

The experiences of people with  
dementia in the acute hospital ward  
setting

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference is made to the work of others.

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## **Abstract**

The accounts of people with dementia about their experiences are essential to provide care that is based on their preferences. Evidence is lacking for factors within the acute hospital setting that contribute to good and poor care experiences. This thesis aimed to explore what people with dementia consider to be important factors that contribute to their experience of being in hospital.

A qualitative systematic review was conducted to assess the evidence for experiences of people with dementia in hospital. The findings revealed variation in experiences which were influenced by their physical and social environment. Most importantly, the review revealed that there are several factors within the care process that can influence both good and poor care. However, the review also highlighted that there was a lack of accounts from people with dementia on their experiences.

A multi-perspective qualitative research study was conducted using interpretative phenomenological analysis to explore the experiences of people with dementia during hospital ward episodes. The analysis revealed several novel findings that contribute to the existing literature: people with dementia perceived that they should not be in hospital and that they were not involved in this decision-making process. Their experiences highlighted for them their sense of failing self and an uncertain future. They faced this uncertainty whilst living with grief of who they used to be, and for some, denial that dementia existed. Staff were mostly blameless in limitations of care and people with dementia appeared to influence responses from staff to evaluate their care as good. They defined poor care as being neglected and ignored and perceived that they had to, and would, respond in certain ways to ensure that this did not occur. The thesis has highlighted the importance of co-producing evidence to inform changing practice and designing research.

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## **Chapter One: Introduction, summary of literature and aim of thesis**

### **1.1 Chapter Summary**

Improving the care experiences of people with dementia is a major focus of attention for the National Health Service (NHS) in the United Kingdom (UK) and for health and social care organisations worldwide. This chapter summarises existing literature about living with dementia and supporting people with dementia within the healthcare setting, focusing upon evidence for principles of good dementia care. The chapter reflects on care that is provided during an acute hospital in-patient episode and identifies gaps in the evidence base. The aims of the thesis are presented, and the chapter concludes with an overview of the remainder of the thesis.

### **1.2 Definition and Prevalence**

#### **1.2.1 Definition of dementia**

Dementia is an overall term that describes a wide range of symptoms associated with a decline in memory or other cognitive skills severe enough to reduce a persons' ability to perform everyday activities. There are several formal definitions in existence, such as that included in the International Classification of Diseases:

*'Dementia is an acquired brain syndrome characterized by a decline from a previous level of cognitive functioning with impairment in two or more cognitive domains (such as memory, executive functions, attention, language, social cognition and judgment, psychomotor speed, visuoperceptual or visuospatial abilities). The cognitive impairment is not entirely attributable to normal aging and significantly interferes with independence in the person's performance of activities of daily living. Based on available evidence, the cognitive impairment is attributed or assumed to be attributable to a neurological or medical condition that affects the brain, trauma, nutritional deficiency, chronic use of specific substances or medications, or exposure to heavy metals or other toxins'. (International Classification of Diseases 11, 2018).*

Alzheimer's Disease accounts for between 60 to 75 percent of cases (Prince, Albanese, Guerchet and Prina, 2014a). Vascular dementia, which is caused by interruptions to the blood supply to the brain often associated with strokes, is the second most common dementia type (Prince, Ali, Guerchet, Prina, Albanese and Wu, 2016). There are many other 'types' of dementia, which generally are

differentiated due to their underlying causes and pathology such as early-onset dementia, Lewy body disease and frontotemporal dementia, and other degenerative diseases such as Huntington's disease and co-existence with other conditions such as multiple sclerosis, Parkinson's Disease and Down's syndrome (Smits, van Harten, Pijnenburg, Koedam, Bouwman, Sistermans, Reuling, Prins, Lemstra, Scheltens and van der Flier, 2015, Chen, Kwong, Copes, Tu, Villeneuve, van Donkelaar, Hystad, Martin, Murray, Jessiman, Wilton, Kopp and Burnett, 2017, Hithersay, Hamburg, Knight and Strydom, 2017). Dementia affects people with the illness differently, especially in the early stages of the disease (Ballard, O'Brien, Morris, Barber, Swann, Neill and McKeith, 2001, Cormack, Aarsland, Ballard and Tovee, 2004, Smits et al., 2015).

Within the literature, the distinction between the different types of dementia has been described by lead experts in the field of dementia research as 'a little academic' (Burns, Twomey, Barrett, Harwood and Cartmell, 2015). It is the presentation of the stage of disease that appears to be important; dementia tends to have 3 stages, mild, moderate and severe. As the terms suggest, the level of impairment is used to describe stages of illness. Generally, the Mini Mental State Examination (MMSE) (Folstein, Folstein and McHugh, 1975), and the amended version, the standardised MMSE (Molloy, Alemayehu and Roberts, 1991) are used to distinguish between the different stages. These are cognitive performance tools which retrieve scores on levels of functioning. Higher scores depict mild dementia, whereas lower scores depict severe dementia. The stages of dementia are characterised through variable, progressive loss of cognitive function beginning with forgetfulness and difficulty concentrating, and progressing to difficulties with reasoning, communicating, recognition and mobility (Killick and Allan, 2001, Innes, 2009, World Health Organisation, 2019).

### 1.2.2 Prevalence of dementia

Estimates of the prevalence of dementia vary considerably depending on how prevalence is measured. In their review and meta-analysis of prevalence rates Prince and colleagues identified wide variation in study quality, design, sample sizes and scope of diagnosis (Prince, Bryce, Albanese, Wimo, Ribeiro and

Ferri, 2013). Probably the most well-known statistics, that one can assume therefore are central to policy priorities, are published and frequently updated on the Alzheimer's Research UK website (Alzheimer's Research UK, 2019). Prevalence is estimated at around 7 percent of people aged over 65 having symptoms of dementia and around 1 in 6 people aged 80 and over having dementia (Alzheimer's Society, 2018). It is estimated that currently 850,000 people in the United Kingdom (UK) live with dementia (Alzheimer's Society, 2018), and world-wide prevalence estimates are at around 50 million (Alzheimer's Disease International, 2018). Estimations of the proportion of people with early-onset dementia, that is dementia in people aged under 65 years, are at around 5 percent of all people living with dementia in the UK (Prince, Knapp, Guerchet, McCrone, Prina, Comas-Herrera, Wittenberg, Adelaja, Hu and King, 2014b). Recent predictions show that there will be over 1.2 million people living with dementia in England and Wales by the year 2040 (Ahmadi-Abhari, Guzman-Costella, Bandosz, Shipley, Muniz-Terrera, Singh-Manoux, Kivmaki, Steptoe, Capewell, O'Flaherty and Brunner, 2017). This increase in prevalence has largely been explained as an increase in life expectancy for people aged 65 years and over (Ahmadi-Abhari et al., 2017). However, there is emerging evidence that the UK appears to be experiencing stagnating or continued declines in life expectancy (Ho and Hendi, 2018), and so one would expect that prevalence rates will remain the same or even decline over time. There is also evidence that the overall incidence of dementia has decreased slightly. It is thought that this reduction may be due to improved cardiovascular health (Pickett, Bird, Ballard, Banerjee, Brayne, Cowan, Clare, Comas-Herrera, Corner, Daley, Knapp, Lafortune, Livingston, Manthorpe, Marchant, Moriarty, Robinson, van Lynden, Windle, Woods, Gray and Walton, 2018).

### 1.2.3 Diagnosis rates

Establishing prevalence rates is not straightforward as there is evidence for gross under-estimation for the existence of dementia. There is great variation across the country, and globally, on diagnosis (Lang, Clifford, Wei, Zhang, Leung, Augustine, Danat, Zhou, Copeland, Anstey and Chen, 2017). There is evidence that accurate diagnosis is lower in ethnic minority groups, younger

people and those living alone, more affluent socio-economic groups and people with physical illnesses (Connolly, Gaehl, Martin, Morris and Purandare, 2011, Lang et al., 2017, Sommerlad, Perera, Singh-Manoux, Lewis, Stewart and Livingston, 2018).

In their recent review of rates of under-detection, Lang and colleagues suggested that these high-risk groups should be targeted for screening to enable early diagnosis of dementia and access to support services (Lang et al., 2017). Studies have shown that the stigma attached to having memory problems (Mukadam, Waugh, Cooper and Livingston, 2015), and lack of knowledge about dementia in general may lead to decreased use of services by particular groups of people (Mukadam, Cooper and Livingston, 2013, Kenning, Daker-White, Blakemore, Panagioti and Waheed, 2017).

In the UK, the process of screening to enable diagnosis generally starts in primary care services, requiring the person to have contact with their general practitioner (GP). The most recent National Institute for Health and Care Excellence (NICE) guidelines that have been produced to assist primary care staff in screening state that assessment should include history taking, informed by the person themselves and close others, elimination of other causes of cognitive decline through physical screening and cognitive testing using a validated brief structured cognitive instrument such as the 10-point Cognitive Screener, the 6-item Cognitive Impairment Test or the Mini-cog (National Institute for Health & Clinical Excellence, 2018). Where dementia is suspected, referral to a specialist dementia diagnostic services is indicated, where further tests can be performed to ascertain dementia type. Since the understanding of dementia is evolving, diagnostic criteria are liable to undergo continual revision (Rockwood, Bouchard, Camicioli and Léger, 2007, de Roos, van der Grond, Mitchell and Westenberg, 2017).

In England, it is estimated that over two-thirds of people aged over 65 years with dementia, have a coded dementia diagnosis recorded in their GP record (NHS Digital, 2018). The introduction of the National Dementia Strategy in 2009 (Department of Health, 2009) has been linked with increased rates of detection (Mukadam, Livingston, Rantell and Rickman, 2014). Improvements in

detection have most likely been facilitated through incentives for diagnosis across the healthcare system including Quality Outcome Frameworks (NHS Employers and British Medical Association, 2018) and Commissioning for Quality and Innovation Frameworks (NHS England, 2014, updated March 2019), as well as improvements in the ability to diagnose early dementia, including new methods for detection in clinical settings (Maclin, Wang and Xiao, 2019). Better recording on death certificates has also impacted on reported statistics (Perera, Stewart, Higginson and Sleeman, 2016).

Estimates for under-detection can be informed by studies that screen for dementia on admission to hospital. In a longitudinal study in a London general hospital, researchers established that dementia was present in 42 percent of a cohort of 617 people aged over 70 years, with only half diagnosed prior to hospitalisation (Sampson, Blanchard, Jones, Tookman, & King, 2009). More recent studies of people of a similar age have reported similar results.

Timmons and colleagues found that on admission to hospital, most dementia was not previously diagnosed, (Timmons, Manning, Barrett, Brady, Browne, O'Shea, Molloy, O'Regan, Trawley, Cahill, O'Sullivan, Woods, Meagher, Ni Chorcorain and Linehan, 2015) and Sommerlad and colleagues found that hospitals did not recognise dementia in a third of their patients admitted for a different reason (Sommerlad et al., 2018).

### **1.3 Living with Dementia**

#### **1.3.1 Models for understanding dementia**

There are two main models for understanding dementia that have different implications for the way in which people with dementia are supported, which in turn have consequences for the experiences of people with dementia.

##### **1.3.1.1 Biomedical model**

The biomedical model posits that some of the symptoms of dementia can be reduced temporarily through medication. Acetylcholinesterase inhibitors, which act to prevent the enzyme acetylcholine in the brain from breaking down, are usually the first line of treatment in mild to moderate dementia. In randomised-controlled trials, use of these medications have demonstrated beneficial effects on cognition function, daily living function and global changes (Dou, Tan, Tan, Cao, Hou, Guo, Tan, Mok and Yu, 2018). There is evidence that combinations



of acetylcholinesterase inhibitors with other neuroprotective drugs such as N-methyl-D-aspartate (NDMA) receptor antagonists can benefit cognitive function for people with moderate to severe dementia (Dou et al., 2018).

In clinical trials, cognitive enhancers do not appear to improve behavioural and psychological symptoms in dementia (Tricco, Soobiah, Berliner, Ho, Ng, Ashoor, Chen, Hemmelgarn and Straus, 2013, Dou et al., 2018). This group of symptoms are generally defined as disturbed thought content, mood, or behaviour that include depression, apathy, sleep problems, agitation, repetitive questioning, psychosis, aggression and wandering (de Oliveira, Radanovic, de Mello, Buchain, Vizzotto, Celestino, Stella, Piersol and Forlenza, 2015). Clinical studies of both pharmacological and non-pharmacological interventions show mixed results. One review identified concerns with the methodological adequacy of a substantial proportion of studies (Forlenza, Loureiro, Pais and Stella, 2017). The weight of evidence suggests that psychotropic drugs used in combination with social and occupational therapies tend to have more effective outcomes (de Oliveira et al., 2015, Forlenza et al., 2017). However, effectiveness is complicated through a lack of agreement as to the causes of symptoms, which can be multifactorial (Kales, Gitlin and Lyketsos, 2015). The causes can be summarised as 'individual neurobiological related disease factors, unmet needs, care giver factors, environmental triggers and interactions of individual, care giver and environmental factors' (Kales et al., 2015 p1). These symptoms are complex and can manifest differentially in individuals, which indicates that approaches need to be tailored to the individual and their care givers (Kales et al., 2015).

The biomedical approach is also dealing with the legacy of inappropriate and unsafe use of antipsychotic medication to manage some of the more distressing symptoms that are closely linked with burden to families and society (Gareri, Cotrontneo, Lacava, Seminara, Marigliano, Loiacono and De Sarro, 2004, Bannarjee, 2009). In the UK, antipsychotics are not licensed for the treatment of behavioural and psychological symptoms of dementia, with the exception of risperidone in some circumstances, yet they are prescribed 'off-label' for this treatment (Maher, Maglione, Bagley, Suttorp, Hu, Ewing, Wang, Timmer, Sultzer and Shekelle, 2011). Government policy (Department of Health, 2009,

Department of Health, 2012, Department of Health, 2015b) and professional bodies (Royal College of Psychiatrists, 2011, Royal Pharmaceutical Society, 2012) have driven reductions in inappropriate prescribing of antipsychotics in treating people with dementia (Donegan, Fox, Black, Livingston, Banerjee and Burns, 2017). This is associated with an increased focus of a psycho-social understanding of dementia, which is discussed in the following section.

#### 1.3.1.2 Psycho-social model

The biomedical model is not able to account for the varying ways in which dementia affects individuals, and the ways in which they respond to having the disease. The psycho-social model of dementia asserts that many of the expressive symptoms described above are, in part, a manifestation of current environmental and social experiences and it is the interaction between the person with dementia and their environment that is amenable to intervention to alleviate severity and occurrence of such symptoms (Pratt and Wilkinson, 2003). However, viewing the psycho-social model of dementia as an alternative to the biomedical model, fails to take into account the interaction between neurological and psycho-social factors, which determines the course of dementia. A bio-psychosocial view is now central to everyday thinking about dementia (Downs, Clare and Anderson, 2008). The remainder of this thesis is concerned with the contemporary bio-psychosocial understanding of dementia.

#### 1.3.2 Loss of self

Within dementia research, the notion of loss of self is central. There are several terms pertaining to self that are used interchangeably throughout the literature including self-image, identity, self-concept, self-awareness for example, each of which relates to slightly different underlying concepts. Generally, the term 'self' is referred to within the research literature on dementia, and so this term is used throughout the remainder of this thesis. This section of the introductory chapter is concerned with laying out the theoretical dimensions of self and how self has been explored in people with dementia.

The concept of self can be understood from two different perspectives; experience of self as a psychological phenomenon closely linked to memory and self as a social identity. The different perspectives have implications for the way in which research is conducted. As a psychological phenomenon, self has

been modelled as being dependent on autobiographical memory which can be examined through performance on an objective memory test for instance (Addis and Tippett, 2004, Davis, 2004). From this point of view, which resonates with the biomedical model to understanding dementia discussed earlier, an inability to retain new experiences as cognition declines, results in a “dismantling of the self until nothing is left” (Davis, 2004 p375).

Such approaches can be criticised for their failure to account for the impact of the persons’ social and psychological environment on their sense of self. A considerable amount of literature has been published that recognises that self remains intact beyond cognitive losses, which suggests that factors other than cognition influence the self (Sabat and Harré, 1992, Kitwood, 1993, Sabat and Collins, 1999, Sabat and Collins, 2004, Sabat, Napolitano and Fath, 2004, Fazio and Mitchell, 2009, Kontos, 2011, Kontos, Miller, Mitchell and Cott, 2011, Eustache, Laisney, Juskenaite, Letortu, Platel, Eustache and Desgranges, 2013).

Changes in memory and other areas of cognitive functioning have implications for social interaction (Harman and Clare, 2006). These changes can disrupt the sense of personal continuity and thus influence an individual’s sense of identity (Harman and Clare, 2006, Caddell and Clare, 2010, Gorska, Forsyth and Maciver, 2018). Attempts to understand this phenomenon draw broadly from the theoretical perspectives of social constructionism and symbolic interactionism (Mead, 1934, Blumer, 1962, Blumer, 1969, Meltzer, Petras and Reynolds, 1980, Wright and Treacher, 1982, Bury, 1986, Harding and Palfrey, 1997, Snyder, 2006). These two approaches to understanding self assume that self is fundamentally social in nature. This understanding allows examination of the ways in which concepts of self occur throughout life.

In their account of the construction and deconstruction of self in people with dementia, Sabat and colleagues proposed the notion of three discursive aspects of self, selves 1-3. Self 1 represents the private self; self 2 comprises the physical, mental and emotional characteristics of a person and the beliefs that they hold about these characteristics and; self 3 the publicly presented social personae (Sabat and Harré, 1992, Sabat and Collins, 1999, Sabat, 2002,

Sabat, 2005a). Through a series of case studies of people with dementia they observed that self 1 persists into the later stages of the disease. This resonates with Kontos's notion of embodied selfhood which is comprised of the unique way in which the body behaves reflexively to express individuality (Kontos, 2011, Kontos et al., 2011). Sabat and colleagues suggest that loss of self 2 and 3 is attributed to how others respond to and interact with the person with dementia (Sabat and Harré, 1992, Sabat, 2001, Sabat, 2002, Sabat et al., 2004, Sabat, 2005b).

Studies that explore how people with dementia experience a sense of self in the later stages of the disease are relatively rare within the literature (Strikwerda-Brown, Grilli, Andrews-Hanna and Irish, 2019), and those that have, such as the work of Sabat and Kontos discussed above, mainly depend on the subjective interpretation of researcher observations of the experiences of people with dementia (Hubbard, Cook, Tester and Downs, 2002), or the accounts of people that do not have dementia (Cohen-Mansfield, Golander and Arnheim, 2000) . This is most likely because of the decline in the ability to communicate through usual channels often seen in people with dementia, and the lack of suitable assessment tools for people who have difficulty communicating. Studies that have adapted methods, such as self-representation tests for use with people with moderate to severe dementia, have provided additional evidence that sense of identity broadly persists despite being in the later stages of the disease (Eustache et al., 2013)

The notion that loss of a public or social self can be shaped through the way in which others interact with people with dementia influenced the development of Kitwood and colleagues work. (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Kitwood, 1993, Kitwood, 1994b, Kitwood, 1994a, Kitwood and Benson, 1995, Kitwood, 1997). This work emphasised the importance of interactions and the social environment in promoting well-being by affirming personhood and meeting psychological needs. Personhood is defined as “...a standing or status that is bestowed upon one human-being, by others, in the context of relationship and social being. It implies recognition, respect and trust.” (Kitwood, 1997 p8). Psychological needs encompass love, comfort, identity, occupation, inclusion, and attachment (Kitwood, 1997).

Through a series of systematic observations of people with dementia in long-term care settings, Tom Kitwood identified 10 aspects of positive interaction and 17 elements of interaction with the potential for psychological damage to personhood (Kitwood, 1997). His work also focussed on labelling and how people labelled with the term dementia are in danger of having their personhood undermined (Kitwood, 1997). From this perspective, loss and maintenance of personhood is attributed to the damaging ways in which others interact with people with dementia, much like Sabat and colleagues assertion of the ways in which self 2 and 3 can be lost (Sabat and Harré, 1992, Sabat, 2001, Sabat, 2002, Sabat et al., 2004, Sabat, 2005b).

However, Sabat's research can be criticised for over-reliance on individual case studies in specific care settings from which to generate theory. This poses difficulties with interpreting findings into other care contexts and across different groups of people with dementia. Kitwood's work was derived mainly from observations of people in long-term dementia care settings, and has previously been criticised for a lack of transparency in observation methods and interpretation of findings as a result (Adams, 1996, Kaufmann and Engel, 2016).

Rather than focusing on loss of self for people in dementia in specific care settings, other studies have sought to establish the ways in which sense of self changes over the course the disease. This is related to personal accounts of living with dementia, where people have talked about struggling with changes and having to adapt while attempting to maintain their quality of life (Sabat, 2001, Basting, 2009, Snyder, 2009, Suchet, 2010, Sabat, 2012, Emery Trindade, Santos, Lacerda, Johannessen and Nascimento Dourado, 2018). People in the early stages of dementia have described that they engage in a cyclical process of registering, reacting, explaining, experiencing, and adjusting as they live through the changes that dementia brings (Clare, 2003). The position that people with dementia can take lies on a continuum between self-maintaining responses, with the aim of maintaining the prior sense of self, and self-adjusting responses, which involve allowing the changes that dementia brings to be integrated into one's sense of self (Clare, 2003, Caddell and Clare, 2010). A considerable amount of literature has been published on people with dementia managing sense of self in this way (Cohen-Mansfield et al., 2000,

Clare, 2002, Pearce, Clare and Pistrang, 2002, Clare, Roth and Pratt, 2005, Harman and Clare, 2006, Downs et al., 2008, Caddell and Clare, 2010, Caddell and Clare, 2011).

Together, these findings are closely related to research findings in other chronic conditions in which there are processes of change and adaptation, normalising the condition (Charmaz, 1990, Robinson, 1993, Joachim and Acorn, 2000, Williams, 2000, Ambrosio, García, Fernández, Bravo, Ayesa, Sesma, Caparrós and Portillo, 2015). Experiences that can disrupt this process, as described by people with dementia, are the tendency to compare themselves with their former abilities and with others (Clare, 2002, Borley, Sixsmith and Church, 2014) and to be humiliated by the consequences of their failing memory (Gillies, 2000), as well as findings that they manage public impressions with tactics deliberately performed for ease of communication (Beard, 2004, Nygard, 2006, Surr, 2006).

The literature on self of people with dementia suggests important implications for the role of family members, friends, carers and other health professionals in managing sense of self in people with dementia. However, there appears to be wide variation in the quality of published studies. Several publications do not report sufficiently on their recruitment strategy or sample demographics which makes it difficult to apply the findings to other settings and groups of people with dementia (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Kitwood, 1993, Kitwood, 1994a, Kitwood, 1994b, Bredin, Kitwood and Wattis, 1995, Kitwood and Benson, 1995, Kitwood, 1997, Sabat, 2001, Phinney and Chelsa, 2003, Beard, 2004). There is a tendency to rely on the accounts of people that do not have dementia and where direct accounts from people with dementia are included, often these are lost in translation due to the emphasis placed on proxy accounts and in some instances, a lack of transparency in how the data was analysed and interpreted (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Sabat and Harré, 1992, Kitwood, 1993, Kitwood, 1994a, Bredin et al., 1995, Sabat and Collins, 1999, Sabat, 2002, Beard, 2004, Sabat and Collins, 2004, Sabat, 2005a, Sabat, 2006, Sabat, 2012, Emery Trindade et al., 2018). There is also emerging evidence that the different types of dementia have differential implications to sense of self (Strikwerda-Brown et

al., 2019), which suggests that limitations in study reporting may have stalled understanding of the concept of self in people with dementia and ability to apply some of the insights that have been gained to their care.

#### **1.4 Government Priorities for Dementia Care**

There are numerous challenges faced by policymakers and those providing care for people with dementia. The economic costs associated with dementia are enormous and unevenly distributed across different care settings (Schaller, Mauskopf, Kriza, Wahlster and Kolominsky-Rabas, 2015, Wimo, Guerchet, Ali, Wu, Prina, Winblad, Jonsson, Liu and Prince, 2017). It is estimated that the cost of dementia in the UK is around £26 billion a year and will rise considerably over the next decade (Alzheimer's Research UK, 2019). These costs are higher than cancer and heart disease combined (Luengo-Fernandez, Leal and Gray, 2015) and despite this, the current level of funding for dementia care is far behind these other major priorities (Luengo-Fernandez et al., 2015).

The UK Government published the first National Dementia Strategy almost 10 years ago (Department of Health, 2009). This five-year plan was to radically transform the quality of life for people with dementia and their carers'. The strategy set out 17 objectives that the Government wanted the NHS, local authorities and other sectors to achieve, all of which focused on improving the health and well-being of people with dementia. Outcomes expected included raising awareness and understanding, early diagnosis and support and living well with dementia. Enhanced investment to support local services to deliver the strategy was provided. The strategy has undergone several revisions, most notably updated in 2012. In the Prime Minister's Challenge on Dementia 2012-2015, the national target was for two thirds of people with dementia to be formally diagnosed (Department of Health, 2012). Latest statistics on recorded dementia prevalence in May 2018 report that this target has been achieved for people living with dementia in England (NHS Digital, 2018).

Early identification of dementia is at the forefront of comprehensive dementia commissioning programmes. Assessment and early diagnosis services, including advice and support to assist with planning for the future is a priority for commissioners of dementia services and remains so (Department of Health,

2011, Department of Health, 2015a, Department of Health, 2019). In the latest Prime Minister's Challenge on Dementia, key aspirations are that by 2020 as well as continued improvements in access to diagnosis and meaningful care, GPs will play a lead role in coordination and continuity of care for people with dementia and that all NHS staff will have received training on dementia appropriate to their role (Department of Health, 2015b, Department of Health, 2019).

### **1.5 Hospital Care for People with Dementia**

Within the research literature, much less attention has been given to complexities involved in caring for people with dementia with other health needs. Over 90 percent of people living with dementia have at least one other health condition, with a third having between 2 and 3 comorbid conditions (Browne, Edwards, Rhodes, Brimicombe and Payne, 2017). There is evidence that emergency admissions to hospitals (referred to as acute or general hospitals in the literature, and hereafter the term hospital is used) are higher for people with dementia than age-matched controls (Sommerlad, Perera, Mueller, Singh-Manoux, Lewis, Stewart and Livingston, 2019). Living with dementia negatively impacts on functional outcomes, particularly when living with multiple chronic conditions (Prince et al., 2014a, Snowden, Steinman, Bryant, Cherrier, Greenlund, Leith, Levy, Logsdon, Copeland, Vogel, Anderson, Atkins, Bell and Fitzpatrick, 2017). It is estimated that at any one time around 25 percent of hospital beds are occupied by people that have dementia (Alzheimer's Society, 2009), although this could be much higher as studies have reported that around half of older people admitted to hospital have cognitive impairment (Goldberg, Whittamore, Harwood, Bradshaw, Gladman and Jones, 2012). The majority of admissions to hospital for people with dementia are coded as being due to pneumonia, urinary tract infections, feeding tube complications and respiratory problems (Sampson, Blanchard, Jones, Tookman and King, 2009, Givens, Selby, Goldfeld and Mitchell, 2012). Admission is associated with clinically significant physical illness and depressed mood, activities of daily living and living condition problems (Sommerlad et al., 2019), therefore having dementia is rarely a reason for admission to hospital; admission is generally the result of worsening of an existing co-morbid illness, cumulative psycho-social factors or



an event that may not be related to the dementia. As a lack of appropriate social care is often a precipitator to hospital admission, more attention is now being focused on bridging this gap (Alzheimer's Society, 2016). In the UK, people with dementia are encouraged to remain at home, with the support of families, and for some, paid carers. Admission to a care home is often seen as a last resort. This is a complicated process which is made more difficult as dementia is not perceived of as a disease from a financial perspective, and therefore people with dementia are required to contribute towards their 'social' care. Being admitted to a hospital may, in some cases, be the only option.

#### 1.5.1 Quality of care

Results from the latest national audit of hospital care for people with dementia identified several factors in the care journey that were involved in sub-optimal care, including assessments, access to specialist services, staffing levels, training and support and discharge planning, all of which may increase the risk of adverse outcomes for patients (Timmons, O'Shea, O'Neill, Gallagher, de Siún, McArdle, Gibbons and Kennelly, 2016). The most recent Care Quality Commission (CQC) report on dementia care concluded that "quality of care for people with dementia varies greatly and it is likely that they will experience poor care at some point along their care pathway" (Care Quality Commission, 2014). There is evidence that people with dementia are likely to stay in hospital longer, even when severity of illness is controlled for (Connolly and O'Shea, 2015). They are at higher risks of falls during their hospital stay than patients around the same age without cognitive impairment (Harlein, GHalfens, Dassen and Lahmann, 2010) and readmission rates are far higher than those without dementia (Blackburn, Hughes, Stokes and Ayling, 2012).

In their themed review of the evidence on the current state of care for older people with dementia in hospitals, Dewing and Dijk reported on the consequences of being in hospital from several stakeholder perspectives (Dewing and Dijk, 2016). The review updated the earlier review conducted by Moyle and colleagues (Moyle, Olorenshaw, Wallis and Borbasi, 2008). The more recent review highlighted that there are mainly negative consequences and outcomes for people with dementia when they go into hospital, with the most serious consequences being a deterioration of the dementia condition

itself. Lack of knowledge and skills in caring for people with dementia have been attributed to deterioration in the condition of the person with dementia, and carers of people with dementia attribute poor outcomes to the actions, or failure of actions of the staff (Dewing and Dijk, 2016). However, this review was heavily laden with evidence from family and carers of people with dementia which more likely reflects a focus on caregiver burden including their own needs, experiences, quality of life and information giving, and there was emphasis on lack of staff skill mix and training, synonymous with the hospital care environment. Included studies were conducted in a range of care settings, including typical acute hospitals and sub-acute care settings. Whilst pooling of evidence from different settings may assist in gaining an overall picture of the state of healthcare organisations, this approach may be unhelpful when discussing specific care settings. In addition, the absence of reporting on the type and quality of the included studies makes it difficult to weigh up the strength of the evidence considered in the review.

Importantly, there were few published studies included that reported on the perspectives of people with dementia on their hospital care, and yet accounts from the patients' perspective are central to improving service delivery (NHS England, 2014, updated March 2019). The few studies that did include the perspectives of people with dementia tended to focus on those aspects of the hospital environment that are not conducive to people with cognitive impairment. The accounts of people with dementia were missing and, as the authors noted, there was reportedly a lack of discussion about this omission within the literature (Dewing and Dijk, 2016). Since their review was published, there has been an increase in literature that reports on the perspectives of hospital care from the viewpoint of the person with dementia. This point is picked up on in more detail in Chapter two, where a systematic review of the accounts of people with dementia on their hospital experiences is presented.

### 1.5.2 Models of care

Government policy for hospital care is that hospitals establish leadership for dementia care, define care pathways and commission specialist liaison older peoples' mental health teams to work into hospitals (Department of Health, 2009, Department of Health, 2015a). One of the aspirations of the Prime

Minister's challenge on dementia 2020 is to create dementia-friendly hospitals. The Dementia Action Alliance Group campaign specifically targets hospitals to support them to work towards being dementia-friendly (Dementia Action Alliance, 2018). Many hospital trusts have signed up to this Charter which signals engagement with, and effort towards achieving this goal. However, the evidence base for different models of care for people with dementia in hospitals is weak. A synthesis of existing data on the nature and impact of specialist services working into hospitals demonstrated a lack of ownership and responsibility for services, and the available information could not be used to support commissioning decisions (Holmes, Montana, Powell, Hewison, House, Mason, Farrin, McShane, McParland, Gilbody, Young, Keen, Baldwin, Burns, Pratt and Anderson, 2010). Almost a decade after this research, most hospitals in the UK have still not commissioned specialist mental health services. Instead, services have evolved locally, with most providing an acute assessment function. There is wide variation in hours of coverage, expectation of response times, staffing levels and grades and provision of age-specific teams (Walker, Barrett, Lee, West, Guthrie, Trigwell, Quirk, Crawford and House, 2018). The most recent published feedback on the hospital experience for people living with dementia states that they are still experiencing poor care compared to other groups of people (Care Quality Commission, 2018). We know more about the quality of care as hospitals are supported to be more transparent in the care that they provide and impact of it on patient outcomes. Campaigns such as the Alzheimer's Society Fix Dementia Care -Hospitals have provided recommendations for improving the care experiences of people with dementia in hospital (Alzheimer's Society, 2016). However, care co-ordination, including staff skills and training, as assessed through various intervention studies, falls short of expectations. (Henderson, Winch, Holzhauser and De Vries, 2006, Yusoff, Koh, Aminuddin, Krishnasamy and Suhaila, 2013, Smythe, Jenkins, Harries, Atkins, Miller, Wright, Wheeler, Dee, Bentham and Oyebode, 2014, Graham, Loughran and Monaghan, 2017, Kang, Moyle, Cooke and O'Dwyer, 2017). Where improvements have been made, they are limited by lack of generalisability of findings which is confined to local context on care delivery.

Training staff to recognise and care for people with dementia is a national priority. In 2018, The Dementia Training Standards Framework detailed the essential skills and knowledge necessary across the health and social care spectrum, where three tiers are described: awareness, basic skills and leadership (Department of Health, 2018). In the last decade there has been a steep rise in the number of hospitals that have a hospital staff training and knowledge framework or strategy that identifies necessary skill development in working with and caring for people with dementia, from 23 percent in 2010/11 to 96 percent in 2016-2017 (Royal College of Psychiatrists, 2017). This latest audit of dementia care in hospitals in 2016 reported that more than 70 percent of hospitals provided mandatory dementia training and that increased support for people with dementia in hospital has been facilitated by senior clinical leads, dementia champions and training provision (Royal College of Psychiatrists, 2017).

Locally developed initiatives, such as the “getting to know me” training led by John Keady and colleagues are effective at improving staff knowledge (Elvish, Burrow, Cawley, Harney, Pilling, Gregory and Keady, 2018). The majority of initiatives report improvements in staff knowledge and motivation to develop practice or attitudes towards caring for older confused people (Teodorczuk, Mukaetova-Ladinska, Corbett and Welfare, 2011, Gandesha, Souza, Chaplin and Hood, 2012, Smythe et al., 2014, Spector, Revolta and Orrell, 2016, Scerri, Innes and Scerri, 2017, Turner, Eccles, Keady, Simpson and Elvish, 2017b, Crowther, 2018). However, concerns remain about lack of knowledge about dementia, managing behaviour, communication, lack of time and inadequate staffing. Staff are aware of the effect that these issues have on people with dementia and on their own work (Smythe et al., 2014). Very few studies have explored the impact of reported improvements in staff knowledge and attitudes on staff behaviour and care quality (Godfrey, Young, Shannon, Skingley, Woolley, Arrojo, Brooker, Manley and Surr, 2018). Those that do show a marked improvement in attitudes, job satisfaction and care efficacy as measured through staff self-reports (Surr, Smith, Crossland and Robins, 2016). However, carers report unmet expectations including activities and boredom, staff knowledge, dignity and fundamental care, the ward environment and

communication between staff and carers (Spencer, Foster, Whittamore, Goldberg and Harwood, 2013). There is an absence of reports on the impact of training for outcomes for people with dementia. The recent synthesis of the evidence from staff training evaluation studies found that most studies do not report directly on participants' roles and responsibilities, or indeed where in the hospital the staff are based (Turner et al., 2017b). People with dementia were traditionally admitted into older people's wards and as the population increases, are now increasingly admitted into all specialities across the hospital. There is growing interest in focusing on hospital nurses and support workers experiences and training needs for delivering routine hospital ward care (Gandesha et al., 2012, Chater and Hughes, 2013, Royal College of Nursing, 2013, Flattery, Fitzpatrick and Sheil, 2017, Sarre, Maben, Aldus, Schneider, Wharrad, Nicholson and Arthur, 2018). The latest NICE guidelines specify that this training should be focused on providing person-centred care, recognising that this model is particularly important in the care of people with dementia (National Institute for Clinical Excellence, 2018).

There is a lack of understanding in the literature as to how improvements in staff training have influenced care for people with dementia across the entire hospital. The different approaches to training and evaluation of these initiatives means that the generalisability of findings is problematic. Meaningful examination of the context and culture of care within the settings being explored is required so as to understand factors that influence care outcomes (Moyle, Borbasi, Wallis, Olorenshaw and Gracia, 2010, Bartlett and Clarke, 2012). Within this literature, there is over-reliance on descriptive accounts of care from the caregiver's perspective. There is an assumption that the accounts elicited by staff are transferable to the people receiving care (Baalen, Vingerhoets, Sixma and Lange, 2010). Prato and colleagues noted that attempts by staff to answer questions about the experience of the person with dementia are often interpreted as a context to discuss ones' own experiences, thus constraining findings (Prato, Lindley, Boyles, Robinson and Abley, 2018). In addition, there is a tendency for staff training to focus on limiting unacceptable behaviours and not about demonstrating caring interaction; the main principle of care for people

with dementia which is discussed in more detail in the next section on person-centred care.

### **1.6 Person-centred Care**

The majority of evidence on best practice for caring for people with dementia is based upon research conducted in care settings that are designated for people with dementia. The central approach to dementia care relies on a psycho-social understanding of ageing, which draws broadly from the theoretical perspectives of social constructionism and symbolic interactionism (Mead, 1934, Blumer, 1962, Blumer, 1969, Meltzer et al., 1980, Wright and Treacher, 1982, Bury, 1986, Harding and Palfrey, 1997, Snyder, 2006). Arising from the work of Kitwood and colleagues (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Kitwood, 1993, Kitwood, 1994b, Kitwood, 1994a, Kitwood and Benson, 1995, Kitwood, 1997), the premise of person-centred care, from this perspective, is an emphasis on avoiding institutionalisation and resulting isolation; frequently termed depersonalisation (Kitwood, 1997). Features of settings where people with dementia have their personhood recognised is that they experience a sense of attachment, inclusion, identity, occupation and comfort (Brooker, 2007). It is widely accepted that the most disabling effects of dementia are to be found, not in the disease process itself, but in the threats to their personhood through their interactions within their social environment. Person-centred care will vary with the nature of the setting in which it is delivered (Edvardsson et al., 2008). The nature of the presentation of the disease, and the environment in which care is taking place are likely to interact. It is important therefore that we understand better how the principles of person-centred care can be translated within different care settings. The ability to operationalise the concept of maintaining personhood in the general hospital setting is limited. The literature is disparate with concepts defined and discussed according to the subjective experience of the authors (Brooker, 2003, Norman, 2006, Edvardsson et al., 2008, Woolley, Young and Hoyle, 2012, Clissett, Porock, Harwood and Gladman, 2013b, Aldridge, Cox and Cunningham, 2016, Surr et al., 2016, Prato et al., 2018). Within the broader nursing literature (Dewing, 2004, McCormack and McCance, 2006, Edvardsson et al., 2008, Moyle et al., 2008, McCormack et al., 2009), the person-centred

nursing care framework focuses on the prerequisites of nursing staff, the care environment, person-centred processes and outcomes. There are few studies that articulate the effectiveness of person-centred nursing from a patients' perspective, particularly from the viewpoint of people with dementia.

A recent review of the literature concluded that the evidence to direct how to respond to the needs identified by Kitwood and colleagues (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Kitwood, 1993, Kitwood, 1994b, Kitwood, 1994a, Kitwood and Benson, 1995, Kitwood, 1997) in settings that are temporary, such as hospital wards is lacking (Godfrey et al., 2018). This is frustrated further through a lack of agreement about responsibility for care for those people with acute medical needs, who coincidentally, have a dementia (Griffiths, Knight, Harwood and Gladman, 2014, Houghton, Murphy, Brooker and Casey, 2016). It appears that there is some resistance to implementing principles of dementia care, with its focus on relationship building and spending time with people with dementia being at odds with the fast pace of acute medical care (Clissett et al., 2013b, Ross, Tod and Clarke, 2015, Surr et al., 2016, Graham et al., 2017, Lourida, Abbott, Rogers, Lang, Stein, Kent and Thompson Coon, 2017). Nursing staff report that even when they attempt to provide some form of person-centred care, they are constrained by the context of the hospital environment (Norman, 2006, Goldberg, Bradshaw, Kearney, Russell, Whittamore, Foster, Mamza, Gladman, Jones, Lewis, Porock and Harwood, 2013, Goldberg, Bradshaw, Kearney, Russell, Whittamore, Foster and Porock, 2014, Surr et al., 2016, Pinkert, Faul, Saxer, Burgstaller, Kamleitner and Mayer, 2018). Surprisingly, with the exception of the recent publication of *The Person, Interactions and Environment (PIE) Programme* (Godfrey et al., 2018), there is little evidence of systematic approaches to implement and embed a person-centred approach in hospital care for people with dementia.

### **1.7 Hearing the perspectives of people living with dementia**

There is growing importance now given to accessing the person's perspective. Listening to people with dementia can help to move forward the conceptual agenda of valuing and integrating their views into the care that is available for them (Beard, 2004). Arising from the work Sabat and Harre (1992) discussed

earlier in this chapter, and other prolific authors in the field, researchers are encouraged to interview people with dementia (Keady, 1995, Feinberg and Whitlatch, 2001, Pratt, 2001, Clare, 2002, Wilkinson, 2002, Clare, 2003, Pratt and Wilkinson, 2003, Harman and Clare, 2006, Keady, Williams and Hughes - Roberts, 2007, Caddell and Clare, 2010, Caddell and Clare, 2011, Clare, Quinn, Jones and Woods, 2016, Miller, Whitlatch, Lee and and Lyons, 2018, Whitlatch and Orsulic-Jeras, 2018). This work forms the foundations upon which this thesis is based. Through adopting a conversational format using open-ended, unstructured guides, researchers have demonstrated that people with dementia can articulate clearly aspects of their experiences, including strategies that they may use to manage positive and negative facets related to their condition. Most researchers have combined an interview-style approach with ethnographic observations in their attempts to understand the experiences of people with dementia. However, a recent synthesis of this evidence demonstrates undue emphasis placed on third-person accounts of experiences in the reported findings (Reilly and Houghton, 2019). At the same time, this review used the VIPS acronym, representing Values, Individualised, Perspective of the person and Social and Psychological (Brooker, 2006, Brooker and Latham, 2016). framework to guide what information should be extracted from studies under review. Whilst this did help to capture views on care, it appears that using an apriori framework that is most often applied to care staff's perspectives may have limited scope for understanding care from the perspectives of people with dementia.

### 1.7.1 Co-production

The recent shift in emphasis of hearing the voices of people with dementia is supported through multiple local projects and, in the UK, membership and activity has increased significantly over the past two years in the Dementia Engagement and Empowerment (DEEP) network (DEEP The UK Network of Dementia Voices, 2020). With the rise in facilitating people with dementia to be heard, there has been a lot more focus on their rights. People with dementia are now driving campaigns to reduce the discrimination that they face in their day to day lives (DEEP The UK Network of Dementia Voices, 2016). In her recent book concerning the human rights of people with dementia, Suzanne



Cahill argues that people living with dementia come within the United Nations Convention on the Rights of Persons with Disabilities and therefore have full entitlement to all the rights contained within the Convention (Cahill, 2018).

User-led research where people with dementia define the questions to be asked and the methods to collect data as well as engaging in data analysis and disseminating findings is coined by the catchphrase “nothing about us, without us”. This approach is central to the aims of the major funding bodies for health research in the UK and is the focus of campaigns by national action groups for people with dementia. All research proposals are now required to establish from where the research aims and objectives were derived and the extent to which patients and members of the public were involved in these decisions, or an explanation as to why they have not been involved. Researchers are encouraged to involve patients and the public in all aspects of the research process, as partners as well as participants (Williams, Robert, Martin, Hanna and O'Hara, 2020). To facilitate the shift to co-design, or co-production, the National Institute of Health Research has published guidance which outlines some key principles and features involved in co-producing research (INVOLVE, 2019b). The key principles of including all perspectives and skills, respecting and valuing the knowledge of all those working together on the research, reciprocity and building and maintaining relationships emphasise the sharing of power in research. Building on this earlier work, INVOLVE are working on publishing a series highlighting co-production in action which shows how the principles are expressed in practice (INVOLVE, 2019a). To add to developing methodologies in the field of co-production and user involvement, McConnell and colleagues scoped the literature and held co-production workshops to define empowerment relevant to people with dementia in general (McConnell, Sturm, Stevenson, McCorry, Donnelly, Taylor and Best, 2019). People with dementia define empowerment as: *“a confidence building process whereby people with dementia are respected, have voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources”* (McConnell et al 2019, p2).

## **1.8 Chapter Conclusions**

Dementia is a devastating disease that can affect anyone. Accounts of living with dementia describe the impact of the social environment on the trajectories of the disease. Major efforts have been made in improving detection rates and timely access to appropriate support. There is evidence that suggests that people with dementia experience poor care when they are admitted to hospital. This is in spite of improvements in hospital staff training, awareness and leadership, and a theoretically-informed framework to guide care for people with dementia. There are problems with translating this framework into the hospital setting, and where person-centred care is practiced successfully, the way in which it is measured often fails to include the perspectives of people with dementia. This evidence gap indicates that there is an urgent need to understand how people with dementia define their care experience. This can influence how they manage their condition, how they relate to others and how they might respond to different kinds of services and support. How people with dementia live with the illness and the meanings that it holds for them during transient environments, such as the hospital setting are not well-understood. To understand this better, research activities need to hear the perspectives of people with dementia and ensure that these remain central to the research aims. The remainder of this thesis is focused on exploring evidence from people with dementia on important aspects of their hospital care experience.

## **1.9 Aims of the Thesis**

This thesis is concerned with exploring and contributing to the evidence base for ways to improve care for people with dementia in hospital. The overarching research question is:

What are the experiences, perceptions and views of people with dementia in relation to staying in acute hospital?

Supplementary questions which underpin this research are:

- How do people with dementia define good care?
- What are the characteristics of poor and good care?
- What are perceived as the barriers and enablers to good care?

- What ideas do they have for what could, or should be done to improve their care experiences?

### **1.10 Thesis Overview**

In order to answer the research questions a range of research methods have been adopted and these are presented in Chapter Two and Three. Chapter Two reports on a qualitative systematic review and narrative synthesis of the evidence on the experiences of people with dementia in hospital. Chapter Three discusses the methodological perspectives that informed the research with a description of the research methods adopted for the empirical study. Chapter Four presents the findings from a multi-perspective qualitative research study with an interpretative phenomenological analysis and interpretation of the experiences of people with dementia in hospital. The final chapter, Chapter Five, discusses the implications of the findings and their contribution to the literature. Methodological considerations in study design are then discussed before reviewing strengths and limitations of the approach that was taken. The chapter concludes with recommendations for future practice and research, with the voices of people with dementia central to these recommendations.

## **Chapter Two: Literature review on the experiences of people with dementia in hospital**

### **2.1 Chapter Overview**

This chapter reports on a qualitative systematic review of the evidence for the experiences of people with dementia in hospital. Firstly, the rationale for the review is presented as well as a discussion around the chosen methodology. Search and selection procedures, following the Centre for Reviews and Dissemination guidelines are described (Centre for Reviews and Dissemination, 2009). The guidance developed by Popay and colleagues informed the production and presentation of a narrative synthesis (Popay, Roberts, Sowden, Petticrew, Arai, Rodgers and Britten, 2006). The robustness of the synthesis is reviewed, and a critical reflection of the process is presented. The chapter concludes with a discussion on the implications of the findings.

### **2.2 Introduction**

Chapter one presented an overview of issues that people with dementia face as they live with the disease. Evidence for problems with translating the principles of good dementia care into the hospital setting was discussed, and where person-centred care is practised successfully, the way in which it is measured often fails to include the perspectives of people with dementia. There is growing interest in eliciting the accounts of people with dementia. This chapter synthesises the empirical evidence from these accounts on important aspects of their care whilst in hospital.

Good quality systematic reviews are viewed as the standard for synthesising evidence in healthcare because of the rigour in the methods used to compile them (Moher, Liberati, Tetzlaff and Altman, 2009, Moher, Shamseer, Clarke, Gherzi, Liberati, Petticrew, Shekelle, Stewart and Reviews, 2015). They are most frequently used to guide clinical practice and inform decision making (Moher et al., 2015). A search of the Cochrane Database of Systematic Reviews and MEDLINE in July 2018 identified that no recent reviews on the experiences of people with dementia in an acute hospital existed. It was therefore appropriate to synthesise the evidence on current knowledge of their experiences and to inform on gaps in the evidence.

A narrative synthesis approach for the evidence of experiences of people with dementia in hospital was conducted. Narrative synthesis is seen as an effective way to identify an overall picture of a topic underpinning a disparate body of evidence by giving reviewers the flexibility to develop themes that bring coherence to the data (Popay et al., 2006, Briner and Denyer, 2012).

The guidance produced by Popay and colleagues was used as an over-arching framework for the conduct of the synthesis (Popay et al., 2006). Established guidelines for conducting a narrative synthesis including principles of organisation, transparency, replicability, quality, credibility and relevance were followed (Popay et al., 2006). Five steps consisting of planning, structured search, evaluating material against agreed eligibility criteria, analysis and thematic coding and reporting (Mays, Pope and Popay, 2005, Popay et al., 2006, Pope, Mays and Popay, 2007) were used to construct the remainder of this chapter. To assist with this strategy, a review protocol was developed and registered on the international prospective register of systematic reviews, PROSPERO (McCrorie, 2018), see Appendix A.

### 2.2.1 Aim and research questions

The purpose was to review and synthesise the evidence for the experiences of people with dementia in relation to staying in hospital. The research question was:

What are the experiences, perceptions and views of people with dementia in relation to staying in an acute hospital?

Supplementary questions which underpin this research are:

- How do people with dementia define good care?
- What are the characteristics of poor and good care?
- What are perceived as the barriers and enablers to good care?
- What ideas do they have for what could, or should be done to improve their care experiences?

## 2.3 Methods

### 2.3.1 Inclusion criteria

#### 2.3.1.1 Participants

Studies were included once the study author(s) stated that participants in the study were included due to the existence of any form of dementia, e.g. Alzheimer's, Huntington's Disease and Creutz-Feldt Jacobs Disease. The rarer dementias were included as the National Dementia Strategy and subsequent Prime Ministers' challenge on dementia recognise their existence as the group of dementias that are a national priority (Department of Health, 2009, Department of Health, 2015b). However, research evidence suggests that a formal diagnosis of dementia was not required for studies to be included in the review (the complexities in diagnosing dementia were discussed in Chapter One, section 1.2.3). Making a distinction between different forms of dementia in the hospital setting is seen as unimportant as it has little impact on how patients are treated, and subsequently their experiences of care (McCarthy, 2003).

The work of Gladman and colleagues, prolific authors in the field of dementia care in hospital settings, provided guidance on literature to search for with regards to defining dementia (Harwood, Goldberg, Whittamore, Russell, Gladman, Jones, Porock, Lewis, Bradshaw and Elliot, 2011, Gladman, Porock, Griffiths, Clissett, Harwood, Knight, Jeurgens, Jones, Schneider and Kearney, 2012, Goldberg et al., 2012, Jurgens, Clissett, Gladman and Harwood, 2012, Clissett, Porock, Harwood and Gladman, 2013a, Clissett et al., 2013b, Goldberg et al., 2013, Clissett, Porock, Harwood and Gladman, 2014, Porock, Clissett, Harwood and Gladman, 2015). The authority and legitimacy of the authors' claims are in their professions as specialists in providing front-line nursing and older peoples' care in hospital. Whilst discussing responses to and from older people with cognitive impairment, the authors suggest that the existence of dementia and delirium are inseparable mental disorders. In all their publications, terms like confusion, dementia and mental health disorders in older people are used interchangeably, suggesting that implications for hospital care are similar across older people who have co-morbid cognitive impairment. As mild cognitive impairment is considered a preclinical stage of dementia (Petersen, Stevens, Ganguli, Tangalos, Cummings and DeKosky, 2001), this

term, and terms such as older people with cognitive impairment or confusion are used to refer to people with dementia throughout the remainder of this thesis.

#### 2.3.1.2 Study setting

Study participants had to have first-hand experience of ward-based care within an acute/general hospital setting for any diagnoses and care interventions including end of life or palliative care. End of life or palliative care were included as lack of advanced care planning discussions with people with dementia has been associated with decisions to admit to hospital (Thune-Boyle, Sampson, Jones, King, Lee and Blanchard, 2010).

#### 2.3.1.3 Types of studies

As the purpose of the review was to develop a conceptual understanding of the experiences of the person with dementia based on their perspectives and perspectives of their experiences held by others around them (including carers, relatives and researchers), the review focused on primary peer-reviewed studies. The review was interested in direct, articulated experiences and the interpretation of these experiences by the author(s). Therefore, studies needed to employ qualitative methodology, report qualitative data (perceptions, views and experiences) and utilise qualitative methods of data analysis (e.g. study data was generated through interviews, focus groups, qualitative observational studies, ethnography or a qualitative case study). An additional search for studies that reported findings from surveys and questionnaires was added to search for findings that reported direct quotes on the experiences of people with dementia, as quotes could inform the themes developed from the synthesis of qualitative studies.

Studies had to be published in English due to time constraints for interpretation. Studies were included from inception (as a view was taken that earlier studies may include case studies with illustrative quotes) to July 2018.

#### 2.3.2 Exclusion criteria

Studies that reported on staff knowledge, learning needs, training needs and readiness to care were excluded as this literature is synthesised elsewhere

(Teodorczuk et al., 2011, Scerri et al., 2017, Turner, Eccles, Elvish, Simpson and Keady, 2017a, Crowther, Brennan and Bennett, 2018).

Studies that reported on the experiences of people with dementia in relation to the role of hospital staff, including their own experiences were also excluded (Eriksson and Saveman, 2002, Moyle, Borbasi, Wallis, Olorenshaw and Gracia, 2011, Baillie, Cox and Merritt, 2012, Spencer, Foster, Whittamore, Goldberg and Harwood, 2014, Ashton and Manthorpe, 2017, Brooke and Semlyen, 2019). Prato and colleagues noted that attempts to answer questions about the experience of the patient are often interpreted as a context to discuss ones' own experiences, thus constraining findings (Prato et al., 2018).

Studies that focused on caregiver burden including their own needs, experiences, quality of life and information giving were excluded from the review. There are several recent publications that discuss and synthesise this literature (Jurgens, Porock, Clissett, Harwood and Gladman, 2011, Petriwskyj, Parker, O'Dwyer, Moyle and Nucifora, 2016, Beardon, Patel, Davies and Ward, 2018, Chen, Tan, Nashi, Naw and Merchant, 2018).

Studies that reported on the observed actions and behaviours of people with dementia in the absence of any interpretation of the meaning of actions and behaviours, were also excluded. This literature is also reported elsewhere (Jones, Borbasi, Nankivell and Lockwood, 2006, Clissett et al., 2014, Smythe et al., 2014, Nilsson, Rasmussen and Edvardsson, 2016, Turner et al., 2017b, Pinkert et al., 2018).

Studies were excluded that focused only on participants with delirium and/or an acute confusional state as these studies report on responses to and from people with a reversible, transient condition, usually in response to an acute medical illness (Andersson, Norberg and Hallberg, 2002, Agar, Draper, Phillips, Phillips, Collier, Harlum and Currow, 2012a, Agar, Draper, Phillips, Phillips, Collier, Harlum and Currow, 2012b).

Studies were excluded that focused on experiences in Accident and Emergency Departments, intensive care and where the care setting was specific to dementia as the settings suggest that those staff providing care had received specialist training, beyond that which would usually be expected in hospital



wards. It is likely that the experiences of people with dementia in these settings would differ from that during in-patient stays on medical care wards.

Studies that reported on experiences of people with dementia in rehabilitation wards, including sub-acute rehabilitation wards, geriatric hospitals and long-term care settings were also excluded, as well as those that were about transitions into and out of hospital. Admission and discharge planning often involves co-ordination of several agencies that are not focused on experiences during an acute medical need (Kuluski, Im and McGeown, 2017).

Other exclusion criteria were: about people with dementia but not focused on their acute hospital care, addresses care of people but not people with dementia and exploring issues around diagnosing dementia.

The inclusion and exclusion criteria are summarised in Table 2.1.

**Table 2.1: Inclusion and exclusion criteria**

Inclusion criteria	Exclusion criteria
Views of people with dementia on their experiences in a hospital ward setting Observations, perceptions and views of family, informal carers, hospital staff and researchers on the experiences of people with dementia in a hospital ward setting	Not primary research Not about people with dementia or it would not be possible to extract data specific to people with dementia About people with dementia but not focused on their hospital ward experiences or would not be possible to extract data specific to their experiences in the ward setting About diagnosing dementia

The eligibility criteria were liberally applied to ensure that no study was excluded without evaluation. One reviewer (CM) assessed titles and abstracts for inclusion. Two reviewers (PM and GM) assessed a random 10% selection of titles and abstracts, applying the inclusion criteria. This was blind to reduce the risk of bias. Level of agreement was 98% and disagreements were resolved through consensus. The inclusion criteria were applied by a second reviewer (PM) to a random 10% selection of full text articles. This was also blind to reduce the risk of bias. Level of agreement was 90% and disagreements were resolved through consensus.

### 2.3.3 Search strategy and information sources

The search terms used were informed by terms cited in recently published systematic reviews concerning care for people with dementia and employing qualitative methodology, and published literature search guides (Prorok, Horgan and Seltz, 2013, Digby, Lee and Williams, 2017, Hennelly, Cooney, Houghton and O'Shea, 2017, Turner et al., 2017a, Glanville, Lefebvre and Wright, 2018).

The search strategy was developed with the support of an information specialist. An iterative process to developing the strategy was used, including scoping searches and repeated piloting. The following terms were used and combined, adjusted for searching in different databases:

1. (dementia or Alzheimer\* or Lewy Bod\* or "vascular dementia" or pick\* or Huntingdon\* or frontotemporal or Creutzfeldt-Jakob or "cognitive impairment" or "confusion" or "delirium")
2. (qualitative or "mixed\*methods" or interview\* or narrative or phenomenol\* or ethnograph\* or "grounded theory" or "case stud\*" or "action research" or "focus group")
3. (knowledge or perspective\* or "subjective experience" or expression\* or experiences\* or perception\* or attitude\*)
4. (acute care or acute ward or acute hospital or hospital)
5. ("survey\*" or "questionnaire\*" or "scale\*" or "inventor\*")

#### 2.3.3.1 Electronic databases

The main databases that are relevant to the subject area were searched from inception until the end of July 2018: Medical Literature Analysis and Retrieval System (MEDLINE), Excerpta Medica Database (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Psychological Information (PsychINFO). The combined search terms used in OVID database are shown in Appendix B. Social Care Online was also searched as this database frequently reports personal accounts from people with dementia.

#### 2.3.3.2 Other sources

As recommended in systematic review manuals, for example Centre for Reviews and Dissemination (2009), reference lists of included papers were checked to identify relevant studies not returned in the electronic search.

Citation tracking was used in Google Scholar and PubMed to identify any additional articles to those found in the electronic databases, and to keep track for any new material as the review progressed. Grey literature, that which is not indexed in databases, was not searched. This was because this literature is for the most part not peer-reviewed, and although findings may be relevant, they frequently are not reported in a format that would allow systematic extraction of themes that emerged from the findings.

#### 2.3.4 Quality assessment

Quality assessment of studies included in the review was necessary as it allows a description of the range of quality within the studies, and a reflection on their contribution to the synthesis (Moja, Telaro, D'Amico, Moschetti, Coe and Liberati, 2005). The Critical Appraisal Skills Program (CASP) qualitative tool was used to appraise the quality of each included study (Critical Appraisal Skills Programme, 2018). CASP was selected as it is a relatively established tool and so could be used to assess quality on papers that were published some time ago. This would allow for comparison to more recent publications that have most likely used more advanced reporting methods than older studies. CASP comprises of 10 questions that assesses the validity, rigour and value of the research, and therefore allows for comparison of quality across studies. No studies were excluded on the basis of this assessment as low- quality papers may reveal different perspectives (Barbour, 2001).

#### 2.3.5 Data extraction

A data extraction template (see Appendix C) was devised so as to standardise what information was to be recorded and to aid the analysis. The template was refined as data extraction progressed. Data extracted included author, year, country in which the research took place, aims of the study, study design, a description of the study setting, participant numbers and characteristics, methods of analysis and findings on the experiences of people with dementia. The review was interested in qualitative evidence, and so an interpretive synthesis of material was conducted. Guidance on what data to extract, published by Pope and colleagues, informed selection of interpretations offered by the authors, in the form of themes for inclusion in the synthesis (Pope et al., 2007).

The process of data extraction commenced with reading and re-reading all included studies so as to become familiar with the material. Findings on the direct experiences of people with dementia in the care setting were extracted. In instances where individual studies reported findings about the experiences and actions of others, as well as the experiences of people with dementia, only those findings that reported on perceptions of, or the direct accounts from people with dementia about their experiences were extracted.

The defining characteristic of a narrative synthesis is that it adopts a textual approach to the process of synthesis to the 'tell the story' of the findings from the included studies (Popay et al., 2006). Therefore, where possible, theme or concept labels, as stated by the authors were extracted, including the description of the theme or concept. Where quotes were provided as examples, these were also extracted. This helped the researcher to stay as close to the authors' interpretation of the meaning of the data as possible.

One reviewer (CM) independently extracted data, using the data extraction template, from included studies. A random selection of three data extraction templates were assessed for accuracy and completeness by a second reviewer (PM).

#### 2.3.6 Developing a preliminary analysis

Textual descriptions of each included study facilitated the process of becoming familiar with the studies and comparing and contrasting findings across studies. Initially, themes and concepts that had been extracted from included studies were presented in a simple case theme matrix to facilitate grouping of themes (Miles, Huberman and Saldana, 2014). Principles of thematic analysis (Braun and Clarke, 2006) were used to systematically identify main and recurrent themes and ideas across studies and to explore for patterns in the data.

Thematic codes were applied to sections of data. The guidance developed by Pope and colleagues informed the approach to coding, whereby themes and concepts (or 'incidents') were coded into categories (Pope et al., 2007). During coding, material in current categories were compared with material in previous categories, in the same and different categories and then compared and contrasted the properties of the different categories. Relationships between characteristics of individual studies and their findings and the relationships

between the findings of different studies were explored (Popay et al., 2006). Through applying the decision-making process involved in the application of the guidance produced by Popay et al (2006), common elements of included studies were then presented visually through a series of concept maps (see Appendix D for an example of concept maps).

The quality assessment applied to individual studies facilitated identification of the more robust studies (Borbasi, Jones, Lockwood and Emden, 2006, Norman, 2006, Clissett et al., 2013a, Porock et al., 2015, de Vries, Drury-Ruddlesden and Gaul, 2016, Hung, Phinney, Chaudhury, Rodney, Tabamo and Bohl, 2017, Prato et al., 2018), which were then applied as building blocks for first iterations of a thematic analysis of findings. Care was taken to not afford more common themes more precedence. Data from all included studies informed the final conceptual model.

In order to explore the relationships within and between studies further, cross-tabulation was used to compare and contrast between positive and negative characteristics of experiences (see Appendix E for an example of cross-tabulation). Conceptual mapping was used to identify moderator variables that informed relationships between study characteristics and findings.

## **2.4 Literature Search Results**

### **2.4.1 Literature search**

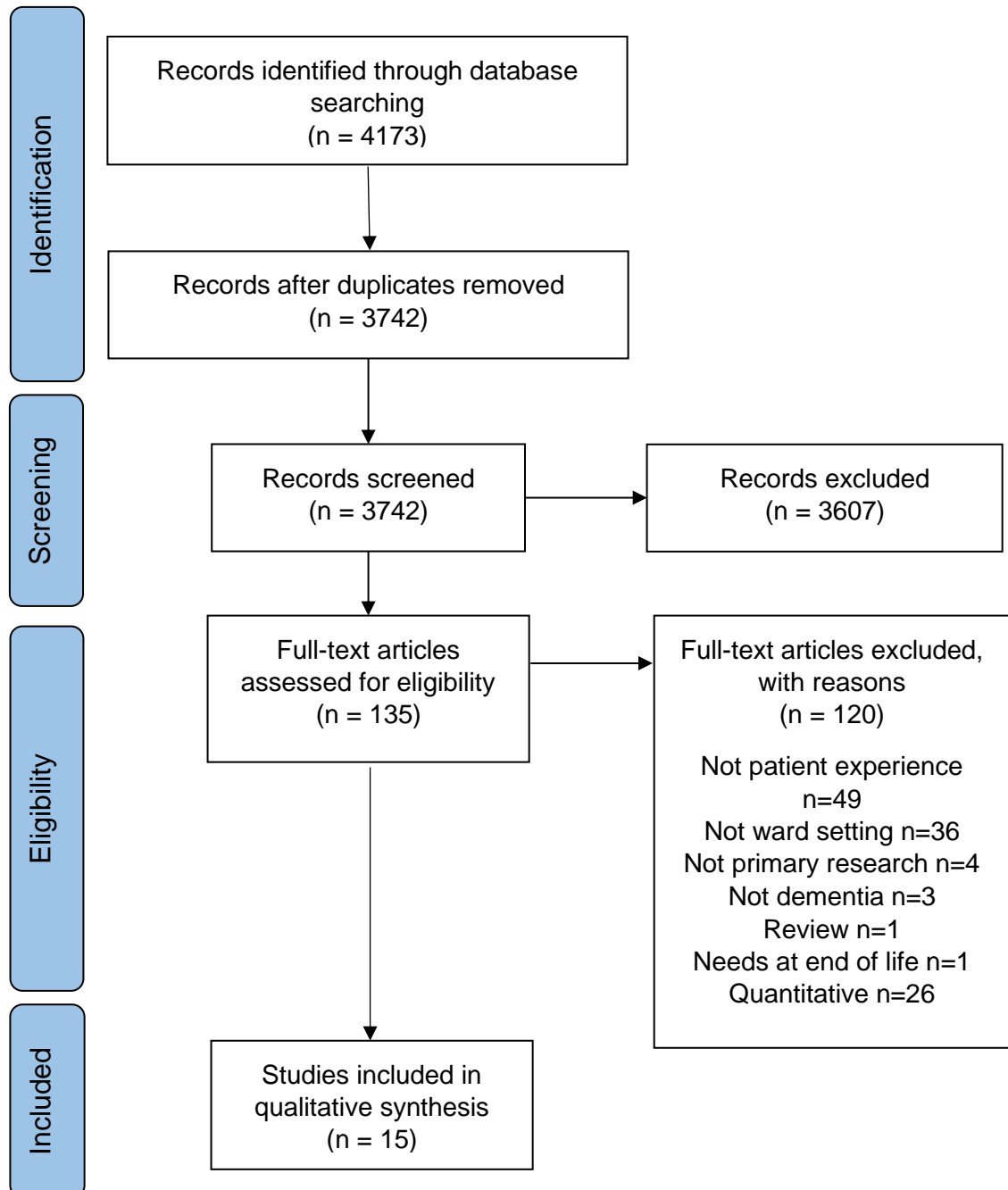
The search of electronic databases in July 2018, using adjusted search terms, returned 3742 records after deduplication. A search of Social Care Online did not return any new records. Reference lists of included papers and citation tracking in Google Scholar and PubMed did not add any further articles for inclusion in the review.

### **2.4.2. Study selection**

A total of 3742 records were assessed for eligibility. Application of the inclusion criteria to titles and abstracts resulted in the exclusion of 3607 records. 135 full-text articles were assessed for inclusion. 94 articles were excluded after application of the eligibility criteria. All of the 26 quantitative studies retrieved from the search were excluded as none of them reported direct quotes from participants in their findings that could be analysed thematically. A total of 15

articles were included in the review. The results of the search and screening are shown in the PRISMA flow diagram (Moher et al., 2009) below in Figure 2.1.

**Figure 2.1: PRISMA flow diagram summarising study selection**



### 2.4.3 Characteristics of included studies

Most of the studies were conducted during and/or shortly after people with dementia had been admitted to an acute hospital. Most studies used an interview-based method to collect data. Six studies also adopted researcher observations on the hospital wards as a method for data collection. The number of participants involved in the studies ranged from 3 to 69. Participant groups included older people with dementia, a range of ward-based health professionals (mainly nurses) and informal carers and relatives. The most commonly reported approach to data analysis was thematic analysis. Two studies developed a grounded theory. The characteristics of included studies are shown in Table 2.2.

**Table 2.2: Characteristics of included studies**

<i>Lead author</i>	<i>Year and Country</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Place of study</i>	<i>Participant characteristics</i>	<i>Methods of analysis</i>	<i>Main findings</i>
Borbasi	2006, South Australia	To explore health care professionals' experiences of managing patients with dementia	Semi-structured interviews	3 large teaching hospitals	25 health care professionals including doctors, nurses and allied health professionals	Thematic analysis	People with dementia perceive of the environment as strange and different and tend to be overlooked in the busy world of nurses. Time spent with them makes a difference to their well-being
Nolan	2007, England	To explore experiences of nurses caring for people with dementia	Conversational Interviews	Older people unit in an acute hospital	7 registered general nurses	Thematic content analysis	The ward environment and routine antagonise people with dementia and limits possibilities in their care
Cowdell(a)	2010, England	To explore experiences of patients and nursing staff of the care received in acute hospitals	Participant observations and opportunistic conversations	3 older people wards in one acute hospital	11 people diagnosed with dementia; 25 registered nurses and 33 nursing assistants	Thematic analysis	Patients found being in hospital a difficult and disturbing experience, delivery of essential care was stressful, and the environment was noisy and hostile. Patients were concerned about and unaware of plans for their future
Cowdell(b)	2010, England	Same aim as above	Same design as above	Same setting as above	Same sample as above	Same approach as above	Patients found the hospital experience to be negative, the ward environment disturbing and interactions with staff dominated by essential physical care
Clissett	2013, England	To explore the way in which care had the potential to enhance personhood	Non-participant observations and structured interviews	One NHS Trust	30 interviews with carers concerning experiences of 29 patients post-discharge	Thematic analysis	Opportunities are taken and missed by staff that impact on attachment, inclusion, identity, occupation and comfort for people with dementia



**Table 2.2: Characteristics of included studies (continued)**

<i>Lead author</i>	<i>Year and Country</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Place of study</i>	<i>Participant characteristics</i>	<i>Methods of analysis</i>	<i>Main findings</i>
Porock	2015, England	To develop a theoretical explanation of the experience of the hospitalised older person with dementia	Same design as Clissett (2013)	Same setting as Clissett (2013)	38 patients, 29 of which had dementia or delirium (same sample as above); 4 co-patients and 35 care-givers	Grounded theory	Patients with dementia are faced with a core problem of disruption to the normal routine and a core process of gaining and giving a sense of control to cope with the problem
Norman	2006, England	To explore ways in which people with dementia are cared for in acute hospitals	Non-participant observations and participant observer	3 wards in a large acute hospital	8 patients with dementia	Grounded theory	The person with dementia expressing 'self', and the nurse identifying and acting towards the person with dementia impact experience through a dynamic interactive process. Nurses role and work the hospital environment contribute to the experience
Prato	2018, England	To establish the factors that create a positive or negative hospital experience for older people with cognitive impairment	Non-participant observations and semi-structured interviews with staff and carers	One NHS trust	6 patients with confusion, 8 of their relatives 59 health care staff	Interpretive Phenomenological Analysis	Positive experiences were associated with valuing the person and empowerment, including families as agents
Moyle	2016, Australia	To explore the role and needs of the family carer across different acute care contexts	Semi-structured interviews with family carers	3 acute hospitals	30 carers directly involved in care of person with dementia	Thematic analysis	Family carers' impacted on the entire hospital experience and meeting the psychological needs of their relatives

**Table 2.2: Characteristics of included studies (continued)**

<i>Lead author</i>	<i>Year and Country</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Place of study</i>	<i>Participant characteristics</i>	<i>Methods of analysis</i>	<i>Main findings</i>
Lichtner	2016, UK	To investigate how pain is recognised, assessed and managed in patients with dementia	Non-participant observations and interviews with staff and carers	4 NHS trusts	31 people with dementia, 53 staff and 4 carers	Thematic analysis	Communicating pain depended on information from the patient. Communication difficulties and organisational context impacted ability to convey presence of pain. Carers interpreted pain cues
Hynninen	2015, Finland	To acquire a picture of the treatment of older people with dementia in a surgical ward	Individual and joint interviews	4 surgical wards	7 people with dementia and 5 close relatives	Inductive content analysis	Patient characteristics, including different presentations of self interact in the environment and contribute to factors that facilitate and hinder good treatment
Simpson	2016, England	To understand the experiences of people with dementia when in hospital through exploring carers' views	Semi-structured interviews	Participants home	7 carers concerning care of 8 people with dementia	Thematic analysis	Events during the hospital stay impact patient well-being, including staff knowledge, nursing care and communication with relatives
Hung	2017, Canada	To identify how specific environment attributes impact on people with dementia care experiences	Action research including go-along interviews, participant observations and videoing	Medical unit in acute hospital	5 patients with dementia	Gadamerian hermeneutics	The environment disables independence, poses threats to physical and psychological safety, limits opportunities for social interactions and is disempowering
Jensen	2017, Denmark	To investigate how medicine is administered to people with Alzheimer's	Non-participant observations	Hip fracture unit in acute hospital	3 patients with a diagnosis of Alzheimer's Disease	phenomenological-hermeneutic approach	Practices around concealed medication and dialogue around medication intake impacts patient well-being

**Table 2.2: Characteristics of included studies (continued)**

<i>Lead author</i>	<i>Year and Country</i>	<i>Aim of study</i>	<i>Study design</i>	<i>Place of study</i>	<i>Participant characteristics</i>	<i>Methods of analysis</i>	<i>Main findings</i>
De Vries	2016, New Zealand	To report findings from family members experiences of supporting a person with dementia during an acute hospital admission	Semi-structured interviews	Participants home	26 family members of people with dementia	Content analysis	The role of family carers and the important contribution they can make to care, including their role as advocates for people with dementia impacts experience

#### 2.4.4 Quality assessment

The outcome of the CASP assessment for each included study is included in Appendix F. All included studies had a clear statement of the aims of the research where a qualitative methodology was appropriate for addressing the research question. All but one of the studies (Jensen, Pedersen, Olsen and Hounsgaard, 2017), included a clear rationale for the chosen methodology.

All studies described the study setting sufficiently. Studies varied widely in the quality of reporting on their recruitment strategy. For 8 articles, reporting on findings from 6 studies, the reasons for inclusion and exclusion of potential participants were not clear or was absent (Nolan, 2007, Cowdell, 2010b, Cowdell, 2010a, Clissett et al., 2013a, Porock et al., 2015, Simpson, 2016, Hung et al., 2017, Prato et al., 2018).

Two studies relied entirely on relative's recall of events, sometime after the person with dementia had been discharged from hospital (de Vries et al., 2016, Simpson, 2016). One study acknowledged that the recruitment method, self-selection from flyers placed at carer's support groups, may have led to recruitment of only those people that wanted to tell their story because they had some concerns about the care being received, which may have limited their findings (de Vries et al., 2016). Porock and colleagues (2015) undertook interviews with relatives as soon as possible following discharge. Their findings may also have been limited through relying on recall. One study, unusually, did not report on the number of participants that were involved in the data collected (Lichtner, Dowding, Allcock, Keady, Sampson, Briggs, Corbett, James, Lasrado, Swarbrick and Closs, 2016).

The findings reported in Cowdell's work were limited through a lack of discussion as to how the interviews with people with dementia were conducted, despite spending more time observing people with dementia as compared to most other studies (in excess of 125 hours) (Cowdell, 2010b, Cowdell, 2010a). The use of both participant and non-participant methods in the study design may have impeded transparency as to how data was collected. Nevertheless, Cowdell's publications are included in the very few studies that considered the relationship between the researcher and their participants as a potential source of bias (Cowdell, 2010b, Cowdell, 2010a,

Jensen et al., 2017). Most studies did not discuss this relationship and the implications of it on the data being collected.

The degree to which included studies reported on ethical issues that were taken into consideration varied widely across studies. Most authors mention that ethical approval was gained in order to conduct the research. It is not clear in the reports from several studies as to how ethical standards were maintained, and what action, if any was taken when researchers observed negative care (Nolan, 2006, Clissett et al., 2013a, Porock et al., 2015, Lichtner et al., 2016).

One study which relied on accounts from hospital staff (Borbasi et al., 2006), stated that attention was paid to participant comfort and respect. However, most staff involved in the study were not regularly involved in providing direct care to people with dementia. Prato et al., (2018) assert that a strength of their study was the relationship that researchers built up with their participants. This gave them access to a richer understanding of their experience and a stronger interpretation of others' perspectives. Three studies do not mention ethical issues at all (de Vries et al., 2016, Moyle, Bramble, Bauer, Smyth and Beattie, 2016, Simpson, 2016).

Six studies contained a detailed account of their approach to data analysis, with sufficient data reported to support their findings (Borbasi et al., 2006, Hynninen, Saarnio and Isola, 2015, Lichtner et al., 2016, Hung et al., 2017, Jensen et al., 2017, Prato et al., 2018). All but one study ((Norman, 2006) reported clear statements of their findings and assessed their credibility. Norman (2006) appeared to draw conclusions from findings that were not always reported in the publication. The findings are also reported elsewhere (Norman, 2003). It was necessary to refer to the thesis to get a clearer picture of the intended messages in the later article.

The extent to which an a-priori framework for analysis was imposed on the data both facilitated and limited reported findings. The research team consisting of Clissett and Porock and colleagues (Clissett et al., 2013a, Porock et al., 2015) examined data for instances of the 5 domains identified by Kitwood (Kitwood, 1997). In their attempts to add to existing knowledge

on the principles of person-centred care, they did not report on data that may not fit within the domains. It is possible that an opportunity for exploration of that which may be particular to the hospital setting was missed during their analysis and interpretations. Similarly, Cowdell's work, which reports mainly a negative experience for people with dementia, was approached through a person-centred dementia care lens (Cowdell, 2010b, Cowdell, 2010a). It is possible that the principles of dementia care are at odds with the acute care environment and attempts to search for these principles will return a negative account.

All studies reported on the implications of their findings in relation to existing knowledge, generalisability, and their unique contribution. Two studies related their findings to relevant literature that had been published five years prior to their publication (Porock et al., 2015, Moyle et al., 2016). This may have been an oversight that could have limited inferences that could be drawn from their data analysis. All studies discuss the limited transferability of small-scale study findings to other populations and settings and identified new areas for research. Hung and colleagues (2017) acknowledged that studies relying on observations are limited by witnessing that which occurs in public places. That which occurs in bedrooms, behind closed curtains and bathrooms is missing from the evidence base.

Seven studies contained direct accounts from people with dementia on their experiences during an acute ward admission (Norman, 2006, Cowdell, 2010b, Cowdell, 2010a, Clissett et al., 2013a, Hynninen et al., 2015, Porock et al., 2015, Hung et al., 2017). The extent to which the studies reported on their direct accounts varied. Researchers in Clissett and colleagues (2013) study spent 72 hours observing and talking with people with dementia and yet their reported results were heavily laden with observations (reporting on 11 observations concerning 10 patients) and accounts from family members (11 instances of quotes from relatives concerning 10 patients). Only one quote was reported from a person with dementia in order to explain the properties of the themes that were generated from their analysis. The lack of accounts from people with dementia themselves may have occurred as their participants required a formal diagnosis of dementia; often the disease has

progressed considerably at this stage (Sommerlad et al., 2018). In contrast, the majority of findings reported in Norman (2006) used participants' own words to generate a grounded theory about the care they received directly from their own words (Norman, 2006). It appeared that the ability to elicit direct accounts was facilitated, partly, through non-exclusion of people without a formal diagnosis.

It is important to note that the work of the lead authors, Clissett and Porock is reported on in a more detailed publication that does address some of the limitations identified in the present appraisal, see Gladman et al (2012). It is likely that word-limits on publications, and previous presentation of evidence, as in Norman's (2006) publication, restricted reporting in the included studies.

## **2.5 Key Findings from Included Papers**

The review was concerned with synthesising the evidence for the experiences, perceptions and views of people with dementia in relation to staying in acute hospital wards. It sought to understand how people with dementia define good care and gather their ideas for what could or should be done to facilitate good care during an episode of acute medical illness.

Four main categories emerged:

- Factors relating to the physical environment,
- The interactions that take place during everyday activities on the ward,
- The person with dementia expressing self and,
- Response to interventions as a disruption to the course of illness.

The domains and their properties are interlinked, they are separated here for ease of reporting. The synthesis showed that the interaction between the organisational framework and physical environment, ward culture and social environment impact on care experiences. The interaction has the potential to expose patients with dementia to particular risks for poor or unsupportive care (Hung et al., 2017) and limit possibilities for independence as well as buffers to good or supportive care experiences that have the potential to facilitate their independence.

### 2.5.1. Physical environment

#### Living and working space

The majority of studies discuss the interaction between people with dementia and their immediate physical environment (Borbasi et al., 2006, Norman, 2006, Nolan, 2007, Cowdell, 2010b, Cowdell, 2010a, Clissett et al., 2013b, de Vries et al., 2016, Hung et al., 2017, Prato et al., 2018). People with dementia tend to view the ward environment as their living space whereas the organisational context of the ward is as a workspace for staff. This tension threatens to exacerbate confusion in people with dementia, and to limit the possibilities of caring (Norman, 2006, Nolan, 2007). A number of people, across several studies, saw the environment as a place to explore or leave. However, an action such as walking within the ward can be viewed as unacceptable by staff:

*‘Frieda leaves the bed area; the nurse joins her. They walk hand in hand along the corridor into bay one. As she returns to bay four she says, ‘This is absolutely ridiculous, let go’, and breaks hands with the nurse . . . ‘I’m going to get my coat,’ says Frieda. The nurse replies that she should sit down in her chair’. [Observation] (Norman, 2006).*

The opportunities to freely move about safely within the ward were limited by what people with dementia termed crowded ‘clutter’ (Nolan, 2007, Hung et al., 2017, Prato et al., 2018). Hospital equipment, such as trollies and monitors lining corridors and ward spaces can be overwhelming, as one participant described:

*“Chaotic clutter makes the brain feel [like it is] getting overloaded by too much stimuli, overly charged with electricity...” [Person with dementia] (Hung et al., 2017).*

Wayfinding was also a common concern. Lack of cues to orientation, such as windows and a clock (Prato et al., 2018), and identical room doors which were non-distinguishable (Hung et al., 2017), made independent movement virtually impossible.



### Location on the ward

The location of people with dementia on the ward impacted on feelings of exclusion from the community (Clissett et al., 2013a, Prato et al., 2018). Where there was a suggestion that things were happening around them might also have this effect (Cowdell, 2010b, Clissett et al., 2013a). Observations suggested that people with dementia found being in a cubicle a negative experience, as they were isolated from other patients and company. Ward staff, relatives and people with dementia commented on the positive nature of being in an area with other patients, as one person with dementia stated: *'It's nice to see other people and what they are doing.'* (Prato et al., 2018). However, the general busyness and noise within the ward frequently affected people with dementia negatively, (Borbasi et al., 2006, Prato et al., 2018). Ward activity was associated with worsening some of the symptoms of dementia:

*"...they can't make sense of what's happening: It is very noisy, there is a lot of stimuli... it makes their confusional state worse..."* [Nurse] (Borbasi et al., 2006).

Hung and colleagues (2017) attempted to explore ways in which the environment could be improved upon to help make the stay in hospital more comfortable. People with dementia suggested important, small and practical changes to make the environment less confusing and a safe place to move around. Use of colour to facilitate way-finding and seating areas in corridors were seen as essential to facilitate their independence (Hung et al., 2017).

### 2.5.2 Risks for poor care

The organisational context, patterns of work, time and division of labour within the ward (Lichtner et al., 2016) impact the experiences of people with dementia in three inter-linked, limiting ways: barriers to communicating their needs, lack of opportunities to reach a shared understanding and lack of opportunities to experience personal comfort.

### Barriers to communicating their needs

For people with dementia, the ability to communicate needs in a way that can be easily or quickly understood is often limited due to their cognitive difficulties. The organisational context of the ward impacts on the ability of

staff to pay attention to their preferred modes of communication (Borbasi et al., 2006, Lichtner et al., 2016, Prato et al., 2018). Staff encounters are often brief, requiring the person with dementia to be ready to answer questions and to recall their experiences with little or no forewarning (Lichtner et al., 2016). Opportunities to communicate needs occurred while people with dementia were otherwise engaged in eating or sleeping, or when they were not prepared to discuss their needs (Norman, 2006, Lichtner et al., 2016). They were often directed to use a call button at the bedside to request assistance. People with more severe dementia may not recognise the purpose of the buzzer or forgot it was there (Lichtner et al., 2016). Researchers also observed that calls for help, including those using a buzzer could not always be answered immediately, leading to distress and confusion for the person with dementia (Cowdell, 2010b, Clissett et al., 2013a, Porock et al., 2015, Lichtner et al., 2016). Often, people with dementia do not recall why they have called for help when staff do arrive (Lichtner et al., 2016). A study which asked hospital staff directly what they saw as the challenges to providing care, reported that people with dementia get overlooked in the busy world of nurses:

*“They [people with dementia] don’t ring the bell and ask to go to the toilet, they don’t ring the bell and ask for a drink, they don’t ring the bell and say “I’m hungry or I want to do this...”. [Nurse] (Borbasi et al., 2006).*

The nature of activity on the hospital ward meant that people were not acknowledged, which was perceived as demeaning and offensive leading to feelings of not being cared for or valued (Hung et al., 2017). Researchers from several studies observed people with dementia seen to be uncomfortable, which could have been dealt with relatively easy (Cowdell, 2010b, Clissett et al., 2013a, Lichtner et al., 2016, Prato et al., 2018). It was apparent that it was necessary for staff to be in close proximity to the person with dementia in order to communicate, and in the same bay or at bedside, as they rarely left their bed or chair (Lichtner et al., 2016).

People with dementia take action, through distressed behaviours to attempt to make it known that they are suffering in some way including distress such

as crying or rocking or stronger responses such as agitation and aggression (Cowdell, 2010a, Porock et al., 2015, Lichtner et al., 2016). Ward staff struggle to deal with emotional encounters, particularly when they become upset (Cowdell, 2010a). Often, the behaviours that prove to most be most challenging for staff are attempts by a person with dementia to gain a sense of control to the threatening situation they find themselves in, as one relative explains:

*'Bernice experienced a strong sense of distress from her mother as a result of being in hospital. She interpreted the following behaviour of her mother as fighting back in response to the threatening situation she found herself in: She turned violent, she said 'I don't want to be here, what they're doing to me is not right, and you shouldn't have brought me in', and I said, 'But I didn't bring you in mum', and she got her stick . . . and she raised it up and they had to press the button, because she was going to hit me with it. Which she'd never done anything like that in her life'. [Relative] (Porock et al., 2015).*

The identification of non-verbal communication cues depended largely on staff skills, experience, knowledge and perceptions which can vary widely amongst ward staff (Cowdell, 2010a, Lichtner et al., 2016). Norman (2006) observed that the quality of interactions was not consistent over time and between staff. The findings from several studies suggest that even when the person with dementia could communicate their preferences, or an advocate communicated preferences for them, these were often ignored or talked over (Norman, 2006, Cowdell, 2010a, de Vries et al., 2016, Jensen et al., 2017, Prato et al., 2018).

Cowdell (2010a) provides a compelling example of how ignoring the persons' preferences can result in the opposite of caring:

*'A patient who was being assisted and who had limited speech expressed distress during the interaction; 'The registered nurse said, 'we're going to bath you' to which the patient responded 'I didn't know'. The nurse went to touch the patient who said 'don't, don't'. The nurse explained what she needed to do and the patient said, 'it hurts, it hurts, I hurt'. While being washed she became overtly distressed struggling to say 'it's very hard now, it's very hard, it's terrible'. [Observation] (Cowdell, 2010a).*

#### Lack of shared understanding

The evidence associates risks for lack of shared understanding with dominance of staff-led interactions leading to lack of connection with the

person with dementia. This is compounded by lack of knowledge on the person and their abilities leading to restraint of movement and expression and through not being informed about treatment or future plans.

The dominance of staff-led interactions focused on practical concerns can lead to a lack of shared understanding, and, in extreme cases, constraint and restraint of the person with dementia (Norman, 2006, Clissett et al., 2013a, Porock et al., 2015, Prato et al., 2018). The evidence for the damaging effects of such experiences to people with dementia was discussed in Chapter One: section 1.3.2. Several authors report that often, whilst staff were communicating with people with dementia, this was functional and task orientated (Norman, 2006, Clissett et al., 2013a, Prato et al., 2018). Clissett and colleagues (2013a) described occasions when opportunities presented themselves for staff to make some connection with the person with dementia, but they seemed unable or unwilling to do so, often by choosing to end the interaction as quickly as possible, for example:

*'The doctor returns . . . he asks Charlotte 'Are you hot?' 'Not today, I'm freezing in here' she replies. 'Has the nurse done your temperature?' he asks. Charlotte ponders this but looks bemused and is clearly trying to please the doctor but unsure how to answer. She responds only with a smile . . . the doctor doesn't respond except to walk away from the patient with his hands in the air, clearly frustrated.'*  
[Observation] (Clissett et al., 2013a).

Norman (2006) discusses how the nurse identifying and acting towards the person with dementia comprised of (1) viewing patients with dementia on the basis of their previous knowledge and experience, (2) their emotions of caring for this group of patients and; (3) their understanding and constructions of each of the individual patients. Generally, patients comprised one of two groups as 'positive and acceptable' or 'negative and unacceptable'. At times nursing staff did not acknowledge the presence of the person when providing care and support. As a consequence of the patient group definitions, participants were observed to experience 'constraint' or 'realisation'. 'Negative and unacceptable' patients often faced emotional and physical constraint, through the use of bedside trolleys to restrict their movement or infantilisation (Kitwood, 1997), being treated in a childlike manner. In extreme instances, staff attempts to manage people with

dementia led to constraint and restraint (Norman, 2006, Cowdell, 2010a, Lichtner et al., 2016, Hung et al., 2017). Within these studies, people with dementia spoke of how their rights to autonomy and control deserved respect. Having their viewpoints disregarded had led them to feel devalued and disrespected. In one case, a patient shared his experience of being restrained and how it made him feel sad and powerless:

*“I spend my day being tied up in this chair most of the time. They worry about if I fall. The first time I fell because I was not used to the kind of floor here in the hospital. The second time my head was a little dizzy. After that, they tied me up. I am one guy who can do nothing.”*  
[Person with dementia] (Hung et al., 2017).

In this example it had been assumed that the person with dementia was incapable of making care decisions, so staff had gone to the family to seek opinion and consent for restraint. However, the family’s perspective may not necessarily be the same as the person with dementia. In this case, the son did not want his father to take risk of falls and insisted on use of restraint. However, the researchers felt that the person with dementia had good insights into the risks of being restrained and would rather have the freedom to walk.

Instances of verbal restraint, typically in the form of nurses forbidding people with dementia to get up and move about were also reported (Hynninen et al., 2015). This was compounded by a lack of awareness of the needs of the person, such as their individual needs (Cowdell, 2010b, de Vries et al., 2016, Simpson, 2016), including movement capabilities, which could have distressing consequences, as described by one relative:

*“I said she [patient] needs a dressing changed. ‘Oh I’ll be there soon’. So finally [the nurse] came and I said oh she’s also got a blister on her heel now. She never had that earlier. When I talked to somebody the next day they said oh it would be friction. I said no. I said she didn’t move. She can’t move her left leg. I said that is just pure pressure...”*  
[Relative] (de Vries et al., 2016).

People with dementia also reported instances where they felt restrained by a lack of involvement in their treatment and decisions about future plans (Cowdell, 2010b, Cowdell, 2010a, Hynninen et al., 2015). Conversely, when patients with dementia were medically well and discharge was delayed due

to events beyond the ward staff's control, relatives report that the symptoms of dementia worsen. Ward staff tend to make literal interpretations of requests, in one instance leading to a patient who requested to go home, being facilitated to do so, despite relative concerns that they would not cope:

*"[Family member] would have staff telling him that [person with dementia] wants to go home. Well we knew that. And they're insisting that we set things in place so that he could go home because he had friends in Australia that he wanted to visit and you know I said to one of the staff nurses one day, well do you know that it's twenty years since he's actually seen these people. You know it was all in his mind it was a distant memory and it was very difficult and I understand that this is difficult because [person with dementia] was so plausible in his speaking that when you're having a conversation with him it's easy to believe everything he said." [Relative] (de Vries et al., 2016).*

Likewise, relatives reported that lack of supervision of people with dementia exposed them to potential harm, including them leaving the ward and going home. One family member described that: *"She [patient] seemed to be able to wander in the hospital and go and do what she liked."* (Simpson, 2016).

#### Lack of opportunities for personal comfort

People with dementia are denied personal comfort through exclusion (Clissett et al., 2013a, Hung et al., 2017), lack of occupation (Clissett et al., 2013a, Hung et al., 2017, Prato et al., 2018), not having basic needs met or having access to personal belongings.

People with dementia felt that due to changes in their cognitive function and the label of dementia, they were viewed and treated as a subclass on the ward (Hung et al., 2017). Clissett and colleagues (2013a) reported that there were occasions when opportunities presented themselves to make the person with dementia feel part of things and included, but members of staff chose not to do this. For example, one relative stated that her father tended to wake up in the middle of the night and, on one occasion, reported that he had found the nursing staff having a drink – an opportunity to invite him to join them for a while. However, they chose not to:

*"He [father] did say that he'd walked down to a little room at night time, because he does wander around about 4am, and all the nurses were in there . . . having a cup of tea and that. I said 'Oh, did you get a cup of tea then Dad?' 'No, they brought me back and put me back in bed'". [Relative] (Clissett et al., 2013a).*

A negative consequence of the clinical ward environment was the experience of boredom. People with dementia expressed their frustration with the mundane environment of the ward and the lack of activity available: “*The same four walls . . . going out of my tiny cranium...*”. (Prato et al., 2018). Lack of opportunities to engage in occupation was common (Clissett et al., 2013a, Hung et al., 2017, Prato et al., 2018), and was associated with increased restlessness and agitation. At these times staff may engage in reactive occupation with people with dementia as a way of managing their behaviour (Clissett et al., 2013a).

Whilst discussing a relative’s stay in hospital, one participant commented:

*“One thing we did feel that was lacking, there was no music on the ward . . . It was deathly silence, there was nothing . . . there was no televisions in the ward . . . and there was no noise whatsoever, so everybody was just bored. They were literally bored out of their brains”. [Relative]’ (Clissett et al., 2013a).*

Hung et al., (2017) observed a sharp contrast between the experiences of the patients and those of the staff:

*‘The traffic in the corridors was heavy and fast paced, and the general ambience of the unit was dominated by clinical activities. The housekeeping staff worked non-stop, sweeping and cleaning. Some of the nurses did not always walk, but hopped and ran, and the laboratory technicians were frequently pushing the diagnostic equipment through. The patients, however, sat for hours and had nothing to do. The participants expressed their feelings of boredom while the staff was under time pressure to get their tasks done’. [Observation] (Hung et al., 2017).*

Relatives reported on occasions when the essential nursing-care needs of their relatives were not met in a timely manner during their hospital stay (Clissett et al., 2013a, Porock et al., 2015, Moyle et al., 2016, Simpson, 2016). This included attention to hygiene and nutritional needs, slow response to call bells and leaving food and medicine in front of patients: “*They would leave his medicines in a pot and not oversee that he took them.*” [Relative] (Simpson, 2016). Conversely, frequent intervention could lead to over-sedation, albeit that recent changes to legislation and advances in medical knowledge (Royal College of Psychiatrists, 2011, Royal

Pharmaceutical Society, 2012) may mean that this is less of an issue in contemporary care:

*“There are still...doctors who are new to the hospital that might not be aware of the doses of anti-psychotics that we would give someone who’s acutely confused...there’s sometimes a tendency to give them too much, over sedate them, and then there are problems of the patient not eating, not drinking and becoming more drowsy...so that conscious state becomes more of a problem than their behaviour” [Relative] (Borbasi et al., 2006).*

From an organisational standpoint, relatives, people with dementia and staff, commented on the constraining impact that the ward routine could have on patient experience. People with dementia were aware of their own passive role in relation to the dominance of the ward environment and often commented upon it and their frustration with it: *“Staff want me to be, a little old lady who waits ...and I don’t know how to be that!”*. [Person with dementia] (Prato et al., 2018).

A lack of personalised effects and missing items were associated with disempowerment and ability to carry out daily activities (Clissett et al., 2013a, Simpson, 2016, Prato et al., 2018). Dentures, spectacles and slippers were lost, which affected their ability to eat and mobilise safely (Simpson, 2016). Prato et al., (2018) observed that:

*‘Many of the patients wore hospital gowns or pyjamas during the entirety of their participation within the research study. A number expressed their distaste for the hospital attire, which can be undignified to wear. ‘Gregg was wearing hospital pyjamas, he sarcastically said these are “marvellous,” he was not pleased to be wearing them.’ [Observation] (Prato et al., 2018).*

### 2.5.3 Buffers for good care

Events within the physical and social environment have the potential to protect people with dementia from poor care experiences and to facilitate good or supportive care. These are based around three inter-related concepts: meeting their needs for social interaction and companionship, facilitating important relationships and developing shared understanding.



### Social interaction and companionship

People with dementia value opportunities for meaningful engagement through spending time with others and being afforded opportunities for purposeful activity (Borbasi et al., 2006, Norman, 2006, Clissett et al., 2013a, Porock et al., 2015, de Vries et al., 2016, Hung et al., 2017, Prato et al., 2018). Ward staff taking opportunities to engage them has the potential to have a positive impact on their well-being (Borbasi et al., 2006), including meeting their needs for inclusion (Clissett et al., 2013a). This occurs in the absence of clarity of roles:

*“this patient was convinced I was his school dancing partner... the fact the he was about 50 years older than me was totally beside the point... We went down for a cappuccino, it was the best cappuccino he’s ever had in his life, it was great, he loved it...”. [Nurse] (Borbasi et al., 2006).*

Opportunities for engagement, seized by staff, enable people with dementia to experience supportive interactions with others (Norman, 2006, Porock et al., 2015). People with dementia were observed to seek out companionship, even when communication skills were limited:

*‘Dean and the man in the bed next to him (another patient with dementia) seemed to spend considerable time together, even though it was clear that neither of them could talk in a way that could be easily understood: A nurse asked Dean if he wanted to get into bed . . . He appeared to agree and got into bed with assistance. Once he was in bed, the neighbour got up and moved Dean’s slippers and sat in the chair right next to Dean’s bed. He continued talking to Dean occasionally nudging him’. [Observation] (Porock et al., 2015).*

There were occasions when people with dementia preferred to spend time alone rather than mingle with other patients (Hynninen et al., 2015). The physical environment and being supported in their individual preferences were important in this regard.

People with dementia wanted the ward to afford opportunities to do familiar things and to be engaged in proactive occupation. Simple things such as going for a walk or meeting someone for conversation were essential to promoting a feeling of independence, maintaining a sense of normalcy and continuity:

*“I can’t sit and do nothing at all. Every day, I make my bed. I always come out to find someone to talk to. It’s nice that if you are capable of doing things. It’s just the way I am. I’m very independent. I do everything. It’s very, very important.” [Person with dementia] (Hung et al., 2017).*

The impact of having something to do was observed to have a positive effect on their experiences by the staff, albeit that the opportunity for occupation was provided by people other than staff. During observations, researchers engaged with people with dementia, utilised picture books and reminisced about their former lives (Prato et al., 2018). Similarly, Clissett and colleagues (2013a) reported that staff were limited in their capacity to promote occupation. Often staff actions were reactive, as a means to manage behaviour seen as disruptive to the ward routine and other patients (de Vries et al., 2016). A person with dementia suggested that having a space to do programmes of activities would be helpful and that staff being involved in the activities “...would help nurses to know what’s more important to a person and why.” (Hung et al., 2017).

#### Facilitating important relationships

Several studies reported on the importance of staff developing relationships with people with dementia (Norman, 2006, Clissett et al., 2013a, Porock et al., 2015, Prato et al., 2018). People with dementia and their relatives described that consistency of staff over time meant that meaningful relationships could develop which had a positive impact on the person with dementia (Norman, 2006, Simpson, 2016).

A sense of attachment on the part of the person with dementia was facilitated through ward staff recognising the relationships that appeared important to the individual (Clissett et al., 2013a, Hynninen et al., 2015).

Consideration for the individual needs of both patients and relatives led to improved perception of treatment and experience on the ward (Hynninen et al., 2015). Frequent presence of relatives provided advocacy for the person with dementia (Clissett et al., 2013a). Ethnographic observations and carer interviews revealed that family members were vital in conveying personal likes and dislikes of the participants (de Vries et al., 2016, Prato et al., 2018). Moyle and colleagues add that family carers’ were agents for providing

reassurance and familiar presence, social stimulation and mobility; those needs that are often not a priority for staff in the ward setting (Moyle et al., 2016). Family members often represented the interests and spoke on behalf of their relatives, when they were unable to express themselves comprehensibly (Lichtner et al., 2016, Prato et al., 2018). For example, In Prato's et al., (2018) study, Ann turned to her husband and said, '*you explain,*' when struggling to recall certain aspects of their professional and personal lives.

Similarly, relatives acted as advocates for the person with dementia who could not communicate:

*"[Following medication with Clonazepam] ... she slept for the next twenty-four hours so we couldn't do anything except. . . I was able to wake her enough to feed her and to keep the pain relief and everything up. Then she became a little bit vocal so they gave her some more Clonazepam. So in the end I had to ask them not to give her Clonazepam because I said you know she's got to be given a chance of rehab here". [Relative] (de Vries et al., 2016).*

Conversely, at times family behaviour was observed to be disempowering for participants. No longer trusting of their relatives' perceptions, some family members expressed that they felt medical staff should consult with themselves primarily, rather than the person with dementia. When Ann [person with dementia] began to feel that her husband and carer had started to listen to medical advice over her own, she described this as like being, '*hit round the face with a wet rag.*' (Prato et al., 2018).

#### Shared understanding

Through the process of staff spending time with people with dementia and facilitating their important relationships, staff get to know their individual preferences and better meet their needs for food and comfort (de Vries et al., 2016, Prato et al., 2018). People with dementia often interpret the ward routine and behaviour of nursing staff in the context of their previous occupation and life experience (Prato et al., 2018). Therefore, whether staff understood and facilitated their individual perspective influenced their hospital experience in a positive or negative way. For example, Betty understood the discharge process and her conversations with medical staff, through the lens of her previous role as a teacher:

*'I've been a teacher long enough to know what's good and what's not,' Betty in response to medical staff explaining medical tests that had to be completed before discharge'. [Observation] (Prato et al., 2018).*

The way in which ward care preserved sense of identity for people with dementia was the nature of the relationship between them and the member of staff (Clissett et al., 2013a). This included using the preferred name to address the individual. Norman (2006) discusses how aspects of positive care are reached through a shared understanding with the person the dementia:

*'A [male] nurse has now entered the bay and goes behind the curtains. The nurse tells an HCA what needs to be done. The [male] nurse leaves, it appears that Georgina did not wish a male nurse to carry out the dressing change. She can be heard asking 'Is that a man or a woman?' The dressing change is carried out by a female HCA.' [Observation] (Norman, 2006).*

Positive communication with staff members can add immeasurably to a patient's experience, particularly in relation to humour *"Ward staff [were] really chatty, really jokey and he was lapping it up like he does. He enjoyed that."* [Carer] (Prato et al., 2018). Relatives mentioned care that went deeper than essential care and could be viewed as attempts to provide a more person-centred approach:

*"They [ward staff] did try to meet his individual needs, for example, letting him go into the office as he has been accustomed to working in an office, and getting him a newspaper."* [Relative] (Simpson, 2016).

Being valued as a person was synonymous with being treated as someone who mattered (Hung et al., 2017). Norman (2006) differentiates between the emotional work of staff, which saw higher levels of collaboration with their patients and a degree of recognition and prioritisation of the needs of their patient (Norman, 2006)}. Within the literature, this was often observed as expressions of warmth from the staff (Norman, 2006, Clissett et al., 2013a). One person with dementia described this as:

*"They [ward staff] were friendly, they were human. You know you weren't treated as a number and left to get on with it sort of thing, they did their damndest with the time they had available."* [Person with dementia] (Clissett et al., 2013a).

The decision making process by ward staff was capable of having a substantial impact upon whether a hospital experience was positive and empowering or negative and disempowering (Clissett et al., 2013a, Prato et al., 2018), particularly in relation to meeting their basic needs for physical and psychological comfort. A compelling example of the impact of staff actions is provided in Prato's et al., (2018) study, where a researcher observed two different members of the ward staff team deliver a meal tray to the same patient. Researchers had previously observed that meal trays can be confusing for patients with cognitive impairment, as they often do not appear to resemble traditional meal components. On one occasion, a member of the staff team placed the tray in front of the patient and proceeded to explain each item on the tray, empowering the patient to understand and eat her meal. In contrast, on another occasion, a researcher observed a member of the health care team place the tray in front of the patient and then leave without explaining the meal. This left the patient unable to understand the meal itself and it was observed that she did not attempt to eat the meal (Prato et al., 2018).

Meeting the need for comfort for the person with dementia had a profound effect on both people with dementia and their relatives. One relative described that they found it comforting that the ward team were concerned about the pain that her mother was experiencing. She stated that the ward had made her mother feel safe and when asked to explain this responded:

*"I think it was just the fact that they cared really, particularly the consultant who seemed . . . very caring and sympathetic towards her frailty and the pain she was in. I think, just the fact that it was acknowledged." (Clissett et al., 2013a).*

In situations in which ward staff involved the person with dementia in their care process, cooperation and shared understanding was reached (Norman, 2006, Clissett et al., 2013a, Hynninen et al., 2015, Porock et al., 2015, Jensen et al., 2017). Jensen and colleagues (2017) explored the practice of covert medication administration to people with dementia. They recognised that through dialogue and engagement, poor practice such as use of covert administration could be avoided (Jensen et al., 2017). Several studies described the actions of people with dementia as expressions of their

engagement, or not, in the care process. Norman (2006) and Porock and colleagues (2015) consider that actions taken by people with dementia such as removing a nasogastric tube or venflon are actions taken by them to withdraw treatment, as they attempt to gain a sense of control over what happens for them. Passivity was also used to express intended withdrawal from involvement in care, as Cowdell observed: *'Two HCAs enter Celia's bed area and close the curtains. I noted that when the HCAs approached Celia, she closed her eyes.'* (Cowdell, 2010b).

#### 2.5.4 Medical interventions

There is very little mention within the literature about the impact of medical interventions, with the exception of over-sedation (Borbasi et al., 2006). That which is reported on suggests that interventions have the potential to antagonise, intervene and disrupt the course of dementia. Family carers report that medication, particularly pain-relief, reduces alertness (de Vries et al., 2016) and expose more their confusion. Unwillingness to use analgesics was one expression of a negative attitude towards medical treatment. One person with dementia stated that dealing with a bit of pain was preferable to taking painkillers and stressed that staying at home would have felt much better (Hynninen et al., 2015). This person displayed a negative attitude towards hospitals in general and claimed to have been taken there involuntarily. In fact, many patients were unaware of the reason for having been taken to and held at the hospital (Hynninen et al., 2015). Recognition, assessment and management of pain in people with dementia involved several information sources and individuals at different times and in different places. The main source of information, the patient, was limited due to cognitive difficulties. The ward routines impacted on their ability to communicate which was also the case for other non-impaired patients (Lichtner et al., 2016).

## 2.6 Discussion

The aim of this review was to synthesis the evidence for the experiences of people with dementia in hospital. It sought to understand how people with dementia define good care and gather their ideas for what could or should be done to facilitate good care during a hospital episode. The synthesis showed

that people with dementia experience both poor, unsupportive care and supportive or good care. The construction of the hospital environment as a living and working space, the impact of nurses' role and work, including practical tasks and their emotional responses are factors that influence the experiences of people with dementia. The type and content of interactions with others, mainly nursing staff, and how they identify and act towards the person with dementia are frequently reported as having impact on care. The role and nature of relationships with relatives and informal carers, and their presence during the hospital stay appear to mediate the care process.

Most studies included in the review report evidence for components of best practice dementia care in their findings. Several studies used the domains developed by Kitwood (Kitwood, 1997) as a framework from which to explore experiences. Only one study developed its own framework which emerged from the data (Porock et al., 2015). Whilst it is useful to develop on existing knowledge of dementia care, it appeared limiting to take components of best practice in long-term settings and apply them to a relatively fast-paced, transient ward setting. This may explain, in part, why the evidence base is weighted more towards poor care experiences. The ability to observe good care practices may be limited by observing care through the lens of best practice in long-term living settings.

This understanding of the experiences of people with dementia in hospital was facilitated mainly by formal and informal carers and researcher interpretations of the actions of people with dementia in the environment. Despite framing evidence as the accounts of people with dementia on their experiences, the literature continues to be dominated by proxy accounts. Very few attempts have been made to include direct, articulated accounts from people with dementia as a basis from which to inform evidence for their experiences, with the exception of Norman (2006). There is a lack of discussion about this omission within the literature (Dewing and Dijk, 2014). There is evidence that what carers report and what is observed about experiences of people with dementia are not similar (Innes, Kelly, Scerri and Abela, 2016). Some authors go as far as to assert that because of this omission, the literature has been giving wrong descriptions of people with

dementia and has created misconceptions (Swaffer, 2014). The issues that patients consider priorities need to be clear to inform developments in care provision. Prato and colleagues (2018) acknowledged in their study of factors contributing to positive or negative hospital experiences that further research is required in partnership with people with dementia.

### 2.6.1 Reflecting critically on the synthesis process

There is much debate in the literature as to whether it is legitimate and feasible to combine the findings of research studies that use different methods (Mays et al., 2005). It has been suggested that synthesis destroys the integrity of individual studies as each study represents a unique view that is not generalisable or transferable (Thomas and Harden, 2008). This is made more complex when different methods, informed by different theories of knowledge have been used (Mays et al., 2005). However, as Mays and colleagues argue, “That while there may well be multiple descriptions or explanations of phenomena, these ultimately relate to some underlying reality or truth – synthesis is accepted as promoting a greater understanding” (Mays, et al 2005, p2). Narrative synthesis is sometimes viewed as a ‘second best’ approach for the synthesis of findings from multiple studies, only to be used when statistical meta-analysis or another specialist form of synthesis (such as meta-ethnography for qualitative studies) is not feasible (Centre for Reviews and Dissemination, 2009). Even when specialist methods are used to synthesise findings from multiple studies, those who want to increase the chances of a scientific synthesis being used in policy and practice are likely to find a narrative synthesis helpful in the initial stages of a review (Popay et al., 2006, Centre for Reviews and Dissemination, 2009). In recognition, this guidance on undertaking systematic reviews produced by The Centre for Reviews and Dissemination suggests that reviewers should first undertake a narrative synthesis of the results of the included studies to help them decide what other methods are appropriate.

The present review provides a worked example of how findings from studies that have used different methods can be combined to reach an interpretation of the phenomena that is embedded within different author’s interpretations of their findings. Although there are variations in analytical approaches taken



in the literature, ‘the common focus of qualitative research is on language and interaction, and on understanding (interpreting) meaning’ (Pope and Mays 2006, in Pope et al 2007, p73), “*the findings of different research studies are seen as providing distinct, unique views of reality... different research methods are seen as eliciting multiple truths such that no single study or method is necessarily seen as providing definitive or superior knowledge*”. (Pope et al., 2007, p74). Through staying as close to the authors’ interpretations and data reported to exemplify the authors’ interpretations, this review provides one conceptual account of how people with dementia experience acute hospital care. It is hoped that the level of transparency offered in the present review will eliminate some of the biases that qualitative research synthesis is often critiqued for.

The process of selecting findings only in relation to the experiences of people with dementia for extraction was more complex than first anticipated. This is because their experiences are inextricably linked with those around them. In reporting findings on experiences, authors tend to switch frequently between first and second person accounts as a way in which to build up their argument for particular points they may wish to make (Borbasi et al., 2006, de Vries et al., 2016, Lichtner et al., 2016, Prato et al., 2018). Through reading and re-reading potential material to extract, a decision had to be made as to the extent to which material was an account of the experiences of the person with dementia or that of others. Although care was taken to ensure that what was extracted was an account of their experiences, another reviewer may reach a different conclusion.

A limitation of the present review is the extent to which it is one reviewers’ interpretation of the interpretation of findings from multiple authors. To address this, transparency in how evidence was selected, and how data was extracted and synthesised is discussed throughout the narrative, with worked examples where appropriate. A second reviewer examining a selection of data extraction forms also facilitated transparency. Any discrepancies between included evidence are discussed throughout the narrative.

Another limitation may be in the categorisation of data as either positive or supportive care or poor, unsupportive care. This required an assessment as to the weight of the evidence towards positive or negative care. Often, authors chose to present negative instances of care within their findings, and to suggest how this could be improved upon, through re-presenting this as positive examples. The reviewer aimed to stay as close to the authors' interpretation as possible through using the direct quotes that had been cited and descriptions to build up the conceptual model discussed above. Another reviewer may produce different results. With this in mind, the author approached the task from an assessment of that which would be most useful in the day to day practice of caring for older people. The author is a trained nurse with years of experience in working with older people with dementia in a variety of health care settings. This knowledge facilitated the process of assessing the weight of the evidence as impacting on positive or negative experiences for people with dementia. One aim was to produce an evidence-based, reference point for actions that are to be taken to avoid poor care, supported by evidence-based examples of good care.

#### 2.6.2 Implications of findings

People with dementia experience both poor, unsupportive care and supportive or good care. Factors within their physical and social environment impact their experiences. Actions that can be taken to avoid poor care and facilitate good care are mainly through quality interactions with staff that are caring for them. Creating opportunities to communicate with others and encouraging important relationships are fundamental to good experiences. The evidence suggests that people with dementia can be better cared for through slight shifts in ward culture and attention to their specific needs, which are low cost and relatively easy to aspire towards.

This review has identified evidence gaps in understanding the experiences of people with dementia in hospital, which requires further exploration. The synthesis shows that despite an increase in literature that reports on the direct accounts of people with dementia, their accounts of their care in hospital are rarely reported. The evidence continues to be dominated by proxy accounts, and where people with dementia have been recruited into

studies, the recruitment strategy is under-reported, and so it is difficult to evaluate for any sampling bias. The review has highlighted that future studies should include attempts to elicit direct accounts from people with dementia.

The review has highlighted that lack of transparency in the relationship between the researcher and research participants has limited the transferability of findings from previous studies. An essential component of qualitative research is to be explicit about researcher roles and the potential influence on the data collected (Charmaz, 2014). Similarly, the ethical responsibilities of the researcher in conducting research with people that may, or may not, be aware that they have, or are labelled as having dementia, is missing from previous research. Establishing a relationship with research participants appears paramount to accessing their experiences, and this should not be based on the existence of a formal diagnosis of dementia – the perception of a permanent cognitive decline appears to provide opportunities for accessing the accounts of people perceived of as having dementia.

Finally, the review has highlighted the role of context. Whilst it is important to ensure that findings are transferable to that which is already known about dementia care, it appears static to continue to impose care principles from different care settings. A more phasic approach to understanding context-specific care needs is required. Questioning what is good, bad, and could be improved in the hospital care setting appears to be a way forward. The review has also highlighted that triangulation of methods produces relatively higher quality evidence.

This thesis aimed to explore the experiences of people with dementia in hospital. This is to generate new knowledge about what influences their experiences, how, and under what circumstances to contribute to the evidence on hospital care for people with dementia. The following chapter presents the research methods for a qualitative study designed to access their experiences during a hospital stay.

## **Chapter Three: Methods for an exploration of the experiences of people with dementia**

### **3.1 Chapter Overview**

This chapter describes the research methods for the empirical study to explore the experiences of people with dementia during acute hospital in-patient episodes. The first section of the chapter presents the rationale for the study aims and design. This is followed by a discussion of developmental pilot work that informed the main study. The research design is presented, followed by a description of the process of gaining access to, and informed consent for participants to take part in different data collection activities; focus groups, qualitative interviews and ethnographic observations. The process of data collection is described, followed by an account of the approach to data analysis, management and conceptual integration of data.

### **3.2 Study Aims**

In Chapter One, the evidence for inequalities in hospital care provision for people with dementia was highlighted. In Chapter Two, a synthesis of qualitative evidence demonstrated that there are potential barriers and buffers to providing quality care for people with dementia in hospital. The chapter concluded that there is a lack of literature reporting on the articulated accounts from people with dementia on their experiences in hospital, and that this omission limits our understanding as to how their care could be improved. The aim of the present study was to understand the lived experiences of people with dementia during an acute hospital episode. The overarching research question was:

What are the experiences, perceptions and views of people with dementia in relation to staying in an acute hospital?

Supplementary questions which underpin this research are:

- How do people with dementia define good care?
- What are the characteristics of poor and good care?
- What are perceived as the barriers and enablers to good care?
- What ideas do they have for what could, or should be done to improve their care experiences?

### **3.3 Study Design**

A multi-perspective interpretative phenomenological analysis (IPA) study was conducted to explore the lived experience of people with dementia in the hospital setting. Qualitative interviews were held with people with dementia which assisted them to describe their lived experiences. Ethnographic observations of people with dementia on acute hospital wards were carried out, where field notes provided context and additional insights into their experiences. Focus groups were held with acute hospital ward nurses, where they discussed and reflected upon their experiences of caring for people with dementia. A conceptual integration of the analysis of data from different sources was used to draw out how people with dementia made sense of their experiences whilst in hospital.

#### **3.3.1 Rationale for study design**

In designing qualitative research, there are several published guidelines, all of which recommend that study design should be guided by the nature of the research question(s) (Denzin and Lincoln, 2000, Yin, 2010, Robson, 2011, Maxwell, 2012, Creswell, 2013, Patton, 2014, Marshall and Rossman, 2015). When the purpose of research is to understand lived experience, in specific care contexts, selection of the research design is not straight-forward. For example, a case-study approach, using multiple sources, should be adopted when the intention is to study well-defined phenomenon; a phenomenological approach should be taken when the intention is to capture participants' experiences, and examine how they make sense of their experiences and; an ethnographic approach when the intention is to study people in their natural environment (Creswell, 2013).

The extent to which the different approaches map onto data collection and analysis methods varies and is open to some interpretation. In this study, elements of phenomenology and ethnography approaches were adopted, using IPA to highlight meanings, emerging themes and clusters of themes so as to provide an account of meaning in relation to the lived experiences of people with dementia. As would be expected, researchers own biases will influence the research process and analysis, which is why these are made explicit throughout this chapter.

### 3.3.2 Use of Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) has its origins in social interactionism and principles of hermeneutics, which is a theory of interpretation (Given, 2008). An interpretive, philosophical approach was adopted for this study as this is suited to explore experiences, as they are 'lived' (Smith, Flowers and Larkin, 2009c). The premise of IPA is that meanings of experiences are constructed by individuals in their social and personal world (Denzin, 1997), and therefore appears applicable as a philosophical approach to exploring the notion of loss of self in people with dementia. IPA is "focused on the subjective meanings people ascribe to events rather than attempting to record or represent objective events" (Flowers, Hart and Marriott, 1999, p486). Through talking to people about their experiences, a personal account of their experience is constructed and given meaning through their use of language. The idiographic stance of IPA is concerned with the detail and the understanding of individual experience, and makes no claims about whole populations; instead it proposes theoretical generalisation (Smith, Flower and Larkin, 2009a).

Because IPA also interprets the individuals' mental and emotional state, thereby requiring the researcher to get close, mentally, to the material of interest (Smith et al., 2009a), it appears to be valuable as an approach to conducting research with people who may have limited verbal skills, as can often be the case for people with dementia. The approach has been used successfully by several authors in order to explore the experiences of people with dementia in a variety of settings, for example with people experiencing early onset dementia (Sakamoto, Moore and Johnson, 2017), behavioural variant-frontotemporal dementia (Griffin, Oyebode and Allen, 2016), diagnosis disclosure (Milby, Murphy and Winthrop, 2015), perceptions surrounding causes and control (Matchwick, Domone, Leroi and Simpson, 2014) and during acute in-patient episodes (Jensen et al., 2017, Prato et al., 2018).

Proponents of IPA have suggested that the approach can be used to explore experiences from more than one perspective, which can open up new ways of thinking about the phenomena under investigation (Larkin, Shaw and

Flowers, 2019). Previous studies have used IPA to facilitate understanding of lived experiences from multiple perspectives, including individual interviews, focus groups and researcher observations (Flowers, Knussen and Duncan, 2001, Larkin and Griffiths, 2002, Larkin et al., 2019). A combination of different perspectives using IPA to facilitate data analysis have also been used to capture the experiences of people with dementia (Clare, 2002, Clare, 2003, Prato et al., 2018). These studies recognise that experiences such as living with dementia are not located solely within the accounts of people with dementia but are also located within the accounts of people who are in their experience (Larkin et al., 2019).

As noted in the critical reflection of the synthesis process reported in Chapter Two: section 2.6.1, the findings reported by Prato and colleagues tend to switch frequently between first and second person accounts as a way in which to build up their argument for particular points that the authors wished to make (Prato et al., 2018), which may have compromised the centrality of accounts from people with dementia in interpretation of their experiences. In contrast, in Clare's (2002) study, interviews with people with dementia were regarded as the primary data source, with observations and focus groups adding context to describe experiences in more detail. This method of integration of data from different sources appears to be beneficial to maintain centrality of the accounts from people with dementia during analysis.

#### 3.3.2.1 Other potential methods for inquiry

IPA shares common features with other qualitative approaches to inquiry, for example grounded theory. If the intention of this study was to explore social processes in environments in which they take place (Charmaz, 2013), then a grounded theory methodology would be appropriate. This study intended to go beyond social processes so as to understand how individuals interpreted their physical and socio-psychological environment, as this was demonstrated in the synthesis of evidence reported in Chapter Two to influence their experiences. Discourse analysis also shares characteristics in that it can facilitate the central role of text in accessing representations of reality (Fairclough, 2003, Gee, 2005). However, discourse analysis relies on interpretation of the language that is used, and therefore limits interpretation

of other means of communication, for example through non-verbal behaviour, which can be a primary source of communication for people with dementia (Hubbard et al., 2002, Hubbard, Downs and Tester, 2003). Thematic analysis as an approach to qualitative data analysis, mainly focuses on patterning of meaning across groups and can capture divergence. The step-wise approach recommended by Braun and Clarke (2006) was adopted to develop initial themes from analysis of the nurse focus group data. Thematic analysis is recognised as useful for alerting the researcher to broad groups of issues within a social setting, while the deeper IPA lens allows the researcher to engage “more critically with the existential aspects of participants’ experiences by focusing the lens beyond an explicit interpretation” (Spiers and Riley, 2019) page 283. IPA is a phenomenological methodology that has dual focus. It allows the researcher to look for the meaning in order to discover the essence of the experiences of individuals and patterns of meaning across groups. As this research was concerned with understanding experiences, IPA provided a suitable framework from which to explore how people with dementia make sense of their experiences. Pairing thematic analysis with IPA provides opportunities for both depth and breadth in data collection and analysis (Smith and Eatough, 2019), which was the intention of the research process presented here.

#### 3.3.2.2 Dementia Care Mapping

One of the most cited measures of person-centred care for people with dementia is Dementia Care Mapping (DCM) (Kitwood and Bredin, 1992, Kitwood, 1994b, Brooker, 1998, Kuhn et al., 2000, Beavis, 2002, Fossey, 2002, Brooker, 2005, Brooker and Surr, 2005, Brooker and Surr, 2006, Jaycock et al., 2006, Lourida et al., 2017, Quasdorf et al., 2017, Surr et al., 2018, Griffiths et al., 2019). DCM is a tool, which has undergone several iterations, that is designed to examine various behaviours between care staff and people with dementia that influence different care procedures. It was developed directly from the work of Kitwood and colleagues discussed earlier (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Kitwood, 1993, Kitwood, 1994b, Kitwood, 1994a, Kitwood and Benson, 1995, Kitwood,



1997), and thereby has an explicit theoretical framework from which to discuss and compare across findings.

DCM is mostly used to record interactions that can be mapped to personal enhancers (interactions that are perceived to have a positive experience on the person and their well-being) and personal detractors, which are perceived to have the opposite effect. These concepts were developed from the positive and negatives elements of interactions identified in Kitwood's work, whereby interaction elements affirm or undermine personhood. In the DCM data collection process, severity of the enhancers and detractors are rated by mappers and recorded in a recognised format (Brooker et al 1998).

DCM has repeatedly been shown to have scope for identifying 'good' and 'bad' care practices and thereby informing staff training (Kitwood, 1994b, Brooker, 2005, Brooker and Surr, 2005, Brooker and Surr, 2006, Sloane et al., 2007, Woolley et al., 2009). It was considered for use in this research study. However, there are several limitations to the tool which meant that it was not used. DCM can be criticised for lack of clarity on how the behavioural categories were developed. The broad categories lose subtle variations in types of behaviours. In addition, it requires observers to map behaviour over a lengthy period, which is not only labour intensive, but can lead to errors in concentration and therefore recording, particular when they are required to make a qualitative judgement about well-being-ill value of patients. At the same time, other factors that influence behaviour need to be understood and explainable within the observed findings.

In the absence of an alternative measure of quality of care that can be used to form the basis for improving care, the DCM approach continues to dominate the literature. It is most frequently used in long-term institutional based care and its usefulness in other care settings, particularly those with high turnover rates has yet to be established. The DCM is not designed to capture the essence of the many different behaviours possible during the course of events within a waking day, and it is unlikely to be able to accommodate all the different routine activities that take place in hospitals. It also does not allow for a greater understanding of staff activities during

periods of indirect care. It tends to generate negative values for behaviour of patients (i.e. distress) if this is not responded to, thereby putting the onus on hospital staff to respond to this immediately, otherwise care is perceived of as negative. The nature of the hospital ward often means that staff are not able to respond immediately to their patients' emotions. At the same time, there is an assumption that particular behaviours require a response from the hospital staff, and yet we do not understand the nature of experiences from the perspective of people with dementia in the hospital. It may be that good and bad practices, as defined by DCM, are out of scope with the hospital setting.

#### 3.3.2.3 Limitations of IPA

IPA has been criticised for its over reliance on accounts as individuals may be just describing their innermost experience, rather than the actual experience itself (Amedeo, 2011). Turning to theoretical explanations for notions of loss of self in dementia, accounts from individuals may represent the social personae of that which they wish to portray (Sabat, 2002).

Nevertheless, an account of an experience is an account, as the individual wants to give it, to others. The current study attempted to explore similarities and differences between accounts, as well as to examine the context in which accounts were elicited, so as to draw conclusions on the impact of hospitalisation on experiences. Qualitative research is by its very nature, interpretive, and so transparency in rationale for study design and how the data collected has been interpreted is necessary to demonstrate trustworthiness, reliability and validity of study findings.

#### 3.3.3 Trustworthiness in qualitative research

The concepts of transferability, credibility, dependability and confirmability are ways in which the rigor of qualitative research can be described (Lincoln and Guba, 1985, Morse, 2015). Transferability refers to the ways in which others can determine the extent to which findings can be applied to other settings, which requires a clear description of the scope of the study. The approach taken, and interpretation of findings are influenced by researchers' biases (Patton, 1999). These are made explicit in the following section on researcher bias, and are referred to throughout this chapter.

Credibility refers to ensuring that the data collected are accurately represented to describe the phenomena (Patton, 1999, Noble and Smith, 2015). Through presenting an in-depth explanation of approach to data analysis in the current study for different types of data, and a description of conceptual integration of findings, an attempt to ensure credibility was made (Patton, 1999, Noble and Smith, 2015). Dependability is achieved through a clear description of approach to research, so that others can attempt to collect data in similar conditions (Morse, 2015).

Confirmability is demonstrated through ensuring that the findings are embedded in what is in the data, or that themes are as close as possible to what was said or observed (Lincoln and Guba, 1985). To this end, an attempt was made to ensure that theme titles, and properties within them stayed as close to the text contained within the transcripts from interviews with people with dementia as was possible. Similar to reporting methods in other IPA studies, findings were presented together with quotes from participants, which illustrated that pre-existing theoretical concepts were not imposed upon their experiences (Larsson, Holmbom-Larsen, Torisson, Strandberg and Londos, 2019). To assist with trustworthiness of the themes that were developed from the analysis of the data, a second researcher (PM) coded 2 transcripts independently and demonstrated congruence with the themes identified. Themes were refined through an iterative process, during which supervisors reviewed the themes against selected data. However, as IPA involves an interpretative process, there will be researcher bias within the analysis and findings.

#### 3.3.3.1 Researcher bias

This section provides a brief, personal account of the researchers' motivations for undertaking this thesis. It has been included here so as to make explicit the biases that the researcher brings to this study.

I am a trained mental health nurse, with additional training and extensive experience in caring for people with dementia. A lot of my practical experience has been in nursing homes and acute hospital wards for older people, most of which did not specialise in the care of people with dementia.

During this time, I witnessed nursing staff struggle to care for people with dementia and it appeared to me that they were constantly being reminded of their failings, with little regard for that which they do well. I wanted to make explicit that which they do well from both nurses and patient perspectives, as well as contribute to the evidence base as to how what nurses do can be improved upon so as to facilitate good experiences for people with dementia.

Throughout the course of this thesis, I had the privilege to meet and discuss dementia with many people who had different understandings and experiences. One of the most insightful descriptions of the experience of dementia, and the implications for caring for them, in my view, was from a trained occupational therapist with many years' experience of caring for people with dementia and their families. In her words:

*“Having dementia, is like being a tall bookshelf which has not been secured to a wall. On the top shelf, sit recent events. Further down, sit automated ‘how to’ complete certain tasks and understanding as to how the world works. At the bottom, sits the permanent trace of the younger person. The bottom is secure. The rest of the shelf moves, sometimes in rhythm to current events, other times at random. The movement displaces recent memories and automated actions, yet memories of a previous self remain intact, long after the other chapters may have become dislodged and eventually fallen from the shelf.”*

*(Shirley McCrorie, personal communication, July 2019).*

### **3.4 Developmental Pilot Work**

A number of groups and individuals (nurses, old age liaison services, medical consultants, Alzheimer's Society dementia café, experts in dementia care and qualitative research) were consulted on a number of occasions during the design and conduct of the research. Their involvement helped in setting up and conducting developmental pilot work, which then informed the research conduct for the main study. The researcher was already working in a researcher role with several old age liaison services. This facilitated access to informal conversations with a range of health professionals about factors they considered important to people with dementia during a hospital episode. The researcher also canvassed opinions and experiences from carers and people with dementia through attending an informal support group and liaising with members of the Alzheimer's Society virtual dementia café.

Attendees and respondents were asked what they considered to be important factors influencing experiences during a hospital stay and what the priorities for research should be. In addition, several conversations took place with experts in dementia care and researchers experienced in eliciting accounts from people with dementia. A level of researcher naivety meant that the activities just described were not formally recorded. Had this been the case, the co-production of this thesis could have been made more explicit. However, the essence of co-production is very much about recognising and taking opportunities to produce research that is informed by those it is intended to impact upon. To this end, what people with dementia and the people tasked with caring for them in hospital perceived to be important informed study design, interpretation of findings and implications for research and practice.

The purpose of the pilot work was to develop methods for data collection, which consisted of three components: a group discussion with acute hospital nurses caring with people with dementia; orientation and familiarisation with the routines of the hospital wards and; exploratory interviews with people with dementia on a hospital ward. For consistency, the term nurse is used throughout this chapter to refer to nursing staff of different grades, including qualified, auxiliary and student nurses.

#### 3.4.1 Gaining access

Ethical approval to conduct pilot work was granted through a substantial amendment (see Appendix G) to an existing multi-site, mixed-methods study, which was focused on evaluating liaison psychiatric services for older people in the acute hospital setting (Holmes et al., 2010). The researcher carried out research design, data collection and analyses for the qualitative component of the larger study.

##### 3.4.1.1 Nurse focus group

In the existing, multi-site evaluative study of liaison psychiatric services for older people referred to above, a series of focus groups, designed to explore nurses' perceptions on caring for people with mental health needs, were scheduled to take place in several acute hospital NHS trusts. A locally-based focus group was selected in which to seek answers to exploratory questions

that would inform the design of the main study for this thesis. These questions sought to: (1) explore the perceptions, views and beliefs on caring for people with dementia in particular and; (2) discuss nurses' ideas on how to explore the experiences of people with dementia that they care for. The enhanced topic guide that was used for this purpose is in Appendix H.

The focus group comprised 5 qualified nurses, 1 senior nurse manager, and 2 nursing auxiliaries. Participants were based in Care of the Elderly, General Medicine and Acute Medicine wards and had on average 8 years' experience of working in acute hospitals (range 1 to 11 years). All participants had experience of caring for people with dementia on the hospital wards. Consent for the discussion to be audio recorded and transcribed verbatim was obtained from individual participants. The focus group ran for 77 minutes, 35 minutes of which was focused exclusively on discussing people with dementia.

The principles of thematic analysis (Braun and Clarke, 2006) were applied to the focus group transcript. Nurses discussed how they tend to 'label' people with dementia through their actions and behaviours. They explained that the behaviour of people with dementia pose challenges to the ward routine, and most were not comfortable caring for them. This analysis informed future discussions with nurses which primarily were centred around understanding the extent to which these views were representative of nurses, from where these views arise and the perceived impact they may have on the experiences of people with dementia.

#### 3.4.1.2 Orientation to hospital ward routines

The researcher spent over 40 hours, in approximately 3-hour sections, at different times of the day and different days of the week, in 2 wards that had patients aged 65 years and over, Care of the Elderly and General Medicine. The researcher role was one of non-participant observer. The orientation period involved shadowing a member of the nursing staff as they went about their work and informal discussions with ward staff and people who were perceived to have dementia. Details about routine events that took place on the wards, including recording timing, length and purpose of events as they

occurred, were recorded in contemporaneous field notes. The notes also contained reflections, by the researcher, as to how what was being observed may impact on the experiences of those being cared for.

The main purpose of the orientation period was to sensitise the researcher to factors within the physical and social environment that may impact on the experiences of people with dementia, and to how one could gain access to their experiences. A more formal process of observing events would be required for the main study. Themes derived from the field notes were presented as a conceptual map which facilitated visualisation of routine hospital life and assisted in the design of the main study. For instance, particular interaction-rich periods (such as the period just before and during lunchtime) and down-time periods (mid-morning and mid-afternoon) were identified. Periods during the day when people with dementia were most likely to be available to take part in the research were identified as the downtime periods.

#### 3.4.1.3 Interviews with people with dementia

Throughout the orientation period, the practicalities of conducting interviews with people with dementia on the ward were explored with staff and patients. This involved speaking with ward staff as to how potential participants could be identified, and their views on where and when interviews could take place. This also involved conducting 2 pilot interviews with people with dementia. The participants were both females, aged 76 years. Consent was obtained from for the interviews to be audio recorded and transcribed. A topic guide, informed by the reviewed literature, the nurse focus group discussion and period of orientation to the ward routines was developed for use during the interviews (see Appendix I). Participants were encouraged to talk about how they felt about being in hospital and how and in what ways they made sense of their experiences. The interviews were 21 and 36 long. Throughout both interviews, participants evaluated their experiences positively, and it was difficult to encourage them to go beyond blanket statements. This experience of interviewing people with dementia informed future interviews in the main study where a more conversational approach was adopted in which to explore why positive evaluation was important to their experiences, from

where these views arise and what other factors they perceived to be important within their experiences. The ways in which the interview process evolved during data collection are discussed in further detail in the description of methods for the main study, section 3.8.2.

#### 3.4.2 Defining the inclusion criteria for patients with dementia

The orientation period, focus group and pilot interviews led to a much more considered approach to recruitment of people with dementia than was first anticipated. There were several factors that needed to be considered to ensure that the research was focused on people with dementia, and sensitive to factors that could impact on their ability to take part in the research. These were in relation to labelling, awareness, time on the ward and dependency on verbal accounts.

##### Labelling

During observations on the wards, several patients were labelled by staff as having dementia although after reading through their medical notes, no record could be found of a diagnosis having been made. That is not to say that these patients had never been diagnosed. This may have occurred outside of the acute care setting and consequently there may be no record of any investigation in their hospital files. When asked about the origins of diagnosis, nursing staff often did not know from where it had originated and indeed whether any definitive diagnosis had been made. Often, they would use statements like *'well it's obvious from how she is behaving that something is not quite right there'* to justify their perception of existence of dementia. The notion that if nurses perceive that a person has dementia then they are likely to care for them in the way in which they a person diagnosed with dementia would be cared for, has been used to explore experiences of dementia in previous research (Tolson, Smith and Knight, 1999, Norman, 2006). As was discussed in Chapter Two; section 2.3.1, making a distinction between confusion and dementia is unimportant as it tends to have little impact on nurses subsequent actions (McCarthy, 2003).

Generally, a cognitive assessment on potential participants is conducted so as to legitimately involve them in the study. The literature on cognitive



assessments advocates the use of the mini-mental state examination (MMSE) as a brief, easy to administer measure of cognitive impairment (Folstein et al., 1975). The researcher conducted the MMSE for both pilot study participants, and reflected that use was uncomfortable for participants as they then wanted to focus discussion on potential deficits and how they felt about exposure to the test. This was not the intention of the research. There was also a concern with the reliability of results of testing following a patients' admission to hospital with an acute medical need. Additionally, there were concerns about use that would be made of such data, were it made available during an acute hospital admission. Cognitive testing was therefore not included as part of assessment for inclusion in the study. The presence of a cognitive test did not mean that a patient could be legitimately included in the study; the presence of a label of dementia did.

### Awareness

The extent to which potential participants were aware that others perceived them to have dementia needed to be addressed. There was a level of uncomfortableness with conducting research in the ethical way it is intended, particularly if patient participants are labelled in ways that they are not made explicitly aware of. However, the impact of disclosing or discussing a possible diagnosis of dementia appeared far more consequential to participants than not discussing it directly. As a compromise, participants were informed that the research was designed to explore what it is like to be a patient on the ward who maybe experiencing memory problems. During the interviews, participants would be asked about whether they perceived they had any problems with their memory and how they felt about this. In the event, most participants spontaneously discussed their experiences of failing memory.

### Exposure

Labelling as an inclusion criterion meant that the persistence of the label had to be considered when sampling potential participants. Repeated exposure to events in which a label of dementia is present will impact on how experiences are constructed. In the focus group, and in subsequent discussions with nurses during the orientation period, nurses suggested that

they have schemas for their perceptions towards known patients, and these schemas were based around the known actions of these patients, which were generally negatively biased. In order to minimise the impact of repeated exposure to labelling, patients would be excluded from the study if they had stayed on the ward within the last six months. Patients would also be excluded from the study if they had been on the ward for less than three days.

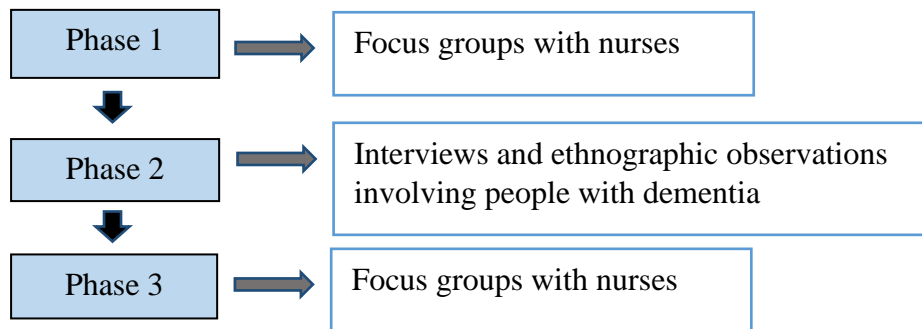
#### Verbal accounts

This research was an exploratory study of the meaning ascribed by people with dementia to the context in which they find themselves in; the emphasis was placed on eliciting a verbal account. That is not to say that meaning cannot be extrapolated from those that cannot communicate verbally; the challenge was to explore verbal accounts as a starting point (Wilkinson, 2002). Exploring meaning making in people who mainly communicate in other ways was beyond the scope of this thesis.

### 3.5 Research Design

The main study consisted of three phases, which are represented in Figure 3.1.

**Figure 3.1: Study design**



#### 3.5.1 Focus groups

Focus groups afford an opportunity to elicit as many opinions as possible (Morgan and Krueger, 1993, Stewart, Shamdasani and Rook, 2006). When planning focus group composition, it is theorised that participants demonstrate some aspect of homogeneity relevant to the topic under investigation, with enough variation amongst participants to allow for contrasting experience (Krueger and Casey, 2008). Originally conceived as the focused interview (Merton and Kendall, 1946), groups can be formulated to elicit the subjective experiences of parties who have undergone a particular concrete situation. Group discussions can be useful for generating understanding on a number of levels. They can generate data that is inherently bound up in relationships between participants and investigating these processes elucidates the content and context of what the participants are saying.

Morgan and Krueger (1993) noted that one of the advantages of focus groups is to enable feedback from those in a position of minimal power to key decision-makers. This can generate information on the ways in which particular groups think and portray themselves. As Stewart and colleagues (2006) state, they are also useful for understanding consensus and conflict, and to investigate motivations behind behaviours, which may be observed through other research methods but not fully considered within the

constructed frames of the actors (Stewart et al., 2006). The objective of focus groups is to stimulate discussions and thereby understand the meanings and norms which underlie the groups' answers to particular questions. Bloor and colleagues emphasise that in focusing the discussion on a particular issue, researchers can consider more than just answers to specific questions, but also the process through which individuals negotiate and share their views (Bloor, Frankland, Thomas and Robson, 2001).

A focus group topic guide was developed for the main study (see Appendix J). The questions were derived from the developmental pilot work and the review of relevant literature. Questions were designed to facilitate discussions around the nurses' experiences, beliefs and attitudes towards caring for people with dementia, and their perceptions of the impact of these on the experiences of people with dementia that they cared for. During the development work, nurses gave emotive responses when discussing their care of people with dementia. It was important therefore to ask how nurses feel about caring for this group of people. The flow of discussion was designed so that nurse's feeling about their care would be elicited at the beginning of the discussion. This would provide the groundwork for exploring consensus and conflict within their expressed feelings and facilitate discussion around perceived impact of their actions and interactions on people with dementia.

Focus groups at the start of the study informed the context in which care is provided for people with dementia. The data collected informed specific areas to pursue during interviews and observations. Focus groups held after speaking with and observing people with dementia provided an opportunity to integrate findings from earlier data collection activities.

### 3.5.2 Interviews and ethnographic observations

#### 3.5.2.1 Interviews

An interview approach was adopted as this provides the 'maximum possible' opportunity for participants to convey their own thoughts and feelings (Downs et al., 2008). The intention during the interviews was to pay attention to not only the words, but also the emotions elicited from the person being asked

about their experiences. Through focusing on how people with dementia presented their experiences, information about how they wished to be understood during the interview process could be gained.

Due to the inherent nature of dementia, and its' association with short-term memory deficits, proximity to experiences was central. It was hoped that conducting interviews during the hospital experience would provide a snapshot of the experiences as they occur. The ability to capture data during the hospital stay would provide a closer approximation of factors that influence experiences than say, retrospective accounts taken after discharge from hospital.

The interviews were designed for participants to talk about their experiences. This could be construed as an assumption that what is lived can be talked about (Shotter, 1989). However, any account of an experience emanates from a primary experience, but the gap between the account of the experience and what was actually experienced will always be huge (Keats, 2000). In the immediately experienced situation, being interviewed about the experience of being in this place, participants' attention would select certain aspects, while others would be ignored. When they then transform their experience into verbal expressions, the account is created and influenced by other things. For example, the account may be given in such a way as to express the person as he or she wants to be known to others (Brehm and Kassin, 2002). The accounts elicited from participants were viewed as an expression of how they wanted to be perceived, in the hospital setting.

#### Planning interviews

There were several factors that needed to be taken into consideration when planning to conduct interviews. These factors were informed through the background reading on techniques on interviewing people with dementia, the researchers' own experiences of talking with people with dementia and issues that were raised in the developmental pilot work. Firstly, the amount of time that could practically be spent on the ward in order to conduct interviews needed to be considered. There are several regular time points during the day that patients are routinely engaged in care or daily living activities that preclude opportunity to take part in research interviews. The

research needed to be carefully planned in order that data could be collected from participants without interfering with essential activities.

Secondly, planning needed to take account of participants' physical frailty and their abilities to converse for periods of time. The interviews needed to be focused enough to ensure that they elicited a sense of participants' experiences but flexible also in that they would not demand long periods of engagement, which would be difficult to achieve in an acute ward setting. Temporal interviews, that took could take place over several different visits were planned.

#### Interviews with relatives and carers

Should the opportunity arise, interviews with visiting relatives and/or carers of participants would also take place. The purpose of these interviews was to explore their views on the experiences of people with dementia in acute hospital settings. The findings would be used to elaborate on the accounts elicited from people with dementia. In the event, only one family member agreed to take part in an interview, and later withdrew their consent. The absence of relative and carer accounts is a potential limitation of this study. However, although their accounts would add important insights into the care experience, this was not a stated purpose of this study. The absence of their accounts is discussed further in the recruitment of patient participants section of this chapter and in the section on limitations of this thesis in the final chapter.

#### 3.5.2.2 Observations

##### Conceptualising observation

The literature review highlighted that ethnographic observations are a useful method for collecting information, albeit from the perspective of the researcher, on the experiences of people with dementia. Observations provided an opportunity to talk with participants about their experiences, outside of the formal interview process. There are various approaches to observational research reported within the social sciences literature (Kitwood, 1997, Tolson et al., 1999, Costello, 2001, Norman, 2006, Wind, 2008, Astell, Alm, Gowans, Ellis, Dye and Vaughan, 2009, Woolley et al., 2009, Emerson, Fretz and Shaw, 2011)}. Approaches can be placed on a continuum ranging

from participant observation at one end, to coding of number, types and frequencies of behaviours at the other. There are numerous explicit biases that will determine where along this continuum to commence a new research inquiry. One of the most important influences on approach to observation is the role adopted by the researcher. Whilst a comprehensive ethnography is advocated for any new line of exploration, true ethnography demands that the researcher becomes fully immersed in the environment under investigation, a participant, for a considerable length of time. The time constraints of research projects often preclude ethnography, as was the case with the present research. The researcher adopted the role of non-participant observer, which facilitated a flexible and adaptable approach to data collection.

#### Structure of observations

Observations were planned to focus on each participant. The main focus of observations was on the interactions that took place between participants and one or more hospital staff members. A guide was developed as to what data should be collected during observations (see Appendix K). This was informed by relevant dementia literature and qualitative research methods (Burgess, 1982, Sanjek, 1990, Strauss and Corbin, 1990, Johnson and Sackett, 1998, Emerson, 2001, Wilkinson, 2002, Mckillop and Wilkinson, 2004, Norman, 2004, Nygard, 2006), and the findings from the developmental pilot work.

Field notes were written during and shortly after periods of observation that contained information on space, actions, activities, objects, acts, events, time, physical appearance and an interpretation of the implicit goals of the interaction(s). This interpretation was facilitated through writing key quotations of participants and hospital staff in the field notes. In the absence of any social interaction, a description of the physical environment and events taking place around the participant was recorded. Field notes also contained the actions of participants in the ward. The visual observation of participants whilst receiving intimate cares was not part of this process. Private care, communicated through screening of participants from the view

of others, was considered as just that. An aural account of what could be heard was recorded at these times.

#### Observation periods

Informed by the developmental pilot work and background reading, observations of each recruited participant were to take place for approximately 90 minutes, on 3 consecutive days, at different times of the day. The planned length of time and when to observe was also informed by previous experiences, where researchers suggest that the problem of observer concentration can be offset through planning observations at information rich periods of the day (Bowie and Mountain, 1993). On hospital wards, this is generally between the hours of 11am and 1pm. The activities focused around organising, preparing, carrying out and facilitating events that occur around lunchtime involve several interactions with participants. One of the observation periods was planned to take place at this time. Observations were also conducted at different times of the day, on different days of the week.

The first observation period was planned to take place immediately following interview of a participant. This would sensitise the data that was collected to issues that had been raised in the participant interview. It was anticipated that consecutive visits to the ward to collect data around a participant would commence with an observation period, followed by an interview with the participant. That which had just been observed could form the focus of discussion in the subsequent interviews.

#### 3.5.2.3 Research conduct

Patient participants were recruited in sequential pairs. This facilitated data to be collected on 2 participants during the same visit to the ward, thus limiting the number of separate visits to Patient participants the ward and making the most effective use of time available in which to collect the data.

Approximately 9 hours of observation and interview data would be collected from each participant. The process of data collection commenced immediately following consent to participate. Each participant would take part in an interview on at least one occasion and up to three separate occasions. The opportunity to take part in more than one interview took



account of varying temporality. Subsequent interviews also provided the opportunity to explore particular lines of inquiry that arose from earlier interviews and observations.

The researcher arranged to meet with each participant on 3 consecutive days, at different times of the day. This would facilitate temporality and provide opportunities to observe participants during different routines that take place on the ward. A maximum of 3 visits was deemed sufficient to explore individuals' experience. Where possible, and if indicated, additional visits to the ward could take place. This would allow some flexibility in demands placed on participants to take part at the time arranged.

Observations of participants would be conducted immediately following their first interview. This would provide information that could be explored further during a subsequent interview.

### **3.6 Research Setting**

Local Research Ethics Committee approval was granted for the main study following a review of the methods, information leaflets and procedures to obtain consent (see Appendix L). The study was set in one hospital of a large acute hospital trust in the North of England. Hospital wards that provided specialist acute care, such as cardiology or intensive care were excluded from the study. The number of people with dementia on these wards at any one time was minimal and people on these wards were likely to be too ill to take part in research. Sixteen wards of similar size and staffing numbers delivered acute hospital care to people aged 16 years and over. These were Elderly Medicine Department, generally for people aged 75 years and over (n=4), General Medicine (n=5), Acute Medicine (n=4) and Acute Surgery (n=3). Data collection took place between December 2008 and March 2012.

### **3.7 Recruitment Process**

#### **3.7.1 Focus groups**

Prior agreement was sought from the Director of Nursing of the hospital for nursing staff to attend focus groups to be held on trust premises, provided that the ward was not left understaffed. This meant that the most convenient time to hold the focus groups was during shift changeover in the afternoon.

At each data collection time point, two focus groups, to be held on different days, were organised. The groups were scheduled to run for an hour each. Exclusion criteria were nurses that do not normally work on a ward that admits patients aged 65 years and over (e.g. obstetrics) and those who do not routinely have any direct contact with patients.

Information about the study was disseminated across all 16 wards by their ward managers. The nurse manager of each ward was approached by the researcher, through a letter of introduction, with an invitation to participate in the study (see Appendix M). The letter was followed up with a telephone call to each ward manager within 10 days of circulation. The purpose of the telephone call was to ensure that the letter had been received, and to gain the manager's verbal consent that nursing staff on their ward could be approached and invited to attend the groups. All ward managers provided verbal consent for information sheets to be disseminated to nurses on all wards, through their nurse manager (see Appendix N). Study information posters and contact details of the researcher were also situated on the wards (see Appendix O).

Staff that were interested in taking part in the research contacted the researcher directly, either during visits to the wards or through contacting the researcher by telephone. Staff members who had expressed an interest were spoken to by the researcher 2-3 days before their planned attendance at an event. The day before each of the focus groups were scheduled, the ward managers were reminded of the event via a telephone call. This was to help ensure that those nurses who had planned to attend were reminded to do so and facilitated to do this by their manager. At the time of this research, there was approximately 400 nursing staff employed to work on the 16 wards that were contacted about the focus groups. Not all staff received invitations due to annual leave and shift rotation patterns. Several members of nursing staff reported, after the events, that they would have liked to have attended but were not aware of it taking place.

At phase 1, 12 expressions of interest were received. Eleven members of nursing staff preferred to attend the same event. It is generally

recommended that focus groups have no more than 8 participants so as to ensure that each member has time to successfully contribute to the discussion (Bloor et al., 2001). The group was larger than what was expected, which may compromise the flow of discussion. Given that it was difficult to gain access to staff outside of their normal work routine, it was decided to go ahead with this group size, and to ensure as far as possible that each participant was supported to contribute to the discussion. The nurse available to attend the second event was offered the opportunity to attend the alternative, which was not convenient to them. They declined the option of an individual interview.

At phase 3, a similar approach to recruitment to that used in phase 1 was conducted, returning 8 expressions of interest. One focus group was held, attended by 6 nurses. Two nurses could attend neither event and requested that they be interviewed instead. An attempt to understand reasons for the comparatively lower uptake of at phase 3 was made through asking ward managers for possible causes. This resulted in one ward manager stating that they would find 'someone to come along and represent us.' It was decided that to continue to pursue this question could lead to attendance through obligation, which was not the intention of the research, and therefore was not pursued systematically across all 16 wards.

### 3.7.2 Patient participants

Two ward managers (Care of the Elderly and General Medicine) gave consent for patients on their ward to be approached to take part in the research (see Appendix M and P for information leaflets and consent forms). As a courtesy, a letter was sent to each medical consultant on the recruited wards informing them about the study (see Appendix Q). Pseudonyms were assigned to the wards: King, Care of the Elderly and Derwent, General Medicine. On all but occasion, during research visits to the wards, they were at bed capacity (32 beds and 28 beds respectively). Derwent ward had 30 beds occupied on one occasion.

The inclusion and exclusion criteria for patient participants are summarised in Table 3.2.

**Table 3.2: Eligibility criteria for patient participants**

Inclusion criteria	Exclusion criteria
Patient perceived to have a dementia by a senior member of nursing staff	Lacks capacity to provide informed consent
Assessed as physically well enough to take part in research	Unable to communicate mainly through spoken English
	Admitted within past 24 hours
	Due for discharge within 3 days

Patient participants comprised a purposive convenience sample. The process of identifying potential participants began with a discussion with the ward manager or senior nurse on duty at each visit to the ward. Nursing staff were asked to identify patients that they considered could be included in the study. The general format for the discussion was to provide the staff member with a brief reminder of the eligibility criteria for patients. The staff member would then identify patients who met the eligibility criteria through systematically going through each patient name on the ward at that time, by bed number order, and commenting as to whether they felt they could take part, or not. This was generally accompanied with a dialogue about the nurses' perceptions of the patients' level of cognitive functioning. The process as just described immediately excluded any patients that were deemed too unwell to take part or were being nursed in restricted bays that required barrier nursing.

#### 3.7.2.1 Informed consent: issues and challenges

Informed consent is deemed to be given once adequate information has been provided to and understood by a competent individual. Competence to make an informed choice is defined as those being able to comprehend and retain information which is then used in the decision-making process (Hardicre, 2014). The issue becomes complex when considering consent from people who may have cognitive difficulties, including those people with dementia. In the past, a degree of paternalism was exercised against the identified vulnerable groups on the part of those responsible for ensuring the welfare and safety of these groups (Mckillop and Wilkinson, 2004). Previous examples of research which claims to represent the views of marginalised groups e.g. (Tolson et al., 1999, Cowdell, 2010a) actually uses the views of

others to represent people with dementia. It is now widely accepted that such practices marginalise and silence those with dementia by distancing them from their own views and experiences. The challenge to researchers is to utilise those who best represent the group in question, even if doing so requires the development of innovative methods of gaining consent (Dewing, 2002, Sherratt, Soteru and Evans, 2007).

The Mental Capacity Act (2005) recommends that participation of people with dementia in research should firstly provide knowledge about the causes, treatment or their care, has negligible risk for the person, does not interfere with the freedom of action or privacy of the person and is not unduly restrictive or invasive to them (Mental Capacity Act, 2005). Each of these concepts informed the development and application of the present research process. Secondly, the person must be deemed capable of giving informed consent to take part in the research; people are deemed capable unless there is evidence to the contrary. To be assessed as capable, the person needs to have a general understanding of what decisions need to be made and why, the likely consequences of making the decision, an ability to understand, retain, use and weigh up the information and be able to communicate this (Mental Capacity Act, 2005).

The basis for consent for this study commenced with ward staff establishing those patients who met study inclusion criteria. The next phase involved providing potential participants with relevant information in a way that was understandable to them to facilitate their decision-making. The framework specified by the ethics committee required the use of standard information sheets, which were not always easily accessible to potential participants. The researcher often used verbal explanation, gauging this at a level that the individual could potentially understand. The researchers' clinical experience and training supported this process. As other studies have noted, the skills and experience of the researcher in interacting with and understanding the needs of people with dementia were paramount in adhering to the informed consent process (McKeown, Clarke, Ingleton and Repper, 2010).

To evaluate capacity to consent, potential participants were required to repeat verbally the aims of the project (to understand their experience), and how they would be involved (through talking to the researcher about being in hospital and through the researcher watching what happens to them on the ward). This process meant that people who used alternative methods to communicate were immediately excluded by the research protocol. This was a difficult decision for the researcher to accept, particularly as, at times, people with dementia do not use verbal methods to communicate their wishes. In order to negotiate this unsatisfactory limitation to the consent framework, potential participants were approached on more than one occasion to evaluate their capacity to consent. Nevertheless, this process did not increase number of recruited participants.

Examples from previous research (Rodgers, 1999, Goldsmith, 2002, Wilkinson, 2002, Norman, 2004), informed the cyclical consent process adapted for the purposes of this research in order to incorporate an inclusive consent procedure. The collation of field notes on concerns around consent, where within the interactions consent was given and how, and reflecting on this process helped the researcher to be reassured that consent met mandatory requirements of the Mental Capacity Act (2005), updated in 2019, after data collection for this thesis took place.

### Cyclical consent process

The cyclical consent process (Norman, 2006) involves re-introducing and re-establishing an individuals' agreement for involvement at each point of data collection and facilitates a personalised method through which people with dementia are able to agree or withdraw their consent whilst using their own favoured method of communication (Norman, Sellman and Warner, 2006).

Throughout data collection recruited participants were approached daily with a view to conducting a temporal interview or observing their interactions or both data collection activities. On each occasion, the cyclical consent process was utilised. There were occasions when on arrival on the ward, the participant was in the process of interacting with another, where they may indicate their awareness of the researcher being there through raising a hand

or smiling towards the researcher. This was taken to mean that the participant recognised the researcher as someone with whom they were involved with. Field notes were then compiled on what was observed. Once the participant was no longer occupied, the researcher approached the participant where an evaluation of their capacity to consent at this point was undertaken. This process produced a dilemma for inclusion of data that had just been produced. Were participants consenting to be observed from this point, and not to what had just taken place? On these occasions, the researcher would then proceed to interview the participants with a focus on what had just observed. This process ensured that ongoing permission was explicit. There was one occasion where a participant who had been observed, and field notes written, in which a decision was made to exclude the data from the overall dataset on the basis that when the participant was approached, she did not respond with any verbal communication, and her non-verbal behaviour indicated that she was distressed and getting increasingly agitated by the researcher presence. Through re-addressing the consent issue at each time of data collection, participants were able to withdraw their involvement should they wish. However, it is possible that participants may have felt obliged to repeatedly consent as a relationship had been struck up between them and the researcher. They may also have continued with taking part in the research as opportunities for interactions with people outside of care practices were limited. This issue is discussed further in the final chapter.

### **3.8 Data Collection**

#### **3.8.1 Focus groups**

The first focus group was attended by 7 nurses (3 qualified nurses, 3 auxiliary nurses and a student nurse). The nurses had, on average, 8 years' experience in caring for older people (range 1 to 16 years). Most of this experience was in the acute hospital ward setting. Five of the attendees worked permanently in Elderly Medicine wards. Two attendees were based on general wards. Nurses were aged between 22 years to 56 years, with an average age of 38 years. All the attendees were female. Of the nurses who expressed an interest but did not attend the event, 4 of them contacted the

researcher beforehand to say that they could not attend due to work commitments.

The focus group held at phase 3 was attended by 6 nurses (2 qualified nurses, 3 auxiliary nurses and a student nurse). The nurses had on average 5 years' experience in caring for older people (range 3 months to 17 years). One of the attendees was male. The average age of attendees was 35 years (range 22 years to 48 years). Nurse participant characteristics are shown in Table 3.1.

**Table 3.1: Nurse participant characteristics**

Phase	Role (n)	Experience ( years)
1	Qualified (3)	1 to 16
	Auxiliary (3)	5 to 9
	Student (1)	2
3	Qualified (2)	1 to 17
	Auxiliary (3)	0 to 9
	Student (1)	3

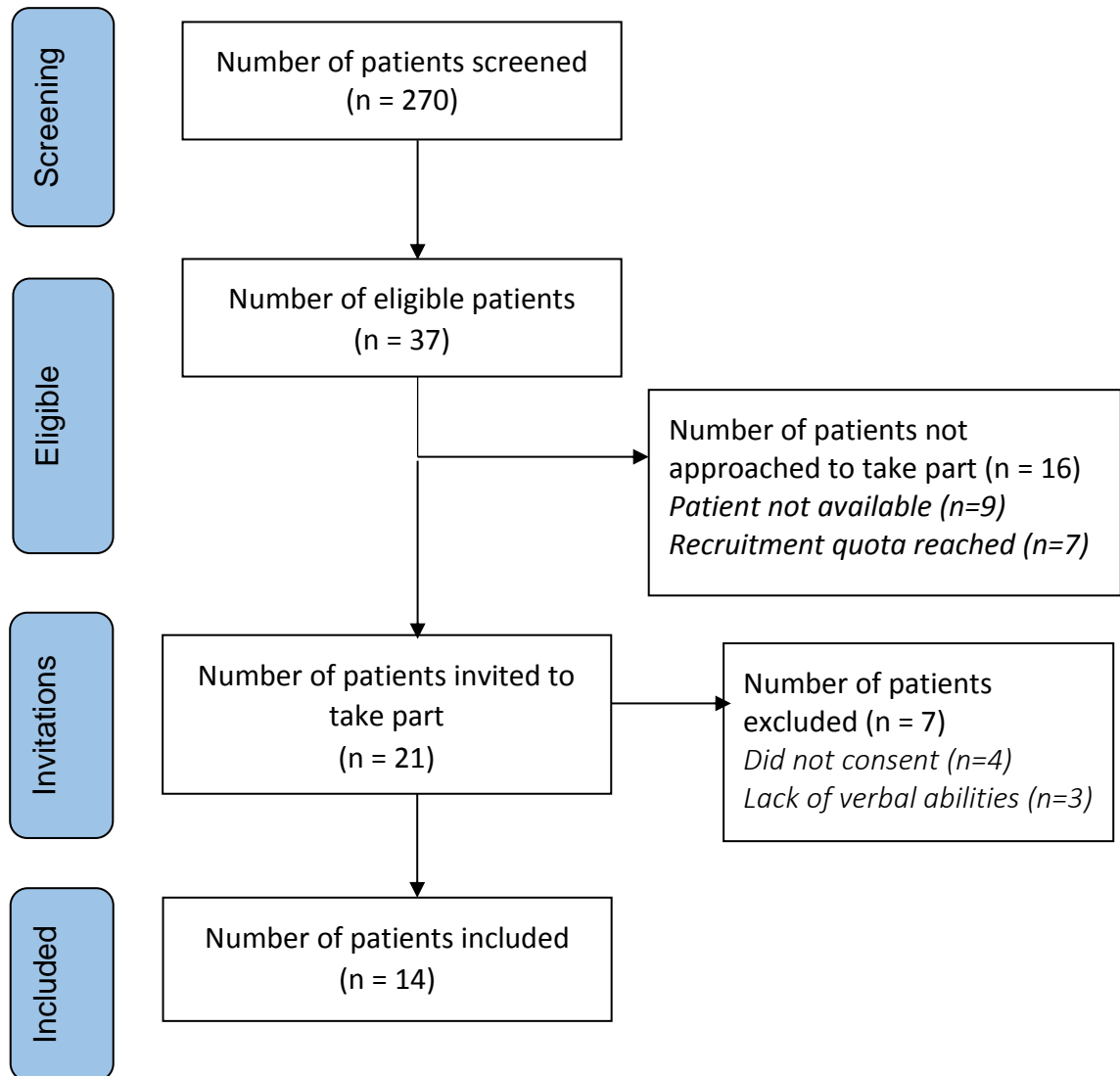
The focus group began with a general introduction to the purpose of the discussion. Participants were asked if they had any questions about the purpose of the group. All participants were required to read through the information sheet about the study and provide written consent for the discussion to be audio-recorded and transcribed verbatim (see Appendix U and V for information sheet and consent form). The ground rules for the group were read out and participants were reminded that they were free to leave the discussion at any point, without giving reason. The group was also reminded that the content of the discussion was confidential to the group. Should any issues be discussed that they deemed to represent unprofessional behaviour or that they found upsetting, they were encouraged to speak with their line managers following the event. They could also contact the researcher or a member of the supervision team if they required further support or advice. The focus groups were 56 minutes and 48 minutes long respectively. Both groups came to a relatively abrupt end as most of the attendees were due to be back on shift straight after the group or had finished their shift an hour prior the group and had stated that this was the only time that they had available to attend.



### 3.8.2 Qualitative interviews

Fourteen patients were included in the study. The number of patients screened and reasons for exclusion are shown in the flow chart in Figure 3.2. Initial screening led to a total of 37 (13%) potential participants. Nine patients were not approached to take part in the study as they were not available at the time of the recruitment visit to the ward. Reasons for patients not being available were because they were off the ward for tests, engaged in the process of care interventions, asleep or occupied with visitors. Seven potential participants were not approached as the recruitment quota for that period had been reached. A maximum number of two participants were recruited at any one time to ensure that the ability to conduct several different data collection activities, over different time periods with the same participant was not compromised by having too many participants to collect data from at any one time.

Twenty-one patients were assessed for inclusion in the study. Initial introductions between the researcher and patients provided the opportunity to determine whether the patient could converse verbally about their experience of being in hospital. This was assessed through the researcher providing a brief introduction on the purpose of the study and checking for their understanding as per informed consent procedure (see Appendix R and S for the patient information leaflet and consent form). Informed consent is discussed in more detail later in this chapter. Three patients lacked the verbal skills necessary to take part in the interviews at the time of the research and were excluded from the sample. Five patients chose to delay their decision about taking part for 24 hours. On these occasions, an information leaflet and consent form were left with them overnight for them to consider their response. On return visits, four patients declined to take part.

**Figure 3.2: Recruitment flow chart for people with dementia**

Pseudonyms were assigned for each recruited participant (see Appendix T for a brief introduction to each participant). Participants were aged between 72 and 86 years, with a mean age of 80 years. All but one of the participants were English-speaking white British; Bert was of African-Caribbean descent. The sample included 8 females. Nine participants were recruited from Derwent ward, and 5 from King ward. The average length of stay for participants on the wards was 14 days (range 3 to 29 days). Patient participant characteristics and research activities are summarised in Table 3.3.

**Table 3.3: Patient participant characteristics and research activities**

Setting	Participant	Age	Length of stay	Number of interviews	Total length (mins)	Number of observation periods	Total length (mins)
Elderly (Derwent)	Elsie	76	29	4	47	2	120
	Mary	83	18	4	82	2	120
	Annie	84	13	4	149	2	150
	Maureen	85	14	1	29	2	70
	Sally	79	30	3	71	3	95
	Vera	86	32	2	67	3	120
	Alfie	72	13	3	145	1	120
	Harry	76	10	3	99	1	60
	Henry	87	15	4	83	1	110
Medical (King)	Ethel	82	20	1	45	1	60
	Maggie	76	12	3	180	1	110
	Stan	70	5	1	40	1	40
	Bob	76	6	4	122	1	110
	Bert	81	16	2	80	2	120

The recruitment process was designed so that a range of patients, with different characteristics would be recruited. Towards the end of the study, male participants were purposely recruited as the sample at that point consisted of mainly females. The sample represents typical ages of patients with dementia that are admitted to acute hospitals (Sampson et al., 2009). The sample is under-represented by patients from different ethnic and minority backgrounds, which limits generalisability in this study. It is of interest that only one patient that was not white British was recommended for inclusion by the ward staff, despite the catchment area for the hospital having

a large African-Caribbean and South Asian population. This in part reflects evidence that dementia is under-detected, despite higher prevalence rates in groups where English is not the dominant language (McCracken et al., 2018), and for people that have left their country of origin (Tuerk and Sauer, 2015). The sample may also be biased towards people with dementia that lack relative and carer support. During recruitment, those patients that were occupied with visitors were not approached to take part in the study, which limited the opportunity to include relatives and carers in the sample. Most participants stated that they had family members who visited them, although the researcher saw little evidence of this, despite being present during scheduled visiting times in the afternoon and evenings. The limitations of the recruitment process are discussed further in the relevant section of the final chapter.

A total of 39 interviews, ranging in length from 29 to 67 minutes were conducted. Each participant took part in at least one and up to 4 separate interviews. Interview lengths were flexible and, responsive to participants' abilities to concentrate on the topic. At times, the interview benefited from being performed in several short sessions, thereby requiring the participant to concentrate just for short periods of time at one sitting. Temporal interviews that occurred at different times, on sequential days were conducted with the majority of participants. Temporality ensured that the topics discussed covered the areas of interest, but also facilitated an opportunity to check out understanding of what had emerged from preceding interviews and observations. One of the disadvantages of temporal interviews is that the elicited accounts were fragmented and often disjointed from the previous accounts that had been given. Paying attention to common factors that were raised across the different interviews facilitated the discussion to remain focused on experiences. At the same time, being vigilant to what was different over time afforded an opportunity to gain deeper insights as to the instability of views expressed about experiences. Finally, the interview duration was participant-led which provided a degree of assurance that what had been discussed was what they wanted to be heard, at that time. Reasons for ending an interview included: natural end, a care task needed

attention, or they implied through their actions that they withdrew consent at this point in time, such as being too tired to continue or distracted from talking about their experiences.

The interview, as a method for data collection with people with dementia, evolved as the study progressed. A flexible, adaptable approach to executing the research design was used. This section of the thesis includes a description of how the method evolved during data collection.

#### Verbal communication with people with dementia

People with dementia have considerable difficulty reasoning about issues, e.g. recalling events and reflecting on their meaning (Killick and Allan, 2001). The active vocabulary of people with dementia appears to shrink where specific words are replaced by, for example, 'stuff' or 'thing' (Wilkinson, 2002). What can often be interpreted as vague and empty speech does have meaning, which can be brought to fruition through careful listening (Hyden and Antelius, 2010). Often verbal communication with people with dementia is not conventional in the sense of following logical patterns and rules of syntax, nor is it structured in ways that researchers can easily make sense of. This is not to say that their verbal communication is meaningless, rather it may be difficult to understand or make sense of within the constraints of an interview setting (Keady et al., 2007).

Through adaptation of interview techniques and through careful listening of participant narratives, it was possible to tell the story of how participants perceived their hospital experience, albeit from the interpretations made of their accounts by the researcher. Four key factors influenced the procedure of individual interviews: time, style of question and guidance, taking care to follow the participant and repetition.

#### Time

People with dementia are often aware of the delay in their speech caused by their word finding difficulties. This can be a frustrating and difficult experience for them. Placing time pressure on them further slows down the process of eliciting their views of their experiences (Sabat, 2006). It is often tempting, and has been advocated that in order to encourage ongoing dialogue with people with dementia, the interviewer could suggest acceptable

alternative words (Killick and Allan, 2001). This has to be done with caution, particularly whilst conducting research, so as to avoid jeopardising the data and misinterpreting the participants' perspective (Haak, 2002, Cambridge and Forrester-Jones, 2003). Whilst conducting the interviews, the researchers' previous professional experiences of conversing with people with dementia lends itself to having some skill in gauging when and how 'word-filling' may be necessary. At times when it was observed that participants may be struggling to find words, and that they may be suffering in some way as a consequence of this, it was only ethical to find a way to help them resolve this struggle. This helped facilitate the mutual trust between the researcher and the participant, who were often delighted that the word that they were looking for had been 'found', as was seen in this dialogue with Annie: *"...and then I put that there, and then I have a sip, and then I put the, I put the thing...I put the..."* researcher: *"the drink?"* Annie: *"yes, that's it love, you've got me. I put the drink there and then they took it..."* (Annie, 2). On such occasions, the researcher could check out whether the meaning of what was being said had been altered through considering what had been said previously and in subsequent text.

At other times, listening and waiting for the participants' own expressions were necessary as word fill could shift their attention away from what they were talking about. On several occasions, it was possible to conduct relatively longer interviews through the deliberate inclusion of pauses and relaxed small talk, which allowed participants to rest. At other times, it was not possible to return to talking about their experience after these pauses as participants would fall asleep or indicated that they withdrew their consent to continue at this time.

#### Style of question and guidance

Open questions may be difficult for people with dementia to answer (Killick and Allan, 2001, Clare, 2002). Caregivers are often advised to use simple yes/no questions to improve communication (Bayles, 2003, de Medeiros, 2010). In this research, an open dialogue was required to gain insights into the experiences of participants. There is some debate within the literature as to whether an elaborate account of the phenomena under investigation can

be elicited through open questions with people with dementia (Wilkinson, 2002, Murphy, Gray and Cox, 2005). Asking questions such as ‘what did you do today?’ may be difficult because it requires recall of the days’ events, selection of numerous words to represent the sequence of activities, followed by organisation of the output (Fisk and Wigley, 2000). Asking questions that require participants to account for ones’ specific actions are generally avoided with people with dementia. However, responses elicited from open questioning, whether organised, sequential or not or focused on one activity or several different activities provided insights into how people with dementia construct meaning of the situation they are in.

In earlier interviews, one of the specific question’s participants were asked was ‘can you tell me about your routine here in hospital?’ This was with a view to understanding how patients with dementia perceive of the meaning of the situation they are in. Generally, their responses to this question provided information about their actions at the start of the day e.g. ‘get out bed, use the loo’, which were not context-specific to the hospital environment. Their dialogue would often stop after listing three to four activities. This was interpreted as the participants struggling to represent the sequence of activities that the word ‘routine’ is designed to elicit. Therefore, this question was changed to ‘what do you normally do here?’, or rephrased (in instances where the first question did not elicit dialogue) to, for example ‘how do you spend your day here?’ Such a question required that participants verbalise their concept of their behaviour (their experience) in this setting, and so is contextually different to the former question. This elicited responses such as *“well I sit here, and I do that, and I sit, and I just stay here and that’s it.”* (Maureen, 1). Exploring how they felt about what they had just described by using key words in their text often led to dialogue about issues in their daily life. For example, when asked, “how do you feel about ‘staying’ here?” participants often expressed their likes and dislikes as in this example from Harry: *“well, I can’t say I’m bothered for it love, I don’t mind it, the food and that. They are all good to you here.”* (Harry, 1).

Throughout the interviews, posing questions (in a paraphrase) about particular likes and dislikes mentioned led to more explicit accounts when

associations are made to certain events. Similar responses have been reported in previous research e.g. (Romero and Wenz, 2001, Shenk, Davis, Peacock and Moore, 2002). To illustrate, the researcher asked Annie: “So they are all good to you in here?” Annie: “Oh yes dear, there isn’t a wrong one amongst em. There’s some that don’t talk to you and there’s some that do, but they are all good”. (Annie, 1). In this instance, it is not clear who ‘they’ are, and it was difficult to explore with Annie her concept of who she was referring to. What became important here was that she was stating that she does not measure the ‘goodness of this place’ by volume of engagement in interaction with some but not others. Open questions about habits and routines elicited accounts of explicit situations and reflections on them, which moved beyond the standard dialogue.

#### Following the participants

In the earlier interviews, and through the process of initial analysis, it was apparent that participants would become very talkative about what seemed to be off key with the subject of interest. A large proportion of the interview transcripts contained text about past experiences and roles within the participants’ lives. Similar studies also report this experience (Hubbard et al., 2003). The question was raised as to whether these were valid accounts for analysis as the researcher tended to encourage their dialogue through affirmative responses, because at least they were talking about something. However, through re-reading over the earlier transcripts, there were many reflections, insightful comments and associations in the overwhelming number of words and side-tracks provided during the interview. Participants’ construction of the meaning of the situation they were in was created through them being supported through a story line whilst the researcher held back leading wordings and avoided detailed control. The events became meaningful because of their placement in the narrative. What they had initially settled on to talk about was viewed as seen as tapping into what they were experiencing at that time. Other researchers have also uncovered these associations through careful reading of interview transcripts (Killick and Allan, 2001, Clare, 2003, Killick, 2011). In fact, several authors report on the value of using conversations about life stories to facilitate connections with



people with dementia (Killick and Allan, 2001, Killick, 2011, Kindell, Burrow, Wilkinson and Keady, 2014, Grøndahl, Persenius, Bååth and Helgesen, 2017, Kindell, Wilkinson and Keady, 2018).

### Repetition

Pauses, during interviews with people with dementia, risk them losing track of the conversation. When pauses occurred, repetition of the topic and what the participant had just said assisted in remaining on track. To illustrate, in the following example of emotional talk with Vera on how she feels about what the nurses do for her, the response was: *“they are there and they are not there . . . .and they just, and they just do, oh I don’t know, and they just [long pause]”* Researcher: *“you were just telling me what you think about the nurses on the ward and that they are there”* Vera: *“oh yeah and they are there and they are not there and they just do what they need to do and are gone again.”* (Vera, 1). Not only was Vera able to pick up on her train of thought; she elaborated on how she felt perceived of as an object, to be done to.

On occasions, participants would repeat that which had already been said before the pause. People with dementia may have trouble weaving a story into the give-and-take of ordinary conversation but can present a story that they have told several times, a ‘rehearsed’ or performed story (Bayles, 2003). A story told several times represents a piece of experience of importance to the teller, therefore adding trustworthiness to the data. Moore and Davis (2002) call these quilting narratives, where we listen carefully for phrases that might be part of the story and then repeat these to allow the speaker to continue the tale or expand an aspect of it, to record the phrases and then return to them later on, when appropriate. However, this approach to conversing with people with dementia is advocated in care giving and it has been suggested that it should be used with caution in research as it may undermine the validity of the data (Nygard, 2006). Throughout the interview process, quilting narratives were used to refocus narrative on that which was the topic of interest. To illustrate, participants sometimes talked at length about experiences that did not seem to relate to their meaning of their situation in hospital. They were focused on repeating the story that they

wanted to tell. When this occurred, phrases that were common within the narrative were used to expand on aspects of the tale that was relevant to their current situation. For example, Vera repeated a story about her dead husband, focusing on what had led up to his death, what she did for him, and how she felt about losing him. It was difficult to move on from this story, as it was so emotive. The researcher reflected on some of the phrases Vera had used throughout her dialogue, such as “I always looked after him” and “He was good to me and I looked after him” and used these to help direct talk about her experiences in hospital. At a subsequent interview, one of the questions asked was: “*Can you tell me what it is like for you to be looked after now? Vera: oh that, oh I hate being in here, I would rather be dead.*” (Vera, 2). This powerful response, likely wrapped up in grief, did open up dialogue about “*what is so bad at this place?*” and “*how could it be better for you?*” which led to a dialogue of the meaning of being hospital for Vera.

Some participants appeared to follow what they were saying, and then forget it quickly. Often this was accompanied with repetitions of topics, comments and questions. One participant, Maggie, informed the researcher that: “*I’m not in hospital love so I can’t tell you about it*” although just three minutes before this she had agreed to take part in the research and had given informed consent. Maggie then asked if the researcher had any scissors and she was asked what she wanted them for. Maggie continued to repeatedly ask for some scissors, looking around her, without engaging in any dialogue with the researcher. She also seemed to be getting increasingly agitated with this repetition. The researcher felt morally responsible for trying to alleviate some of her distress but also gauged that the researcher presence may be adding to her agitation. Hence the interview was terminated with a view to returning later.

At the time, the researcher perceived that they were unlikely to receive any new information about Maggie’s experience of being in hospital, but on reflection, it was considered that this was her experience that she was verbalising. She did not have around her what she felt she needed around her and no-one was providing her with what she needed, despite asking for what she needed. Communicating needs through different modalities was an

important theme emerging from the data. That which at first appeared to be out of context for research purposes, was now fundamentally important in the interpretation of the data.

#### Non-verbal behaviours

It is estimated that nonverbal behaviour comprises 55-97% of the message communicated in adult interaction (Gross, 2010), and includes body movement, facial expression, touch, physical appearance, personal space, and vocal communication such as pitch, intonation, and speech rate.

Throughout the interview process, contemporaneous field notes were used to document observed non-verbal behaviours, to provide context to what was being discussed. Touch and body posture were often used by participants as a way in which to facilitate conveying the emotional tense of what was being discussed. Participants would frequently put their hand on the researchers' arm, or physically turn more towards the researcher, indicating that they wanted to engage in conversation. Often, they would put their head closer to the researcher which may have been because they were communicating something that they wished to remain private, or due a hearing impairment or both.

#### 3.8.3 Ethnographic observations

Most events that take place for people in hospital occur in and around their ward bed area, and mostly involve nursing staff. Observation periods were conducted in public ward areas and focused on what was occurring for and around recruited patient participants.

It was intended that each participant would be observed for approximately 90 minutes on 3 different occasions. The average length of time each participant was observed was 100 minutes in total (range 40 to 150 minutes). Not all participants were observed on three separate occasions and not all observation periods were of 90-minute duration. The planned sequence of observing participants prior to interview on at least two occasions did not always take place in this order. As the study progressed, several factors influenced the ability to observe participants at planned times and in the order and for the duration length planned. Each participant was observed at least once during an interaction-rich period (e.g. medication, preparing for

lunch, assisting to dress). Where interaction-rich visual observation was not possible, for example using screens during intimate cares, aural observation continued and so these interactions are represented in the data. To enable a broader range of observations, interactions outside of the ward routine were subsequently focused upon. Outside of ward routine observation involved observing participants at quieter times during 'unplanned' interactions. These observations revealed a relative dearth of interactions during these periods; interactions that did occur were primarily task focused. The outside of ward routine observations did not yield the breadth of experience anticipated. Oftentimes the planned observation period was truncated due to participants resting or sleeping for extended durations.

Ethnographic observations, as a method for data collection with people with dementia, evolved as the study progressed. This section of the thesis includes a description of how the method evolved during data collection. Four main factors informed the development of the process of non-participant observations: (1) participants' actions when not receiving physical cares; (2) events that took place that precluded the ability to observe participants; (3) the interaction between the cyclical consent process and participant preferences and; (4) actions of hospital staff within their environment.

#### Participants' actions when not receiving physical cares

Data was collected on the interactions that took place with the participant and at least one other, and events that took place around the participant were also recorded. A description of the participants' physical environment and the actions of the participants when not interacting with others was also part of this dataset.

Following the recruitment and data collection from three participants, it was clear that the content of field notes was repetitive and that the interactions that were observed were based around completing tasks to be done by the staff initiating the interactions. This felt like an account of how nursing staff go about the task of getting the business of routine care completed and did not seem to capture the experiences of people with dementia. Interactions that occur outside of the 'expected' interactions were important. Otherwise this study would only be able to provide an account of the experiences of

people with dementia receiving direct care. However, it became clear that observing what occurs outside of the ward routine tasks contained relatively little data about interactions with others compared to the volume of data about the actions of participants when not interacting. Events outside of an interaction generally consisted of participants sleeping or resting (with eyes closed) for long periods. It was felt that continuing to observe this behaviour served little purpose for the benefit of the research. The persistence of observing in the face of not recording any new data seemed futile. If this study had been a measure of how people with dementia spend their time on the wards, or a measure of the number and frequency of interactions, then recording length of time between interactions, and what occurs in-between these events would be required.

#### Events that took place

Certain events that took place on the wards during the process of data collection precluded the ability to collect data (n=11). On two occasions, the researcher was asked to stop observing by the nurses. This was to facilitate them cordoning off bays in which participants were being observed in order to carry hospital tasks. Three participants became too poorly to continue in the research, 2 were moved to other wards in the hospital or discharged and 3 participants passed away during this research. On one occasion, a senior nurse requested that observations were stopped due to the protected meal-times initiative (PMI). This was the first time this nurse had been on duty on the ward during the research. The nurse stated that she was not aware of the study and that PMI meant that no research could take place at these times. Although this was incorrect, it was felt that it was important to follow the nurses' wishes at this point. Following this event, the researcher spoke with the ward manager to confirm that observations during PMI were acceptable and that all nurses were made aware of this.

#### Participant led

The adoption of the process of cyclical consent (discussed in section 3.10.1 of n this chapter), required some form of communication with participants at the start of each data collection period. Participants were required to give

their ongoing consent to take part in the research at each ward visit. If consent was not elicited at the start of data collection, consent could not be assumed. On those occasions where participants were either interacting or sleeping at the start of a planned observation period, data could be collected for the purposes of this part of the observation study (n=10). Consent would then be sought retrospectively from participants. On these occasions, except for one period for one participant, there was an agreement for this data to be included in the study dataset. However, if participants were alert and not engaged in an interaction with another, it was difficult to start observing them without first acknowledging them in this process through verbal communication, and thereby ensuring that they consented to be observed. Often, participants expressed a preference to be interviewed at this juncture, rather than to be observed (n=7).

#### Actions of hospital staff within their environment

Hospital ward staff that interacted with a participant during an observation period were included in the sample. All members of staff gave verbal consent for data collected about them to be included in the data set. The sample consisted of a wide range of hospital staff that one would expect to encounter in a typical hospital ward. Participants comprised 17 members of nursing staff (including 9 qualified nurses, 7 nursing auxiliaries and 1 student nurse), and 10 members of hospital staff (4 catering staff, 3 doctors, 1 member of cleaning staff, 1 physiotherapist and 1 porter).

### **3.9 Data Analysis**

#### **3.9.1 Approach to data analysis**

The data sets from focus groups, interviews and observations were analysed separately and concurrently. The findings were integrated to develop a conceptual framework for the experiences of people with dementia in the hospital setting. An Interpretative Phenomenological Approach (IPA) (Smith, Flower and Larking, 2009b) was used to facilitate data analysis (Flowers et al., 2001) and interpretation of the findings. Generally, IPA has a set of flexible guidelines which are adapted according to specific research objectives (Pietkiewicz and Smith, 2014), which was the case for this study. Within IPA methodology literature, there is very little guidance on combining

data from multiple perspectives, with the exception of the recent publication by the developers of the approach (Larkin et al., 2019). This publication, and research reported by authors that have used IPA to facilitate multi-perspective data analysis for the experiences of people with dementia (Clare, 2002, Prato et al., 2018) were also used to guide the analytical approach and integration of data. The challenge in analysis of data obtained from different perspectives is *'to retain IPA's commitment to understanding participants' claims and concerns (when, across the sample as whole, there may be more variation than in a traditional samples) whilst also illuminating those insights gained through inclusion of additional perspectives. These additional insights can arise from matters of congruence, contrast, or both'*. (Larkin et al., 2019).

The following section describes the approach taken to analysis and integration of the different datasets, which is discussed separately to ease reporting. In practice, the process of analysis was not linear as data were analysed concurrently.

### 3.9.2 Analysis of interview data

#### 3.9.2.1 Analytical process

Interview recordings were transcribed shortly after they occurred. The researcher transcribed interviews that took place earlier in the fieldwork, to become familiar with the data. Later interviews were professionally transcribed, and edited by the researcher, through listening to the recordings whilst reading the transcribed text. Transcripts were read and re-read several times. Notes were made on initial interpretations of what was being described by participants. These notes were read alongside the reflective notes that were made during, and shortly after the interviews. The notes contained researcher thoughts and comments on content, language use and context around each interview process. Working with the notes, rather than the transcript, the aim was to transform notes into emerging themes (Pietkiewicz and Smith, 2014). This formulated phrases, at a higher level of abstraction, that were established in the detail of the account given by participants.

### 3.9.2.2 Interpreting meaning

The text contained within interview transcripts was often disjointed, at times incoherent and at others not easily decipherable as to what participants were referring to. Analysing chunks of text was not straightforward, particularly because participants could jump from one topic to another in the absence of any sign-posting. Paying particular attention to the temporal nature of comments in their narratives was crucial to being able to interpret an understanding of what they may wish to convey (Feis and Astell, 2011). Thus, memo writing was used in several ways in various phases of the analysis. They were used to describe the different emerging themes, how text had been interpreted and why, and to explore similarities and differences across themes. To ensure that the essence of what participants were describing was maintained, and therefore ensure validity in interpretation of their accounts, individual transcripts were then re-constructed, as a narrative, entitled: 'what is this participants' story?' This facilitated further the process of maintaining the uniqueness of individual accounts and to search for concepts that were familiar across different participants' accounts.

For most participants, transcripts contained data detailing their past roles and life events. The purpose of analysis was to extract and interpret information from their narratives that was focused on their accounts of experiences in the ward setting. Chunks of text, which were based on accounts of their previous experiences, were excluded from the emerging themes. The relationship, as inferred through the participant's narrative, between their previous experiences and roles and their experiences in the present were retained within the narrative. This approach to interpreting meaning was intuitive; as one participant surmised towards the end of a relatively incoherent interview: '*we'll see what we can dig up about it all*' (Annie, 2). The accounts, as they were told, were perceived as snapshots of their experiences in a fragmented world. An example of exploratory comments made and emergent themes from extracts of 2 of the interview transcripts is shown in Figure 3.3.

**Figure 3.3: Example of exploratory comments and emergent themes**

Emerging themes	Transcript text	Exploratory comments
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Lack of choice in how occupy time	<p><i>Interviewer:</i> 'Can I ask you how is it different being here compared to being at home? What is different for you?'</p>	<p>Talks about choice of activities (what and when) being restricted/limited by the routine and layout of the hospital setting. She seems to be talking about not having to think through her daily routine as it is imposed upon her and a sense of reluctant acceptance of this imposition.</p>
Limited by changes in me	<p><i>Interviewee:</i> 'Oh being in hospital, well I like being at home more, and I like, err you know, getting me food and I can watch television when I want, or if I don't want to. Its' surprising chick, how many things you don't think about you know. You just let them go over your head and you think oh there'll be another day tomorrow. At one time I wunt have been like that.' (Vera:44)</p>	<p>Talks about needing to show others how she was previously in order to prove that she is not how she used to be. Perhaps she feels she would be 'treated' differently, or feel different/better through previous appearance. She seems to be suggesting that she has given up on herself. Is this because others give the impression they have given up on her?</p>
	<p><i>Interviewee:</i> '...I've never had teeth like these, I've let em go and let em go and let em go.'</p>	
	<p><i>Interviewer:</i> 'why is that do you think?'</p>	
	<p><i>Interviewee:</i> 'cos I think it is because I can't be bothered, i can't be bothered, Err, and I have some err toothpicks that I use for my teeth and when I have, do you know sometimes, I think I'll bring a photograph of me with my perfect teeth to hang up and that's me when I were in perfect health, well not perfect, but with a smile. You do let yourself go though...'(Annie:122)</p>	

### 3.9.3 Analysis of focus group data

The focus group transcripts were analysed in much the same way as the interview transcripts, albeit that this process was relatively easier as the text followed a more logical pattern. Notes were made on initial interpretations of chunks of text that related to descriptions of the experiences of people with dementia. Again, working with the notes, rather than the transcript, the aim was to transform notes into emerging themes (Pietkiewicz and Smith, 2014). The emerging themes that developed from the analysis of the interview transcripts sensitised to patterns to search for within nurses' accounts. The analysis also remained open to new and different experiences to those that had been derived from the interview data analysis.

#### 3.9.4 Analysis of observation data

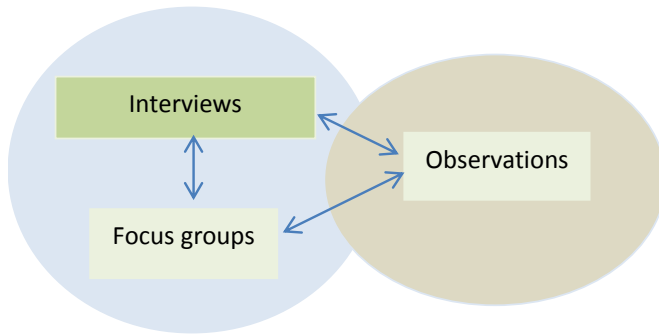
Most field notes were typed up shortly after each observation period. When it was not possible to type up field notes due to time constraints, additional hand-written notes were made on initial impressions as to what had been observed. Analysis of data from observations was conducted in two stages. The first involved initially analysing all field note data thematically, following guidance as outlined by Braun and Clarke, 2006. Following the thematic analysis, the extent to which the themes mapped onto the emerging themes derived from the analysis of interviews with people with dementia were explored. Through integrating the field note analysis within the themes developed from the analysis of the interviews, the interpretation of data collected from observations was embedded within themes sensitive to the issues raised by people with dementia whilst remaining open to new and emerging ideas.

#### 3.9.5 Integrating the findings

Figure 3.4 depicts the approach taken to data analysis for the different methods of data collection that were used. The figure shows the distinct approach that was taken for analysis of each data set, as well as the relationships between approaches taken, preliminary analyses and data collection activities. The figure also highlights that it was the elicited accounts from people with dementia (interviews) that was the first 'real' attempt at data analysis. This was to ensure that the emerging findings would be embedded in the descriptions of their experiences.

### **Figure 3.4: Diagrammatic representation of approach to data analysis and integration**

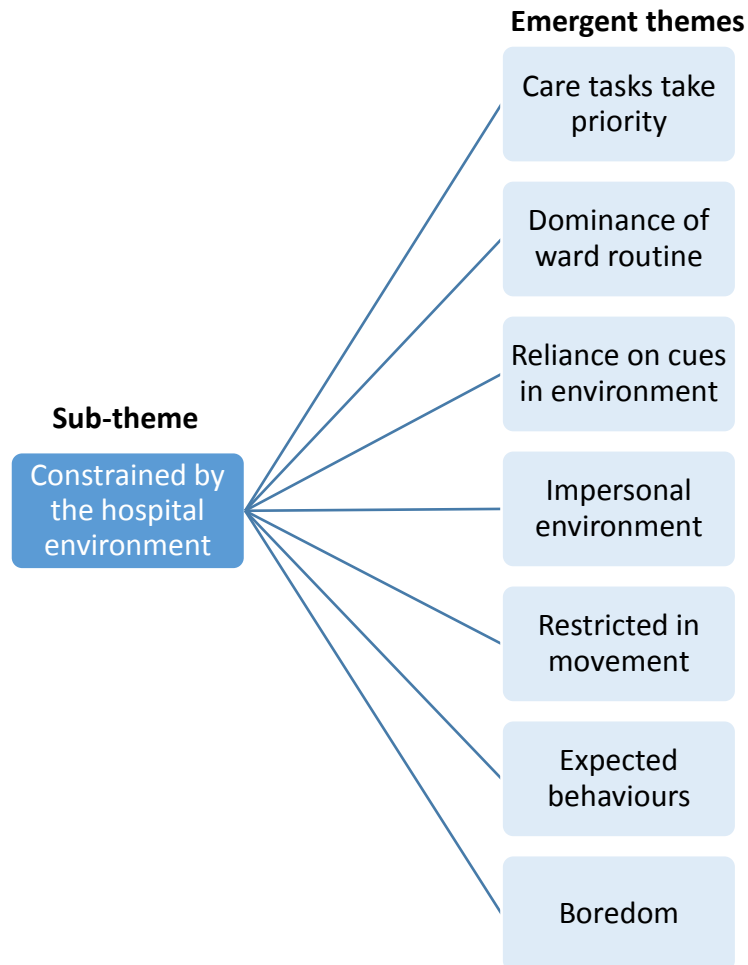
### Interpretative Phenomenological Analysis



#### 3.9.5.1 Developing themes

The next stage of analysis involved comparing and contrasting across emerging themes, searching for associations between them and delineating what was distinct about each one. Descriptions of emerging themes were changed to accommodate expansion of their meaning. Similar themes were then grouped together into clusters of sub-ordinate themes. To demonstrate this process, multiple reading of transcripts, researcher notes, and exploratory comments were used to inform concept mapping which resulted in seven emerging themes that were related through the notion of being constrained by the hospital environment. The construction of this sub-theme is shown in Figure 3.5. Appendix W shows the coding framework with illustrative quotations.

**Figure 3.5: Example of developing theme ‘constrained by the hospital environment’**



As the analysis progressed, a structure of super-ordinate themes was developed. The accounts of people with dementia on their experiences were central to the aims of this thesis. Data from interviews were perceived of as the foundation layer, with focus group and observation findings providing additional layers, from which to expand on first iterations of interview data analysis. The integration of focus group, interview and observation data made three main contributions: a productive iterative process whereby an initial understanding of the context of care for people with dementia in the ward setting guided an exploration of perceptions held by nurses on the impact of their care to the experiences for people with dementia. Individual accounts of experiences, a focus on observations of care behaviour, and successive individual data further enriched the conceptualisation of the experiences; identification of the individual and contextual circumstances

surrounding the experience, which added to the interpretation of the structure of the experience; and convergence of the central characteristics of the experience across observations and elicited accounts.

### 3.9.6 Data management

#### 3.9.6.1 Data storage

All personal identifiable information was removed from interview transcripts, focus groups and field notes shortly after data had been collected. Individual patient participants were assigned pseudonyms, and hospital staff members were identified only through their role title. All data was stored on a secure server at the University which was only accessible to the researcher. Signed consent forms were stored in a locked filing cabinet at the University. In accordance with data protection policy at the time of undertaking the research, data was stored for 7 years.

#### 3.9.6.2 Handling data

During the earlier stages of data collection, analysis commenced with working with paper copies of the data. Phrases and sections of text were underlined, and notes and emerging themes ascribed to them. Diagrams, representing how the themes linked together were produced. As data collection progressed, the Nvivo (version 8) software package was used to support organisation of emerging themes. The use of the memo function within the program facilitated development of theme content. Use of the software, combined with concept mapping in the form of hand-written maps, visual representation of the themes and relationships between them, facilitated data management.

### **3.10 Chapter Summary**

This chapter has described the research methods used to explore the experiences of people with dementia in hospital. The rationale for adopting an IPA approach to data collection and to facilitate data analysis was discussed. The approach taken to develop methods for data collection was outlined. The research design was presented, followed by a description of the different data collection activities: focus groups with nurses, interviews with people with dementia and non-participant observations of their

experiences. The ethical considerations in conducting research with people with dementia were outlined and the usefulness of the cyclical consent process in ensuring consent over time was presented. The development of data collection methods during the course of the main study was discussed. The approach to data analysis, management and data integration was presented. The next chapter presents the findings from the multi-perspective qualitative study.

## Chapter Four: Findings on the experiences of people with dementia

### 4.1 Chapter Overview

This chapter presents the findings of the qualitative study using IPA to explore the experiences of people with dementia in hospital. The study used a multiple perspective approach which included people with dementia, nursing staff and non-participant researcher observations. The first section of the chapter outlines three discrete, but inter-related super-ordinate themes that emerged from the data: power and control, notions of self and mechanisms for coping. This is followed by a discussion on the integration of analysis of different sources of data. The themes are then presented, with extracts from transcripts that present the essence of the themes. The findings are presented as an interpretative account of the lived experience of people with dementia.

### 4.2 Themes

The themes that represent the lived experiences of people with dementia are shown in Table 4.1.

**Table 4.1: Super-ordinate themes and themes**

Super-ordinate theme	Themes
Power and control	Control over decision-making about being on the ward Constrained by the hospital environment Power in interactions
Notions of self	Living with a failing self Expectations for a future self Grief for an expected self
Mechanisms for coping	Non-complaining Normalising interactions Denial of existence of dementia

To assist with transparency and validity of the results, paying attention to the level of recurrence of themes across accounts is important (Smith et al., 2009b). This is advocated in analysis of data from larger IPA studies (Smith et al., 2009b). For a theme to be recurrent, it is suggested that it should be present in between a third and half of all participants' accounts. Table 4.2 shows a matrix of themes cross referenced by participant. Participants' names are pseudonyms assigned for the purpose of reporting.

**Table 4.2: Matrix of themes**

Super-ordinate theme	Power and control		Notions of self				Mechanisms for coping		
	Control over decision-making about being on the ward	Constrained by the hospital environment	Power in interactions	Living with a failing self	Expectations for a future self	Grief for an expected self	Non-complaining	Normalising interactions	Denial of the existence of dementia
<i>Elsie</i>	X	X	X	-	X	-	-	X	-
<i>Mary</i>	X	X	X	X	-	X	-	X	-
<i>Annie</i>	X	X	X	X	X	X	X	X	X
<i>Maureen</i>	X	-	X	X	-	-	-	X	-
<i>Sally</i>	X	X	X	-	X	-	-	X	-
<i>Vera</i>	X	X	X	X	-	X	X	-	-
<i>Alfie</i>	X	X	X	X	X	X	X	-	X
<i>Harry</i>	X	-	X	X	-	X	-	-	X
<i>Henry</i>	-	X	X	X	X	-	-	-	-
<i>Ethel</i>	X	-	X	-	-	-	X	X	-
<i>Maggie</i>	X	X	-	-	-	-	X	X	-
<i>Stan</i>	X	-	-	-	-	-	-	X	-
<i>Bert</i>	X	X	X	X	-	X	-	X	-
<i>Bob</i>	X	-	X	X	-	X	-	-	-
<b>Prevalence of themes</b>	13	9	12	9	5	7	5	9	3

Key: X = present, - = not present

The prevalence of each super-ordinate theme occurred for most people with dementia. In line with the principles of IPA, although indicating a prevalence of themes across accounts is important, there is scope for considerable variation within themes. The same theme may manifest differently in the responses of the participants, and different participants may manifest the same super-ordinate theme in different themes (Smith et al., 2009b). The degree of variation is revealed within the narrative account of the findings. Themes that were not recurrent may also be important, especially in a study exploring the patients' perspective as a novel area in this field. Their



inclusion allows the analysis to focus on particular concepts as well as identify patterns between emerging themes (Smith, 2011).

A narrative supporting each theme is presented in the following section. As the accounts of people with dementia on their experiences were central to the aims of this thesis, direct quotes from their interviews have been selected because they present the essence of themes, or because they represented the most articulate expression of the themes (Flowers et al., 2001). Extracts from interview transcripts from people with dementia that took part in more than one interview are denoted with the temporal point when data was gathered (1=first interview, 2=second interview and so on).

The analysis of the data from focus groups with nurses and non-participation observations were used to expand on the themes, and data from the different sources that facilitated this are presented in the narrative. Extracts from the focus groups with nurses that were carried out at different time points are shown as time 1=T1 and time 2=T2. Extracts from field notes from the observations of people with dementia in the wards are denoted by their pseudonyms.

#### 4.2.1 Power and control

A strong, recurrent theme related directly to the ways in which people with dementia lived with a lack of power and control whilst in hospital. This super-ordinate theme consisted of three themes: control about decision-making about being on the ward, constrained by the hospital environment and power in interactions.

##### 4.2.1.1 Control over decision-making about being on the ward

Most people with dementia discussed their own understanding of the reasons for them being in hospital, as well as how they felt about their understanding. Annie was aware of possible antecedents to her admission, as Annie put it:

*“I went in err, I went and fell and that’s what caused the, can you see that? [points to marks on arm]. Oh, it first caused that [points to bandage on leg], and then I fell again and it cause that [points to forehead]”. (Annie, 1).*

Despite Annie's account of the accident that had led to her admission, she saw little point to her being in hospital, which to her was something to be endured and put up with:

*Interviewer: "Do you think that you need to be in hospital at the moment?"*

*Annie: "Well I can't see the point to it. You think, 'oh well just shut up and plod on with it'". (Annie, 1).*

Most people with dementia expressed some confusion and uncertainty about the rationale for decisions that were made about them being on the ward.

When asked about why he was in hospital, Bert responded with:

*"No. it's not that I don't know, it's just that I can do it for myself anyway. There's nothing I haven't been able to do. I have a few things that are getting less I suppose". (Bert, 1).*

The above extract draws attention to how some people with dementia would on occasion give abstract responses to direct questions, which was to be expected during interviews with people with dementia. In Bert's response, he alluded to the notion that he was in hospital due to a deterioration in his ability in some way to take care of himself. A minority of participants, when asked the same question, gave relatively convoluted responses. It was clear however that they were troubled by being in hospital, such as in Stan's reference to being alarmed:

*"Well it's a good question. Erm, I think erm, I came along for, this should be something that I could do for. And erm, and I would be err, I would be alarmed away. It's really something like that. Alarmed away. It's really something like that. I don't know". (Stan, 1).*

Despite the reason for coming into hospital being a point of confusion at times, most people with dementia felt that they had not been involved in the decision to come into hospital and that they did not agree with the decision:

*"... I got up one morning...they sent me to [hospital]. All that was one big mistake...because I was a hundred percent fit really". (Bob, 1).*

Maggie demonstrated one of the most explicit attempts at articulating a lack of involvement about her circumstances, protesting that she did not want to come into hospital and that decisions about her were not made by her:

*"I didn't have a choice in it. I had to come. I didn't want to come in here and it's for them to decide... I didn't want to come in here. It was put on me". (Maggie, 1).*

When discussing who may have been responsible for decisions that had been made about them coming into hospital, some people with dementia felt that it came about because of their family's wishes. This was usually in relation to the family members perceptions that the person with dementia was unable to look after themselves at home, as Alfie explained:

*"I'm not a hundred percent sure. Just, my family. They think I'm not looking after myself but I keep telling them I am". (Alfie, 1).*

For other people with dementia who protested about being in hospital, they suggested that being old, and having dementia were reasons for them being in hospital:

*Interviewer: "Can you tell me a little bit about why you have come to be in hospital?"*

*Harry: "Because somebody decided to label me and I'm old and that's what they do. But I'm Alzheimer's, dementia, old, I'm all of them". (Harry, 3).*

In the above extract, Harry's reference to being labelled indicated that for him, some of the negative attributes that are commonly associated with his societal group were the reasons for his admission. This suggested that some people with dementia felt that labels were imposed upon them that they did not want.

In contrast, Henry, who talked at length about his frustration at being in hospital, appeared to create a story that may have helped him to make sense of where he was:

*"I'm here and I want to be at home, nearby you know? I spent some time now here and they don't think there is much else they can do so may as well be out. It just so happened that it was unfortunate that someone died and I got this bed. I wouldn't be here otherwise. They would have patched me up and sent me off on my way". (Henry, 3).*

In the extract above, Henry suggested that his admission was precipitated through random events that had little to do with him and that these events were related to him having no control over where he was. Another

participant, Ethel, also appeared to create a story line that may have helped her to make sense of the reasons for her being in hospital:

*Interviewer: "Can you tell me what has happened to you since you have come into hospital?"*

*Ethel: "Well, I've met one or two people about different things and about different illnesses which I think is very good to learn. And you can sort of pass it on then, to what you've got to know, to other people you see and they can pass it on....I think that's sort of a good idea is that, so, I'm hoping it works". (Ethel, 1).*

Although Ethel was not specifically asked during the interviews why she had come into hospital, she appeared to qualify her role in hospital as being there to help others, with caveats of 'pass it on', and 'they can pass it on', suggesting that there was a purpose to her experiences which other people could draw upon. However, Ethel, like Annie, felt that there was nothing that could be done to help her through being in hospital: "*I mean you are in hospital but there's nowt they can do for you*". (Ethel, 1), which suggested that she too felt that she had little control over where she was.

Another participant, Vera, denied that she was in hospital after being asked:

*"I'm not in hospital love so I can't tell you about it". (Vera, 2).*

Vera's response was surprising given that she had, just a few moments before, provided informed consent to talk with the researcher about her experiences in hospital. When asked where she was, Vera responded with: "*I don't care for it love...*" and then went on to ask for some scissors. In this instance, the interview was drawn to a close as it was not clear that Vera had capacity at that time to take part in the research. However, her denial that she was in hospital suggested that Vera may also have felt that she lacked control over going into hospital.

### Nurses accounts

Similar to people with dementia, nurses who participated in the study felt that they had little say in decisions about being on the ward. On discussing how they felt about caring for people with dementia they revealed that:

*“A lot of the time you're thrown in with these patients and the thing is sometimes you don't have just one or two on a ward, you can have quite a few”. (Nurse, 4:T1).*

In the above extract, the sense of being *‘thrown in’* with quite a few people with dementia indicated that nurses felt that some of their patients were different to those that they expected to care for, and that they had little choice over their placement. In the following abstract, one nurse described how they were often suspicious about the reasons for some people with dementia being in hospital:

*“You find you treat the UTI [urinary tract infection] and all of a sudden there are all these problems, ‘oh, they are not managing at home’, and they don't tell you when they first come in. They always tell you the day before they are going home”. (Nurse, 1:T1).*

The interesting thing to note from the above extract is that it appeared that nurses required that their patients have a definitive medical diagnosis that could not be treated in the community to legitimise their stay in hospital. Likewise, some of people with dementia felt that they had come into hospital for social reasons, due to an inability to care for themselves in some way, which they too felt was not a genuine motive for their hospitalisation.

Nurses were also concerned that people with dementia may stay in hospital longer than was medically necessary due to their social circumstances, which was at odds with being in hospital:

*“It [dementia] seems secondary. The doctors are focused on that one [medical] treatment... Acknowledging [dementia] could keep them longer in hospital... They could be hanging around for 3-5 days to get a psychiatric review”. (Nurse, 1,3 & 4:T1).*

In the extract above, nurses indicated that hospital staff may be motivated to ignore the existence of dementia, particularly for those people who were not already known to psychiatric services and were therefore unlikely to have been formally diagnosed with dementia. Although nurses did not state that this actually occurred, they indicated a tension between acknowledging the existence of dementia and a focus on their responsibilities to meet the targets of senior management.

#### 4.2.1.2 Constrained by the hospital environment

Most people with dementia said that they found the ward environment not conducive with their own preferred or usual routines, as expressed by Alfie: *“I’d rather be at home where I’ve got my own routine.” (Alfie, 1)*. The ward routine appeared to dominate what they could and could not do. Irrespective of whatever else a participant may have been engaged in, at particular times during the day when tasks needed to be carried out by the ward staff, participants were directed towards the task at hand. The following excerpt from the field notes demonstrated how this would occur:

*‘Staff interrupt whatever is going on to get their tasks completed, for example shortly after I had started my conversation with Mary, a catering staff member entered the bay and talked to her at the same time as she was talking to me’. (Field notes, Mary).*

Some people with dementia felt that often care tasks took priority over their own wants and needs. There were occasions when the dominance of the ward routine appeared to be odds with what they understood that they should be doing, as Alfie stated:

*“They tell you to get bed rest and then when you do go to bed they wake you up to do something”. (Alfie, 1).*

Sally also commented on the lack of sense in the routine of the ward, which for her was a source of annoyance:

*“They wake you up in all hours to give you tablets and I think they wake me up to put me to sleep”. (Sally, 3).*

On other occasions, some people with dementia appeared to interpret the actions of the staff as prompts as to what was expected of them next. For example, regular events, such as meal-times or medication rounds were precipitated by particular items that were brought into the ward by the staff, as described in the following extract from the field notes:

*‘Catering staff entered the bay, pushing in a refreshments trolley. Mary immediately sat down in her chair (like she is preparing herself for the next event, after not being able to identify what she ‘is supposed to be doing’). Shortly after, a sandwich and whole apple are placed on her bedside trolley within her reach. The catering staff member did not speak to her at all while doing this. Mary picked up the sandwich, took one bite and replaced it on the plate. I’m not certain how she will eat an apple (as she does not have any teeth)’. (Field notes, Mary).*

In the above extract, Mary appeared to be aware of what she was expected to do, despite the lack of dialogue between her and the staff member. This suggested that parts of the routine, like physical care and interventions discussed earlier and, as seen here, delivering meals to patients, were established as fixed processes for staff, which in this instance may not have required a dialogue with their patients. However, the lack of attention to what would be appropriate for Mary to eat indicated that that the processes through which staff carried out their work could be impersonal, and on this occasion incongruent with Mary’s individual needs. Like the sentiments expressed by Alfie and Sally, there was an apparent discord between the care that was delivered and the individual preferences and needs of some of the people with dementia, which acted to disempower them.

On discussing cues within their environment, people with dementia appeared to rely on them so as orientate themselves to time of day and events within the ward routine. There was little evidence from the observations that attempts had been made to orientate people with dementia to time and place. On one of the wards, there was an orientation board with details of day, date and special events written on it that had been placed in the middle back wall

of one of the bays. This was visible only to those entering the bay, and not to patients who were at their bedside area. Often, it was out-of-date, with *'Wimbledon men's final'* stated as an upcoming event, although this had in fact occurred 3 days prior for example. Feeling displaced through lack of orientation was expressed in the following sentiment from Maggie:

*"I don't know what day it is here and yet I knew the day and time and where I was going (before I came in here)". (Maggie, 1).*

In the above, extract, although Maggie did not specifically state that she required cues to help with her orientation, it can be inferred through her reference to not knowing the day and time. Likewise, Sally described how she did not know where she was due to the ward being moved around:

*"For some unknown reason they have moved the ward around and you don't know where you are at times". (Sally, 1).*

The above extract was elicited from Sally during an interview that took place shortly after she had moved into a different bed on the ward. The reasons for the move were not clear to Sally or the researcher. What was clear is that the move likely contributed to her feeling disorientated. The ward regimen and lack of orientation cues appeared to act to constrain some participants, and for some, contribute to the confusion that they felt and expressed.

Most people with dementia stated that they were often distracted by noises from events taking place within close proximity to them that did not involve them directly. This too contributed to feeling disorientated. It was common for people with dementia to be distracted during interviews.



The following extract from an interview with Maggie provided an example of the ways in which such distractions could interrupt her train of thought and be a source of frustration to her:

*Interviewer: "Do you remember we were talking before about...?"*  
*Maggie: "Yes, about three days, something like that"*  
*Interviewer: "How are finding things now?"*  
*Maggie: "Oh, it's very nice. Good. They are all very good to you"*  
*Interviewer: "Are they?"*  
*Maggie: "Yeah" [Interruption – discussion with ward manager]*  
*Interviewer: "We were talking about everyone being good to you here. That's what you need, isn't it?"*  
*Maggie: "It is love, yeah. Yes, it's what you need. Oh for goodness sake, stop buzzing" [background noise of buzzer]*  
*Interviewer: "Is that bothering you?"*  
*Maggie: "It does and it doesn't. I suppose she has to let them know". (Maggie, 1).*

In the above extract, Maggie suggested that common events that take place within the ward could act to disempower individuals. The lack of control that they had over what took place may have contributed to a lack of agreement to being on the ward.

For other people with dementia, their individual environment took on importance. During the observations, people with dementia were observed to spend time organising and using items within their immediate reach, such as Ethel: *'Ethel frequently opens her handbag and puts her hand in it as if she is checking for something'* (Field notes, Ethel). However, the position of personal items within their personal space potentially presented confusion over the sequencing of required actions, as is described in the following extract from the field notes: *'There is a hair comb sat next to the soup bowl. I cannot see a spoon on the table'* (Field notes, Vera).

The majority of their time in hospital was confined to their bed space area, which for most people with dementia was devoid of anything personal.

Some lacked essential items and were frequently observed to be concerned as to the whereabouts of their belongings:

*"They brought me in with no teeth in. They brought me in with no glasses. Nothing." (Mary, 1), and:*  
*Mary: "Do you know where my slippers are love?"*  
*Nurse: "You've got them on your feet."*

*Mary [looking down at her feet]: "These are not mine."*

*Nurse: "You can keep them for now."*

*Mary laid her head back and closed her eyes'. (Field notes, Mary).*

For Mary, not having her personal belongings with her was a constant source of anxiety. The extract above was typical of staff responses to her concerns. This indicated that what was important to Mary was not seen as important to staff. This manifested as erosion in her trust in the integrity of the nursing staff, as she explained in the following extract:

*"I've asked, but I've asked please get me my things...The said they'd give it to me, they'd do it, and I'm still waiting. I've got now that I can't trust...They say they are going to do something and they are just out for what they can get...If I've asked once, I won't say who to, I've asked a thousand times". (Mary, 3).*

For other people with dementia who expressed similar worries, it was not clear whether belongings were missing or lost. What was important was their sense of not having around them that which they deemed of personal import:

*"I struggle to hear...Do you know, I can't find my hearing aid anywhere. I've looked and I can't find it". (Henry, 1).*

Lack of access to individual aids to support daily functioning may have exacerbated feelings of disempowerment. Conversely, of those participants who did have personal items in hospital, such as Alfie and Vera, these appeared to provide opportunities for empowerment. Photographs of loved ones and other items that were personal to them were often employed by them to steer the topic of conversation during their interviews.

They also provided prospects for them to converse with other people on the wards:

*'Alfie stated, to the ward, "this is my great-grandson, whilst holding up a picture of him. A nurse approached him and asked if she could have a look. They conversed for several minutes about his family. Alfie appeared more animated throughout and happy to be talking with her'. (Field notes, Alfie).*

The above extract draws attention to the ways in which people with dementia chose to manage their time beyond the dominance of care tasks, which varied across the group. Bert, felt that he could do what he wanted to do, which mostly involved going into the television lounge:

*Interviewer: "How do you spend your time here?"*

*Bert: "Well I go and watch TV quite a bit. It's on all the time you see. I turn the sound up when I'm interested in it". (Bert, 1).*

Other people with dementia felt more restricted, particularly if what they wanted to do was at odds with the usual routine of the hospital ward, as Sally put it:

*Interviewer: "How are things different for you here compared to being at the home?"*

*Sally: "That's the problem you see. You sit here and it bores me to death and then I go to my bed. If I go to bed earlier, they ask you why you are and don't believe you when you say that you are tired. They ask where have you been and I say I've only been resting on my bed and they don't believe me so I tell them, alright go and have a look. They say you have been getting out of the way of doing anything"*

*Interviewer: "What is it they want you to do?"*

*Sally: "Well that's all I wanted really, I've always liked to rest". (Sally, 1).*

In the above extract, Sally's attempts to alleviate her sense of boredom was discouraged by the staff, likely because of their belief that she did not need to be in bed. This was despite Sally having, what was for her, a legitimate reason for going to bed. Being in hospital appeared to restrict the ability to make choices as to what people with dementia did when, as expressed in the following extract from Vera about her thoughts on being at home:

*"I like being at home more, and I like, you know, getting my food. And I can watch television if I want, or if I don't want to". (Vera 3).*

Vera's comment indicated that it was a lack of freedom to choose what she could do in hospital that was problematic for her. Like the sentiments expressed by Sally earlier, participants complained about boredom through their lack of activity and occupation whilst on the ward. The mundane nature of their experiences was clearly expressed in the following extract from Elsie:

*Interviewer: "How do you spend your day here?"*

*Elsie: "Sometimes I go to the toilet, I come back and that's about all". (Elsie, 1).*

Some people with dementia attempted to alleviate some of the boredom that they felt through seeking out different places to go:

*“There is nowhere else to go... I’ve tried sitting somewhere else but I get in the way. They refuse to let me”. (Sally, 2).*

In the above extract, Sally indicated that she was prevented from going to different places by the staff. This restriction appeared to impose a sense of incarceration for some people with dementia, as Sally stated: *“I just want to do my time and get back where I belong...” (Sally, 1)*. Often this appeared to be used as a means of cheering oneself up by making light of their situation. When asked to describe her usual routine, Vera replied:

*“I get up, have breakfast, erm, and then I muck about with the, either with the nurses and doctors, and then muck around with the staff and the inmates as well. Interviewer: Inmates? Vera: [laughs] It is as well. In fact I think it’s probably the worst I’ve ever been, being in here”. (Vera, 3).*

In the extract above, Vera described how she felt that she, and other patients were inmates, which conveyed a strong sense of powerlessness within the hospital. This sense of removal of freedom, control or choice was perhaps expressed most vividly by Annie:

*“You’ve got to do this, and you’ve got to do that, and stay here”. (Annie, 4).*

Alfie also commented that his mind felt worse through being in hospital:

*Alfie: "Most of them [other patients] just want to sit there and talk about their illnesses. Makes you want to go home even more, it's depressing"*

*Interviewer: "So do you think being in hospital's made things worse for you?"*

*Alfie: "Well health-wise I'm not sure but my mind certainly feels worse". (Alfie, 1).*

Although Alfie did not specifically state that his mind felt worse due to a lack of activity, he indicated that lack of variation in what others talked about contributed to his sense of well-being.

Like other people with dementia who chose to occupy their time through going to other spaces on the ward, this generally raised concerns from the nurses, particularly in the case of Maggie, who frequently entered into other patients' personal space. The nurses often took control of the extent to which she could move around the ward through constraining Maggie in a chair from which they could observe her:

*'Maggie has been positioned in a chair opposite the nurse's station with a bedside trolley in front of her. I think this is to keep a closer eye on her as she often stands up and is asked to sit down. She frequently states "I don't know what to do" which is not acknowledged by passing staff for the majority of the time although one nurse passed and said "there will be a cup of tea shortly, might as well stay for that". Maggie said "Okay, will do" and sat back down for a short period'. (Field notes, Maggie).*

In the above extract, nurses took actions to ensure that Maggie perceived that she was in control over her personal environment through a process of negotiation; in this instance through waiting for a cup of tea. However, the placement of items that prevented Maggie from walking meant that staff had physically restrained her movement.

### Nurses accounts

Although observations of the type of restraint described above were rare within the data, nurses acknowledged that at times they took actions to restrict choice and freedom for people with dementia:

*“He went bananas, climbing up the walls trying to climb out windows...we had to sedate him very, very heavily because it was the only way we could manage him for his safety”. (Nurse, 1:T1).*

As implied in the above extract, such actions were taken to ensure the safety of their patients. However, nurses were uncomfortable with some of the ways in which they restricted people with dementia, as one nurse described:

*“It doesn’t sound caring some of the things we say. You know, someone will go ‘sit down’, ‘sit in that chair’, ‘get her sat down’...and I feel like saying ‘if you told me to sit down that many times I’d punch you.’ And I sometimes think – and I don’t mean this to sound awful – but I’d rather have the risk of the lady falling than to be pushed back in – not literally pushed – but encouraged back into a chair 300 times a day”. (Nurse, 4:T2).*

This introduced the notion that caring for some people with dementia may at times be considered as uncaring. In the extract above, restricting spontaneous movement was particularly difficult to do, but necessary so as prevent injury. Generally, the ways in which people with dementia were restricted in their choice and freedom was more subtle. Nurses were acutely aware of the limited opportunities for people with dementia to engage in purposeful activity on the wards and felt that there was very little that they could do to help with this situation:

*“You can see them going down and getting depressed as there is nothing for them to do, they are up and they dress, they have their breakfast, they have their dinner, we come round and do observations, they have their dinner, we check them again...there’s hardly a book to read, there’s no activities for them to do. There is one telly but it’s knackered, there’s nothing”. (Nurse, 2:T1).*

In the above extract, like the sentiments expressed by people with dementia, nursing staff alluded to the notion that lack of activity could worsen the mental health of people with dementia.

There were also accounts from relatives and nurses that confusion could become worse for some people with dementia through being in hospital:

*“They [relatives] are saying that he's been getting worse and worse because he's in a hospital setting...he gets confused where his bed is. He's certainly got worse since he came in it was mild and it's extreme... That's not unusual”. (Nurse, 8 & 6:T1).*

In the above extract, the notion that it was the entire setting, rather than specific aspects of the environment that could increase cognitive symptoms of dementia was mentioned. The statement that it was *‘not unusual’* for this to occur indicated that nurses felt that through people with dementia being in hospital, it was likely that their symptoms would worsen. In fact, nurses held strong opinions about the inappropriateness of the hospital environment for people with dementia and expressed a range of views on how the environment could be made more suitable. Their ideas included in-house training to help equip nurses to manage people with dementia more effectively to separate specialist units staffed by mental health trained professionals. A common middle ground was the desire for a specialist nurse to be available to support existing ward-based nurses. It is of interest that nurses felt that changes to their knowledge and skill set in caring for people with dementia in hospital could improve the appropriateness of the care environment. This indicated that nurses felt that they were ill-equipped to care for people with dementia, which meant that the care that they received was less than adequate, as one nurse commented on how they felt about their own practice:

*“I'm completely out of my depth, I don't know what I am doing”. (Nurse, 4:T1).*

Nurses felt that they as a group were not properly trained to care for people with dementia:

*“We are not trained I don't think properly in dementia. I think that's basically what it is, we're just not...we don't have the right training”. (Nurse, 1:T2).*

The consequences of not being adequately prepared to care for people with dementia was that nurses perceived it limited the quality of the care that they provided, which may have contributed to feelings lack of control and powerlessness for people with dementia.

#### 4.2.1.3 Power in interactions

People with dementia talked about who they interacted with, when, during their day. The nature and type of interactions that people with dementia discussed were varied, all of which had in common the potential to shape their hospital experience.

Linked to the dominance of care tasks discussed earlier, some people with dementia talked about how staff would appear to do tasks and then leave, as Vera described:

*Interviewer: "How do you feel about being looked after here?"*

*Vera: "Well they don't. They do and they get off and that's it really. They are there and they are not there.....and they just, and they just do, oh I don't know, and they just..."[long pause]*

*Interviewer: "You were just telling me what you think about the nurses on the ward and that they are there..."*

*Vera: "Oh yeah and they are there and they are not there and they just do what they need to do and are gone again"*

*Interviewer: "Okay. And how do you feel about that? How does it...?"*

*Vera: "I don't mind it. Erm, I do what needs to be done and that's it you know". (Vera, 3).*

Whilst some people with dementia, like Vera, appeared not to mind that the nurses came to do what they needed to and were gone again, others indicated that they wanted the nurses to do more than just what needed to be done, as Bob explained:

*Bob: "It's grossly unfair. I mean even when I did have home care I had a couple of very good ones. Not like in here... It's not fair. If I get 10 minutes attention in 24 hours I'd be lucky."*

*Interviewer: "What is it that you want more of Bob?"*

*Bob: "You see they don't talk to you, with you. They talk at you". (Bob, 3).*

In the above extract, Bob alluded to the notion that through being in hospital, he did not get to talk with people that were caring for him due to the lack of their availability. His sense that staff did not talk with him, but at him, indicated that for Bob, the way in which his care was organised and delivered was unfair, as it constrained his ability to talk with others. For him, there was a lack of power in his interactions with the staff.



It was common for people with dementia to feel physically and emotionally distant from those tasked with caring for them. Henry also highlighted problems with limited availability of nursing staff:

*Interviewer: "What are the nurses doing for you here?"*

*Henry: "They do everything and nothing. They do a lot and don't tell me. That's it. They are rushing around."*

*Interviewer: "What do you mean?"*

*Henry: "They are here and they are there and I know they are busy I suppose. They have everything to do, and nowt for me, and they have loads to do. Not worth it for me". (Henry, 1).*

For Henry, the consequences of nurses having 'nowt for me' appeared to indicate a sense of unimportance, and a lack of connectedness with that which the staff were busy with. Similarly, Harry said:

*"They come and they start fussing around and telling you when they start doing little bits and pieces for you, but they haven't got the time to sit down and talk to somebody like me. They are busy doing their jobs, aren't they?". (Harry, 2).*

In the above extract, Harry's statement that the staff 'haven't got time to sit down and talk to somebody like me' conveyed a sense that he felt that he was inferior in comparison to some of the other patients. He also indicated that he would like to spend time talking with staff, and like Henry, that this need was not a priority for the staff that were taking care of him.

Other people with dementia were more specific about what it was that they wanted help with. Annie held negative views on the availability of staff to help with her needs, particularly around being able to mobilise in her environment. She was unable to do so without support, which often she perceived was not available to her:

*"They haven't got the time...I think they are very busy aren't they? They don't have time and because I've got so I can't walk, it's not going to get better even if they do have time. They're not gonna get rid of, err get rid. I'll be rid soon enough. Probably they think it's not worth bothering". (Annie, 1).*

In the above extract, the notion of not being important within the scope of nurses' work is again highlighted. For Annie this manifested as *being 'not worth bothering'*, which suggested that limited availability of staff was internalised as evidence that some participants' needs were beyond help.

This appeared to be at odds with the caring role of nurses. Other people with dementia suggested that it was the number of patients of the wards that prevented nurses from doing their jobs properly:

*“Top and bottom of it is that there’s far too many people in here for them to do their job properly. Especially when they are all together like this. Fortunately I can talk. There’s some that can’t. We are more or less on our own”. (Sally, 2).*

In the extract above, Sally suggested that patients who may have difficulty in communicating their needs took up a lot of the staff time, and therefore, those who could talk were more or less abandoned.

The most important element of being cared for seemed to be getting the right help, when it was needed. A minority of people with dementia that required support with their daily living were keen to assert that had access to support when it was needed (Sally, Alfie and Maggie), as Maggie stated: *“There’s always someone there if you need them”*, (Maggie 1). This was despite having a sense of being unimportant to the work of the staff:

*“They do what they can for you and it’s not their fault if they’ve got all these others to see to and can’t get to me”. (Sally, 3).*

The perception that participants expected that most of their needs were met appeared to be held only by those people with dementia who stated that they could communicate their needs successfully. The extract below from Alfie illustrated his understanding that he was responsible for ensuring that his needs were met:

*“If I need something or I want something then I’ll ask them for something... And if they are not busy then they will. You know, they don’t fuss over you...”. (Alfie, 1).*

In the above extract, Alfie draws attention again to the limitations of being assisted. His use of terms such as *‘if they are not busy’* and *‘they don’t fuss over you’* indicated that some people with dementia negotiated getting their needs met through an understanding of the busy nature of hospital work.

In the following extract Sally suggested that she was responsible for monitoring and communicating her own needs, which she sometimes chose not to do because of the perceived priority of needs of other patients:

*Sally: "Well, I don't eat what they have cos it makes me poorly. It isn't like I can have it"*

*Interviewer: "Is there anything different that you can have?"*

*Sally: "No, no. I don't want it. They've too many others to bother with, you know. Don't mind me [pause]". (Sally, 2).*

The above extract indicated that in the absence of overt monitoring, which would require staff to approach their patients to enquire as to their well-being, that some people with dementia, including those who could verbally express their needs, felt that they were limited in the amount of control that they could exert over getting their needs met. Another participant, Henry, talked about being in a lot of pain and of having communicated this to the staff, although he was not certain which staff members were aware of his condition:

*Henry: "I have a huge, a huge lump on the other side and it is sore. It's burning. I complain about it and I don't complain about things a lot. So of course I came in here to sort it out. I feel like a stranger in paradise really"*

*Interviewer: "Do you really?"*

*Henry: "Yes, it's very big, very busy. It's upset me most of all cos I'm in terrible agony with my knees and they are hurting now and they are. I hurt all the time and I don't like to say owt, anything. I've never known anything like it"*

*Interviewer: "So do you get help with it here? Do you ask?"*

*Henry: "I don't think they can do anything"*

*Interviewer: "So do you still..."*

*Henry: "I get cold feet so I don't think that I will say anything, do anything you know. I spoke to some of them, they work here but I wouldn't know if I saw them". (Henry, 1).*

In the above extract, Henry conveyed a sense that there were lots of staff that he had spoken to but that he would not be able to identify them if he saw them. His sense that he had discussed his pain, was still in pain and was hesitant to raise the issue with staff suggested that he felt that there was nothing that the staff could do about it. The idea that participants would speak to different members of staff and were not clear on which staff members could help them with their specific needs suggested that some people with dementia felt that they lacked any power to influence what could be done to help them.

In their accounts of relationships with staff, most people with dementia talked about their awareness of good and not so good staff, which indicated that for these people with dementia, the length of time that they had been on the

ward was enough to determine which staff they preferred to care for them. In the following extract from Harry, he expressed how variation between the attributes of the different members of staff impacted on his ability to get what he needed:

*Interviewer: "How do the staff help you here?"*

*Harry: "It depends on whose working because there's some nice ones, there's some not so nice ones, and there's some of them that just can't be bothered. So it depends who it is... There is some that actually assist me when I can't do and there is some who can't be bothered and just come and throw it at me and there is some who don't even talk to me. They don't like it here". (Harry, 3).*

What appeared to be important to Harry was a sense of being helped when needed, and that he was treated with respect. Harry suggested that in his view, the unhelpful staff were not happy at work, and as a consequence of this he lacked power in his interactions with them, which manifested as being unable to get the care that he needed.

Other people with dementia talked about variations in staff willingness to support them to communicate in their preferred way. In the following extract from Bob, he described how, after ringing his buzzer in order to summon staff for help, often the responses of younger staff members were intimidating and as a result, he was unable to express his needs:

*"The older nurses are a delight to deal with, they really are. But the younger ones, they, you press your buzzer, they walk up and stand over you, and they won't even say hello. 'Yes Bob?' That's the way they speak to me, 'yes Bob? What do you want? What are you buzzing for? That's the fourth time you've buzzed today. We're not here, blah, blah, blah'. Now I don't have to be here". (Bob, 3).*

The extracts above suggested that inconsistencies in staff attributes might contribute to a positive or negative appraisal of their experience. Whilst older staff members were deemed as behaving appropriately, younger staff members were perceived as having negative attitudes towards Bob's expressed needs. An important point to note here is that Bob perceived that he lacked control over who cared for him and felt powerless to change the situation. Other people with dementia who chose to summon staff through using their buzzer talked about how they too were discouraged from doing so:

*Annie: "They say I've had everything and then I'm coughing my guts up and there's nobody here to help"*

*Interviewer: "Oh dear. Are you ringing your buzzer to get some help?"*

*Annie: "I do. And I feel sorry for myself"*

*Interviewer: "And do they come?"*

*Annie: "They do come yeah and they are telling me I can't have my buzzer. That is very, what's the word? Discouraging, annoying really"*

*Interviewer: "Yeah. I'm not sure why...?"*

*Annie: "They keep telling me I've had everything, there's nothing more. I'm sure they know what they are doing, I suppose". (Annie, 3).*

In the extract above, the notion that staff should only be summoned if they perceived that there was more that they could do to assist people with dementia was again raised. This suggested that for some people with dementia the limits in what the staff could do to help them acted to exert control over what the person with dementia could do.

Some people with dementia stated that they were lacking support with attending to their basic needs, which suggests that their requests for staff time were not unreasonable. It may well be that they had forgot or misinterpreted the support that had been given as something else.

One participant, Bob, who was particularly critical of staff, felt that he was ignored and through this, that the staff were not doing their job:

*Bob: "They don't do their job properly so I just have to sack them"*

*Interviewer: "What is it you want them to do?"*

*Bob: "Well it's upfront...They just don't do their job. There ain't an ounce of sympathy or reaction. You can swear at them, you can shout at them, and they just walk out". (Bob, 1).*

In the above abstract, Bob clearly stated that he felt powerless to provoke reactions from the nurses, which for him may be about receiving sympathy. He internalised this as evidence that the nurses do not care for him.

Some people with dementia talked about other patients being be a source of frustration, particularly when they invaded personal space:

*Alfie: "You get some tricky ones. I couldn't believe it last night. Two o'clock in the morning, he (pointing towards another patient) walked over here. I'm not going to keep putting up with them. I said what are you doing?"*

*Interviewer: "What was he doing?"*

*Alfie: "Well, it's his illness, isn't it?"*

*Interviewer: "Is he a bit confused do you think?"*

*Alfie: "Yeah. I mean most of them are. When they talk to you they come right up to your face and it does me in". (Alfie, 3).*

The sense of frustration that Alfie expressed from another patient being in his personal space indicated that he felt that he could not control what the other patient was doing. In the above extract, Alfie also indicated that perhaps his co-patient lacked some control over what they were doing because of their confusion, and that this therefore limited his ability to exert some control over what took place.

Several other people with dementia talked about how they lacked power in their interactions with other patients due to the nature of their conditions. They wanted to socialise with other patients, yet opportunities to do so were limited. As well as a lack of places to go on the ward, the limiting conditions of other patients in the ward meant that opportunities for interactions with them were rare, as Maureen explained:

*"There isn't much that can walk about. No there isn't much talking goes on because they are all elderly". (Maureen).*

In describing other patients within her immediate environment, Sally, like Alfie complained that they could be a source of annoyance to her:

*"And you hear her there always rolling about in pain, crying out. I could do with a side room...The nurses came and told her to go back through. She looked like she were gonna kill me...And her there...looks like a banana doesn't she? I told her she does too [laughs]. She said she doesn't know why she is here. She had a hat on and she took it off and I got such a fright. A nutter's ward". (Sally, 3).*

In Sally's account, she described her environment as 'a nutter's ward' which for her meant that she did would prefer to be isolated from her co-patients. It appeared that on the one hand, some people with dementia felt that they lacked power in their interactions with other patients as they were unable to get to be near them, and on the other because other patients were perceived of as confused, and unable to interact in conventional ways.

Other people with dementia talked about the importance of other people in their lives to them. On discussing visitors, people with dementia often preferred to spend time with members of their family. Alfie had several family members that would visit him, which he looked forward to:

*Interviewer: "Who will be visiting you today?"*

*Alfie: "Could be one of the kids, one of the grandkids. Me great grandson might pop round more. He always makes me laugh. I like it when he comes round". (Alfie, 2).*

In the extract above, Alfie indicated that often he was not certain as to which family members would visit; this was something which he did not have control over. A similar sentiment was expressed by Elsie:

*Interviewer: "Are you expecting a visitor today?"*

*Elsie: "Well I don't know, I know if they'll come..., anyway if they come they come". (Elsie, 1).*

Other people with dementia talked about how they were prevented from being with their relatives as in the following extract from Sally:

*Interviewer: "What have you been doing this morning Sally?"*

*Sally: "Nothing really, I've just been sat here. I usually just sit here or on my bed. There's a patient there who wanders about but not me. I just sit here. I haven't seen anyone today so I can't really tell you much. I haven't seen my daughter for a while. She'll be busy"*

*Interviewer: "Oh has she not been to see you?"*

*Sally: "No. No she hasn't been. So that's it. Have you ever felt you are not wanted?"*

*Interviewer: "Yes, at times. What's making you feel that way do you think?"*

*Sally: "That's how I feel"*

*Interviewer: "Is that because she hasn't been to see you?"*

*Sally: "I'm not bothered about that but she could have come once. She's busy and unfortunately like a lot of them, and they err, I don't know. I think I'll have a cup of tea in a bit". (Sally, 2).*

In the extract above, Sally appeared frustrated that her daughter had not visited her and tried to rationalise that this came about as she was maybe too busy to visit. It was not clear if Sally and other people with dementia that talked about family members that did not visit them would usually spend more time with them when they were not in hospital. What was clear was that they expressed a lack of control over who they saw, when.

Although most people with dementia wanted their relatives to visit, accounts of visits were rare within the data. This could have been a feature of their memory impairment rather than reality. On the one occasion where a person with dementia spoke about what occurred during a visit from a relative, Bert talked about how his visitors could antagonise him through their responses to his condition.

In the following example of how this might, Bert talked about how his relative would patronise him about his tendency to forget things:

*Interviewer: "You mentioned that you sometimes forget things. Are you worried about it?"*

*Bert: "My what? [laughs]. Yes, quite a bit really. It comes to me eventually but not soon enough. It depends what it is really. My family I know. I've had to make an effort with other things, people in here, what they've done and that. It's exceptional. Sometimes I don't know what day it is, a lot. Most days are the same to me and sometimes I usually think it doesn't matter now really. It confuses me sometimes. Always work it out in the end. I don't need to make decisions so I don't worry about it. The nurses and doctors and all in here do it for me. For instance my daughter came to see me the other day and she left these for me [notebook and pen] and I was a bit annoyed because she didn't think that I deserved them, you know. She behaved as if I was a slightly incapable young brother or something. It was a bit irritating but it was for me. I've always been like that. People might think I'm a bit dis-jointed because my ideas flit a bit from time to time". (Bert, 1).*

In the extract above, Bert indicated that one way in which he managed his cognitive impairment in hospital was to rely on others to make decisions for him. Through the behaviour of his daughter when leaving him memory cue materials, the irritation he felt was likely because he felt constrained through being patronised by her and being forced to collect information so as to inform decisions that he did not want to make.

In their accounts of their interactions with others, most people with dementia conveyed a lack of power and control in their interactions with others, which was due to their individual circumstances on the wards. One of the most recurrent findings in their accounts was the impact of powerlessness on their abilities to control interactions, including their ability to seek out the company of others that was important:

*"Ten years ago I could go out and walk anywhere...walk and see people, but not now", (Elsie, 1) and; "I've been fastened down...and I've been isolated more or less...I haven't seen or spoke to anyone". (Harry, 1).*



### Nurses accounts

Nurses stated that they were frustrated with the amount of time that people with dementia may require from them. They were concerned that the attention required in order to manage some people with dementia distracted them from going about their work:

*“There is currently one (person with dementia) now that is, is just taking the attention of the whole staff and we are just doing what we can, and when we can, try different things”. (Nurse, 1:T1).*

It was common in the focus groups for nurses to talk about how caring for people with dementia evoked negative emotions for them:

*“This man was tending to repeat himself a lot, when am I going home?[...] and after a while he just got on my nerves to put it bluntly, and I said I don’t want to talk to you, go away”. (Nurse, 4:T2)*

The absence of talk around positive emotions suggested that nurses viewed their role in caring for people with dementia as relatively unimportant; consequently at times they may take actions to avoid such patients:

*“Sometimes you’ve got to just walk away...and you’re not doing your job, you’re just trying to get away from that patient...it’s uncaring.” (Nurse, 2:T1), and:  
“You sometimes avoid that patient so you don’t have to deal with them anymore”. (Nurse, 1:T1).*

The extracts above suggested that as well as some people with dementia feeling powerless to initiate interactions with staff, that staff took actions to avoid some people with dementia.

Nurses echoed the views of people with dementia and some nurses felt that there should have been a higher staff to patient with dementia ratio on the wards. This was despite staffing levels being for the most part at establishment numbers during the period of data collection. There appeared to be a dichotomy regarding what the hospital organisation felt was appropriate resourcing in terms of staff and what people with dementia and nurses felt was adequate. Some felt anger and devalued by the lack of support they received in caring for people with dementia:

*“You don’t get no thanks for it [after describing being physically assaulted by a person with dementia], you get on with it and it makes you angry sometimes because you just feel that you’re of no*

*consequence. So as long as you're doing it, they [management] are happy for you to do it and they'll just let you get on with it". (Nurse, 1:T2).*

For other staff, they felt undervalued by the entire organisation:

*"When they knock us about we are just meant to fill in a form and that's the end of it. But it's not like that for us. We are the ones getting knocked from pillar to post and nobody bats an eyelid. It's like well, that's your job, get on with it, but we don't know what we are doing". (Nurse, 4:T1).*

The above extracts suggested that people with dementia who felt that staff did not care may be a consequence of the staff themselves feeling neglected.

#### 4.2.2 Notions of self

This super-ordinate theme refers to the way in which people with dementia talked about their own understanding of how they lived with dementia in hospital. This theme is made up of three themes: Living with a sense of failing self, expectations for a future self and grief for an expected self.

##### 4.2.2.1 Living with a failing self

This sub-theme refers to the way in which people with dementia talked about a decline in their physical abilities, and more importantly, the ways in which they lived with a sense of failing self due to a decline in their cognitive abilities.

Some people with dementia were unable to do much for themselves due to their physical condition. In the following extract, Bob, who had difficulty in moving his upper body, described how he attempted to reach a drink that is in front of him:

*"I sure [want it], but it's difficult. I can't reach it. I'm bugged. Can't lift my arms, can't stand, can't walk, can't see. It's guess work". (Bob, 1).*

In the above extract, Bob described how he felt helpless in his situation.

Henry also described how he was unable to do for himself, pointing out where he needed assistance from others with getting dressed for example:

*"Well I can't fasten them cos I can't use my fingers. But they help me and I put it on and they come and help me. I cannot lift my arms for it. They have to pull them down...". (Henry, 2).*

For Bert, his reduced mobility was associated with a loss of pride in himself

for not being able to go where he wanted to go:

*“I’m not as mobile by any means though, no. I used to pride myself on the way I could go. Go anywhere, do anything. Go where I wanted, when I wanted”. (Bert, 1).*

In the following extract, Bob described how his inability to get himself to the bathroom on time, was associated with a sense of embarrassment at his failing self:

*Bob: “This morning I couldn’t stand, I couldn’t walk and I dropped my trousers. It goes round like a ladies hairdresser. It goes right round the ward in 5 minutes. Every single person in this hospital knows the mess that went on. Everybody knows, and they hold it against me”*

*Interviewer: “I’m sure they don’t Bob, how would everyone know?”*

*Bob: “ Not joking”*

*Interviewer: “How would they know that? I’m not sure that everybody does know”*

*Bob: “Ladies hairdressers. They are all the same”. (Bob, 2).*

In the above extract, Bob alluded to the notion that the hospital was a public place in which intimate details of other patients were on display. Although the event described above was exceptional, it highlighted the notion that being cared for in a public place could have humiliating consequences, which for Bob, led to him feeling isolated from other people on the ward.

Other people with dementia talked about how they felt that there was nothing to be done that would change the course of their failing self. This was related to the idea discussed earlier about lack of control over coming into hospital, as Annie described:

*“Just being used as guinea pigs now we are and there’s not much else for us. We are old and getting older and they come and prod and poke and talk and it doesn’t stop it, does it?”. (Annie, 3).*

This sense of hopelessness was similarly expressed by Harry:

*“I’ve always said it, I’ve always said there’s nowt for the old folk, just chuck them on the scrapheap”. (Harry, 1).*

This suggested that some people with dementia felt neglected because of their age, and that this may not just be specific to the hospital care context, but to being old in general.

As well as living with physical difficulties, it was common for people with dementia to live with feeling confused, lack of concentration and understanding and a failing memory as Harry stated when asked about how he felt about being in hospital: *“I wouldn’t like to say because my mind’s in a turmoil”*, (Harry, 1). This sense of failing self appeared to take on more significance when people with dementia talked about how they interacted with others in hospital. Similar to the lack of control and power over the nature and type of interactions that they could experience, the importance of their cognitive difficulties seemed to be highlighted through their interactions with others, as Bob described:

*“I suffer from Alzheimer’s or dementia or a touch of both for the past 3 years and you change the subject and you’ve lost it”*. (Bob, 1).

Some people with dementia described how they lacked understanding when talking with the staff, which may explain, in part, why they felt that important information was withheld from them. In the following extract, Annie described how during her interactions with staff she was unable to understand what was being talked about:

*“There were two...people talking about medication, young boys you know, and I didn’t understand and I get it wrong with them and then I think I can’t be bothered with it all and there isn’t really anything you can do about anything at all you know”*. (Annie, 1).

In the extract above, Annie indicated that through her awareness of not understanding what was being discussed, her response was to *‘not be bothered’* as she felt powerless to do anything about it.

An inability to stay focused contributed towards a sense of being ungrounded, unstable and not in control during an event, as Annie said:

*“...I don’t really know, you kind of err, you lose track, you lose track and I think you can’t be bothered, and you get back on your feet again...”*. (Annie, 1).

People with dementia were aware that these changes rendered them as different from how they used to be and from other people. In the following extract, Alfie stated how frustrating it can be to not remember:

*Interviewer: “Do you spend time talking with others in here?”*

*Alfie: "When I can, yeah. There isn't many. There is a lot of them and then me memory and I can't tell you anything at times"*

*Interviewer: "It can be frustrating that, can't it?"*

*Alfie: "It is when you can't remember a damn thing, very, very frustrating. Well they think I am frustrating. It's important to me. I have to know what to say and do, you know?". (Alfie, 2).*

A further tension arose when people with dementia perceived that they had to work hard in order to recall their personal preferences and convey what these were to other people. When asked what she likes to drink for example, Annie stated that her understanding of the impact of her failing memory was that it eroded her ability to be herself:

*"This is another thing, that I could remember anything I wanted to, now I'm having to think". (Annie, 2).*

It was common for several people with dementia to associate not understanding or getting it wrong with being put off talking with others. In the following extract from Alfie, he elaborated on how getting it wrong, which was generally associated with forgetting things, made him feel stupid and angry:

*Interviewer: "Have there been any problems with you remembering things?"*

*Alfie: "Well nothing major, you know, if somebody tells me something like, I don't know, if me grandson says he's gonna call round in a couple of days and I'll be surprised and he says 'well, I told you I were gonna come.' You know, or if me son wants to take me shopping and he turns up and I'm not ready, you know? Things like that I might forget".*

*Interviewer: "How do you feel about that? If you are forgetting something?"*

*Alfie: "Well I fell a bit stupid which only makes me feel angry, like I'm an old dithering man or I've just forgotten a simple thing". (Alfie, 1).*

This sense of feeling stupid and angry may have led some people with dementia to avoid interactions that would expose their forgetfulness, and the labels that they associated with such behaviour, as Vera stated shortly after attempting to answer one of the interview questions:

*Interviewer: "Have you always been a good sleeper?"*

*Vera: "Oh, almost yeah. Almost. You see we can't, and I can't...[long pause]. I'm soon put off when err, I'm talking to people and I've got it wrong. Erm, I like to err, I like to know what I'm talking about". (Vera, 3).*

One of the ways in which people with dementia attempted to reduce the impact that a failing memory had on them was through taking control of an

interaction from the beginning. In the following example from Maureen, when asked to talk about what it was like for her in hospital, she stated that it may be difficult for her:

*“I’ll try to talk about it, see what we can see...there’s no point cos I don’t know, I don’t know, it’s a bugger when you can’t remember. Time just runs by”. (Maureen).*

In the extract above, Maureen suggested that there was little point to talking as she could not remember. Through being explicit about having limited ability to recall events, this may have softened the impact of the effect that a failing memory had for some of the people with dementia. Annie was the only participant that talked explicitly about strategies that she had developed to help with her failing memory:

*“Memory. Memory. That’s the trouble at the end of the day. I keep saying to err, Paul [her son]: ‘I’m gonna get a book’, we did get a book, I haven’t got that book here, ‘and every time I do something I put it down, and try to remember what we have done’”. (Annie, 1).*

Although Annie was unable to explain why she did not have her book, the absence of it suggested that this strategy was not seen as important by her family in the hospital setting. As Bert intimated in the extract about his relative bringing in an memory aid, this may be because there was a perception that memory aids were not required as some people with dementia were not required to remember events that may inform subsequent decisions whilst in hospital. Although this finding is tentative, it does indicate that strategies that may help a person with dementia with their sense of failing self were abandoned when they go into hospital.

#### 4.2.2.2 Expectations for a future self

Some people with dementia discussed their uncertainty about their future, which was related to their sense of a lack of control as to what was happening to them. They spoke of their future in relation to decisions that would be made by people other than themselves:

*“I just want to get back where I belong. I don’t know when that will be, they don’t tell me. They come and they do things to me, poke about but don’t tell me”. (Sally, 1).*

The interesting thing to note from the above extract is that Sally felt that things were done to her, physically, even though she had no idea what would happen next. This demonstrated how devastating not knowing may be. The following extract from Alfie, when asked about what will happen next for him, highlighted how there was a perception that hospital staff had information that was withheld from him:

*“The nurses and doctors will know. I honestly do not know”. (Alfie, 2).*

Similarly, Henry described a lack of information as to what was happening for him:

*“I’ve been left for days, without an explanation as to what was happening to me. Don’t tell me anything”. (Henry, 1).*

In the above extract, Henry alluded to the notion that a lack of information can be translated into feelings of abandonment. It is possible that some people with dementia may not recall what information had been given to them due to their cognitive impairments. However, an important feature of their experiences was a sense of not having the information that they wanted and having no control so as to gain access to the required information.

One way in which people with dementia gained information about their future appeared to be through the perceptions that they held about other patients, whom they perceived to have more advanced dementia.

In the following extract from Annie, she described how a lot of others were in a worse state than her:

*Interviewer: “Is there anything else that you can tell me about what it is like to be here?”*

*Annie: “Err, I mean some are in a, lot of people in a lot worse state than me. Err you know, mentally. They have, they are not there. Yeah, I didn’t realise and I was horrified”*

*Interviewer: “Was you?”*

*Annie: “Just sat here watching em, and nothing happening and no-one, err, I, no-one speaking. You think what am I doing here? Oh it was, is terrible.*

*Interviewer: “Oh, that must have been awful?”*

*Annie: “It was. Depressing. Knowing what’s coming and you have to say I, and err, they could be somewhere else”. (Annie, 1).*

Although Annie did not specifically state that the people that she was referring to had dementia, it can be assumed from her description of them *'mentally not there'* that she was referring to other patients on the ward who most likely had more advanced dementia. Her use of the term *'they are not there'* suggested that to her these patients were incapable of a relationship. Annie's reference to *'I didn't realise'* indicated that through her coming into hospital, her awareness of the decline in functioning that is associated with more advanced dementia had increased. Her use of the term *'I was horrified'* indicated that for Annie, seeing people with more advanced dementia evoked strong emotions for her. This was most likely related to her concern that she would become like those others, which she found very upsetting. Sally expressed similar concerns:

*Sally: "And you see, they have put some new ones in [patients] down there [points to bottom of bay]. And I'm sorry, don't get me wrong, they can't help it but unfortunately people can't talk properly, there is something wrong with them. And I'm sorry; it sends me round the bend. I can listen for so long, and then it really upsets me, and I think to myself. Oh never mind"*

*Interviewer: "Go on. What do you think?"*

*Sally: "There but for God's grace, go I. and it's hard isn't it?". (Sally, 2).*

In the extract above, Sally indicated through *'I can listen for so long'* that she preferred to not be in the same vicinity as those people that she perceived to be worse off than her. Her uncomfortableness was associated with thoughts that she could go the same way, and like Annie, being worse off was associated with not being able to converse, or to talk in ways in which others could understand, as Sally described: *"They talk a load of rubbish and you get a bit fed up of it"*. (Sally, 1). In the following extract from Elsie's talk about how she lived with memory problems, she suggested that an inability to develop new relationships was synonymous with expectations for a future self:

*Elsie: "I do forget stuff sometimes. I forget people's names, but today was a day"*

*Interviewer: "Is that something particular that happened today?"*

*Elsie: "Well you see, no. A lot of my friends have died cos they have. We are all getting old you see. I talk to one or two and I forget their name here and I lose, I get to where I was and I can't think, err..."*

*(Elsie, 2).*



On discussing relationships with other patients, Alfie, was the only people with dementia who appeared to have a relationship with another patient:

*Alfie: "I've a very good friend there (points to a patient in the opposite bed), and he looks out for me."*

*Interviewer: "So he looks out for you then?"*

*Alfie: "He does, yeah. He walks up and down to see you and he is there and err and he talks to me in a roundabout way. He lets me know. I don't know whether he can hear me now, but he is there for me". (Alfie, 3).*

In the above extract, Alfie introduced the notion that other patients look out for each other. Despite this being one of only two instances of this idea within the dataset, it is reported here as it indicated that some people with dementia drew on their alliances with other patients as looking out for them and being there for them if needed. The lack of accounts from people with dementia on helping others, and the absence of such events in the field notes suggested that some of the people with dementia were seen by others as needing additional supervision. A similar sentiment was expressed by Ethel, when asked whether she had much to do with other patients:

*"No, not really, I don't, very rare, erm, at times there are patients that might want to speak to somebody, and they'll come to you, have you so and so and so and so. And you help them and they help you". (Ethel, 1).*

The extract above suggested that although relationships with other patients were rare, that some co-patients were vigilant to the needs of others. This also indicated that despite people with dementia having been in hospital for a short period of time, that there was potential to develop relationships in the ward within this time.

Only one person with dementia, Henry, talked about how the aggressive actions of another patient with dementia took on importance:

*Henry: "When I first came, now I haven't seen him across there for a couple of days. I know they pulled the curtains round and I've asked about him but they are not allowed to tell me and I think he must have died. I don't want to upset anyone. He were, what do you call when you start being silly and not making sense?"*

*Interviewer: "Like Alzheimer's? Dementia?"*

*Henry: "Dementia. He had that I think. And it's a terrible thing isn't it? I mean he's probably, I think what made the decision was that he hit nurses, he hit them. And he were probably like that before he got it.*

*But they don't need that. So I don't know. They may have moved him but I don't know, I can't find out and you can't ask. They are not allowed to tell me. I said, where is he? We are not allowed to tell you. I suppose there's got to some stop to it. I mean they tried gently with him and that. He was a mess. I don't want to go like that. I'm not going like that. It's a bugger...". (Henry, 3).*

In the above extract, Henry's account of the person with dementia as '*not making sense*', indicated that he held similar views to those of Sally and Annie in that they cannot communicate successfully. Henry also expressed concern that he did not '*want to go like that*'. In fact, he stated that he was '*not going like that*' and indicated that an act of violence, such as hitting the nurses, was not a consequence of the existence of dementia, but something that this patient would have likely been capable of before he got dementia. Although this was an isolated event within the dataset, it introduced the notion that people with dementia held different views about the causes of some of the actions of people with dementia to those held by nurses.

#### Nurses accounts

Nurses' descriptions of people with dementia were of a difficult to care for homogenous group "*They are like really confused, they are aggressive*". (Nurse 5, T1). The terms used by nurses in their accounts of caring for people with dementia, such as '*wanderer*', '*agitated*', '*go bananas*' and '*they just kick off*' indicated that they grouped people with dementia within a set of circumstances, all of which had in common inappropriate behaviours:

*"The wanderers, if you try taking them back to the ward they just get more and more agitated...A few patients [with dementia] attack you, and it's supposed to be zero tolerance, you call the police, you call security and they turn round and say but the patients' got dementia, he doesn't know what he is doing. I personally think call the police, call security, every time". (Nurse, 3:T1).*

The existence of a dementia was in itself perceived to be a cause of particular actions, with often little understanding of antecedents to unacceptable behaviours. Some nurses appeared to not recognise dementia as a specific condition that could be responded to in specific ways. This was despite understanding what might lead a person with dementia to exhibit volatile behaviours:

*“All they know is that they want to get out and that you are stopping them going from where they want to go...”. (Nurse, 4:T1).*

In the following extract from the focus groups, a nurse described how allocation of additional staff members could potentially support nurses in caring for people with dementia:

*“...if we had 5 or 6 more staff, they probably wouldn't kick off as much because you'd get that one to one... don't take this the wrong way, instead of doing lots of research and lots of projects, that money could be put into extra staff”. (Nurse, 6:T1).*

In the above extract, this nurse suggested that there are implications for how research should be designed to boost resources on wards. Another interesting point to note from the above extract is the perception that limited staff availability may be a cause of some of the inappropriate behaviours.

Despite these views, throughout the course of the fieldwork, none of the volatile behaviours that nurses described were observed. However, this finding may be limited by the methods of data collection. The implications of this are discussed in more detail in the final chapter.

#### 4.2.2.3 Grief for an expected self

Several people with dementia talked about how they expected to have reduced activity with getting older. Their feelings towards reduced activity represented a reduced sense of well-being, which seemed to be heightened through being in hospital, as Bert described:

*“I can't do very much for myself when I'm confined in here ....I'm full of energy but unable to do what I want to do. It's gloom, getting old. It's very hard. I don't like getting old. I can't do anything about it...I do get upset about that. I feel gloomy some of the time and that's because I'm getting old and can't do anything about it...”. (Bert, 1).*

The above extract suggested that for Bert, it was through being in hospital that the issue of reduced activity became a central feature of himself.

Through not being able to do what he wanted to do, Bert attempted to reconcile loss of independence with getting older. However, getting older was equated with gloom and upset; feeling low and helpless, which revealed a deep sense of grief over loss of abilities.

Other people with dementia referred to ideas that a lack of ability, or opportunities afforded through being in hospital, heightened their perceptions of loss of an expected self. People with dementia indicated that they desperately wanted to do normal things, but were unable to do so, and therefore felt like they were no longer themselves, as Harry stated:

*“I always like to do and be able to do and not being able to do, you just feel... you are longer yourself. You just don't feel like, they don't give you no reason to go on and go. Makes you feel like, you know, you've got nothing”. (Harry, 2).*

The extract above illustrated the simultaneous engagement with not being able to do things on the one hand and organisational constraints for providing opportunities that was discussed earlier in the theme power and control. For some people with dementia lack of activity appeared to be associated with feeling empty, and at extremes to giving up hope for the future. In the following extract, Vera talked about the association between lack of abilities and giving up, despite her perception that she is much better off than some of the other patients:

*Interviewer: “So what kind of things do you do here?”*

*Vera: “I can't do anything much but sit. You give up. I think you do give up after a while. But I can do a lot more than a lot of them can. But you get fed up”. (Vera, 3).*

In the extract above, Vera's use of the words ‘you give up’ and ‘but you get fed up’ alludes to the idea that it is not just her that gives up, but also other patients who cannot be their ‘normal’ self. This sense of discontinuing as a ‘normal’ self was reflected in participants’ observations on how they are not occupied whilst being in hospital, which resulted in, for some, real suffering. When Bob talked about where he was, he did so as to describe the decomposition of himself:

*“I'm just here, rotting. That's all I'm doing, is rotting. I don't know. This hospital in one sense is to be exaggerated”. (Bob, 1).*

The above extract also illustrated the association between what Bob felt about himself and the organisational constraints as shaping these feelings. For these people with dementia, there appeared to be a conflict between the wish to be active and the limitations on how this could be enacted whilst in

hospital. For Alfie, not being able to do what he wanted to do was associated with a deep sense of hopelessness:

*“You see I can’t do very much with anything. I mean it’s a bit grim and that. I just sit here and watch them and I can’t do owt”. (Alfie, 3).*

Across several accounts there was a sense of progression of grief for an expected self, brought on by their being in hospital. In the following extract, Harry described feeling a sense of having no value in his current situation:

*“I do nothing at all. I was strapped up and did nothing and now, nothing. That’s if I can remember it, which is not good for me. I’m old now and done with. Do nothing. Makes it a long day...”. (Harry, 2).*

Annie described her reaction to being in hospital as one which she was not being able to portray herself as she would like to be portrayed, to others. She talked about wanting to be seen differently by others, perhaps to conceal her dementia and her sadness at her situation:

*“I think, I’ll bring a photograph of me in, with my perfect teeth to hang up, and that’s me when I was in perfect health. Well not perfect, but with a smile”. (Annie, 2).*

In the above extract, Annie’s reference to wanting to be seen with a smile indicated that she grieved for a previous version of herself. For Alfie, not being able to remember, coupled with his exceptional insights into his cognitive decline, reflected his expectations that eventually he would cease to exist and disappear:

*Alfie: “So what are you doing again? I know you’ve told me”*  
*Interviewer: “This is for my study about what it is like for you and other people to be in hospital”*  
*Alfie: “Well we can have a talk about it and that, and I can tell you. We are, I mean, I’m left to my own devices. They can’t do much for it because I’m here and I’m not here, and I will disappear, like them ones. It’s all that’s left and all that they will see. Not me, but it looks like me, do you know what I mean?”. (Alfie, 3).*

The extract above illustrates the simultaneous engagement with being in hospital on the one hand and a sense that there is no help to be had on the other. Clearly, for Alfie, being around other people who also had dementia shaped his expectations for his future self. This idea is critical to understanding the ways in which people with dementia perceived of their situation. Alfie’s concern was that he would no longer be ‘present’ and

'disappear', much like the perceptions that he held of people with more advanced dementia on the ward. Given the deep sense of loss and grief that people with dementia in hospital can have, it is not surprising that amongst their narratives there were accounts of taking stock of what the future held for them, which were similarly expressed through deep emotions.

A limited ability to do what they wanted to do, was for some people with dementia, too much to bear. In the following extract from Annie, she talked about having had enough:

*"I mean, 84 years and I'm still plodding on here and there, and you know love I don't like it. I don't want to say I wish I was dead but I'm not far off that, I'm not far off that". (Annie, 1).*

In the extract above Annie alluded to the notion that living with a failing self required her to plod on, which she did not like. For Annie, she indicated that to continue as she was led her to wish that she was dead. In a later interview, Annie went on to explain that:

*"I was always very busy when I was alive, when I was normal, not alive. I shouldn't say that should I?". (Annie, 2).*

In the above extract, Annie's use of the term '*when I was alive*' indicated that for Annie, her inability to be as she was 'normally', which was to be busy, felt to her as if she was dead, metaphorically speaking. Mary too talked about how she felt that she could not be bothered, and although not as graphic as Annie, indicated that she felt that she may as well be dead:

*"...I've got so I can't be bothered with it all. May as well be pushing up daisies...". (Mary, 3).*

#### 4.2.3 Mechanisms for coping

This final super-ordinate theme addresses the ways in which people with dementia talked about how they coped with living with a lack of power and control and their notions of self during a hospital episode. Three themes make up this theme: Non-complaining, normalising interactions and denial of the existence of dementia.

##### 4.2.3.1 Non-complaining

Some people with dementia interspersed their discussions about their experiences with blanket evaluative statements that were positive, generalised and non-critical of the staff.

When asked to describe what it was like for them to be in hospital, the following comments were typical of the expressed sentiment from these people with dementia:

*“They’re ever so good to you in here”. (Vera, 1).*

*and;*

*“You’ve only got to sort of say, oh, I could do with so and so, and it’s there for you, they’ll get it for you... They’re all the same, all nurses and all staff, you can’t find a wrong one amongst them”. (Ethel, 1).*

In the following account from Annie, she stated that all the staff were good, despite her feeling that not enough was being done to help her, and that the staff were too busy to spend time with her, which meant that she felt powerless in her interactions with staff:

*“They are all good, everyone one of them. I don’t mind saying it. They do for you...there isn’t a wrong one amongst ‘em. There’s some that don’t talk to you and there’s some that do, but they are all good”. (Annie, 2).*

This suggested that despite concerns about lack of power and control in hospital, some people with dementia did not require this for staff to be perceived as being ‘good’ staff. This introduced the notion that ward staff were blameless for some of the most negative experiences of some of the people with dementia, and that it was the organisational demands that were placed on them that was problematic. In fact, throughout all the accounts from people with dementia, with the exception of Bob, there was no reference to the staff being to blame for negative experiences. It is of interest that Bob,

through his frequent reference to having dementia, appeared to have the most insight into the existence of dementia as compared to other people with dementia. It may be that complaining, for Bob, was one way of him coping with his acute awareness of his condition. On the other hand, Alfie, who raised concerns about the responses that got from particular groups of staff, offered a possible reason for what he saw as unkind behaviour, in that those staff who he perceived could not be bothered were perhaps not happy with their work. Unlike Bob, in Alfie's accounts, he did not talk about behaving in certain ways towards the staff that he perceived were failing him in some way. Instead, he felt a great sense of protectiveness towards the staff, as he explained:

*"I don't complain if I get bad or nothing. What are you complaining for? You can't be feeling better and they are doing their best. Friendly. Good to me. If others say anything I do get annoyed". (Alfie, 2).*

In the extract above, Alfie suggested that even when he 'got bad', this was beyond anything that the staff could control. Although he did not specifically state what getting bad meant to him, it can be inferred from the above comment that Alfie felt that the staff were doing the best that they could and that 'getting bad' was no reason for him, or others to complain.

Oftentimes during the interviews, it was difficult to encourage people with dementia to go beyond these seemingly blanket, positive appraisals of their experiences. This was despite talk by some people with dementia of being uncomfortable and at times experiencing immense pain:

*"And I say to them 'Thank you'. I don't want to say that I'm complaining, it doesn't do anything for me... I've got a lot of pain in my back...I mean it is absolutely killing, but I keep taking the tablets and keep it low, don't get all into it. That's my point. If they think they can help you they will do. If they can't help you they'll leave you alone, and that's what you want. You don't want putting in a corner and leaving you know? 'Oh, leave her alone, she's alright'. You don't want that". (Maggie, 1).*

In the extract above, Maggie indicated that one of the consequences of complaining that she was in pain could be that she would be 'put in a corner and left', which she wanted to avoid. Ethel also expressed that she would not complain about her pain as she perceived that there was nothing that



could be done to help her, and she too talked about a fear of being left in a corner:

*“I do get pain, you get up in a morning, and you think well what am I going to do today? You know, and there’s nothing they can do that will help you or other, but if there was, you might be able to find it, yeah. Find it meself cos if the nurses and that don’t do it makes them not doing what they can, so they don’t come. And then I see, I, I don’t want to be left in a corner...I wouldn’t do without ‘em [nurses]. I couldn’t be without their help and company”. (Ethel, 1).*

In the above extract, Ethel’s use of the word ‘company’ is interesting. It suggested that nurses provided companionship through being with her. This was despite reports that nurses lacked time to be with their patients over and above the necessity of care tasks. The above extracts from Maggie and Ethel suggested that some people with dementia lived with a fear that if they drew attention to themselves, through defining limitations in their care which could be labelled as complaining, that they risked being ignored or isolated. This association resonated with a lack of power in interactions discussed earlier, where Alfie talked about a lack of opportunity to communicate with staff about persistent pain. However, in the accounts above, people with dementia suggested that should the opportunity present itself to reveal that they were still in pain, despite the efforts of the staff, that they would not do so. It appeared that feeling secure in the knowledge that they would not be ignored or isolated took priority over seeking physical comfort. It is also likely that through living with a failing self, where some people with dementia expected to live with ailments that are associated with ageing, that a level of physical pain was expected, and to an extent, accepted by some of the people with dementia. In their accounts, similar to those expressed above, it was their cognitive difficulties in their abilities to reach a shared understanding with others that were commented on more frequently, and this appeared to be most important in how they coped with their experiences.

Throughout the course of the fieldwork, numerous instances were observed where nurses approached people with dementia through using their preferred name such as *“Hello Elsie, can I just check...”* (Field notes, Elsie) or *“Mr Forsyth, are you awake?”* (Field notes, Harry), or asked for a participants’ opinion for example:

*'A nurse walked into the bay and asked 'Do you think it is too dark in here Ethel? Do you want the lights turning up?'. (Field notes, Ethel).*

On other occasions, nurses were observed to show concern through what they said or did whilst engaging with people with dementia, such as in this example in their approach to Annie:

*'The nurse approached her and asked if she could take her blood pressure. Annie did not respond. The nurse then sat down near Annie and maintained eye contact with her as she explained what she was about to do'. (Field notes, Annie).*

Facilitative actions such as those above appeared to support notions of autonomy and connectedness with some people with dementia, which most likely will have contributed to their positive evaluations of the staff. Although the ways in which nurses approached people with dementia varied across the staff group, an interesting point to note here is that nurses appeared to be unaware that some people with dementia were generally uncritical and accepting of the limitations of their care. The lack of observations of interactions outside of care tasks, indicated that through their approach to care tasks that opportunities for staff to meet some of the emotional needs of people with dementia were recognised and responded to appropriately. These findings coupled with the lack of talk of positive experiences of caring for people with dementia suggested that nurses were also not aware of that which did well.

#### 4.2.3.2 Normalising interactions

For some people with dementia, it appeared that in order to cope with lack of power, control and their notions of self they took actions to regulate and make meaningful that which they could. The ways in which they did this varied across the group, which had in common a desire to normalise their experiences.

In the following extract, Sally, who was relatively independent in her ability to carry out activities of daily living, suggested that the staff did very little for her:

*Interviewer: "What kind of things do they do for you here?"*

*Sally: "Well they don't do anything. I dress myself, I undress myself. I go to the bathroom in the morning and wash my own bits and pieces. Really they don't do a great deal for me. Mind you, I don't want them to". (Sally, 1).*

In the above extract, Sally indicated that she did not want the staff do things for her that she could do herself. For other people with dementia, being independent required a great deal of self-determination, as Bert explained:

*"I can't just sit here and expect them [nurses] to bring me everything. Everything's there that I need though. I have a lot of free time now. I do what I need to do, slowly. I do it because I want to do it. I could let the nurses do it for me, but I do it myself because I want to". (Bert, 1).*

The extract above illustrated that in order to maintain his independence, Bert felt that he had to be motivated and able to do things at his own pace. Likewise, Annie discussed how in order to meet her basic needs such as going to the bathroom that she also needed to be able to do move at her own pace:

*"So far, I'm alright for spending a penny although we have a chair that we can get in, if it's urgent, I don't like that". (Annie, 1).*

In the extract above, Annie indicated that her slow mobility could often lead to her depending on others for help. Although it was not clear from the data whether Annie's use of the term '*I don't like that*' was about her dependence on staff on these occasions or the experience of using the '*chair*', her account of her experience, and Bert's narrative above suggested that some people with dementia negotiated maintaining their independence through being able to do what they wanted to do, when, and that this also had to be communicated successfully to the nurses.

For other people with dementia who experienced difficulties with verbal communication and shared understanding, they appeared to regulate events that drew attention to such difficulties. During the ward routine, there were occasions when people with dementia who preferred to avoid interactions due to their lack of ability to exert control within them where avoidance was not possible. This was evident during direct requests from people with dementia to make choices, such as when ordering meals. In these instances, for these participants, it appeared that they and staff alluded to the notion of choice, as a way in which to normalise interactions:

*Catering staff: "What would you like for dinner tomorrow? Some fish fingers?"*

*Ethel: "Some fish wingers?"*

*Catering staff: "Or some roast pork?"*

*Ethel: "I don't know what that is"*

*Catering staff: "How about the fish fingers? With cauliflower? Or cabbage?"*

*Ethel: "Yeah, I don't know"*

*Catering staff: "Cabbage?"*

*Ethel: "Yeah, I expect so"*

*Catering staff: "Alright, thank you". (Field notes, Ethel).*

The extract above from the field notes demonstrated one of the ways in which people with dementia and staff coped with a lack of shared understanding. It introduced the notion that at times when an affirmative response was required from people with dementia that was not forthcoming, ward staff would make decisions for them. The extract also highlighted how there were occasions when there was little attempt from the staff to facilitate a better understanding. In the above example, this was surprising, given that Ethel's accounts of her experiences were relatively coherent. What appeared to be important was that the notion of choice was alluded to to normalise the meal order. The extract above draws attention to the notion that nursing staff also appeared to regulate events so that they appeared meaningful. For Ethel, experiences such as these may have contributed to her sense of failing self. Maureen expressed how this could manifest in her talk about choices about meals:

*"I just eat what they put on the table and if I can't eat it, I can't eat it, and that's it". (Maureen).*

Although observations of being offered choices were rare within the data, when this did occur, it was usually focused on participants' preferences for the type of support that they got from the staff to complete a task, such as mobilising around the ward:

*'Maggie called out to the nurse 'can you help me to go?' I presume to the bathroom. The nurse responded 'would you like to walk down or go in the wheelchair?' Maggie replied 'what would you like to do?' (Field notes, Maggie).*

For other people with dementia who could not communicate their needs in conventional ways, the nurses needed to be in close proximity to respond to

them. Often times their beds were in bays that were some distance from the nursing station, where nurses tended to congregate in-between care tasks. Mary was frequently observed to call out 'nurse' to the ward, and often this would not be responded to, even when staff were close by:

*'Mary is saying 'nurse' repeatedly. Several staff walk straight past, without acknowledging her'. (Field notes, Mary).*

Similarly, Elsie and Stan were often observed to share their emotions through vocal expression. Frequently, these expressions were directed towards no one in particular. They uttered quietly to themselves or shouted out, to the ward, about how they felt. Mainly, these were expressions of negative emotions, such as distress. There was an absence of shared understanding from these expressions as they were often not responded to by another. The lack of response from others on these occasions could have contributed to a sense of lack of control and a failing self. Distress was also observed to be shared through the words and noises that people with dementia used when they were receiving intimate care from the nursing staff:

*'The auxiliary nurse then told Elsie, who was behind curtain that 'you are getting changed' to which there was no response. The staff nurse is saying 'come on now; let's get you into bed, onto your tummy'. I can hear Elsie moaning (previously noted that Elsie makes moaning and groaning noises during cares indicating that she dislikes what is happening to her). The staff nurse continued to talk to Elsie, telling her how to move herself: 'over this way, that's it, beautiful, there you go, you can lie back again now. Well you wouldn't want us to leave you dirty now, would you?' There was no verbal response from Elsie'. (Field notes, Elsie).*

Whilst nurses often responded to this distress through offering reassuring words, this reassurance was often accompanied by persuasive comments so as to get the task completed, and not to acknowledge the participants' wishes. On other occasions, staff responded to participants' expressed needs, particular for reassurance whilst transferring around the ward, as can be seen in the following extract from the field notes:

*'The nurse said to Stan, as she guided him towards his bed "this is your bed, yes that's it". Stan appears unsteady and hesitates. His expression is one of confusion. He looks very was unsteady on his feet. The nurse said "I've got you, you're not going to fall". She*

*partially lifted him up onto his bed, making a swinging noise as she did, as one would with a baby'. (Field notes, Stan).*

In the above extract, the reassurance given to Stan likely supported him to feel safe. However, the noises that the staff member made were babyish in nature, which indicated that their actions served to constrain him as someone who was dependent, which may for him have contributed to a sense of failing self.

#### 4.2.3.3 Denial of existence of dementia

Some participants appeared to use denial of the existence of dementia as a way to cope with living with it. This was particularly evident during the interviews with male participants:

*Alfie: "And now see, they've said I've got it, Alz whatever. I'm down for it. My son has put me down for it. He says he put me down for it cos I keep forgetting things. I can't keep track of things. I mean, who can? Anyway I'm down for it"*

*Interviewer: "So he reckons it's a bit more than just being forgetful?"*

*Alfie: "Yeah, I don't know why. Cos anybody I speak to in here or owt, they ain't too different to us. I mean I always, I mean I do forget things, anyway". (Alfie, 3).*

In the above extract, Alfie denied that he had dementia and that it was due to his son that he had 'been put down for it'. This suggested that Alfie felt that he lacked control over identifying the presence of his condition. He rationalised his tendency to 'keep forgetting things', as being the norm, and appeared to affirm this through aligning himself with how other patients that he was around behaved, through stating '*they ain't too different to us*'. This indicated that for Alfie, being around other patients who may also be forgetful assisted him with his denial of the existence of dementia, despite his family insisting that he did have it.

Conversely, family members would also use denial as a means normalise their interactions with their relatives:

*"I mean, she will talk to me but I don't think she is seeing me. She's just seeing Dad. I mean I am her Dad, but... she pretends, and tries to pretend that there's nothing going on for me, that there's nothing wrong with me. Which in a way is good, but I know it's frustrating because she'll be talking to me and I don't remember what she's done. And I lose conversation when I'm talking to her. So sometimes I don't know if she's talking to me or not...". (Harry, 2).*

In the above extract, Harry talked about how his daughter *'pretends'* that there was nothing wrong with him, despite his own awareness. His suggestion that his daughter is *'just seeing Dad'* and not him indicated that Harry felt that his role in his family took precedence over how he felt about himself. The way in which others responded to Harry may for him have triggered awareness of his failing self, and a distance between those that he cared for.

Bob, who was more accepting of the existence of dementia, was acutely aware of the impact of his dementia on his ability to remain focused, and to remember things. He was, unusually, upbeat about the impact of the disease on his mental functioning:

*"And with Alzheimer's, with your temporary, loose brain, I can't remember the name of my pet nurse, but it will come back to me in 5 minutes time". (Bob, 1).*

In the above abstract, through Bob making fun of having *'temporary, loose brain'* it indicated that for Bob, the fluctuating nature of forgetting and remembering that is characteristic in dementia, was an expected, and to a degree, accepted way of being.

Not all people with dementia denied outright that they had dementia – of those that did not, such as Bob, he expected staff to care for him in specific ways, which he perceived did not happen in the ways that he wanted. Those that did tend to deny the existence of dementia appeared to use denial as a way in which to cope with living with it in hospital. Interestingly, for those people with dementia that tended to be non-complaining about their care, there was a lack of talk about expectations for a future self, or grief for an expected self. Instead, most were concerned with their cognitive difficulties and how these affected their ability to establish shared understanding with others. It is possible that through normalising their interactions, which appeared to maintain their connectedness with others, that they too acted to deny the existence of dementia, albeit in more subtle ways than some other participants. It may also be the case that these people with dementia lacked insight into the possibility of them having a dementia and that the process of

being non-complaining and normalising served to reinforce denial. Similar to the notion discussed earlier where nurses alluded to being motivated to deny the existence of dementia, it appeared that the way in which some people with dementia interacted with others also acted to deny that they had dementia.

### **4.3 Chapter Summary**

This chapter has presented the findings of the qualitative study that explored the experiences of people with dementia in hospital. Multiple perspectives informed the development of three super-ordinate themes. The dimensions of each theme were presented with direct quotes from interviews with people with dementia that represented the most articulate expression of the themes. Field notes compiled from ethnographic observations and transcripts from focus groups held with nurses were used to expand on the themes.

The integration of data from different sources made three main contributions to the findings: a productive iterative process whereby an initial understanding of the context of care for people with dementia in the ward setting guided an exploration of perceptions held by nurses on the impact of their care to the experiences for people with dementia. Individual accounts of experiences, a focus on observations of care behaviour, and successive individual data further enriched the conceptualisation of the experiences; identification of the individual and contextual circumstances surrounding the experience, which added to the interpretation of the structure of the experience; and convergence of the central characteristics of the experience across observations and elicited accounts.

The findings indicate that perceptions of power and control that people with dementia had in hospital, such as elements in their current situation and how they made sense of them, formed the basis of their lived experience. Several factors were shown to influence this process. First, people with dementia varied in their perceptions on their abilities to acquire control over their current situation, given similar experiences in their interactions in hospital. This was likely a function of their individual sense of failing self, influenced by their physical condition and level of cognitive impairment. They projected



their experiences onto a future self. In addition, people with dementia adopted certain mechanisms for coping that may act to filter and interpret the ward environment. Lived experience was a function of the state of the hospital environment in terms of the nurse's roles and responsibilities and the form in which these take to provide care. Other features of the ward routine, including the priority of care tasks above individual needs and wants, other patients and the clinical nature of the environment also affected the lived experience. The role of each of these individual and environmental factors was addressed through the three super-ordinate themes that were derived from the analysis of their individual accounts, and additional contextual information from the analysis of data from multi-perspectives. The next Chapter summarises the key findings and includes a discussion of the implications of these findings and their contribution to the literature.

## **Chapter Five: Discussion and Conclusions**

### **5.1 Chapter Overview**

The main aim of this thesis was to explore and contribute to the evidence base for ways to improve care for people with dementia in hospital. A range of research methods were adopted to elicit evidence from people with dementia on important aspects of their hospital ward care experience. Supplementary questions which underpinned the research were related to how people with dementia define good care and the characteristics of poor and good care. The research was also concerned with investigating what people with dementia perceive as barriers and enablers to good care, and to elicit their ideas for what could or should be done to improve their care experiences.

Three super-ordinate themes that emerged from the research study findings described the experiences of 14 people with dementia in hospital. The first section of this chapter provides a summary of key findings and discusses their contribution to the literature. Methodological considerations in study design are then discussed before reviewing strengths and limitations of the approach that was taken. The chapter concludes with a discussion of the implication of findings, with recommendations for future practice and research.

### **5.2 Summary of Findings and Contribution to the Literature**

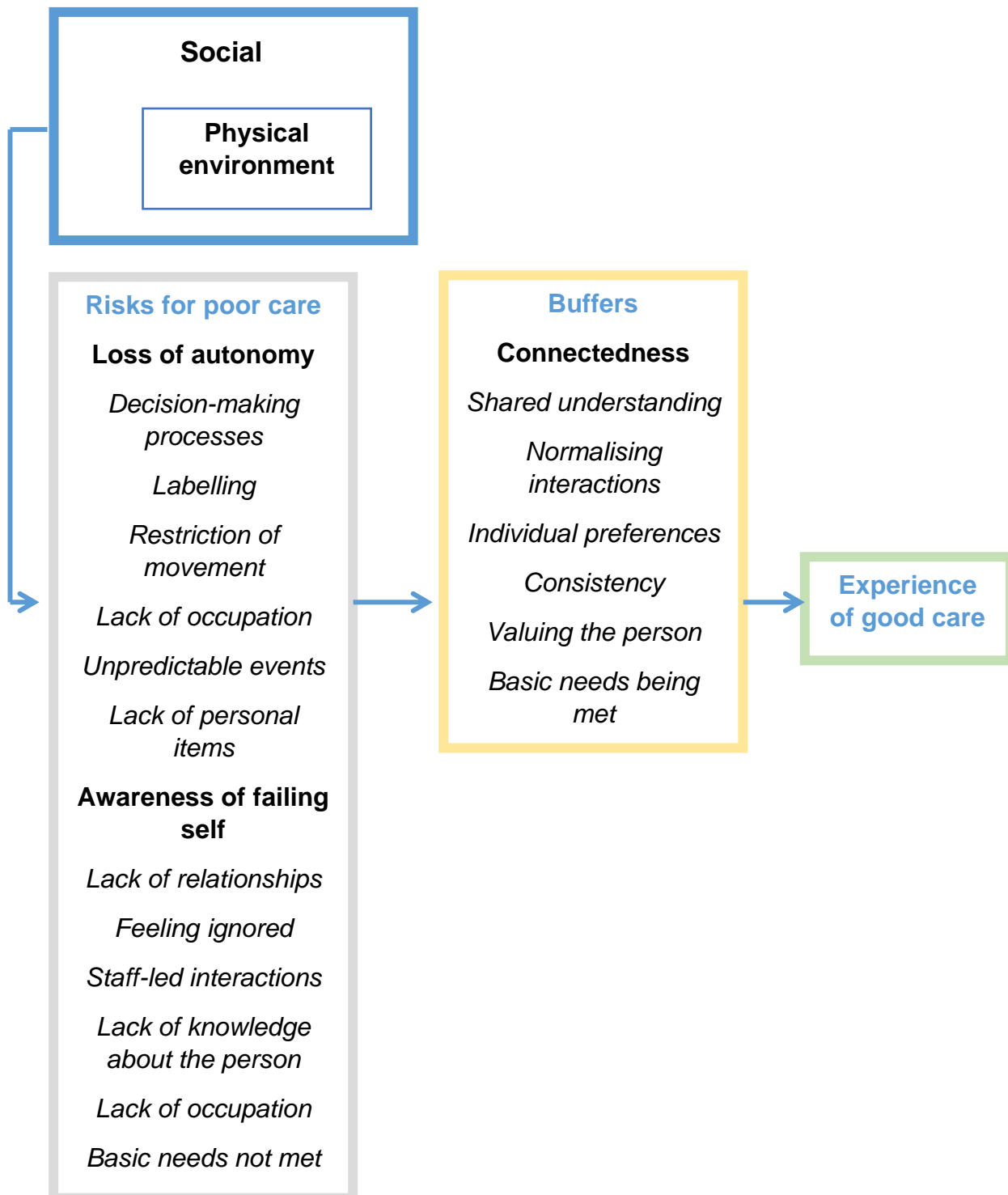
#### **5.2.1 Summary of key findings**

The majority of people with dementia who participated in the empirical study perceived that they should not be in hospital and that they were not involved in this decision-making process. Their experiences highlighted for them their sense of failing self and an uncertain future. They faced this uncertainty whilst living with grief of who they used to be, and for some, denial that dementia existed. Staff were mostly blameless in limitations of care and people with dementia appeared to influence responses from staff so as to evaluate their care as good. The organisational context of care contributed to perceptions of poor care, which they mostly defined as being neglected and ignored. Many perceived that they had to, and would, respond in certain

ways to ensure that this did not occur. Good care was facilitated through maintaining connectedness with self and others in their environment. In their accounts of how they came to understand and make sense of their experiences, most people with dementia talked about being unable to communicate successfully. They had to work hard to achieve a shared understanding with nursing staff, which was one of the most important aspects of their care. During an acute hospital stay, their awareness of their deterioration in cognitive abilities was heightened. How they, and others around them, responded to their deteriorating abilities reinforced or protected their failing sense of self. Their expectations of care were negotiated through awareness of the limitations in which care is organised. Their ability to control what occurred, when and the impact of this on their sense of failing self was central to the lived experience of people with dementia. Through their accounts on their lived experience in hospital, people with dementia shared their ideas on what could and should be done to improve their care experiences. These included exploring alternatives to coming into hospital, personalised environments, opportunities to discuss their sense of failing self and being facilitated to communicate their individual and changing needs successfully.

Features of their experiences, views and perceptions in hospital that they associated with risks for poor or unsupportive care and buffers for the experience of good or supportive care are shown in Figure 5.1. The subsections that follow provide a discussion on how the main concepts of loss of autonomy; living with a failing self and; maintaining connectedness contribute to the literature.

**Figure 5.1: Conceptual framework for understanding factors that contribute to good care experiences**



### 5.2.2 Loss of autonomy

People with dementia associated not necessarily realising why they were in hospital with not being involved in the decision-making process for them to be there. It is possible that due to the existence of dementia, that they had forgot or were confused about the reasons for their hospitalisation. However, most participants were concerned that they or others around them perceived that a decline in their abilities to look after themselves had led to their admission, and yet they felt that the hospital was not an appropriate place for them to be. Similar findings were reported by Hynninen et al (2015), where people with dementia appeared to be unaware of the reason for having been taken to and held at the hospital. This suggested that one of the ways in which they made sense of their experiences was through feeling disempowered about decisions that had been made for them. This notion was repeated across and within individuals' accounts, which was unexpected, signifying that the decision-making process for some people with dementia to be in hospital was a genuine concern that requires further investigation.

There are several possible explanations for this finding. One of the most obvious is that lack of control over where they were was echoed in nurses' accounts, who were suspicious about the reasons for people with dementia going into hospital. This finding supports evidence from previous studies of a lack of agreement about responsibility for care for those people with acute medical needs, who coincidentally, have a dementia (Griffiths et al., 2014, Houghton et al., 2016). It is possible that lack of an acute medical crises in apparent reasons for admission for some participants contributed to their uncertainty and confusion about why they were in hospital. Documented reasons for admission such as 'urinary tract infection' in the case of Harry and Ethel, and for Alfie, 'concerns about neglect' (see Appendix T – brief introduction to patient participants), is indicative that admission to hospital, for these participants, may have been prevented through support in the community. It was perhaps through their awareness of a perceived lack of medical reasoning for admission that some people with dementia felt disempowered about their being there.

There is evidence that avoidable admissions are more frequent in older people with cognitive impairment (Wolf, Rhein, Geschke and Fellgiebel, 2019), and this has been related to a lack of engagement with community-based support for people living with dementia (Herron and Rosenberg, 2017). In the absence of suitable alternatives, admission to hospital can often be precipitated by several crises where there is nowhere else for the person with dementia, their family and carers to turn (Toot, Devine, Akporobaro and Orrell, 2013, Toot, Hoe, Ledgerd, Burnell, Devine and Orrell, 2013, Orrell, Toot, Hoe and Ledgerd, 2014, Ledgerd, Hoe, Hoare, Devine, Toot, Challis and Orrell, 2016, Ouslander, Naharci, Engstrom, Shutes, Wolf, Alpert, Rojido, Tappen and Newman, 2016). It may be that people with dementia who stated that they were in hospital due to not taking care of themselves had lived like that for some time and were aware that this culminated in a crisis leading up to their admission. In fact, it is often through an emergency admission that access to appropriate support can be gained, although this does not always happen (Reilly, Miranda-Castillo, Malouf, Hoe, Toot, Challis and Orrell, 2015).

Getting access to appropriate community support can be time consuming, labour intensive and varies with characteristics of carers (Farina, Page, Daley, Brown, Bowling, Basset, Livingston, Knapp, Murray and Banerjee, 2017), which may partly explain evidence that people with dementia tend to stay in hospital longer than older people without cognitive impairment (Connolly and O'Shea, 2015), and why some participants in this study felt that people of an older age were neglected in general. There is evidence that people who are more supported by informal carers often avoid unnecessary admissions due to the advocacy role that family members take (de Vries et al., 2016). It may be that the absence of family members involved with people with dementia in this study was related to avoidable admissions. A note of caution is due here as the recruitment method used in this study may have limited access to family member accounts. The strengths and limitations of the recruitment method are discussed in further detail later in this chapter in section 5.4. Conversely, family members may force the point for admission when medical staff believe that admission is not

necessary (de Vries et al., 2016). In the present study, Alfie expressed concerns that his family had forced the admission, and although this was not explored further it does suggest that people with dementia are aware that this can occur, which they associate with loss of autonomy.

The findings are consistent with that of Porock and colleagues (2015), where the disruption caused through hospitalisation had the potential to cause loss of personhood; the condition of being an individual person. This may manifest as threats to what Sabat and colleagues termed self 2 and 3 (Sabat and Collins, 2004). Self 2, which is comprised of ones' physical, mental or emotional characteristics, and also ones' beliefs and desires about them (Sabat, 2001), is likely to be vulnerable when ones' beliefs about a failing self are at odds with the purpose of the healthcare setting in which they are in. Self 3 is also vulnerable when the desired presentation of self; the publicly presented aspect of themselves (Sabat, 2001), is perceived of as lacking control through being regarded as a patient when one does not realise why they are a patient.

Another important finding was that some people with dementia lived with labels that they felt had been imposed on them that they did not want and were concerned about avoiding being labelled due to their cognitive difficulties. They associated labels with negative experiences and for some as being beyond help. Similar experiences have been observed in previous studies in hospital settings, where labels acted to constrain them through being viewed and treated differently to how they wished to be treated and through expectations that they should behave in certain ways (Hung et al., 2017, Prato et al., 2018). Participants in Hung et al's (2017) study felt that the label of dementia was associated with being viewed and treated as a subclass on the ward. Kitwood (1997) has illustrated that labelling people with dementia increases the potential for people to respond to the label instead of the person, which can result in damaging interactions that undermine personhood (Kitwood, 1997). The findings presented here suggest that people with dementia are aware that this could happen for them; indeed some described vivid accounts of the implications of such labelling, which were not just associated with changes in their cognitive abilities, or the

label of dementia, but also where they felt abandoned by society in general due to being of an older age. Further support for this idea comes from previous accounts of being regarded as a patient which has been associated with experiencing a lack of respect, as professionals were seen to not treat people with dementia as they would expect (Harman and Clare, 2006). An implication of this is that people with dementia in hospital not only resist the notion of being a patient, but also the notion of having dementia.

The ways in which people with dementia attempted to make sense of their situation was to predict their future, which for many was uncertain and bound up in the perceptions that they held about other patients. Like their doubts about the reasons for them being in hospital, their uncertainty about their future may have also been because they had forgot or misinterpreted information that they had been given as something else. However, this finding is consistent with previous studies that have identified a lack of involvement of people with dementia in decisions about their future whilst they are in hospital (Cowdell, 2010a, Cowdell, 2010b, Hynninen et al., 2015), which suggests that experiences of people with dementia could be improved through efforts to ensure their involvement in decisions about them, and the ways in which they are involved being more readily accessible to them within their future plans.

People with dementia have previously described how they try to cope with their uncertainty about their future through comparing self with former abilities and with others who may be worse off than them (Clare, 2002). They tend to use this comparison to develop a fighting spirit and as a means of cheering oneself up (Clare, 2002). However, the findings of the current study suggest that people with dementia in hospital associate comparison with the perceptions that they held about others with more advanced dementia with their awareness of their failing self and their grief for an expected self.

There has been no detailed investigation into the perceptions of people with dementia on their co-patients in hospital. There is an emerging, but limited evidence base on the views of people that do not have dementia on people with dementia in hospital (Porock et al., 2015). Co-patients of people with



dementia in Porock et al's (2015) study experienced disruption from sharing spaces, and often felt vulnerable and afraid. These findings are like the experiences of people with dementia in the current study. Their accounts of patients who were likely to have more advanced dementia revealed that people that were worse off than them were unable to have relationships. Their resistance to being viewed the same as them appeared to be a manifestation of their fear of what their future may consist of, which for most was fear for a future in which they could not maintain a public, or social self.

Turning now to the ward environment in which they lived, people with dementia experienced a tension between their living space and the workspace of the nurses. These findings support evidence from previous studies that have explored the interaction between the person with dementia and their immediate physical environment (Norman, 2006, Nolan, 2007, Hung et al., 2017, Prato et al., 2018). Consistent with these studies, people with dementia felt that the dominance of care tasks in hospital contributed towards feelings of frustration and confusion, as they struggled with unfamiliar spaces and routines. Building on the work by Hung et al., (2017), which focused on the conduciveness of the physical environment for people with dementia, participants in this study suggested small changes in their immediate environment. The hospital environment manifested loss of autonomy in three important ways: restriction of free movement, confusing cues within their environment and lack of important personal items.

People with dementia experienced boredom and a sense of frustration at the lack of opportunities for them to engage in meaningful activities. These findings contribute to the evidence for the value of meaningful engagement for people with dementia in hospital (Clissett et al., 2013a, Hung et al., 2017, Daykin, Parry, Ball, Walters, Henry, Platten and Hayden, 2018, Prato et al., 2018). In the current study, people with dementia sought out opportunities to promote their independence and maintain a sense of continuity which they were often prevented from doing so within the confines of the hospital wards. This resonates with Kitwood's assertion about the importance of occupation for the psychological well-being for people with dementia (Kitwood, 1997). One notable difference between previous studies and the present findings is

that people with dementia associated being restricted with incarceration; a vivid description of how being restricted in hospital has the potential to deny the existence of an individual identity for people with dementia.

Another important finding was that visible cues within the hospital environment appeared to facilitate or hinder orientation, often at random. This meant that some participants found the hospital environment unpredictable. People with dementia rely on cues within their environment to orientate them to time, place and events (Kitwood, 1990a, Kitwood, 1990b, Kitwood and Bredin, 1992, Kitwood, 1993, Kitwood, 1994b, Kitwood, 1994a, Kitwood and Benson, 1995, Kitwood, 1997). Previous studies have shown how an inability to predict events in hospital has the potential to increase confusion for people with dementia (Hung et al., 2017, Prato et al., 2018). Lack of consistency and predictability has been associated with disrupting sense of personal continuity and influencing sense of identity (Caddell and Clare, 2010, Gorska et al., 2018).

Previous studies have described how people with dementia want the hospital to be a place of safety, which they describe as a psychological need to feel safe emotionally, not just physically (Hung et al., 2017). In the present study, like findings reported in Simpson's (2016) hospital-based study, missing items such as hearing aids and spectacles were associated with an inability to carry out daily activities comfortably and safely. Missing hearing aids are particularly disempowering for people with dementia as this can limit their ability to converse (Hubbard et al., 2003), and is therefore likely to disrupt sense of self.

Turning to other personal items that were important to some of the people with dementia, these appeared to afford them opportunities to be emotionally connected with their loved ones, and to converse about their emotions with others. A previous study of hospital patients with dementia associated personal symbols with improved well-being (Tolson et al., 1999). However, most participants in the present study lacked personal effects, which similar to findings reported in previous studies, (Clissett et al., 2013a, Simpson, 2016, Hung et al., 2017, Prato et al., 2018), denied opportunities for personal

comfort. This can manifest as not respecting the rights of people with dementia in hospital (Hung et al., 2017), which can disrupt sense of self. This finding also resonates with Kitwood's recognition of the psychological needs of people with dementia in terms of their comfort (Kitwood, 1997). A possible explanation for missing items is that because participants had gone into hospital as an emergency admission, and were recruited early in the admission process, that there had not been enough time to ensure that they had their personal belongings. It is of interest that the length of time that they had been in hospital was enough for people with dementia to make evaluative judgements on their care however, and for some to establish relationships and categories of characteristics for 'good' staff.

### 5.2.3 Living with a failing self

A number of previous studies have discussed the potential for interactions between people with dementia and staff to facilitate or hinder their experiences of care in hospital (Borbasi et al., 2006, Cowdell, 2010b, Porock et al., 2015, de Vries et al., 2016, Lichtner et al., 2016, Jensen et al., 2017, Prato et al., 2018). With the exception of Norman (2006), previous findings have relied mainly on subjective interpretations as to what constitutes good and poor care from the perspectives of people that do not have dementia. This study has highlighted that accounts from people with dementia on living with a sense of failing self can contribute to the evidence base on ways in which interventions could improve their care experiences.

The ways in which people with dementia managed 'self as a patient' varied across the group, and within their individual level of awareness of where they were and what took place around them. It has been suggested that self 3 is particularly vulnerable in situations that depend on the affirmation and co-operation of others to construct and support a valued sense of self (Sabat, 2002, Sabat et al., 2004, Snyder, 2006), indicating that this sense of self is more susceptible to damage than other selves (Sabat, 2005a). The accounts of some of the people with dementia in the current study appeared to represent a struggle with affirming themselves as an independent self on the one hand, while reconciling this with their confinement and dependence on the other.

Within their accounts, people with dementia talked about how their cognitive difficulties took on importance in their interactions with others. An awareness of the ways in which changes in their cognitive abilities, such as forgetfulness and not understanding what was being talked about, was acknowledged by most participants. The ways in which they responded to and managed this varied across the group, such as withdrawal, avoidance and self-deprecating talk, perhaps as a way of protecting themselves from exposure of their vulnerabilities. The findings are consistent with that of Clare (2003) who also found varying judgements in the meaning and impact of memory problems. However, Clare (2003) reported that responses by people with dementia run on a continuum from self-maintaining to self-adjusting. Self-maintaining responses relate to attempts to normalise the situation so as to maintain continuity with prior sense of self and self-adjusting responses relate to attempts to confront the difficulties and adapt sense of self accordingly (Clare, 2003). Most people with dementia in Clare's work gave accounts of self-maintaining responses (Clare, 2002).

Contrary to this view, the responses by people with dementia in the present study appeared to be mostly concerned with self-adjusting responses, and it was the responses of others to their cognitive difficulties as they attempted to normalise their deficits so as maintain continuity with the prior self, that were problematic. One possible explanation for this is differences in the healthcare needs of participants in the different studies. Participants in Clare's (2003) study were recruited through an out-patient memory clinic and were therefore unlikely to have had acute medical care needs. It may be that when hospitalised, people with dementia experience a transition from maintaining continuity with prior self, to a focus on adjusting and adapting sense of self. In contrast, other people around them, including family members and those caring for them in hospital, focus on maintaining continuity, perhaps as a way of coping. This was particularly evident in Harry's account of the way in which a family member used denial of the existence of dementia to normalise their interaction with him. Previous research has demonstrated that often families focus on preserving the relationship as normal (Jurgens et al., 2012, Mockford, 2015, Miller et al., 2018), and like the experiences of people with

dementia in the current study, there is evidence that nursing staff also may act to normalise situations (Norman, 2006, Clissett et al., 2013a, Porock et al., 2015, Prato et al., 2018), which for the most part is due to the dominance of functional, task orientated interactions.

People with dementia were aware that this can take place. Their awareness indicates that they use self-adjusting strategies to manage sense of self, and that behaviours such as withdrawal and avoidance may not be expressions of psychological symptoms associated with dementia, as the biomedical model would suggest (de Oliveira et al., 2015). Instead, the responses from others to their cognitive difficulties, including not discussing them and ignoring them, describes what Kitwood termed as malignant positioning (Kitwood, 1997), defined as an inability to reject being positioned in ways that they find objectionable due to their cognitive difficulties (Sabat, 2003). Within their struggle to reposition themselves, this is often characterised in dysfunctional ways by healthy others (Sabat, 2003). The findings reported here suggest that behaviours such as avoidance and withdrawal could be deliberate attempts by people with dementia to manage some of the consequences of negative interactions with others. In addition, there were occasions when people with dementia preferred to not interact with others, and to spend time alone. Similar findings were reported in Hynninen et al's study (2015). Interestingly, this was one of the rare studies that included direct accounts from people with dementia. Taken together, these findings suggest that that a lack of interactions for people with dementia in hospital is not as important as the meaningfulness of them, which varies with individual preferences.

Previous studies have described how people with dementia use tactics to ease communication as a way in which to adopt desirable social roles and manage public impressions of them (Beard, 2004, Nygard, 2006, Surr, 2006). Like people with dementia in the present study, they may avoid talking about things that they find difficult or seek validation from those that they are interacting with that they are on the 'right track' (Beard, 2004). However, unlike previous studies, people with dementia in the present study appeared to not be as concerned with impressions that others held about them, and

more concerned with the impressions that they held about themselves and others around them. This may be related to participants in this study being positioned as a hospital patient, which as a socially-constructed concept, has a set of pre-defined expectations and particular ways of behaving (Bury, 1986), unlike participants in previous studies who were mostly based within the community. It is likely that existing in the role of hospital patient, whether this is perceived of genuine or otherwise, impacts the ways in which people with dementia cope with threats to self through their interactions with others differently than in other environments. Taken together, the findings indicate that threats to self in people with dementia living in hospital has implications for the ways in which others should respond to them, and findings from studies conducted in different environments are not always transferrable to their experiences in a hospital setting.

Despite accounts of self-adjusting responses, which suggests an adaptive way of coping (Clare, 2002, Pearce et al., 2002, Seiffer, Clare and Harvey, 2005, Porock et al., 2015), the implications of coming to terms with threats through becoming withdrawn and avoiding talk so as to integrate changes within self (Clare, 2002), risked exposing people to dementia to events that would escalate threats to self. Through avoiding opportunities to interact with others, they limited their ability to maintain connectedness with others and yet most participants in the current study lived with a fear of being ignored or neglected, which was dependent on their ability to interact with others.

One study that reported on personal accounts from people with dementia in hospital talked of patients feeling isolated, which was associated with an increase in levels of distress (Prato et al., 2018). However, participants in Prato et al's (2018) study were concerned about the location of people with dementia on the ward, in particular those being cared for in single cubicles. There was evidence that once people with dementia were moved to shared spaces that they felt more settled, although the findings reported do not state what being more settled entailed. The accounts of relatives and nurses that there was a reduction in the behavioural and psychological symptoms of dementia indicated that location on the ward was an important factor in feelings of isolation, and in how this was responded to.

The current study found that people with dementia desired companionship with others and would often seek this out, despite accounts of not being able to do so due to being restricted in their movement and by the frailty of other patients. Previous studies have highlighted the value of people with dementia spending time with others (Borbasi et al., 2006, Norman, 2006, Clissett et al., 2013a, Porock et al., 2015, de Vries et al., 2016, Hung et al., 2017, Prato et al., 2018), and they will often seek out companionship, even when communication skills were limited (Porock et al., 2015).

An unexpected finding was that people with dementia articulated their fear of being neglected and ignored so clearly, and location on the ward did not appear to be related to this fear. Previous studies have related the dominance of staff-led interactions as a process through which people with dementia were observed to be ignored (Norman, 2006, Cowdell, 2010a, de Vries et al., 2016, Jensen et al., 2017, Prato et al., 2018). In the present study, people with dementia articulated their awareness of this threat and related this to their uncritical acceptance of negative experiences. These findings suggest that one of the ways in which people with dementia in hospital manage threats to self is through upholding perceptions that others are blameless in their limitations of care, and that it is the wider organisational context, including perceptions of the needs of other patients around them in which they are ignored, that contributed to threats to self. This also accords with findings discussed earlier, which showed that people with dementia in hospital may perceive of themselves as illegitimate patients, and perhaps because of this, some expected to be, and accepted being ignored.

This finding also suggests that the perceptions that people with dementia held about what constituted an authentic patient, which were mostly concerned with those that were likely in the more advanced stages of dementia and were demanding of the attention of the staff, moderated how some people with dementia managed their feelings of being neglected and ignored. Perhaps through feeling ignored and neglected, they could perceive of themselves as not as bad as others, which they feared they would become like. This is not to negate the perception of being ignored, clearly people with

dementia felt that this did occur. Nurses were also aware that this could happen, albeit that their reasons for doing so were embedded within the challenges that some of the more expressive symptoms of dementia can present carers with. Taken together, the findings suggest that being ignored can disrupt sense of self in two important ways; through the ability to maintain prior sense of self on the one hand and preventing adjusting to a current self on the other. It would be difficult to develop adaptive coping strategies under these circumstances, which suggests that feeling ignored in hospital could be catastrophic to the selfhood of people with dementia.

#### 5.2.4 Maintaining connectedness

Similar to findings reported in previous studies, people with dementia associated the hospital environment with barriers to communicating needs and a lack of opportunities to reach a shared understanding (Borbasi et al., 2006, Norman, 2006, Cowdell, 2010b, Cowdell, 2010a, Clissett et al., 2013a, Porock et al., 2015, Lichtner et al., 2016, Hung et al., 2017, Prato et al., 2018). Despite concerns that the staff did not have time to spend with people with dementia beyond specific care tasks, for some people with dementia, it was the attributes of particular groups of staff that appeared to take on importance in their evaluation of them. Consistency of staff over a period of time appears to have a positive impact on people with dementia (Clissett et al., 2013a), as it can facilitate the notion of attachment, one of Kitwood's five conditions for care (Clissett et al., 2013a). Like the accounts reported in the current findings, Norman (2006) also observed that the quality of interactions was not consistent over time and between staff. However, in the current study, the notion of having relationships with particular staff members appeared unimportant to people with dementia. Instead, it was important that staff were able to respond to their needs and in doing so, treat them with respect. Inconsistencies between and across different staff members manifested as being unable to get the care that they needed. This resonates with Kitwood's recognition of the psychological needs of people with dementia (Kitwood, 1997). Affirming identity, through responding to individual wants and needs was an important factor influencing care experiences.



Another important finding was that people with dementia felt responsible for ensuring that their needs were met, which relied on their abilities to communicate their needs successfully. Generally, this involved securing staff attention and reaching a shared understanding. People with dementia existed with unpredictability on being able to express their needs successfully and their ability to influence their needs being met. In the absence of a response from another, some people with dementia appeared to express their needs to the ward. Similar to findings reported in Lichtner et al's (2016) observations, it was apparent that it was necessary for staff to be in close proximity to the person with dementia in order for them to communicate.

Interestingly, staff were perceived off as too busy to respond to needs that may be communicated in conventional ways, as one of the perceived causes of lack of availability of staff was that they were occupied with other patients who struggled to communicate. This suggests that contrary to the notion that preserved communication capabilities in people with dementia are related to opportunities for interaction (Kitwood, 1994b, Brooker, 2005, Brooker and Surr, 2005, Brooker and Surr, 2006, Sloane et al., 2007, Woolley et al., 2009, Godfrey et al., 2018), for people with dementia in hospital, preserved ability to communicate in conventional ways may be related to reduced opportunities for interaction with nurses. In their accounts of the ways in which their interactions with others shaped their experiences, some people with dementia felt that they needed more time with the staff. An inability to be able to do so manifested as being unimportant, and for some was internalised as their needs being beyond help. At the same time, the evidence suggests that because nurses were perceived to spend most of their time with patients who were more unwell, and nurses described caring for patients with dementia as difficult, that people with dementia who could communicate their needs represented those that the nurses desired to avoid. This finding needs interpreting with caution however as it was beyond the scope of this study to explore the decision-making process involved in how nurses allocate their time to individual patients.

On the other hand, there were occasions when people with dementia chose not to communicate their needs, usually when they were experiencing some

discomfort, such as pain. They rationalised this through the needs of other patients being a higher priority for the staff, which manifested as feeling unimportant. Accounts from people with dementia as to reasons why they may not communicate known needs are rare within the literature. Previous studies have identified that the organisational context of the ward impacts the ability of staff to pay attention to preferred modes of communication (Borbasi et al., 2006, Lichtner et al., 2016, Prato et al., 2018), and even when people with dementia were observed to summon help, including those using a buzzer, their requests could not always be answered immediately, which is associated with leading to distress and confusion for the person with dementia (Cowdell, 2010b, Clissett et al., 2013a, Porock et al., 2015, Lichtner et al., 2016). Being in pain is associated with an increase in behavioural and psychological symptoms of dementia (Sampson, White, Lord, Leurent, Vickerstaff, Scott and Jones, 2015). Despite a relative lack of some of the more distressing symptoms that people with dementia can experience observed in the present study, taken together, the findings demonstrate that undetected pain results in poor care. Although pain assessment and management were not the focus of the current study, this indicates that more should be done to facilitate people with dementia to communicate their pain. Lichtner et al's (2016) study highlighted how communicating pain is dependent on information from the person with dementia, and that it was the skill and knowledge of staff in interpreting pain cues that facilitated appropriate pain management.

For the most part, nursing staff were blameless for limitations in care. People with dementia gave positive evaluative statements about the work of the nursing profession. The accounts from nurses suggested that overall they were uncomfortable with the care that they gave to people with dementia and were unaware of that which they did well. Divergence between different perspectives has been reported in similar studies. Despite showing genuine and extensive insight into the experiences of people with dementia, in Prato's study, nurses were mainly concerned about focusing on that which they perceived that their profession needed to do to enable them to deliver better care (Prato et al., 2018). Taken together, these findings indicate that despite

nurses feeling that their care for people with dementia is undervalued that nurses are motivated to improve care.

### 5.2.5 Section summary

This section has provided a discussion of the implications of the findings and their contribution to the literature. Similar to findings reported in previous studies, it was the ability to meet the psycho-social needs that were most significant to people with dementia. Medical interventions and the biological underpinnings of their condition were not discussed within their accounts. The discussion has demonstrated that people with dementia navigated multiple factors that contributed to their lived experience. They had considerable insights into the interaction between a sense of failing self and their environment. This was particularly noticeable in their accounts of interactions with other people in hospital. It may be that when people with dementia face hospitalisation, the reciprocal relationship between self and others is accentuated and may contribute to an increased sense of failing self through this experience. The dominance of authority that is associated with being cared for in hospital and the heightened awareness of their own cognitive difficulties means that people with dementia had significant difficulties in achieving shared understanding. They defined good care through exploring alternatives to coming into hospital, personalised environments, opportunities to discuss their sense of failing self and being facilitated to communicate their individual and changing needs successfully.

## **5.3 Methodological Considerations**

This section presents a discussion of methodological and ethical considerations that emerged during the research process that can inform future work. This is followed by a critique of the methodology, including a discussion of the strengths and limitations of the approach.

### 5.3.1 Methodological contribution

At the inception of this study in 2008 the rationale for the thesis was based on the context that although people with dementia have been systematically studied, the focus of enquiry has remained relatively narrow; researchers have failed to engage with people with dementia directly and have relied on

third party reports or observations rather than connect with people with dementia themselves. Since then, there has been a major shift to conduct research that includes the accounts of people with dementia. There has also been an increase in hospital-based research over recent years. Despite this, their findings continue to be dominated by proxy accounts, reliance on retrospective details and a focus on interactions from the carers' perspective.

This thesis has presented a systematic way to investigate the experiences of people with dementia in hospital and has highlighted the role that they can take in influencing their experiences. The temporal interview style and flexibility in research design reported here demonstrates that it is not only possible to elicit rich accounts of their experiences, but also that the accounts themselves offer insight into the ways in which people with dementia manage sense of self in hospital. The use of unstructured observations, as opposed to the use of pre-defined measurement tools that focus on particular aspects of behaviour and events (Kitwood, 1994b, Brooker, 2005, Brooker and Surr, 2005, Brooker and Surr, 2006, Sloane et al., 2007, Woolley et al., 2009, Godfrey et al., 2018), facilitated an understanding of the experiences of people both during care tasks and events that take place outside of this. The use of focus groups with nurses facilitated an understanding of their perspectives of the experiences of people with dementia. Conducting the groups at different phases of the study afforded the opportunity to check out interpretations of experiences arising from analysis of earlier data. This strengthened the reliability and trustworthiness of the findings (Noble and Smith, 2015), and helped to capture a sense of the overall experience of people with dementia within the organisational context of ward routines.

The use of a multi-perspective IPA to facilitate data analysis and interpretation was challenging, mainly because there is a lack of publications that report on a tripartite approach from upon which to draw. The approach reported in this study contributes to the development of multi-perspective research designs to explore lived experiences. Through ensuring that the voices of people with dementia were central to the themes that developed during data analysis, the findings provided an account of their experiences and how they made sense of these.

### 5.3.2 Ethical considerations

There were several ethical considerations in the design and conduct of the study. Those that related to informed consent were discussed in Chapter Three: section 3.10. A number of potential issues emerged during the conduct of the study which were unanticipated and therefore are important to reflect upon for future research.

#### 5.3.2.1 Recruitment of relatives

There was an unexpected lack of relatives of study participants with dementia that were recruited to the study. Despite their accounts of relatives visiting, and on occasion the researcher observing that relatives visited at least 5 of the participants, only one relative was recruited to the study, and later withdrew their consent. One reason for their lack of inclusion is that the recruitment method may have limited their ability to consent to take part in the study. The opportunity for relatives to take part in the study was communicated through posters displayed around the wards, direct approach by the researcher if visitors were not engaged in conversation with their relatives during data collection periods, and information sheets that were given to participants to pass onto their relatives. The posters and information sheet contained details on how to contact the researcher should a relative wish to take part in the study. Despite accounts from people with dementia that they had passed on the information sheets in most cases, the only other system that had been put in place to check that this had been done was that on return visits, the information sheets were no longer visible within the participants' bed area. It may be that people with dementia had forgot to do this or had mistaken the information sheets as something else.

Another possible reason is that people with dementia that were recruited to the study lacked relatives that regularly visited them in hospital. It is possible that through asking nurses to identify patients that they considered to have dementia, that they biased their selection to those patients whom they perceived were lacking companionship, were at risk of being ignored and who they felt may benefit from spending time with the researcher. Not having visitors has been associated as a risk factor for neglect (Samonis, Giannousi,

Varbobitis, Sardi and Falagas, 2009), and some of the participants in the study did appear to lack support as evidenced through the reasons for their admission. Similarly, although the current study did not explore the journey into hospital, there is evidence that people who are more supported by informal carers often avoid unnecessary admissions due to the advocacy role that family members may adopt (de Vries et al., 2016). This also broadly supports the finding that people with dementia in the current study believed that they should not be in hospital.

This suggested bias in recruitment processes is supported by nurses' accounts where they did state that research would be better conducted through additional resources on the ward, and because of this perhaps through the researcher being on the ward this was seen as an extra resource that could be used to benefit some of their patients. In fact, some of the accounts of people with dementia, particularly in the case of Annie, suggested that they were low in mood and may have been suffering from depression, although this was not specifically explored. Nurses may have been aware of this also which may have biased selection to benefit some patients. It would have been useful to examine for differences in the number of visiting relatives between potential participants and non-participants to examine for these biases. However, this was not possible due to about confidentiality.

#### 5.3.2.2 Researcher role

There were several issues around the researcher role on the wards. Often, participants and other patients would ask the researcher for assistance with their daily living needs. Non-invasive support, such as passing drinks or personal items did not present any dilemmas. However, participants were often frustrated when the researcher denied assistance with their physical care; in these instances, a member of staff was immediately informed of any requests. This presented several dilemmas, most notably in ensuring that participants had an accurate understanding of the intended researcher relationship. Through adopting the cyclical consent process, discussed in Chapter Three: section 3.10, this helped to establish the researcher role.

The researchers' previous nursing experience also helped with communicating to participants the boundaries on what the researcher could do to assist them. Being clear about boundaries, checking out this understanding with participants and using common sense, such as ending interviews when participants appeared agitated with the line of questioning, helped to ensure informed consent during data collection.

Through being asked for assistance and having to refuse to help on some occasions this was a difficult dilemma for the researcher, which resulted in a struggle to establish a legitimate role on the ward. It is possible that in order to establish a critical distance from care, this influenced researcher observations. Again, applying common sense and being sensitive to what nurses did well as well as that which influenced participants' negative experience helped to ensure that the data collected was not overtly biased.

## **5.4 Methodological Strengths and Limitations**

### **5.4.1 Applicability of the research**

#### **5.4.1.1 Gaining access to experiences**

The main strength of this research is that it has included direct conversations with people with dementia, a very vulnerable and under-represented group. The findings build on the work of Turner and colleagues (2017) that reported on the observed actions and behaviours of people with dementia in the absence of any interpretation of the meaning of actions and behaviours. In the present study, the experiences of people with dementia were captured during their hospital stay which helped to avoid, as much as possible, reliance on recall after the event. Temporal interviews allowed material to be revisited and expanded upon and to explore new lines of inquiry that were context-specific. The detailed account of the process of interviews that was given in Chapter Three: section 3.8.2, provided a transparency in interview method, which could be used to inform future research. The use of observations to inform subsequent interviews facilitated exploration of the researchers' interpretations of their experiences as they unfolded. The inclusion of the perceptions that nurses held as a group in the data analysis and interpretation of findings, helped to provide context to the experiences of

people with dementia within nurse's definitions of their roles and responsibilities in caring for them. This study has used evidence from multiple perspectives to understand the experiences of people with dementia in hospital. Evidence from more than one perspective has facilitated rigour and transparency in the findings (Larkin et al., 2019). The findings from the empirical study corroborate findings from those included in the review, and extend upon them, thus supporting the credibility of the design and findings of the research study.

#### 5.4.1.2 Convenience sample

The sample of people with dementia that were included in this study represent a convenience sub-sample of people with dementia in hospital and cannot be considered as representative of the population of people with dementia in hospital. It is possible that through a focus on their accounts, that factors that influenced their experiences and their interpretation of them were context specific and as such generalisation to the experiences of other people with dementia in other settings should be undertaken with caution.

However, the findings are representative of data that has been collected from different sources and perspectives to develop a picture of lived experience in hospital, and therefore provide a representative version for those in other, similar environments (Lincoln and Guba, 1985, Larkin et al., 2019). In addition, the findings build on existing evidence of the experiences of people with dementia in hospital and map onto the construction of self of people with dementia – a recognised theory for understanding the experiences of people with dementia – and may be considered transferable to other acute hospital settings caring for people with dementia.

#### 5.4.1.3 Sample demographics

The sample may potentially have only included participants who had strong concerns about their experiences of being in hospital. As the sample was recruited based on the opinions of the nurses, and nurses felt undervalued in their care of people with dementia they may have filtered out patients who would be less complimentary about their care. Participants were mainly white British, English speaking patients and so cultural differences between



people with dementia from diverse ethnic and religious backgrounds could not be explored. Around half of all participants had relatively longer length of stays than national averages for length of stay at the time of the study, which indicated a possibility that there were social factors related to their hospital stay. However, the similarities across experiences suggests that the findings are relevant to multiple reasons for staying in hospital. Undertaking data collection across two different wards, which broadly represented key areas for which people with dementia are admitted, and the decision to purposely recruit males and females, ensured that diversity in setting and gender was obtained.

#### 5.4.1.4 Existence of dementia

##### Method of recruitment

Participants were recruited to the study based on the perceptions that nurses held on them as having dementia. It is possible that participants did not have dementia and that the accounts that were elicited represent experiences of people living with memory problems. However, several participants did refer to having dementia and most recognised that they lived with changes in their cognitive abilities. In addition, when discussing the research study with potential participants and throughout the course of the data collection period, the researchers' opinion did not differ from that of the nurses, which added strength to the belief that the recruited participants most likely had dementia.

A limitation of this study is the reliance on nurses as gatekeepers to the accounts of people with dementia. Participants were recruited on the basis of perceptions around the existence of specific behaviours associated with the existence of dementia. In their descriptions of their experiences of people with dementia, nurses mainly focused on expressive symptoms as behaviours which they had to manage. Such behaviours were not observed during the data collection. This suggests that nurses may have filtered out people that tended to exhibit such behaviours during the recruitment process. One possible reason for doing this is that from the nurses' point of view, expressive symptoms are mainly seen in those people with dementia that would not be able to consent to take part in research or converse in conventional ways. It may also be that nurses did not put forward those

patients that expressed behaviours that the nurses found difficult to manage, as they may be critical of their care.

A limitation of this study is that people with more advanced dementia were not within scope. However, the discussion on implications of findings presented in section 5.2 of this Chapter demonstrated that the experiences of participants in the current study are similar to findings from previous studies that have observed people with more advanced dementia, and therefore may broadly represent how people with dementia in general make sense of their experiences.

### Authenticity

It is possible that the lack of discussion with people with dementia about the possible existence of dementia, may have inadvertently influenced the authenticity of their accounts. In the discussion on loss of self in Chapter One: section 1.3.2, findings from these studies suggested that people with dementia desire to be treated as normally as possible. Not specifically discussing dementia may therefore disrupt the course of managing self and have altered the accounts that were elicited as a result. The accounts may reflect instead their experiences when dementia is ignored. However, during the interviews most participants volunteered information about how changes in their cognition made them different from other people and from who they used to be, which indicated a level of awareness of the existence of changes that are associated with dementia. Moreover, three participants talked about their experience of awareness of dementia, albeit that they denied it existed, or normalised their condition as part of the ageing process. This suggests that although awareness was not explicitly measured, that the accounts reported here are indicative of the experiences of people with dementia in hospital. The findings do need to be interpreted with caution however, as the review of medical records found that only one participant was formally diagnosed with dementia and although dementia was queried by professionals in a further four participants case notes, no record of formal diagnosis was made.

#### 5.4.1.5 Researcher reflexivity

The trustworthiness of the research was facilitated through presenting an in-depth explanation of approach to data analysis and a description of conceptual integration of findings. The findings are embedded in what is in the data. To this end, an attempt was made to ensure that theme titles, and properties within them stayed as close to the text contained within the transcripts from interviews with people with dementia as was possible. Similar to reporting methods in other IPA studies, findings were presented together with quotes from participants, which illustrated that pre-existing theoretical concepts were not imposed upon their experiences (Larsson et al., 2019). To assist with trustworthiness of the themes that were developed from the analysis of the data themes were refined through an iterative process, during which supervisors reviewed the themes against selected data. However, as IPA involves an interpretative process, there will be researcher bias within the analysis and findings.

#### 5.4.2 Data collection

##### 5.4.2.1 Study period

The delay between data collection and reporting of study findings here raises an important methodological issue. A potential limitation of this study is that the experiences of people with dementia in hospital were captured over 8 years prior to writing up the thesis. The delay in reporting the findings was due to changes in the personal circumstances of the researcher. However, during the delay, the original data was reanalysed so whilst the experiences of people with dementia were captured some years ago, the analysis and interpretation of the data occurred more recently during 2018 and 2019. The literature review was also redone to take account of the most recent evidence available. The motivation to pursue the research was not only driven through a need to ensure that the voices of those that took the time to discuss their experiences were heard, but also that their accounts, in relation to current evidence, appear just as relevant today as they were then. Despite care of people with dementia remaining a political, training and research priority since the inception of the research (see Chapter One, section 1.5), with a two-fold increase in the number of empirical studies reporting on their

experiences in hospital over the past 8 years (see Chapter Two, section 2.4.3), the findings reported here suggest that their experiences in hospital have not altered significantly over that time. Still, very few studies have attempted to elicit direct, articulated accounts from people with dementia. The accounts elicited in this study were novel and contribute to existing evidence in this field. The authority of the findings comes from adapting robust research methods.

Another potential limitation of the study is that at the time of data collection, the hospital was introducing novel, enhanced liaison psychiatry services, which was related to the larger study in which this work was initially embedded. In their accounts of people with dementia, nurses may have focused on those behaviours that would likely meet requirements for additional staffing levels, so as not be overlooked in any potential staffing enhancements.

A further potential limitation in relation to timing is the length of time that participants remained in the study. It is possible that as most stayed in hospital much longer than they were studied, that their experiences were different outside of the study period. However, the findings are necessarily a snapshot of their experience and this had to be observed within the limitations of researcher availability and funding constraints.

#### 5.4.2.2 Interviews with people with dementia

There were several factors to consider in the data collected from interviews with people with dementia, some of which were discussed in the development of methods section in Chapter Three: section 3.8.2. The researchers' previous nursing experience may have implicitly created the potential to bias responses towards socially desirable answers. It is also possible that despite assurances of being independent from influencing their care, that the association of the researcher with the hospital could also bias their responses.

Whilst several strategies were employed to facilitate the flow of discussion during the interviews, conducting interviews within public spaces may have limited that which participants could express in confidence. During some of

the interviews, participants could give relatively convoluted or abstract responses that required a high level of interpretation, which is common practice in qualitative analysis. However, their accounts expressed their present descriptions, which were open to change. The interviews elicited their construction of their experiences over a short space of time and would have been influenced by the relationship with the researcher, motives for taking part in the research and perceived consequences to them of the accounts that they portrayed.

Nevertheless, the interviews did generate rich and detailed descriptions of their experiences, and the flexibility in design assisted participants to discuss that which was important within their experience, at that moment. One of the limitations of using temporal interviews as a method for data collection was that subsequent interviews may elicit accounts of different experiences, particularly for people in cognitive decline who may not recall their earlier accounts. Through adopting a conversational approach to the interviews, and not focusing on recall as a method for understanding experiences, the accounts that were elicited across temporal interviews represented, as much as possible, their interpretation of their experiences across time, which facilitated credibility of their accounts.

The process of taking part in the interviews was for some participants seen as an opportunity to focus on past events, suggesting that the interview process prompted their autobiographical memories, which is associated with affirming a sense of self (Gibson, 1994). Whilst this produced data which would not be reported in the study, this highlighted how the interview process could reveal through their accounts of their experiences, how they managed sense of self within their experiences. It is possible that through the process of taking part in the interviews, people with dementia were given a sense of power and legitimacy. A similar conclusion was drawn in Hung et al's (2017) publication, where they concluded that the accounts of people with dementia gave recognition of their expertise of the experience of care.

#### 5.4.2.3 Focus groups with nurses

One of the disadvantages of focus groups is that perhaps only those people with vested interest in discussing care of patients with dementia were included in the sample. Similar to findings reported by Prato and colleagues (2018), it was difficult to encourage nurses to answer questions about the experience of the person with dementia, which were often interpreted as context to discuss their own experiences. This limited findings about their perceptions of the experiences of people with dementia, but not about care of people with dementia. Often during the focus groups when nurses shifted the focus to their own experiences, it felt ethically and morally incorrect to prevent them from doing so. This may be related to the researchers' nursing background and associated empathy with lack of opportunities to discuss feelings about being undervalued, and some naivety in conducting focus groups with health professionals. Nevertheless, their accounts expanded upon the themes that were initially derived from the accounts of people with dementia, and demonstrated the important divergence from their accounts, in that which they are perceived to do well.

#### 5.4.2.4 Non-participant observations

The duration of non-participant observations in this study are below those reported in other studies of people with dementia in hospital. For example, Clissett and colleagues (2013) spent over 72 conducting observations concerning 30 carers and 29 people with dementia, and Prato and colleagues (2018) reported that 73 participants were recruited during almost 53 hours of non-participant observations. The longer duration of observations may be related to the main research method of these studies, and a lack of direct, articulated accounts from people with dementia during the analysis and interpretation of their reported findings. This limitation was discussed in Chapter Two: section 2.4.4, where despite evidence being framed as the experiences of people with dementia, this literature is dominated by proxy accounts.

The process of conducting non-participant observations evolved during the current study in response to what was being captured in the data. The way

in which this occurred was discussed in detail in Chapter Three: section 3.8.3. The final set of field notes contained data gained over the 23 hours of observations of people with dementia which was sufficient to explore that which they characterised as important factors that influenced their experience, which included interactions with nursing staff. The original target of the study was to observe people with dementia for a longer duration; the patterns and understanding which emerged during the 23 hours of observation suggested saturation of themes had been achieved and that observing for longer periods would not yield sufficient gains to justify the time and intrusion into the lives of people with dementia and staff. The 23 hours of observation provided important insights into interactions between people with dementia, their physical and social environment and the research process.

## **5.5 Implications of Findings**

The findings from this study have raised awareness of the experiences of people with dementia in hospital and provided a conceptual framework from which to understand their experiences. It does not claim to represent the entire experience of hospitalisation. Medical intervention, care in other departments, admission and discharge procedures, and end of life care have not been investigated. Instead, this research has focused on that which occupies most of the time that is spent as an in-patient; time on the wards. The following section discuss the implications of the findings for practice and future research.

### **5.5.1 Implications for practice**

The findings from this research suggest that several important changes could be made to improve the hospital experience for people with dementia. Firstly, it is worth reiterating that despite living with lack of power and control in their social environment, particularly in their interactions with the staff, people with dementia did not appear to require this to evaluate their care as good and nurses did not appear to be aware of that which they do well. There is, at present, very little opportunity for people with dementia to formally give feedback to the nurses caring for them, with the exception of

complaints, and yet there is increasing evidence of the impact of positive feedback on shifting care culture (Hollnagel, 2015). Taken together, these findings support recommendations whereby nurses are facilitated to understand better that which they do well, and to do more of it.

The evidence from the research study, combined with the findings from the literature review indicates that person-centred care for people with dementia in hospital is achieved through practice that facilitates good care and mitigates risks for poor care. Factors associated with good and poor care are shown in Figure 5.1 (page 170). Meaningful interaction with patients with dementia is a priority, and the evidence suggests interactions are meaningful through the way in which they facilitate a person with dementia to have shared understanding.

The organisational context in which care is provided potentially limits care and this remains virtually unchallenged. This is despite previous evidence, and as was discussed in the present study, that changes to the environment and slight shifts in established routines have the potential to improve care experiences. The conceptual model presented in Chapter Two could be developed alongside existing initiatives to inform good practice.

More needs to be done to recognise the unique needs of people with dementia when they go into hospital, and these need to be prioritised in much the same way as other groups of people who go into hospital with specific needs. Existing with dementia, or the possibility of it should not be viewed as coincidental in the hospital setting, but as very much part of the patient that is there to be cared for.

People with dementia have raised genuine concerns that for some, they may not be legitimate patients in hospital. They associated this with feeling disempowered, which had negative consequences to their emotional and psychological well-being and continued throughout their hospital experience. There is evidence that in spite of several initiatives that have been set up to prevent unnecessary admissions in recent years, that admission rates for people with dementia remain virtually unchanged (Sommerlad et al., 2019). As well as improved availability and access to support in the community, the



findings indicate that alternatives to hospital should be prioritised and that where this is not possible, there is consensus across the healthcare organisation and with people with dementia as to legitimate reasons for admission.

Being in hospital is likely to always include periods of inactivity, and for some be associated with boredom. The findings from the current study add further evidence for the negative impact of being restricted in movement and ability to engage in meaningful activities. Attempts to improve opportunities are generally seen as beneficial. One study reported on the benefits to patients of taking part in music making to their well-being. Improvements in well-being were elevated mood, enjoyment and engagement and opportunities for socialising. Although staff found their roles uncomfortable and it was a challenge to fit the activity in around hospital routine, it was possible (Daykin et al., 2018). However, such initiatives are costly, rare, and often not a priority due to the nature of acute medical care. More needs to be done to understand the longer-term effects of such initiatives, particularly where there are cost savings, for these to be better received and increase the chances of hospital management buying into the benefits. Ways in which to sustain such initiatives, once implemented also need to be established to ensure continuity in improved care.

A collaborative approach to improvement is needed. Staff training, linked to direct, personal accounts from people with dementia, and support from senior managers would facilitate better care for people with dementia. Evaluations of training interventions indicate that training delivered in the clinical setting is feasible and has greater potential to enhance practice (Smythe et al., 2014). Interestingly, in Smythe's et al (2014) study, hospital staff thought that the best way to teach staff about dementia care was through observation, which resonates with the principles of dementia care mapping that were discussed in Chapter One. It is perhaps through the development of a more user-friendly, less time-consuming guide to observation, such as that discussed by Godfrey et al (2018) that hospital staff will be able to achieve this ambition in a more systematic, evidence-based way. The current study has emphasised the importance of the perspectives of people with dementia, which do not

always converge with that which is observed. Taken together, this indicates that staff training initiatives may have improved success if they are based on the principles of experiential learning and reflection, and in conjunction with people with dementia.

### 5.5.2 Implications for research

This study has adapted research design and analytical procedures to facilitate understanding of the experiences of people with dementia, from their perspective, with additional contextual data from other sources. The use of a multi-perspective IPA to facilitate data analysis and interpretation in a tripartite study design was challenging, mainly due to the lack of publications that have successfully used this approach in research involving people with dementia. The study has highlighted that multi-perspectives of the experiences of people with dementia can inform conceptual frameworks for understanding their experiences.

The study has shown that people with dementia can and should be engaged in co-design of research for quality improvement. Through adopting a conversational format using open-ended, unstructured guides, people with dementia were facilitated to clearly articulate aspects of their experiences, including strategies that they may use to manage positive and negative facets related to their condition.

The study has also highlighted how future research should consider exploring the experiences of their family members and other people caring for them. However, because of previous tendencies to report proxy accounts, an IPA approach to understand meaning of experiences from different perspectives, would require separate analyses, with meaningful integration of different accounts. Like previous studies that have reported on the experiences of people with dementia from multiple perspectives using an IPA approach (Clare, 2002, Clare, 2003, Prato et al., 2018), the integration of data in the present study suggests how this can be achieved.

This study has highlighted that ones' ability to interact with others is important in how people of dementia evaluate their experiences of care. Future research should consider using a standardised reporting method for level of

physical functioning in activities of daily living, such as the Barthel Index (Mahoney and Barthel, 1965). This would provide an objective measure of the different abilities of people with dementia in hospital which would help in discussing context of what may be possible for the person with dementia and that which is available to them.

Future research may also consider observing what staff are doing when they are not directly interacting with people with dementia. Often, as was the case in the present study, staff roles and responsibilities are inferred from data that has been collected that was not focused directly on their role. Such an approach would provide further context to important factors that impact experiences of people with dementia in hospital.

The many different models that are used to study self in dementia, including that which has been used here, means that a wide range of methodologies have been used. This has resulted in a wide range of disparate evidence, which was summarised in Chapter One: section 1.3.1.2. Since the review published by Caddell and Clare (2010), the evidence base has increased considerably. While it was beyond the scope of the current work to systematically explore and synthesise the literature on the interaction between healthcare and self of people with dementia, it appears timely to do so. Strikwerda and colleagues (2019) have recently synthesised the evidence on self of dementia, across different contexts which could provide a framework for mapping out existing and potential healthcare interventions in the future.

The value of the conceptual framework of lived experience developed in the current study is that it may also be applicable to people with dementia in other situations. It may be of relevance to understanding the experiences of people living in different settings with chronic conditions for example.

Finally, this thesis has demonstrated that despite being only one year away from realising the ambitions of the latest government dementia strategy, that the evidence base is not derived the people that the strategy was designed to impact upon. The research has highlighted the value of exploring the experiences of people with dementia during a hospital episode. There is an

urgent need for more publications that report findings from the accounts of people with dementia.

### **5.3 Final Words**

This thesis has explored the experiences of people with dementia in hospital and has developed a conceptual framework to describe important factors that impact their lived experiences. People with dementia demonstrated rich insights into their experiences which influenced their sense of self. They have raised several areas for improvement that can be addressed through changes to the culture of their care in hospital, and this thesis contributes to these changes.

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## List of Abbreviations

CASP	Critical Appraisal Skills Programme
DCM	Dementia Care Mapping
IPA	Interpretive Phenomenological Analysis
NHS	National Health Service
PMI	Protected Mealtime Initiative
PRISMA Analyses	Preferred Reporting Items for Systematic Reviews and Meta-

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## A: Prospero registered systematic review protocol

PROSPERO

**NIHR** | National Institute  
for Health Research

International prospective register of systematic  
reviews

What are the experiences, perceptions and views of people with dementia on their general hospital ward care: a narrative synthesis.

*Carolyn McCrorie*

### Citation

Carolyn McCrorie. What are the experiences, perceptions and views of people with dementia on their general hospital ward care: a narrative synthesis. PROSPERO 2018 CRD42018106394

Available from:

[https://www.crd.york.ac.uk/prospéro/display\\_record.php?ID=CRD42018106394](https://www.crd.york.ac.uk/prospéro/display_record.php?ID=CRD42018106394)

### Review question

The overarching research questions is what are the experiences, perceptions and views of people with dementia on their general hospital ward care?

Aims and objectives are:

1. To synthesise the evidence on the experiences, perceptions and views of people with dementia on their general hospital ward care
2. To synthesise the evidence from formal and informal carers views on the experiences, perceptions and views of people with dementia on their general hospital ward care
  - How do people with dementia define good care?
  - What ideas do they have for what could or should be done to improve their care experiences?
  - What are the characteristics of poor and good care?
  - What are perceived as the barriers and enablers to good care?

### Searches

The following electronic databases of published literature will be searched, with search strategies tailored to each database: MEDLINE, MEDLINE Epub Ahead of Print 2014 to daily update, EMBASE, CINAHL, PsycINFO, Social Care Online. In addition, reference lists of all included studies will be hand-searched. Grey literature will be searched for empirical data. Websites of organisations that report dementia research, such as Alzheimer's Society will be searched.

The search in Boolean operators is: dementia OR Alzheimer\* OR "Lewy Bod\*" OR "vascular dementia" OR pick\* OR Huntington\* OR frontotemporal OR Creutzfeldt-Jakob OR "cognitive impairment" OR "confusion" OR "delirium" AND qualitative OR "mixed\*methods" OR interview\* OR narrative OR phenomenol\* OR ethnograph \* OR "grounded theory" OR "case stud\*" OR "action research" OR "focus group " AND knowledge OR perspective\* OR "subjective experience" OR expression\* OR experiences\* OR perception\* OR attitude\* AND acute care OR acute ward Or acute hospital OR hospital.

### Search strategy

#### Types of study to be included

Inclusion criteria: Primary research about experiences of care either within a general hospital WARD setting (not Accident and Emergency Department or Intensive care) that is physician led such as enhanced care in specialised dementia care units and the focus on care is on the acute medical need. Studies will be included if they are focused on the views of people with dementia and their formal and informal care givers on the experience of general hospital ward care for people with dementia.

Exclusion criteria: Study focused is on caregiver needs/burden. About people with dementia but not focused on their general hospital care. Addresses care of people but not people with dementia in particular. Focused on discharge planning process. Focus on assessing learning and training needs of general hospital staff. About delirium as a consequence of medical illness, superimposed on dementia.

#### Condition or domain being studied

Experiences of people with dementia in the general hospital ward setting, where dementia is coincidental to the reason for admission during an acute illness episode.

## **A: Prospero registered systematic review protocol (continued)**

### Participants/population

People who have a dementia without restriction to age. A formal diagnosis of dementia is not required. Studies will be included once the study author(s) state that participants were included due to the existence of dementia.

People who are involved in caring for the people with dementia, including formal and informal carers and their families.

### Intervention(s), exposure(s)

Participants will have had first-hand experience of care within a general hospital ward setting for any diagnoses and care interventions including end of life or palliative care in the general hospital ward setting. If possible, a sub-analysis by intervention will be carried out.

### Comparator(s)/control

Not applicable

### Context

General hospital setting - hospital admittance due to an acute medical illness/injury

### **Main outcome(s)**

Establishing the evidence base for the experiences, perceptions and views of people with dementia who receive general hospital ward based care.

### Additional outcome(s)

None

### **Data extraction (selection and coding)**

The author will independently read the title and abstract of every retrieved reference to decide which studies should be further assessed. The author will also independently extract data including: Country, study setting, study aims, date range, sampling techniques, sampling size, participant characteristics, data collection method, size/length of data set, ethics, researcher role, data analysis approach, theoretical frameworks used, thematic overview with quotations, acknowledged limitations, implications and conclusions.

Consensus for inclusion/exclusion will be sought through 20% double screening by PhD supervision team. Differences in opinion will be resolved by discussion.

### **Risk of bias (quality) assessment**

Quality assessment will be assessed through CASP. The author will rate individual studies using the CASP qualitative tool. No studies will be excluded on the basis of quality rating.

### **Strategy for data synthesis**

A narrative qualitative synthesis is planned.

### **Analysis of subgroups or subsets**

If possible, a sub-analysis of the accounts of experiences of people with dementia from different sources (e.g. people with dementia, formal and informal caregivers), in different types of ward setting (e.g. care of the elderly, general medicine) and with different types of care delivery (usual care and enhanced care) will be conducted.

### **Contact details for further information**

Carolyn McCrorie

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**Organisational affiliation of the review** Leeds Institute of Health Sciences, University of Leeds

[https://medhealth.leeds.ac.uk/info/600/leeds\\_institute\\_of\\_health\\_sciences](https://medhealth.leeds.ac.uk/info/600/leeds_institute_of_health_sciences)

### **Review team members and their organisational affiliations**

Carolyn McCrorie. Leeds Institute of Health Sciences, University of Leeds

### **Type and method of review**

Narrative synthesis, Synthesis of qualitative studies, Systematic review

**Anticipated or actual start date** 01 May 2018, **Anticipated completion date** 30 November 2018, **Funding sources/sponsors** PhD thesis, **Conflicts of interest** None, **Language**

English, **Country**

England, **Stage of review** Review Ongoing, **Subject index terms status** Subject indexing assigned by CRD, **Subject index terms** Dementia; Hospitals, General; Humans; **Date of**

**registration in PROSPERO** 21 August 2018; **Date of publication of this version** 21

August 2018, **Versions** 21 August 2018

**B: Combined search terms used in Ovid database**

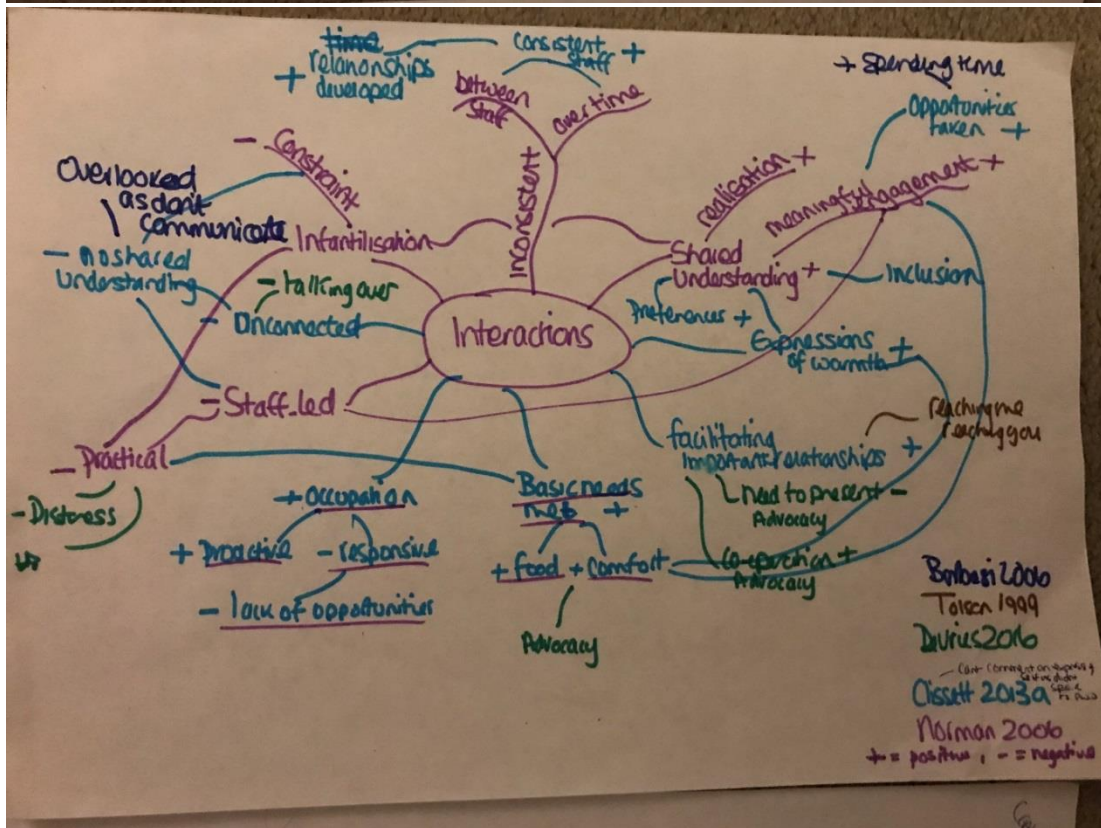
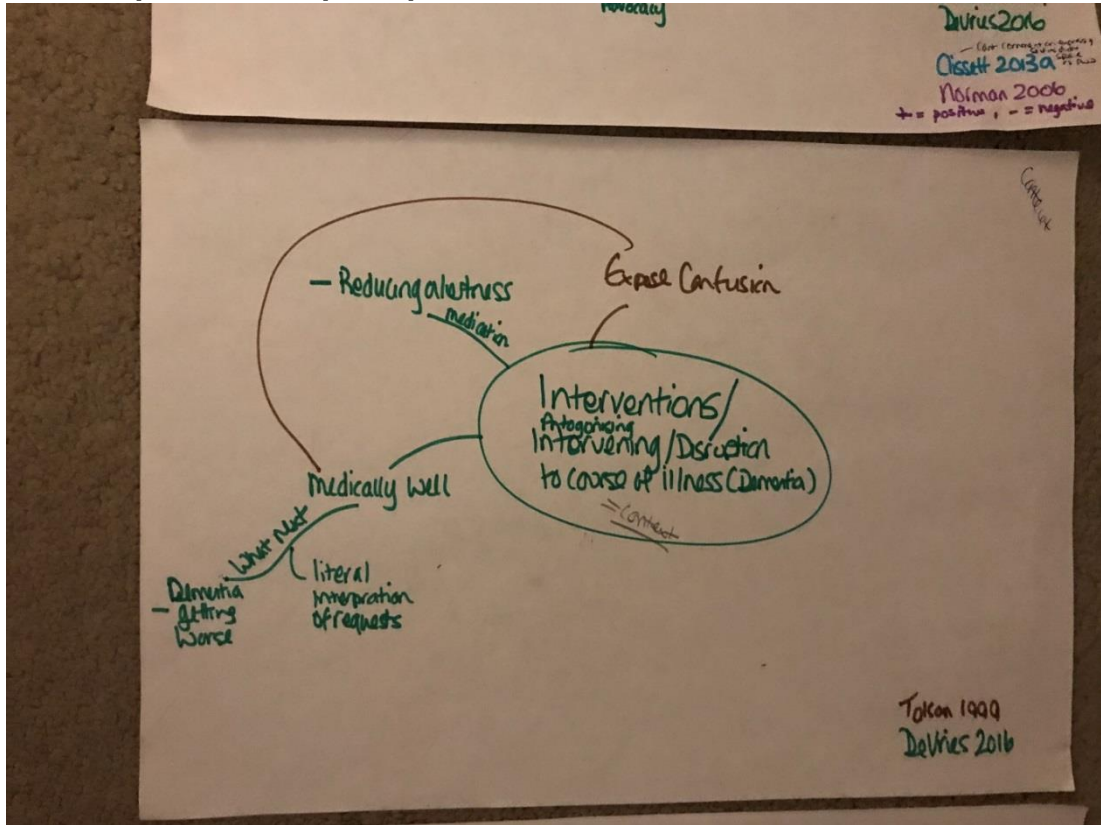
1. (dementia or Alzheimer\* or Lewy Bod\* or "vascular dementia" or pick\* or Huntingdon\* or frontotemporal or Creutzfeldt-Jakob or "cognitive impairment" or "confusion" or "delirium")
2. (qualitative or "mixed\*methods" or interview\* or narrative or phenomenol\* or ethnograph\* or "grounded theory" or "case stud\*" or "action research" or "focus group")
3. (knowledge or perspective\* or "subjective experience" or expression\* or experiences\* or perception\* or attitude\*)
4. 1 and 2 and 3
5. (acute care or acute ward or acute hospital or hospital)
6. 4 and 5
7. ("survey\*" or "questionnaire\*" or "scale\*" or "inventor\*")
8. 2 or 7
9. 1 and 3 and 8
10. 5 and 9
11. remove duplicates from 10



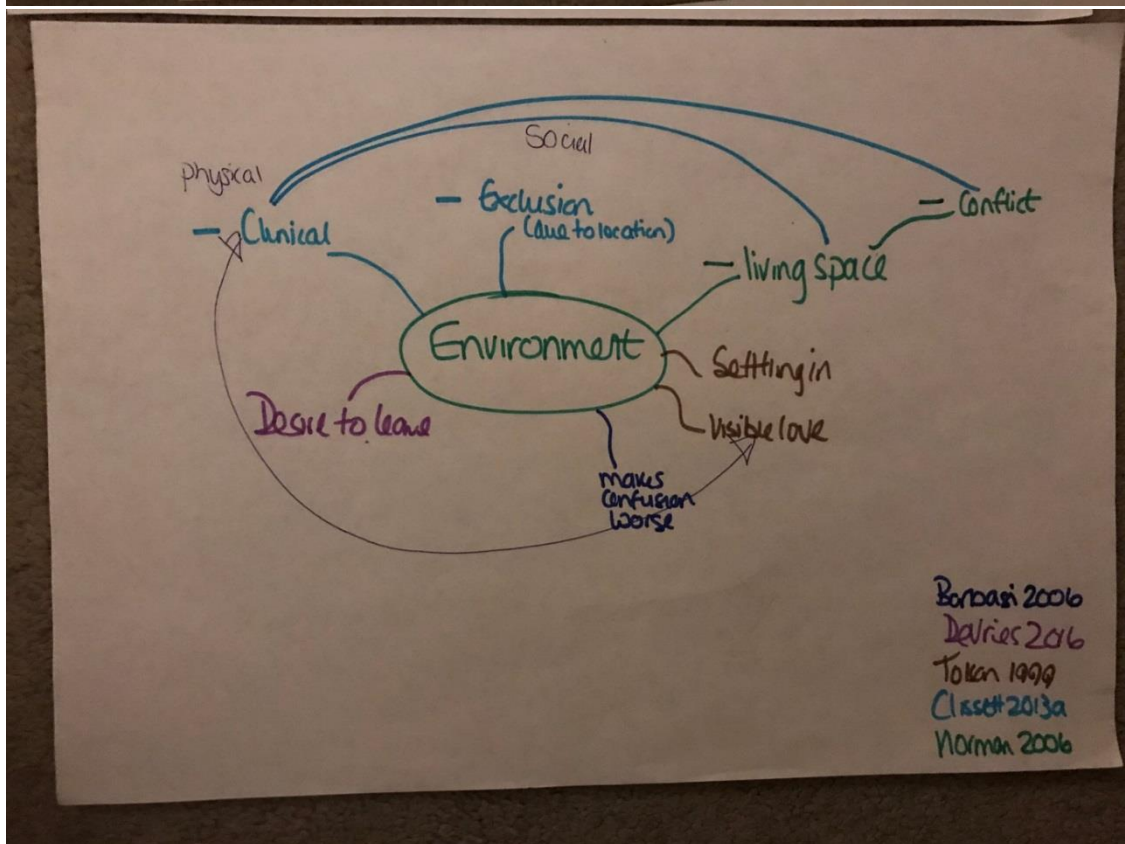
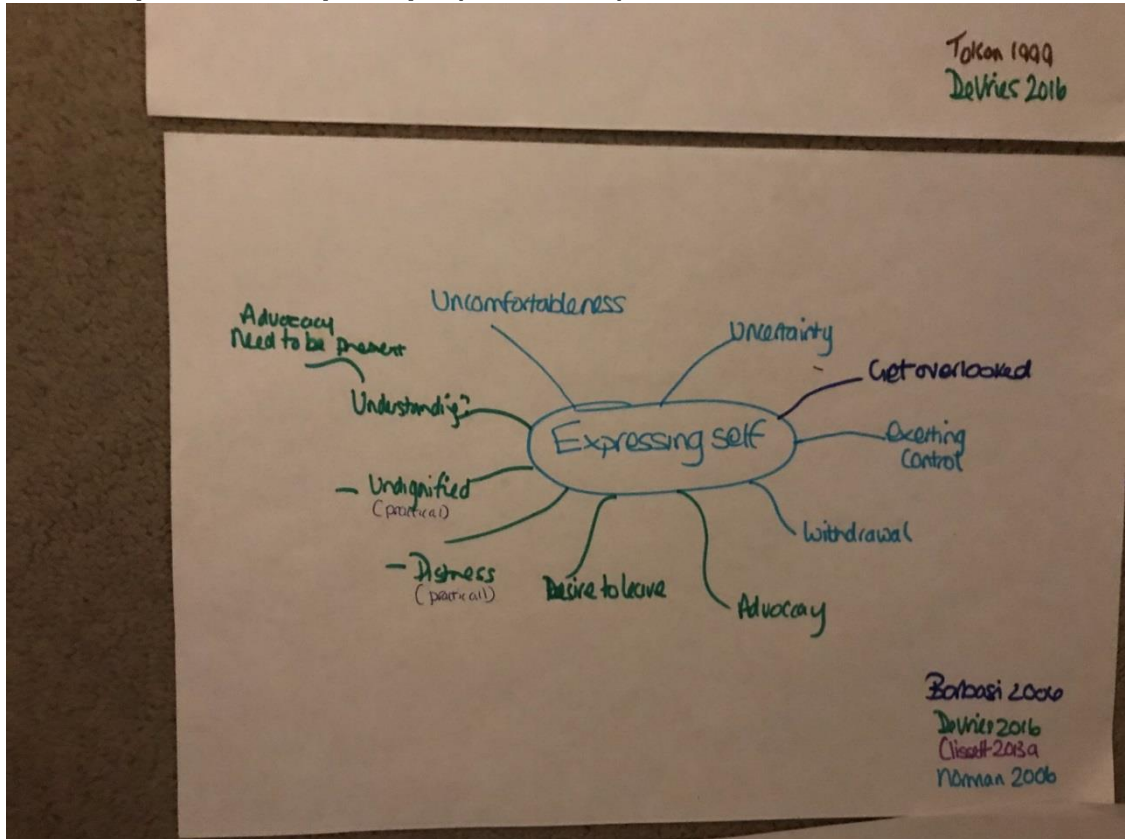
**C: Data extraction template**

Author, Year, Title, Jnl, Vol, Pg
Country
Study setting
Study design
Study aims
Date range
Recruitment techniques
Sample size
Participant characteristics
Primary/secondary reasons for episode
Data collection method
Size/length of data
Ethics etc.
Researcher role
Data analysis including amount of detail given
Theoretical frameworks
Themes overview
Theme 1
Theme 2
Theme 3
Theme 4 etc.
Acknowledged limitations
Implications and conclusions
What is the study about and what does it add?
Any other comments

D: Example of concept maps



D: Example of concept maps (continued)



**E: Example of cross-tabulation**

<i>Lead author</i>	<b><i>Negative experiences or unsupportive care</i></b>
<b><i>Norman (2006), De Vries (2016), Borbasi (2006), Jensen (2017)</i></b>	Lack of attention to and understanding of preferred modes of communication
<b><i>Lichtner (2016)</i></b>	Communicating pain
<b><i>Norman (2006)</i></b>	Inconsistent interactions between staff and over time <ul style="list-style-type: none"> <li>• Infantilisation leading to constraint</li> </ul>
<b><i>De Vries (2016)</i></b>	Absence of family carers as advocates for preferences
<b><i>Prato (2018)</i></b> <b><i>a. Clissett (2013)</i></b>	Lack of opportunities for occupation <ul style="list-style-type: none"> <li>a. Responsive occupation</li> </ul>
<b><i>Norman (2006), Prato (2018)</i></b> <b><i>a. Clissett (2013), Prato (2018), Cowdell (2010a)</i></b> <b><i>b. De Vries (2016), Norman (2006), Lichtner (2016), Cowdell (2010a&amp;b)</i></b> <b><i>c. De Vries (2016)</i></b> <b><i>d. Prato (2018)</i></b> <b><i>e. Jensen (2017)</i></b> <b><i>f. Cowdell (2010a)</i></b>	Staff-led interactions focused on practical concerns <ul style="list-style-type: none"> <li>a. Lack of shared understanding, unconnected</li> <li>b. Signs of distress and uncomfortableness ignored</li> <li>c. Being talked over</li> <li>d. Lack of knowledge on patients' life story</li> <li>e. Wishes being ignored</li> <li>f. Impersonal care</li> </ul>
<b><i>Borbasi (2006)</i></b>	Over-sedation
<b><i>Prato (2018)</i></b>	Lack of personal belongings/effects
<b><i>Cowdell (2010b)</i></b>	Lack of involvement in and knowledge of future plans
<b><i>Clissett (2013)</i></b>	Exclusion from being part of things

<b>E: Example of cross-tabulation (continued)</b>	
<i>Lead author</i>	<b><i>Positive experiences or supportive care</i></b>
<b><i>Hung (2017)</i></b>	Alterations to the physical environment
<b><i>Lichtner (2016)</i></b>	Having personal belongings/symbols
<b><i>Norman (2006), Clissett (2013)</i></b> a. <b><i>Clissett (2013), Lichtner (2016)</i></b>	Consistent staff a. Relationships develop
<b><i>Norman (2006), Clissett (2013)</i></b> a. <b><i>Clissett (2013), Prato (2018)</i></b> b. <b><i>Jensen (2017)</i></b> c. <b><i>Clissett (2013)</i></b> d. <b><i>Norman (2006), Clissett (2013), Borbasi (2006), Porock (2015), Moyle (2016), Prato (2018)</i></b>	Shared understanding with staff a. Individual preferences acknowledged and acted upon b. Involving the patient in the care process c. Sense of inclusion d. Opportunities for meaningful engagement [linked to involving the patient in the care process]
<b><i>Clissett (2013)</i></b>	Expressions of warmth
<b><i>Clissett (2013), de Vries (2016), Prato (2018)</i></b> a. <b><i>de Vries (2016), Moyle (2016), Lichtner (2016)</i></b> b. <b><i>De Vries (2016)</i></b> c. <b><i>Prato (2018)</i></b>	Facilitating important relationships a. advocacy through family carers b. co-operation with family carers c. Through location on the ward
<b><i>Clissett (2013), Prato (2018)</i></b>	Basic needs for food and comfort being met
<b><i>Clissett (2013), Hung (2017), Porock (2015), Prato (2018)</i></b>	Proactive occupation
<b><i>Norman (2006), de Vries (2016), Porock (2015)</i></b>	Sense of control

## F: CASP quality appraisal outcome

<b>CASP questions</b>	<b>Yes</b>	<b>Can't tell</b>	<b>No</b>
<b>1. Was there a clear statement of the aims of the research?</b>	Borbasi 2006, Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Jensen 2017, Norman 2006, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Lichtner 2016, Hynninen 2015, Simpson 2016		
<b>2. Is qualitative methodology appropriate?</b>	Borbasi 2006, Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Jensen 2017, Norman 2006, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Lichtner 2016, Hynninen 2015, Simpson 2016		
<b>3. Was the research design appropriate to address the aims of the research?</b>	Borbasi 2006, Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Norman 2006, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Lichtner 2016, Hynninen 2015, Simpson 2016	Jensen 2017	
<b>4. Was the recruitment strategy appropriate to the aims of the research?</b>	Borbasi 2006, Porock 2015, Jensen 2017, Norman 2006, de Vries 2016, Moyle 2016, Lichtner 2016, Hynninen 2015	Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Hung 2017, Prato 2018, Simpson 2016	
<b>5. Was the data collected in a way that addressed the research issue?</b>	Borbasi 2006, Nolan 2007, Clissett 2013, Porock 2015, Jensen 2017, Norman 2006, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Lichtner 2016, Hynninen 2015, Simpson 2016	Cowdell 2010(a), Cowdell 2010(b)	
<b>6. Has the relationship between the researcher and participants been adequately considered?</b>	Cowdell 2010 (a), Cowdell 2010 (b), Jensen 2017	Lichtner 2016	Borbasi 2006, Nolan 2007, Clissett 2013, Porock 2015, Norman 2006, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Hynninen 2015, Simpson 2016
<b>7. Have ethical issues been taken into consideration?</b>	Borbasi 2006, Cowdell 2010 (a), Cowdell 2010 (b), Jensen 2017, Norman 2006, Hung 2017, Prato 2018, Hynninen 2015	Nolan 2007, Clissett 2013, Porock 2015, Lichtner 2016	de Vries 2016, Moyle 2016, Simpson 2016
<b>8. Was the data analysis sufficiently rigorous?</b>	Borbasi 2006, Jensen 2017, Hung 2017, Prato 2018, Lichtner 2016, Hynninen 2015	Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Norman 2006, de Vries 2016, Moyle 2016, Simpson 2016	
<b>9. Is there a clear statement of findings?</b>	Borbasi 2006, Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Jensen 2017, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Lichtner 2016, Hynninen 2015, Simpson 2016	Norman 2006	
<b>10. Will the results help locally/how valuable is the research?</b>	Borbasi 2006, Cowdell 2010 (a), Cowdell 2010 (b), Nolan 2007, Clissett 2013, Porock 2015, Jensen 2017, Norman 2006, de Vries 2016, Hung 2017, Prato 2018, Moyle 2016, Lichtner 2016, Hynninen 2015, Simpson 2016		

## G: Ethics approval – substantial amendment

### Leeds (West) Research Ethics Committee

A/B Floor, Old Site  
Leeds General Infirmary  
Great George Street  
Leeds  
LS1 3EX

Tel: 0113 392 6788  
Fax: 0113 392 2863

15 May 2008

Dr John Holmes  
Senior Lecturer  
Leeds Institute of Health Sciences  
University of Leeds  
Charles Thackrah Building  
101 Clarendon Road  
Leeds  
LS2 9LJ

Dear Dr Holmes

**Study title:** In-depth evaluation of liaison mental health services for older people in general hospital settings  
**REC reference:** 06/Q1205/204  
**Amendment number:** Amendment 4 Substantial  
**Amendment date:** 07 May 2008

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 15 May 2008.

#### Ethical opinion

- *To develop an observational rating tool following a period of observational periods on participating wards.*

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Patients/Relatives	V2	06 May 2008
Participant Information Sheet: General Hospital Staff	V2	06 May 2008
Participant Consent Form: Ward Manager	V2	06 May 2008
Participant Consent Form: Patient	V2	06 May 2008
Notice of Substantial Amendment (non-CTIMPs)	Amendment 4 Substantial	07 May 2008

**Membership of the Committee**

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

**R&D approval**

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

**Statement of compliance**

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

<b>06/Q1205/204:</b>	<b>Please quote this number on all correspondence</b>
----------------------	---

Yours sincerely

Miss Anna Fawlk  
Assistant Administrator  
**On Behalf of**  
**Mr Jon Silcock**  
**Chair**

E-mail: [anna.fawlk@leedsth.nhs.uk](mailto:anna.fawlk@leedsth.nhs.uk)

Enclosures	List of names and professions of members who were present at the meeting and those who submitted written comments
Copy to:	Ms Clare Skinner, The University of Leeds  R&D, Leeds Teaching Hospitals NHS Trust



## **H: Developmental pilot study - Nurse focus group topic guide**

[Adapted from Appendix 14: Evaluation - Mental health services focus group topic guide Liaison Mental Health Services for Older People Project]

- Introduction to interview (purpose/length/confidentiality/agreement to audiotaping/signed participation agreement)
- Service model currently in use and preferred model
- Recent/projected changes to service model
- Factors influencing development of services
- Sources of funding for services
- Staff activity/skill mix
- Staff training undertaken – past/present/future
- Number of referrals to service
- Source of referrals (by wards and approx % received from hospital and other sources)
- Changes in referral rates/patterns seen
- Referral procedure
- Referral criteria
- Response time/prioritisation procedure
- Process after initial assessment
- Procedure for patients already under mental health services care
- Protocols in use for diagnosis and management of common mental health problems
- Formal/informal training education provided to general hospital staff
- Relationships between different services
- Interface issues
- Routine clinical outcome measures
- Thoughts/ideas on how services can develop

### **Additional questions for developmental pilot work**

#### **How do you feel about nursing people with dementia?**

Probes: How do you know that a patient has dementia? How might you nurse them differently to a patient who does not have dementia? How do you know what they want/need if they have communication difficulties? How comfortable are you in nursing patients with dementia?

#### **How do you think patients with dementia feel about being on the ward?**

Probes: Can you describe a typical day on the ward for a patient with dementia? How might their experience be different compared to a patient without dementia? Why is their experience different?

#### **What impact do you think that you have on their experiences?**

Probes: How do you influence their behaviour? In what way? How do you feel about this?

- Closure/thanks/contact details

## **I: Patient participant interview topic guide**

### **Patient interview guide v.3**

#### Introduction

Thank you for agreeing to talk with me about what it is like to be in hospital. I am interested in finding out what you think about the nursing care that you receive in here, in hospital. There are no right or wrong answers to this. I just want to get your views on what happens to you here.

#### Opening questions

Why are in hospital? / What did you come into hospital for?

How does being in hospital make you feel?

What is different for you now that you are in hospital?

How do you feel about these differences?

Is there anything that particularly worries you about being in hospital?

Have you had chance to discuss this with someone?

Did this help / what is being done to help with this

#### Changes since coming into hospital

Can you tell me what being in hospital has changed for you in your daily life?

Can you give me examples?

What do you normally do here? Or How do you spend your time here?

What has happened to you since you came into hospital?/(prompts about things that may find difficult i.e. can you get out of bed to go to the toilet?/ do you have to ask staff for help?/ do you have to wait? How do you feel about this?)

How is this different from how things are at home?

#### How feel about being in hospital

How do you feel in yourself? (prompts about things that may be happening i.e. have you any pain or discomfort?)

How did you come to be here? (prompts about what led up to being in hospital)

#### Interactions with others

Have you got to know/talk to other patients on the ward? (prompts about how they may feel compared to you)

How well do the nurses on the ward know you?

Is there a particular nurse that you know/recognize/like?/why? What do they do that is different to others?

#### Remembering

*Do you have any problems with remembering things? (probes: If so, can you give me examples?; How does this make you feel?; Do the nurses know about this?; If so, how do you know that they know?*

#### **Prompts**

- Try to imagine a typical morning/afternoon/evening/night, during that period ....
- What sort of things happened?
- Can you give me an example of what happened that made you feel that way?
- Getting back to your experiences of the nurses and the care.....
- Are there any particular experiences that stand out during that time?
- What about other things the nurses did?
- There's no right or wrong answers, I'd just like to get you thinking about things

#### **Probes**

- What was that like?

- What happened then...?
- Go on...
- Is there anything else?
- How did that make you feel?
- How was that helpful?
- How do you mean?
- Tell me more.
- Why do you think that happened?
- Was that what you expected?
- Are there any other reasons?
- What did that mean to you at the time?
- What were you thinking then?

## **J: Main study – Nurse focus group topic guide**

### **Nurse focus group guide v.2**

#### Introduction to the group

Purpose, aims & objectives

Rules; speaking at once, leaving room, phones, refreshments, length

#### Key questions/prompts

#### **Question: How do you feel about nursing patients who have dementia?**

*Experiences, beliefs and attitudes towards nursing patients with dementia*

Probing questions

How do you know that a patient has dementia? How might you nurse them differently to a patient who does not have dementia? How do you know what they want/need if they have communication difficulties? How comfortable are you in nursing patients with dementia?

#### **Question: How do you think patients with dementia feel about being on the ward?**

*Understanding of experience from patients' perspective*

Probing questions

Can you describe a typical day on the ward for a patient with dementia? How might their experiences be different compared to a patient without dementia? Why is their experience different?

#### **Question: What impact do you think you may have on their experience?**

*Understanding of the nature of interaction and consequences*

Probing questions

How do you influence their behaviour? In what way? How do you feel about this?

#### Other questions arising out of observations/interviews

- How well do you know your patients? (what is the allocation system)
- Role of catering staff in monitoring/helping with fluids/food?
- Are patients placed strategically on the ward and if so why? Does this help in the management of patients with dementia and if so in what way?
- What does managing a patient mean?
- How do you know how to look after people with dementia?
- What do nurses mean when they say they don't know how to do it?
- What do nurses mean when they say they want to help them?
- How feel about dementia not being a priority?
- Do you know why dementia patients behave in the way that they do?
- What do people with dementia need?

## **K: Main study - Observation guide**

Contemporary definition of person-centred dementia care describes four essential elements (Brooker D 2007):

- (1) Valuing people;** Valuing people with dementia and those who care for them; promoting citizenship rights and entitlements regardless of age or cognitive impairment, and rooting out discriminatory practice.
  - Vision/mission statement on providing care that is person-centred?
  - Are systems in place to ensure that staff feel valued?
  - Are management practices empowering to staff delivering direct care?
  - Are there systems in place to support development of a workforce skilled in person-centred care?
  - Are there supportive and inclusive physical and social environments for people with cognitive disability?
  - Are quality improvement mechanisms in place that are driven by knowing and acting upon needs and concerns of patients?
  
- (2) Individualised care;** Treating people as individuals: appreciating that all people have a unique history and personality, physical and mental health, and social and economic resources, and that these will affect their response to dementia.
  - Do care plans identify strengths and vulnerabilities across a wide range of needs, and are there individualised care plans that reflect a wide range of strengths and needs?
  - Are individual care plans reviewed on a regular basis?
  - Do patients have their own personal clothing and possessions for everyday use?
  - Are individual likes and dislikes, preferences and daily routines known about by direct care staff and acted upon?
  - Are staff aware of individual life histories and key stories of proud times, and are these used regularly?
  - Are there a variety of activities available to meet the needs and abilities of patients?
  
- (3) Personal perspectives;** Looking at the world from the perspective of the person with dementia; recognising that each person's experience has its own psychological validity, that people with dementia act from this perspective, and that empathy with this perspective has its own therapeutic potential.
  - Are patients asked for their preferences, consent and opinions?
  - Do staff show the ability to put themselves in the position of the person they are caring for and to think about decisions from their point of view?
  - Is the physical environment (noise, temperature) managed on a day-to-day basis to help patients with dementia feel at ease?

- Are the physical health needs of patients with dementia, including pain assessment, sight and hearing problems, given due attention?
- Is 'challenging behaviour' analysed to discover the underlying reasons for it?
- In situations where the actions of a patient with dementia are at odds with the safety and well-being of others, how are the rights of the patient protected?

**(4) Social environment;** Providing a supportive social environment; recognising that all human life is grounded in relationships and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth.

- Are patients with dementia helped by staff to be included in conversations and helped to relate to others? Is there an absence of people being 'talked across'?
- Are all patients treated with respect with an absence of people being demeaned by 'telling off' or labelling?
- Is there an atmosphere of warmth and acceptance to patients? Do patients look comfortable or intimidated and neglected?
- Are patient's fears taken seriously? Are patients left alone for long periods in emotional distress?
- Do staff help patients to be active in their own care and activity? Is there an absence of patients being treated like objects with no feelings?
- Is there evidence that patients can use local community facilities and that the local community visit regularly?

#### Recording guidelines

- Space – where the participant was on the ward, how many other people were within close proximity of them and the roles that these other people represent to the participant;
- Actions – the actions of the participant and nurse(s) within this area;
- Activities – what activities were occurring within this area;
- Objects – what objects were visible within this area;
- Acts – what the participant and the hospital staff were doing in this area;
- Events – what events were taking place in this area;
- Time – the length of time involved in the different factors being observed;
- Goals – an interpretation of the implicit goals of the interaction(s);
- Key quotations – of participants and hospital staff. This involved paying attention to their verbal behaviour e.g. slang, dominance, tone interruptions and non-verbal behaviour;
- Details of physical appearance of the participant

**L: Ethics approval for main study****Leeds (West) Research Ethics Committee**

First Floor  
 Millside  
 Mill Pond Lane  
 Leeds  
 LS6 4EP

Telephone: 0113 3050122  
 Facsimile:

10 June 2010

Miss Carolyn Montana  
 PhD research student  
 The University of Leeds  
 Charles Thackrah Building  
 101 Clarendon Road  
 Leeds  
 LS2 9LJ

Dear Miss Montana

**Study Title:** Patient perspectives: The experience of coincidental dementia in general hospital acute nursing care  
**REC reference number:** 10/H1307/34  
**Protocol number:**

Thank you for your letter of 23 April 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

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

**Conditions of the favourable opinion**

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

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

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

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

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

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		05 March 2010
REC application		24 March 2010
Investigator CV		
Participant Consent Form: Nurse Focus Group Consent Form	2	05 March 2010
Participant Consent Form: Ward Manager Consent Form	2	05 March 2010
GP/Consultant Information Sheets	2	05 March 2010
Evidence of insurance or indemnity		08 October 2009
Interview Schedules/Topic Guides	2	05 March 2010
CV - John Holmes		
Study Overview - For Nurse Focus Group	2	05 March 2010
Study Overview - For Relatives and Ward Staff	2	05 March 2010
Protocol	3	23 April 2010
Participant Information Sheet: Nurse	1	04 May 2010
Participant Information Sheet	3	24 April 2010
Participant Consent Form: Nurse	1	04 May 2010
Participant Consent Form	3	24 April 2010
Response to Request for Further Information		23 April 2010

### Statement of compliance

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

### After ethical review

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

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

The attached document “*After ethical review – guidance for researchers*” gives detailed



guidance on reporting requirements for studies with a favourable opinion, including:

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

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

<b>10/H1307/34</b>	<b>Please quote this number on all correspondence</b>
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Yours sincerely

**Dr Rhona Bratt  
Chair**

Email: [Elaine.hazell@leedsth.nhs.uk](mailto:Elaine.hazell@leedsth.nhs.uk)

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

*“After ethical review – guidance for researchers”*

*Copy to: Mrs Rachel E de Souza*

*R&D, Leeds Teaching Hospitals NHS Trust*

**M: Ward manager introduction letter**

School of Medicine and Health  
Leeds Institute of Health Sciences  
PhD research

Perspectives of older patients staying in general hospital

*Study overview (for ward managers)*

Background and purpose

Older people occupy 70% of UK general hospital beds at any one time. Within this population, up to 35% will have some form of dementia. Responsibility for recognition and medical treatment lies with doctors, who tend to provide this in only 1% of cases. In the absence of screening and appropriate diagnostic tests, the business of caring for un-diagnosed patients, and those patients for which the condition is formally recognised, is ultimately at the hands of ward based acute care nurses. The majority of research in this area has tended to focus on what the nurses should (or should not) be doing to care for these patients. Frequently this research leads to recommendations for changes in nurses' behaviour and attitudes. Rarely, are the views of this group of patients taken into account. Even when they are, researchers have refrained from talking to patients about their expectations and experiences. This study is designed to address the needs of this group of patients from their perspective.

What is involved?

You are being asked to consider whether you would like your ward to take part in this study. With your permission, I would like to undertake the following:

Observe the routine of the ward in order to get a sense of how it operates on a daily basis.

Identify up to six patients aged 65 years or over. Four of these patients should have problems with their memory most likely related to dementia (two patients should have a formal diagnosis of dementia) and two of these patients should not have any problems with their memory or be perceived to have dementia.

The researcher would like to recruit these patients (through informed consent) to take part in up to three short interviews during their current hospital stay and observe periods of acute nursing care over three separate occasions.

The researcher would also like to take the opportunity to engage in informal conversations with members of staff, relatives and carers during the study period.

The purpose of this will be to seek clarification about issues relating to patient perspectives and what the researcher has observed.

Towards the end of the study period, nurses will be invited to take part in a focus group designed to discuss the findings that emerge from the patient interviews and non-clinical observations of care.

What happens next?

You are being asked to provide written consent for the study to take place on the ward that you are responsible for. Agreement to participate ensures that the researcher can gain access to the ward at agreed times and speak with members of your nursing staff in order to identify patients that could potentially be involved in the study.

The researcher will then approach these patients on an individual basis during which the purpose of the study will be explained and informed consent will be sought. Patients will be reassured that consent or decline will not adversely affect their nursing care in any way.

It is expected that any members of your staff who do not wish to be observed as part in the study will inform the researcher directly, and they will subsequently not be observed during delivery of care for recruited patients.

In order to ensure that all members of staff, relatives, carers and visitors are aware that the research is taking place, and that they may be approached (or indeed, approach) the researcher, it would be helpful if you could display posters and leaflets around the ward giving brief details about the study.

Medical Directors, Consultants and other allied professional leads who frequently attend the ward will be informed that the study is taking place, and that they may opt out of involvement (non-clinical observations and informal discussions) if they wish through contacting the researcher directly.

What happens to the information collected?

Patient interviews and nurse focus groups will be audio-taped with their consent. These interviews/discussions will be transcribed and completely anonymised at this point. No identifiable patient data will be collected as part of the study and all information collected from patients will remain completely confidential between them and the researcher. All other data collected (informal discussions and non-clinical observations of care) will be written records which will be completely anonymised at the point of collection, and no names or identifiable data will be used in any reporting of the study.

Who is undertaking the research?

The researcher is a trained mental health staff nurse with 12 years experience of working with people with mental health needs, the majority of this has involved the care of older people. The researcher also has 5 years health research experience, most of which has involved interviewing and discussing mental health related care with all stakeholders in the NHS.

This research will contribute towards a PhD thesis which is being supervised by Dr John Holmes (Consultant Old Age Liaison Psychiatrist), Dr Shenaz Ahmed (Lecturer, University of Leeds) and Professor Allan House (Director, LIHS). The study will also have a group of people who regularly convene to help with the development, design, implementation and analysis of the work (study steering group committee). This group will comprise of nurses, academics and at least one older person with previous experience of hospital care, and at least one carer of a discharged patient with coincidental dementia.

#### Timeframe

The research has been approved by Leeds (West) ethics committee and research governance approval has been obtained through [REDACTED]. The researcher holds an honorary research contract with [REDACTED]. Data collection is likely to start in mid-August 2010, although this will be negotiated around your ward commitments such as reviews, audits or other research being undertaken. It is anticipated that two patients will be recruited, interviewed and undergo non-clinical observation over a five day period, rendering a maximum total of 20 researcher visits to your ward. This research is being conducted on a part-time commitment basis, over a maximum of 4 wards, and as such there may be gaps between researcher visits. It is planned that data collection for the entire project will have completed by June 2011. You will be kept informed of progress and activity at all stages.

#### What now?

If you do decide that you would like to participate in the study, the researcher will ask you to sign a ward consent form. Arrangements will then be made for the display of posters/leaflets around the ward, and researcher visits will be arranged at your convenience. [Further details](#)

If you would like further details about the study, have any questions or concerns; please contact Carolyn Montaña in the first instance. Further support and advice can also be sought from the PhD supervisors; Dr John Holmes or Dr Shenaz Ahmed at the details given below:

Carolyn Montaña  
PhD student  
School of Medicine & Health, LIHS, The University of Leeds, Charles  
Thackrah Building, 101 Clarendon Road, LEEDS, LS2 9LJ  
Tel: 07772 457806

Dr John Holmes  
Lead Supervisor  
School of Medicine & Health, LIHS, The University of Leeds, Charles  
Thackrah Building, 101 Clarendon Road, LEEDS, LS2 9LJ  
Tel: 0113 343 2269

Dr Shenaz Ahmed  
Co-Supervisor  
School of Medicine & Health, LIHS, The University of Leeds, Charles  
Thackrah Building, 101 Clarendon Road, LEEDS, LS2 9LJ  
Tel: 0113 343 2441

**N: Nurse information sheet - observations**

School of Medicine and Health  
 Leeds Institute of Health Sciences  
 PhD research  
 Carolyn Montaña

**Nurse information leaflet****An exploration of older patients experiences of staying in general hospital****Background and purpose**

Older people occupy 70% of UK general hospital beds at any one time. Within this population, up to 35% will have some form of dementia. Responsibility for recognition and medical treatment lies with doctors, who tend to provide this in only 1% of cases. In the absence of screening and appropriate diagnostic tests, the business of caring for un-diagnosed patients, and those patients for which the condition is formally recognised, is ultimately at the hands of ward based acute care nurses. The majority of research in this area has tended to focus on what the nurses should (or should not) be doing to care for these patients. Frequently this research leads to recommendations for changes in nurses' behaviour and attitudes. Rarely, are the views of this group of patients taken into account. Even when they are, researchers have refrained from talking to patients about their expectations and experiences. This study is designed to address the needs of this group of patients from their perspective.

In part one of this study (commencing in October 2010), I will be spending time on the ward talking to patients (who give me their informed consent) about their experiences of staying in general hospital.

In order to do this, I will ask nurses to identify patients who may be able to take part in the study. You do not have to be involved in this if you do not want to. Patients who agree to take part will be involved in a series of short conversations with the researcher designed to elicit their views about their experiences. This may also lead to informal observations of their care (part two of the study). If this occurs, I will ask you for your consent to take part. Before you decide, it is important that you understand why the research is being done, why I wish to involve you, and what would be required from you if you were to take part in the study.

Please take time to read the following information carefully and discuss it with others if you wish. Please 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.

### The reason for the research

I am research student based at the University of Leeds, with an interest in improving the hospital care for older people, particularly those who may have problems with their memory at times.. As part of this work I want to talk to patients that either do, or do not have memory problems in order to understand what different patients expect from nursing care whilst staying in hospital.

I am a trained mental health staff nurse with 12 years experience of working with people with mental health needs, the majority of this has involved the care of older people. The researcher also has 5 years health research experience, most of which has involved interviewing and discussing mental health related care with all stakeholders in the NHS.

This research will contribute towards a PhD thesis which is being supervised by Dr John Holmes (Consultant Old Age Liaison Psychiatrist), Dr Shenaz Ahmed (Lecturer, University of Leeds) and Professor Allan House (Director, LIHS). The study will also have a group of people who regularly convene to help with the development, design, implementation and analysis of the work (study steering group committee). This group will comprise of nurses, academics and at least one older person with previous experience of hospital care, and at least one carer of a discharged patient with coincidental dementia.

### What is involved in part two?

I will be recruiting up to six patients who are currently staying on the ward you work in. These patients will have consented to take part in qualitative interviews with the researcher and agreed that the researcher can observe their care as it takes place. You are being asked to consider whether you would like the researcher to observe your interactions with these recruited patients. Agreement to participate ensures that the researcher can gain an understanding of how patients and staff interact on the ward. These observations will include things like communication style, inference of level of patient understanding, utterances, length of interaction, who else is involved, purpose, subjective outcome.

### What is being asked of you?

You are being asked to consider whether you would like to take part in the second phase of this study (this is called giving consent). This requires you to make an informed decision whether or not to participate in the study.

With your permission, I would like to observe the interactions that take place between your patients and the nurses caring for them. I would like to take written notes during these interactions to act as memory prompts for me. No-one else will have access to these notes. I will not include your name or the name of any other staff and patients in any of my notes.

I would like to observe interactions on between three to six separate occasions. Your confidentiality, and the confidentiality of other people involved in these observations will be strictly maintained at all times. No identities will be recorded and individuals will not be identifiable at any point in the study (data collected will relate only to observed care and will in no way record or enable recognition of individuals). If the study is presented or published, all means of identifying individuals, wards and hospitals involved in the study will be removed.

You do not have to take part in the study if you do not wish too. If you do wish to take part, any information collected about your nurse interactions will be kept strictly confidential and you, and your patients will not be identified in any subsequent reporting of this work. If you aren't sure about what the information in this leaflet is telling you or you have any questions, please feel free to ask the person who has given you this information.

If you do wish to take part in the study, I will ask you to sign a consent form when I next visit. If you change your mind about taking part, you may withdraw from the study at any time. All you need to do is tell me, either during my next visit, or by contacting me on the details given below.

What will happen to the information that is collected about you?

All information collected during the course of this study will be kept strictly confidential. I will do this by anonymising the information collected. Neither your name nor any other identifying information will appear on any information collected about you. The anonymised information collected about you in this study will always be kept in secure conditions, that is to say on password protected databases, or in locked cabinets in a locked room, for which only the researcher will have access to. I will not reveal the contents of our conversations to anyone that can identify you. However, if you do reveal, or I observe an issue that I deem as professional misconduct by any member of staff, I will follow [REDACTED] procedure on reporting professional misconduct and University of Leeds research governance procedures on reporting adverse events during the process of research. This will mean that I will have to tell hospital and university staff about what has occurred. In the event that this occurs, I will make every effort to ensure that your confidentiality is maintained, however, depending on the nature of the event, you may be requested to discuss this issue with hospital staff further. Occurrences like these are extremely rare. My purpose is not judge the individual merits of care that you deliver, but to observe facets of interactions between patients and staff that help me to understand how care is communicated. The information will be used to help build up a picture of the complexities involved in caring for older people in general hospital settings, particularly those patients who may have memory problems and/or a diagnosis of dementia.

If you have any questions about the information contained here or about the study in general, please do not hesitate to contact me – contact details below.

#### Timeframe

The research has been approved by Leeds (West) ethics committee and research governance approval has been obtained through [REDACTED]. The researcher holds an honorary research contract with [REDACTED]. Part one data collection will commence mid-October 2010. Part two of the study will be negotiated around your ward commitments such as reviews, audits or other research being undertaken. This research is being conducted on a part-time commitment basis, over a maximum of 4 wards, and as such there may be gaps between researcher visits. It is planned that data collection for the entire project will have completed by June 2011. You will be kept informed of progress and activity at all stages.

#### What now?

If you do decide that you would like to participate in part two of this study, the researcher will ask you to sign a nurse consent form. The researcher will arrange to visit the ward around your shift patterns in order to observe recruited patients' care. In the event that you change your mind about taking part, you may tell the researcher at any time and withdraw your consent, without having to give an explanation.

#### Further details

If you would like further details about the study, have any questions or concerns; please contact Carolyn Montaña in the first instance. Further support and advice can also be sought from the PhD lead supervisor; Dr John Holmes at the details given below:

Carolyn Montaña

PhD student

School of Medicine & Health, The University of Leeds, Charles Thackrah Building, 101

Clarendon Road, LEEDS, LS2 9LJ

Tel: 07772 457806

Dr John Holmes

Lead Supervisor

Tel: 0113 343 2269

May I take this opportunity to thank you for your interest in this study.



## O: Study information poster



School of Medicine and Health  
Leeds Institute of Health Sciences

### **Perspectives of older patients staying in general hospital** *Study overview (for relatives and ward staff)*

Ward [insert ward/hospital name] is taking part in a research study designed to understand the experiences of older people, with and without memory problems, during their hospital stay. Several individual patients on this ward have agreed to take part in interviews and for their nursing care to be observed by the researcher, Carolyn Montaña. The ward manager has also consented for these observations to take place.

Please take time to read the following information carefully and discuss it with others if you wish (relatives, friends, and nurses for example). Please ask if there is anything that is not clear or if you would like more information.

#### **The reason for the research**

I am research student based at the University of Leeds, with an interest in improving the care for older people, particularly those patients who may be perceived by nurses to have memory problems, in general hospitals. As part of this work I want to understand what patients expect from their nursing care whilst they are in hospital.

In order to do this, I have asked individual patients if they would like to take part in interviews and observations of their care. This work will take place between [insert start dates] and [insert end date].

#### **What is being asked of you?**

If you have particular views, thoughts and/or experiences that you would like to share with the researcher, please do approach her when she is not visibly recording data. Your views are important and vital to providing context to the data already being collected. The researcher may also approach you to seek clarification on patient perspectives and/or what is being observed.

You **do not** have to take part if you do not want. If you decide not to take part, this will in no way affect the care that any patient receives during data collection. If you aren't sure about what the information in this leaflet is telling you or you have any questions, please feel free to ask the person who has given you this information.

If you do wish to take part in the study, please approach the researcher (when she is not in the process of taking notes). The researcher will make notes during your conversation to aid with recall. You may also wish to arrange to discuss your views with the researcher at a different time. Please do talk to the researcher about this at your earliest opportunity.

### **What will happen to the information that is collected about you?**

It is important that you fully understand what taking part involves.

All information collected during the course of this study will be kept strictly confidential. All the information collected will be anonymised. Neither your name nor any other identifying information (i.e. ward, hospital) will appear on any information collected from you. The anonymised information collected in this study will always be kept in secure conditions, that is to say on password protected databases, or in locked cabinets in a locked room, for which only the researcher will have access to. No information will be shared with hospital staff, patients or relatives.

The data collected will be used to form a conceptual framework from which to understand the experience of nursing care for patients with and without memory problems in the general hospital setting.

May I take this opportunity to thank you for your interest in this study, and hope that you will agree to help towards improving the services older people in general hospitals currently receives.

### **Further details**

If you would like further details about the study, have any questions or concerns; please contact Carolyn Montaña (researcher) in the first instance. Further support and advice can also be sought from the Lead PhD supervisor; Dr John Holmes at the details given below:

Carolyn Montaña  
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School of Medicine & Health  
LIHS  
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Mob: 07772 457806

Dr John Holmes  
Lead Supervisor  
School of Medicine & Health  
LIHS  
The University of Leeds  
Charles Thackrah Building  
101 Clarendon Road  
LEEDS  
LS2 9LJ  
Tel: 0113 343 2269

**P: Ward Manager consent form**



Leeds Institute of Health Sciences  
PhD research

**Perspectives of older patients staying in general hospital**

**Ward Manager Consent Form**

I have read the information sheet – Ward manager introduction letter (version 2; 05.03.10)	<input type="checkbox"/>
I understand the reasons for the research and what will happen if the ward takes part	<input type="checkbox"/>
I understand that the ward is free to withdraw from the research at any time	<input type="checkbox"/>
I understand that all the information about my ward will be kept strictly confidential and that information will be anonymised	<input type="checkbox"/>
I understand that any of my nursing staff are free to withdraw from the study by informing the researcher directly.	<input type="checkbox"/>
I agree for ward [insert ward/hospital name] to take part in the study	<input type="checkbox"/>
Signed..... Date..... Print name..... Witnessed by.....(researcher signature) Witness name.....	
1 copy ward manager, 1 copy researcher	

**Q: Medical consultant letter**

School of Medicine and Health  
Leeds Institute of Health Sciences  
PhD research  
Carolyn Montaña  
Charles Thackrah Building  
101 Clarendon Road  
LEEDS  
LS2 9LJ  
Tel: 0113 343 1964  
Mob: 07772 457806  
E: [c.montana@leeds.ac.uk](mailto:c.montana@leeds.ac.uk)

Date [insert today's date]

Dear [insert consultant name/title]

This letter is to inform you about a research study being conducted on ward [insert ward/hospital name]. Some of your patients may have consented to be involved in the study.

Please find attached details about the research and my contact details. Please do not hesitate to contact either myself, or the Lead Supervisor, Dr John Holmes – Consultant Old Age Psychiatrist (tel: 0113 343 2269, E: [j.d.holmes@leeds.ac.uk](mailto:j.d.holmes@leeds.ac.uk)) if you have any questions or concerns about this study.

Yours sincerely

Carolyn Montaña  
PhD student

Enc:  
Patient information sheet v2 05.03.10  
Ward information leaflet v2 05.03.10

**R: Patient participant information leaflet**

School of Medicine and Health  
 Leeds Institute of Health Sciences  
 PhD research  
 Carolyn Montaña

**Patient information leaflet****An exploration of older patients experiences of staying in general hospital**

You are being asked to consider if you are willing to take part in a research study. Before you decide, it is important that you understand why the research is being done, why I wish to involve you, and what would be required from you if you were to take part in the study.

Please take time to read the following information carefully and discuss it with others if you wish (relatives, friends, and nurses for example). Please 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. If you do decide not to take part, this will not adversely affect the care that you receive in the future.

**The reason for the research**

I am research student based at the University of Leeds, with an interest in improving the hospital care for older people, particularly those who may have problems with their memory at times.. As part of this work I want to talk to patients that either do, or do not have memory problems in order to understand what different patients expect from nursing care whilst staying in hospital.

**What is being asked of you?**

You are being asked to consider whether you would like to take part in this study (this is called giving consent). This requires you to make an informed decision whether or not to participate in the study.

With your permission, I would like to talk to you about your expectations and experiences of nursing care during this hospital stay. This should take no longer than one and half hours of your time in total. I can arrange to visit you to talk to you about this for shorter periods of time if you wish, for example, three half hour periods. I would like to record these discussions in order to allow me to remember our conversations in detail. No-one else will have access to this recording, and I will destroy the tape once I have typed up the interviews. I will not include your name, or the name of anyone you mention in this typed record.

I would also like to watch what care you receive. This will involve me taking notes as you are provided with nursing care on the ward on three separate occasions, for approximately one and half hours each time. Your confidentiality, and the confidentiality of other people involved in these

observations will be strictly maintained at all times. No identities will be recorded and individuals will not be identifiable at any point in the study (data collected will relate only to observed care and will in no way record or enable recognition of individuals). If the study is presented or published, all means of identifying individuals, wards and hospitals involved in the study will be removed.

I would also like to take a brief look at your medical notes held on the ward. This will help me to understand what you are in hospital for, how you are being cared for and what support you may have when you leave hospital.

You **do not** have to take part in the study. If you decide not to take part, this will in no way affect the care you receive. If you aren't sure about what the information in this leaflet is telling you or you have any questions, please feel free to ask the person who has given you this information.

If you do wish to take part in the study, I will ask you to sign a consent form when I next visit. This will enable us to arrange to have the discussion described above and for me to arrange to observe the care you receive. If you change your mind about taking part, you may withdraw from the study at any time. All you need to do is tell either me, one of the nurses or your visitors/relatives and ask them to contact me at the details given below.

#### **What will happen to the information that is collected about you?**

All information collected during the course of this study will be kept strictly confidential. I will do this by anonymising the information collected. Neither your name nor any other identifying information will appear on any information collected about you. The anonymised information collected about you in this study will always be kept in secure conditions, that is to say on password protected databases, or in locked cabinets in a locked room, for which only the researcher will have access to. I will not reveal the contents of our conversations to anyone that can identify you. However, if you do reveal, or I observe an issue that I deem as professional misconduct by any member of staff, I will follow [REDACTED] procedure on reporting professional misconduct and University of Leeds research governance procedures on reporting adverse events during the process of research. This will mean that I will have to tell hospital and university staff about what has occurred. In the event that this occurs, I will make every effort to ensure that your confidentiality is maintained, however, depending on the nature of the event, you may be requested to discuss this issue with hospital staff further.

If you have any questions about the information contained here or about the study in general, please do not hesitate to contact me – contact details below.

May I take this opportunity to thank you for your interest in this study, and hope that you will agree to help towards improving the services older people in general hospitals currently receives.

**Further details**

If you would like further details about the study, have any questions or concerns; please contact Carolyn Montaña in the first instance. Further support and advice can also be sought from the lead PhD supervisor; Dr John Holmes at the details given below:

Carolyn Montaña

PhD student

School of Medicine & Health, LIHS, The University of Leeds, Charles Thackrah Building, 101 Clarendon Road, LEEDS, LS2 9LJ

Tel: 0113 343 1964

Dr John Holmes

Lead Supervisor

Tel: 0113 343 2269

**S: Patient participant consent form**



Leeds Institute of Health Sciences  
PhD research

**An exploration of older patients experiences of staying in general hospital**  
**Patient Consent Form**

<p>I confirm that I have read and understood the information sheet – <b>An exploration of older patients experiences of staying in general hospital</b> (version 3 dated 23.04.10). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	<input type="checkbox"/>
<p>I understand my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.</p>	<input type="checkbox"/>
<p>I understand that all the information about me will be kept strictly confidential and that information will be anonymised. I also understand that if I discuss anything, or the researcher observes any of my care that is deemed as professional misconduct by any member of staff that the researcher will have to follow [REDACTED] [REDACTED] procedures on reporting professional misconduct and University of Leeds research governance procedures, which may lead to me having to discuss this event with hospital staff further.</p>	<input type="checkbox"/>
<p>I understand that my interview with the researcher will be tape recorded and transcribed</p>	<input type="checkbox"/>
<p>I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.</p>	<input type="checkbox"/>
<p>I agree to take part in the above study</p>	<input type="checkbox"/>
<p>Signed.....</p> <p>Date.....</p> <p>Print name.....</p> <p>Witnessed by.....(researcher signature)</p> <p>Witness name.....</p>	
<p><i>1 copy patient, 1 copy researcher</i></p>	



## T: Brief introduction to each participant

Elsie, 76 years old. She was admitted onto the ward following a fall at home. She had a history of hypertension, diabetes and osteoporosis. There was no mention of a diagnosis of dementia in her hospital records. Length of stay 29 days.

Mary, 83 years old. She was admitted onto the ward from home with dehydration. There was no mention of a diagnosis of dementia in her hospital records. Relatives had secured a place in a residential care home for her on discharge. Length of stay 18 days.

Annie, 84 years old. She was admitted onto the ward from home with unmanaged pain associated with chronic back pain. She had scoliosis of the spine and a history of anxiety and depression. There was no mention of a diagnosis of dementia in her hospital records. Length of stay 13 days.

Maureen, 85 years old. She was admitted onto the ward from home with unmanaged diabetes. She had an existing intensive home care package, a history of heart failure and was registered blind. There was no mention of a diagnosis of dementia in her hospital records. Length of stay 14 days.

Sally, 79 years old. She was admitted to hospital from a care home following increased confusion. She had previously been diagnosed with stomach cancer. She had a diagnosis of dementia recorded in her hospital records. Length of stay 30 days.

Vera, 86 years old. She was admitted from sheltered housing onto the ward for assessment following a number of unexplained falls. She was hard of hearing and had a long history of diverticulitis. There was no mention of a diagnosis of dementia in her hospital records. Length of stay 32 days.

Alfie, 72 years old. He was admitted onto the ward from home, following concerns by home care staff that he was neglecting himself. On admission, he was malnourished. He had a long history of alcohol abuse and was in liver failure. There was no mention of a diagnosis of dementia in his hospital records. Length of stay 13 days.

Harry, 76 years old. He was admitted onto the ward from home, where he lived with his wife, with a suspected urinary tract infection. He had become increasingly agitated, had a high temperature and appeared confused just prior to admission. There was no mention of a diagnosis of dementia in his hospital records. Length of stay 10 days.

Henry, 87 years old. He was admitted onto the ward following a road traffic accident. He lived at home alone on admission. There was mention of confusion where dementia was queried, but no definitive diagnosis was evident in his hospital records. Length of stay 15 days.

Ethel, 82 years old. She was admitted onto the ward from a residential care home with a urinary tract infection and increased levels of confusion. There was mention of dementia in her hospital records, although no evidence of an official diagnosis having been made. Length of stay 20 days.

Maggie, 76 years old. She was admitted onto the ward from home following family concerns about her memory problems and increased agitation. She had been diagnosed with dementia by her GP around 18 months prior. Length of stay 12 days.

Stan, 70 years old. He was admitted onto the ward with gastroenteritis. There was no mention of a diagnosis of dementia in his hospital records. He passed away in hospital after being on the ward for 5 days.

Bob, 76 years old. He was admitted to hospital with uncontrolled angina. There were concerns from family that he was not coping at home due to increasing confusion. There was no mention of a diagnosis of dementia in his hospital records. Length of stay 6 days.

Bert, 81 years old. He was admitted onto the ward with a kidney infection that was not responding to antibiotics. He lived at home with his wife. A referral to liaison psychiatry had been made during the admission due to concerns about disinhibited behaviour and level of cognitive functioning. Length of stay 16 days.

**U: Focus group information sheet**

School of Medicine and Health  
 Leeds Institute of Health Sciences  
 PhD research  
 Carolyn Montaña

**Perspectives of older patients staying in general hospital*****Study overview (nurse information sheet)***

You are being asked to consider if you are willing to take part in a research study. Before you decide, it is important that you understand why the research is being done, why you are being asked to be involved, and what would be required from you if you were to take part in the study.

Please take time to read the following information carefully and discuss it with others if you wish. Please ask 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. If you do decide not to take part, this will not adversely affect your role in any way.

**The reason for the research**

I am research student based at the University of Leeds, with an interest in improving the care for older people, particularly those patients who are perceived to have symptoms indicative of a dementia-type illness in general hospitals. As part of this work, I have been asking patients what they expect from their nursing care and observing care as it is delivered to them. I would now like to discuss my initial findings with nurses, in order to ensure that their perspectives are understood and included in my findings.

**What is being asked of you?**

You are being asked to consider whether you would like to take part in this study (this is called giving consent). This requires you to make an informed decision whether or not to participate in the study.

Please could you attend one focus group being held on either:  
 [Insert date/time/venue of both groups]

During this focus group, you will be asked to discuss your views on the issues raised during the first part of this study. The group will be attended by a maximum of 8 nursing colleagues from different wards around the hospital and will last approximately one and half hours.

The discussion will be recorded in order to allow the researcher to recall the conversations in detail. No-one else will have access to this recording, and

the tape will be destroyed once following transcription. Your name or the name of anyone you mention will not be included in this typed record.

Your confidentiality, and the confidentiality of other people involved in this study will be strictly maintained at all times. No identities will be recorded and individuals will not be identifiable at any point in the study. If the study is presented or published, all means of identifying individuals, wards and hospitals involved in the study will be removed.

You **do not** have to take part in the study. If you aren't sure about what the information in this leaflet is telling you or you have any questions, please feel free to ask the person who has given you this information.

If you do wish to take part in the study, please could you contact the researcher directly to indicate that you intend to join one of the groups (shown above). When you attend the group, you will be asked to sign a consent form.

### **What will happen to the information that is collected about you?**

All information collected during the course of this study will be kept strictly confidential. Neither your name nor any other identifying information will appear on any information collected about you. The anonymised information collected about you in this study will always be kept in secure conditions, that is to say on password protected databases, or in locked cabinets in a locked room, for which only the researcher will have access to.

If you have any questions about the information contained here or about the study in general, please do not hesitate to contact the researcher – contact details below.

May I take this opportunity to thank you for your interest in this study, and hope that you will agree to help towards improving the services older people in general hospitals currently receives.

### **Further details**

If you would like further details about the study, have any questions or concerns; please contact Carolyn Montaña in the first instance. Further support and advice can also be sought from the lead PhD supervisor; Dr John Holmes at the details given below:

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Lead Supervisor  
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E: j.d.holmes@leeds.ac.uk

**V: Nurse focus group consent form**

Leeds Institute of Health Sciences

PhD research

**Perspectives of older patients staying in general hospital****Nurse focus group Consent Form**

I have read the information sheet – nurse information sheet (version 1; 05.03.10)	<input type="checkbox"/>
I understand the reasons for the research and what will happen if I takes part	<input type="checkbox"/>
I understand that I am is free to withdraw from the research at any time	<input type="checkbox"/>
I understand that all the information about me will be kept strictly confidential and that information will be anonymised	<input type="checkbox"/>
I understand that I am free to withdraw from the study by informing the researcher directly	<input type="checkbox"/>
I understand that the discussion will be audio recorded and transcribed	<input type="checkbox"/>
I agree to take part in the study	<input type="checkbox"/>
Signed.....	
Date.....	
Print name.....	
Witnessed by.....( <i>researcher signature</i> )	
Witness name.....	
<i>1 copy nurse, 1 copy researcher</i>	

## Appendix W: Coding framework showing themes, sub themes and illustrative quotations

### Power and control

Sub-theme	Emerging themes	Illustrative quotations
Control over decision making about being on the ward	Should not be in hospital	"Well first of all, when I tell you that I shouldn't be in here at all, because everybody says that especially if they've got Alzheimer's or what have you...but I can be at home if they would let me..." (Bob, 3)
	Not involved in decision-making process	"...they're good places, they're there to help you, but I didn't want help, I just wanted to live in peace." (Elsie, 1)
	Labels associated with reason for being in hospital	"Because somebody decided to label me and I'm old and that's what they do. But I'm Alzheimer's, dementia, old, I'm all of them". (Harry, 3).
Constrained by the hospital environment	Reliance on cues in environment	"...and when it's nearly mealtime, they'll sort of come to us and say 'oh it will be teatime soon'...and that's what will happen now you see." (Ethel, 1)
	Impersonal environment	"...I wish I had my comb. It's such a mess... I had it. I don't know where it is now though." (Maggie, 1)
	Restricted in movement	"...They [nurses] don't give us much to do...sometimes I go to the toilet, I come back and that's all." (Elsie, 1)
	Expected behaviours	"When she [new member of staff] came in first, she was dancing up and down there and I put a complaint and I said it's not very nice when other people can't walk when the staff are dancing up and down." (Sally, 1)
Power in interactions	Staff too busy with others	"They haven't got the time...I think they are very busy aren't they? They don't have time and because I've got so I can't walk, it's not going to get better even if they do have time. They're not gonna get rid of, err get rid. I'll be rid soon enough. Probably they think it's not worth bothering." (Annie, 1)
	Other patients demand staff time	"They are here and they are there and I know they are busy I suppose. They have everything to do, and nowt for me, and they have loads to do. Not worth it for me". (Henry, 1).
	Avoid demanding time from staff	"I think they are short staffed, and it's not easy for them...It's easy to get to the loo here and I don't want anybody to do anything for me." (Sally, 1)
	Lack control over who speak to when	"That's where we are really. I mean people come in... but we don't know who it is..." (Maggie 1: 169)

## Appendix W: Coding framework showing themes, sub themes and illustrative quotations (continued)

### Notions of self

Sub-theme	Emerging themes	Illustrative quotations
Living with a failing self	Changes in abilities	"I've never been looked after all my life. I've looked after myself, looked after other people..." (Mary, 1)
	Sense of hopelessness	"...if I drop dead tomorrow I'll have gone and that's it...I'm old, what it is it erm, 80 year?" (Annie, 1)
	Living with memory problems	"...it's so frustrating when you can't remember." (Annie, 2)
	Frustrated with failing memory	"...when you can't remember a damn thing, very, very frustrating. Well they think I am frustrating. It's important to me. I have to know what to say and do..." (Alfie, 2)
Expectations for a future self	Uncertainty about future	"...Don't think I'll be here long. Think I'll be...I don't know how long I'll stay. They didn't say. I'm hoping I'll be able to go home." (Maggie, 1)
	Comparing self to others	"You see some of them [points to other patients] don't know. I always say, your nothing if...you need your mind, I don't want it to let me down. You see of them don't know." (Sally, 1)
Grief for an expected self	Limited by changes in me	"It's tricky isn't it when something you like isn't working very well and you've got to do something else. Cos, err, it's not want you want it be..." (Stan, 1)
	Loss of 'being'	"I'm just here, rotting. That's all I'm doing, is rotting. I don't know. This hospital in one sense is to be exaggerated". (Bob, 1).
	Feeling hopelessness	"I do nothing at all. I was strapped up and did nothing and now, nothing. That's if I can remember it, which is not good for me. I'm old now and done with. Do nothing. Makes it a long day..." (Harry, 2).

## Appendix W: Coding framework showing themes, sub themes and illustrative quotations (continued)

### Mechanisms for coping

Sub-theme	Emerging themes	Illustrative quotations
Non-complaining	Uncritical acceptance	"... There's always someone there if you need them. It's like that here..." (Maggie, 1)
	No point in complaining	"I don't complain if I get bad or nothing. What are you complaining for? You can't be feeling better and they are doing their best. Friendly. Good to me. If others say anything I do get annoyed". (Alfie, 2)
Normalising interactions	Maintaining independence	"Well they don't do anything. I dress myself, I undress myself. I go to the bathroom in the morning and wash my own bits and pieces. Really they don't do a great deal for me. Mind you, I don't want them to". (Sally, 1)
	Expressing passivity	"I just eat what they put on the table and if I can't eat it, I can't eat it, and that's it". (Maureen)
Denial of existence of dementia	Normal part of ageing	"You see this is where, this is err. They put me in here with err, all the err, all the dementia patients and I thought 'Oh God, what am I doing here? Why do they think I'm a dementia patient? I'm not and I can't be bothered with it all." (Annie, 1)
	Labelling	"And now see, they've said I've got it, Alz whatever. I'm down for it. My son has put me down for it. He says he put me down for it cos I keep forgetting things. I can't keep track of things. I mean, who can? Anyway I'm down for it" (Alfie, 3)

