony as the invisible man, Bob as the fit and active man, Wendy as the fighter and Patrick as the carpenter hero.*

*Another of the things I did was changing my method of data analysis – as I looked at the dyads transcripts as a whole I began to get a different*

*perspective and interpretation of their relationships, identities, sense of selves and hopefully how they as a couple experienced falls and the consequences. However my analysis also often looked at the part and saw similarities between experiences of carers and people with dementia.*

It is interesting that earlier in my attempts at analysis I was nervous about looking at the account from the participants as a whole, perhaps because some of the transcripts seemed to have “thin” data and I struggled with analysing the individual parts of the text. It was only when I began to reflect on the transcript as a whole that I could see the parts and analyse the data more interpretatively.

## **Chapter 6 - The experiences and consequences of falling: Findings to Primary Study - Part 1**

### **6.1 Introduction to findings for primary study**

The findings in this chapter and the next chapter (chapter seven) answer the research question in the primary study – “what are the experiences of falling among older people with dementia and their carers?”. These two chapters present the emerging themes that not only consider the falls experience itself but also the perceived consequences of falls for the participants. Findings for the secondary study are presented in chapter Eight. A reflexive section relating to the analysis and presented findings for the primary study can be found in Chapter Seven (section 7.4) and for the secondary study in Chapter Eight (section 8.6).

An alternative analysis of the falls experiences of participants from the primary study is also presented in appendix M. Subsequent consideration of the data and the findings suggested that an alternative approach to IPA could capture the experience of falling in more depth. It was therefore decided to present a phenomenological description of the falls experience. This phenomenological description is based upon the method of analysis proposed by Giorgi and Giorgi (2008). Descriptive phenomenology is in keeping with, and complements the descriptive layer of IPA analysis and also the different approaches and analytical processes carried out in the primary and secondary studies reported in this chapter, chapter Seven, and in chapter Eight.

As already stated in the methodology and methods chapters (chapters four and five), this stage of the research used interpretative phenomenological analysis (IPA), with data being collected by one to one and joint interviews and focus groups. In IPA studies it is acceptable for description of findings and interpretation to occur concurrently (Smith 2008), and this has been carried out in this chapter and chapter seven. However, an overall discussion of the findings from the primary and secondary studies (chapters six to eight) takes place in chapter nine. Quotations from the older person with dementia or

memory problems are presented in blue and quotations from carers in red (and interviewer in black) in all three of the findings chapters. Actual names of participants have been replaced with pseudonyms in all instances.

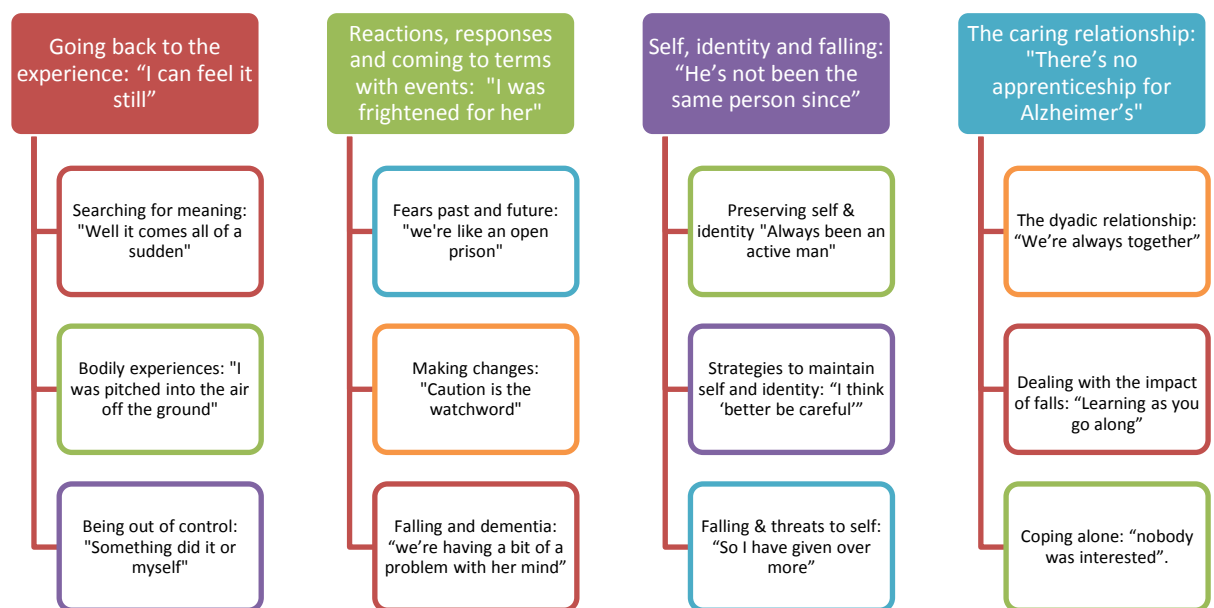
This chapter provides a brief introduction to all the higher level themes that have been inferred from the data from the primary study. The findings for both the primary and secondary studies in chapters six to eight have been illustrated by the use of direct quotations from participants and have been colour coded for easy differentiation (as described in the previous paragraph). The term “care-recipient” will be used in this chapter and chapter seven to represent the older person experiencing dementia or memory problems, so that these participants can be differentiated from those participants who were carers.

Four higher level themes were inferred from the data. These themes appear in the data from all of the interviews and focus groups. These are:

- 1. Going back to the experience: “I can feel it still”**
- 2. Reactions, responses and coming to terms with events: “I was frightened for her”**
- 3. Self, identity and falling: “He’s not been the same person since”**
- 4. The caring relationship: “There’s no apprenticeship for Alzheimer’s”**

All of the higher level themes consist of a cluster of sub-themes and these can be seen in figure 6.1. As already stated in chapter five, the IPA data were analysed more than once, and indeed it is considered that analysis and interpretation of the data carries on until the findings are finally written (Smith et al 2009). Therefore examples of earlier analysis and themes are presented in appendices J,K and L. As IPA seeks to articulate the voice and experience of the individual, the presence of the sub-theme is determined by its power of illumination of the experience and not necessarily its prevalence across the data set (Smith et al 2009). However the presence of the subthemes amongst participants’ experiences is indicated by tables when each higher level theme is presented.

This chapter will present the first two themes from the primary study where the findings relate to more immediate experiences and perceived consequences of falls events.



**Figure 6.1 Higher level themes with their component theme**

The recent paper by Smith (2011) has been used to guide the writing of this chapter and chapter seven in the desire to enhance the quality of the presented findings. The higher level themes and their component themes have also been “tagged” by short quotations from the participants, to provide more of a “flavour” of these themes, similarly to studies by Eatough and Smith (2006b) and Hill et al (2009). The themes reported in this chapter are:

- 1. Going back to the experience: “I can feel it still”**
- 2. Reactions, responses and coming to terms with events: “I was frightened for her”**

The first higher level theme presents findings relating to a remembered falls event experienced by participants, who retold their experiences and tried to make sense of this. The second higher level theme considers the reactions, decision making, emotional and behavioural consequences of falls described by both carers and care-recipients. Tables 6.2 and 6.3 indicate the prevalence of the subthemes for each higher level theme, across the participants.

### **6.2 Going back to the experience: “I can feel it still”**

This higher level theme relates to the participants’ recollection of the fall experience that they identified for discussion. However, this higher level theme represents more than a summary of straightforward answers to the interview question as the participants dwelled on this experience. The falls experience had emotional resonance for participants, and they returned to it during the interview. Indeed this experience was a significant aspect of the lifeworld for these participants, with evidence of “hot cognitions” (Eatough et al 2008) with the feelings and vivid sense of engagement in the event being present in the interview although the fall had happened sometime in the past (McCormack 2002).

The quotation “I can feel it still” associated with the title of this higher level theme comes from George’s narrative (care-recipient) when he discussed the first fall he remembered having soon after his diagnosis of dementia. In this higher level theme, the participants (both care-recipients and carers) were trying to make sense of their own falls experience, or that of the “other” in the dyad. The making sense of experiences (such as falling), is considered within IPA to be a cognitive process, where meaning making and contextualisation of the experience are made by participants, within the interview, and by the researcher during data analysis (Bruner 1990, Eatough and Smith 2006, Smith et al 2009). Participants not only discussed the event itself but also considered why and

how they had fallen. There were two windows onto the falls event; one from the perspective of the person who had fallen (both the care-recipient and, occasionally the carer describing a personal fall) and the second by the person who had witnessed the event or was involved in its aftermath (in these instances, the carers). This first higher level theme is made up of three themes and these can be seen along with their prevalence in table 6.1.

**Table 6.1 Prevalence of themes for higher level theme 1 across participants**

<b>Participants</b>	<b>Searching for meaning: “Well it comes all of a sudden”</b>	<b>Bodily experiences: “I was pitched into the air off the ground”</b>	<b>Being out of control: “Something did it or myself”</b>
George & Vicki	*	*	*
Tony & Susan	*	*	*
Wendy & Bernard	*	*	*
Vera & Paul	*	*	*
Rita & Neil	*	*	--
Sheila & Patrick	--	*	*
Bob & Norma	*	*	*
Eileen & Karl	*	*	*
Bridget, Harry & Alison	*	*	*
FG 1	*	*	*
FG 2	*	*	*
FG 3	--	*	*

### 6.2.1 Searching for meaning: “Well it comes all of a sudden”

When asked to describe what she thought a fall was, Rita (care-recipient) gave the explanation given in this title quotation. Like Rita, all participants were asked to define what they thought a fall was, to help locate their experience within the context of the research. Even though this was a direct question to “set the scene” for the interview; in the majority of instances participants seemed to

base their definitions and locate these within their own personal experiences. Wendy suggested:

“Well I think it’s either your balance not exactly as it should be. Or you stub your foot against a raised stone. Not paying attention which I must say is probably true of me as well...” (Wendy, care-recipient, I.557)

Others agreed with Wendy’s suggestion of loss of balance, however the definitions also varied, with Tony (care-recipient) considering that a fall was “if my hands hit the ground” (I.509). Tony’s description implies a sudden and out of control movement which Rita echoes:

“Well it comes all of a sudden doesn’t it? ... Don’t know when it’s coming. ... You just fall and have the results afterwards” (Rita, care-recipient, I.11).

The experience of lack of control over a fall, is also echoed by Susan and Paul (carers). However in Rita’s narrative it would seem that the consequences or results of a fall lingered longer than the memory of the fall itself. Others describe a fall in emotional terms. Karl (carer) suggested that a fall was “a shock” (I.394) followed by fear. Bridget (care-recipient) considered that a fall “involved being silly” (I.28), which suggests a social and stigmatising dimension to falling. A fall often had different meanings for individuals so that they would differentiate some falls as being worse than others. Harry and Alison (carers) considered a “bad fall” as one that would have a worse outcome such as resulting in a visit to the local hospital. However the temporality of a fall determined its severity for Derek (carer, FG 2) who felt that a fall at night was much worse than one at any other time. In these instances one can surmise the fear and anxiety experienced by these carers witnessing and coping with the fall of the person they were caring for.

Most participants, including carers, struggled to describe a fall in a more general way even when asked to consider what they would expect to see as a “dictionary definition” of a fall. Their concepts of a fall were heavily influenced by



their own subjective experiences, with the feelings of shock, embarrassment, humiliation and fear being privileged here.

### 6.2.2 Bodily experiences: “I was pitched into the air off the ground”

In this theme, embodied and disembodied experiences are recounted, along with perceptions of bodily alienation.

Many of the older people with dementia did not remember what might be regarded as objective details such as the dates, where or when their fall occurred but they had bodily memories of a particular fall itself and its consequences. The title quotation comes from Bob’s narrative, when he recounted how he caught his foot on a stone and rather than falling to the ground as he anticipated, had the sensation of being thrown into the air. Other participants had a sensory memory of their fall. Vera didn’t necessarily remember her falls but she realised that she had suffered a fall because of the feelings she was experiencing. She said:

“...because it’s there and it’s painful. Every move I make. And I just sit down till it’s easy...” (Vera, care-recipient, I.69).

George could not remember how or where he fell but he remembered that he had been moving from one part of the house to another, in a hurry and then being flat on the ground. He said:

“No, no, I remember it well. I was saying I didn’t, but I remember about it – I can feel it still...” (George, care-recipient, I.19).

For some participants, their fall was conveyed through the use of more visual images of their experience. Geoff (carer) from one of the focus groups described his own fall, saying:

“...you’re walking along and the next minute your feet shoot out from underneath you...” (Geoff, carer, FG3, I.18).

The use of the word “shoot” clearly conveys the sudden nature of the bodily experience and the lack of control in this narrative, and are echoed both by Eileen and Tony. Tony’s description of one of his falls at a railway station provides a clear visual image of his feelings of helplessness and embarrassment:

“...you feel a right Charlie, don’t you? Sprawled across the station platform...”  
(Tony, care-recipient, I.131).

Bob, Bridget and Eileen could all describe which part of their body was involved in their fall, but not necessarily where or when. For Bob and Bridget these disembodied memories were catching their toe and tripping causing them to fall, whereas Eileen remembered that:

“I fell on my head...well knocked my head on the floor...” (Eileen, care-recipient, I.37)

Carers also recalled disembodied memories of the falls of the care-recipient. Paul was aware of his mother Vera experiencing falls, not because of her ability to recall these but by seeing the bodily consequences of bruising on her arms and legs, as well as Vera’s complaints of aches and pains. Bernard described a disembodied memory of one of Wendy’s falls, by recounting that all he could see of Wendy was a solitary hand knocking on the glass door of the kitchen as she lay on the floor following a fall.

Other participants described experiences that could be described as alienating, with the body “playing tricks” on the individual. Bob talked about being “...pitched in the air off the ground...” (I.855) when he hit a stone. When recounting about another fall George said his memory “lingered all the time” (I.1484) and described his fall experience:

“I felt that I was floating, but I was touching the ground, I think, most of the time...” (George, care-recipient, I.1682).

Later whilst still describing the same fall George said that he felt he was recovering from the fall because “...I wasn’t floating quite so much...” (I.2993). Eamonn remembered that he had been knocked unconscious following his fall and said:

“...I do know that I was out, you know it went out, I don’t know what happened to it, I was underneath. Knocked myself out...” (Eamonn, FG2, I.255).

Both Eamonn and George (care-recipients) recount a surreal experience in these narratives. The visual imagery of George floating above the ground contrasts with Eamonn’s story of being “underneath”. One can only imagine what Eamonn felt he was underneath – was this sensation of being submerged under water or buried underground? However in both narratives there is a sense of disconnection or alienation in their lived bodies. Eamonn’s use of the word “it” rather than “I”, Bob’s description of “the toe” (I.26) rather than “my toe” and Vera recounting how “...I just fall, or otherwise it just goes on its own...” (I.104) also depersonalise their falls experiences, considering their bodies as object rather than self. The narratives of other participants objectify the falls experience. Tony described how his foot became “unhinged” (I.32) like a door, Alison described how her mother, Bridget fell “like a sack of potatoes...” (Alison, carer, I.477) and Patrick describing Sheila’s fracture following her fall “just as if it was a mitre (joint)” (Patrick, carer, I.612).

In all of these narratives even though the factual memory of “the where” and “the when” of the falls are not communicated by care-recipient participants; embodied, disembodied and alienating memories of the experiences are clearly conveyed. Indeed, carers also objectified the bodily experiences of the care-recipients’ falls, through the use of metaphor to try and communicate their experiences more easily.

### 6.2.3 Being out of control: “Something did it, or myself”

This statement was made by George when he was considering how he had fallen. Like George, the majority of the participants articulated both intrinsic and

environmental reasons and experiences of falling. In many instances participants gave many rationales for the same experience as they perhaps were not really sure why they fell. Indeed care-recipients and carers often suggested differing reasons for the same fall. Here one can consider that these were co-constructions of the experience in the moment with the interviewer. The many differing rationales being co-created for the same event also reinforces the phenomenological position that participants are not necessarily accessing a single 'factual' reality, but are highly engaged in meaning-making.

Participants attributed various factors external to themselves for their falls. They described tripping over their cat, a door mat, their pyjamas, over uneven pavements as well as cigarette papers and catching their feet on the kerb when crossing the road. Indeed Karl (carer) recounted how Eileen (his wife and care-recipient) tripped when crossing the road pulling Karl over with her. This was echoed in an experience by Peter (carer) who was pulled down into an excavation of a pavement by his wife when she tripped and fell in. Wendy (care-recipient) blamed her varifocal glasses for her increasing number of falls. George's account of one of his falls seems to describe a less specific extrinsic, but yet malevolent force that he fought to remain upright. He said:

“...No, I kept off the ground...” (I.1668)

and then later:

“...but it never got the whole of my body...” (I.1766)

then later again he reiterates:

“...I go against these things trying to get me flat, and I am trying to hold myself up. Not drop over.” (George, care-recipient, I.1831).

This sensation of being controlled by an external force was echoed by other participants. Bob (care-recipient) recalled how he was pushed forward when he stumbled, and when discussing how she slipped off the bed, Vera (care-recipient) explained “...but it sort of turned me halfway...” (I.104). Bernard's

exasperation with Wendy (his wife and care-recipient) was clear in the dialogue below, however Wendy defended her behaviour as being out of her control:

“Bernard: you are inclined of walking into a pool of water rather than...

Wendy: ...walk round it

Bernard: ...go over and round it. Very often I say ‘now follow me’ but you don’t. You go somewhere else.

Wendy: Well I don’t walk through puddles though. Not deliberately.

Bernard: No, no but you are attracted to them.” (l.641).

The lack of control and sense of powerlessness over the falls experience was also expressed by Eileen who described that she “didn’t have a chance – I just fell” (l177).

In these instances it can be seen that participants felt that something external to themselves – either an invisible force or something in their environment caused them to fall. Indeed these participants convey a sense of helplessness or being threatened by a fall.

Intrinsic reasons for falling were also given, either by the care-recipient themselves or by their carers, as suggestions for the fall. These reasons for falling have an element of self-blame, with Bridget (care-recipient) saying:

“Oh I know I should lift my feet a bit more” (l.811).

This was echoed by Tony (care-recipient) and also by Paul (son carer) about Vera (care-recipient), and by Marion (carer) about Eamonn (husband and care-recipient). Rushing to the toilet was seen as a potential cause by Tony, George (care-recipients) and Kathryn (carer). Participants also articulated somatic reasons for their falls such as being ill, problems with their feet and giddiness. Others considered being tired yet Patrick puzzled over the possible reasons for Sheila’s falls, rejecting tiredness as an adequate explanation:

“But she wasn’t tired when she smashed her head; she wasn’t tired when she broke her left arm. And her right arm she wasn’t tired” (Patrick, carer, I.1764).

Here Patrick seemed to be putting a great deal of effort into trying to make sense of Sheila’s falls. One also gets a sense of Patrick’s frustration at the inexplicability of falling and how powerless he feels about the regular harm being experienced by his wife, as a result of these inexplicable falls.

In Tony (care-recipient)’s narrative he unfavourably compared his skills to that of a hurdler, suggesting that he lacked the cognitive or sensory awareness to regain his balance adequately:

“...sometimes my foot hits something, a step I’m trying to make, um, is not completed properly, uh but um my ...um, gearbox up here is telling me the balance, um, if you um watch a hurdler, which I’m not, if you watch a hurdler, on TV, they’re really quite out of balance when they’re going through the motions, what they’re doing, but they have this facility to regain the proper balance on landing...” (Tony, care-recipient, I.348).

Bridget (care-recipient) also implied a lack of cognitive awareness, reasoning that she was always busy thinking of other things:

“...The old brain is always moving, or thinking about shopping or something, you know...” (Bridget, care-recipient, I.816).

Not paying attention or thinking of more than one thing was also suggested by other participants as being implicated in falls. Vicki (carer) suggested on more than one occasion that her father George (care-recipient) was more at risk of falling when dividing his attention. She said:

“... but I think that he had two things on his mind and that’s not a good idea in his case...” (Vicki, carer, I.510).

The contribution of thinking of other things as a cause of falls was discussed at some length by Tony (care-recipient). He suggested that he could have fallen

because he was distracted by his wife pointing something out to him, or as a keen birdwatcher, by the sound of a bird. He described an “overlap” of concentration from one task to another and also stated how he found it difficult to think of more than one thing at once in other situations:

“There are a lot of other things beyond falling.... Er, um, if you’re writing something down and you think of something else, then you forgot what you were going to write” (Tony, care-recipient, I.444).

Christine, one of the spouse carers also described how thinking of other things, particularly in her caring role, also made her more vulnerable to falling:

“...there’s so many things to think of and you’re thinking of somebody else as well as yourself...” (Christine, carer, FG1, I.366).

Indeed, in some of the carers’ narratives it was a surprise to hear them talk about their own experiences of falling. In these narratives, the interrelatedness of the carer and care-recipient became painfully more apparent. Whereas Christine attributed her fall to thinking about the “other” (her husband and care-recipient), Patrick’s story of his fall immediately truncates the caring relationship he has with Sheila, as he was admitted to hospital. Moreover once home, feelings of powerlessness in the caring relationship were conveyed as he shared his inability to care for Sheila as he wished.

In these narratives the consideration of external and sometimes malevolent forces were articulated as reasons for the participants’ falls. In a few instances participants considered that there were reasons that were potentially within their control, such as not rushing or picking their feet up when walking. In many other circumstances participants’ attributions for falling were related to failures within their body – either due to temporary illness or as part of the ageing process (such as problems with divided attention), or role overload. However in some instances where it was difficult to ascertain why a fall happened, there was a sense of frustration and helplessness, as experienced by Patrick.

#### **6.2.4 Summary of findings to higher level theme 1**

This higher level theme has presented findings appertaining to the falls experiences and events of both the individuals with dementia who fell and also the individuals that cared for them. In some instances carer participants also talked about their own falls. Whereas the carers seemed to remember the “facts” of the fall (e.g. date, time, place), the care-recipient had embodied and disembodied recollections of these experiences. The sudden and surprising nature of falling were conveyed by all those participants that fell, however participants searched for reasons for the falls, not only to rationalise the experience and perhaps to increase their sense of control, but also to try and prevent them from happening again.

#### **6.3 Reactions, responses and coming to terms with events: “I was frightened for her”**

Higher level theme two presents findings related to participants’ feelings and emotions related to falling and its immediate consequences. The title quotation comes from Karl’s (carer) narrative, when he related his fear of the consequences for his wife following her fall. Fear of the consequences of future falls was also present in the findings. How participants expressed their experiences of changes to behaviour and the environment in reaction to the falls event will be considered here. Finally, the reckoning presence of dementia in the participants’ narratives will be presented, and how these experiences are intertwined with their falls experiences. Table 6.2 indicates the prevalence of these themes amongst participants.



**Table 6.2 Prevalence of themes for higher level theme 2 across participants.**

<b>Participants</b>	<b>Fears past and future: “We’re like an open prison”</b>	<b>Making changes: “Caution is the watchword”</b>	<b>Falling and Dementia: “we’re having a bit of a problem with her mind”</b>
George & Vicki	*	*	*
Tony & Susan	*	*	*
Wendy & Bernard	-	*	*
Vera & Paul	*	*	*
Rita & Neil	*	*	--
Sheila & Patrick	*	*	*
Bob & Norma	*	*	*
Eileen & Karl	*	*	*
Bridget, Harry & Alison	--	*	*
FG 1	*	*	--
FG 2	*	*	*
FG 3	*	*	--

### 6.3.1 Fears past and future: “We’re like an open prison”

In this quotation Karl (carer) was voicing the negative emotions of the majority of the participants in this study (both care-recipients and carers). These relate to the feelings experienced by participants in response to the fall that had happened, or to the reactions of others, as well as fear of potential consequences of any future falls. When asked about any changes that they had made following Eileen’s fall (wife and care-recipient), Karl (carer) replied:

“...Well as a result you know we’re like [pause] open prison really, because we can’t go ...

I: Right, go out [pause] that's what you feel like, yeah?

Karl: Yeah. And I don't try to leave her [pause] well not first year because she was still better of course [pause] but I'm afraid to leave her alone. Because after if anything happen to her, if she fell or something I would feel responsible for this you know" (Karl, carer, I.708).

In Karl's narrative, the contracting lifeworlds of both Karl and Eileen are exposed. In one sense home is the place of safety for Eileen, but in another it is a prison, a place that is difficult to leave for both of them. Karl was fearful of leaving Eileen alone in case she fell again, however other emotional consequences of falling, such as feelings of stupidity, loss of confidence, feeling silly or embarrassed, scared, miserable and needing reassurance were all expressed by care-recipients and carers. In some instances the reactions of others (especially strangers) seemed to be associated with feelings of stigma, shame and social exposure. Andrew (care-recipient and focus group participant) communicated his assumption that bystanders had thought he was drunk because he had tripped and fallen in the street, which perhaps conveys how humiliated he felt by the experience. Paul described how his mother seemed miserable at times and he surmised that this was because Vera did not want to tell him that she had fallen over; being fearful of the consequences, such as being moved into residential care. He said:

"...so I think she had sort of tottered then. But I think it worries her more than anything else. When she does she sort of just sits there and doesn't want to say anything to me in case I do something about it. You know there's a lot of fear there. But I mean we wouldn't - this is her home and she'll stay as long as she can..." (Paul, carer, I.552)

When talking about his recent falls, Tony (care-recipient) gave conflicting opinions; indeed two of his falls were very public events at railway stations – one where Tony fell on to the platform rushing to catch a train and another where he fell down between the train and the platform whilst attempting to get out of the carriage. Tony's narrative perhaps reflects his attempt to suppress his

memory of both events or to rationalise why he couldn't fully remember these dramatic events. In the first quotation Tony described his memory of one of his falls:

“The thing is you get an impact like that and it gets lodged into the brain box. But what went on before or the following day or anything like that...” (Tony, care-recipient, I.65)

In this narrative, Tony was perhaps suggesting that some memories such as his fall at the railway station became stuck and unforgettable, when other memories are lost. Later in two separate instances he talked about not remembering falls:

“You go from the site of the disaster and move away from there, and of course it all fades away. You don't want to remember it, in other words”. (I.157)

“...One reflects on these things and some of the things that happen fade away. Your memory ... sort of filters out bits you don't want to remember or bits that are irrelevant”. (Tony, care-recipient, I.208).

In these later narratives, Tony is almost contradicting himself; here he suggested that his memory loss was due to repression of unpleasant events such as his falls, rather than attributing this to his dementia. This filtering of memories is also alluded to by Peter, a carer, in one of the focus groups. Sarah (his wife and care-recipient) shared with the group that she did not remember falling; and Peter replied that it was probably better not to remember it, if she could. Vicki and Patrick also voiced their own memories of the falls of the person they cared for. Vicki described how she could see George deteriorate as a consequence of his first fall and Patrick described both his fear and feelings of anxiety and helplessness when finding Sheila on the floor:

“...I woke up, no Sheila. Bedroom door shut. So I dashed out and there she is, sitting with her back to the door jamb in the toilet, the toilet door open, light on....Not a tear, not saying anything, just mute. I said ‘How long have you been here?’ She says ‘10 minutes’. She was frozen really, I don’t know how long she’d been there...” (Patrick, carer, l.2166).

In this narrative, Patrick’s use of the present tense brings the experience into the present. Indeed, it is as if he is re-living the event during the interview, and by use of vivid and detailed description wanting the interviewer to share the experience with him. Susan’s narrative (carer) also portrayed feelings of anxiety and helplessness when she witnessed Tony’s fall (husband and care-recipient):

“...I mean I...was aware that he was falling, but couldn’t do anything to stop him.. he’s just too heavy, you know, and he slid right down between the platform and the train, and then somebody said ‘the train isn’t going is it?’..” (Susan, carer, l.503)

In this case one can only guess that Susan’s feelings related not only to her inability to prevent Tony from falling, but also the sense of helplessness and fear that the train was going to move with him stuck underneath it.

Whereas some participants, like Susan were fearful of the immediate repercussions of falls, other participants voiced different fears. Karl’s feelings of responsibility for Eileen (his wife and care-recipient) to prevent future falls, was related to his determination that she should not be admitted to residential care. Tony (care-recipient) related his fear of future falls to possible injury. Interestingly, Tony had not experienced any injuries that had required medical attention following his falls, and one wonders if he was more fearful of public embarrassment and humiliation. George’s perception of falls in relation to other life events can be seen in the following narrative:

I: Yeah. How does that make you feel knowing that you've had three falls? How does it affect you? In what way?

George: That I might be frightened, now, or you know. Death and things... - these things don't trouble me. I mean I know it will eventually, but um ...

I: But you're not frightened of falling again?

George: Oh well if it's falling. I don't like it.

I: Yeah so how do you ...

George: I go against these things trying to get me flat, and I'm trying to hold myself up. Not drop over". (George, care-recipient, I.1825).

Earlier in theme one, George's narrative indicated an association of falling with a malevolent force and here one can see the menacing nature of falls more clearly, as it would seem that George found the thought of dying preferable to the thought of falling again. What this narrative also indicates that George did not have a submissive reaction to falls but was determined to stay in control and not be defeated by those "things trying to get me flat".

This theme has presented findings related to the participants' fears (both care-recipients and carers) in relation to their falls. Feelings of embarrassment and helplessness following a fall were conveyed. In some instances the fear associated with future falls seemed substantial, such as the fear of admission to residential care, or even the fear of the unknown being greater than the fear of dying.

### **6.3.2 Making changes: "Caution is the watchword"**

This quotation is taken from Tony's narrative and relates to the changes that he described making following his falls in an attempt to prevent further falls. This theme presents findings relating to accounts of changes in behaviour and to the home environment that care-recipients and carers described making, to prevent falling over again. These environmental changes were not intended only to

make the home safer for the care-recipient but also to make it easier for them to continue their everyday activities following their fall.

Tony (care-recipient) talked at great length about the changes he made to his behaviour, implying that he retained a level of control over falling. Not only did he describe situations where he was more careful; such as holding onto both banisters when using stairs but he also expressed how much more vigilant he had become to the extent of curtailing activities and 'sitting on the sidelines'. A common thread through Tony's (care-recipient) and Susan's (wife and carer) first and second interviews was their love of bird-watching. However Tony also identified an awareness of his difficulty with dual-tasking and the strategies he used to control such situations. By the third interview, Tony's narrative not only included a premeditation of disaster but also hinted at how restricted Tony's attention had become in his efforts to avoid falling:

"Say walking through a strange bit of woodland or something like that, I'd miss all the flowers and the birds and things. (laughs) Because I'm always looking for something to trip over or to avoid tripping over". (I.1986)

It is interesting that Tony suggested that he first looked for something to trip over, before trying to avoid it. It is, perhaps, that Tony had a fatalistic belief that he would fall, rather than believing that he would not. Tony's lack of confidence in his own ability to remain upright and an awareness of the vigilance required indicated that he would choose to avoid activities and avoid being with others, to minimise his risk of falling:

"I mean if I was like at the seaside ... and somebody said 'Come down on the beach collect shells or something', I'd I think invariably decline because of the unevenness of the sand, but also if there were pebbles, the washed up pebbles that you get in corners ... Sometimes it's the whole beach... I sit at the top, wait for them to come back. (Tony, care-recipient, I.1239)

During this last interview Tony and Susan also describe that Tony had decided to give up the bird watching as he was now too slow:

Tony: Haven't been on a bird-watching ...

Susan: Not since June we went and you said you didn't want to go again.

Tony: Yeah.

Susan: Not an organised one, because he couldn't keep up....

Tony: ...Couldn't keep up with the rest of them ... I mean they rushed off to see something, by the time I got there they were coming back again, you know." (I.2006)

From Tony's narrative, one could perceive him as being one of the washed up pebbles on the beach, discarded and ignored by others as a result of his change in behaviour and attempt to stay in control. One can also suggest that not only did Tony (care-recipient) find that his speed of walking was affected by his avoidance of falls, but also through the effort involved in being extra vigilant in identifying potential hazards, it became impossible for him to participate and enjoy his hobby. Derek (carer, FG1) and Joyce (carer, FG3) also both described a slowing down and being more aware of where they themselves were walking. Like Tony, Wendy (care-recipient) described how she needed to see where she was putting her feet when walking.

Other changes to routine and behaviour in the aftermath of a fall were discussed. Neil initially considered that very few changes had been made after Rita's falls (his mother and care-recipient) but then corrected this by saying:

"...Because I used to come and go. I had a girlfriend I was seeing you know ... and uh ... well I came back you know and I'm living with her (Rita) permanently now you know. Well I can't see her go in a home... So ever since I've been a 24 hour carer since December.... So I'm on 24 hour. Actually when I say 24 hours I am 24 hours." (Neil, carer, I.373)

In this narrative Neil described profound changes to his own life in order to care for his mother. He shared how he ensured that his mother Rita, did not walk anywhere in the house without his assistance to prevent her from falling.

Some participants described changes that they had made to their home environment to reduce the risk of falling. Both Patrick and Karl (carers) had had a downstairs toilet installed for their wives so they didn't have to climb the stairs too often. Both of them had also tried to make the stairs safer by fitting extra rails, with Derek (carer) described how he fitted a gate at the top of the stairs to prevent his wife from falling down. However not all participants felt that major changes were appropriate. Norma perceived that making changes to the stairs was unnecessary for Bob even though he had fallen down them before. She said:

“Well I don't think it needed any change. But I do try and take things away from the bottom, in case he did fall” (I.502).

Although Tony's narrative clearly conveys a highly cautious behaviour, the change in behaviour in the desire to prevent falls happening again, or to deal with the consequences of falling, was apparent in all narratives. Many of the carers seemed to become more vigilant to prevent falls, with their increased vigilance of the care-recipient rippling out into their own lives and behaviour. For some, the most obvious described changes were behavioural whereas others described changing the environment to reduce risks and make it safer.

### **6.3.3 Falling and dementia: “we're having a bit of a problem with her mind”**

This theme appeared in most of the transcripts, and relates to the presence of dementia within the participants' narratives. In many instances the relationship of falling and the diagnosis of dementia were alluded, to or hinted at, but not explicitly acknowledged. However the presence of dementia in the participants' lived experiences was felt. For some participants, the falls experience meant that a deeper recognition of dementia occurred. The quotation associated with this theme title comes from Harry's narrative when he was surmising why his wife Bridget (and care-recipient) was falling over.



For some individuals the falls were attributed to the care-recipient having dementia, however it was a different story for others. Eileen (care-recipient) and her husband Karl (carer) did not articulate the word “dementia” and neither did they explicitly refer to any memory problems, even though the diagnosis was known to them both and discussed at the beginning of the interview. It would seem that Eileen (care-recipient) and Karl (carer) had the hypothesis that Eileen’s fall caused her dementia:

“...Well I knocked my head on the floor. And from that on it started, you know, feel [pause] uh, not well” (Eileen, care-recipient, l.39).

Here, one can assume that “it” relates to Eileen’s dementia, and that the perception was a sudden onset of her symptoms rather than having a growing awareness. Susan (carer) also hypothesised that a fall could have led to the onset of the dementia for Tony (care-recipient):

“...That was a nasty fall and I just wondered whether it had any effects on the Alzheimer’s coming on or...you know.” (Susan, carer, l.1050).

Earlier in the interview Susan had asked the interviewer:

“...Have the falls got any bearing on the Alzheimer’s or is it just age?” (l.950)

It would seem that in Susan’s narrative she voiced uncertainty, and was seeking reassurance or knowledge from the interviewer about Alzheimer’s disease, and the relationship of Tony’s falls to his dementia. Although Susan was happy to use the term “Alzheimer’s” within her individual interviews, she preferred to use the term “memory problems” in Tony’s presence.

For others there was a clear articulation of what the participants perceived as the close relationship between the experience of falling and dementia. This was most evident in George (care-recipient) and Vicki’s narratives. Vicki (daughter-carer) considered how her father’s fall was:

“...the manifestation of the dementia” (l.740)

It would seem that in Vicki's narrative, George's fall brought them all crashing into the experience of dementia, rather than a gradual awareness. For example, George's first fall had been preceded only a few days before by a diagnosis of dementia. Vicki (carer) had earlier articulated her father's emotional response to this event:

“The whole experience has been ... yeah I think being told just before Christmas you know although he really knew what was wrong with him and has known probably for quite a long time that there was something wrong with him and wasn't really surprised, that wasn't a very nice thing to learn. And then on 1st January to fall down the stairs and that sort of confirmed his worst ... I mean for a few days afterwards he was saying 'I don't think I want to go on, you know, like this'...” (Vicki, daughter-carer, I.650).

Whereas George and Vicki considered falling to be a catastrophic event, it would seem that falling was not portrayed as so significant for Norma (carer) and her husband Bob (care-recipient). Indeed when asked how she felt about her husband Bob experiencing several falls in the preceding months she replied:

“Well he doesn't make a fuss about it, so I don't think it is the worst thing” (I.748).

It would be interesting to surmise what Norma felt was “the worst thing”. When probed a bit further she described how she watched Bob constantly because he got easily lost in the house and how important Bob's medication was for his behaviour and everyday performance. Indeed one could interpret from Norma's narrative that for her, Bob's wandering and difficulty with everyday activities as a result of his dementia were more significant than his falls

Only a few care-recipients acknowledged their memory problems, with others, such as Tony and Wendy attributing their poor memory of events to being a normal desire to block out negative memories. However Eamonn in one of the focus groups said:

“... And I mean I haven’t got ... I get told about anything. I have got one or two other things that I had years ago, they’ve all gone, I can’t remember them now” (Eamonn, care-recipient, I.515 FG2).

George (care-recipient) also was able to articulate his memory loss:

“I know I’ve been going, you know, down the slope quite a bit ... and my memory is now not very good.” (I.1778).

For others, the diagnosis of dementia or Alzheimer’s disease was articulated by carers in their one-to-one interviews but not in the joint interview or by the care-recipients in their interviews. Paul (carer) considered if his mother’s dementia contributed to Vera’s (care-recipient) falls and both Bernard and Patrick openly talked about their wives’ dementia in their own interviews, but not in the joint interviews. As already considered, this was the case in Susan and Tony’s narrative. It would seem that both Susan and Tony struggled with the diagnosis and were fearful of what the future would hold. In one of their joint interviews, Tony (care-recipient) and Susan (carer) played out what the future might hold for them both:

Tony: “Think about what my memory’s going to be like when I’m 90. ‘Where am I?’

Susan: You gonna stay that long?

Tony: Yes

Susan: Oh my God!

Tony: Where’s my soup? ‘You don’t have soup’...

Susan: Down your front dear.

Tony: ‘You don’t have soup for breakfast’. Oh don’t we? ” (I.1015)

In this interaction one can interpret Tony and Susan’s feelings of impending loss of control and confusion, yet this was managed with some humour, perhaps as a coping strategy. The interaction also provides a glimpse of their close dyadic relationship. Whereas Tony reveals an awareness of his memory loss both in

the narrative above, and also in the narratives already discussed in theme one, his actual diagnosis was not alluded to in his individual or the joint interviews. As already stated, Susan mentioned the onset of Tony's dementia several times in her own interviews, wanting advice and reassurance from the therapy researchers. She referred to Tony's joking of memory loss:

“And he's always joking, he'll look at me sometimes - ‘And who are you?’ I said ‘Don't joke [pause] could joke about it, but you may come to that.’ Because that's the sort of thing [pause] you know in their advanced stages they do, they forget people.” (Susan, carer, l.1815).

Whereas Susan (carer) exhibited fear of what the future could hold for them both, it could also be said that Tony's diagnosis sat unspoken and not discussed in the middle of their relationship, like the elephant in the room.

Other examples of dementia appearing in the subtext of narratives can be suggested in the second interview with Patrick, who described how Sheila's appointments with the local falls group were stopped:

“I got a phone call which said ‘Look it would be inappropriate for Sheila to come here anymore because we haven't got the necessary [pause] is it facilities to deal with her.’ It was along these lines anyhow. And I just accepted that” (Patrick, carer, l.2297).

In this narrative, it is not the dyad that talked in riddles, but the health professionals. Again, the care-recipient's dementia feels present in the conversation but not acknowledged. Whereas the lack of acknowledgement of dementia within the dyad might be perceived as reducing the stigma of the diagnosis, or encouraging a lack of awareness by the care-recipient (perhaps through collusion or denial), the possible subtext in the transaction between the health professional and Patrick is interesting. There is also an awareness of Patrick's feelings of resignation about the way Sheila was being treated by services because of her dementia. This diverges from the previous interview, where Patrick (carer) articulated his feelings about and his observation of other people's attitudes to Sheila (care-recipient) because she had dementia. During

one admission to the local accident and emergency department following a fall and subsequent upper limb fracture, Patrick found Sheila unattended in one of the toilets unable to clean herself, whilst the ward staff were anxious to talk to Patrick about discharging Sheila home. Patrick described how upset he felt at the way Sheila was being treated and said:

“I thought there she is, a kind of old, this woman with Alzheimer’s with a broken hip and a broken arm...” (Patrick, carer, l.1058).

Patrick’s sense of injustice and helplessness at the way he considered Sheila to be treated was communicated in this narrative, however this was not so apparent in the second interview and one can suppose that he had become more resigned to the attitudes of others to his wife with dementia.

This theme has considered the perceived relationships between falling and dementia by participants. The relationship between falling and dementia was revealed in differing ways; for some falls were hypothesised as being the cause of the dementia. For others the falls event revealed the stark reality of living with dementia and also precipitated increased fear of the future. In others the attitudes of others led them to feel that the care-recipient was a “second-class” citizen because of their diagnosis. However for some it is suggested that falling was less significant than other issues such as behavioural problems and loss of everyday functioning, when living with dementia. In many instances the term “dementia” was not verbalised, or if so, was not stated in front of, or by the care-recipient, even though the interview participants were aware of their diagnosis.

#### **6.3.4 Summary of findings for higher level theme 2**

The higher level theme of “reactions, responses and coming to terms with events” and the themes within it, have revealed the lifeworld of these participants in relation to falling. Participants communicated the emotional consequences of their falls and the changes they made to try and prevent falls happening again. Not only did participants voice their feelings of fear and helplessness in relation to previous falls, but also verbalised fear relating to

future falls. Changes made to their behaviour and the environment were also discussed. Findings relating to participants' beliefs and attitudes to dementia also emerged. For many participants, dementia and falling were interrelated and the impact of one on the other was revealed. Participants attributed their falls to a multitude of reasons with only a minority considering if the dementia may have been a factor. Whereas many of the carers articulated the diagnosis of dementia, none of the care-recipients acknowledged this. Care-recipients attributed their falls and reactions to being part of normal ageing and behaviour, rather than considering whether their dementia may have a part to play. It could be said that these participants lacked awareness of their diagnosis, however Tony, George and some of the focus group participants acknowledged their memory loss. One could also suggest that the carers were trying to protect the care-recipient from their diagnosis, or were in denial themselves. For some carers, the attitudes of others meant that the diagnosis of dementia could not be ignored.

#### **6.4 Summary of higher-level themes 1 and 2**

In these two higher level themes the more immediate emotional and behavioural consequences of falls were expressed by participants. Whereas participants' stories of their falls emerged in the first higher level theme in terms of embodied memories, and meaning making of the falls experience, the emotional responses to the fall and any perceived links between the fall and dementia were revealed in the second higher level theme. The overriding perception from the findings presented in these two higher level themes is of falling being a malevolent force within these participants' life worlds – not only physically, but emotionally.

In the next chapter the remaining two themes from this primary study will be presented, with the discussion of the findings from this chapter and chapters seven and eight taking place in chapter nine.

## **Chapter 7 - The experiences and consequences of falling: Findings to Primary Study - Part 2**

This chapter presents the second part to the findings to address the research question in the primary study – “what are the experiences of falling among older people with dementia and their carers?”.

A reflective section relating to the findings presented in both this chapter and chapter six can be found in the final section (7.4).

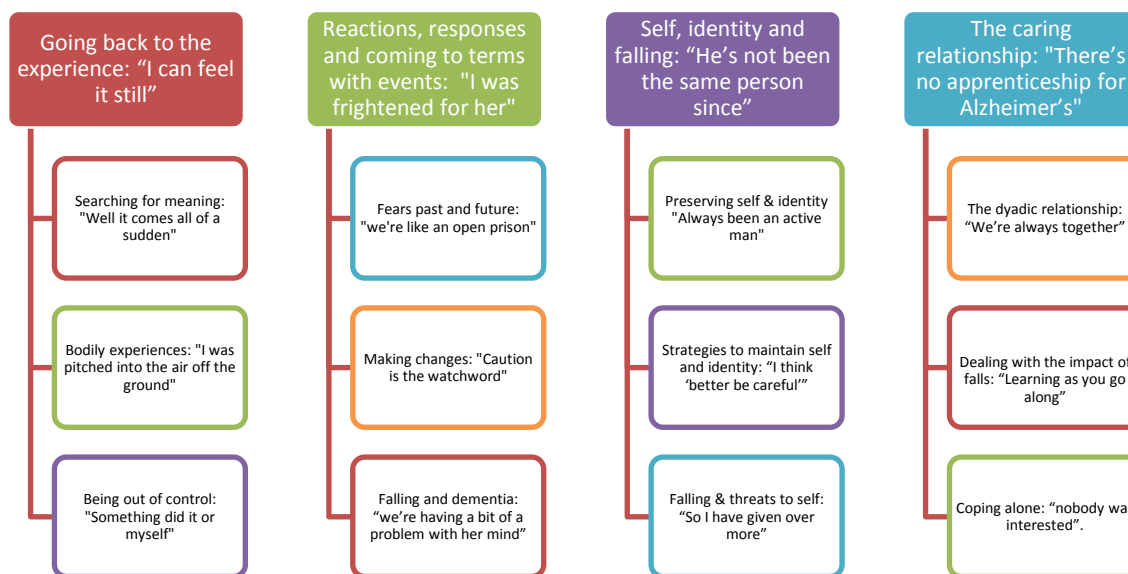
Whereas chapter 6 presented themes that considered the more immediate experiences and perceived consequences of falls for older people with dementia and their carers, this chapter presents themes where the impact of falls have rippled out and manifested in less obvious ways.

As stated in the previous chapter, four higher level themes were inferred from the data and these themes appear in the data from all of the interviews and focus groups. The themes presented in this chapter are:

- 3. Self, identity and falling: “He’s not been the same person since”**
- 4. The caring relationship: “There’s no apprenticeship for Alzheimer’s”**

Figure 7.1 places these latter two higher level themes in the context of the overall findings for the primary study, along with their component themes. The presence of the themes amongst participants’ experiences is indicated by tables when each higher level theme is presented.

The third higher level theme presents findings that articulate how the participants’ sense of self and identity (or personhood) have been impacted upon by falls and the fourth higher level theme presents findings about the impact of falls on the caring relationship. Super ordinate theme 4 has been published by the journal *Ageing and Society* as McIntyre and Reynolds (2011) (currently on Firstview) and a copy of this article can be found in appendix N.



**Figure 7.1 Higher level themes with their component themes**

### 7.1 Self, identity and falling: "He's not been the same person since"

This higher level theme presents findings relating to the challenges to the participants' sense of self and identity that participants attribute to their falls. The findings suggest that although the falls experience had great emotional significance for participants, this was intertwined with other changes and challenges that were also occurring as part of dementia. This higher level theme will present findings relating to how participants portrayed a preserved sense of self and identity and how they attempted to maintain their sense of self in the face both of dementia/ memory problems and falls experiences. Challenges to participants' perceptions of their core selves will also be presented.

The quotation accompanying the theme title is from Vicki's narrative. In her second interview, Vicki (carer) recounted how her father George's (care-recipient) behaviour and ability had deteriorated since a cataract operation followed by further falls. Here it would seem that Vicki was communicating not only how George's sense of self efficacy and autonomy were affected post-operatively but also that his embodied sense of self was affected, resulting in George becoming more frail and physically less able. Care-recipients' and their



carers' perceptions of themselves in terms of changing identity, self belief and autonomy are explored through the following component themes:

- **Preserving a sense of self: “Well of course I have been a very active man”**
- **Strategies to maintain self and identity: “I think ‘better be careful’”**
- **Falling & threats to self: “So I have given over more”**

This higher level theme is present in all transcripts and the prevalence of the individual themes can be seen in table 7.1.

**Table 7.1 Prevalence for subthemes across participants for higher level theme 3**

<b>Participants</b>	<b>Preserving a sense of self: “Well of course I have been a very active man”</b>	<b>Strategies to maintain self and identity: “I think ‘better be careful’”</b>	<b>Falling &amp; threats to self: “So I have given over more”</b>
George & Vicki	*	*	*
Tony & Susan	*	*	*
Wendy & Bernard	*	--	*
Vera & Paul	*	*	*
Rita & Neil	*	--	--
Sheila & Patrick	*	*	*
Bob & Norma	*	*	*
Eileen & Karl	*	*	--
Bridget, Harry & Alison	*	*	*
FG 1	*	--	*
FG 2	*	*	*
FG 3	*	*	--

### 7.1.1 Preserving a sense of self: “Well of course I have been a very active man”

This theme can be found in all transcripts and presents findings relating to positive identity claims. Here one could suggest that these claims were a form of defence against the potentially humiliating consequences of falls. In most instances participants found meaning in their current sense of self through emphasising past identities and recall of previous activities. The quotation accompanying this theme title comes from Bob’s (care-recipient) narrative (I.248). Here both Bob and Norma (his wife and carer) talked about how active and strong Bob had been in the past in each of their individual interviews. Whilst Norma reflected that being active and having good balance should prevent falls, she rationalised that even though Bob’s previous strength and activity had not prevented his recent falls, these attributes had probably meant that he suffered less as a consequence:

“You know he’s fairly strong really in a way. He doesn’t make a fuss of it really. Just got himself up. I asked him had he hurt himself and he said no” (Norma, carer, I.649).

One could suggest that Norma not only attributed Bob’s reaction to his fall to his past physical strength but also to an emotional strength, or stoicism. It would seem that other participants maintained their current sense of self and identity by referring back to past experiences, and by portraying themselves in a favourable light. When asked if he had taken part in any research before, Vicki answered instead of George in their joint interview saying:

“Well my father was a scientist and so that’s one of the things that he ... he was a researcher himself, interviewing farmers and people all the time.” (Vicki, carer, I.950).

In other instances participants communicated not only their past roles as surrogate parents for their younger siblings, but also their academic and sporting prowess. Bridget said:

“I used to cycle from.-. Do you know Kells in Kilkenny?. I wish I had it (cycle) now” (Bridget care-recipient, I.134).

Wendy talked several times of how she had not let her poor eyesight defeat her in the past:

“Well if you can’t see really properly. In fact before the 11 Plus I was fortunate they didn’t stop me going because afterwards they were sort of saying well do you think it’d be a good idea. Because, obviously, when you go a bit further up, you get homework to do. Whereas you don’t if you stay in the elementary school. But luckily for me they said it was okay. Or I don’t know whether they took no notice, but even then before I was 11 they were already humming and ha-ing a bit. But they said don’t do homework, but I did just the same”. (Wendy care-recipient, I.853).

In all of these instances the memories were of successful and positive experiences promoting a sense of satisfaction for the participants, which seemed to conflict with their skills and abilities at the time of the interview and after their falls. It can be supposed that these participants preserved their current selves by communicating stories of successful past selves.

Participants also conveyed a sense of stoicism when recounting how they had dealt with recent falls, perhaps again as a way of maintaining their sense of identity and control. This was most evident in Tony’s transcript and in several instances he minimised the injuries he had received as a result of the fall:

“no apart from grazing, you know, I could still walk. And er, my hands were difficult to use, temporarily” (Tony, I.44).

Later in a second interview:

Tony: “With this leg screwed up. But um, when I pulled myself up into a walking a position again and I was walking along of course I noticed that it was a bit more difficult to move the leg.

I: You'd hurt your right leg had you?

Tony: Well it went off. It seemed to be in a temporary sort of shock". (I.1114)

In his narrative Tony is perhaps downplaying the significance of the emotions or reactions he felt as a result of his fall by using the third person to describe his leg as "it", not "my" leg. It is almost that by doing this he could dissociate himself from the reactions to the fall to maintain his sense of personhood or identity. In other instances Tony used self-deprecation to minimise an obviously anxiety provoking experience when he was trapped underneath the train between the platform and the undercarriage:

"But it was quite interesting just for a few seconds to look at the underside of the railway carriage...and hope that they weren't going to move it". (Tony, care-recipient, I.1001)

Other participants also minimised their experience of falling, and this was not gender (male) specific. When asked how she felt after her falls, Bridget said:

"Ah no, I couldn't care less. I'm still here, that's the main thing." (Bridget, care-recipient, I.130).

In both Tony and Bridget's narratives there seems to be a dissonance with the experiences expressed in relation to the more immediate consequences of falling, in higher level theme 1. It is suggested that for some individuals, the immediate fears and reactions are replaced with a sense of stoicism or downplaying of events, because they had the opportunity to re-appraise the experience at more of a temporal distance.

Whereas the findings in theme one revealed Vera's negative experiences of falling, here she described how she picked herself up both physically and metaphorically and "got on with it" (I.174). Rita also described how resilient she was and how she recovered from her falls because she was "strongwilled" (I.135). However her son Neil told a different story:

"...because she'll always be calling me. She's very dependent and she feels very nervous" (Neil, carer, I.481).

It is perhaps in Rita and Neil's stories that one sees the different interpretations and experiences of the same objective event. It could also be said that both of these conflicting messages portray a positive sense of identity that both Rita and Neil each had the strong stoic mother and the capable, indispensable carer son.

Some carer-participants were self-deprecating about their own behaviour which they felt had been the cause of their falls. In focus groups 2 and 3 carers seemed to have greater confidence in communicating what they considered as irresponsible behaviour. Sally (carer) described how she slipped whilst coming down the stairs:

*"Coming down the stairs [pause] down the stairs with my socks. Naughty me".*  
(I.117, FG2)

and Joyce (carer) recounted how she fell running to catch a bus:

*"...I say to myself 'you must not run after buses' but I still do it."* (I.116,FG3).

One could suggest that these carer-participants were able to criticise or admonish themselves and make light of their experiences because they had an intact self-belief and confidence in their ability to manage the risk of falling. This did not seem to be the case for the care-recipients. When asked to remember when they had fallen over both Tony and George gave differing reasons for not remembering the dates or details of their falls. Tony's suggestion that traumatic falls were best forgotten contrasted with George's narrative:

*"No, no, it's hard to remember. But bad falls, you would remember them, so I don't think I could have."* (George, care-recipient, I.278)

Wendy had another reason for not remembering her fall and said:

*"Where did I fall this week? I don't even remember. You know it's become so commonplace in a way."* (Wendy, care-recipient, I.292).

In these narratives one could infer that care-recipient participants presented their loss of memory of their falls events as a defensive strategy to preserve

their self-belief. One could suggest that consideration that their poor memory of their falls may have been a consequence of their dementia was potentially too threatening to both their own private sense of self and also how they wished to present themselves to the researcher and others.

This theme has presented findings that consider how participants preserved or presented their identity and sense of self through valuing their past experiences, which provided positive memories of their skills, abilities and identities, for example, as sportsman, scientist or scholar. By portraying themselves through past identities, participants were able to resist being defined by their fall and by their dementia or memory problem. Participants also portrayed themselves in affirming ways by recounting stoic and minimising reactions to their falls.

### **7.1.2 Strategies to maintain self and identity: “I think ‘better be careful’”**

The findings for this theme appear in most of the transcripts, and consider how participants tried to maintain their sense of autonomy, independence and control, as well as their identity, such as birdwatcher, shopper or driver. What were also revealed in the findings were the strategies that participants used to maintain autonomy whilst dealing with the consequences of recent falls and prevention of further falls. In some transcripts, the involvement of the carers in maintaining the care-recipient’s self and identity is apparent. The quotation accompanying this theme title is from George’s second interview where he related to the interviewer how he tried to prevent further falls. Both Bob and Sheila also talked about being careful after their falls, with Sheila saying:

“Well I guess I thought ‘Oh well I’ve got a bad ankle’, you know. ‘I’ll have to take care of it, I can’t do this and I can’t do that. I’ll have to watch it’. You know.” (Sheila, care-recipient, I.62).

However both Sheila and George described how changes to one’s behaviour were not always easy, with George adding that his urgent need for the toilet often outweighed his need for caution. Sheila talked about how her awareness of being careful wore off after a while, and that she went back to her old habits; especially as she could rely on her husband to look after her. In both of these

narratives one can suggest that the effort involved in self-reliance and regulation became too much for George and Sheila, leading them to become more dependent upon their carers.

Participants' desire to maintain their sense of self and identity was conveyed by individuals discussing what they were able to do. When asked if she felt her fall had made her change her behaviour, Bridget (care-recipient) said:

“No, I don't think so, I just act natural like, you know. I don't worry too much about things, you know. I just keep going. ... I think of a lot of things, you know. I think of my cooking or I think of the kitchen. I do my little jobs and things ...”  
(Bridget care-recipient I.222).

Tony (care-recipient) talked about reading his books and magazines and watching sport and drama on the television. Patrick (carer) described how he considered that going out to the shops everyday provided Sheila (care-recipient) and himself with something to talk about and observe. Possibly the daily outing to the local shops allowed this dyad to be part of a community and have a social identity beyond “carer” and “carer-recipient”. However, the normal everyday activities that perhaps shaped and maintained these participants' identities weren't always easy to achieve without help. Eileen (care-recipient) said:

“I feel I can't walk by myself, I feel afraid to go out by myself...” (I.76)

and shared that her shopping opportunities were limited and dependent upon help from her husband and son.

For some participants, maintenance of their sense of identity was conveyed through discussion of a variety of strategies to stay in control and carry out their valued occupations, despite their perceived vulnerability to falls. Tony's narrative conveys many instances of what could be seen to be controlling behaviour to prevent himself from falling. Such strategies involved detailed examination and monitoring of his own behaviour, for example:

“But um ... I’m pretty careful to make sure that when I take a pace or something like that and my foot lands conveniently somewhere near the centre of a slab or across the join between two ...” (Tony, care-recipient, I.1306).

However, Tony’s chosen management strategy to maintain an intact sense of self could be considered as both positive and negative. Susan voiced her frustration at Tony’s slowness with walking, and observed that:

“...because he is so slow now. And it drives me mad; I mean if I’m being honest. I have to put up with it; I’m learning to live with it...” (Susan, carer, I.2306).

Interestingly, Susan’s narrative also revealed a sense of irritation and lack of awareness of Tony’s preventative strategy, as she wondered if “there’s a certain resistance to walking any faster” (I.2342). Indeed, it is difficult to know if Tony’s slowing down when walking was a recent development or was already part of who Tony was:

“...if it’s possible to go any slower then he goes. He’s never been a hare; he’s always been a tortoise.” (Susan, carer, I.1699).

However, in another instance Susan acknowledged that being slow and at the back of the group when bird watching had advantages, as Tony would often see a bird that everyone else had missed. Here, like the story of the tortoise and the hare, Tony won over the rest of the group. One can also question if Tony’s behaviour, likened by Susan to that of a tortoise, was accentuated by both the occurrence of his falls and his dementia.

Tony also described other strategies such as avoidance, which he used to control his behaviour and maintain a stronger sense of self. He considered that if he was invited to go to the beach, he would prefer to sit at the top to avoid falling, waiting for his companions to come back. Even in Tony’s third interview where he related that he had chosen to give up his treasured bird watching, it could be perceived that he was still in control of his decision making, because he was no longer able to participate as he wished, or at the speed of his companions.



This theme has presented findings that have considered the challenges that both care-recipients and carers faced when trying to maintain a sense of self and identity for the care-recipients, when confronted with the consequences of both falling and dementia. Both of these experiences are intertwined challenges and their subjective significance is not easy to separate. It can be inferred that many care-recipients valued their everyday activities as a means of reinforcing their own self-belief and identity. What has also been revealed is that care-recipients and carers seemed to have developed different strategies to maintain “normality” such as describing past endeavours or by daily trips to the local shops. However, there are also glimpses within the findings that participants found the psychological, social, and emotional effort to maintain their existing activity too great, and that falls created turning points in the decision to continue their participation. One can only surmise what impact this curtailing of activity would have had on their sense of self and identity, even when carried out through choice rather than imposition.

### **7.1.3 Falling & threats to self: “So I have given over more”**

In this theme, the findings that consider the threats to participants’ sense of self will be presented; particularly that relating to the care-recipient. Most of the findings presented in this theme that emerged from the data will consider how loss of self belief, personhood, identity, self efficacy and autonomy seem intertwined with the experience of falling, by the intrinsic beliefs of participants and the attitudes and influences (or social persuasion) of others. Like the other themes within this higher-level theme of self and identity and falling, the co-existence of dementia and the impact of falls have emerged from the findings. This theme appears in most, but not all of the transcripts.

The quotation associated with this theme title comes from George’s narrative (care-recipient), where he described how he handed over formal and financial responsibility for himself to his daughter, Vicki (carer) following his fall. A lack of self-belief and confidence in his own ability and competency to carry out these tasks seemed to be precipitated by his fall. There was a sudden shift from being not only independent and contributing to the family activities to needing

help with everyday activities such as dressing and being reliant on his daughter and her husband for all decision making:

George: "So I've given over more, everything, you know ..."

I: "Have you? "

George: "Signing things. Transferred it and then she looks after me. Everything." (I.325,).

In other instances there are glimpses of George's declining self-efficacy. He had concerns about not being able to find his way back home, or finding the toilet in a new environment. He also had an awareness of his loss of abilities when he said:

"I had words that I can't now recall. I've lost a lot of them" (George, care-recipient, I.1359).

In Bob's narrative (care-recipient) it would seem that he had uncertainty in his competency to get his story or view across to the researcher at the time of the interview:

Bob: "Well if I had been a new man it would be easier.

I: If you'd been...?

Bob: It'd be easier for me to talk you into what I thought" (I.344).

Here it is interesting to consider the meaning of Bob's (care-recipient) statement "...if I had been a new man...". Did Bob not like the person he had become, did he want to be someone else, or did he not want to be old? Both Bob (care-recipient) and Norma also identified how Bob had been "an active man" (I.248) in the past and it would seem that Bob had little confidence or belief in his ability or competency to communicate to the researcher his true or preferred identity.

The belief of falls being caused by becoming old was apparent in many of the transcripts, not only in the narratives of care-recipients but also of those carers who fell. It would appear that their falls experience precipitated feelings of frailty and loss of self belief, which they associated with being old. Ageist beliefs are

evident in many of the transcripts – often internalised by the participants themselves. On several occasions Wendy rationalised her fall to be explained by age, because she was over 80. Indeed Bernard her husband also considered that he often felt unbalanced and again suggested that this was because he was 85. Tony considered that at 76, it was unsurprising that he had joint stiffness and Sheila described a loss of speed as part of growing older. Diana, a carer from focus group 1, also said:

“...I have to tell myself that I’m old now and I’m treading carefully, I tell myself ‘slow down.’ It’s very annoying. Because I’ve always hurried...” (Diana, carer, I.303).

Vicki recounted how George’s first fall was a sign to him that not only that he was old but also that he had dementia:

“Because I think he always thought that other people were old and other people had this and that wrong with them. And even though he’d been diagnosed with dementia he didn’t really think of himself as having ... I mean he knew he’d got problems with the memory but physically he didn’t really think he’d got a lot wrong, which was quite true really” (Vicki, carer, I.3058).

However not all ageist attitudes were self-directed. Patrick related how Sheila was refused an investigation for digestive problems:

“And they said ‘if she was a younger woman then we would operate on it...’ And I thought yeah, if her name was Rooney, or Dili or Beckham or something like that, somebody with some laparoscopy would come in and do a nice little job. But I suppose they think ‘well she’s only here for 10 minutes’...” (Patrick, carer, I.2459).

In Patrick’s dialogue it is not clear if he felt that Sheila was refused help because of her diagnosis of dementia or because of her age. Indeed the phrase ‘...she’s only here for 10 minutes’ could signify both a perception of imminent death, or loss of memory or even identity. In other instances, carers discussed experiences where there was more explicit undermining of the care-recipients

sense of personhood by others. Vicki recounts an interaction between George and his General Practitioner (GP):

“...his doctor won't suggest anything, because he thinks that once you've got dementia you shouldn't be alive practically. (laughs) He was busy telling my father when he first was diagnosed 'Well you're wasting your time taking these tablets'.” (Vicki, carer, I.2598)

The attitudes and behaviours of others were also referred to by Eamonn who talked obliquely about how he had given up an activity he enjoyed:

“...I had a car, it was mine, you know. She (wife) didn't have one, she couldn't do one and I had mine. I did mine quite a lot ... but I wasn't going very fast, you know, I was going reasonable. But all the young ones keep coming, pushing, you know, going on” (Eamonn, care-recipient, FG2, I.594).

Although Eamonn had word finding problems, he was able to communicate his loss of role and identity as a responsible driver and provider to his wife. In his narrative, he conveyed how he tried to use different strategies to carry on driving, but then was apparently forced to stop driving by the behaviour of other drivers. Like Tony, in the previous theme, he felt conscious of, and pressurised by other people. However, unlike Tony, Eamonn seemed to lack a sense of autonomy in the decision to stop driving and therefore it could be said that his personhood was threatened by the expectations and behaviours of others.

Whereas carer participants tried to maintain treasured and “normal” activity for care-recipients as much as possible, some also perceived that a lack of engagement in everyday activity threatened the care-recipient's sense of self as a result of the lack of awareness of others. Patrick relayed his observation of Sheila's behaviour on one of her hospital admissions following a fall:

“...But she was getting agitated, she was ... I'd a box of handkerchiefs and she would be taking them out, folding them up, unfolding them, putting them back under her pillow. And I could see that she was mentally deteriorating because she wasn't being engaged you know...” (Patrick, carer, I.696)

Here the lack of engagement imposed indirectly by Sheila's fall could be said to have undermined her cognitive and behavioural functioning, disempowered Sheila and threatened her sense of personhood.

Loss of confidence in the care-recipient's ability, following falls, and the consequential curtailing of activity, were discussed by many carers. Whereas some care-recipients recounted that they had ceased activities through their own choice, through lack of self-belief, confidence or awareness of their own difficulties, others perceived that their activities had been curtailed by their carers. Here the care-recipients' independence and sense of autonomy were threatened and reduced seemingly because the carer lost confidence in the care-recipient's abilities. Indeed, in some instances, it would seem that falls were pivotal experiences in the imposition of restriction in everyday activity. This can be observed in Paul's narrative when he discussed how he stopped taking his mother Vera for a walk because she became too unsteady, by Neil who related that Rita did nothing without his assistance (to prevent her from further falls) and by Norma who talked about monitoring Bob at all times as he became easily lost, even at home. Within Paul's, Neil's and Norma's narratives it is difficult to ascertain if the curtailment of activity for their care-recipients, Vera, Rita and Bob, was through mutual agreement or simply imposed by the carers.

In these instances the care-recipients actual or threatened lack of autonomy and sense of self, also seemed to impact upon the relationships between the dyads, so that they became care-recipient and carer. In Vicki and George's narrative, it would seem that George chose to hand over all responsibility to his daughter, Vicki, who described how their relationship changed with George handing over all decisions:

“...And so now he's either asking my husband or myself 'Oh what do I do next?'...” (Vicki, carer-daughter I.662).

Other changes in relationship and roles that could threaten identity and sense of self were revealed in some of the carers' narratives, where controlling

behaviours can be inferred. Susan talked about when she and Tony used public transport:

“...Well that’s what I do say to Tony. I said you know sit down quickly, don’t bother looking for the seat you prefer to sit in, sit in the nearest one...” (I.1669).

Threats to identity through depersonalisation and infantilisation were also glimpsed in carers’ narratives, for example, in Norma’s dialogue when she told the researcher to “sit him (Bob) here” (I.812) rather than talking to Bob (care-recipient) himself. Other instances were seen in Susan’s interview when she talked about Tony (care-recipient) in his presence, and in her own interview asked the researcher what she thought of Tony:

“...not as a man but as an Alzheimer’s sufferer” (Susan, carer, I.656)

Here it would seem that Susan was objectifying Tony, asking the researcher to view him as someone without personhood or identity. It can be assumed that Susan wanted an objective, professional (and therefore perceived as reliable) opinion, confirmation or reassurance of Tony as a man with Alzheimer’s disease.

This theme has considered how care-recipients’ (and carers’) sense of selves were threatened not only by their falls experiences but also by dementia. In the narratives it is not always easy to untangle where threats to self and identity were specific consequences of the falls experience or attributable to the wider and progressive nature of dementia. The participants’ own perceptions of their falls being related to growing older had implications for their personhood. However, extrinsic factors such as depersonalisation and infantilisation by their carers, and the attitudes and behaviours of others would have also influenced their beliefs in their own competencies and sense of self. One could suggest that intrinsic factors threatening the self seemed to be falls-related whereas the extrinsic factors such as the attitudes of others were perhaps related to the care-recipients’ diagnosis of dementia.

### 7.1.4 Summary of findings for higher level theme 3

This higher-level theme has presented findings that relate to the care-recipients' and carers' perceptions of self and identity in relation to falls and dementia. For most participants their sense of self was multifaceted. In many instances, participants were able to preserve a sense of self, identity and autonomy through recollections of their previous and preferred selves, where perhaps they wished to present themselves to the interviewer in a more favourable identity than that of faller or person with dementia. For example, Bridget as a good housewife, Wendy a promising scholar and George as a scientist. The findings also illuminate how these participants attempted to maintain their self-belief and identity whilst adjusting to the consequences of falling and dementia. Unfortunately, these participants' self-beliefs were threatened and undermined by feelings of being old and frail, as well as by the behaviours and attitudes of others. In many instances, falls were the turning points in the participants' lifeworlds. Falls often acted as a trigger for participants to curb their own activities, or carers to curb and monitor the care-recipients' activities. It is unclear if the fall precipitated an inevitable loss of self, identity and autonomy because of dementia. In these findings, falling and dementia are enmeshed in preservation and threats to self for these participants. It would seem that these two life experiences cannot be separated from each other, and it is likely that falling and dementia are intertwined experiences for these participants.

### 7.2 The caring relationship: “There’s no apprenticeship for Alzheimer’s”

This fourth higher-level theme was originally written and has been published as a paper for Ageing and Society. It has therefore been presented albeit with a few further interpretations that occurred as part of the writing up process, as is common with interpretative phenomenological analysis (Smith et al 2009).

In this higher-level theme the relationship between the dyad is explored. Threats to the relationship precipitated by both falls and dementia emerged from the data and are explored here. It is worth considering that these findings do not focus exclusively on the falls experiences. It was difficult to consider

these experiences in isolation from the dynamics of the dyadic relationship of the care-recipients and their carers. The falls experience both permeates, and is permeated by this relationship. Three component themes that relate to the caring relationship and falls are presented here. The three themes are:

- The dyadic relationship: “We’re always together”
- Dealing with the impact of falls: “Learning as you go along”
- Coping alone: “nobody was interested”.

Whereas the first theme considers the couple’s experiences and maintenance of their relationship in response to falls, the remaining themes relate more to the carers’ experiences and perhaps demonstrate the tensions that existed for carers to maintain the caring relationship, and to deal with changes that occurred as a result of falls. All the themes occur in the majority of the data sets from both interviews and focus groups. Table 7.2 identifies the themes and their prevalence across the data set.



**Table 7.2 Prevalence for subthemes across participants for higher level theme 3**

Participants		Themes		
Care recipient	Carer	The dyadic relationship: “We’re always together”	Dealing with the impact of falls: “Learning as you go along”	Coping alone: Nobody was interested
George	Vicki	*	*	*
Tony	Susan	*	*	*
Wendy	Bernard	*	*	*
Vera	Paul	*	*	-
Rita	Neil	-	*	-
Sheila	Patrick	*	*	*
Bob	Norma	*	*	
Eileen	Karl	*	*	*
Bridget	Harry & Alison	*	*	*
<b>Focus group 1</b> David, Andrew, Bill, Edward	Kathryn, Diana, Christine	*	-	*
<b>Focus group 2</b> Eamonn, Verity, Bill	Maggie, Sally, Marion, Derek,	-	*	*
<b>Focus group 3</b> Sarah, Rena	Joyce, Geoff, Peter, Deidre, Joe	-	*	*

### 7.2.1 The Dyadic relationship: “We’re always together”

This theme presented itself in different ways, but demonstrates the close relationship between the dyads, although this closeness carried various

meanings. Sheila (care-recipient) who made the statement “we’re always together” considered that she didn’t worry about falling over outside, or the consequences of a fall as she rarely went out without her care-giving husband. Sheila expressed great satisfaction and happiness about being together as a couple, going to the shops and sharing the enjoyment of the social interaction with others. The togetherness of the relationship, and reliance on her husband not only to protect her from harm but also to provide enjoyable activity was also illustrated by Sheila immediately referring the interviewer to Patrick, her husband for memory of facts or incidence of falls, rather than attempting to remember this herself. The reliance upon the carer to remember the facts of their falls was also expressed by Bob, George and Bridget (care-recipients). George’s rationale for doing this was his concern to “get the facts right”.

In other circumstances, in joint interviews and focus groups, the couples had a joint memory of a fall with the carer facilitating the care-recipient’s recollection of their fall, by either confirming their recall or by prompting and telling the story of the fall together. This can be seen in the interchange between Wendy (care-recipient) and Bernard (carer):

**Bernard (husband-carer):** “... The serious one was when we were expecting Pauline and you decided to clean the wall in the kitchen.

**Wendy (care-recipient):** Oh yes, I remember it happening

**Bernard:** and you fell off the stool

**Wendy:** it’s my sense of balance. I don’t think I’ve got a good sense of balance” (1.599).

The telling of a joint story was not exclusive to spouse couples. For example, Vicki (daughter-carer) and George (care-recipient) also talked about a fall which Vicki had not observed. Vicki hypothesised that her father, George (care-recipient) fell because he couldn’t decide between the need for the toilet or a drink. In another instance Vicki prompted George’s memory of events of a recent fall:

**Vicki (daughter-carer):** You said that you saw the flowers in Prince John’s Park.

George (care-recipient): Oh yes, well I did.

Vicki: Because you told me how nice the flowers were.

George: Yes, they all were very good.

Vicki: And I know that he hadn't been down there recently to that...

George: ...It's quite a little walk, you know. (I.2960)

In other instances, the sharing of experience extended to the care-recipient's rehabilitation, for example, where carers said "we go to physiotherapy". Patrick's (carer) involvement in Sheila's home exercise programme was apparent:

"... And he has given us special exercises on the bed where she'll put her legs that way, brings them together. And then we put a roll of kitchen towel under her legs and lift her legs up and down..." (Patrick, husband-carer, I.1433).

In Vicki's and George's narrative the closeness of the relationship between father and daughter is evident, and in Patrick's narrative the intimacy of the relationship of husband and wife are fore-grounded rather than the relationship of carer and care-recipient. However it could be said that Patrick's lifeworld has also shrunk and become delineated by Sheila's falls rehabilitation.

Sheila's narrative also showed her feelings for Patrick. She relied on Patrick, her husband, not only for memories of facts and the successful carrying out of everyday activity, but also for emotional support:

"...No I didn't feel embarrassed - because Patrick being with me. If I'd have been on my own I would have been... But seeing he was there, you know. I suppose he was there before I fell" (Sheila care-recipient, I.102).

In some instances the obvious affection and the acknowledged reliance of the older person on their carer was marred by the impact of the dementia on the relationship. Vera's and Paul's conversation provides an example of this:

Vera (care-recipient): "...I don't know what I would do if I didn't have him.

Paul (son-carer): Can't even remember my name.

Vera: Pardon?

Paul: You can't even remember my name.

Vera: No, I can't. I can't talk to you half the time can I?

Paul: Well I think you've done alright." (1.694).

In IPA, dissonant experiences are valued as well as shared accounts. For Paul (carer) and Vera (care-recipient), the "being together" in sharing of the falls experiences was limited. Paul (carer) expressed feelings of guilt that he rarely witnessed his mother falling – but that he deduced that this had happened by finding her on the floor or through an awareness of her being more subdued and uncommunicative. Vera (care-recipient) could not recall falling but was aware that she probably had fallen because she had "aches and pains" and felt "stupid". Because of Vera's limited awareness, Paul tended to make unilateral decisions for changes to Vera's home such as removing furniture and rugs, or restricted her activity by no longer taking her for a walk outside. This was based on his supposition of how or why Vera fell, according to where he found her.

Being together for Neil and his mother Rita occurred after Rita had a series of falls and subsequent hospital admission:

Neil: "They said to me then that she can't be left alone any more...Because I used to come and go. I had a girlfriend I was seeing you know ... and uh ... well I came back you know and I'm living with her permanently now you know. Well I can't see her go in a home...So ever since I've been a 24 hour carer.

Int: so if your mum wants to get up in the middle of the night do you ...

Neil: I'm there, I'm on call. I'm there. Yeah she's only got to call out". (Neil, son carer, 1.379).

Neil's use of surveillance in his concern for his mother Rita (care-recipient) to prevent her from falling was also apparent in other relationships. Harry (carer) voiced how he tried to ensure his wife Bridget remained with him at all times when they went shopping to prevent her from falling and possibly from getting

lost. Harry himself had health problems and poor mobility and used a mobility scooter when they went out together:

“A lot of women are like this, I see them here. The wives walk 10 yards behind the husbands ... Well time and time I said ... And I said “hold the back of the scooter when you’re coming out with me...so... Of course the fact that she’s behind me, [but] I look – she’s missing...” (Harry, husband-carer, l.316).

Harry’s narrative portrayed his anxiety about the consequences of Bridget not doing as instructed by not staying together. Bridget’s sense of agency and autonomy was also indicated in the interview. Although Bridget had mild dementia at the time of the interview she did not go out alone, but expressed enjoyment of times of solitude in their home and in recollections of the past. However in this narrative, Bridget’s time alone resulted in her falling on the pavement, unable to get up and being found by a passer-by. Harry’s desire to keep Bridget together with him did not always prevent her from falling. Bridget and Harry’s daughter, Alison recounted how she had taken her mother, Bridget shopping:

“... the pavements were really bad, and that’s obviously how she fell. I mean she was actually holding my arm, but she still went just down like a sack of potatoes” (Alison, daughter-carer, l.477)

Different aspects of “being together” have been portrayed here. For some the intimacy and closeness in the relationship are apparent even in joint participation in post-falls exercises or in sharing a supportive facilitation of memories during the interview. In other instances the “being together” involved bodily surveillance by the carer and some discord between the couple, with the carer placing restrictions on the person with dementia to prevent falls from happening again. It could be said that the falls experience acts as a third partner, as a shadowy presence that the couple has to reckon with, perhaps revealing the strengths and weaknesses in their relationships.

### 7.2.2 Dealing with the impact of falls: “Learning as you go along”

This theme relates to how carer participants considered how they learned to deal with the impact of falls, how they tried to prevent them re-occurring, as well as their struggles to maintain the status quo. Falls created transitions in relationships, creating great dependency of the care-recipient on the other, often because of physical care needs. The theme is taken from an extract of Neil’s interview (carer) and he, like many other participants, expressed how he learned to care through trial and error. Carers recounted how they learnt to physically look after the care-recipient who had had a traumatic injury after a fall, such as fractures, lacerations or painful bruising. Other carers found themselves providing assistance with everyday activity because of the care-recipient’s fall-related loss of confidence. In some instances, carers described deciding that they needed to take more responsibility and control following a fall. The care-recipients’ accounts revealed an increasing reliance on the carers to prevent falls, with a handing over of responsibility to remind them of potential hazards or protect them from harm. Carers talked about changing their own behaviours but sometimes the change in behaviour was described as more of a challenge, or as perhaps requiring too much of a mental load:

“... And sometimes it’s not that you haven’t got the will; it’s sometimes that you’re not concentrating on what you’re going to do, perhaps you know that you don’t take in all the circumstances, but yes it has changed my behaviour. I have tried to be more solicitous when we’re near kerbs...” (Susan, wife-carer, I.639)

Carers voiced their concerns in different ways, especially about possible injury to the care recipient as a result of the fall. Peter, a carer in one of the focus groups, talked about his distress after finding his wife Sarah (care-recipient), following one particular fall:

“ I heard a noise coming from my wife’s room, a groaning sound, so I went in there and she was laying on the floor at the foot of the bed, face down, and I sort of moved her slightly to make sure she was still breathing and so as not to

do further injury I phoned the ambulance service .... And anyway they tested her and released her that same day. And I've come to the conclusion that the accident was caused by the bedcovers draping onto the floor by several feet. There was about a foot sort of laying on the floor. So she got her feet and went out that side of the bed, entangled her feet in the bedcovers, and fell. Though the moral of that is of course always tuck your bedcovers under the mattress to avoid that." (Peter, husband-carer, FG3, I.66).

It seemed that many carers like Peter, learned what to do by trial and error, responding to upsetting or serious fall experiences. Carers described many strategies to prevent further falls, including advocating for more investigations for the care-recipients from their General Practitioner (GP), using surveillance or control by locking doors, or by trying to eradicate home hazards such as rugs, stools, or gas ovens. The dilemma of 24-hour monitoring to prevent falls from happening again was recounted by others:

"...of course I have to watch him; sometimes he forgets where he's going. He doesn't know where the toilet is and I have to go and show him where it is. Well, he's better in the morning because he has the tablets you see." (Norma, wife-carer, I.755).

Maggie (daughter-carer) also advocated a monitoring approach in caring for her mother saying:

"You have to be there for them as they don't know what the consequences could be..." (Maggie, carer, FG2, I.409).

Not all monitoring was intended to prevent falls. Norma locked the house doors to prevent Bob (care-recipient) from going out; not just to stop him from getting lost, but also to prevent him from knocking on their neighbours' doors. Such bodily surveillance and control could be said to prevent Bob from carrying out socially stigmatising behaviour.

Other carers found supervising and monitoring difficult to adjust to. Vicki perceived her father George (care-recipient) to have lost his confidence and independence overnight after a fall. George had been independent and actively contributing to family life. However immediately after his fall he became very dependent upon Vicki and her husband for everyday tasks such as knowing what to wear and how he should dress. His sudden dependency and inability to make decisions changed their relationship dramatically, and also that with his grandchildren and his role within the family.

Susan had conflicting feelings about the changes that were occurring in her relationship with Tony (care-recipient) and she seemed undecided in what she needed to learn in this relatively new role from wife to carer:

“It has just made me realise that I’ve got to keep an eye on him. I haven’t got to the point where I don’t feel he can go out on his own, because I don’t think that would be right... There’s no way I am going to sort of mother him or smother him so he doesn’t do anything. I mean I do a lot for him...” (Susan, wife-carer, I.1837).

Indeed Susan’s suggestion of not mothering or smothering Tony in the future phrase is interesting and perhaps the strongest indication of her perception of what caring for Tony would be like in the future. It has an almost sinister feel to it, and perhaps indicates her concern at not being able to care (both physically and emotionally) for Tony when he requires more help.

Dealing with the impact of falls, trying to prevent them from happening again and coping with everyday life provided unwanted challenges for many carers. Patrick (carer) found himself increasingly caring physically for his wife, as Sheila’s mobility declined after fractures to both her humerus and femur following two successive falls:

“...walking and toileting is the bane of my life. I go to bed some days and I think to myself ‘when is it going to end, do we see any end to it?’ I mean when you think about the Alzheimer’s to start with you think ‘oh that’s a piece of cake’. But it’s the things that come along ...The consequential things that come along



... That you don't know about do you? ... Like bringing up kids, you don't get an apprenticeship" (Patrick, husband-carer, I.2667).

Patrick's sense of hopelessness and isolation demonstrates the struggle that carers were undergoing on a daily basis, learning by often negative experiences in how to care for the care-recipient. These struggles related not only to the progression of the dementia but also in dealing with the consequences of falls. Indeed, in Patrick's narrative the consequences of Sheila's falls seemed to be the focal point of their relationship, and changed Patrick's behaviour. It would also seem that many carers, like Patrick, were increasingly attending to the body rather than the person they were caring for, either because of the care-recipient's physical injury or loss of confidence as a consequence of the falling. It could also be inferred that the carers focussed on the falls as perhaps these were experiences that they felt they had some control over and sense of agency. The monitoring and restriction of activity to prevent falls and subsequent injury is likely to have led to a loss of autonomy for the care-recipient, a change in the relationship between the dyad and also a subsequent change in role for the carers (and potential loss of identity) from wife, husband, son or daughter. In some accounts, these changes were represented as occurring suddenly, and in other accounts, quite insidiously.

### 7.2.3 Coping alone: "Nobody was interested"

The two preceding themes have considered the dyadic relationship between the care-recipient and their carer, and how they as couples, or families, responded to the falls experiences. However, this theme reveals the feelings of isolation, vulnerability, sense of responsibility and impact on the health and well-being of the carer, particularly associated with a fall by the carer or the care recipient.

The quotation "nobody was interested" was taken from Patrick's (carer) narrative as he talked in one instance of feeling at the point of collapse. He later related how his own fall at home had resulted in admission to hospital with consequential surgical intervention. Sheila, his wife (and care-recipient) was cared for by their son and family until Patrick was discharged from hospital.

Waking up during his first night home, he found his wife Sheila huddled on the floor and he recounted how he struggled to get her back into bed, even though he had been advised not to do anything too strenuous following his surgery. This feeling of coping alone and putting one's own health second, was echoed by another husband-carer, Harry, who had also been advised not to do any heavy lifting because of his own health condition. Even so, he recounted struggling to get Bridget, his wife and care-recipient up from the floor after she fell during the night. The challenge of trying to deal with their own health issues whilst caring for their spouse after a fall and dealing with the expectations of health care professionals that they should be able to cope is illustrated in another instance by Patrick (carer):

“At no time was I as a carer addressed. They (acute care services) don't care that I've got prostate cancer, which I have, or whether I'm asthmatic or whether I'm now half blind, they couldn't care less about that...” (I.1331)

Similar concerns were voiced by other carers. They described feeling that their GP and acute care services were unsupportive and had little understanding of their situation or had poor attitudes to people with dementia.

Karl's desire to maintain his wife Eileen's opportunities to go shopping (a favourite activity) and to run necessary errands made going out to the local shops a challenge. Karl (carer) recounted how Eileen (care-recipient) had fallen over crossing a road, also pulling him to the ground. As a result of Eileen's deteriorating mobility, increase in falls and Karl's own declining health and abilities, Karl described going to the GP for help. However, he was dismayed that the GP refused to sign an application for a disabled parking permit. Karl felt he had little option but, to buy a wheelchair for Eileen:

Karl (carer): “I mentioned to the doctor that I was going to buy one. He said don't buy one because she will, she will, uh...”

Eileen (care-recipient): ...recover

Karl: ...it would be no good for her. Where if I didn't then it would be...

Eileen: ...stuck in the house all the time” (I.626).

This lack of understanding of the couple's difficulties left Karl feeling powerless and unsupported in trying to maintain his wife's main social interaction and enjoyment whilst preventing falls and struggling to manage the daily routine. In this narrative one can also wonder what Karl *didn't* say. A supposition of what was unsaid was perhaps the GP's concern for potential deterioration in Eileen's mobility if she used a wheelchair, versus Karl's concern about a potential reduction in their quality of life, Eileen's mental state and his ability to cope if they were both limited to the house. However this can only be surmised.

Karl's (and others') resolution to avoid falls and their consequences, was often framed as an attempt to prevent admission of the care-recipient to residential care. Even though Karl felt his own health and wellbeing being was at risk, he had a greater fear of long term care for Eileen (care-recipient), as a result of witnessing the distress and deterioration of a family friend whilst in a nursing home:

"In future even I think if we need home help then I don't want her (Eileen) to go to an old people home, you know. I never ... I kept some cuttings from newspapers and I have a friend in one of these homes and when we used to go to visit her she was always knocked over ... not because she was beaten, but fell down". (Karl, husband-carer, I.323).

Where support had been given by services, carers sometimes described negative experiences. Neil (son-carer) voiced his concerns about respite care:

"...she (Rita) went in for a couple of weeks at XXXX and she had a fall, she come home one day and she was ... well she came out... As I collected her from the vehicle and she couldn't hardly walk. She couldn't hardly stand, I should say ... I said – 'You weren't like this when you were here'. I don't know, I weren't there I'm not criticising, but she went downhill..." (Neil, son carer, I.450).

As a result of the fall during respite care and her consequent lack in mobility, Neil felt that he could no longer trust others with the responsibility of his mother, Rita. He considered refusing respite care for his mother, but also voiced the dilemma that he needed relief from caring.

In other narratives, carers' own vulnerability to falls emerged. Carers related how they themselves had been pulled to the ground by their spouse as they fell. Carers also described their own falls, attributing these to getting older, feeling unsteady, being busy or distracted. In one focus group, wife-carers Christine, Diana and Kathryn talked about how they had fallen whilst out without their husbands, with Christine suggesting that her pre-occupation about her husband, amongst other demands, led to her fall.

It could be suggested that the mental load and feelings of responsibility for the care-recipient, even when they were not physically present, made these carers themselves more vulnerable to falls, with consequential feelings of frailty.

Where support was given or requested from service providers, carers often felt let down, ignored or left with a sense of mistrust, thus increasing their potential sense of isolation. The impact of falls and their prevention on the health and well-being of the carer and also the interdependence of the health and well-being of both members of the dyad did not seem to be fully understood or acknowledged by those around them. This seems particularly pertinent for Karl, Harry and Patrick; all older spouse carers with their own health conditions and activity limitations. Indeed one could also argue that the carers themselves (for example Neil and Christine) either ignored or placed their own health and well-being needs second to those they were caring for.

#### **7.2.4 Summary of findings for higher level theme 4**

The findings that have been presented in this higher-level theme have explored how the experiences of falling and dementia are intertwined in the caring relationships of these participants. The first theme has shown how the experience of being together changed because of the care-recipients' falls. For some dyads, the intimacy of their relationship was maintained through the sharing of intervention and the carer facilitating the care-recipient's physical and psychological recovery following the fall. For others the "being together" created changes in the caring relationship, with the care-recipient becoming less autonomous and more dependent upon the carer, for either physical or

emotional needs, or indeed, both. In some instances, the care of the care-recipient was handed over by them, in other instances the care of the care-recipient as taken from them, either by the carer, or because of the consequences of falls. The second theme relates more to how the carers learned to deal with the consequences of falls. Carers voiced different and conflicting views of caring, perhaps demonstrating what a complex and multi-faceted role it was. The final theme conveys how the carers own vulnerabilities and their feelings of isolation which emerged as a result of trying to cope with consequences of falls as well as trying to prevent them happening again, were expressed in their narratives.

### **7.3 Summary of higher level themes 3 and 4**

In this chapter, the presented themes address less obvious consequences and ramifications of falls. What emerged was the intertwining of falls and dementia, so that the falls experience rippled out into the lifeworlds of the care-recipient and carer as the manifestation of dementia. The consequences of this intertwining of falling and dementia within the participants' lifeworlds, seemingly led to threats to identity and sense of self for both care-recipient and carer, and threatened the relationships of the dyads. In many instances, the consequences of falling either lead to a change in relationship from husband and wife, father and daughter, or mother and son, to carer and care-recipient, or the fall reinforced and highlighted the change in roles and relationships.

Whereas carer and care-recipient shared some of the experiences, other experiences differed. Whereas the care-recipients' sense of self were perhaps threatened by a loss of independence, the carers' sense of self and identity were threatened by taking on the role of carer, which seemed to be accompanied by an increase in physical and emotional burden, health risks and feelings of a lack of awareness and support from services.

## 7.4 Reflecting on the analysis and findings from the primary study

As already discussed in Chapter Five, several different ways of analysing the data were followed to find the best way of presenting the data to answer the research question. Each time the data were analysed my skills improved and I became more interpretive. My early attempts were quite descriptive and concerns at this time that my data was too 'thin' became groundless. I began to realise that I had a large amount of data and began to feel overwhelmed.

As already discussed in section 5.7 I had begun to reflect on the participants' accounts as a whole, and also those parts of the interview that I had considered "off topic" at the time of data collection. I began to reflect on the meanings of Tony's story about when he played cricket at school, or Wendy insisting on going to grammar school in spite of her visual problems. From these parts of their accounts I began to see an overall picture and then analysed other parts of the transcript more deeply.

I started to get braver with my analysis as I understood the paper by Smith (2004) more and looked more closely at the language that participants used – either their metaphors or individual words. The following excerpts from my diary provide examples:

27<sup>th</sup> May 2010

*George describes an external "being" involved in his falls as if someone/thing was playing tricks on him. In the first interview there is an embodied sense to the fall and his recollection of his body. A very physical and sensory description. In the second interview he talks about being lumbered and tugging as if he is disembodied or being controlled like a robot – a slightly surreal picture.*

*In the joint interviews both George and Vicki construct the story. In the 1<sup>st</sup> carer interview Vicki seems irritated that her father is worried about getting lost, and in the 2<sup>nd</sup> interview she worries about him getting lost so he no longer goes out alone.*

*In the 1<sup>st</sup> interview George switches from “I” to “we” – is this the “politically correct response” and not necessarily his own belief or decision?*

*In Tony’s 1<sup>st</sup> interview he reinforces the normal everyday interests he has – is this to identify his normal identity and not as a person with dementia? However he seems very determined to keep himself under control so he doesn’t make a fool of himself. It is interesting that his hobbies/interests always involve him looking out beyond himself (bird and train watching, sport). But now he is always looking at his feet for cracks/bumps in the pavement, to as he says, “trip over”.*

What I have become aware of is that the analysis of the data never stops. In between writing up theme four for publication and finalising the writing up of this chapter I reflected as follows:

Feb 2011

*Even though I am pleased to have submitted the Ageing and Society paper I have been thinking about the levels of interpretation carried out. So may have “thrown” some of the quotes away. So I need to relook at the use of metaphors (e.g. mother or smother) and unpack these more. Also need to look more at the 3<sup>rd</sup> level of analysis – use of individual words “the”, “It” etc. (Smith et al 2009 - 3<sup>rd</sup> level of analysis).*

Even now I become aware of alternative interpretations for some of the quotations presented in these chapters. I find this a stimulating process and confirm how time and subjective experience can influence analysis and perhaps how my skills of interpretation have changed.

## **Chapter 8 - Elaboration and illumination of the falls experience: Findings from secondary study**

In this chapter, the research question “*What are the elaborations and illuminations of older people with dementia and carers of the falls experiences of others?*” is addressed. As already stated in chapters four and five (Methodology and methods) the aim of this stage of the research was to stay true to the phenomenological core of the research and to Heidegger’s concept of illumination and uncovering (Moran 2000) through elaboration of data from the primary study. In this second stage of the research, data were collected from participants in two focus groups. Both focus groups were carried out with pre-existing groups from a London branch of the Alzheimer’s Society – one group with older people with dementia and the second with carers. These groups were from a different branch of the Alzheimer’s Society and therefore involved different participants from those recruited in the primary study. Information about the participants has already been presented in the methods chapter and all names have been replaced with pseudonyms.

The data collected from both of these focus groups were subjected to inductive thematic analysis, as described and justified in the methodology and methods chapters (four and five). As already stated in the methods chapter (five) the data were analysed so that individual accounts could be revealed and presented (see appendices O and P).

Any similarities in the themes between the primary and secondary studies were not engineered or anticipated during the analysis. Participants were given large numbers of cards that were not sorted by the themes presented in chapters six and seven, and these were used to prompt and trigger discussion. There was a six-month time period between the final analysis and writing up of this secondary study and the writing up of the findings from the primary study. Therefore, it is suggested that similarities in the analysis is coincidental. However, it is perhaps inevitable that some carryover from one study to the other may have occurred, but the inferred themes in this secondary study can be defended by supporting quotation. It is also acknowledged that within a more

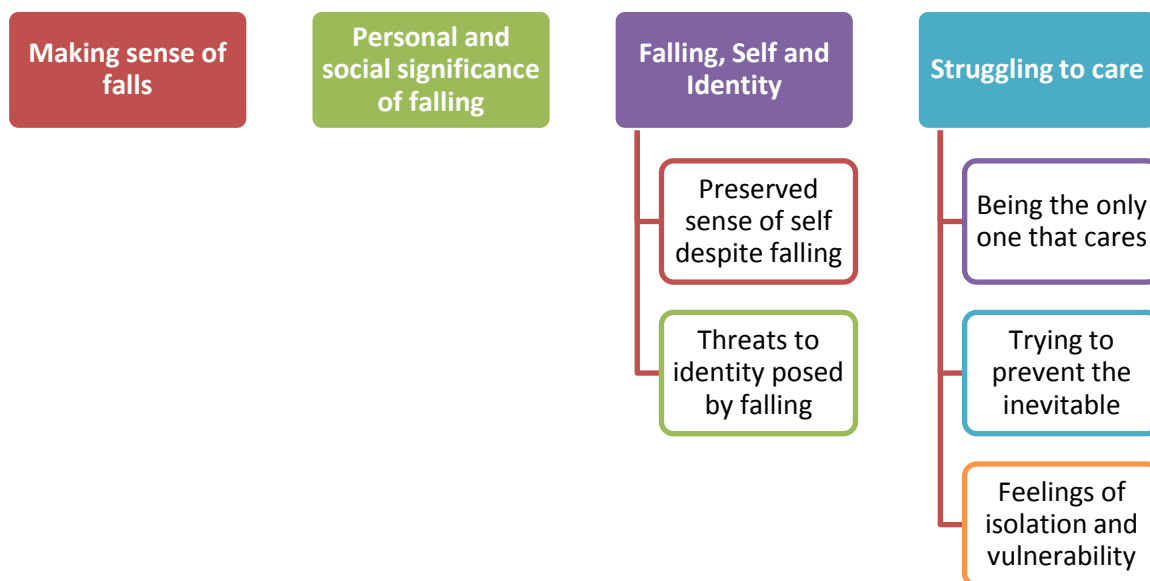


interpretative phenomenological framework that the interpreter has pre-conceptions and pre-understandings, but that they attempt to privilege and prioritise the new phenomenon through a deeper engagement with the data (Smith et al 2009, Finlay 2011). The major themes that came out of the data are:

- 1. Making sense of falls**
- 2. The personal and social significance of falling**
- 3. Falling, Self and Identity**
- 4. Struggling to care**

The first and second themes – making sense of falls and the personal and social significance of falls relate to data from both focus groups. However, the remaining two themes have a common thread but have different nuances because of the different perspectives and experiences of the participants in the groups. Theme three considers the sense of self and identity expressed by the people with a recent diagnosis of dementia. The final theme considers the identity of carers and the accompanying roles and responsibilities that in the main had developed over several years, especially in relation to their care-recipients' falls. Even though themes three and four have similar overarching considerations of identity, there are many differences. It was therefore considered pertinent to present these findings as separate themes. The findings presented in themes three and four have also lent themselves to being presented under subthemes. The major themes and subthemes (where used) are presented in figure 8.1.

As in the previous findings chapter for research question one “What are the experiences of older people with dementia and their carers of falling?”, the findings presented in this chapter have been illustrated by the use of direct quotations from the participants in stage two of the research and have been colour coded for easy differentiation. Quotations from the older person with dementia are in blue and from the carer are in red.



**Figure 8.1 Major themes and subthemes addressing research question two**

### 8.1 Making sense of falls

When presented with the cards of summarised data and quotations from stage 1, these participants were asked to consider whether they agreed with the content of the cards of what previous participants thought a fall was, or would like to suggest further explanations. Even though participants from both focus groups felt that these statements and quotations resonated with their own experience, they then related what they considered a fall to be specifically from their own perspectives. Only Felicity in the carers group suggested the more generalised concept of a fall being a loss of balance and Stephen in the group of people with dementia suggested that a stumble could be considered a fall. It would seem that the majority of these participants made sense of the data by attributing their own meanings and experiences to it. However, Stephen returned to the quotations from the cards a few times, questioning the logic of some of these, especially the quotation “if I fall I fall properly” (Kathryn FG1, l.25). Stephen’s response to this quotation was “well you either fall or you don’t”

(I.126) and developed his reasoning further by associating the concept of a fall to his own experience:

“Well it’s so quick isn’t it? If you trip you fall. That’s all there is to it. You can’t say as you’re falling ‘oh I’d better ...’” (Stephen, I.132)

Kathryn had implied jokingly that if she fell it had serious repercussions, which Stephen did not consider and instead had taken a literal interpretation of Kathryn’s experience. Interestingly no other participant passed any opinion about the quotation from Kathryn, nor did they follow up on Stephen’s interpretation. It is therefore unclear if they understood or interpreted Kathryn’s humour in conveying her fall as a momentous experience, or that they did not want to confront or contradict their co-member of the group.

When considering the summarised quotation “landing on the floor without warning” Martin and Stephen (both with dementia) had the following discussion:

Martin: “Well I was saying that this one presumably is when you’re coming downstairs and you miscount the stairs...”

Stephen: “Do you count the stairs when you come down, do you?”

Martin: “I beg your pardon?”

Stephen: “do you count the stairs?”

Martin: “no I don’t count them, but subconsciously I get them wrong, and there’s either one more or one less than I have been expecting – for some reason or another.” (I.51).

In response to this quotation Martin interpreted the “landing on the floor without warning” to relate to falls on stairs, and indeed in other parts of the discussion he mentioned incidents where he or others had fallen, had nearly fallen, or were anxious of falling on stairs and steps. He later talked about “an unexpected step is a nasty one” (Martin, I.283) and one can only guess his anxiety about his own risk of falling on stairs. In their conversation Stephen seemed curious, wanting to understand and make sense of Martin’s experience, perhaps finding it easier to gain a sense of the meaning of falls by engaging in the dialogue with Martin

rather than trying to relate to the quotations of unknown and faceless others from the primary study within the research.

The same summarised quotation of “landing on the floor without warning” provoked discussion in the carer’s focus group about what a fall is:

Mary: “and this one, you suddenly are down”

Interviewer: “landing on the floor without warning, yes?”

Liz: “from a standing or sitting position?”

Mary: “From a standing position, usually walking and suddenly you are down” (l.82-86).

Once again it can be considered that Mary’s interpretation of the summarised narrative resonated with her own experience. This occurred in other instances, (and in both focus groups), but perhaps were more directly related to the participants’ experiences of loss of balance, stumbling or tripping, with Martin (person with dementia) and Liz (carer) recounting how their partners had tripped on paving stones or by catching their feet. Liz said:

“I think it’s catching feet as well, because they stand up and suddenly, you know, they want to move and the feet are not moving and they sort of – well in a way they do stumble but it’s catching on each other” (Liz, carer, l.95).

Participants quickly moved to exploring the perceived causes of falls in more detail in both focus groups, with the identification of a fall and its cause being closely linked. In some instances, participants from both focus groups accepted the causes of falls given by stage 1 participants – such as varifocal glasses, infections and medications, without debate. However, participants also related perceptions and experiences of falling that were different to those presented to them from stage one, such as an individual’s legs “giving way” or slow reactions when changing position. Mary (carer) considered that falls were “connected with the blood pressure” (l.37), which she related to both her own and her husband’s situations.

Participants in both groups, but particularly the group of people with dementia, discussed extrinsic causes of falls such as poor lighting and also footwear. Alan told his story of a fall that he considered had been a life-changing event:

“Well that’s what happened to me about 3 years ago I broke my left leg. Somebody bought me ... one of my relatives bought like slip on shoes, the sort of thing I wouldn’t have bought myself; I always buy lace-ups. And as I was coming down the stairs one of the shoes came off and I slipped down” (Alan, person with dementia, I.359).

Even though members of the carers’ group talked about extrinsic causes such as slipping in the bath, they also considered more intrinsic causes for falling. Daniel (carer) said:

“Well I thought that a fall could be caused by absence of your surroundings and then you step out or whatever happened, assuming that what you’re seeing, that’s what you’re doing. But it could be the opposite to what is there, you’re actually doing. So you step into an area that is not there ... but that’s what you can see, and you get a fall from that as well” (Daniel, carer, I.65).

One wonders here if Daniel is not necessarily describing his own experience but perhaps puzzling or trying to make sense of why his wife fell. His narrative of something being “there”, but “not there” could be interpreted as an internal “malfunction” which is also explored in Iris’ story:

“I’d like to say that I think it’s because people with dementia or Alzheimer’s, you see, their brain doesn’t work quickly. Because often I have to say my husband something three times before it gets there. So I think whatever they do, like standing up, takes longer for it to get to the brain, so therefore they go. Whereas we would just do it automatically, they take you know perhaps a minute or more to get you know ... for it to connect. Sometimes it doesn’t connect at all.” (Iris, carer, I.129).

Trevor from the group of people with dementia, also described a feeling of disconnection, but in his story it was not his brain or cognitive dysfunction that he considered as the cause of his fall:

“Well if I’m trying to run somewhere that’s a disaster really because my legs cannot keep up with the movement of my body” (I.245)

Later in the carers’ focus group, participants considered the reason given for falling from the primary study; “thinking of other things” and further explored how the mind or body itself could compromise and cause falls. Christopher and Felicity suggested that one could fall because one was distracted, either by other people or by negative thoughts. The dialogue within the group then developed further:

Christopher: “well that means you’re not concentrating on what you're doing, so you're more likely to...”

Iris: “... too much on your mind”

Mary: thinking for people” (I.169)

Fiona then further developed the idea of thinking for two:

“I mean I’m sitting there and I’m thinking for two people. Because my husband comes from the day centre and I’m thinking I don’t want to be late ... you know you’re always thinking for two people.” (I.180).

Later Fiona and Felicity found meaning in the quotation from the primary study of trying to do two things at once, which Daniel explored further:

“It’s the same thing I was saying, when you’re not on focus on that thing, anything can happen, you can fall. Because you’re talking to me and you forget where you’re putting your foot, next step, and you down in a ditch and over you go. So I would completely agree with that.” (Daniel, carer, I.205).

Daniel also observed that there are many different reasons for falls and some of these were difficult to comprehend. He struggled to understand how his dependant wife had fallen out of her wheelchair and been injured when she was being transferred from one place to another in her nursing home:

“I also find that a fall comes in so many different ways. Falls come even in attending to your wife, your husband, or mother. Where my wife was, she receive an ugly gash under there. And what they told me, she was in attendance in a wheelchair trying to get from A to B and she fell. And you know that never leave my mind. I been looking at the pictures today and it’s a problem. So therefore even attending to them you do find that fall come, rightly or wrongly I don’t know, I still can’t see how somebody could in an attendant chair, putting them there and they fall out to get a cut under there. I can’t understand such things, so if that is true then even having them in a wheelchair to move around, you do have falls. What cause it I don’t know.” (Daniel, carer, I.569).

It is worth considering if here, Daniel was reluctant to openly criticise the care staff for not looking after his wife better. In a way his “not understanding” is an ironic understatement of the lack of information about his wife’s fall from the nursing home. This also suggests that he had an on-going anxiety about his wife’s welfare and a lack of trust in the staff if he was not there to monitor the situation.

In this theme participants from both focus groups considered the summaries and quotations from the primary study. All of the participants engaged with and made sense of the data by elaborating upon it, telling of their own experiences and stories. Whereas Martin and Alan from the focus group with people experiencing dementia, associated falls with external causes such as steps and shoes, many of the participants from the carers’ group attributed their own and their partners’ falls to intrinsic causes, such as being distracted, thinking for too long or having slow thought processes. For others, such as Daniel, falls seemed to have mysterious causes, especially where it was assumed that all risks of falling had been eliminated, with an underscore of unstated blame of his wife’s care staff.

## 8.2 The personal and social significance of falling

This theme considers the impact of falls on individuals both from a personal and social perspective. Once again participants were asked to consider the stimulus cards derived from the primary study data. However their own experiences and opinions were soon fore-grounded in their discussion. In the focus group with the people with dementia the impact that a fall had, or could potentially have, was debated:

Stephen: “Well you just ... fall and that’s it, it’s gone, it’s in the past isn’t it?

I: so you’re quite, you know practical about it?

Stephen: yeah practical, yeah I fell over, I get up that’s it, it’s gone.

I: yeah. What about you?

Martin: I think it depends on whether you hurt yourself...” (I.151)

Although Stephen considered that he quickly recovered from a fall in the extract above, in a later discussion he voiced feelings of social embarrassment when falling in public, as the dialogue between Keith and he demonstrates:

Stephen: “you feel a right character.”

Keith: “Yes ... and you remember it.”

Stephen: “... fall over and you think ‘god, what an idiot!’ (I.467)

One could suggest that in these two separate focus group segments, Stephen presented with conflicting responses to his falls, from a potentially pragmatic minimisation of the experience to resultant feelings of embarrassment. Alan suggested that a fall must be more significant if one didn’t know what had caused it.

“... But yeah the thing is with me, I mean I know what did it. But if you don’t know and you’re suddenly coming down the stairs and suddenly you just fall it must be bad...” (Alan, person with dementia, I.508)

Participants in the carers’ focus group also discussed the consequences and impact of falling for themselves and their care-recipients. Mary and Fiona



echoed some of what was said in the focus group with people with dementia by saying:

Mary: "You feel embarrassed."

Fiona: "Oh yes, you try and get up as quickly as you can."

Mary: "You just look around - who saw you!" (I.642).

Iris, Mary and Felicity considered how falling could cause more than embarrassment, but also bruising, aches and pains for both the person with dementia and the carers. Carers described practical strategies to prevent the person with dementia falling, such as finding the "right" shoes, and having rails fitted in the house. When commenting on the story of carers in the primary study being pulled to the ground when the person they were caring for had fallen over, Iris recounted how she held her husband in a particular way so that if he fell she did not fall with him. Iris was perceived as "the expert" (I.3), by others in the group. Her commitment to preventing her husband from falling is demonstrated in the following narrative:

"But after Brian has had a fall I've sort of gone and sit down, think about it and think, now I can't let that happen again, what do I do? You know ... and try to resolve it." (Iris, carer, I.671)

Iris's desire to change behaviours and strategies after a fall was echoed by others in both focus groups. Whereas Trevor considered that he would also have to think things through, Alan considered how he had become more cautious:

"Well I try to think it over very carefully how that happened. I have just got to put out my hands you know. I don't know how I went all the way down to my face." (Trevor, person with dementia, I.795)

"I'm much more careful on the stairs now. When I go up, and coming down, now. I never used to bother, I used to fly up and down the stairs, I never gave it a thought. Made me much more wary " (Alan, person with dementia, I.858).

In this theme the significance of falling was considered by participants. Whereas Stephen portrayed a pragmatic approach to falls in one part of his account, suggesting that these lacked personal significance, others considered how different factors such as falling in public, the severity of the consequences or knowing why one had fallen would influence the impact. Changes in behaviour were also discussed to prevent further falls. Here participants used the data from stage one of the research to elaborate and discuss their own experiences and yet much of their discussion mirrored that of participants in stage one.

### **8.3 Falling, Self and Identity**

This theme considers the findings arising from the group of participants with dementia. These participants broadly described a different experience of falling in comparison to the people with dementia in the primary study and also the carers in the other focus group in this secondary study. Whereas most of these participants communicated a strong sense of autonomy, identity and self, in some instances threats to identity and sense of self also emerged. It could be said that because of the nature of focus groups already discussed in chapter five (Methods) these participants mainly wanted to present their more positive “public selves” to other group members or the researcher. It is also possible that participants with dementia in this phase were less affected by Alzheimer’s disease and therefore more independent and autonomous. This theme has been considered as comprising of two subthemes, namely, the preserved and the threatened sense of self described by the participants with dementia. Table 8.1 shows the prevalence of these subthemes for the focus group with people with dementia.

**Table 8.1 Prevalence of subthemes across participants**

<b>Participants with Dementia</b>	<b>Preserved sense of self despite falling</b>	<b>Threats to identity posed by falling</b>
Alan	*	*
Keith	--	*
Martin	*	*
Trevor	--	*
Stephen	*	--

### **8.3.1 Preserved sense of self despite falling**

This subtheme explores how participants with dementia described themselves as trying to cope with and respond to falling over by maintaining their previous sense of self and identity. At several points in the discussion, Stephen considered that there wasn't a conscious decision about how one walked to prevent falls, and he argued that after falling over he would get up and carry on with no repercussions physically or psychologically. In several instances during the discussion when asked to comment on the summaries and quotations from primary study participants, Stephen voiced a "no-nonsense" approach to falls. In his experience, one didn't need to consciously change behaviour to prevent further falls but needed to put them in the past and forget them. This mirrored Tony's narrative (person with dementia) from stage 1 of the research, who also talked about forgetting falls. However in both instances Tony and Stephen did remember their falls. Tony's desire to forget his falls has already been highlighted in findings chapter six. Like Tony, Stephen remembered the injury and embarrassment and mentioned hurting his shoulder and feeling "an idiot" (l.551), "a bloody fool ... (and) a right carrot" (l.901). But unlike Tony, Stephen also recounted how he tried to act as if nothing had happened after a fall, "out-staring" passers-by as if to say "what are you looking at!" (l.445). He suggested

that he had become immune to falls, wanting to just get on with things because he felt he was “...more case-hardened” to the experience (I. 566).

It would seem that Martin also wished to portray himself in a positive light, sharing his experiences of falling to potentially entertain the group. He told his story of falling off the side of a yacht a couple of times, with a slightly different and more sensational “spin” on the repeat:

“Oh I suppose it is fairly humorous really. But I’ve fallen off a yacht once or twice ...” (Martin, person with dementia, I.396)

“But I’ve fallen off a yacht two or three times for various reasons. Once I’m sure my wife pushed me ... there’s a period when you know you know you’re going to go overboard, you’ve lost your balance, and you’re suspended above the water and you usually say something profane like ‘oh ...” (Martin, person with dementia, I.416).

Martin also recounted an instance where he also fell down the stairs:

“I once fell down the stairs and I’d only got my pyjama top on and I caught my leg in the banister and I was hanging upside down by my leg. And my wife was at the top of the stairs just couldn’t help me for laughing.” (Martin, person with dementia, I.156).

Stephen and Martin especially seemed to take control of how they presented their falls experiences to others. By choosing to describe the incidents in a humorous way to entertain the other members of the group, they were still able to retain a sense of self-worth and esteem, and a clear social role within the group.

Not only did these participants seem to retain a sense of self in the focus group, but seemed able to co-construct falls experiences not only through discussing topics with each other, but also being interested in each other’s stories and opinions. Stephen was curious about other people’s perspectives, Trevor and Alan empathised with the experiences and extracts from participants in the

primary study and related these to their own and their families' experiences. Martin and Stephen described their wives' reactions to their falls:

“... when I've fallen over my wife says 'what are you doing down there? Get up'...” (Stephen, person with dementia, l.531).

In this narrative one can infer that Stephen's wife had little concern about his falls, but this may be a self-presentational strategy to minimise pity from the other group members. In Martin's account, also, he communicated that his wife found his falls to be funny rather than causing any concern and anxiety. It could be said from Stephen and Martin's narratives that their wives' behaviour mirrored that of Susan in stage 1 of the research by not “*mothering or smothering*” Tony, her husband (Susan, carer, stage 1, l.1152). One could suggest that Martin and Stephen perceived themselves as autonomous individuals and as spouses to their wives, rather than vulnerable individuals needing care and assistance. Alternatively one could consider that these individuals coped with the potentially stressful repercussions and social implications of falls with humour and attempts at jollying each other along during the storytelling process in the group. The camaraderie of an already formed group can be seen here, and perhaps this helped individual participants to reveal their strategies of how they presented themselves and also helped to preserve their positive identities. These findings contrast with the notion of falls as key turning point in coping with dementia (including relationships and restriction of activities) that emerged from the primary study, with Martin and Stephen in particular belittling their significance. One could also suggest that this may have been because of the social context of the group and/or because of their relatively early stage of dementia.

### **8.3.2 Threats to identity posed by falling**

Even in Martin's story, where he presented himself with a confident and positive self-image, one can also distinguish nuances of threats to his confidence and self-efficacy from his falls experiences. He described feelings of apprehension when using steps at a race-course and also recounted stories of other people's

falls and anxieties on steps and stairs. In the initial stages of the focus group discussion, Alan despite portraying a preserved sense of self and positive self-image during the group, also recounted how he was much more careful and slower at descending stairs, and qualified this by saying:

“I mean I’ve never fallen, I’m quite wary now, I never used to be.” (Alan, person with dementia, l.81).

However, further in the discussion Alan described how he had indeed slipped descending stairs and fractured his leg. Nonetheless, he suggested that even though he had a painful limp as a result of the fracture, he experienced limited emotional or psychological consequences as there was a specific reason for his fall. It would seem here that Alan told conflicting stories; either he did not perceive that his slip down the stairs was a fall, or he initially wanted to present a more favourable self-image to the interviewer and the rest of the group, early on in the session. Later in the discussion, Alan’s narrative changed and it could be said that he acknowledged the adverse consequences of falling down the stairs, with a sense of loss for his old self and previous activity:

“I used to enjoy walking around, I used to love walking around, well I used to do a postman job, I never used to mind walking. That’s spoiled it now, I can’t go out. Well I can go out walking but now I’ve got this bloody limp I’m so self conscious about it that has spoiled my life quite a lot.” (Alan, person with dementia, l.81).

Keith’s and Trevor’s stories portrayed a more threatened sense of self and identity. Keith initially seemed more hesitant to contribute to the focus group discussion than the other participants but increasingly engaged in the discussion as the session progressed. This could be due to a variety of factors, such as personal lack of confidence in speaking in a group or lack of confidence or trust in the other group members. It could also be surmised that he did not want to portray himself in a less than favourable light to the interviewer or the others in the group, preferring to reveal a “public face” rather than sharing more personal narratives. However, Keith ultimately shared how feelings of foolishness and embarrassment following a fall or trip were remembered:

... and sometimes you feel a fool as well, you know ... and you remember it.

(Keith, I.459)

A threatened sense of self and identity was more apparent in Trevor and Stephen's narrative:

I: "...you said about hurrying and you said I'm not going to hurry any more. Did you?"

Trevor: Well I did you know, and I did it again.

Stephen: What were you hurrying for?

Trevor: Well once I was playing football.

Stephen: Oh I see. Football, at your age? Good gracious.

Trevor: And I really didn't think I was very old because I used to play a lot of basketball. ... Just getting old.

Stephen: I played cricket.

Keith: Been wondering about that.

Stephen: What? Getting older?" (I.570-80).

During the focus group, Keith had played little part in the discussion, and in this segment one wonders if his contribution was a jokey interjection about ageing or a difficulty in sustaining attention and the thread of the discussion.

Trevor shared that he had experienced many falls, including one on the day of the focus group. He attributed his falls to getting old, being too tall and also to his legs being too weak. Trevor's feelings of vulnerability were also expressed through his self-questioning, of why in one instance he did not save himself from falling to prevent damage to his face and teeth. He asked advice from the interviewer about what he should do, asking:

"Do you think I should take a cane when I go out? ... Shall I take a cane? Shall I have a cane?" (Trevor, person with dementia, I.110).

It is more noticeable in Trevor's narrative that his sense of identity and self-image were threatened by feelings of ageing and also by his declining ability to play football, run or get out of a chair. Interestingly, like participants in the

primary study, Trevor attributed his falls to other factors than dementia, perhaps preferring to normalise his behaviour to becoming older, and resist a more stigmatised identity of being an individual with dementia.

This theme has presented findings that relate to the sense of self and identity of the participants with dementia, with specific reference to falls experiences. Rather than being solely a discussion and an elaboration of the narratives from stage 1 of the research, these findings uncover and illuminate aspects of self and identity that were mainly different from those of people with dementia in the primary study. Whereas the majority of the participants with dementia in this second stage of the study seem to have a preserved sense of identity and self, and minimised the personal consequences of falls, one can interpret that nevertheless there are some threats to their identity and sense of self-efficacy as a consequence of their falls.

#### **8.4 Struggling to care**

In this final theme, the burdens of roles and responsibilities that had been heightened by fall experiences, as described by the participants from the carers' focus group are presented. Such responsibilities included the physical care of their care-recipient either as a consequence of previous falls, or to prevent future falls. The identity of "carer" was strongly conveyed by these participants and perhaps this is not surprising as they were (or had been) members of a pre-existing carers' group. Even though these participants seemed to communicate a strong sense of self, this was often conveyed in a relational way, through their identity as "carer". Threats to these participants' sense of self were also expressed through their feelings of isolation and sole responsibility for the care recipient, not only as a result of the care-recipient's dementia but also because of the added burden of coping with falls. This theme has been presented as three subthemes:

- Being the only one who cares
- Struggling to prevent the inevitable
- Feelings of isolation and vulnerability



**Table 8.2 Prevalence of subthemes across participants**

<b>Participants</b>	<b>Being the only one who cares</b>	<b>Struggling to prevent the inevitable</b>	<b>Feelings of isolation and vulnerability</b>
Christopher	*	--	*
Daniel	*	*	*
Felicity	*	*	*
Fiona	*	--	--
Iris	*	*	*
Liz	*	*	*
Mary	*	*	*

#### **8.4.1 Being the only one who cares**

This subtheme conveys the strength of participants' perceptions of their role as carer to their care-recipient. More specifically this subtheme explores the responsibility the participants seemed to experience to prevent the care-recipient from falling or to minimise the risk of injury or distress. The participants in the carers' focus group discussed that they cared for their care-recipient differently to those formal carers with whom they had come into contact. The following quotation from Fiona demonstrates how she felt about her responsibilities for the person she was caring for:

*“Well you have an empathy with the person rather than a [formal] carer, because this is your husband. You know from experience and ... yeah. But a carer just coming in wouldn't.” (Fiona, carer, l.485).*

In this narrative Fiona was responding to a discussion with Liz, Mary and Christopher where they considered that formal, professional carers didn't have

the same relationship or level of commitment, skill or interest in looking after the person with dementia. The feeling of empathy also emerged from Felicity and Mary's dialogue about the fear experienced by people with dementia:

Felicity: "I think they're afraid. There's this fear. When you think the brain is being eaten away gradually all the time but nobody knows which part is going to go next, or even what part has gone already. So they must have this terrible fear inside them. I've often thought that, they must be really frightened.

Mary: Its making them feel more secure being near to someone they know."  
(Felicity and Mary, carers, I.504).

In many instances it could be said that these participants perceived themselves as experts, in relation to dementia generally and falls more specifically. Liz, Mary and Fiona discussed how an intimate knowledge of their husbands enabled them to look after their husbands much better than a formal carer: What is also intimated here is their lack of trust in formal, paid carers.

Liz: "I think as well we're speaking as the wives who are looking after our husbands, but when you get [professional/paid] carers, you're into a different ball game altogether because they're not trained to do anything. And that is when ... and they haven't got the interest, so that is when things do happen.

Mary: And then you know you're living with a person like this, you more or less know how to hold him. At the same time I cannot hold him by hand because I know he will lose balance and I'll go with him, so you have to hold him so that he feels that he's leaning on you, his elbow, and you know his body's leaning on you and you can feel it very often, that they do lean on you very much." (Liz and Mary, carers, I.474).

Here Mary seemed to convey an intuitive understanding of how to support her husband, not only to provide him with reassurance but also to prevent him from falling. At the same time she also conveyed how she allowed her husband to lean on her quite heavily to provide him with physical support and yet at the

same time not feel that she was at risk of falling over herself. By leaning on his wife, it could be inferred that Mary's husband was relying on her for emotional as well as physical support. Later Mary also considered how she had automatically used her handling skills for her ill sister, helping her to get out of a chair in the same way as she had helped her husband in the past. It is perhaps only in Christopher's narrative that there was some uncertainty in his newly acquired role as carer for his mother, and whether having a close relationship could be an obstacle to caring for her.

It would seem that these participants had difficulty trusting others to look after their spouse, and yet it could be regarded that a fall by their care-recipient could have precipitated more formal care, or a perceived need by others for more formal help. It would seem that this care might have come at a price for the carers, in terms of distrust of the formal carers' expertise and motivation to care and potentially a loss of control or loss of role for themselves. Not only did participants feel that they had lacked support from their GPs but also they were concerned about how the person with dementia was treated. Felicity voiced how horrible she found it when her husband was being hoisted whilst he was in hospital and "being like a lump of meat" (I.375) rather than being physically lifted by the nurses. From Daniel's previous narrative, where he questioned how a person who was constantly in the care of others could fall, it would seem that he and also other participants were fearful of the neglect of the person with dementia by formal carers:

Felicity: "Well this is why Daniel and I agree on this - Daniel goes every day and sits all day with his wife, and I went every day to the hospital and sat all day with my husband. And we feel by doing that they're getting more attention ... well at least the staff know they can't do anything they shouldn't because we're right there to watch. Now if you watch the person who doesn't get any visitors, it's different again isn't it?"

Mary: They're forgotten. Especially dementia people, they tend to be forgotten when they are in hospital.

Felicity: Absolutely." (Felicity and Mary, carers, I.512).

Later Mary shared how she felt that ward staff had little understanding of people with dementia, quickly labelling them as aggressive:

“...and they (ward staff) don’t tend not to look after them as they should really. And of course people like this (with dementia), they suddenly will get up and of course they don’t realise that they cannot get up because they’ll fall straight away. But then if they come to lift them up, they start fighting. My husband would fight with them and they’re aggressive (inaudible) and whatever. You know and it’s not aggression it’s just ...frustration, because he wants to get up” (Mary, carer, I.526).

It would seem that Mary considered that the professional carers’ lack of understanding of how dementia affects an individual made their task of coping with falls and the consequences much worse. The lack of understanding and possibly lack of interest in people with dementia by professional carers also seemed to arise in other narratives. There was a perception that the carer had to take charge “because nobody else will do it” (Iris, carer, I.684). However carers also voiced that they came to realise over time that they couldn’t manage without help from others – especially the Alzheimer’s Society, friends and family. Indeed Iris suggested that when the diagnosis of dementia was first made that there was a desire to keep this hidden from everyone, with the carer trying to keep control of the situation.

Even though the wife carers in the focus group emphasised their role as “...wives who are looking after our husbands...” (Liz, carer, I.474) their narratives seemed to concentrate on their ability to care for the person with dementia rather than being a spouse. Indeed it feels as if the person they cared for was de-personalised, with the individual being referred to as “he” or “she” much of the time, or being perceived (by Mary) as a six year old child who had lost their mother. Christopher, as the only individual in the group caring for a parent, talked about his changing relationship with his mother:

“Because my mum’s started to be like ... you know the dog that sort of follows you and walks behind, you turn around and I’m always standing over her.”  
(Christopher, carer, I.498).

It could be said that these participants’ accounts focussed on their caring role in relation to attending to bodily needs, rather than any other relationship they might have had with the person experiencing dementia. However, it should be acknowledged that this might have been because of the purpose of the focus group rather than their everyday perception. It would seem from the focus group narratives that these participants distanced themselves from formal carers and health professionals, perceiving themselves as the experts and the only person who genuinely cared for their spouse or parent. Indeed, one could infer that not only were these carer participants trying to protect the care-recipient from falls, but also from other people – especially professional carers. It would seem that these participants perceived these formal, professional carers as having little understanding of how to physically care for their care-recipient or treat them as human beings. However, these participants also seemed to demonstrate an intuitive way of caring for their care-recipients, to avoid and manage falls, so that they were indeed experts in looking after their spouse or parent. One could also argue that they perceived their role as carer as a continuation of their role of spouse or son looking after the person with dementia.

#### **8.4.2 Struggling to prevent the inevitable**

When they discussed how they dealt with the consequences of falls, the participants in the carers’ focus group reflected both on their own personal experiences of falling, as well as falls by the person with dementia. Interestingly when presented with a summarised extract from people with dementia from stage one of the research about being more careful, Felicity and Christopher briefly observed that the person with dementia wrongly took responsibility for their fall. Instead, these participants seemed to take the responsibility themselves, for the person with dementia, in relation to falls. The participants discussed how they managed the consequences of falls and also how they actively tried to prevent them from happening again. They recounted their

experiences of falling over themselves when trying to help their spouse and also their awareness that through looking after the person with dementia they themselves were at greater risk of falling. Iris and Mary recounted how they had difficulty getting their husbands out of the bath:

Iris: "I know with my husband he doesn't sit in the bath but he crouches, so I just pour the shower all over him. But we've got handles sort of everywhere. You tell him to hold on to the handle and sometimes as I've said it doesn't connect straight away. So you say hold on, hold on ... hold on the wall, and he'll put his hands up and then down he goes. And he always lands on his bottom, and then it's how to get him up.... I've never yet ... three times this has happened this year but I have to sort of haul him up and try and get a low stool under him. Otherwise it's calling the ambulance men, or the fire service or whatever.

Mary: It's very difficult when they slip, because the surface is very slippery, I used to get inside the bath with no water and try that because...

Iris: It's very frightening because it's ... you know you think '*what do I do next*', you know. So, and my husband's about 11 stone and I'm only 8. So you know trying to heave him up is, is quite um ...

Mary: ...difficult". (Iris and Mary, carers, l.432).

Whilst discussing a comment from participants in stage one of the research in relation to falls and manoeuvring stairs, Iris shared her concern of her risk of falling when helping her husband to climb the stairs:

"...I mean we live in a flat one floor up, but I always told Brian to hold onto the banister and then I'm the other side of him, I'm holding his arm. So but if he went head first down the stairs then I'd go too I expect. But so far that's not happened, because I keep a tight hold on him and make sure that he slides his hands you know down the banisters" (Iris, carer, l.467).

It would seem that these carer participants were explicitly taking risks themselves to prevent the person with dementia from falling. However they also recounted how in some instances they could not stop this happening:

“You know sometimes they suddenly want to do something that you don’t want them to do and they have their mind on it, and they will do it even if you don’t, not looking, do that and they are on the floor.” (Mary, carer, I.596).

However Daniel thought that falls were preventable. He considered that the one way to prevent falls was to be much more observant and to take time when carrying out activities in order “to secure a certain amount of security or safety as you go along” (I.930). In further discussion, it felt that in response to Daniel’s perception of falls being preventable, Mary wanted to justify her own experience of falls as being unpredictable, despite her efforts at constantly monitoring and anticipating risk factors:

“When someone has a fall, you know, you’re sort of watching him and you’re talking to him ‘Oh stand there and I’ll just pour the tea.’ And then the moment you turn he’s on the floor, and you’ve been watching him for half an hour you know beforehand or so...” (Mary, carer, I.960).

The idea of reducing risks by making the environment safer were explored by the group, in response to the stimulus cards from the primary study about moving and removing furniture. Iris described how she tried to make the home environment safer for her husband by fitting night-lights on the dark landing. She also described other strategies she used to make the home safer for her husband:

“The advice I would give to people if they told me, like one of these here, that their loved ones had fallen, I’d say well look around and you know make sure that you remove stuff even if you stick it in the cupboards or in a shed or something to make sure that their pathway is always clear...” (Iris, carer, I.1035).

Even though Mary agreed with Iris's suggestion, she had an opposite view as she explained how she left furniture rather than clearing it away as it provided her husband with support:

“Sometimes they like the chair, because they got hold of it don't they? You know I have sort of ... he goes through the kitchen and the chairs are there, so I could see that he was holding on the chairs, which gave him little bits of support in a way.” (Mary, carer, l.1073).

When asked if they gave up doing activities, the following discussion took place:

Felicity: “Well you do yes, by taking them on a bus, you eventually realise you just can't do it anymore, it's not possible.

Iris: I never take Brian shopping any more. And I never take him out unless I've really got to.

I: What about the rest of you?

Fiona: I never take him on a plane, I won't do that again.

Felicity: Well I had to take a wheelchair because he couldn't walk places...

Iris: I've got a wheelchair as well now, so if I take him on the common ... if I take him to the barber's I take him in the wheelchair.

Liz: Mm, I do too.

I: So how easily do you do this one? Do you fight this one?

Felicity: Well you do for a while, but then it just gets too much.

Mary: Well you try to do it, but then if you see that there is no way out, you just give up. Things are just like that.

I: So you do things differently, okay. Okay. So ...

Felicity: ... you don't take risks actually.

Iris: Well you try not to.

Felicity: yes, you try not to...”

(Felicity, Iris, Fiona, Liz and Mary, carers, l.699).



In this previous extract, it would seem that these carers were still locked in a struggle to negotiate between doing activities with their husbands and trying to prevent them from falling over. These carers seemed to calculate the risks of what they did with their husbands, sometimes considering that the risk of falls or injury were too great. Interestingly, these calculations of risk versus benefit of activity did not appear in the discussion of the participants with dementia in the other focus group. This may have been because they were oblivious to their carers' struggles or because they were less affected by their dementia or the consequences of falling.

Participants with lengthier caring experience also shared how they struggled to care for the person with dementia for as long as they possibly could, which seemed to be linked to their distrust of professional carers. Liz recounted the following:

*“We all try to go on as long as we can. And some of us say, well I’ll never let him go, I’ll look after him forever until the day comes that he goes, but it isn’t always possible.”* (Liz, carer, I.1208).

However, all the participants considered that sharing of skills with each other and being trained by experts, to handle the person with dementia when they had fallen would have helped them manage falls better. They discussed the value of having a good contact person, that is, a professional who would constantly offer them help and provide support, even though they might refuse it several times. The choice of the word “constantly” is interesting, in that it implies a badgering or insistence on the part of the person offering help, and yet it would seem here that these participants felt that they could only accept help when the time was right, with the right time potentially being a crisis rather than prior to a crisis occurring. Falls were considered to present important crisis points, such as having to ask for help when they were unable to get the care-recipient up from the floor on their own, after falling once or twice every night. Once again the accounts of the participants with dementia from the other focus group did not describe falls as such pivotal moments.

### 8.4.3 Feelings of isolation and vulnerability

In this subtheme, the dilemma of who supports the carer will be considered. For these participants, the responsibility and role of carer for their spouse or parent with dementia seemed to lead to feelings of isolation and vulnerability. These feelings of vulnerability and isolation were communicated by all of the participants, apart from Daniel.

As already discussed in the previous subtheme, participants described giving up certain activities where they felt too vulnerable. It is uncertain whether this was because they felt the risk of not physically managing the situation or because they felt very much alone and unsupported. The feelings of isolation can be interpreted from both Felicity and Mary's narratives:

*"If you haven't got a family you're on your own."* (Felicity, carer, l.798)

Mary recounted how she was lucky that her sister and brother-in-law lived nearby, as her 87 year old brother-in-law would come every time to help get her husband up off the floor. When asked why she didn't call for an ambulance to help her, she replied:

*"But this is what they said when my husband had a fall before he was taken to hospital – you should call us when he has a fall, but I said 'But I would be doing it every day'. Okay once, twice, three times you come, but then you may refuse."* (Mary, carer, l.360).

The feelings of uncertainty about services refusing to give help had seemingly been reinforced by Mary's experience of being refused the help she wanted from her GP. In this instance she recounted that her GP was only interested in helping her find residential care for her husband. One could suggest that she was fearful of the consequences of calling the ambulance service too often, in case this led to the same discussion of residential care provision.

However, there was a discussion within the group that carers had to learn to ask for help, and that perhaps knowing that they were not the only one needing

it would make acceptance of help easier. Liz discussed how carers should be trained to manage falls:

“yes, before your back goes, your stomach goes, before, like myself you fell over several times with your husband because he is 6 foot plus. He loses his balance and I am doing very well if I manage to sustain him, but the first time we fell down together I burst into tears, because it becomes very stressful. You don’t know when it is going to happen.” (Liz, carer, l.1218)

It can be seen from these narratives that these participants from the carers’ group felt physically and emotionally vulnerable, with feelings of being unable to cope, specifically triggered by falls experiences. Feelings of vulnerability and isolation were also portrayed by participants when they talked about their own falls:

Felicity: “Nobody comes to pick you up do they, no that’s true.

Mary: You’ve got to do; you’ve got to go on. (laughs)”. (Felicity and Mary, carers, l.638).

Daniel suggested that the only way to cope with looking after someone with dementia was by keeping a positive attitude and not feeling frustrated with life. Daniel no longer looked after his wife (and person with dementia) on a daily basis, as she was living in long-term care. It could be suggested that his more positive outlook was influenced by more pleasurable memories and experiences of caring, rather than recollection of daily responsibilities for self-care tasks. For others, the feelings of isolation and vulnerability were thought to be lessened by getting support from someone reliable and knowledgeable about what resources were available to them. However, even these participants acknowledged that it could be quite a challenging task for professionals to provide help, especially where carers were not even aware that they needed it, as Mary explained:

“But then again you know I found that I didn’t realise what was happening. I thought that I was the God and I could do everything, which I couldn’t, but you

don't realise, you don't think. You think why should I bother other people about this, I still manage" (Mary, carer, I.1224).

In this narrative Mary described herself as "the god", which again can feel like an isolated (but highly responsible) role for the carer to take. Her narrative relates back to the first subtheme where the carers felt that they were the only one that cared and could be trusted. It would seem that these carers also found it difficult to relinquish or share their role of carer with anyone else.

This theme has considered how the participants in the carers group considered their roles and responsibilities to the person with dementia that they cared for. Even though they did not specifically identify themselves as "carers", (i.e. formal carers) who they felt lacked expertise and empathy for people with dementia, they extensively discussed their experience of caring for their spouse or parent. Participants reflected in depth upon their responsibilities in keeping the person they cared for safe and to prevent falls from occurring. It would seem that they felt unable to trust anyone other than close family, friends or neighbours. Therefore one can suggest that the impact of caring for the person with dementia resulted in these participants feeling vulnerable and isolated. However, they also discussed how carers of people with dementia should ask for help and be well or better supported. It would seem that the falls experiences crystallised the feelings of isolation and vulnerability for the carers. One could suggest that the recommendation for others came from their own experiences of talking sole responsibility for their care-recipient, resisting help from anyone they felt that they could not easily or quickly trust, or who might challenge their decisions.

### **8.5 Summary of findings for secondary study**

The findings for this secondary study have similarities in the major themes that emerged from the primary study. However, these participants had differing experiences of dementia and care-giving, with the majority of the people with dementia in this study having a recent diagnosis (and probably a milder form of dementia at the time of data collection) and the majority of carers caring for

people with more severe dementia than those participants in the other focus group and probably than that experienced by participants in the primary study. There was also a difference in the accounts of falling, with participants with dementia in this secondary study seemingly experiencing less physically and psychologically traumatic consequences of falls, whereas the carers' experiences conveyed greater vulnerability, isolation and exertion as a result of their care-recipient falling and in their attempt to prevent further falls. This has led to an elaboration and greater illumination of the falls experiences of people with dementia and their carers. The findings from this secondary study will be discussed in chapter nine along with the findings from the primary study, where comparisons and contrasts between the studies that have emerged from the data will be discussed.

### 8.6 Reflecting on the analysis and findings from the secondary study

Once again I had been concerned that I would not have much data to analyse from two focus groups. I wasn't sure how I would also analyse the data, would I treat the two sets of data differently or not? However once I had analysed the data it became much clearer to me that I had plenty of data to analyse for the secondary study presented in this chapter. I became anxious about the similarities in the main themes between the two studies, and re-analysed the data to ensure that the analysis was plausible and discussed this in supervision. By going back through my diary it was interesting to read the following:

September 2007

*Carers had difficulty defining a fall or even wanting to discuss the primary study data. But wanted to tell their own story. So stimulus cards acted as a vehicle or stimulus for FG discussion but did not dictate it.*

February 2011

*I have had concerns about the similarities in the themes, and yet in RQ2 stimulus cards followed the topic guide in RQ1 so themes not engineered or anticipated. RQ1 findings also analysed after RQ2 data collected.*

Having confidence in my analysis was important and indeed when bringing the secondary study findings in this chapter together, it became clear that there were divergences and convergences within the data not only between the two focus group sets of data, but also between the two studies.

## Chapter 9 - Discussion

The preceding chapters of this thesis have provided a justification for studying and exploring the experiences of falling of older people with dementia and their carers. This chapter provides a discussion of the findings presented in chapters six to eight and relates these findings to the extant literature. As the primary study has used IPA to answer the research question and the secondary study has used an inductive and interpretative approach, the purpose of this discussion is to present the interpretations and understandings of how falling enters the life-worlds of the older people with dementia and carers who participated in the primary and secondary studies. Interpretation of participants' accounts is an essential part of IPA research (Larkin et al 2006), however these interpretations of the lifeworlds of participants should be placed in the wider context of the existing literature (Smith et al 2009). Therefore, in the first section 9.1, themes that emerged from the primary study findings are discussed and related to the literature. In section 9.2 the emerging themes from the secondary study will be discussed, along with their relationship to the primary study. The findings from both studies will be discussed in section 9.3 and section 9.4 evaluates the strengths and weaknesses of the research in terms of the methodology, the primary and secondary studies and the findings. A final chapter (10) will follow this chapter to the thesis where a conclusion to the study is presented. This will include the implications of the research and contributions of the research to knowledge.

### 9.1 The experiences of falling: Discussion of findings from the primary study

The primary study to the thesis explored the life-worlds of older people with dementia, or memory problems, and their carers, in relation to their experiences of falls and their perceived physical, social and emotional consequences. The participants' accounts provided insights into their experiences of the fall event itself, the immediate consequences in terms of behaviour and emotions as well as a longer-term rippling out of responses and reactions into their everyday

lives and relationships. Smith et al (2009) suggest that the analysis and interpretation of IPA data continue into the writing phase, and indeed although the findings were presented as four themes in chapters six and seven, the interpretation of these themes have developed and are discussed here under two overarching themes: falling as a malevolent force and falls being experienced as the manifestation of dementia. These relate, respectively, to the more immediate lived experiences (falling as a malevolent force) and the more distal perceived consequences (falling as the manifestation of dementia).

### 9.1.1 Falling as a malevolent force

**Falling:** *Move downwards quickly and without control, collapse to the ground*  
(Oxford English Dictionary, 2001)

The findings from chapter six addressed what can be inferred as the immediate experiences of falling. In these higher level themes and subthemes, participants recalled falls experiences and the immediate responses to the fall. Those who fell (older people with dementia and carers alike), and those who observed the fall (carers), had differing memories and experiences of falls. Whilst many of the participants struggled to describe what they thought a fall was, their description intimated their subjective experiences of being out of control, feeling silly, or experiencing a shock; and indeed, the dictionary definition above, hints at the emotive associations with falls events in the use of the words “without control” and “collapse”. Like the study by Health Scotland (1999), few participants voiced physical descriptions of falling, which are fore-grounded in more biomedical definitions, such as those by Tinetti et al (1988) and Lamb et al (2005), discussed in chapter two. Such differences between lay and research-orientated descriptions and definitions of falls are unsurprising, when Hauer et al (2006) identified a great heterogeneity of terminology within the research literature itself. The negative connotations and descriptions of falls both within the dictionary definition at the beginning of this section, and also by these participants communicate how their fall impacted upon the participants’ sense of self, body and world (Finlay 2011). The more subjective accounts of falls by these participants also convey the more sudden and unpredictable nature of



falling, that the Lamb et al (2005) definition neglects; and also are perhaps better indications of the negative consequences of falls experienced by many older people. Indeed, these narratives potentially feed into the conjecture by Kingston (2000) that falls are “a powerful metaphor of decline” (p.218).

In discussion prior to the interviews, (and therefore not recorded or transcribed) it was assumed by many of the carers that their care-recipients would not remember their fall because of their dementia or “memory problems”. This assumption reflects one commonly made within the literature; that older people with cognitive impairment or memory problems are poor at recalling their falls (Cummings et al 1988, Ganz et al 2005, Delbaere et al 2012). However, in both interviews (and focus groups) these participants’ accounts revealed quite vivid memories of falls, but not the precise dates, times and places of the event which relate more to episodic memory loss in dementia (Clare et al 2003). The care-recipients’ memories of their falls were imbued with personal meaning and revealed their embodied accounts and understandings of their falls event. Through their narratives of their falls, care-recipients communicated memories of complete lack of control, unpredictability and vulnerability, with narratives of being flung into the air, or sprawled on the ground. In other instances feelings of vulnerability were expressed in more surreal or menacing terms of disconnection and other-“bodyness” of floating or being ‘underneath’. In all of these accounts, participants’ taken-for-granted bodies became suddenly foregrounded as a result of their fall. The immediate repercussion of bodily injury, discomfort and embarrassment made their bodies visible, to themselves and others. This fore-grounding of the body is described by Toombs (1988) and Svenaeus (2009) as bodily objectification and is resonant with the philosophy of Merleau-Ponty, and Sartre. The findings from this primary study resonate with phenomenological studies of experiences of people with MS (Toombs 1993, Finlay 2003), dementia (Phinney and Chesla 2003) and Parkinson’s disease (Sunvisson 2006). These researchers explored how the body became disrupted, unreliable and therefore a visible object for concern or scrutiny for the participants.

In certain other accounts gathered in the primary study, the objectification of the body could be perceived as bodily alienation or disembodiment, where the participants' focus on their bodies as "other" (and "not me") because of its sudden unpredictability and lack of control. One interpretation is that participants wanted to dissociate themselves from the part of their body, which they felt had failed them by causing the fall; describing "the leg" rather than "my leg". These feelings of bodily alienation coincide with work by Toombs (1988, 1993), Finlay (2011) and Svenaeus (2009); with Toombs (1988) suggesting that such impersonalisation allows the individual to dissociate themselves from less acceptable and more unpleasant reasons for their failing or unpredictable body. The study by Berlin Hallrup et al (2009) also reveals how their cognitively normal older women participants felt that they were strangers to their own bodies following their falls. However in their study, Berlin Hallrup et al (2009) considered that their participants' changed awareness and insecurities about their bodies were subsequent to (and a result of) injury and reduced mobility, rather than in the findings of this primary study where the perception of bodily alienation related to the falls event itself.

The participants in the primary study gave many reasons for their falls, including differing accounts of the same fall. Indeed, it is worth noting that carers and care-recipients rarely gave similar reasons for the same fall. Whereas it could be considered that participants lacked any certainty of the reason for falling, the findings also coincide with work by Rubenstein (2006), who suggests that the exact reason for a fall can be difficult to determine because an older person probably has multiple pre-disposing risk factors for falling. Carers were more likely to want to find a cause for the care-recipients' falls, and one can suggest here that not only was it important to them to understand why the care-recipients fell, but also to prevent recurrence. These findings would concur with those of Buri and Dawson (2000) in their study of carers of older people with dementia who had fallen and also with the study by Roe et al (2008) where it was suggested that being able to assign blame and understand the reason for a fall not only alleviated the psychological and emotional severity of the fall by the person experiencing it, but also enabled them to try and control the identified cause to prevent further falls. Indeed, in other studies by Cwikel et al (1990),

McKee (1999), Kong et al (2002) and Ward-Griffin et al (2004), the attribution of a fall to extrinsic factors (such as environmental hazards) seemed preferable as the participants felt that these extrinsic factors can be controlled or modified, or conversely were completely out of their control (and therefore not their fault). Therefore, the attempts described by carers to control and prevent further falls and modify the environment to keep the care-recipient “safe” reflect that seen in existing literature including that by Buri and Dawson (2000), Davey et al (2004) and Horton and Arber (2004).

The experience of being out of control was voiced by many participants in the primary study. These findings are interesting in that in some instances the struggle to keep control and avoid falling, against an invisible and seemingly malevolent force is portrayed with neither self-blame nor identification of extrinsic causes. Whereas findings from studies carried out by Kong et al (2002) and Yardley et al (2006a) articulate a sense of fatalistic and passive acceptance of a lack of agency and powerlessness against unknown or unidentifiable causes, these current findings communicate the opposite, with some participants fighting to retain control against ethereal causes to prevent themselves from falling over as well as presenting themselves as victims of unknown and malevolent forces.

Where intrinsic reasons for falls were given by participants in the primary study, these were specific, such as rushing to the toilet or being ill, rather than generalised attributions (for example – being old), and mirrored those of Ward-Griffin et al (2004) where it was considered that such reasons enabled participants to deflect blame away from the individual. Other participants such as Bridget and Tony (care-recipients), Christine and Vicki (carers) considered that cognitive factors such as poor concentration, awareness or attention were risk factors for falling. Indeed, it could be seen that there was an interconnection being made between the mind and body (or self and body). One can consider these findings from both a phenomenological and a more cognitive neuroscience perspective. When participants described that they were vulnerable to falls when thinking of other things, one could suggest the balance between self and body was affected, resulting in the self and others becoming

fore-grounded at the expense of the body, so the body failed, resulting in a fall. It could also be suggested that like the study participants of Phinney and Chesla (2003), these participants voiced a slowing of the body and a loss of smooth bodily movement as a result of their dementia. Whereas Phinney and Chesla (2003) interpreted their findings as their participants having an embodied awareness of how dementia entered their lifeworlds, one could suggest that in the primary study findings this can be interpreted further. It would seem that the participants' accounts from the primary study, revealed an embodied awareness of their dementia and that their fall foregrounded their body even more.

A more positivist cognitive neuroscience approach might consider that the demands of dual tasking or an overloaded attentional system increase the risk of falling in older people, especially those with cognitive impairment (Baddeley et al 1991, 2001, Yardley et al 2001, Verghese et al 2002). Indeed, one participant, Tony (care-recipient) linked his difficulty in concentrating and being distracted to other activities such as writing lists, which relates to the findings from the study of Phinney and Chesla (2003) whose participants recounted laboured and faltering execution of activities. It is suggested that in this account that Tony has an awareness of his declining cognitive functioning, with his fall another reminder of his mind in decline.

An awareness of poor memory of falls was apparent within the participants' accounts. However, similarly to studies by Clare (2003, 2005), Pearce et al (2002) and van Dijkhuisen et al (2006) the participants in this study did not explicitly relate their poor memory to their diagnosis of dementia. In some instances, care-recipients such as Wendy and Tony justified their poor memory of particular falls as a normal desire and coping mechanism to block out negative memories and relieve distress, similarly to findings of Clare (2005). It could be argued that this coping mechanism did not reflect denial of either their diagnosis or the fall itself (as observed by Kong et al, 2002 of cognitively normal older people), but allowed these participants to live in the present day, as suggested by Hellström et al (2005b) and not dwell on the implications or potential consequences of their falls. The primary study also highlighted how participants varied in their acknowledgement of the care-recipient's diagnosis.

Whereas in the interviews, all of the participants had been made aware of their diagnosis, this was not the case with the focus group participants. Many of the carers taking part in the interviews discussed Alzheimer's disease or dementia in their own interviews, but not necessarily in the joint interview with the care-recipient. It could be said that these carers were trying to protect their care-recipient from the stigmatising diagnosis of dementia and its potential implications, similarly to studies by Blum (1991, 1994), Graham and Bassett (2006) and Dunham and Cannon (2008); it could also be interpreted that some carers were themselves in denial about the diagnosis, as they did not use the term 'dementia' but described problems with the care-recipient's 'mind' in their own accounts, which was also observed in the study by Quinn et al (2008). Interestingly, Patrick (carer) recounted how his wife Sheila's appointments at a falls intervention programme were stopped. Patrick described the health professional as suggesting the unsuitability of the care-recipient for the intervention. Patrick's account suggests that he had to come to terms with Sheila being excluded from the falls intervention, which Patrick felt could have helped her, but the reason for the exclusion was not made explicit to him. It is worth highlighting that these data were collected in late 2006, prior to the RCP (2011) audit of falls services which stated that people with cognitive impairment should not be excluded from, nor assumed that they would not benefit from falls intervention. This audit also stated that falls intervention should be tailored to the needs of those individuals needing intervention, rather than providing a more generalised falls programme (RCP 2011). The data were also collected prior to the NICE/SCIE (2006) guidelines on dementia care becoming more widely known, which stated that there should be no discrimination in service provision on grounds of age or diagnosis of dementia.

The inter-relationship between falling and dementia was apparent within the participants' accounts; however this was more explicit in some accounts than others. For some carer participants, falling was perceived to play a pivotal role in the dementia experience, both for themselves and the care-recipient, and interestingly these accounts were where the care-recipient's fall took place either shortly prior to, or immediately after diagnosis. Some participants, like those in the study by Clare et al (2006), voiced concerns that the care-

recipients' falls caused their dementia. However, for Vicki and George, the falls event rapidly fore-grounded the diagnosis and implications of dementia, and in their accounts George's fall became more symbolic of the onset of his dementia. For one couple, Norma and Bob, the care-recipient's fall was not considered as a critical incident, however for others, the care-recipients' falls initiated or exacerbated change in how the participants carried out their everyday lives, in terms of physical ability, confidence and self-belief. Indeed, these findings reflect those of Buri and Dawson (2000) where the carers perceived the care-recipients' falls as creating chaos and disorder within the life-worlds of both members of the dyad.

These findings also revealed participants' emotional responses to the falls episode and subsequent changes in their reported behaviour - especially restriction in activity. As in studies of cognitively normal older people by Ward-Griffin et al (2004), Yardley and Smith (2008) and Roe et al (2008), these care-recipients expressed embarrassment at falling in public, and similarly to these previous studies, care-recipients (Tony, especially) increasingly avoided social and public activities. Like cognitively normal older participants in the study by Roe et al (2008), Andrew (care-recipient) expressed fear of being perceived as drunk by passers-by. Other fears were of subsequent injury, however George voiced that his fear of falling was greater than his fear of dying, which compares with findings by Salkeld et al (2000) of cognitively normal older women. As is common in IPA studies, there was also divergence within the findings, with not all participants having a negative response to the care-recipient's fall. Indeed, Norma's hypothesised that Bob had minimal repercussions to his fall because of his physical fitness. One could suggest here, that Norma's more mechanistic account of Bob's body as a machine meant that the consequences of the fall were minimised, like some of the cognitively normal older participants in the study by Borkan et al (1991).

In many instances the carers expressed greater fear of further falls than the care-recipients themselves, which was also observed in the study by Liddle and Gilleard (1995) of carer- participants of cognitively normal older people who had fallen. Karl, Pat and Neil voiced fears of leaving the care-recipient alone in case

they fell, and in Pat's narrative, his distress at finding Sheila on the floor was strongly articulated. This fear of finding the care-recipient on the floor potentially with an injury, after a fall, was voiced by one carer for an individual with dementia from the study by Faes et al (2010) in their study of frail older people (including people with dementia). This was also voiced by carer-participants with care-recipients with stroke and Parkinson's' disease in studies by Davey et al (2004) and Kelley et al (2010). Whereas many carers used constant monitoring and vigilance to allay their fear of the care-recipient falling, as in studies by Buri and Dawson (2000), Davey et al (2004) and Horton and Arber (2004), other newer carers, such as Susan and Vicki were uncomfortable about the need for surveillance. Not only were carers fearful of not being able to physically manage to get the care-recipient up from the floor after a fall, or cope with resultant disability, but more importantly fear of the care-recipients being admitted to residential or nursing home care was expressed by carers. In studies by Salkeld et al (2000), Ward-Griffin et al (2004) and Lee et al (2008), fear of nursing home admission as a consequence of falling was expressed by the cognitively normal older person themselves, but not apparently in studies involving carers.

In other instances, there was fear, not necessarily relating to falls, but to the impact of dementia. An example of this was the fear of becoming lost by the care-recipient when out in the local community and how the fear transferred from one member of the dyad to the other over a period of time. Whereas Vicki reported George's own fear of getting lost following his first fall and subsequent loss of confidence in her first interview, in her second interview, eleven months later, she herself was fearful of George's ability to get home safely. In this account, and that of other carer participants, the balance of enabling the care-recipient to maintain their desired level of activity and independence and yet prevent further falls was a dilemma for many carers, with some deciding to care for the care-recipient and control their activity, which mirror those findings of Buri and Dawson (2000) of family carers of older people with dementia and Johansson et al (2009) of nursing staff caring for people with dementia. Unfortunately, these decisions to restrict activity clash with evidence within falls research (and the premise of global falls management both on an individual and

community level) that identifies that maintenance of activity and therefore mobility, is desired to prevent further falls (WHO 2004, AGS/BGS 2010, Gillespie et al 2010). The rationale for maintaining optimal activity and mobility levels is to avoid decline in general levels of fitness and flexibility, an increase in muscle weakness and gait problems; all of which increase the risk of falling (Yardley and Smith 2002, Rubenstein 2006, AGS & BGS 2009).

The findings discussed here relate to the first and second higher level themes within the primary study, where the memories of and reasoning for the falls events were voiced by both the care-recipient and carer participants in this study. The more immediate responses and reactions in terms of resultant fear of falling and curtailing of activity were also explored along with the inter-relationship of the care-recipients' falls and their dementia. Whereas much of the extant literature on the experience of falling concentrates on the consequences and reaction of cognitively normal or impaired older people who fall, these findings reveal experiences of the falls event itself. Interestingly, care-recipients' accounts suggest that they had both embodied and disembodied memories of their falls, which does not seem to have been reported upon in the existing literature of either cognitively normal older people that fall or the literature appertaining to those older people with dementia. Like the study by Faes et al (2010), these participants expressed fear of falling, however this study provides a more in depth understanding of what older people with dementia and their carers were frightened of. What is also interesting in the findings of this primary study that carers and not care-recipients voiced fear of the care-recipient being admitted to nursing home or residential care as a result of future falls, which does not seem to appear in the extant literature.

### **9.1.2 Falling as the manifestation of dementia**

The findings discussed in this section relate to the third and fourth higher level themes within the primary study, presented in chapter seven, where it is considered that some experiential consequences of falls are more distal, and permeating other aspects of the participants' life-worlds. It could also be



interpreted that the experiences of falling and dementia were intertwined within the life-worlds of both the care-recipients and carers in this study. In most instances the participant's fall (whether a care-recipient or carer) initiated a re-evaluation of their sense of self and their relationship as a dyad.

Within the literature, the impact of dementia on people's sense of self and identity has been explored (Kitwood 1990, 1997, Sabat and Harré 1992, Clare 2002, Pearce et al 2002, Sabat 2002). The impact of falling on self and identity has also been explored with older people (without cognitive impairment), but mainly in terms of social identity (Yardley and Smith 2002, Yardley et al 2006a, 2006b, 2007, Horton 2007, Ruthig et al 2007). All of these studies have identified that both of these particular life events have resulted in a personal lack of self-belief, confidence and sense of autonomy, or has resulted in a change in the perception of the individual by others. However this study has been unusual in exploring both falls **and** dementia experiences. In this primary study, the findings suggest that the impact of falling and dementia are enmeshed and perhaps when experienced together are particularly likely to accelerate changes to the care-recipients' sense of self or challenge their attempts to maintain their sense of self, identity and autonomy. These findings reveal how participants perceived themselves and how they wished to portray themselves to others, the strategies they used to maintain their sense of self and identity and how their own behaviour, or that of others, threatened their sense of self.

The care-recipients' accounts from this primary study particularly reveal attempts at preservation of personal selves and identities through presentation of positive self-attributes and self-image. Not all of these directly related to the falls experience, with the recall of previous identities, stories from the past and personal attributes to promote a positive sense of self in the narratives, which perhaps concurs with some previous research with people with dementia by Kitwood (1992) and Bender and Cheston (1997). For some care-recipients, their impaired memories of their falls were normalised as reasonable behaviour with diverging justification for reasons for forgetting their falls – from blocking out a traumatic event to not remembering such commonplace occurrences. These

findings echo the studies by Pearce et al (2002) and MacRae (2011) whose participants attributed their memory loss to normal ageing rather than their dementia, however these studies explored experiences of dementia and not experiences of falls.

Preservation of self was also articulated through stories of positive self-image and attributes such as being “strong-willed”, and stoicism and minimisation of the consequences of their falls. Not all of these directly related to the falls experience, but perhaps were more related to how these participants wished to be perceived by the researcher or others, including in terms of past identities and roles. Minimisation of the injury and impact of their falls were revealed in some of the participant accounts, similarly to research by Ward-Griffin et al (2004). For example, Bob and his wife Norma reasoned that there were no negative consequences to Bob’s fall because of his previous levels of fitness and activity. Recall of previous protective attributes coincides with findings by Roe et al (2008) whose cognitively unimpaired participants minimised the impact of falling because they were fit and healthy. Similarly to findings by Borkan et al (1990), some participants in this primary study conveyed a mechanistic or dissociated view of their bodies following their fall which may also have minimised the threat of the fall to the participants’ sense of self. Differences in perception of self varied between the care-recipient and carer in some instances, for example Rita, who portrayed herself within the interviews as a stoical and autonomous person, but was portrayed by her son, Neil, as lacking confidence and dependant. These findings are similar to those by Ballinger and Payne (2000) of cognitively unimpaired older people who had fallen and resonate with Sabat and Harré (1992) who considered that maintenance of self (especially the social self) is dependant upon the co-operation and perception of others. Interestingly, some of the carers who had fallen seemed to be less worried about portraying themselves in a positive manner. These carer participants, who blamed themselves for their careless behaviour resulting in their falls, were younger and more active older people, who perhaps like the participants in the study by Ruthig et al (2007) retained feelings of control, optimism and self-belief.

Not only did care-recipients in particular convey positive self-image and sense of self, but their accounts also revealed strategies that these participants used to try to preserve their sense of self, following their fall. They articulated how they realised that they had to change their behaviour following their fall, by being more careful when walking, for example. However, the sustainability of their responsible changes in behaviour was not always possible, and like the study by Simpson et al (2003) involving cognitively unimpaired older people, these care-recipients voiced that taking care following a fall required conscious effort and was not always possible, especially when distracted or multi-tasking.

Even though a sense of autonomy and identity was reflected in care-recipients' accounts of the value and enjoyment in everyday activities, similarly to findings of Phinney et al (2007), diverging accounts revealed changes in behaviour and cessation of meaningful activity to also maintain a sense of self. Not only did care-recipients recount maintaining and attempting to preserve their sense of self through controlling and monitoring their own behaviour, but activities were also curtailed because of a personal lack of confidence, in successful performance. It would seem that some of these participants gave up social activity or modified their behaviour to avoid further falls and thus avoid falling in public and social embarrassment, similarly to cognitively normal older people in the study by Berlin Hallrup et al (2009). Whereas downgrading of activity through choice could be interpreted as an autonomous action as noted by Charmaz (1983) to maintain a "normal" life and valued self, the curtailing of valued activity because of the reactions and decisions of others was perceived as upsetting and threatened participants' self-belief and identity. The support of others to maintain valued activities was important, but not always forthcoming. Indeed, the giving up of activity could perhaps indicate a lack of self-belief, self-efficacy and fear of social embarrassment, so that not only was the personal sense of self threatened but also the social self by perceptions and attitudes of others.

Participants were not always successful at preserving their sense of self and identity. It would seem that some identity threats were preferable to others, with some participants blaming their falls on being or becoming old. This diverges

with findings by Roe et al (2008), Hanson et al (2009) and Walker et al (2011), who suggested that their cognitively unimpaired participants perceived falls as stigmatising and indicators of increasing age and frailty and therefore were more likely to blame external factors for their falls than associate them with being older. One can suggest that associating falling with growing older was less stigmatising than accepting the identity of a person with dementia, in this study.

Handing over of responsibilities and becoming more dependant on carers as a result of falling, occurred for the majority of the care-recipients, according to their accounts. Some participants did this willingly, and it was not always clear if these participants perceived that they had difficulty coping with everyday tasks, and/or had a lack of confidence in their own competence such as those participants in the study by Clare et al (2008). Findings also reveal how care-recipients (such as Sheila and Eileen) described becoming more reliant upon their carers to protect and defend them from experiences of public mortification and embarrassment. However, in some instances the care-recipients' sense of self was threatened by a lack of understanding by carers, of their changes in behaviour (such as walking slowly) to manage and prevent further falls, or through infantilisation or objectification.

Elements of preserved and threatened sense of self and identity appear within the same narratives. These participants implied that they tried to maintain a positive self-belief and to hold onto favoured attributes and identities in spite of the attitudes and behaviours of others. Whereas the previous research literature considers either threats to self from falling *or* from dementia, the participants in this primary study were trying to manage *both* of these disruptive life events. It can also be observed that the consequences of both falling and dementia are so enmeshed that each of these experiences impacted upon the other, giving rise to change and uncertainty. Although cognitive impairment and dementia are considered as high risk factors for falls (AGS & BGS 2009), the findings from this primary study also indicate that falling has a detrimental effect on the sense of self (or personhood) of the care-recipients. Kitwood (1997) suggested that any threat to personal identity (or personhood) influences the manifestation of

dementia. Indeed within this study the falls experience seemingly not only forced the realisation of the dementia diagnosis for some care-recipients and carers but also heightened the negative aspects of the dementia experience, such as the stigmatising behaviour of others. It is therefore considered that the combination of the falls experience and dementia led to the majority of these care-recipients having what Kingston (2000) considered as 'salvaged identities', rather than a maintained or preserved sense of self and identity, where they portrayed and perceived themselves "...in the best possible light, despite the adversities" (p212).

The findings in the primary study presented in chapter seven have also demonstrated the complexity of the caring relationship for these dyads. The experiences of falling were recounted as turning points in relationships, causing greater physical and emotional reliance on the carer by the care-recipient. Even though much of the responsibility for the management of falls seemed to be shouldered by the carers in this study to maintain the care-recipients' quality of life, it could be said that the carers' reaction to the fall and their attempt to manage the consequences through bodily surveillance and curtailment in activity also impacted upon the self and identity (personhood) of the care-recipient - a process also noted by Horton and Arber (2004) in their study of cognitively normal older people who had fallen and their carers.

The subjective impact of falls on the carers' health, wellbeing and sense of self is also present in the findings. Most of the carers described themselves as dealing with the consequences of the care-recipients' falls by providing physical assistance with self-care tasks, indoor and outdoor mobility. Skaff and Pearlin (1992) suggested that carers are more vulnerable to their own loss of self and identity when immersed in self-care tasks of the care-recipient rather than engaging in treasured occupations and social contacts. It is also worth noting that some of the older spouse-carers discussed their own health conditions and mobility problems, with one carer identifying that the fear of his wife entering residential care meant that he would continue to care for her even at the expense of his own health. These findings when combined with evidence from Ross et al (2008) where older spouse carers tend to spend more time on caring

than other groups and are seen to have a heavier burden of care, indicate that the health and wellbeing of these older spouse carers are at risk. Younger carers did not seem to experience the same negative aspects of caring, apart from one son carer who was solely providing 24 hour care for his mother. This may have been because the person they cared for had less severe dementia at the time of data collection, or because the younger carers had more family and social support or sharing of care or greater physical fitness.

Interestingly, spouse carers also discussed their own falls with various negative consequences, ranging from hospital admission to feelings of being old and vulnerable. One carer's attribution of her own fall to always thinking of the care-recipient, highlights the psychological impact of caring on the health and wellbeing, whether the care-recipient is physically present or not. The impact of carer burden or lack of support on the mental and physical health of carers is well recognised (Farran et al 2008) but the association between carer health, wellbeing and falls has not been fully considered before this study. Role engulfment as a result of a necessary commitment to the self-care needs of the care-recipient following their falls, and also the loss of self-esteem and efficacy as a result of their own falls, all indicate a potential loss of self or personhood of the carers in this study and reflects findings by Skaff and Pearlin (1992) of carers of older people

The findings also demonstrate readjustments to the dyadic relationship not only because of the care-recipient's dementia but also as a consequence of falls. Re-orientation of relationships, change in roles and challenges to couplehood by extrinsic circumstances were revealed and resonate with findings by Hellström et al (2005a) who explored the couple relationship where one member of the dyad had dementia. Surveillance and monitoring of the care-recipient by carers occurred not only to minimise the physical risk and consequences of falling, but also to prevent them from getting lost when out in the community. For example Norma seemed to constantly monitor Bob and his activity, so that he did not leave the house and knock on their neighbour's doors. One could suggest that she was not only attempting to prevent Bob from falling, and perhaps trying to avoid its accompanying emotional and

psychological distress, but also to avoid the stigmatising societal response by her neighbours to “wandering” individuals. Bartlett and O’Connor (2010) and Brijnath and Manderson (2008) suggest that bodily surveillance of the care-recipient by carers resonates with Foucauldian theories of power tensions between the carer, the care-recipient and society. In most circumstances these care-recipients complied and accepted the control of others, but in other instances the carers’ power and control were challenged by the care-recipients either leaving the house and knocking indiscriminately on neighbours’ doors (like Bob) or walking alone at their own pace (like Bridget). Such power struggles could be said to impact on both the relationship between the dyad and also the sense of self of the care-recipient (Kitwood 1997, Bartlett and O’Connor 2010).

The activity of caring for the care-recipient also impacted upon the roles and identities of study participants. Most carers endeavoured to maintain their previous relationship within the dyad, whilst also struggling to fulfil their role of carer; often learning by negative experience. Whereas daughter-carers described taking a more facilitative approach to their parents with mild dementia, the two son-carers revealed a monitoring and controlling approach to prevent falls and to keep their mothers safe, creating a reversal in the parent/child relationship; similarly to the study by Horton and Arber (2004). In these instances the mothers had moderate/severe dementia at the time of the interviews and perhaps were less aware of potential risks or their own needs.

Even though the differences in the caring experience in relation to the severity of the dementia cannot be deduced from the available data, it is interesting to note that carers, whose care-recipient had mild dementia at the time of the interview, described trying to adjust to their new role of carer. It could be argued that their own sense of self and identity were being threatened and the role of carer enforced not only by the progression of the dementia symptoms, as suggested by Karner and Bobbit-Zeher (2005) but also by the fall and its consequences. O’Shaughnessy et al (2010) suggest that carers’ own needs and identity become overwhelmed by having to take sole responsibility in the relationship and “working alone” (Keady and Nolan 2003). It is potentially in

Patrick's story of his unmet needs as a carer that we can perhaps see this transformation of identity and the 'working alone' in the spousal relationship. However, this was not a constant element in all the relationships. Indeed, even within Patrick and Sheila's accounts, there was evidence of working together, and intimacy, for example, where the couple shared the experience and enjoyment of social activity and post-fall exercises.

The delight in doing things together was voiced by many of the care-recipients with even the carrying out of everyday activities together being of psychological importance. The joint telling of experiences in this study are also examples of the dyads working together to support the competencies of the care-recipient (Perry & O'Connor 2002). Hellström et al (2007:395) describe older dyads as making the best of "life's little pleasures" to maintain past relationships and ensure mutual enjoyment. Going out, especially to the shops, seemed to be of particular importance to the spousal dyads; indeed this was possibly the only joint social interaction with others that the couples had. Not only is it considered that joint activity encourages reciprocity and interdependence in dyads, which Vikström et al (2008) suggest sustains the care-recipient's personhood, but enables the carer to also maintain their sense of identity as spouse, son or daughter (Perry and O'Connor 2002). However threats to sense of self of the dyad, especially (but not exclusively) for older spouse-carers, were also articulated where service providers ignored or did not comprehend the needs of both individuals to manage and prevent falls and maintain valued activities.

### **9.1.3 Summary of discussion of primary study**

Findings have been discussed above from the primary study for the research where older people with dementia and their carers were interviewed, and older people with memory problems and their carers participated in three concurrent focus groups to explore how falling impacted upon their life-worlds. For most participants, falling was a negative experience, and for some a life-changing one. The consequences of falling on their life-worlds were far-reaching, and seemed to create major and possibly permanent changes to their lives.



Even though care-recipients did not remember the dates, times or places, they communicated embodied memories of their falls. Falls were represented as turning points in these participants' lives, not least because they foregrounded their dementia as a consequence. One can suggest that this foregrounding of dementia within the participants' lifeworlds as a consequence of falling is a new finding. What is also revealed in this study is how falling and dementia were enmeshed experiences for these participants, with the consequences of one impacting upon the other. Falling, according to these qualitative accounts, seemed to often precipitate change and threaten the sense of self of the care-recipient, impacting on the dyadic relationship and potentially the sense of self of the carer and their capacity to care. Whereas the progression of dementia already threatened the sense of self or couplehood of the dyad, it can be seen here that a fall often accelerated or accentuated this threat, with the carer working alone (often by trial and error) to control or prevent falls of the care-recipient (and even their own), rather than working together to preserve couplehood (Hellström et al, 2005a). It is suggested that the enmeshed experiences of falling and dementia creating changes to the caring relationship, are new findings, with little being reported in the extant literature examining the impact of dementia along with other co-morbidities (such as falling).

## **9.2 Elaboration and illumination of the falls experience: Discussion of findings from secondary study**

This secondary study sought to elaborate on the falls experiences of participants from the primary study by carrying out focus groups with other older people with dementia and carers who were members of local Alzheimer's Society branch groups. The findings have been presented in chapter eight of the thesis as four major themes. The first two major themes presented data that was perceived to be shared between participants in both focus groups, which relate to making sense of falling and the personal and social significance of falling. Even though the third and fourth major themes present common issues of self and identity within the data, the third major theme relates more

specifically to data from the people with dementia and the fourth major theme to data from the carers.

### 9.2.1 Elaborating and illuminating

Like the previous stage of the research (and in keeping with qualitative research traditions), there was convergence and divergence within the findings, not only between primary and secondary study data, but also between participants within the two focus groups in the secondary study. In many instances, participants from both focus groups made sense of the summarised data and quotations from primary study (such as the descriptions, reactions and reported consequences of the falls). Not only did these summarised data and quotations resonate with their own experience but also the presentation of the data prompted a further elaboration and uncovering of falls experiences. It could be said that these participants made sense of what they were presented with by bestowing these quotes and summarised data with their own personal meanings; as suggested by Bruner (1990) and Eatough and Smith (2006). Understanding and empathy are considered by Bruner (1990) to enable us to enter into meaning and sense making of another's experience. In only one instance was an extract of the primary study data ("if I fall, I fall properly"), not understood by a participant, Stephen, from the group of people with dementia. One can suggest that this statement did not make sense to Stephen, or resonate with his experience. As Heidegger proposes, Stephen was perhaps unable to relate to the quote ("if I fall, I fall properly") authentically as the phraseology or description of the participant from stage one was out of his experience (Moran 2000). It is also possible that the intended (possibly ironic) meaning of the narrative from the primary study participant was lost out of its context. Although Stephen seemed unwilling (or had difficulty understanding) the quotation from the primary study participant, during the focus group Stephen seemed to not have a general problem in making sense of others' experiences as he was willing to ask for clarifications in face-to-face interaction. Interestingly, even though the participants from this stage made sense of nearly all of the data presented to them from stage one, their experiences were, in the main,

different from those of primary study participants. In this secondary study most of the participants from the group of people with dementia did not construe their falls as having particularly traumatic consequences. However the use of focus group methodology could have influenced these participants' self-presentation, because of the possibility of socially desirable responses (Smith et al 2009), and this will be returned to in section 9.4 where the study is critically evaluated. The participants from the carers group in this stage seemed to experience a greater physical load than the majority of carers from the primary study, as it seemed that these participants were caring for people with more severe dementia than those in the primary study. It could also be said that the carers in the secondary study were experiencing more objective burden than the carers in the primary study, who potentially were experiencing more subjective burden, as described by Morgan and Laing (1991). It is possible that the different experiences (and severity) of dementia between the participants in both stages allowed a different facet of the falls experience to be uncovered, which would reflect Heidegger's (2002) belief that experiences reveal themselves determined by the mode of access that an individual has to these experiences.

Like many of the participants with dementia from the primary study, these participants with dementia in the secondary study focus group mainly considered extrinsic causes for falls. Although in this secondary study focus group the older participants with dementia were more able to relate these to specific incidents, such as falling down the stairs as a result of wearing badly fitting shoes. However one participant with dementia could not relate his falls to a specific cause, but could only conjecture that his body lacked co-ordination. Participants in the focus group of people affected by dementia hypothesised that being able to identify specific reasons for falls would enable an individual to accept the fall and not suffer any long term consequences. They also suggested that a fall resulting in a negligible impact (i.e. injury) would also prevent any long-term concerns. The positive effects of being able to rationalise why a fall occurs echoed the findings from a study by Roe et al (2008) of cognitively normal older people. Here, Roe et al (2008) suggested that understanding of a fall occurrence enables a cognitively normal older person to maintain their

autonomy and control over their daily lives. Indeed it would seem from this study that the participants with dementia who cited specific reasons for their falls conveyed a greater sense of autonomy and intact sense of self than their co-participants, and also compared with those people with dementia in the primary study, who could not identify a specific reason.

Interestingly, the participants from the carers' focus group mainly elaborated upon intrinsic reasons for falling, either for their care-recipient or for themselves. They not only considered the idea of thinking of other things as a potential reason for falling but also discussed how they were always thinking for two – not only for themselves but also for the person with dementia who they cared for. These participants interpreted thinking of other things both for themselves and for people with dementia as not only increasing the likelihood of being distracted but also misinterpreting the environment. One could suggest that there are possible differing interpretations of these findings. Whereas difficulties with dual tasking, divided or overloaded attention are identified within the positivist cognitive neuroscience approach as often increasing the risk of falling in older people with cognitive impairment (Verghese et al 2002, Yardley et al 2001, Baddeley et al 1991, 2001), the burden of care has perhaps increased the attentional demands for these carer-participants so they were at greater risk of falling themselves. A more interpretivist or interactionist perspective taken by Persson and Zingmark (2007) and Karner and Bobbit-Zeher (2005) would suggest that the caring for a person with more severe dementia leads to the lives of carers and care-recipients with dementia becoming so intertwined that the increased risk of carer burden or stress is heightened because the carer takes on sole responsibility for the person with dementia whom they care for. Wood (2007) takes this further in a more psycho-analytical way to suggest that carers of people with severe dementia become “containers” to preserve the identity of the person with dementia and the two selves become merged. One could therefore suggest that the demands of a merging of identity for the carer becomes too great and increases their own risk of falling.

Even though there were many differences in the responsibilities of caring that were recounted between the two studies of the research there were also some

similarities. Like many (but not all) of the carer participants in the primary study, all of the carers from the secondary study felt that they were solely responsible for their care-recipient. In the primary study, some of the carers were coming to terms with the recently acquired role of carer, like Christopher in the secondary study. However for the majority of carer participants in the secondary study, the feelings of isolation and vulnerability and the distrust of formal service provision were communicated more strongly than in the findings in the primary study, with the idea of being a “couple of one” or working alone as suggested by Hellström et al (2005a) and Keady and Nolan (2003) being more obvious in these accounts. However these feelings of despair, vulnerability and the need to carry on despite their own health issues mirror the experiences of both Karl and Patrick from the primary study. Like Karl and Patrick, these focus group carers found the falls of their care-recipient to be turning points in their ability to care and trying to cope with the consequences of falling (including trying to get their care-recipient up off the floor), perhaps shattered their belief in their own invincibility. Skaff and Pearlin (1992) highlight that role-engulfment and pre-occupation with self-care tasks of the person with dementia leads to loss of self and identity of carers. Certainly these participants focussed very much on their caring role in relation to physical needs, and the need for surveillance of their care-recipient. Interestingly, Brijnath and Manderson (2008) describe a person with more severe dementia as being “a body in chaos” (p609), and it would seem that these carers’ accounts highlight how they struggled to control the unpredictable and chaotic life-world of their care-recipient. They also portrayed themselves in the role of spouse caring for their partners, not as carers, which reflects work by Perry (2002), Perry and O’Connor (2002) and Sanders and Power (2009) whose findings suggest that the caring role is perceived as being part of being a spouse and a couple, and not a different role or identity. However, these carers in the secondary study discussed how extrinsic circumstances such as service provision, support and environmental factors all became barriers to them doing things as a couple. From these findings one can surmise that a reduced opportunity to do things together impacted upon their sense of couplehood (Hellström et al 2005a) and their role as spouse (Perry 2002). One can also imply that the curtailment of everyday activity for their care-

recipient, (or for themselves) as a consequence of falling, would have a negative impact on their care-recipients' personhood (Kitwood 1997) and would also threaten their own sense of self (Skaff and Pearlin 2002, Horton and Arber 2004).

In many respects, from their accounts, the carers in the primary and secondary studies seemingly provided different levels of care at the time of data collection, with the carers from the secondary study recounting higher demands made upon them and a lengthier involvement in care-giving. Therefore the findings from this secondary study uncovered more about the stressful roles and responsibilities of carers, partly arising as a result of falls of the people with dementia that they were looking after. Nevertheless, there were some similarities in the findings between both studies, especially in accounts where carers voiced distrust for formal carers or services to provide them with appropriate support – such as Mary, Felicity and Daniel in this secondary study and Karl and Patrick in the primary study. It could be said that the experiences of carers from the primary study and secondary study differed, not in the amount of carer burden they were experiencing, but perhaps in the way that the burden was manifested. It would seem from the carers' accounts from the secondary study, that they provided more physical care to their care-recipient than most of the carer-participants from the primary study (Patrick a carer from the primary study, is perhaps an exception here). Whereas primary study carers perhaps experienced subjective burden, the secondary study participants experienced both subjective and objective burden. Similar carer experiences have also been acknowledged in the study by Faes et al (2010) and Kuzuya et al (2006) of carers of frail older people (including dementia).

### **9.2.2 Summary of discussion from secondary study**

This stage of the research presents findings from two focus groups, one group of people with dementia, and the second a group of carers. The purpose of this study was to elaborate upon the research findings from stage one and not to generalise or validate the findings. Participants from both focus groups reflected on and related to most of the summarised extracts presented to them from

stage one of the research. Indeed they made sense of the data by elaborating upon it, uncovering different facets of the falls experiences for both people with dementia and carers. It is possible that these somewhat different experiences of falling related to their differing experiences of dementia. Even though the severity of dementia could not be formally ascertained, the participants from the focus group for people with dementia were recently diagnosed and most likely to have mild dementia, whereas the participants from the carers' group appeared mainly to care for (or had cared for) people with more severe dementia.

In this secondary stage of the research, the personal experiences of falling of the older people with dementia seem similar to the extant literature on falls of cognitively normal older people, in relation to loss of self-efficacy and sense of control (Ruthig et al 2007, Horton 2006). The account by carers of 'always thinking for two' or 'of others' relates more to the literature of caring for people with dementia which has not previously considered the falls experience in detail (Karner and Bobbitt-Zeher 2005, Persson and Zingmark 2007). Whereas research from the cognitive neurosciences associates dual tasking, divided or overloaded attention with increased risk of falling among cognitively impaired older people (Verghese et al 2002, Yardley et al 2001), this has not been noted in older people who are cognitively normal, and yet this was a theme arising in carers' accounts. One could suggest that the demands of caring and coping with falls impact upon the health and well-being of these participants. It is perhaps in this secondary study of the research that the vulnerabilities of carers of older people with dementia are illuminated most clearly.

### **9.3 Summary of findings from primary and secondary studies**

The primary and secondary studies within this research have explored the experiences of falling of older people with dementia and their carers. Themes from both the primary and secondary studies have been discussed in the previous sections, however in this section the findings from both studies are summarised.

The experience of falling had entered the lifeworlds of all of the participants in both the primary or secondary study, whether through personal experience, or vicariously as a family member caring for someone that had fallen. Falling was also a transforming experience for most of the care-recipients in the primary study and all of the carers from both studies. The older people with dementia from both studies shared their memories of their falls experiences, and whereas these participants from the primary study had embodied memories of their falls, the participants from the secondary study appeared to have more factual memories. It is possible that these less 'emotive' memories of falling were either because of a more intact episodic memory, or because these participants were sharing their experiences in a focus group situation and therefore were more guarded in what they said.

Threats to self seemed to appear in the accounts of most of the participants from both studies, and whereas these threats to self were more enduring for most of the participants from the primary study, these threats seemed almost transient, or more superficial for the older people in the secondary study. Threats to the carers' sense of self and also to the dyad's sense of couplehood seemed more apparent in all of the carers' accounts from both studies. Although dyads conveyed feelings of spousal or parent-child relationships, these identities often seemed threatened by the impact of falls and dementia. Carer burden also seemed to be part of the carers' lifeworlds from both studies, but this could be perceived more as subjective burden for most primary study carers, and objective burden for secondary study carers.

The impact of the monitoring and managing of falls of the care-recipient alongside more general caring concerns appeared to not only impede the carers' opportunities to attend to the life-world and sense of self of the care-recipient, as suggested by Ashworth (2006), but increased the carers' own vulnerabilities, health issues, and potentially precipitated their own falls. Carers from both studies recounted being old, being distracted and always thinking of the care-recipient as reasons for their own falls.



The findings from the primary and secondary studies present both converging and diverging accounts, which have resulted in a multi-faceted view of how falling impacts upon the lifeworlds of older people and dementia and their carers. As already discussed in section 9.2.1, a reason for these differing experiences of falling by the participants from the two studies might be because of their differing experiences of dementia (especially the severity of the dementia experienced). This perhaps emphasises how falling and dementia are enmeshed experiences in these participants' life-worlds.

#### 9.4 Evaluating the research

The research presented in this thesis consists of two different studies, with the primary study being an IPA study and the secondary study being an exploratory qualitative study not aligned to any specific methodological tradition (for reasons elaborated on in Chapter Four). However both of these studies have been carried out within a contextualist position, which has allowed the multiple realities of falling in people with dementia and their carers, to be explored. Both studies have used an inductive and interpretative approach and in line with other research of this kind, the influence of the researcher on data collection, analysis and presentation of the data is acknowledged. Like other inductive and interpretative studies, this research does not profess to make generalisations to larger populations. However, vertical or logical generalisation (as described by Yardley 2008) can be suggested as the findings resonate with existing literature as well as presenting new findings. However, it is important to evaluate the strengths and weakness of these studies in terms of their quality or rigour.

How qualitative research should be evaluated has been widely debated within the literature (Elliott et al 1999, Spencer et al 2003, Yardley 2008), especially when the philosophical and theoretical positions vary between (and sometimes within) qualitative research traditions (Yardley 2008). Criteria described by Yardley (2008) have therefore been used to consider the validity of these two studies, because the criteria are not aligned to any theoretical perspective but provide a framework for different qualitative approaches. The studies are critiqued using the four criteria suggested by Yardley (2008) - sensitivity to

context, commitment and rigour, transparency and coherence, impact and importance, to establish that the research studies are sound and rigorous in their construction, procedure and analysis and discussion. The strengths and weaknesses of the research studies are also considered in relation to a guide for evaluating IPA studies by Smith (2011), and in relation to the paper by Braun and Clarke (2006), who have provided guidelines for the conduction of research using thematic analysis. The impact and importance of the research will be considered in the following chapter - chapter ten, the conclusion to the thesis.

#### **9.4.1 Choice of theoretical and research approaches**

Yardley (2008) suggests that a coherent piece of research and one that is sensitive to the context of the research question is informed by an exploration of the empirical literature and informing theory. It is suggested that the exploration and critique of the literature in chapter three (literature review), my experience as a practising occupational therapist and academic (stated in chapter one), and the consideration of current governmental policies and guidance in chapter two (background) have helped to contextualise and demonstrate why the research questions for this study were pertinent. It is also proposed that Chapters Four (development of method) and Five (chosen research methods) in this thesis have highlighted why a qualitative and inductive approach, informed by contextualism, was appropriate.

Not only did greater understanding of what issues might arise with carrying out research with older people inform the choice of qualitative approaches (as justified in chapters four and five) but also my practice experience as an occupational therapist reinforced the desire to explore the subjective, or lived experiences of older people with dementia and also their carers. The use of IPA and also an approach independent of any tradition in the secondary study have been already justified in terms of their sensitivity to context in chapter five, especially for participants who are perhaps more marginalised and difficult to access, as with older people with dementia.

An initial lack of full appreciation of interpretative phenomenological research and IPA in particular, and a limited understanding of the ontological and epistemological influences for IPA when the study commenced in 2003, meant that the use of a secondary study to improve the rigour of the research was considered, at the proposal stage of the research. As the primary study progressed, a greater understanding of interpretivism and the focus of interpretative phenomenological research challenged this decision. It was decided to still undertake a secondary study, but the focus of this was to elaborate upon the data from the primary study for further illumination of the impact of falling on the life-world for older people with dementia and their carers through an elaborative triangulation as discussed in Chapter Four (see section 4.4.1). Choosing a research approach that was sensitive to the theoretical context of IPA in the primary study also took some deliberation. It was important to choose an approach that would be sympathetic to a contextualist and inductive and interpretative orientation. The choice of an approach that was not aligned to any tradition, but would compliment the primary IPA study was decided upon. Rather than have a more 'laissez-faire' approach to choice of design for the secondary study, the choice was informed by the guidelines on thematic analysis by Braun and Clarke (2006). These authors suggest that although thematic analysis is not constrained by a theoretical framework, it does not preclude theoretical frameworks from informing or influencing analysis. Therefore, an exploration of Heidegger's principles of uncovering and illumination of the life-world (Moran 2000) led to the analysis of the findings from the secondary study being influenced by phenomenology.

#### **9.4.2 Collecting the data**

The justification for the choice of participants for both studies has already been made in chapter five. There was an awareness that the opportunity to gain the experiences of such a relatively hard to reach group such as older people with dementia whose experiences were relatively underexplored at the time of data collection could be problematic. It was acknowledged that certain procedures would have to be put into place to ensure sensitivity to context, in that the

research took place within an ethical framework and to safeguard the participants. The use of key workers as gatekeepers to access potential participants for both studies has been shown to have many benefits within the empirical literature (Dewing 2007, Davies et al 2010), not only to safeguard the potential participant but also to encourage recruitment. Although the use of gatekeepers was advantageous, especially in recruitment for the focus groups in both the primary and secondary studies, it also had its disadvantages. Recruitment for the interviews of the dyads in the primary study was carried out by the keyworkers within the community mental health team. Recruitment was therefore reliant upon their understanding of the project and also their commitment to it; especially at a time when their workload was changing and increasing, and recruitment to the primary study was not their priority. In other instances, carers also acted as gatekeepers, as they tended to answer telephone calls made to arrange the interview appointment. Therefore some carers refused participation in the research on the care-recipients' behalf, even though initial agreement by the care-recipient had been made. Initial exploration and consultation with key health care staff within the NHS trust involved in the data collection, indicated that recruitment to the study would not be problematic. However, the recruitment to the primary study was very slow, with six dyads being recruited within the first six months of the study and then a period of nine months where no potential participants were recruited. Some were lost to the study before data collection because of escalating deterioration in the health of the older person with dementia, with subsequent acute hospital admission or death.

At the time of data collection the common sample size in IPA studies was between four and ten (Smith and Osborn 2003) and therefore there was anxiety around the perceived smaller sample size in this study and the potential impact upon the rigour of the study. Interestingly, whilst this research has taken place, IPA has developed as a research approach, with greater emphasis on more idiographic and interpretative analysis of data and therefore smaller sample sizes are often advocated (Smith and Osborn 2008; Smith et al 2009). However, in 2006 when recruitment for interviews had faltered, the opportunity to recruit potential participants of older people with dementia and their carers

from a local Alzheimer's society branch, to boost the sample size and perceived rigour of the study, was seized. Interestingly, whilst the use of focus groups within the primary study were being negotiated and ethical approval given, three more dyads were recruited to the study, providing a total of nine dyads being interviewed.

Sensitivity to the socio-cultural context of the research was also important when carrying out the focus groups in the primary study. The Alzheimer's Society branch manager requested that the correspondence for the potential participants (invitation letters, information sheets, consent letters etc.) should be addressed to older people with memory problems as it would seem that not all the members were aware of, or had had a formal diagnosis of dementia. However it is likely that these older people did have dementia because their problems were significantly noticeable at the time of data collection. The branch manager also requested that a group interview be carried out, as this was a familiar format for the participants. These issues have been discussed and justified in Chapter Five.

It is considered that some of the weaknesses of these studies include a lack of appreciation of how much falls experiences would impact on the carers' health, wellbeing and personhood, so that certain demographic data such as age of carer, ethnicity and socio-economic group were not collected. The age of the carers in the interviews and all focus group participants from both primary and secondary studies can only be surmised by the researcher's observations at interview and also in relation to the age of the care-recipient. Therefore the relationship between some of these factors and the qualitative accounts cannot be fully explored.

The use of focus groups in IPA is currently debated. Smith et al (2009) articulate a concern that there is more limited opportunity to gather idiographic data from group interviews with less sharing of personal experiences and more socially desirable responses, which could impact upon the rigour of the study. The missed opportunity to attend the Alzheimer's Society group meetings prior to data collection meant that opportunities were limited to modify or facilitate the concurrently run focus groups in the primary study more effectively. Even

though most of the interviews in the primary study were carried out on the first time of meeting the participants, it was easier for the interviewers to adjust their communication and use of prompting on a one to one or joint basis in the interviews. Furthermore, the use of a naturally occurring and already established group as participants in this study, facilitated the sharing of personal experiences, as also observed by Tompkins and Eatough (2010). The carers' accounts were also more dominant within the primary study focus groups, which can be seen as a weakness in this type of data collection. However, their involvement as "equals" in the focus groups meant that carers talked about their own falls as well as those of the care recipient. This resulted in the revisiting of the interview data to explore the dynamic of the carer's health in the dyadic relationship, and the uncovering of a new issue.

The procedure for the interviews with the dyads in the primary study has been described and justified in Chapter Five. Indeed, the choice of one to one and joint interviews arose from a sensitivity to the practice context where this was a common procedure, rather than from examples in the research literature. Both the researcher and her colleague (who carried out three interviews and two repeat interviews) were experienced in interviewing people with similar characteristics in their clinical practice. They were both aware that the sole use of joint interviewing led to a possibility of collusion by individuals, to protect the other from what they perceived as potentially distressing topics and potentially domination of the carers' voice, whereas the use of joint interviews in conjunction with one to one interviewing allowed for different experiences to be explored. The strength of using joint interviews in IPA research (within the primary study), allowed for the co-construction of experiences, and provided opportunity for the sharing of accounts by the dyads, sometimes for the first time since falling. This sharing of experience allowed the carer to attend to the life-world of their care-recipient from a different perspective, which Ashworth (2006) discussed as potentially enabling the carer to understand and care for the person with dementia in a more meaningful way. The inductive and interpretative research approaches in both studies have also highlighted how the experiences of falling and dementia are intertwined in the accounts of these

participants and seemingly impact upon the sense of self, health and well-being of both older people with dementia or memory problems and their carers.

The involvement of two people carrying out the interviews needs to be considered in relation to the rigour of the research process. As already described in Chapter Five (sections 5.4.4.4 and 5.4.5), there was an awareness of the need for consistency in data collection. The carrying out of four pilot interviews where each observed the other in two of the four interviews formed an important part in ensuring the robust process of data collection. As previously discussed in Chapter Five, both interviewers were experienced at interviewing older people with dementia and carers as part of their clinical practice. However it was important that the subjective experiences of the participants about their falls were explored, and each interviewer didn't slip into 'therapist' mode and try and seek information to formulate their own opinion and deduction within a more realist framework. Therefore the regular 'debrief' after interviews and the keeping of reflective diaries were important.

Whereas the use of focus groups with people with dementia and groups with carers have been critiqued within the literature (Bamford and Bruce 2000, Cheston et al 2003, Mills 2003), this was not the case for joint focus groups. In the primary study, the procedure for the focus groups was therefore determined by the practice experience of the interviewers. It was envisaged that the carers would support their care-recipient in sharing their experiences of falling, and although this did happen, there were instances where the pace of discussion between the carers in the groups meant that the care-recipients contributed only when encouraged by their carer or the focus group facilitator. Therefore, unlike the interviews where care-recipients and carers were given equal status in the interaction, with neither being privileged over the other, in the primary study focus groups, the carers' accounts were, by default, mainly privileged over the accounts of their care-recipients. As a result of this experience, the decision was made that each focus group in the secondary study would involve either people with dementia or carers, to promote equal privilege of accounts within and between the group participants, especially in the focus group for people with dementia. However this meant that there was no opportunity to run more

than two separate focus groups, as it appeared that there were no other existing groups for older people with dementia run by the Alzheimer's Society in the region, at the time of data collection in the second study.

Awareness of the need for sensitivity to context, commitment and rigour and transparency and coherence in the conduction of the interviews and focus groups has already been discussed in Chapter Five. The need for a flexible and open-ended topic guide was not only informed by the research literature, but also therapeutic practice, where the use of a conversational style and a "playing down" of the research interview (as suggested by Keady 1999) allowed for easier sharing of the participants' experiences. Prompts within the topic guides for both studies, allowed for the story of the fall experience to unfold in a chronological order of events, and as the experience in research interviewing grew, so did the confidence of the interviewer when the conversation seemingly went "off topic". Indeed, what seemed to be "off topic" during some of the interviews, was later considered being meaningful and evocative at analysis (please see reflexive statement Chapter Seven, section 7.4).

It was initially hoped to have carried out more repeated interviews in the primary study, to have built upon the experience of falling by these participants. Only three dyads were recruited to carry out repeat interviews and unfortunately only one dyad was interviewed three times, with the other two being interviewed twice. As already discussed in section 5.4.3.3 in Chapter Five, these participants were lost to the study, through death or poor health, which is not uncommon in longitudinal research (Matthews et al 2004, McMurdo et al 2005). As a result of this, any temporal changes of experience could not be fully explored. However, the use of IPA as a means of capturing people's subjective experience was an advantage in this study with older people with dementia. IPA is valued as a means of capturing and exploring how participants make sense of their experiences, and not to establish objective facts or the truth of what they say (Smith et al 2009). Therefore it was not important that the older people with dementia did not remember where or when they fell, but that they were able to share their more subjective experiences.



### 9.4.3 Analysing and presenting the data

The realisation of the considerable amount of data collected became apparent during the preparatory stage of analysis, and a further literature search of published IPA studies took place to inform the analysis (as described in Chapter Five). As Smith et al (2009) state, analysis is not a prescriptive process within IPA, however having the guidance published in early literature was helpful to the novice (e.g. Smith and Osborn 2003). Early analysis of the data from the primary study was very descriptive and this provided content for the stimulus cards used in the secondary study. However, as already discussed in Chapter Five (section 5.4.9), using the first three transcripts to inform the analysis of subsequent accounts (as suggested in Smith and Osborn 2003, 2008) seemed restrictive and insufficiently idiographic at that time. Also analysing the data separately from the care-recipients, carers and joint interviews (plus focus groups) appeared to not fully allow for the shared experiences and co-construction of falling to be portrayed. Therefore, analysis of the dyad interviews as one data item was decided upon, and this decision was made following discussion at an IPA conference. Unfortunately the opportunity to parse the focus group data from the primary study, for individual accounts, as suggested by Smith (2004), was not fully possible because of the poor quality of the audio recordings limited detection of individual voices. Subsequently, each focus group transcript was considered as one data item. Fortunately there was greater opportunity to parse the data for individual accounts in the secondary study focus groups.

Immersion and reiterative analysis of the data over a period of time allowed for greater sensitivity to the participants' contexts. Miller and Crabtree (1999) suggest that the analysis phase within a study ends with the writing up of the report, paper or thesis. Indeed, during the final stages of writing this thesis, other interpretations of the data have also sprung to mind as immersion in the data continues.

Whereas early analysis had almost ignored some of the accounts that had been considered as "off topic", the repeated immersion in the data lead to a deeper understanding and interpretation of what participants were conveying. For

example, in Tony, Wendy, Norma and Bob's accounts, a greater understanding of their telling of stories from the past arose from a fuller appreciation of the hermeneutic circle, in thinking of whole-part-whole (Smith et al 2009). The "off topic" extracts then became considered in terms of the whole interview and then other parts of the interview, so that the transcript and others were revisited and re-analysed in relation to this interpretation. For example, participants recounting stories about their past skills or identities as a cyclist, good scholar, bowler or scientist, allowed for greater understanding of their sense of self and how this was potentially threatened or preserved within their accounts (please see reflexive section 7.4 in Chapter Seven).

The development of IPA and publication of IPA research during the period of analysis (2006/7 to 2011) also stimulated a commitment to more detailed and nuanced analysis and interpretation of the data. Encouragement by Smith et al (2009) for IPA researchers to pay more attention to the language used or the linguistic constructions in participants' accounts formed part of this more nuanced interpretation. Consideration of the use of certain phrases, metaphors and words led to an interpretation of bodily alienation and being out of control, within the first higher level theme, for example (see Chapter Six). This transformed this theme from being more descriptive to a theme arguably more appropriate to an IPA study. Even though the use of language by older people with dementia is said to be impaired within a medical (and positivist) model of dementia (Harding and Palfrey 1997), Kitwood (1997a, 1997b) suggests that the use of "metaphor and allusion" (Kitwood 1997a: 128) should be listened to carefully as these stories and metaphors of past events often relate to their current feelings and situations (Kitwood 1997b). Therefore it was considered that such an interpretation of phrases, words and metaphors was not only appropriate within the analysis, but was being sensitive to the context of the person with dementia and their experiences. For example, in George's account "...I wasn't floating quite so much..." (I.2993), not only can this be interpreted as George's feelings of recovering from his fall, but perhaps also helps to convey this as a surreal experience.

Immersion in the data and reflexivity of the analysis were also necessary for the secondary study, and there was a time difference of approximately six months between the analysis of this study and writing up of the findings in chapter eight, in order to become open to the new phenomena in the secondary study and put aside or bracket off the analysis and preconceptions from the primary study as far as possible, as suggested by Langdridge 2007, Finlay (2008) and Smith et al (2009). When inductive analysis of the secondary study data was clustered into similar themes to those in the primary study, the data were looked at again to ensure that these themes were appropriate and not overly influenced by the primary study. However, it was considered that these themes were indeed representative of the data and that these could be supported by sufficient verbatim quotes from secondary study participants to ensure sufficient rigour within the analysis.

Commitment and rigour within the analysis can be demonstrated by clearly explained methods of data analysis for both studies in chapter five. As a novice qualitative researcher it was important to have early analysis of the transcripts explored by the first supervisor, who considered the plausibility of the coding and clustering of themes within both studies. Rigour within qualitative data analysis is often demonstrated through participant validation or member checking. As already discussed in Chapter Five (section 5.4.10), it was decided not to use this more realist process, as this is a debatable procedure within interpretative research, because the participant may not understand the researcher's interpretations, or may have a partial (or one-sided) understanding of their experiences (Ashworth 1993, Langdridge 2007, Yardley 2008, Finlay 2011). Other ways of showing rigour, and indeed, transparency and coherence in the analytical process has been the provision of an audit trail from transcript to final themes in appendices I to L, O and P.

Smith (2011) also considers that rigour within an IPA study can also be demonstrated through a representative use of verbatim quotes within the themes presented in the study findings. Through demonstration that inferred themes are present in all transcripts and that certain subthemes occur in the majority of transcripts, sufficient evidence for the interpretations has been

made. Divergence as well as convergence within the data has also been presented in the findings to demonstrate an idiographic focus as well as commitment and transparency in the analytical process. It has been endeavoured to present the data within the findings chapters (six to eight), and the discussion of the findings within this chapter, to allow for a coherent argument to be presented.

In conclusion, the primary and secondary studies presented in this thesis have explored the experiences of falling of older people with dementia and their carers. The primary study has used IPA to explore how older people with dementia and their carers made sense of their falls experiences and explored the consequences of their falls. The secondary study asked other older people with dementia and carers to elaborate upon these experiences, and in their own accounts provided further illumination of the falls experience and how falling enters the lifeworlds of these participants, who already are experiencing dementia, either personally or vicariously as carers. The following section will explore what would be done differently if the studies were run again. The final section in this chapter will provide a reflexive section. A final chapter, Chapter Ten then follows to provide a conclusion to the study.

### **9.5 Suggestions for repeating the study**

Much has been learnt about carrying out qualitative research and inductive and interpretative research in particular. Whereas there would be no hesitation in using the research methods already used, and indeed a primary study and an elaborative secondary study, other suggestions are now made.

Greater understanding of IPA, and in line with more recent development and maturity of this research approach, provides greater confidence in recruiting smaller numbers of participants for future studies, and to provide opportunity for a more case-study approach to analysis.

The opportunity to recruit more dyads for repeat interviews (and possibly 'over-recruiting' to accommodate any attrition) to gain an understanding of the more temporal experiences of falling would be of interest.

The use of one to one and joint interviews with dyads would certainly be repeated, as this was considered as a valuable part of the research process.

What was disappointing was the use of focus groups that jointly involved older people with memory problems and carers in the same group, as this did not allow for co-constructed experiences as hoped. What may alleviate this issue, and indeed would be ideally carried out in future, is the carrying out of more than one focus group with the same participants to build up a rapport with them and gain an understanding of any communication needs or issues to facilitate more equal participation. Carrying out a repeat focus group would be the favoured future method of choice even where joint focus groups are not used.

### **9.6 Final reflection of the research presented in this thesis**

Having confidence in my ability as a qualitative researcher has been an important part of the research process for me. I came to qualitative research as a complete novice; I now have a better understanding and appreciation of it, but would not call myself an expert. It has been fascinating to use a relatively new research approach such as IPA, which has been developing whilst I have been carrying out my research. In many respects, researchers have been trying out different ways of carrying out IPA research, with differing ways of collecting data, sample sizes, participant groups and from differing disciplines. This has added to the development of IPA, but also has strengthened the identity of IPA too, as researchers endeavour to produce and publish research that remains true to the original aims of Smith (1996) and is of a recognisable quality (Smith 2011).

I have enjoyed using different research methods for the two studies in this thesis, even if this has felt rather risky at times. I now know that I have greater confidence in my research abilities. As already reflected upon in previous chapters, I had an initial worry that my data was too “thin”, but as my interpretative skills increased I realised that the accounts were rich with metaphors and meaning. What I have also appreciated is that my

understanding of phenomenological philosophy has developed, alongside my increasing skill in interpretation of the data.

I did not (and could not) have foreseen the journey I have taken whilst carrying out the research presented in this thesis. What is exciting is that I know that it is a continuing journey and I look forward to developing my skills, knowledge and understanding as I travel.

## **Chapter 10 - Conclusion to the thesis**

This concluding chapter seeks to summarise the research, including highlighting what the findings from both studies have revealed and what the key contributions of the research are to knowledge. Any practice or clinical implications of the research will also be discussed.

### **10.1 Summary of the research**

#### **10.1.1 Identifying the gaps**

Falling by older people is of significant global concern as the population ages, because of increased risk of subsequent injury, disability, admission to long-term care and mortality. Older people experiencing dementia are twice as likely to fall with more severe consequences. Unsurprisingly, carer-burden increases when a care-recipient falls. When this research started in 2003, the literature indicated that few older people had been asked about their experiences of falling, and that older people with dementia were even more rarely asked about their experiences. In the period since 2003, older people and people with dementia have been increasingly involved in sharing their experiences. However, it was only in 2010 that Faes et al (2010) asked older people with cognitive impairment and dementia in the Netherlands, about their experiences of falling.

The UK policy that informed at the commencement of the study in 2003, was the National Service Framework for Older People [NSFOP] (DH 2001) which conveyed themes of respect for the individual (through person-centred care for older people and their carers and their involvement in service development and provision). Other themes in the NSFOP (DH 2001) included provision of evidence-based specialist care (including falls intervention and prevention and mental health provision), along with consideration of promotion of health and well-being in older age within all service provision. As this research progressed, guidance was forthcoming from NICE (2004), and the Department of Health

(2006) which updated the NSFOP (DH 2001) to acknowledge that those older people with complex needs (for example people with dementia) and their carers needed integrated services co-ordinated by a keyworker. However, in 2011 the Royal College of Physicians established that 6% of services were explicitly excluding older people with dementia from falls service provision, and that involvement of any older person in falls service development and evaluation was limited. What has also become more obvious is that not all (cognitively normal) older people are taking up falls intervention offered to them as it they feel that this is not applicable to them (Yardley et al 2006a, 2006b, Nyman and Victor 2011).

Therefore, when this research started in 2003, a gap within the research literature was identified; that older people with dementia were not being asked about their falls experiences, and that there was only a partial exploration of carers' experiences. Consequently there was limited evidence to inform falls service provision. Moreover, it would seem that this is still the case in the UK.

### **10.1.2 Exploring the experiences of older people with dementia and their carers**

This thesis has presented an exploration of the experiences of falling of older people with dementia and memory problems and their carers, by using a primary study and a smaller secondary study. A contextualist approach, using qualitative methodology was chosen for the studies. The research question for the primary study was:

- **What is the lived experience of falls among older people with dementia and their carers?**

The aims of the primary study were to explore the lived experiences of falling and the consequences for older people with dementia and their carers.

The research question for the smaller **secondary study** was:

- **What are the elaborations and interpretations of older people with dementia and carers of the summarised falls experiences of others?**



The aims of the secondary study were to explore whether other older people with dementia and carers found that the findings from the primary study resonated with their own experience.

The primary study used IPA as a means of exploring the experiences of nine older people with dementia and their ten carers in one to one and joint interviews, and nine older people with memory problems and 12 carers in three focus groups. The secondary study was inductive and interpretive, and independent of any tradition. Two focus groups were carried out, one with five older people with recently diagnosed dementia and the second with seven carers. The data collected in the secondary study related to an illumination and elaboration of the falls experience, based upon the discussion of quotations and summarised quotations from primary study participants to further explore how falls enter the life-worlds of older people with dementia and memory problems and their carers.

### **10.1.3 What the findings revealed**

The findings from the primary study suggest that participants experienced falling as a malevolent force, where negative and embodied memories of falling were expressed. Participants' emotional responses to falling included accounts of fear of falling, and seemingly permanent changes in behaviour and restriction in activity. These findings also suggest that participants experienced falling as the manifestation of dementia, where falling and dementia were intertwined with longer reaching consequences, such as threats to self and identity and also threats to the caring relationship.

Findings from the secondary study suggested that participants were able to make sense of the falls experiences of the primary study participants. They elaborated upon these experiences by sharing their own accounts of falling. Extrinsic causes for their own falls were mainly identified by the older people with dementia, whereas intrinsic reasons were articulated by the carers for both their own and their care-recipients' falls. The significance of falling within the life-worlds also varied. Whereas the older people with dementia in this study did

not, in the main, describe long-term consequences of falling, the carers in this study did express longer reaching consequences. The older people with dementia in this secondary study seemed to maintain an intact sense of self despite their falls experiences, even though some accounts revealed threats to identity. Carers' accounts in this study strongly conveyed the identity and responsibilities of being a carer, including how they tried to control and prevent falls in the care-recipient.

Whereas the findings from the primary study participants and the carers in the secondary study suggest that the falls experiences acted as turning points in their lives and experience of dementia, this is not so apparent in the accounts of the older people with dementia in the secondary study. It could be suggested that the more recent diagnosis of dementia meant that this had not as yet entered their life-worlds and threatened their sense of self. The enmeshing of falls experiences and dementia in the carers' accounts in both studies reveal feelings of vulnerability, isolation and being overwhelmed by the caring role. The accounts of these carers suggest a heightened risk of falling themselves, as well as injury and threatened health and wellbeing.

These findings reinforce current policies that the needs of both people with dementia and their carers should be recognised and supported to maintain their health, wellbeing and personhood, both as individuals and more importantly as couples to address the challenges of falls and dementia.

## **10.2 What the research contributes to knowledge**

This is one of only two studies that have considered the impact of falls on older people experiencing dementia, their carers and most especially, the couples' relationships. However it is the first study to only consider the experiences of older people with dementia and their carers. It is also one of the first IPA studies to explore how falling enters the life-worlds of participants. The findings within this study both confirm the existing research literature but also add to the body of knowledge.

Whereas existing research has explored how dementia impacts upon an older persons' sense of self and identity, there has been limited research that considers how falling impacts upon older peoples' sense of self and identity. This research provides new findings that relate to how self and identity are threatened by the falls experiences of older people with dementia and also their carers.

Whereas previous research has suggested that older people with dementia do not remember their falls, this study highlights that these participants do have memories of their falls, but rather than relating to objective dates, times and places, these participants' memories are embodied and full of emotional meaning.

Existing research has identified how cognitively normal older people experience fear of falling and a curtailment of activity, and this research identifies that older people with dementia are also fearful of falling, and as a consequence restrict their activity, or have it restricted by their carers.

Previous research has explored carers' perception of risk in relation to falling by older people with dementia, however this research suggests that falls also impact on the sense of self and identity of the family member providing the care, so that they become carer, rather than daughter/son or wife/husband. Potential engulfment in the caring role because of falls is also suggested to impact upon the relationship of the dyad, their sense of couplehood and the health and wellbeing of the carer.

Subjective and objective burden and threats to health and well-being have been explored in carers as a consequence of their cognitively normal care-recipient falling (Kuzuya et al 2006). However, this research provides new findings about the perceived relationship between the impact of care of the older person with dementia and the carers' own falls.

Kitwood's concept of malignant social psychology theorises that a person with dementia is disabled by the interplay of their neurological impairments, personal sense of self and how they are perceived and treated by others - resulting in a reduction in activity (Kitwood 1992). Older people who fall also experience a

threatened sense of self, feelings of stigma and social embarrassment as well as physical impairment resulting in reduction of activity. Therefore the findings from this study take Kitwood's concept malignant social psychology further (Kitwood 1992) (see figure 10.1) and suggest that the consequences of falling are so enmeshed in the consequences of dementia so that the experiences of falling potentially exacerbate the malignant social psychology experienced by older people with dementia. It is also worth considering that a reduction in activity also increases an individual's risk of further falls (Rubenstein 2006).

**Figure 10.1 The enmeshed experiences of Dementia and falling**

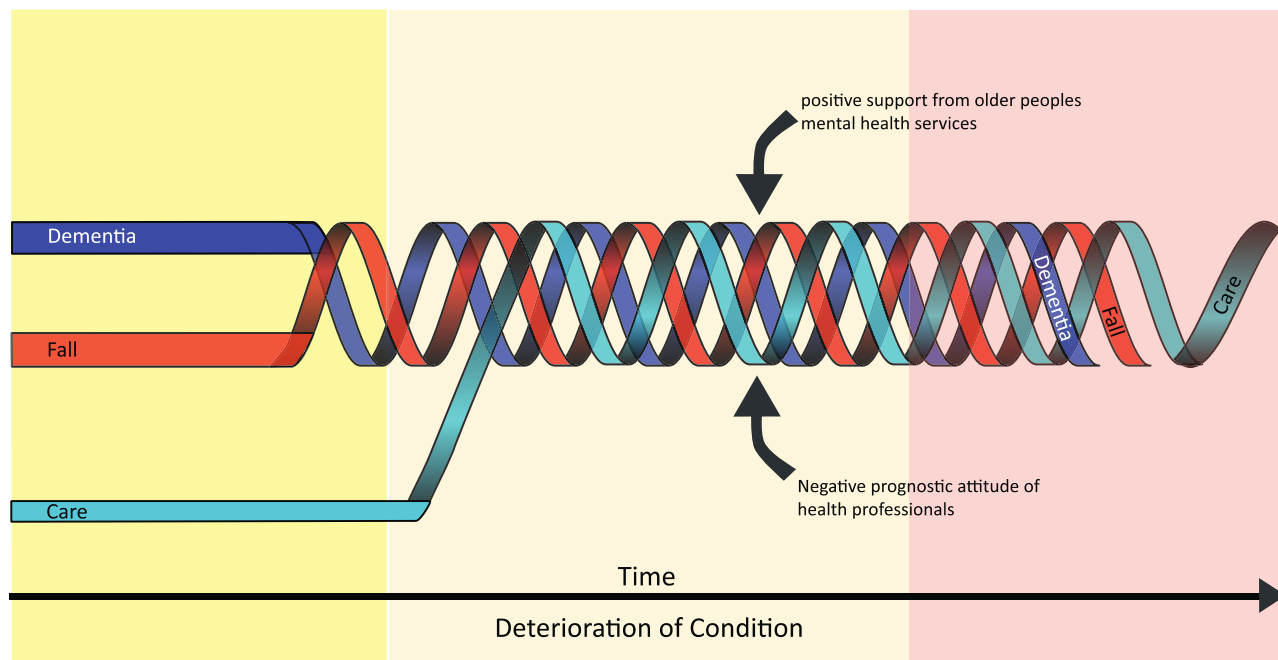


Figure 10.1 suggests that whereas the experiences of falling and dementia are initially loosely connected for older people with dementia and their carers, with the progression of dementia and more falls, these experiences become more closely intertwined over time. The experience of caring by the spouse or daughter/son also becomes caught up in the falling and dementia experiences, so all three become increasingly entangled. The positive and negative

involvement of health professionals can also impact on how ensnared these experiences become. One could also suggest that the personhood of the participants with dementia is eventually engulfed by the increasing demands of caring for them, and by the desire to prevent further falls. The consequential reduction in activity and the increasing caring demands for the person with dementia therefore impact on the personhood, health and well-being of the carer and potentially increase the carer's own risk of falling.

### **10.3 Implications for future research and practice**

As interpretative research does not aim to generalise to larger populations, but to report on the idiographic and subjective experiences of the participants in the study, this section concentrates more on what can be considered as "interesting, important or useful" (Smith et al 2009:183).

#### **10.3.1 Implications for research**

The use of one to one and joint interviews in IPA has been reported by de Visser and McDonald (2007) with younger heterosexual adults, but has not been reported with older people and particularly those with dementia. Whereas de Visser and McDonald (2007) used the joint interview to gain an understanding of the more public accounts of their participants, in this study, the joint interview helped to provide a shared rather than public experience of falling. This was useful, in that in some instances, the joint interview enabled the accounts and experiences of older people with dementia to be heard for the first time by their carers.

The use of focus groups in research with older people with dementia and also with carers is reported within the literature. However, the involvement of older people with dementia and their carers together, in a focus group, had not been critiqued or reported on within the literature. Although this format facilitated equal sharing of the falls experience by carers as well as older people with dementia, informed the data analysis for the research and provided new findings, the accounts of carers tended to dominate over those of the older

people with dementia. This was an interesting observation and led to subsequent focus groups being carried out with each group separately to facilitate equal opportunity to share experiences.

As interpretative phenomenological research does not seek to generalise to other or larger populations, the use of a secondary study, following on from a phenomenological study could be debated. However, the secondary study is perceived as an important and integral part of the overall research. The secondary study provided an elaborative triangulation where the accounts not only revealed agreement between the participants from both studies, but also divergences and ambiguities within the data, which may not have been revealed by the analysis of the primary study data alone. It is suggested that the secondary study participants were more able to access the experiences of those primary study participants because of similarities in experience from both an embodied and psychological perspective. This can be supported by the Gadamerian concept of the fusion of horizons (Langdridge 2007, Finlay 2011), where overlapping and shared understanding of experiences by the secondary study participants facilitated a more critical dialogue with the data.

### **10.3.2 Implications for practice**

The inductive and interpretative approaches used in both studies within the research have allowed for the subjective and contextualised experiences of falling of older people with dementia. Many health and social care practitioners such as occupational therapists, community physiotherapists and nurses work within a bio-psychosocial framework of practice, because of the understanding of the body-person-environment interaction where an individual has a health condition such as dementia (WHO 2001). Although a relatively marginalised group within research, the difficulties that these older people and their carers face are highly relevant to health and social care practice, especially those practitioners who work with older people who fall and/or older people with dementia.

Interesting findings that have arisen from the research, which can contribute to health and social care practitioners' understandings of the experiences of older people with dementia and their carers are:

- That older people with dementia may give many differing reasons for their falls and these may not coincide with the reasons given by the carer. Therefore it is important to hear the accounts of both the older person and their carer.
- Older people with dementia do remember their falls, but these relate more to embodied memories and negative emotions rather than dates, times and places.
- The fall by the older person with dementia, impacts upon the carer's sense of self, health and well-being, therefore carers' needs should be also considered.
- The subjective and objective burden of caring can precipitate the carer's own falls. Therefore it is also important to be aware of the carer's history of falling.
- Many older care-recipients and carers (especially spouses) have a 'couple identity' and therefore the dyad should be perceived as a couple by health and social care services, so that joint assessment and intervention is considered to preserve couplehood for these dyads.
- The experiences of falling and dementia cannot be separated for older people or their carers, but are enmeshed experiences, with one impacting on the other. It is suggested that any intervention or service provision should perhaps acknowledge and address the intertwining of these two experiences, rather than consider the experiences as two separate issues.
- These findings also perhaps reveal and suggest that falls are only one example of how ageing and physical health conditions can impact upon the experience of dementia.

### **10.3.3 Implications for education**

It is suggested that the implications for health and social care education would involve those already discussed in the sections above. However, it is hoped that

this research contributes to an understanding of the multi-faceted experiences of older people and especially the complexity of the dementia experience for the individual diagnosed with the condition and the family members.

These findings also highlight that many older people with dementia consider themselves as part of a couple or family relationship, therefore although their needs as an individual should be addressed, there should be an awareness of the inter-related needs of the person with dementia and their carer. It is also important to consider how an experience such as falling can ripple out into the life-world of an older person with dementia and that of significant others.



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## **APPENDICES**

**Appendix A – Ethics approval letter**

**Appendix B – Key worker Participant recruitment letters**

**Appendix C – Participant information sheets and consent forms  
(Interview) Primary study**

**Appendix D – Protocol for interviews – Primary study**

**Appendix E - Participant information sheets and consent forms (Focus  
groups) Primary study**

**Appendix F - Protocol for focus groups – Primary study**

**Appendix G - Participant information sheets and consent forms-  
Secondary study**

**Appendix H – Protocol and topic guide – Secondary study**

**Appendix I – Transcript from Primary study**

**Appendix J – Clustering of themes for one participant – Primary study**

**Appendix K – Early analysis for one theme – Primary study**

**Appendix L – Development of themes – Primary study**

**Appendix M – Phenomenological description of “Going back to the experience”**

**Appendix N – McIntyre and Reynolds (2011)**

**Appendix O – Transcript from secondary study**

**Appendix P - Early analysis – Secondary study**

# Appendix A – *Ethics approval letter*



**Wandsworth Local Research Ethics Committee**

Room 1.027, 1<sup>st</sup> Floor Grosvenor Wing,  
St Georges Healthcare NHS Trust  
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Our Ref:CH/FR/03.0238

17<sup>th</sup> March 2004

Mrs Anne McIntyre  
Brunel University  
Faculty of Life Sciences  
Osterely Campus  
Borough Road  
Isleworth, Middlesex TW7 5DU

Dear Mrs McIntyre

**Re: What are the experiences of older people with dementia and their carers of falls and "near falls"?**

Thank you for your letter dated 1<sup>st</sup> March 2004 concerning the above study. Your letter has satisfactorily addressed the points raised by the Committee and we are now happy to give final approval for this project to proceed.

Yours sincerely

**Dr Christine Heron**  
**Vice Chair/Clinical Secretary – Wandsworth Local Research Ethics Committee**

## South West London and St. George's

Mental Health NHS Trust

Anne McIntyre  
Honorary Research Occupational Therapist,  
C/o Jubilee Day Hospital  
Springfield Hospital  
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### Research and Development

**Director:** Dr Mohammed Abou-Saleh

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**R&D Assistant:** Ms Barbra O'Keefe

**Email:** [eeboda@sghms.ac.uk](mailto:eeboda@sghms.ac.uk)

**Direct Line:** 020 8725 3463/2802

**Fax:** 020 8725 3538

Thursday, 04 March 2004

Dear Anne,

**Research Title:** **A client-centred falls management programme for older people with dementia and their carers.**

**Project ID:** **PF180**

Following various discussions your project has now been approved. This letter ensures that you and the researchers holding a Trust/NHS contract are indemnified by the Trust under DoH (HSG (96) 48) (**only for non-commercial research**). Under your contract of employment you are required to adhere to the Research Governance Framework and Trust research monitoring procedures.

In addition to ensuring that the dignity, safety and well-being of participants are given priority at all times by the research team, you need to ensure the following:

- **Patient contact:** Only trained or supervised researchers holding a Trust/NHS contract (honorary or full) are allowed to make contact with patients.
- **Informed consent:** is obtained by the lead or trained researcher according to the requirements of the ethics committee. The original signed consent form should be kept on file. Informed consent will be monitored by the Trust at intervals and you will be required to provide relevant information.
- **Data Protection:** All data involving patient data will remain anonymised, where possible, and held on protected systems so as not to compromise the Data Protection Act.
- **Adverse events reporting:** Adverse events or suspected misconduct must be reported to the R & D department, in conjunction with the ethics committee.

Terms and conditions of Approval

- **Annual review:** An annual review form will be sent to you, which you will be required to complete and return to the R & D Department.
- **Closure Form:** On completion of your project a closure form will be sent to you (according to the end date specified on the R & D database), which needs to be returned to the R & D Department.
- **Publications:** Any publications will need to be reported to the R & D Department. This is vital in ensuring the quality and output of the research for your project and the Trust as a whole.

The R & D Department needs to be informed of any changes to the protocol such as patient recruitment, funding, etc. If any major changes are made to the protocol then this would need to go to the R & D Committee.

If you have any queries regarding the above points please contact Enitan Eboda, R&D Co-ordinator on 020 8725 3463 (St. George's), e-mail: [eeboda@sghms.ac.uk](mailto:eeboda@sghms.ac.uk).

Yours sincerely,



Dr. Mohammed Abou-Saleh  
**Chairman**  
**Research & Development Committee**



School of Health Sciences and  
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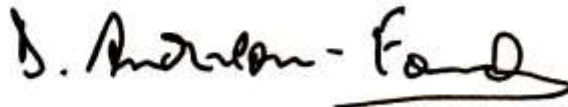
3 September 2004

**Proposer:** Anne McIntyre

**Title:** A client centred falls management programme for older people with dementia  
and their carers

Further to our letter of 1<sup>st</sup> April 2004, the Committee is now in receipt of your amended proposal form. Approval is given on the understanding that the conditions set out below are followed.

- The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.



David Anderson-Ford  
Chair, Research Ethics Committee  
School of Health Sciences and Social Care

**Appendix B** – *Key worker  
Participant recruitment letters  
(Interviews), Primary study*

## LETTER FOR KEY WORKER IN CMHT

(NHS TRUST LETTER HEADING)

March 2004

### **What are the experiences of older people with dementia and their carers of falls and “near falls”?**

This research is a collaborative project between South West London and St George’s Mental Health NHS Trust (Older Peoples Directorate) and Brunel University. This research aims to help meet standard 6 of the NSF for Older People (2001) which has set targets for NHS trusts to have person-centred involvement in all stages of health provision to prevent falls and provide rehabilitation as a result, as well as ensuring effective services for older people with mental health problems and their carers. This study also forms part of Anne McIntyre, (the lead researcher)’s, doctoral study.

The research has been approved by the South West London and St George’s Local Research Ethics Committee and Research and Development Committee and also the Brunel University Research Ethics Committee and has the support of Dr Debbie Stinson, Clinical Director of the Older Peoples Directorate.

Recent research by Shaw et al (2003) has unfortunately failed to provide evidence that falls management programmes used effectively with cognitively normal older people are significantly effective with clients with cognitive impairments. Few researchers have considered clients’ perspectives of falls and even fewer have considered those of older people with dementia. Even though some researchers have identified that individuals have different falls experiences (or events) (Campbell et al 1990) this also does not seem to be taken into account in falls management programmes in the literature.

As clients with dementia are commonly excluded from research they and their carers have little opportunity to voice their opinion or experiences. However involving carers of clients with dementia is crucial as it considered by Buri and Dawson (2000) that carers selectively accept or reject advice from professionals.

We therefore want to document the views and experiences of clients with dementia and carers about a fall or “near fall” (when they stop yourself from falling) that they have had. To do this we would like your help.

It is important that potential participants will be existing clients of the Older Peoples Directorate of the SWL and St Georges MH NHS Trust.

We would like to select subjects in equal numbers from each service area within the trust from those clients with mild, mild-moderate, moderate, moderate-severe, severe dementia of predominately Alzheimer’s type.

We would therefore be very grateful if you could identify any client with dementia and carer who meet the following inclusion and exclusion criteria who

you think may happy (and able) to participate in this study. We would be grateful if you could approach them on our behalf and ask if they would be willing to let us have their relevant details, by completing the enclosed form.

There are no specific guidelines on the issue of informed consent when involving older people with dementia in research, however the following arrangements have been agreed and subject to scrutiny: -

1. Capacity for consent will be determined in line with section 2.1 of Draft Mental Incapacity Bill (2003).
2. As the psychiatrist for the client you will determine whether the client has the capacity to give consent.

We have decided upon the following criteria for selecting potential subjects for the study:

#### Inclusion Criteria

1. Clients with dementia of pre-dominantly Alzheimer's type over the age of 65 who are patients of the Older Peoples Directorate of the SWL and St Georges MH NHS Trust.
2. Clients will be living in the community with their permanent carer (e.g. partner, daughter, son, sibling or friend).
3. Clients with mild dementia will be identified by a Mini Mental State Examination (MMSE) score of 24+
4. Clients with mild/moderate dementia will be identified by a MMSE score of 20 –23.
5. Clients with moderate dementia will be identified by a MMSE score of 15-19.
6. Clients with moderate/severe dementia will be identified by a MMSE score of 10-14.
7. A MMSE score of 9 and below will identify clients with severe dementia.
8. Clients will have a history of unsteadiness or a fall.

#### Exclusion Criteria:

1. Clients or carers who are not aware of the diagnosis of dementia.
2. Clients in long term residential care.
3. Clients with moderate / severe behavioural and / or communication problems.
4. Clients currently involved in other research.
5. Carers with cognitive impairment or severe communication problems.

Who should you contact for further information?

If you wish to know more about the study please contact Anne McIntyre, Honorary Research Occupational Therapist at Brunel University on 020 8891 0121 x2633 or email [anne.mcintyre@brunel.ac.uk](mailto:anne.mcintyre@brunel.ac.uk). OR ~~XXXXXXXXXXXXXXXXXX~~

THANK YOU FOR YOUR HELP

## INITIAL CONSENT LETTER TO BE APPROACHED TO PARTICIPATE

### (NHS TRUST LETTER HEADING)

October 2003

**Falls are common in older people and many people become unsteady, as they get older. There is a lot of research on falls in older people to try and manage falls more appropriately. However more importantly people with dementia and their carers are not often given the opportunity to give their perspective of their fall or a “near fall” (when you stop yourself from falling) in research.**

My name is Anne McIntyre. I am an honorary research occupational therapist with the South West London and St. George’s Mental Health NHS Trust (Older Persons Directorate).

As part of my I studies for my doctorate I am interested in interviewing older people with dementia and also their carers about a fall or “near fall” that they have experienced. It is hoped that this information will provide useful information for the management and prevention of falls in the South West London and St. George’s Mental Health NHS Trust (Older Persons Directorate).

If you are interested in helping with this research please sign below so that your details can be passed to Anne McIntyre, the lead researcher for this study.

Thank you for your time and consideration

---

I agree to have my details passed to Anne McIntyre, honorary research occupational therapist.

Name:

Signature:

Date:

Name of person taking consent:

Signature:

Date

**Appendix C** – *Participant information sheets and consent forms (Interview), Primary study*

## **FULL INFORMATION SHEET FOR PARTICIPANT WITH DEMENTIA (INTERVIEWS)**

(NHS TRUST LETTER HEADING)

February 2004

### **What are the experiences of older people with dementia and their carers of falls and “near falls”?**

Both you and your carer are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other people 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.

**Thank you for reading this.**

### **What is the purpose of this study?**

Falls are common in older people and many people become unsteady, as they get older. Even though there is a lot of research on falls in older people, people with dementia are not often given the opportunity to give their perspective of their fall or a “near fall” (when you stop yourself from falling).

The aim of this study is to hear from clients with dementia and also their carers about their fall or near fall.

We hope that the results of this study will provide useful information for the management and prevention of falls in the South West London and St. Georges Mental Health NHS Trust.

I will be carrying out this study as part of my doctoral piece of research.

### **Why have I been chosen?**

This study wishes to hear the experiences of older people with dementia, with their carers on a fall or near-fall they have had. We hope to interview 30 people from the XXXXXXXX Areas.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. Your carer will also have to decide whether they want to take part. If you do both decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part in this study will not affect the standard of care you receive.

### **What will happen to me if I take part?**

Taking part in the study will involve you and your carer being interviewed about a fall or near fall that you have had. You will only be interviewed once and this will take approximately 90 minutes of your time at home. The interview will be audio taped so that the interviewer can concentrate on listening to you and your carer.

If you would like to be part of a slightly longer study you will be interviewed once every 6 months for 3 years about the same topic and in the same way. However only a few people will be needed to take part in this study.

**What will I have to do?**

It would be useful for you and your carer to think about a fall or near fall you may have had before the interview. You will each be interviewed separately for approximately 30 minutes and then you will be interviewed together for the same amount of time. During the interview you will be both asked to talk about the fall, and to give your view on how you think it happened, and what you did afterwards. Time has also been allowed for you to take a break between interviews.

**What are the possible disadvantages or risks of taking part?**

There should be no disadvantages or risks at taking part in this study.

**What are the possible benefits of taking part?**

The information we get from this study may help us provide better intervention for older people with dementia who fall or are at risk of falling, however you will not benefit directly from being interviewed.

**What if new information becomes available?**

If any new information becomes available it will inform the study but not change it.

**What happens when the research study stops?**

This will make no difference to your care, but the information you give will inform future practice by the Older Peoples Directorate of the South West London and St Georges Mental Health NHS Trust.

**What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available on request.

**Will my taking part in this study be kept confidential?**

Any information collected about you during this study will remain confidential to the research team, with your name and address removed so that you cannot be recognised at any time. However any disclosure of inappropriate behaviour may necessitate further action or referral back to the care team.

The audiotapes will not have your name on them; they will be stored securely and will be destroyed when the research has been completed.

Your GP and key worker will be informed about your participation in this study if you agree to take part.



The interviewer is a qualified health professional and as such is bound by their professional code of conduct.

**What will happen to the results of the study?**

The results of this study will inform a second study. It is likely that the results of this study will either be presented at a professional conference or published in a professional journal, but you will not be identified in anyway. If you wish to have a copy of the results of the study this can be arranged for you.

**Who is organising and funding the research?**

This research is being funded by the South West London and St Georges Mental Health NHS Trust (Older Peoples Directorate). The research also involves the Department of Health and Social Care at Brunel University as part of Anne McIntyre's PhD research project.

**Who has reviewed the study?**

The Wandsworth Local Research Ethics Committee and also the Research Ethics committee of Brunel University have reviewed this study.

**Who should I contact for further information?**

If you wish to know more about the study please contact Anne McIntyre, Honorary Research Occupational Therapist, or ~~XXXXXXXX~~

**Please sign the enclosed form if you wish to take part in this study.**

**Once again thank you for taking time to consider taking part.**

Anne McIntyre, Honorary Research Occupational Therapist

## SUMMARY INFORMATION SHEET FOR PARTICIPANT WITH DEMENTIA (INTERVIEWS)

(NHS TRUST LETTER HEADING)

February 2004

### **What are the experiences of older people with dementia and their carers of falls and “near falls”?**

My name is Anne McIntyre and I am an honorary research occupational therapist with the South West London and St Georges Mental Health NHS Trust. As part of my doctoral research I would like to interview you and your carer about a fall or “near fall” you have had. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask me if there is anything that is not clear or if you would like more information. The Wandsworth Local Research Ethics Committee and also the Brunel University Research Ethics committee have approved this study.

**Many older people fall or have “near falls”. Even though there has been a lot of research carried out on falls, older people with dementia have not been included in the studies. This means that they are not given the opportunity to give their story of their fall or “near fall”. Even though you will not personally benefit from taking part, it is hoped that this research will provide better interventions for older people who have fallen over or had a near fall.**

It is up to you to decide whether to take part. Your carer will also have to decide. You will be given this information sheet and a sheet with more information on it to keep. You will be asked to sign a form showing that you consent to take part in the research. If you decide to take part and then change your mind you can withdraw from the study without giving any reason. If you do decide to withdraw from the research it will not affect your care by the South West London and St Georges Mental Health NHS Trust, at any time

You will be interviewed for 30 minutes on your own about your fall or “near fall”. Your carer will also be interviewed and then you will be interviewed together. The interviews will be audio taped so that the interviewer can concentrate on what you are saying. Any thing you say will remain strictly confidential to the research team and there will be no way of identifying you on the tapes. These audiotapes will be kept securely until after the research has been finished when they will be destroyed.

If you would like to take part in a slightly longer study you will be interviewed once every 6 months about the same topic and in the same way, but only a few people will be needed for this.

***Thank you for taking time to consider taking part and if you wish to know more about the study please contact Anne McIntyre, Honorary Research Occupational Therapist, or XXXXXXXXXXXXXXXXXXXX***

***Anne McIntyre, Honorary Research Occupational Therapist***

## CARER INFORMATION SHEET

(NHS TRUST LETTER HEADING)

February 2004

What are the experiences of older people with dementia and their carers of falls and “near falls”?

You are being invited to take part in a research study as a carer for ..... . Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other people 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.

Thank you for reading this.

### **What is the purpose of this study?**

Falls are common in older people and many people become unsteady, as they get older. Even though there is a lot of research on falls in older people, people with dementia and their carers are not often given the opportunity to give their perspective of their fall or “near fall” (when you stop yourself from falling).

The aim of this study is to hear from clients with dementia and also from their carers about their fall or near fall.

The results of this study will provide useful information for the management and prevention of falls in the South West London and St. Georges Mental Health NHS Trust.

I will be carrying out this study as part of my doctoral piece of research.

### **Why have I been chosen?**

This study wishes to hear the experiences of older people with dementia, and also their carers on a fall or near-fall that the person with dementia has had. Both ..... and your name were suggested by ..... We hope to interview 30 people with dementia with their carers from the XXXXXX Areas.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. The person you care for will also have to decide whether they want to take part. If you do both decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part in this study will not affect the standard of care the person with dementia or you receive.

### **What will happen to me if I take part?**

Taking part in the study will involve both of you being interviewed about a fall or near fall that ..... has had. You will each be interviewed separately for approximately 30 minutes and then you will be interviewed together for the same amount of time. During the interview you will be both asked to talk about the fall, and to give your view on how you think it happened, and what you did afterwards. The interview will be audio taped so that the interviewer can concentrate on listening to you both. You will be able to take a break between interviews.

If you would like to be part of a slightly longer study you will be interviewed once every 6 months for 3 years about the same topic and in the same way. Only a few people will

be needed to take part in this study. However you do not have to decide about this now.

**What will I have to do?**

It would be useful for both of you together to think about a fall or near fall that ..... may have had, before the interview takes place. During the interview you will be both asked to talk about the fall, and to give your view on how you think it happened, and what you did afterwards.

**What are the possible disadvantages or risks of taking part?**

There should be no disadvantages or risks at taking part in this study.

**What are the possible benefits of taking part?**

The information we get from this study may help us provide better intervention for older people with dementia who fall or are at risk of falling, however you will not benefit directly from being interviewed.

**What if new information becomes available?**

If any new information becomes available it will help us to develop the study further, but not change it.

**What happens when the research study stops?**

This will make no difference to the care you both receive, but we hope that the information you give will inform future practice by the Older Peoples Directorate of the South West London and St Georges Mental Health NHS Trust.

**What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available on request.

**Will my taking part in this study be kept confidential?**

Any information collected about you during this study will remain confidential to the research team, with your name and address removed so that you cannot be recognised at any time. However any disclosure of inappropriate behaviour may necessitate further action or referral to the care team.

The audiotapes will not have your name on them; they will be stored securely and will be destroyed when the research has been completed.

Your GP and key worker will be informed about your participation in this study if you agree to take part.

The interviewer is a qualified health professional and as such is bound by their professional code of conduct.

**What will happen to the results of the study?**

The results of this study will inform a second study. It is likely that the results of this study will either be presented at a professional conference or published in a professional journal, but you will not be identified in anyway. If you wish to have a copy of the results of the study this can be arranged for you.

**Who is organising and funding the research?**

This research is being funded by the South West London and St Georges Mental Health NHS Trust (Older Peoples Directorate). The research also involves the Department of Health and Social Care at Brunel University as part of Anne McIntyre's PhD research project.

**Who has reviewed the study?**

The Wandsworth Local Research Ethics Committee and also the Research Ethics committee of Brunel University have reviewed this study.

**Who should I contact for further information?**

If you wish to know more about the study If you wish to know more about the study please contact Anne McIntyre, Honorary Research Occupational Therapist, or  
XXXXXXXXXXXXX

**Please sign the enclosed form if you wish to take part in this study.**

**Once again thank you for taking time to consider taking part.**

**Anne McIntyre, Honorary Research Occupational Therapist**

## **CONSENT FORM – PARTICIPANT WITH DEMENTIA (INTERVIEWS)**

(NHS TRUST LETTER HEADING)

FEBRUARY 2004

**Project Title:**

**What are the experiences of older people with dementia and their carers of falls and “near falls”?**

**Name of Researcher: Anne McIntyre**

**I confirm that I have read and understand the information sheet dated May 2006 for the above study and have had the opportunity to ask questions.**

**I understand that my participation is voluntary and I am free to withdraw at any time, without giving reason, without my medical care or legal rights being affected.**

**I understand that sections of any of my medical notes may be looked at by responsible individuals from Brunel University or from regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records.**

**I agree to take part in the above study.**

**Name:**

**Signature:**

**Date:**

**Name of person taking consent:**

**Signature:**

**Date:**

**Researcher:**

**Signature:**

**Date**

**CONSENT FORM -CARER (INTERVIEWS)**  
(NHS TRUST LETTER HEADING)

FEBRUARY 2004

**Project Title:**

**What are the experiences of older people with dementia and their carers of falls and “near falls”?**

**Name of Researcher: Anne McIntyre**

I confirm that I have read and understand the information sheet dated May 2006 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and I am free to withdraw at any time, without giving reason, without my legal rights being affected.

I agree to take part in the above study.

**Name:**

**Signature:**

**Date:**

**Name of person taking consent:**

**Signature:**

**Date:**

**Researcher:**

**Signature:**

## **Appendix D** – *Protocol for interviews, Primary study*



## **What are the experiences of older people with dementia and their carers of falls and “near falls”?**

### **PROTOCOL FOR INTERVIEW**

- Telephone to arrange a time for interview after receiving the initial consent letter from key worker. Ask that they jointly think about one fall or near fall event for discussion.
- Start session with both client and carer together to explain the research, give the information sheet and explain issues of confidentiality, right to withdraw. Ask them to sign consent letters.
- Explain how it will take place and time of interviews (30-45 mins individual interviews, 30 mins joint interview) and use of audiotape. Give choice of joint session if they do not want to be interviewed individually.
- Remind them that they were asked to think about one fall or near fall event.
- Ask if they have any questions about the research and also state that if they have any questions during the research these may have to wait until the end of the interview (unless they are for clarification).
- Start the individual sessions – ideally interview the client first.
- Start individual session and repeat the issue of confidentiality between interviewer and interviewee. Also that during the joint session that they have the right to disclose what they wish.
- In joint session repeat that they have the right to say what they want but explain that you wish to go over the details from the previous interviews.
- If they disclose any inappropriate action or behaviour in their management please advise that their key worker will be informed.
- If distressed inform the key worker.
- If either of the interviewees becomes distressed ask if they wish to continue with the interview. If either leaves the room ascertain if this is temporary and due to distress and if so terminate the interview.

## **What are the experiences of older people with dementia and their carers of falls and “near falls”?**

### **TOPIC GUIDE FOR INTERVIEWS**

#### **Introduction to research – both client and carer together.**

What the research is about, issues of confidentiality, withdrawal etc.

To recap that the interview is about one fall that they have both previously decided upon before the interview.

Have they been involved in research before?

#### **Individual interviews**

##### **Background information -**

A brief biography, age how long they lived there, been with their carer, etc.

Introduction to fall – their definition of a fall

Introduction of their own fall or near fall (or that of the person with dementia).

What were they doing before the fall (that day, immediately?).

Their thoughts and feelings of that day (how did they feel?)

Any different from other days?

The actual fall – describe it, what happened?

Thoughts and feelings of the fall - how, what was the cause?

##### **Immediate Consequences –**

e.g. “Tell me what you did immediately after the fall?”

Thoughts and feelings (including bodily reactions and behavioural response).

##### **Longer term Consequences -**

Changes that have been made by themselves, or other people. Why?

Thoughts and feelings of changes?

e.g. “tell me about any changes that you have made as a result of the fall (near fall)?”

Other falls or “near falls” –

Comparison of this fall with other falls

How many, how often.

##### **Summing up –**

Summarise main topics

Unfinished business?

#### **Topic Guide – joint interview**

What were they doing before the fall (that day, immediately?).

Their thoughts and feelings of that day (how did they feel?)

Any different from other days?

The actual fall – describe it, what happened?  
Thoughts and feelings of the fall - how, what was the cause?

**Immediate Consequences –**

What did you do immediately after the fall?  
Thoughts and feelings (including bodily reactions and behavioural response).

**Longer term Consequences -**

Changes that have been made by themselves, or other people. Why?  
Thoughts and feelings of changes?

**Other falls or “near falls” –**

Comparison of this fall with other falls  
How many, how often, consequences and feelings.

**Summing up –**

Summarise main topics  
Unfinished business?

**Appendix E** - *Participant information sheets and consent forms (Focus groups), Primary study*

## INFORMATION SHEET FOR FOCUS GROUPS PRIMARY STUDY

### (BRUNEL UNIVERSITY LETTER HEADING)

December 2006

### PARTICIPANT INFORMATION SHEET

#### **What are the experiences of older people with memory problems and their carers of falls and “near falls”?**

My name is Anne McIntyre and I am a lecturer in occupational therapy at Brunel University and an honorary research occupational therapist with the South West London and St Georges Mental Health NHS Trust.

As part of my doctoral research I would like to carry out a group interview with you about falls. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask me if there is anything that is not clear or if you would like more information. Take your time to decide whether you would like to take part.

#### **What is the purpose of this study?**

**Many older people fall or have “near falls”. Even though there has been a lot of research carried out on falls, older people with memory problems have not been included in the studies. This means that they are not given the opportunity to give their story of their experiences of falls or “near falls”. Even though you will not personally benefit from taking part, it is hoped that this research will provide better interventions for older people who have fallen over or had a near fall.**

#### **Do I have to take part?**

It is up to you to decide whether to take part. You will be given this information sheet to keep. You will be asked to sign a form showing that you consent to take part in the research. If you decide to take part and then change your mind you can withdraw from the study without giving any reason. If you do decide to withdraw from the research it will not affect your involvement with XXXXX Alzheimer’s Society, at any time

#### **What will happen to me if I take part?**

You will be interviewed for approximately 30 minutes with a group of other people from your lunch club. The interviews will be audio taped so that the interviewer can concentrate on what you are saying. Any thing you say will remain strictly confidential to the research team and there will be no way of identifying you on the tapes. These audiotapes will be kept securely until after the research has been finished when they will be destroyed.

#### **What will happen to the results of the study?**

The results of this study will inform a second study. It is likely that the results of this study will either be presented at a professional conference or published in a professional journal, but you will not be identified in anyway. If you wish to have a copy of the results of the study this can be arranged for you.

#### **What if I have any further queries about the study or how it was carried out?**

If you wish to know more about the study, please contact me at the above address.

#### **Who has reviewed the study?**

The Brunel University Research Ethics committee and also the Wandsworth Local Research Ethics Committee have reviewed and approved this study.

**Please sign the enclosed form if you wish to take part in this study. Thank you for taking time to consider taking part.**

Anne McIntyre

## CONSENT FORM FOR FOCUS GROUPS PRIMARY STUDY

### (BRUNEL UNIVERSITY LETTER HEADING)

9<sup>th</sup> January 2007

#### Participant Consent Form

**Project Title:** What are the experiences of older people with memory problems and their carers of falls and “near falls”?

**Name of Researcher:** Anne McIntyre

I confirm that I have read and understand the information sheet dated December 2006 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and I am free to withdraw at any time, without giving reason, without my legal rights being affected.

I agree to take part in the above study.

**Name:**

**Signature:**

**Date:**

**Name of person taking consent:**  
(if different from researcher)

**Signature:**

**Date:**

**Researcher:**

**Signature:**

**Date:**

## **Appendix F** - *Protocol for focus groups, Primary study*



## PROTOCOL & TOPIC GUIDE FOR PRIMARY STUDY FOCUS GROUPS

### Focus Group January 2007

There are 30 people expected for this session, which will last 45 minutes. The plan is to run 3 simultaneous sessions facilitated by Anita, Di and Anne and assisted by Eleanor.

Just a quick reminder about focus groups...

The role of the facilitator is to “people manage” –so that the shy participant is encouraged to speak and the talkative one discouraged at times. Handle any disagreement or discomfort with diplomacy. If someone gets upset ask them if they want to continue or sit out of the session. It is quite likely that the carers will speak more than the clients.

When referring to clients please state people with **memory problems** as not all have had a formal diagnosis or are aware that they have a diagnosis of dementia.

### Introduction and ground rules

I will introduce the study and make sure that everyone understands that there is confidentiality for the research and between participants outside of the group. Also about withdrawal.

Give them the information sheets, consent letters and name badges.

Please collect the consent letters in and ask participants to wear their name badges.

If you can recap the purpose of the study – that we are interested in hearing their opinion of falls.

Remind people to not speak over other people and listen to what others are saying.

Confirm that we will finish in 40 minutes.

Don't forget to turn the voice recorders and microphones on!

If you can write any notes as the group progresses please do. It would be useful to know who is speaking when for transcription and any non verbal communication..

Eleanor may be able to take some as she goes round.

At the end please thank participants and confirm confidentiality, also if anyone wants any further information about the study.

Please give participants sweets as a thank you.

THANK YOU!

## TOPIC GUIDE FOR INTERVIEWS

### **Introduction**

Have they been involved in research before?

What do they think a fall is – can they explain this?

Have they or any one they know had a fall?

If they have had a fall or someone they know has had could they remember what were they doing before the fall (that day, immediately?).

Their thoughts and feelings of that day (how did they feel?)

Any different from other days?

The actual fall – describe it, what happened?

Thoughts and feelings of the fall - how, what was the cause?

### **Immediate Consequences –**

e.g. “Tell me what you did immediately after the fall?”

Thoughts and feelings (including bodily reactions and behavioural response).

### **Longer term Consequences -**

Changes that have been made by themselves, or other people. Why?

Thoughts and feelings of changes?

e.g. “tell me about any changes that you have made as a result of the fall (near fall)?”

### **Other falls or “near falls” –**

Comparison of this fall with other falls

How many, how often.

### **Summing up –**

Summarise main topics

Unfinished business?

**Appendix G** - *Participant information sheets and consent forms, Secondary study*

## PARTICIPANT INFORMATION SHEET, SECONDARY STUDY

(BRUNEL LETTERHEADING)

June 2007

### **What are the experiences of older people with dementia and their carers of falls and “near falls”?**

My name is Anne McIntyre and I am a lecturer in occupational therapy at Brunel University and an honorary research occupational therapist with the South West London and St Georges Mental Health NHS Trust.

As part of my doctoral research I would like to carry out a group interview with you about falls. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask me if there is anything that is not clear or if you would like more information. The Brunel University School of Health Sciences and Social Care Research Ethics committee and also the Wandsworth and St Georges Local Research Ethics Committee have approved this study.

#### **What is the purpose of this study?**

**Many older people fall or have “near falls”. Even though there has been many research studies carried out in this area, older people with dementia have not been included in the studies. This means that they are not given the opportunity to give their perspective of falls or “near falls”. Even though you will not personally benefit from taking part, it is hoped that this research will provide better interventions for older people who have fallen over or had a near fall.**

#### **Do I have to take part?**

It is up to you to decide whether to take part. You will be given this information sheet to keep. You will be asked to sign a form showing that you consent to take part in the research. If you decide to take part and then change your mind you can withdraw from the study without giving any reason. If you do decide to withdraw from the research it will not affect your involvement with theXXXX branch of the Alzheimer’s Society, at any time

#### **What will happen to me if I take part?**

You will be interviewed for approximately 60 minutes with a group of other people from your Thursday group. The interviews will be audio recorded so that the interviewer can concentrate on what you are saying. Any thing you say will remain strictly confidential to the research team and there will be no way of identifying you on the recordings. These recordings will be kept securely until after the research has been finished when they will be destroyed.

#### **What will happen to the results of the study?**

The results of this study will inform further stages in the research project. It is likely that the results of this study will either be presented at a professional

conference or published in a professional journal, but you will not be identified in anyway. If you wish to have a copy of the results of the study this can be arranged for you.

**Please sign the enclosed form if you wish to take part in this study. Thank you for taking time to consider taking part and if you wish to know more about the study please contact me at the above address.**

Anne McIntyre

## CONSENT LETTER SECONDARY STUDY

(BRUNEL LETTERHEADING)

June 2007

**Project Title:**

**What are the experiences of older people with dementia and their carers of falls and “near falls”?**

**Name of Researcher: Anne McIntyre**

I confirm that I have read and understand the information sheet dated June 2007 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and I am free to withdraw at any time, without giving reason, without my legal rights being affected.

I agree to take part in the above study.

**Name:**

**Signature:**

**Date:**

**Name of person taking consent:**

*(if different from researcher)*

**Signature:**

**Date:**

**Researcher:**

**Signature:**

**Date:**

## **Appendix H – *Protocol and topic guide, Secondary study***

## PROTOCOL & SCHEDULE FOR FOCUS GROUP, SECONDARY STUDY

### Procedure for Group selection

**Interested members of the Alzheimer's Society XXXXXX branch will be asked if they would like to participate in a focus group – one for users with early stage dementia and one for carers.**

Each focus group will have a membership of 6 – 12 people and last for one and a half to two hours. Each group will be audio recorded.

### Schedule for Focus Group

(The following headings are the main structure for the focus group with examples of the themes to be explored.)

#### **Introduction**

Set the scene, introducing the research and also the ground rules of the group process. Each individual group member to introduce themselves.

#### **Opening topic**

Group discussion and definition of “falling” **and any personal experience of falls or near falls.**

Card sorting exercise – the group members will be presented with cards based upon the (anonymous) data acquired from the previous stage of research. They will be asked to consider these cards for their validity and sort (if possible) into similar groupings or categories.

#### **Discussion**

The group will be asked to discuss the validity, commonalities and differences between the cards. Summary

Summing up of focus group, with opportunity for further comment from participants.



## TOPIC GUIDE FOR FOCUS GROUPS, SECONDARY STUDY CLIENT FOCUS GROUP

### 1. Introduction

- Explain the research
- ground rules
- Everyone introduce themselves

### 2. What is a fall? - card ranking

- trip
- slip
- catching feet
- stumble
- a shock
- landing on the floor without warning
- ???

### 3. Why we fall? - card ranking

getting older  
feeling giddy  
eyesight  
glasses  
anyone can fall  
thinking of other things  
being in a hurry  
being too speedy  
trying to do two things at once  
walking and talking  
having a urine infection  
not feeling well  
tablets wearing off  
not putting the light on  
wearing socks  
not looking  
not paying attention  
???

### 4. What we remember about falls - cards (agree/disagree)

you would remember bad falls  
you filter out bad falls  
I can feel what the fall was like  
a fall is bad enough, so anything before or after is insignificant  
if I fall, I fall properly

### 5. Where we fall – discuss cards – are there any more?

outside  
at the train station  
crossing the road  
on the pavement  
at the kerb  
indoors  
getting out of bed  
on the stairs

country path  
over obstacles  
holes in the road/pavement

## **6. What happens after a fall? – discuss**

### **we feel:**

- frustrated
- silly
- stupid
- embarrassed
- scared
- shaky
- lacking confidence
- need to get up and carry on

### **The result of the fall:**

- bruises
- lacerations
- aches and pains
- broken bones
- going to A and E
- going into hospital
- lose confidence
- being referred to other services

## **7. What changes we make: cards sort into agree/disagree**

give up doing things  
walk slower  
be extra vigilant  
be careful  
rely on others  
wear different shoes  
work together with our partner/family  
develop a different strategy  
plan where and how we are going to walk  
not take risks  
fit banisters and rails  
move and remove furniture  
turn on the lights  
use a stick  
look at where I put my feet when walking  
its not always easy to make changes

## **8. What is our attitude after a fall: discuss and offer as suggestions after discussion**

I cant cope  
time is a great healer  
have a positive outlook  
avoid a fall at all cost  
I have to accept that I fall  
the fall is the dementia  
falls are part of dementia

fall caused dementia  
I am fearful of having another fall  
I'm getting older  
I need to be more careful

**9. What can we recommend: any ideas??**

- a. for ourselves
- b. for others
- c. for services

**10. Summary**

**11. Any comments?**

## **CARER FOCUS GROUP**

### **12. Introduction**

- Explain the research
- Ground rules
- Everyone introduce themselves

### **13. What is a fall? - card ranking**

- trip
- slip
- catching feet
- stumble
- a shock
- landing on the floor without warning
- ???

### **14. Why we fall? - card ranking**

getting older  
feeling giddy  
eyesight  
glasses  
anyone can fall  
thinking of other things  
thinking for 2 people  
being in a hurry  
being too speedy  
trying to do two things at once  
walking and talking  
having a urine infection  
not feeling well  
tablets  
not putting the light on  
not wearing the right footwear  
not looking  
not paying attention  
being pulled over  
???

### **15. What we remember about a fall? - discussion**

you would remember bad falls  
you filter out bad falls  
I can feel what the fall was like  
a fall is bad enough, so anything before or after is insignificant  
if I fall, I fall properly

### **16. Where we fall – discuss cards – are there any more?**

outside  
at the train station  
crossing the road

on the pavement  
at the kerb  
indoors  
getting out of bed  
on the stairs  
country path  
over obstacles  
holes in the road/pavement

**17. What happens after a fall? – discuss we feel:**

- frustrated
- silly
- stupid
- embarrassed
- scared
- shaky
- lacking confidence
- can we cope?
- need to get up and carry on
- fear
- isolated
- unsupported

**The result of the fall:**

- bruises
- lacerations
- aches and pains
- broken bones
- going to A and E
- going into hospital
- lose confidence
- being referred to other services
- change in role
- change in relationship

**18. What do we do?: cards sort into agree/disagree**

take charge  
take on a different role  
try and prevent falls happening again  
give up doing things  
not take risks  
walk slower  
be extra vigilant  
look at where I put my feet when walking  
be careful  
rely on others  
work together with our partner/family  
develop a different strategy

have a different routine  
plan where and how I walk  
wear different shoes  
fit banisters and rails  
move and remove furniture  
turn on the lights  
use a stick  
its not always easy to make changes

**19. What is our attitude after a fall: discuss and offer as suggestions after discussion**

I cant cope  
time is a great healer  
have a positive outlook  
avoid a fall at all cost  
I have to accept that I fall  
the fall is the dementia  
falls are part of dementia  
fall caused dementia  
I am fearful of another fall  
I'm getting older  
I need to be more careful  
Challenges of Dementia  
being philosophical

**20. What can we recommend: any ideas??**

- a. for ourselves
- b. for others
- c. for services

**21. Summary**

**22. Any comments?**

**Appendix I** – *Excerpt from transcript from Primary study*

Interview: 12040504

Interviewers: I and I2, Respondents: Vera, Paul

**CLIENT INTERVIEW - Vera**

- 1 Vera: Where's he gone?
- 2 I2: I'm going to sit here Vera I think.
- 3 Vera: No, where's he gone?
- 4 I: He's gone to sit in the other room for a few  
5 minutes. Because we wanted to have a little  
6 chat with you on your own first. And then he'll  
7 come back in and answer a few questions later.  
8 Is that all right?
- 9 Vera: Mm.
- 10 I: Okay. So the reason ... the reason we've come  
11 to talk to you today is because we know that  
12 you've had a fall or two in the past. And we're  
13 trying to sort of gather some information on how  
14 people find it when they fall. Okay?
- 15 Vera: Well I've been more or less lucky. While I've  
16 been so queer, I've fallen in here. I mean right  
17 now my neck is painful.
- 18 I: I wondered to start off with, because Paul  
19 mentioned you'd had a fall here, on the floor in  
20 the sitting room. And I just wondered if you could  
21 start off by telling me about that one fall. Can  
22 you tell me something about it?
- 23 Vera: Well when I do these things I'm afraid I don't  
24 remember ...
- 25 I: Okay.
- 26 Vera: ... what I've done. I get up as though I've done  
27 nothing, but I'm painful.
- 28 I: You get up after the fall as if you've done  
29 nothing, but then you discover you've hurt  
30 something. Is that what you're saying?
- 31 Vera: Mm. As I say my neck is painful. And one day  
32 this week I fell right through here.
- 33 I: Can you tell me what happened then?
- 34 Vera: Well um ... I had the uh ... oh ... I can't think ...

suspicious

as  
contradictory  
statement

threatened  
self-efficacy

memory of  
effect not  
incident

embodied  
memory  
remember the  
consequences not  
the event



- 35 I: are you talking of the TV?
- 36 Vera: Yeah yeah. Um I had some ... I was trying to go  
37 back to get some to pick it up but instead of that I  
38 fell over, and it come this way.
- 39 I: Do you remember how you landed?
- 40 Vera: Yes I had the ... that was there and I went  
41 through the two. (*pointing to chair and footstool*)
- 42 I: Okay.
- 43 Vera: It was sort of [inaudible] in the ...
- 44 I: What do you think happened to make you fall  
45 over?
- 46 Vera: Well I don't know, it's happened so many times,  
47 just ... maybe I'm not thinking.
- 48 I: Mm.
- 49 Vera: And I just fall. Or otherwise it just goes on its  
50 own.
- 51 I: When you fell over here were you able to get  
52 yourself back up? What happened straight after  
53 the fall?
- 54 Vera: I just come and sat down.
- 55 I: So you got yourself up and you sat down on the  
56 sofa.
- 57 Vera: Mm.
- 58 I: Were you aware of hurting anything at the time?
- 59 Vera: Well I don't think of it, not then. But it is, when  
60 I'm out of it I find that there's a pain of some sort.
- 61 I: So later aches and pains come on.
- 62 Vera: Mm.
- 63 I: Okay. How do you feel after you've had a fall?
- 64 Vera: Quite honest, stupid.
- 65 I: Is that what you feel? Yeah?
- 66 Vera: [laughs]

maybe I'm  
not thinking

it happens for  
no reason

painful after

feel stupid

Poor concentration

disembodied  
cause.

Passive  
acceptance/  
Solism

Negative  
emotion  
- self blame

- 67 I: Is there any other thoughts or feelings that you  
68 have afterwards?
- 69 Vera: Well ... I can't answer that. Because it's there  
70 and it's painful. Every move I make. And I just  
71 sit down till it's easy.
- 72 I: Mm. How many falls do you think you've had  
73 Vera?
- 74 Vera: Well I would say about four.
- 75 I: About four. Have they all been inside of the flat?
- 76 Vera: Yes.
- 77 I: They have.
- 78 Vera: Um I fell off the bed in there sometimes. And this  
79 one yesterday ... not yesterday, the day before.  
80 I've had quite a few ... well I would say at least  
81 four.
- 82 I: What do you remember about the one off the  
83 bed? What time of the day was that?
- 84 Vera: When I got up this time ... well ... I mean I  
85 always get up very early.
- 86 I: So it was early in the morning.
- 87 Vera: Yeah.
- 88 I: And you were getting out of bed, what, for the  
89 first time?
- 90 Vera: I always sit and rest for a while but that day I just  
91 come straight out.
- 92 I: So you normally sit on the edge of the bed do  
93 you?
- 94 Vera: Mm.
- 95 I: But you got ... that day you got straight out of  
96 bed.
- 97 Vera: Yeah.
- 98 I: And where did you fall? Right by the side of the  
99 bed? Where did you actually fall? Had you got a  
100 bit away from it?

Pain very  
present

time a great  
healer  
acceptance

change of  
routine

change in  
behaviour

**Appendix J** – *Example of clustering of themes for one participant, Primary study*

## Vera and Paul – emerging themes

Vera – client interview		Paul – carer interview		Joint interview	
Threatened self efficacy, 15	Well I've been more or less lucky. While I've been so queer, I've fallen in here. I mean right now my neck is painful	Feeling guilty 265, 277,	I hadn't been ... I come down twice a day, but this day I hadn't been down in the morning. Cos I was out somewhere. And I came at about half past 5 I guess and it was dark. All the lights were out so I obviously got worried. I have a key so I got into the porch and couldn't get in through this door. I couldn't open it in fact. And then I realised that something was stopping ... of course I thought the worst then ... but then I heard a moan and it was mum	Trying to manage the unmanageable? 611, 670,	I mean we've tried to eradicate almost everything now  I: Have you made any changes? V: No, he's done most of it. I: What's Paul done? V: Made me sit down

			<p>here</p> <p>I had to push the door open, push her aside really, and sort of crawl in as much as I could, and she was down here</p>		
<p>Embodied memory 26,</p>	<p>I get up as though I've done nothing, but I'm painful.</p>	<p>Reason for fall 282, 355, 431, 476,</p>	<p>I don't know what ... no I don't think she slipped, no I think she was ill because she had a chest infection</p> <p>I've witnessed her tottering about. You know she'll get up. If there's a sudden movement that's when she goes</p> <p>I thought some of the falls were tripping over. But i think of late its not that at all. I think is giddiness od</p>	<p>Restricting activity 670,</p>	<p>I: Have you made any changes?  V: No, he's done most of it.  I: What's Paul done?  V: Made me sit down</p>



			dizziness or something.  But she's independent, she stays here and she ... you know she's carried on. And you know she eats very well now. But the falls we don't know about. No idea. We don't know what it is		
Intrinsic cause 46, 151	...it's happened so many times, just maybe I'm not thinking.  Sometimes I'm sitting there like I am now and I'm alright, but when I get up I've got a headache.	Proof of fall 292,	But the other falls I've not witnessed at all. I know that she's had them because she's got aches and pains and she's banged her arms or she's got a bruise or something	Negative emotions 674, 680,	No if he's anywhere near he picks me up and looks after me. Then I feel stupid.  ...Mainly I suppose because I can't have anybody to talk to
Disembodiment 49,	And I just fall, or otherwise it just goes on its own				

**Appendix K – Excerpts from  
early analysis for one theme,  
Primary study**

Sub theme 3 - cause of fall – APRIL 2010

Bridget, Harry & Alison	Plenty of causes 810	B: Well the mat, it could be the mat there yeah.
		I: Yeah.
		B: Oh I know I should lift my feet a bit more.
		I: Yeah. Mm.
		B: And I think sometimes I wasn't even looking where I was going, you see I was looking ahead of me.
		I: Right yeah yeah. Do you think sometimes you're busy thinking about something else? Something ... whatever it is you're going to do?
		B: Yeah it might be, yeah, yeah. The old brain is always moving, or thinking about shopping or something, you know
	Reasons for fall 91,	I must have fell over the mat or something
	96	Or sometimes when I get out of bed like that I get a bit dizzy so that might have happened...
	Possible causes 556	It was only ... cos at that time we were having problems with her eating. I mean she's still obviously ... she's not sort of overweight by any means
	563	I mean this is all part of then why we escalated it when she had the fall, because I actually felt that part of the reason that she fell was that she was dehydrated, you know
Wendy and Bernard		W: Well its old age isn't it
		B: Well yes I suppose it is.
	701	W: I suspect I didn't really look where I was putting my feet.
	Getting older 343,	But I didn't used to fall like this. Probably age has got something to do with it. Exactly why I don't know.
	372	Certainly I've fallen more as I've got older, I mean I'm over 80 now. But I'm still very lucky; I'm able to get about.
	390	I didn't used to fall as often.... I do now. It's probably age, I don't know.



	Issues of growing older 175,	But what can you do? I don't know, maybe you know what it is. Losing your balance, I don't know. I must admit I mean after all she is 83 and I'm going for 85. So is that the reason, I don't know.
	186	She should walk with a stick really. But you still think that you're a young person, you can do it without any help.
		B: ..go over it and round it. Very often I say "now follow me" but you don't. You go somewhere else.
		W: Well I don't walk through puddles though. Not deliberately.
		B: No, no but you're attracted to them ...
	Extrinsic cause of fall 94	She likes to walk sometimes on her own and in those days she had bifocal....
		She sort of blame that.
		But since then she's got the ....what do you call
		it?
		I: Varifocal?....
	166	I dint know if it's the fall, I don't know if it's a question of... I must admit the paving are not very good round here. She seemed to be missing the step...
	Losing balance 103	So she doesn't seem to worry about it except that she now loses her balance.
	108	I heard a thump. So I rushed upstairs and she was on the floor. She lost her balance.
Bob and Norma	Finding a cause 437	well I think he was coming down the stairs and he just slipped and fell down. I suppose he hadnt been holding onto the the banister at the time. Always I tell him to hold onto the banister
	469	I suppose he wasn't concentrating where he was. And he just missed a foot or something and slipped.
	Extrinsic cause of fall 241	I: You said you caught your toe on something when you were walking in the street one time.
		B: Oh yeah - on the curb.
	278	I stumbled. Yes - a kind of push forward.
	external pressures/causes 577	N: well the one time getting off the bus he did nearly fall, you know. With the curb, you know, coming down.

		I: What was happening?
		N: Well I think he only put his toe on the curb and then he stepped like..... but he didn't hurt himself much
		I: Okay
		N:...but he didn't hurt himself much.
		I: Did he end up on the floor?
		N: well yes, he went down
	599	Well you have to ... you have always to try to hurry up when you're getting off the bus, because they close the doors quickly sometimes
	692	Oh you see he has cataracts, and they didn't do them. The ... what do you call it ... the lady in the eyes ... um optician, she sent a letter to the doctor and the doctor said that it was refused. So I don't know why
	Mind- body split 709	N: It's the brain really, it's the brain that's confused, that's doing it I think.
		I:How does that affect him do you think?
		W:That's why he's not getting his eyes done I think, he's not getting his cataracts done.
		I:How do you think the confusion affects him when he's moving around? Like getting off the bus, I mean do you think it has a big impact?
		N: Well he'd forget to get off if I wasn't there, he'd forget to get off, and just go on.
Eileen & Karl	Anyone can fall (carer falling) 573,	once we went to doctor, I suppose a year and a half ago, and we both fell just outside doctor in the middle of the road, because ... crossing the road to the car, she tripped, fell over in front of me, and I over her.
Vera and Paul	Reason for fall 282	I don't know what ... no I don't think she slipped, no I think she was ill because she had a chest infection
	355	I've witnessed her tottering about. You know she'll get up. If there's a sudden movement that's when she goes
	431	I thought some of the falls were tripping over. But i think of late its not that at all. I think is giddiness od dizziness or something.

## **Appendix L** - *Development of themes, Primary study*

## **GROUPING OF THEMES FOR PRIMARY STUDY**

### **Notes following initial grouping of themes – 23<sup>rd</sup> June 2010**

I think I need to look at the carer themes more closely.

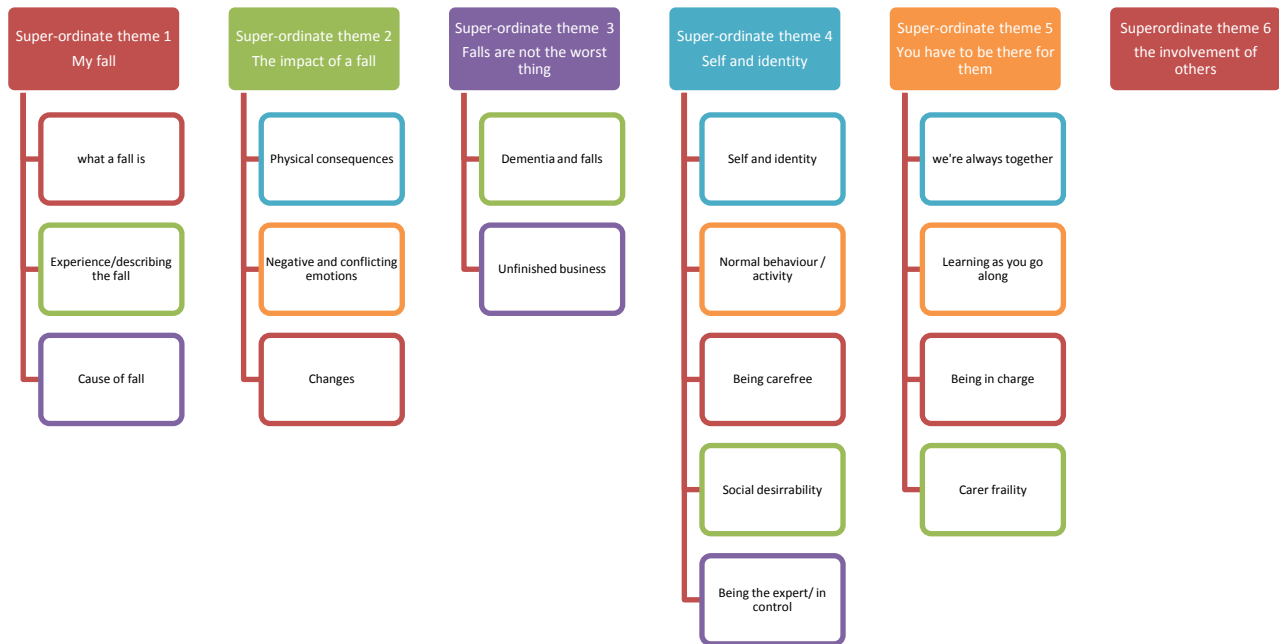
I also need to look at the subthemes before grouping things together in more detail.

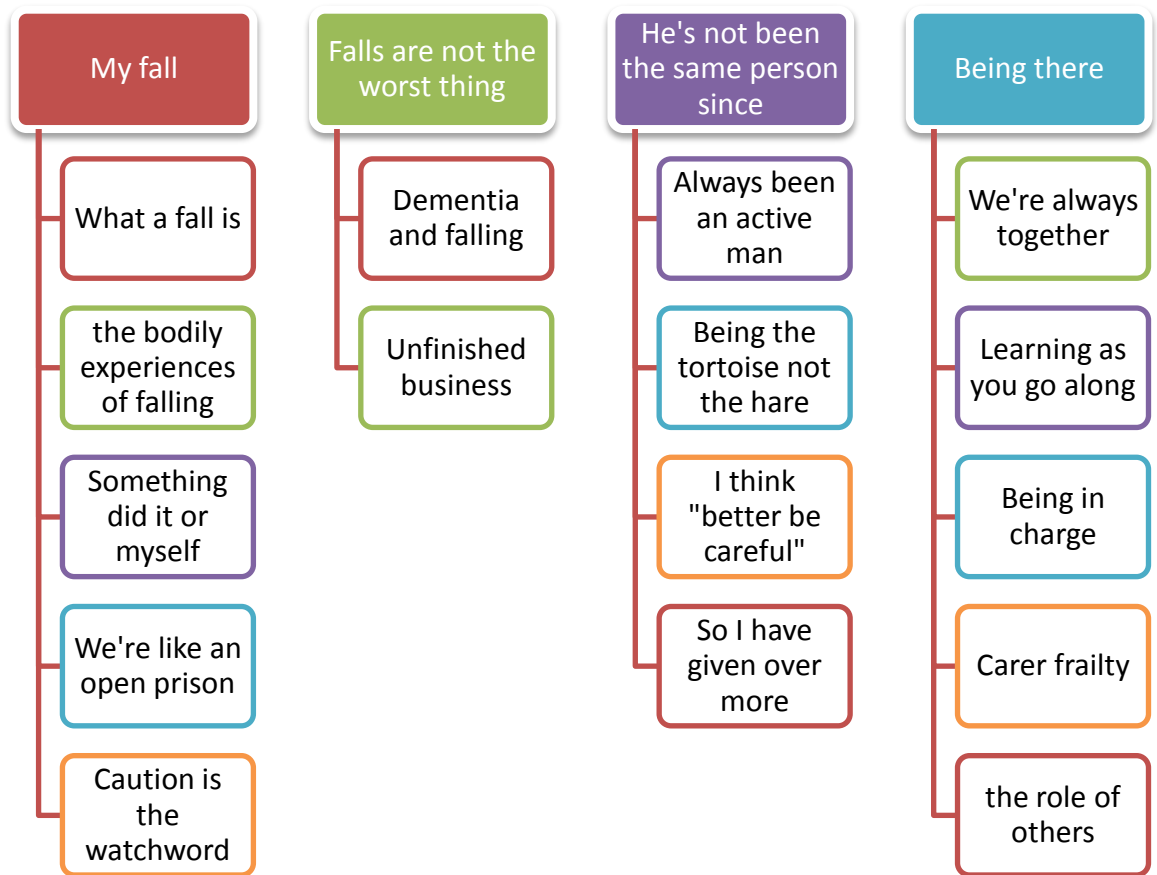
There are some descriptive themes - e.g. definition, cause, rationale etc.

Current Major theme suggestions:

1. Response to fall - currently consequences of fall
2. Memory of fall? - visual, factual, embodied
3. Impact of fall on self/identity (this would also address that self/identity already challenged by dementia)
4. Dementia - elephant in the room?? Also here the relationship between fall and dementia
5. Carer theme - "You have to be there for them" - to prevent further falls, to preserve personhood, learning on the job, impact on carer, getting support

## RQ1 Grouping of themes from analysis 6<sup>th</sup> August 2010





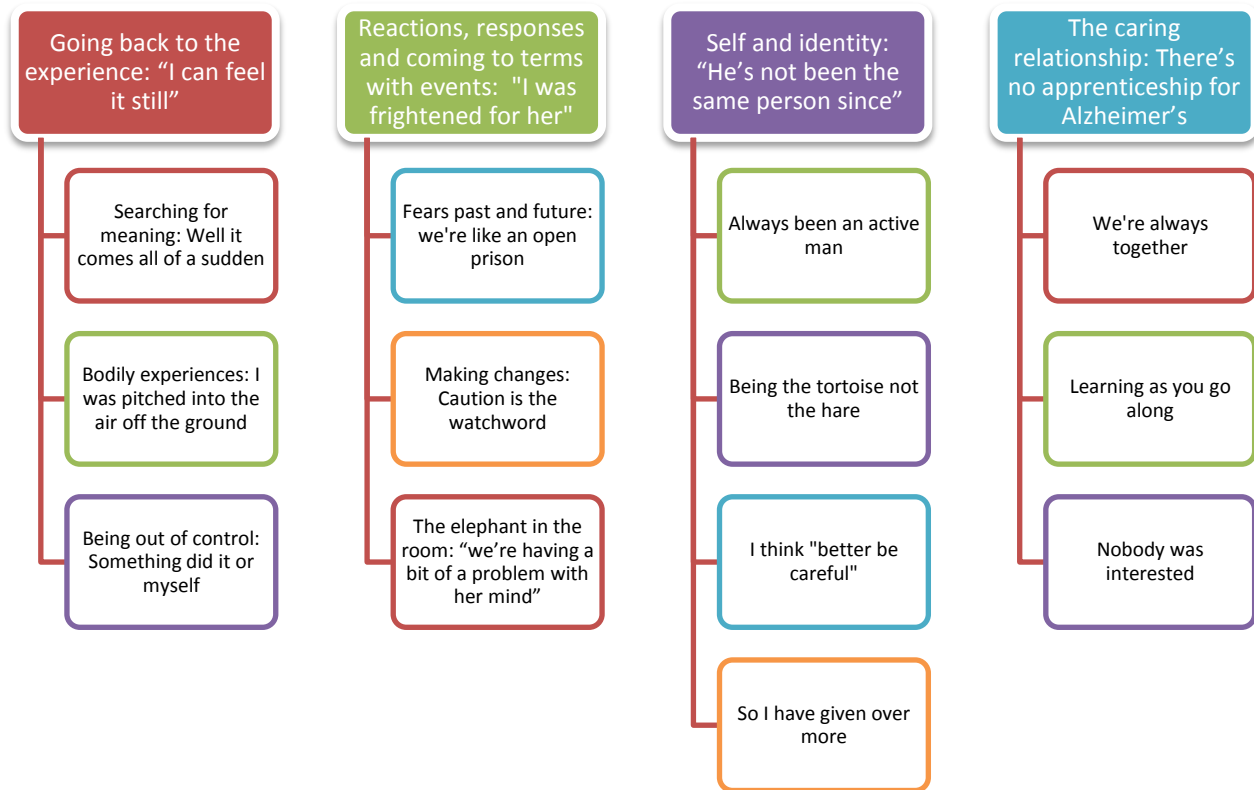


RQ1 Findings v4 February 2011





RQ1 Findings v5 29<sup>th</sup> May 2011



**Appendix M** – *“Going back to the experience”: a phenomenological description*

## **“Going back to the experience”: a phenomenological description**

### **Introduction**

In chapter six, section 6.1, an alternative analytical process has been proposed to capture the experience of falling of primary study participants in a desire to “go back to the things themselves” as declared by Husserl (Moran 2000, p92). This led to an analysis of the personal experiences of falling using a phenomenological reduction to reveal the essence of falling by these participants. (maybe link with descriptive phase of IPA??)

A descriptive phenomenological method has been used to analyse the data from the primary study, which has been based upon Giorgi’s method of analysis (Giorgi and Giorgi 2008). The method of analysis has also been informed by Finlay (2011), Langdrige (2007) and Todres (2002), in their discussion, description and examples of descriptive phenomenology. Like Bargdill (2000), Bilhult et al (2007), and Todres (2002), quotations from participants have been included to provide examples to illuminate the description of the phenomenon.

### **The Experience of Falling**

Falling was a multi-faceted experience for the care-recipient and carer participants in this primary study. A more general description of falling was asked of participants to situate the focus of the interview. Falling was described as being a slip, trip or stumble as well as a loss of balance and these descriptions suggest a straightforward recourse to dictionary definitions. However participants also portrayed falling in more emotive and subjective ways that perhaps related to their own personal experiences. The lack of warning and sudden nature of falling were described as being “out of the blue” or a shock. The lack of premonition with falling was also associated with embarrassment, fear, and feeling shaken, silly or insecure. Participants expressed their concept of falling in the following ways:

*[If you had to describe what a fall was to someone, like from a dictionary, how would you describe a fall?]*

“Well it involved being silly, I suppose...” (Bridget, care-recipient, I.28)

“A fall, I would say, was something totally unexpected and you end up on the ground” (Susan, carer, I.1032).

“Well it’s a shock, yes it is a shock” (Karl, carer, I.394).

Although all participants identified the surprising and unexpected essence of falling, some experiences also seem drawn-out and more surreal. In the following examples participants describe struggling to maintain or regain consciousness and control:

“...Hit the stone and then I was kind of pitched, but not to the ground, but I was pitched in the air off the ground” (Bob, care-recipient, I.855)

“I felt that I was floating, but I was touching the ground I think most of the time.” (George, care-recipient, I. 1682)

“I do know that I was out, you know, it went out, I don’t know what happened to it, I was underneath. Knocked myself out.” (Eamonn, care-recipient, FG2, I.255)

Participants’ memories and descriptions of their own falls seemed embodied and kinaesthetic in nature rather than being related to specific times and places. Care-recipients remembered how their fall felt and the position they found themselves in; for example being sprawled on the ground or their legs in a ditch. Other memories of the falls experience that were foregrounded were feelings of bodily pain and discomfort as a consequence of their fall, rather than the actual fall itself. Indeed the sudden nature of the falls experience is counterbalanced by the remembrance of the lingering consequences.

Falling can be suggested as being a mysterious event. Not only did the participants not have any premonition of their fall, but they were also unable to specifically identify why they fell. Many reasons were given, with many theories given for the same event by individual participants and dyads. Intrinsic and extrinsic reasons were suggested as contributing or causative factors for falling. Whereas suggested extrinsic causes involved tripping over mats, uneven pavements, steps, and pyjama trousers, or badly fitting slippers, or wearing varifocal spectacles. Falls were also attributed to intrinsic factors such as not walking properly (e.g. not picking one's feet up sufficiently), feeling tired, dizzy or unwell. The need to hurry to get to the toilet was also cited as a reason for falling. Indeed in some instances the intrinsic and extrinsic reasons were linked. The body being failed by the mind was also expressed as a reason for falling, such as being distracted and having poor concentration. Thinking of other things was also suggested as a reason for falling, whether it was more pleasant daydreaming by care-recipients or feelings of burden and concern for the care-recipient by carers:

"The old brain is always moving, or thinking about shopping or something, you know." (Bridget, care-recipient, I.899)

"...there's so many things to think of and you're thinking of somebody else as well as yourself..." (Christine, carer, FG1, I.366).

Other reasons for falling had a more sinister nuance, with participants articulating a feeling of being controlled by an external and malevolent force that caused them to fall. These experiences are expressed as follows:

"...I go against these things trying to get me flat, and I am trying to hold myself up. Not drop over." (George, care-recipient, I.1831).

"...but it sort of turned me halfway..." (Vera, care-recipient, I.104).

"Well I don't walk through puddles though. Not deliberately." (Wendy, care-recipient, I.641).

## Summary

Falling is a multi-faceted experience for these participants. There are many conceptualisations of falling, however the common thread is the sudden and surprising nature of the experience and associated negative emotions. The memories of falling have personal meaning and are subjective, embodied and kinaesthetic rather than objective recollections of times and places. Although the fall itself was a quick and transient event, these participants' lived experiences are suffused with the lingering consequences of their fall. The consequences are not only physical injury but also the perception of the fall being a malevolent controlling force. The reasons for falling are many and varied and it could be said that these reasons were articulated to try and make sense of the falls experience and perhaps prevent reoccurrence.

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## Appendix N – McIntyre and Reynolds (2011)

*This has now been removed for copy right reasons.*

*The full reference now is:*

McIntyre A and Reynolds F (2012) There's no apprenticeship for Alzheimer's: the caring relationship when an older person experiencing dementia falls. *Ageing and Society*, 32(5) 873-896.

**Appendix O** – *Excerpt from transcript from secondary study*



Secondary study PWD focus group 2007

- 242 Martin yeah yeah, and loose, being loose as well you know.
- 243 I yeah yeah. Any other thoughts where you might have  
244 fallen or you've seen other people fall or ...
- 245 Trevor well if I'm trying to run somewhere that's a disaster really  
246 because my legs cannot keep up with the movement of  
247 my body.
- 248 I right, so like running for the bus or rushing for the train.  
249 Mm, mm, mm. Any other thoughts? One of the places  
250 that we identify is the bathroom and yet nobody talked  
251 about the bathroom.
- 252 Trevor so many things to hang onto in the bathroom.
- 253 I possibly yes you're right possibly. Yeah.
- 254 Stephen its better to shower in the bathroom. - sensible comment
- 255 I right, so it's not so dangerous.
- 256 Stephen You don't need to get into the bath if you have a shower.
- 257 I I think a lot of people it was unfortunately on the  
258 pavement, on the uneven ...
- 259 Keith yeah that's where you stub your foot.
- 260 I yes yeah, either at the curb or on the pavement. So  
261 people were out and about and they were falling over. So  
262 um ...
- 263 Stephen is that because like you know they're doing it casually, but  
264 they're not putting their feet where they should be?  
265 They're just sort of bumbling along sort of thing.
- 266 I possibly, it could be, it could be. Because ...
- 267 Stephen you don't go out and say 'oh I've got to walk properly like  
268 you' ...
- 269 I (laughs)
- 270 Stephen ... you just walk, don't you, it's the way you are.
- 271 I yeah. And I think that's what a lot of people then said is  
272 that you know they talked about reasons why they might  
273 have fallen and one of them was that they weren't  
274 watching where they were going
- 275 All Mm, (general agreement).

legs can't keep  
up with the body

- sensible comment

not  
concentrating

you don't  
think about  
it

Secondary study PWD focus group 2007

276 I The other thing was is that they were doing more than one  
277 thing at once, so they were either talking and walking, or if  
278 it was on the stairs they were carrying something. Or they  
279 were just concentrat- ... had their mind on other things.  
280 So those were quite common reasons why people fell. So  
281 I think perhaps it was not necessarily looking where you're  
282 going.

283 Martin an unexpected step is a nasty one.

- a shock

284 I yes.

285 Martin I was in a pub once and getting into this pub you had to  
286 go up a step to get into it, you know fairly normal thing. I  
287 was in there once, and the door opened and bloke came  
288 in, he tripped on the step and fell on the floor, and the  
289 chap at the bar says 'I'll have a pint of what he's drinking'

stairs seem  
to be a recurring  
theme for  
Martin

290 (general laughter)

291 I that was on his way in.

292 Martin yeah.

293 I yeah yeah. (laughs) yes, that would be cheap wouldn't it?  
294 Yeah. Was that the lighting do you think?

295 Martin I beg your pardon?

296 I do you think that was anything to do with the lighting?

297 Martin no, well it may have been a bit dim I don't know, but the  
298 principle force was the fact that it was an unexpected  
299 step.

an unexpected  
step a surprise

300 I yeah yeah yeah. Cos I think they were other things, and  
301 I'm going to have to look at my lists now because ... and  
302 this is where I sort of juggle with my glasses. And I've got  
303 loads of cards here, we might not put these out, but ...  
304 people's reasons ... this was 'getting older' was one thing  
305 they said was a reason for falling, which was a bit of a  
306 shame. (?) 'feeling giddy' - some people felt giddy.

307 Alan that was my mum I think feeling giddy.

308 I right yeah. Um ... some people talked about their  
309 eyesight not being terribly fantastic and they couldn't  
310 necessarily see the uneven pavements or the bits, so they  
311 talked about that.

312 Alan well I've got glaucoma and can't see too well, but I think  
313 you do compensate by trying to be more careful.

compensate  
for poor vision

## **Appendix P – *Example of early analysis, Secondary study***

## Emerging themes – Secondary study

Stumble	Stephen	64	I'd say it was a stumble
unexpected		132	Well it's so quick isn't it? If you trip you fall. That's all there is to it. You can't say as you're falling...
tripping	Alan	71	I think with my mum she used to catch her feet. She'd sort of literally trip herself up.
personal experience?	Martin	51	well I was just saying this one presumably is when you're coming downstairs and you miscount the stairs etc.
personal experience		74	my wife has had a bit of trouble tripping over paving stones.
personal experience	Mary	37	Well like Felicity said, you said it was probably the blood pressure, connected with the blood pressure. But I think it might be right in my case as well, in my case when I was looking after my husband.
personal experience	Daniel	65	Well I thought that a fall could be caused by absence of your surroundings and then you step out or whatever happened, assuming that what you're seeing, that's what you're doing. But it could be the opposite to what is there, you're actually doing. So you step into an area that is not there ... but that's what you can see, and you get a fall from that as well.
personal experience	Liz, Felicity, Mary	95	I think it's catching feet as well, because they stand up and suddenly you know they want to move and the feet are not moving and they sort of ... well in a way they do stumble but it's catching on each other.
			F: It is a balance thing isn't it?
			M: It's the balance really yes (inaudible)
	Mary	82	and that's this one - you are suddenly down
	Fiona	88	I thought it was just tripping
	Felicity	92	I'd say if you tripped
	Mary	94	yes you can trip, you can stumble
personal experience	Iris	103	slipping as well ...especially in the bath

	Mary	127	changing position
	Felicity & Mary	106-110	I find a lot of people sit for a long time. Like your husband when he comes out of a long drive in a coach, they get up all right then they walk one or two step and then the knees give.
experience of caring for PWD	Iris	129-36	I'd like to say that I think it's because people with dementia or Alzheimer's, you see, their brain doesn't work quickly. Cos often I have to say my husband something three times before it gets there. So I think whatever they do, like standing up, takes longer for it to get to the brain, so therefore they go. Whereas we would just do it automatically, they take you know perhaps a minute or more to get you know ... for it to connect. Sometimes it doesn't connect at all.
infection	Mary	219-25	M: Yes. That's true, my husband had that and I found that he had more falls than usual.
			Int: yes. So...
			M: But they didn't recognise that it was a urine infection and they treated him but obviously the antibiotics didn't work.
			Int: yes...
			M: And I found he had a lot of falls then.
Wearing glasses	Felicity, Iris & Liz	143-8	Int: one of the things that seemed to be problematic for some people especially people with dementia was if they had new bifocals or varifocals.
			F: Well it's not just with dementia it's (inaudible) (laughs)
			L: With everybody, yes that's right.
Carer falls	Mary	80	I've had several falls since my husband died.
Thinking about other things	Felicity	154	Int: So ... what people also talked about was thinking of other things ...
being distracted			F: Yes, your mind's not on what you're doing, that's right.

negative thoughts	Christopher	159	Isn't that most accidents? Because I've got a theory of accidents that you're always thinking about something not necessarily nice. So your mood's not in the sort of nice gentle groove. cos I cut myself just before we came, I was in a rush trying to get my mum to go off ... you're always thinking of something else just before the accident, just before the thing happens.
not concentrating	Christopher	167	well that means you're not concentrating on what you're doing, so you're more likely to...
	Iris	169	too much on your mind
	Mary	170	Thinking for two people
		180	I mean I'm sitting there and I'm thinking for two people. Because my husband comes from the day centre and I'm thinking I don't want to be late ... you know you're always thinking for two people.
being in a hurry	Iris	187	Yes, you're always in a hurry
Dual tasking	Daniel	205	I would agree with that. It's the same thing I was saying, when you're not on focus on that thing, anything can happen, you can fall. Because you're talking to me and you forget where you're putting your foot, next step, and you down in a ditch and over you go. So I would completely agree with that.