"Knowing the person" - The use of families' knowledge and expertise in delivering care and valued outcomes for people with dementia on acute wards

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Intellectual Property and Publication Statement

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Abstract

Background

A quarter of general hospital patients have dementia and they have worse experiences and outcomes of care than people without dementia. At home, many people with dementia are supported by family members who often have an in-depth understanding of the person. However, few previous studies have explored the involvement of families, or their knowledge, in the planning or delivery of hospital care.

Aims

To explore how the use of families' knowledge and expertise affects experiences and outcomes of hospital care for people with dementia.

Methods

Ethnographic data were collected from two elderly care wards via observations, conversations and interviews with people with dementia, their families and staff. In total, 400 hours of observations and 47 interviews were undertaken across two 7-9 month periods.

Results

People with dementia often experienced a lack of connection on multiple levels - from pre-hospital life as well as life on the wards - where they could spend long periods of time without interacting with anyone. There was great variation in the degree to which staff used opportunities, or were able, to make connections with people with dementia. The knowledge and expertise of families played a crucial role in facilitating more meaningful interactions and demonstrated how person-centred connections and care are possible in busy hospital settings. Despite such benefits, the involvement of families and their knowledge was not routine. Opportunities to bring together the different perspectives and knowledge of families, staff and people with dementia were often missed, resulting in difficulties in care provision

and decision-making, extended lengths of stay, and decisions which did not always meet the needs or wishes of people with dementia.

Conclusions

This study demonstrates the many benefits of involving families and their knowledge in care, advocating for family involvement, alongside the involvement of people with dementia, to become a more routine component of hospital care.

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Chapter 1

Background Literature

1.1 What is dementia?

Dementia is an umbrella term covering a range of progressive conditions which affect the brain and result in impairment of the person's function. There are many different types of dementia, of which Alzheimer's Disease and Vascular Dementia are the most common (Alzheimer's Society, 2017), and some people may present with more than one type, leading to a range of symptoms (WHO, 2016). Each person will experience dementia differently but typical symptoms include memory problems, communication difficulties, impaired reasoning and spatial ability, and confusion or disorientation (Alzheimer's Society, 2017). Specific examples include: difficulties with short term memory; increasingly repetitive conversations; forgetting or struggling to recall previously familiar words, names, people or places; difficulty orientating to time and place, especially in unfamiliar settings; difficulty concentrating on and sequencing tasks; impaired judgment and decision making abilities, and changes in behaviour or personality (Chertkow et al, 2013; Alzheimer's Society, 2017). These symptoms can disrupt the person's ability to live independently, may affect their social relationships (Dementia UK), and are particularly problematic when the person is in unfamiliar surroundings with unfamiliar people, as is often the case when people with dementia are admitted to hospital.

1.2 Prevalence and characteristics of dementia in general hospitals

There are 850,000 people with dementia in the UK and this figure is predicted to rise to one million by 2025 (Prince et al.,2014). Globally these figures stand at 46.8 million people currently living with dementia with an estimated increase to 74.7 million by 2030 (Prince et al, 2015). These steeply rising rates are reflected in the increasing numbers of people with dementia admitted to general hospitals, where in the UK one in four patients has dementia and up to one in two may have some form of cognitive impairment (Alzheimer's Society, 2016; 2009; Royal College of Psychiatrists, 2005). To put these figures into context, it has been estimated that in a typical district general hospital with 500 beds, 330 will be occupied by older people of whom over 100 will have dementia (Royal College of Psychiatrists, 2005). In addition, the prevalence of dementia across hospital departments means that staff in most services will come across people with dementia, with up to 97% of hospital staff reporting they have provided care for someone with dementia (Alzheimer's Society, 2009).

The care needs of hospitalised people with dementia vary considerably, influenced not only by their physical ill health but also by the degree and effects of their cognitive impairment, (Knopman et al., 2003). People are often admitted to acute care for reasons other than their dementia (Dewing & Dijk, 2016) and can have a wide range of one or more co-morbid health or medical problems (Porock, 2015), some of which can exacerbate their dementia (such as delirium or infections) and create a complex and highly varied set of care needs. Despite the frequency with which people with dementia utilise the acute care system, a growing body of research and other reports has indicated that these complex and wide-ranging needs are not well met in the general hospital environment (e.g. Alzheimer's Society, 2016; 2009; Royal College of Psychiatrists, 2011; Cowdell, 2010; Sampson et al., 2009).

1.3   Problems with general hospital care for people with dementia

Research and reports (by organisations such as the Alzheimer's Society and the media) have levied strong criticism at the quality of experiences and outcomes of care for people with dementia admitted to general hospitals. Evidence of the problems in these two important areas of experience and outcome is summarised below.

1.3.1 Experiences of care

A small but growing body of research has begun to explore experiences of hospital care from the perspective of people with dementia. These studies consistently suggest that experiences of care are often poor (Porock et al, 2015; Cowdell, 2010). Hospital wards are often viewed by people with dementia in negative terms as disturbing, distressing, frightening and bewildering environments (Alzheimer's Society, 2016; 2009; Porock et al, 2015; Cowdell, 2010) in which loud clinical activity can be alarming and difficult to interpret (Cowdell, 2010). Interactions with people with dementia are often cited as problematic, with examples of people with dementia being ignored and talked over (Goldberg et al., 2014; Cowdell, 2010) and receiving little compassion (Moyle at el., 2011) or unsympathetic responses to their distress (Borbasi et al., 2006). Studies consistently report that interactions are limited or dominated by the delivery of physical care at the expense of interactions on a personal level and the meeting of people's emotional and social needs (Moyle et al, 2011; Cowdell, 2010; 2008). As a result, attempts made by people with dementia to communicate their feelings, needs and remaining capabilities are often unrecognised or overlooked (Borbasi et al., 2006; Norman, 2006; 2003).

The impersonal nature of care delivery, especially when meeting personal hygiene needs, can be distressing (Cowdell, 2010) and even the most basic of care needs can be poorly managed (Department of Health, 2008a, Department of Health, 2009), especially in the areas of nutrition, hydration and mobility (Alzheimer's Society,

2009). As a result, high rates of malnutrition, dehydration and function decline are seen amongst general hospital patients with dementia (Mukadam & Sampson, 2011; Osbourne, 2014) as are failures to provide adequate pain relief (Morrison et al., 2000) and end of life care (Sampson et al., 2006). Although old age can in itself make hospital care more problematic, studies repeatedly suggest that experiences of hospital care are worse for people with dementia, with the deficits in care experienced by older people compounded by having dementia (Pritchard & Dewing, 2001).

Widespread dissatisfaction with care is also reported by families and other carers (Alzheimer's Society, 2009; Jurgens et al., 2012). Families' perceptions of care are often negative, characterised by concerns over failures to help people with dementia to eat and drink, to provide social interaction or to treat the person with dignity and respect (Alzheimer's Society, 2009; Boltz et al., 2015b). Partly as a result of these care concerns, hospital admissions are often a time of worry, disappointment, stress, bewilderment and conflict for families (Jurgens et al., 2012; Boltz et al., 2015b; Bloomer et al., 2014) and therefore have the potential to impact negatively on the well-being of the family as well as the person with dementia (Douglas-Dunbar & Gardiner, 2007). Staff also identify care concerns, including communication problems, difficulties managing challenging and unpredictable or wandering behaviour, not having sufficient time to spend with people with dementia, and ensuring patient safety (Alzheimer's Society, 2009).

These studies indicate that nurses and other hospital staff often struggle to provide good quality care to people with dementia (Cowdell, 2008; Norman, 2006). Positive examples of care are reported (Scerri et al., 2015; Cowdell, 2010; Tolson et al., 1999, Norman, 2006) and are important to recognise, but such examples are seen to constitute pockets of good practice rather than a consistent approach to care (Doherty & Collier, 2009). Too often practices in general hospitals do not accord with the holistic, best practice principles of person centred care (Kitwood, 1997) or preservation of self-hood (Sabat, 2001) and lead to erosion of the person's well-being and sense of identity (Cowdell, 2007). As a result, the experience of general hospital care for people with dementia and their families is often negative which,

coupled with the unfamiliarity of the environment, leads to distress, anxiety, and loneliness (Cowdell, 2007, Nolan, 2006) and exacerbates symptoms of cognitive impairment, in particular levels of disorientation and confusion (Fortinsky, 2001).

1.3.2 Outcomes of care

Alongside poor experiences of care, on a range of measures, outcomes for people with dementia are often poorer than for other patients. Hospitalised people with dementia have an increased risk of delirium, greater losses in physical function, more delayed discharges, longer lengths of stay, and are more likely to be discharged to institutional care than are people who do not have dementia (Sampson et al., 2009; Godfrey et al., 2008, Department of Health, 2008a, Department of Health, 2009, Royal College of Psychiatrists, 2005; Holmes & House, 2000; Sands et al., 2003· Mukadam & Sampson, 2010). For example, people with dementia spend, on average, twice as long in hospital as other people aged over 65 (Alzheimer's Society, 2016) and, compared to older people without dementia, are three times more likely to be discharged to residential or nursing care (Sampson et al., 2009). Failed or problematic discharges are common (Tolson, 1999; Naylor et al., 2007) and, most concerning of all, people with dementia have higher rates of in-hospital and short-term mortality (Holmes & House, 2000; Sampson et al., 2009). For example, Sampson et al (2009) found that in-hospital death rates were twice as high amongst patients with dementia, and four times as likely in those with significant cognitive impairment, and Holmes and House (2000) found that people with dementia admitted with hip fracture were 2.5 times more likely to die within 6 months compared with their psychiatrically well counterparts.

When people with dementia leave hospital, they frequently do so in worse physical and cognitive health than when they arrived, which families often attribute to the effects of hospitalisation rather than the person's medical condition. For example, around half of family carers surveyed by the Alzheimer's Society (2009) felt that being in hospital, independent of the medical reason for admission, had a significant

negative effect on the physical health and dementia symptoms of their relative, such as becoming more confused, less independent, incontinent, and less mobile, and losing communication skills. Perhaps due in part to such decline, discharges into residential care are common, with over a third of people with dementia who were living at home prior to hospitalisation being discharged to a care home setting (Alzheimer's Society, 2009).

In relation to outcomes of care, people with dementia report concerns and uncertainty about their future and express fear and a lack of control over discharge destinations from hospital (Cowdell, 2010). While many older people feel fear or a lack of control over what happens to them following a hospital admission, this is particularly the case for people with cognitive impairment (Bridges et al., 2010) - a report by the Care Quality Commission (2014) identified high levels of variable or poor involvement of people with dementia or their families in decisions about care.

1.3.3 Explanations for the poor quality of acute care of people with dementia

Some studies have identified explanations for the poor experiences and outcomes of acute care experienced by people with dementia, with multiple factors suggested as potentially responsible.

The presence of dementia in itself may complicate care, communication of symptoms and acceptance of treatment for other conditions (Scrutton & Brancati, 2016). Poor recognition of dementia (Alzheimer's Society, 2009) - with only 50% of people with dementia having a diagnosis on admission (Sampson et al., 2009) - may limit recognition of the need for care to be tailored to meeting these challenges. Poor outcomes may also be partly explained by higher levels of co-morbidity (Zekry et al., 2009) and increased physical care needs (Sampson et al., 2009) although studies have found that dementia is still associated with worse outcomes even when co-morbidity is adjusted for (Sampson et al., 2009, Morrison & Siu, 2000). In addition, many of the co-morbidities that people with dementia develop in hospital,

such as delirium, urinary tract infections, injuries from falls, malnutrition and dehydration, are potentially preventable (Bail, 2013) indicating that care quality may play a part in effecting poorer outcomes. Whilst a causal relationship between poor quality of care and poor outcomes seems possible (Sampson et al., 2009), potential interactions between these two factors have not been explored in any depth.

Staff expertise is a common explanatory theme, with staff often cited as lacking the skills, understanding and personal knowledge required to provide high quality dementia care and to tackle the challenges of developing therapeutic relationships with people with dementia in acute settings (Turner et al., 2017; Griffiths et al., 2014; Nolan, 2007; Bourne, 2007). Pre-registration dementia training for general nurses, occupational therapists and social workers is often lacking; some courses provide no dementia specific training and when dementia training is provided it averages only 3 hours in length for most professions (Pulsford, 2007). In addition, examination of undergraduate curricula for medical students shows considerable variation in the delivery of teaching about dementia (Tullo & Allan, 2011). General hospitals have traditionally providing little or no post-qualification or in house dementia training for their staff (Griffiths et al., 2014) and, although recent improvements have been made with this (Royal College of Psychiatrists, 2013), levels of training remain variable and releasing staff from busy and pressurised ward environments to attend training remains a challenge (Griffiths et al., 2014). In addition, traditional models of nursing care have centred around daily functioning and so have not directed a focus to cognition (Gladman et al., 2012) and theoretical concepts taught to nurses and other staff predicated on concepts of humanism and holistic care become difficult to enact in typically bureaucratic and outcome focused clinical settings (Henderson, 2002).

Alongside a lack of dementia-specific training, skills and knowledge, staff also explain care deficits through considerable constraints on their time, the unsuitability of the design of acute environments for people with dementia, and hospital cultures and systems focused on physical health and efficiency which make it difficult to meet the individual needs of people with dementia (Digby et al., 2016; Nilsson et al., 2013; Nolan, 2006; Nolan, 2007; Borbasi et al., 2006; Atkin et al., 2005; Eriksson &

Saveman, 2002). These constraints mean that even if staff do understand, and strive to give, good quality dementia care they may not manage to achieve this (Cowdell, 2010). This leads to feelings of powerlessness, frustration and feelings of failure amongst staff and the increased use of medication to control challenging behaviours (Eriksson & Saveman, 2002}.

1.4   Improving acute care for people with dementia

The above literature on care quality and constraints highlights two things. Firstly, there are multiple constraints to the delivery of high quality acute dementia care, including knowledge, environmental, time and organisational barriers, which need to be fully understood and addressed if the quality of acute dementia care is to be improved. Secondly, improvements are needed in both the provision of basic care (such as nutrition, hydration and toileting) and also to developing more attentive, meaningful and individualised interactions and relationships with people with dementia. Such an approach accords with the principles of person and relationship centred care; two central and related theories of quality dementia care practice which both emphasize the importance of positive and individually meaningful interactions and relationships with people with dementia, as described below.

1.5   Theoretical perspectives on best practice in dementia care

The following sections summarise person-centred and relationship centred approaches to care, both of which are considered central to the delivery of high quality care for people with dementia. As these approaches are not a common feature of hospital settings at present, and their theoretical underpinnings were not developed in acute care contexts (Clissett et al., 2013), how such approaches might

be implemented within the particular complexities and constraints of hospital settings is also explored.

1.5.1 Person-centred care

Explicit in the medical model of dementia is the assumption that cognitive decline and the associated memory impairment is solely responsible for the loss of self in individuals with dementia. This assumption denies the impact that care-giving contexts, environments, interactions and relationships have on the experiences and sense of self of individuals with dementia. It is now well recognised that an interplay between neurological and socio-psychological factors influences the retention or loss of self-hood rather than neurological factors alone (e.g. Kontos, 2005; Kitwood 1997; Downs 1997; Sabat & Harre 1992). Social psychological theories of dementia, including those of person and relationship centred care, argue that even people with advanced dementia can retain a sense of self (Kitwood, 1997; Sabat, 2001) which is influenced by not only their neurological impairment but also by their physical health, personality, personal biography, interactions with others and the social psychology of the environment in which they live (Prettyman, 2008; Kontos, 2005; Sabat, 2001; Kitwood, 1993). When considering how to improve hospital care for people with dementia, it is important to recognise that this interplay of factors, of which physical health and cognition is only a part, will impact upon experiences and outcomes of care.

1.5.2 The importance of care-giving relationships and interactions

The central importance that the quality of care-giving interactions and relationships have on self-hood are emphasised throughout socio-psychological theories of dementia, with self-hood described as; "a standing or status that is bestowed upon one human being by others, in the context of relationship and social being"

(Kitwood, 1997). This suggestion of self-hood as socially contrived stems from social interactionist theory which argues that the self is social and is secured through social interaction (Kontos, 2004).

Attempts to describe the attributes of self-hood enhancing interactions with people with dementia include: paying attention to what people with dementia say and do, and the meaning behind this; respecting their rights, values and beliefs; involving them; and entering their world (Kitwood, 1997; Prettyman, 2008; Edvardsson et al., 2008; McCormack, 2004). The premise behind the benefit of such interactions is that when the personhood of individuals with dementia is recognised and valued, they are valued as a respected social being (Kitwood, 1997) with a sense of self that exists despite their cognitive impairment (Skaalvik et al., 2010).

Kontos (2004) has broadened definitions of self-hood enhancing communication by arguing that a sense of self is derived not only from social interaction but also from inherent behaviours that may be undertaken even when a person is severely cognitively impaired. He argues that meaning can be expressed in actions such as maintenance of appearance, social etiquette, behaviour towards others, customs and habits/habitual movements and gestures, movements, tones and patterns of communication (Kontos, 2004). Responding to these behaviours can enable 'embodied communication' to occur even if the person has advanced dementia and limited, no or seemingly unintelligible language use (Kontos, 2004).

1.5.3   Relationship centred care

Recognition of the importance of care-giving interactions for people with dementia has led to the development of relationship centred care; an approach which places particular emphasis on the impact of care-giving interactions and relationships on people with dementia (NICE, 2006). Advocates of relationship centred care argue that person centred approaches do not fully capture the interdependence of care giving relationships (Nolan et al., 2002) and that a less individualistic approach focused on 'quality of lives' rather than quality of life more adequately captures the

highly relational nature of caregiving (Post, 2001). Relationship centred care therefore centres around the belief that a person's sense of self is primarily sustained through relationships with others (Smebye & Kirkevold, 2013), placing great emphasis on these relationships and suggesting that families and staff have the ability to directly promote or diminish personhood through their relationships and interactions with people with dementia (Nolan et al., 2002; Surr, 2006).

Attention is placed on the quality and nature of caring relationships and interactions with all types of care-givers (NICE, 2006), indicating that it is not just relationships with health professionals that are important in care settings, but also the maintenance of relationships with family members and close friends (Nolan et al., 2002). The importance of understanding and supporting people with dementia's past and present relationships with others is highlighted; relationships which have the potential to be highly sustaining caring relationships if close emotional bonds exist between carer(s) and the person (Smebye & Kirkevold, 2013). In the context of improving hospital care, this approach focuses attention on the quality, nature, development and maintenance of relationships and interactions between people with dementia, hospital staff, and the person's family and friends.

1.5.4   Delivering Person and Relationship Centred Care in hospital settings

Both person centred and relationship centred care have been criticised for failing to adequately define how these approaches can be implemented in practice (McCormack, 2004). This is particularly true in the context of general hospital care where relatively little work on person or relationship centred care has taken place (Clissett et al., 2013). To aid provision of these approaches in care settings, several models have been developed indicating the features required to deliver person and relationship centred care (Nolan et al, 2006; Brooker, 2007; McCance, 2011). As indicated by the existence of multiple models, a shared consensus has not been agreed but, as a broad summary, these models indicate that person centred care

should include some of the following: a sense of attachment, engagement, identity, occupation, comfort, shared decision making, holistic care, working with the person's beliefs and values and a sympathetic presence (Brooker, 2007; McCance, 2011). The Senses Framework of relationship centred care (Nolan et al., 2006), which includes some over-lapping features with the person centred models, focuses on - a sense of security, continuity, belonging, purpose, achievement and significance - but insists that these features must be present for everybody involved; people with dementia, their families and staff if care is to improve.

Essentially, as summarised by McCormack (2004), these concepts are predicated on knowing and interacting with the person, their biography and relationships. However these models, and the theories on which they are based, were developed in long-term care settings (Clissett et al., 2013) where greater opportunities exist for embodied communication and expression of self to occur through pursuance of familiar care-giving relationships and shared understandings of preferred routines, behaviours, habits and customs. Acute settings present multiple challenges to the delivery of such care; the priorities of rapid assessment, diagnosis and intervention and cure (if possible) coupled with short, highly routinized lengths of stay make the delivery of person and relationship centred care particularly problematic (Thompson, 2013; Clissett et al., 2013). The relationships required to deliver these care approaches, which are most easily achieved through consistent longer term care-giving relationships (Clissett et al., 2013), are particularly hard to achieve in fast paced acute settings where multiple rotations of patients and staff occur. In such settings staff typically do not have the capacity, expertise or individual patient knowledge to provide person and relationship centred care that recognises, values and responds to individual methods of communication and expressions of self-hood, including the at times difficult to understand and embodied communications of people with dementia.

1.5.5 Improving the delivery of person and relationship centred acute care

Research and initiatives focused on improving acute care for people with dementia have centred around areas such as staff training (e.g. Surr et al., 2016) and environmental adaptations (Waller, 2012). One largely unexplored potential means of overcoming some of the challenges of delivering person centred care, and simultaneously embracing the notion of relationship centred care, is the engagement of families and friends in the care of people with dementia. This approach is supported by the recent development of practice support documents such as the 'Triangle of care' by the Royal College of Nursing (Carers Trust, 2016) which encourages nurses to consider how the involvement and inclusion of carers can lead to better care for people with dementia. As the RCN document advocates, families and friends have the potential to benefit the hospital care of people with dementia in multiple ways, but their involvement and its impacts has received very little research attention (de Vries et al, 2016). Existing knowledge about the involvement of families and friends, and the range of ways in which they could contribute to improving person and relationship centred acute care for people with dementia, is summarised below.

1.6 Utilising families' expertise and knowledge to improve care

People with dementia are often supported or cared for outside of hospital by family and friends. There are 700,000 informal carers of people with dementia in the UK (Office of Health Economics, 2014) who could be a source of personal knowledge and expertise in relation to the care of individuals with dementia. These caring roles typically develop from existing relationships between family and friends (Seltzer & Li, 1996) and mean that the individuals involved are often highly familiar to each other, frequently having known or lived with each other for extended periods of time thus resulting in many shared memories and life histories (Smebye & Kirkevold, 2013). As

a result, individuals providing support to a relative or friend with dementia often have an in-depth and unique knowledge and understanding of that person and, over time, may build up an extensive repertoire of skills and strategies to help them support and care for the person (Nolan et al., 2002b; Redfern et al., 2002).

Whilst not all carers will possess such expertise, many carers have knowledge and skills that they could either use to provide more person centred care directly (Smebye & Kirkevold, 2013), or could share with staff to enable them to improve their interactions with people with dementia and to plan and provide care in a more individualised and person centred way (Nolan, 2006). For example, carers have often developed care routines that are familiar to the person with dementia and are skilled in understanding and responding to the person's individual needs and methods of communication (Nolan et al, 2002b; Clarke, 1999). They can also have valuable in-depth knowledge of the person's life and cognitive history, individual needs and preferences, usual level of functioning and strategies for overcoming communication and behaviour challenges (Nolan, 2002b; Clarke, 1999; Bray et al, 2015) which could help to address the knowledge gaps of some staff around dementia, how it affects individuals and their care needs (Bray et al., 2015; Thompson, 2016). Such knowledge, if employed in acute settings by families and friends or conveyed to staff, could help to enhance and personalise care, decision making, communication and engagement with people with dementia, and reduce distress and negative experiences. Involving families and friends in care provision could also help to meet more basic care needs such as hydration, nutrition, hygiene and mobility needs, and identification of pain. Engaging family and friends in care could also meet the central focus of relationship centred care; the maintenance of key care-giving relationships. And by engaging family and friends in acute care these valuable care-giving relationships could be supported and maintained, aiding the provision of care and the continuation of care-giving both during and after hospitalisation.

1.7   Willingness to engage families in care

It is important to recognise that not all carers will be willing or able to provide input into the hospital care of a relative or friend, and their input may not be welcomed by the person with dementia or staff. For example, a hospital admission can be stressful for carers (Li, 2005; Douglas-Dunbar & Gardiner, 2007), and so any opportunities for involvement in care must be balanced against the potential to cause additional strain. Greater emphasis on the importance of relationships with family and friends also requires a challenging orientation away from the professional as expert to a position that recognises informal carers and people with dementia as experts in their own experience (Nolan et al., 2002).

However, recent evidence suggests that some carers of people with dementia would welcome the opportunity to use their knowledge and skills to improve hospital care, for example by participating in hands on care or by sharing their expertise with staff (Cowdell, 2007; 2008). Involving family carers to improve acute care has been cited as a priority by people with dementia, carers and staff (Royal College of Nursing, 2011) and family carers have launched two national campaigns asking for carers of people with dementia to be allowed greater access to acute wards to support relatives and friends that have been admitted (Jones & Gerrard, 2014; National Federation of Women's Institutes, 2016). There is also evidence that carer involvement can lead to positive effects for carers, including increased satisfaction with care, better understanding of their relatives' condition, reduced stress levels, and greater preparedness for discharge (Li et al., 2004; Bull et al., 2000).

1.8   Policy context surrounding family engagement in care

There has been significant recent policy support and initiatives setting out strategies for improving hospital care for people with dementia, including the involvement of carers in care. For example, carers are acknowledged as expert partners in care (Department of Health, 2001, Department of Health, 2008b) who should be fully and meaningfully involved in care planning and decision making (National Institute for

Health and Clinical Excellence, 2006, Department of Health, 2008b; Carers Trust, 2013) to enable the integration of knowledge from carers and staff (Department of Health, 2001) and to promote improvements in care (Carers Trust, 2013). Several healthcare institutions have recently produced guidance on improving general hospital care for people with dementia, all of which strongly advocate the need to involve family carers as partners in care (e.g. Carers Trust, 2016; Royal College of Nursing, 2011; Society of Radiographers, 2015). Initiatives outside of general hospitals, such as Intermediate Care, also support the concept of greater family involvement by shifting care formerly provided in hospital to the home.

1.9   Current practice surrounding family engagement in care

Despite the many potential benefits of engaging families and friends of people with dementia in acute care, and policy, research and theoretical support for this approach, care is often delivered without involvement or consultation from carers (MacLeod et al., 2005). The limited available research in this area suggests that the expertise and knowledge of informal carers of people with dementia is often not recognised or sought out by staff (Cowdell, 2008; Nolan et al., 2002b; Douglas-Dunbar & Gardiner, 2007), information exchange with carers is often insufficient (Walker & Dewar, 2001; Douglas-Dunbar & Gardiner, 2007) and families can be excluded from discharge planning (Care Quality Commission, 2014; Department of Health, 2009). This failure to involve family carers, and to utilise their knowledge and expertise, may miss an opportunity to provide more person-centred care and to improve experiences and outcomes of hospital care for people with dementia and their carers (Department of Health, 2009*)*. It also contrasts with the many initiatives, policies and campaigns that advocate the engagement of families in care.

1.10 Research exploring family engagement in acute dementia care

Interestingly, despite apparently widespread support for engagement with family carers, very little research has explored the involvement of carers, or their personal knowledge, in the hospital care of people with dementia (de Vries et al., 2016; Thompson, 2016). Involving carers in care has been shown to have beneficial effects for people with dementia, carers, and staff in nursing home settings (e.g. Robison et al., 2007), but we know very little about the processes, challenges or impacts of involving families and their knowledge in the hospital care of people with dementia. Whilst much has been written about how health professionals and family carers should relate to each other, we know very little about how these relationships actually develop in practice (Ward-Griffin & McKeever, 2000). This means that policies, initiatives and campaigns that support the involvement of families in hospital dementia care do so with little knowledge of how best to engage families and their knowledge in hospital care, and without a full understanding of the nature, challenges or impacts of such engagement for people with dementia, families or staff. The involvement of family carers in the general hospital care of people with dementia therefore provides the focus for this thesis.

1.11 Chapter Summary

Exploring the existing literature on general hospital care for people with dementia highlights the many problems with hospital care and an opportunity for improving care which has been largely overlooked; the engagement of family and friends in care. Family carers have the potential to make many contributions to improving hospital care for people with dementia including the provision of valuable personal knowledge and expertise relating to care and communication with the person. However, little research has explored the involvement of families in hospital dementia care or the impacts of this involvement on experiences and outcomes of care for people with dementia, their families or hospital staff. To contribute to addressing this evidence gap, this study explores the involvement of families of

people with dementia in hospital care. The study focuses on the use of families'
knowledge and expertise in relation to the hospital care of people with dementia,
constraints to undertaking this partnership working, and how engagement with
families impacts upon experiences and outcomes of hospital care for people with
dementia.

Chapter 2 will explore some of the key research and conceptual evidence available in
this area, to further set the context for the study and to identify gaps in the design
and focus of existing research, which this study will then aim to address.

Chapter 2

Existing literature relevant to family involvement in the general hospital care of people with dementia

2.1   Introduction

Chapter 1 summarised the background literature relevant to this study and identified
the focus of the research; the use of families' knowledge and expertise in the general
hospital care of people with dementia. This chapter begins by exploring contextual
literature on family care-giving which sets the scene for considering the engagement
of families of people with dementia in hospital care. The limited number of studies
exploring the involvement of families in general hospital dementia care are then
discussed to identify existing knowledge in this area and limitations in the design
and content of these studies. This discussion identifies how existing knowledge on
this topic predominantly focuses on particular aspects of families' involvement in
care, overlooking the range of ways in which families might be involved, and has
been conducted largely from the perspective of families thus excluding the views
and experiences of staff and people with dementia. The chapter concludes by

summarising how existing studies and their limitations have shaped the design and content of this study.

2.2 General care-giving literature

In recent decades there has been a huge increase in family care-giving research which has resulted in a large and diverse knowledge base. The following discussion draws on aspects of the care-giving literature that are relevant to understanding the interface between formal and informal carers in the general hospital care of people with dementia.

2.2.1 Who are family caregivers of people with dementia?

There are around 6.8 million unpaid carers in England and Wales (Office for National Statistics, 2002), of which around 700,000 care for somebody with dementia (Office of Health Economics, 2014). Research on care-giving has established that carers have a range of backgrounds and relationships with the cared for person. As people age their care networks, including those of people with dementia, are increasingly made up of close relatives, most typically spouses or adult children (Carers UK, 2012), but also sometimes grandchildren, siblings or wider relatives or friends (Rutherford & Bowes, 2014). Although more women take on care-giving roles, including to people with dementia, changing demographics and social norms mean that male carers are increasingly becoming providers of informal care (Baker & Robertson, 2008); the ratio of female-male care-givers of people with dementia in a recent study was 1.6:1 (Wimo et al, 2013).

Social-gerontological literature on care networks has identified that a network of supporters often surround the cared for person. Whilst one person in the network may take up a core care-giver role, the wider care network can comprise of multiple 'secondary' supporters (Rutherford & Bowes, 2014). This suggests that many informal carers may play a part in the hospital admission of a person with dementia, highlighting the need for research exploring care-giving triads to consider the

'family' arm of the triad as, along with the staff arm, potentially incorporating numerous people rather than one individual (Lingler et al, 2008; Schulz & Martire, 2004). In addition, interdependent roles may exist, with members of the network, particularly older people, reciprocally giving and receiving care (Lingler et al, 2008; Godfrey & Denby, 2004).

The diversity that exists among care-givers and the variety of contexts, relationships and trajectories through which caring takes place has implications for considering the involvement of families in hospital care. Family carers' expectations, behaviour and preferences for involvement are likely to be influenced by their characteristics and experiences as care-givers outside of the hospital. For example, depending on their prior care-giving roles, family carers may bring different degrees of care-giving expertise, different levels of knowledge about the person, and different expectations of their involvement to the hospital setting. Carers from within the same care network may therefore have different requirements, expectations and goals when it comes to their involvement in hospital care (Naylor et al, 2007). In response to family carers' diversity, the sampling strategy described in Chapter 4 was purposively designed to recruit family carers with a range of backgrounds, relationships and care-giving expertise, including those from within larger family care networks, in order to explore variability between and within families in their preferences and expectations for involvement in hospital care.

A final point to make here is that, because of the diversity that exists among care-givers, no one standard term is used to describe people who provide care to a relative or friend. In recognition of the likelihood of family members providing care to older people with dementia, the terms 'family', 'family members' or 'family carers' are therefore used interchangeably hereafter in this thesis to refer to families or friends who provide support or care to people with dementia.

2.2.2 What roles do family caregivers undertake?

The diversity that exists amongst family carers, their care-giving situations and relationships leads to great variability in the roles and actions they undertake. Understanding the range of roles and behaviours that constitute family care-giving is vital to understanding the different types of knowledge and expertise that families can possess and the range of ways in which they might contribute to hospital care. Literature on care networks, and the wider but related concept of social networks, move beyond narrow conceptions of care-giving to consider a range of supportive roles, tasks and actions that might be provided by family carers, including instrumental (practical), emotional and informational/appraisal support (House, 1981). Social network theory also encourages consideration of aspects of care-giving such as reciprocity, emotional closeness and complexity within care-giving relationships and, importantly for this thesis, the extent to which informal care-giving relationships are formally embedded in organisational or institutional structures (Heaney & Israel, 2008). This variability in care-giving roles and actions is considered in more detail below.

2.2.2.1 Practical components of care-giving

Care-giving research, and care settings, can focus on the obvious practical and task-orientated aspects of care-giving (Tolson et al, 1999; Nolan et al., 1996, Dupuis & Norris, 1997), although these aspects are not necessarily a priority for family carers (Lindhardt et al., 2006). Examples of these task oriented roles include the provision of personal care (e.g. feeding, washing, dressing and toileting), and assistance with other activities of daily living (e.g. managing medication, finances, housework and shopping). The range of actions considered to be caring have been extended by some to include more 'managerial' activities (Nolan et al., 1996) such as monitoring care, exchange of knowledge and information, and involvement in care-planning and decision-making (Li et al., 2006; 2000, Walker & Dewar, 2001). Caring for a person with dementia can involve all of these tasks, and is associated with

particularly high levels of physical care. For example, a survey of dementia care-givers found that 65% of respondents provided personal care and nearly 25% of carers provided 40 or more hours of care per week, compared to 16% of non-dementia care-givers (Alzheimer's Association, 2007).

2.2.2.2 Emotional, relational and informational components of care-giving

Less tangible aspects of care-giving include an affective component; the act of providing emotional support or 'being there' and 'looking out' for someone (e.g. Li et al., 2000). These relational elements are important as, for many family carers, maintaining their relationship with the person they care for is their primary concern, particularly when the progression of an illness such as dementia increasingly threatens their ability to do so (Tolson et al, 1999). Preservation of the carer-cared-for relationship is often given priority over other elements of the caring role (Caron & Bowers, 2003) and is an example of how family carers can view care-giving in terms of its meaning or purpose rather than the type of actions involved (Duncan & Morgan, 1994; Bowers, 1987). This leads to purpose-based definitions of caring such as: anticipating needs prior to their arrival; preventing illness or deterioration; supervising and organising care; providing hands on care; preserving the person's self-image and relationship with family; building or rebuilding an identity and future for the person; and reciprocal care (Nolan et al, 1996; Bowers, 1987). These definitions highlight the potential for conflict in relationships and priorities with staff, who may prioritise practical and task orientated aspects of care over less tangible socio-emotional aspects which are central components of person and relationship centred care. These multi-dimensional and complex components of family care-giving imply that families may be interested in contributing to hospital care in a variety of ways, some of which may not be routinely considered by hospital staff or research studies.

2.3   Influences on families contributions to care

Outside of studies specifically exploring the involvement of families in hospital dementia care (explored in Section 2.6) the general care-giving literature identifies aspects of care-giving experiences and relationships which are likely to impact on the extent to which families become, or wish to become, involved in hospital care.

2.3.1 Quality of prior relationships

Related to emotional components of care-giving is the suggestion that care-giving behaviour is an extension of a range of actions and interactions from within a pre-existing familial relationship (Quinn, 2009; Schulz & Martire, 2004; Nolan et al., 1996). The quality of these prior relationships (e.g. degree of affection, closeness, and past reciprocities) is therefore central as these prior qualities will shape current care-giving behaviours, relationships and experiences (Clarke, 1999; Quinn et al, 2009). The prior quality of relationships between people with dementia and their families is therefore likely to shape involvement in the person's hospital care and the nature of their shared interactions in hospital, making these interactions and relationships an important component of any study exploring families' involvement in formal care-giving.

2.3.2 Quality of triadic relationships

The quality of triadic care-giving relationships (between families, patients and staff) are thought to play a central part in determining the roles and behaviours that family carers develop in formal care settings (Dupuis & Norris, 1997). In relation to the involvement of families in care, it has been suggested that the quality and nature of triadic relationships and interactions will have an important influence on families' levels of engagement in care (Adams & Gardiner, 2005; Nolan, 2002b) as well as experiences of care for patients, families and staff (Quinn et al, 2009; Ryan et al,

2008; Fortinsky, 2001). This implies that understanding how families might become more involved in hospital care requires understanding of the current nature of relationships and interactions between people with dementia, families and hospital staff (Ward-Griffin & McKeever, 2000). Although these triadic relationships have received much theoretical attention, very few researchers have taken these ideas beyond a conceptual level to explore them in empirical research (Keady et al., 2007), especially in general hospital settings (Fortinsky, 2001). As a result, we know very little about the nature of relationships and interactions between dementia care-giving triads, particularly in hospital settings; knowledge which is vital to shaping future practices for working collaboratively with family carers (Ward-Griffin and McKeever, 2000).

2.3.3 Transitions and temporality

Studies that acknowledge the temporal nature of care-giving recognise that caring roles are not static, but are defined and redefined over the course of the care-giving career and in response to experiences, the environment, and interactions with others (Nolan et al., 1996, Dupuis and Norris, 1997). Care-giving is seen as existing along a trajectory over which care-giving roles and behaviours are likely to change and evolve over time. For example, the roles and actions that a family member undertakes may vary over the course of the cared-for person's illness, or depending on the environment in which care is being provided or on who the family member is interacting with (Dupuis and Norris, 1997). Care trajectories are particularly relevant in progressive conditions such as dementia, where the speed and nature of decline is unpredictable, there is potential for transitions through both behavioural and physical symptoms, and disease progression involves transitions through multiple stages of increasing severity and ultimately, end of life care (Rose & Lopez, 2012).

Temporality is also likely to be particularly relevant to the involvement of families in hospital care for two reasons. Firstly, a hospital admission represents a temporary transition from care provided at home, often by families, to care provided in a formal

setting, typically as a result of a worsening health condition or a crisis point being reached (Fortinsky, 2001, May et al., 2001). Many aspects of this transition, including experiences of the admission process, the health of the person with dementia, the hospital environment, the course and quality of care, and relationships with staff, may change over the course of the admission (Ward-Griffin & McKeever, 2000) and could affect a family members willingness or ability to contribute to care. Secondly, each carer will be at a different stage of their own care-giving trajectory, which could affect whether and how they are willing to be involved in hospital care. For example, some carers will be relatively new to caring (Procter et al., 2001) where as others will be experienced carers with larger 'stocks of knowledge' to draw on (Dupuis & Norris, 1997), or may be considering their involvement in the care setting against a back drop of deciding when to 'let go' of their caring responsibilities (Caron and Bowers, 2003). Understanding these trajectories, and the points different carers are sit along them, is therefore another important consideration in research exploring the involvement of families in hospital care settings.

2.3.4 Stress and burden

Transitions between care settings are one of many potential sources of stress for family care-givers, marking hospital admission as a time when carers are likely to experience extra anxieties in addition to the usual strains of care-giving. Specific stressors at this time include worries about the person's health, their future care needs, the quality of hospital care, the course of the hospitalisation, and likely discharge plans (Bradway & Hirschman, 2008; Li, 2005). These additional stressors can be compounded by other stresses and negative effects of care-giving, such as psychiatric and physical morbidity, psychological distress, burden, financial strain, and social isolation (Schulz & Martire, 2004; Cuijpers & Nies, 2014; Butcher et al, 2001; Fortinsky, 2001). Family carers of people with dementia may also experience additional burden and psychological distress compared with other care-givers (Kim & Schulz, 2008).

Any attempts to involve families in care must therefore be balanced against the potential to cause additional stress. This does not, however, preclude the involvement of families in formal care. Studies exploring family involvement in care settings report that greater involvement can lead to a variety of positive effects for family members, including increased satisfaction with care, higher quality of life, better understanding of their relative's condition and increased preparedness for discharge as well as reduced concerns about hospitalisation (Li, 2005; Li et al, 2004). Hospital admissions also offer opportunities to support and maintain family care-giving relationships through the provision of emotional and practical support from staff, upskilling of family members, and the provision of opportunities for families to maintain or develop aspects of their usual care-giving role in the hospital setting.

2.4   The interface between informal and formal care-giving

Prior research on the interface between informal and formal care (i.e. between family carers and formal services such as hospitals) indicates that such interfaces can be problematic. As well as having the potential to alleviate difficulties, contact with formal services can be a source of distress, concern or frustration for family carers. Difficulties include poor quality relationships, communication and knowledge exchanges with staff, and concerns over the quality, reliability, personalisation and motivations of the care provided by formal services (Fadyl et al, 2011; McPherson et al, 2014; Carpentier et al, 2008). Family carers can hold high expectations of services which are not always met - there are frequent conflicts between the expectations and reality of service delivery - and problematic knowledge exchanges are prevalent, including inconsistencies in the value attached to families' expert knowledge and to information exchanges with them (McPherson et al, 2014). Relationships and interactions between families and professionals are largely professionally determined, for example the time and place of meetings, what resources are available, the type of language used, the content of communication and the stakeholders involved (Carpentier et al, 2008) indicating the potential for power imbalances between professionals and families. These findings highlight multiple

potentially problematic areas in the interface between families and professionals. However notably, most studies do not consider the interface between families and hospital systems, the impact of these interfaces, or interfaces involving multiple players within the staff or family arms of the care-giving triad.

2.5   Summary of the above literature and its relevance to this study

The above literature highlights families' diverse personal circumstances, the multi-dimensional nature of care-giving roles and relationships, and the propensity for care-giving roles to change over time or in response to the environment or the players involved (Dupuis & Norris, 1997. Family carers' roles and behaviours in hospital settings are therefore likely to be unique to each family member and shaped by their background, characteristics, prior care-giving experiences, and their relationships and interactions with others, as well as their stage in the care-giving trajectory, the care environment and the staff they are interacting with. This draws attention to how the social, cultural, organisational and environmental contexts of care settings, and relationships and interactions within them, influence the care-giving roles and behaviours families undertake in hospital settings. For example, an organisation's philosophy, policies, procedures, power hierarchies and physical structure may all shape the extent to which families are involved in care (Dupuis & Norris, 1997). In addition, families may possess variable degrees of knowledge and expertise in caring for relatives with dementia and may try to involve themselves in care in a variety of ways alongside or other than the provision of physical care, such as providing emotional or social support, managing or supervising care or providing knowledge about the person with dementia.

Collectively, the above literature suggests that studies of family involvement in care settings, such as this study should consider the following:

- The characteristics, expertise and relationships of family caregivers

- The range of roles families undertake in hospitals, including less tangible aspects of care-giving

- The nature of relationships and interactions between families, people with dementia and staff, and their impact on care-giving (including prior care-giving relationships and when multiple members of staff or families are involved)

- The stage of the care-giving trajectory and journeys across the course of hospital admissions

- How social, cultural, organisational and environmental contexts of care settings shape families involvement in care

- The impact of families involvement in care on the cared for person

These aspects therefore feature in the study design and the focus of the data collection described in Chapter 4, for example helping to shape the sampling frame, observational framework and interview guides.

Although the above literature highlights important considerations for research exploring families' involvement in care settings, the difficulties of gaining consent and collecting data from people with dementia mean that they, and sometimes their families, are excluded from many care-giving studies. In particular, people with dementia and their families have been excluded from many studies about the involvement of families on elderly care wards (e.g. Li et al, 2003; Lindhardt et al., 2006; Walker & Dewar, 2001). In order to build on the understandings gained from the more general care-giving literature, and to explore what is known about family care-giving in the context of general hospital care for people with dementia, an extensive literature search was conducted to identify studies focused on this topic. Details of this search and the resulting papers are discussed below.

2.6 Literature on family involvement in the hospital care of people with dementia

2.6.1 Literature search

An extensive literature search was conducted to identify studies that explore the engagement of family caregivers in the general hospital care of people with dementia. The search was conducted in PsychInfo, Embase, Medline and Cinahl using suitable variations, depending on the database, of search terms for each of the following: "family carers" (such as 'famil$' 'relative$' 'carer$' and care-giver$) "dementia" or "older people" (such as 'dement$' 'cognitive adj impair' 'alzheimer$' 'elder$' 'older adj people$') and "general hospital" (such as 'hospital$' 'acute adj care' and 'nursing adj care'). The titles and abstracts of the resulting papers were read to identify studies which may contain data on the experiences or engagement of families in the general hospital care of people with dementia. Full copies of potentially relevant papers were obtained to confirm whether they contained useful data. The reference lists of included papers were checked for any further papers that had been missed by the search.

When the search was originally conducted in 2009, only two studies (Tolson et al, 1999; Douglas-Dunbar et al, 2007) were identified which explored the engagement of families in general hospital dementia care. Therefore, despite thorough searching, the evidence which initially informed this study was largely drawn from studies exploring family engagement in elderly care wards generally (i.e not specific to people with dementia) or in the care of people with dementia in care home settings. As this PhD was conducted over 7 years, in order to incorporate two periods of leave and part-time working, the literature search was repeated periodically in order to identify newly published studies. The final search, conducted in 2016, identified seven additional studies leading to a total of nine data containing studies (reported in 14 papers/reports) exploring aspects of the engagement of families in the general hospital care of people with dementia. The lack of research in this area has been corroborated by recent literature reviews on the topic by Boltz et al (2015b), Bauer et al (2011) and Porock et al (2015) whose "careful search of the major health science databases revealed only six published studies that focused specifically on the

experiences of patients with dementia and/or their family carers in a general hospital setting" (p38).

2.6.2 Literature review – Family engagement in general hospital dementia care

The nine existing studies exploring aspects of the experiences and involvement of families in general hospital dementia care are represented by 15 published papers/reports as summarised in Table 1.

Table 1: Previous studies on family involvement in the hospital care of people with dementia: Overview of study designs

Study	Authors and date	Participants and setting	Data collection methods
1	Tolson et al (1999)	Quantitative component: People with cognitive impairment (n=231). Qualitative component: People with cognitive impairment (n=5) and family carers (n=41) from 4 hospital wards.	Quantitative data from patient assessments. Qualitative interviews and medical note review.
2	Douglas-Dunbar et al (2007)	Family carers (n=9) of people with dementia from one hospital ward who had previously been cared for at home.	Qualitative interviews after discharge.
3	Bauer et al, (2011a & 2011b)	Family carers of hospitalised people with dementia (n=25) from numerous hospitals and wards.	Qualitative interviews after discharge.
4	Gladman et al (2012) Jurgens et al (2012) Clissett et al (2013) Porock et al (2015)	People with dementia (or occasionally delirium or other mental health problems) (n=*unknown**), family carers (n=35), hospital staff (n=60) and co-patients (n=4) from 11 different wards in one hospital.	Non-participant observations (all participants) and conversations with staff during observations. Qualitative interviews after discharge (with families, co-patients, staff and some* people with dementia).
5	Bronson & Toye (2015)	Nurses from 3 acute hospital wards (n=16).	Questionnaire feedback on an information booklet for family carers (limited relevant data).
6	Boltz et al (2014; 2015a & b)	Quantitative component: People with dementia (n=84) and their families (n=84) from 5 medical units in two hospitals. Qualitative component: Family carers (n=50) from 3 medical units in one hospital.	Quantitative data from assessments with patients and families. Qualitative interviews (family members only).
7	De Vries et al (2016)	Family carers of people with dementia (n=26) from multiple hospital sites.	Qualitative interviews after discharge.
8	Bloomer et al (2014)	Family carers of people with dementia discharged into residential care from one hospital facility (n=20)	Qualitative interviews.

9	Naylor et al (2007)	Single case study example of 1 participant with dementia and their family carer reported as part of a collection of case studies.	Case study (limited data).

Footnote: * The authors state that people with dementia were encouraged to be present and participate where possible but that sometimes just the care-giver was present and most information came from carer participants. The number of people with dementia taking part in interviews is not reported.

2.7   Design limitations of existing studies

Examination of Table 1 reveals multiple limitations in the design of existing studies, some of which have been corroborated by other authors (e.g. Jurgens et al, 2012). Whilst existing studies have begun to explore the many issues surrounding the engagement of family carers in general hospital dementia care, their findings must be interpreted in light of their design limitations. These limitations are discussed below, thereby enabling the subsequent discussion of the findings from these studies to take place with these limitations in mind.

2.7.1 Participants and settings

In terms of participants, studies commonly exclude people with dementia and their views or the views of staff (e.g. de Vries et al, 2016; Bloomer et al, 2014; Boltz et al, 2014 & 2015a&b). This means that existing understandings of family engagement in acute dementia care, and the resulting recommendations for practice, are based largely on the views of families and exclude the other arms of the care-giving triad. In addition, some papers focus on sub-groups of participants, such as those transitioning into care homes (Bloomer et al, 2014) or previously living at home (Douglas-Dunbar & Gardiner, 2007), which are unlikely to reflect the range of experiences of the broader groups from which these sub-groups are taken. In addition, some studies recruit participants from a large range of hospital wards, units and hospital Trusts (e.g. de Vries et al, 2016; Bauer et al, 2011a & b; Gladman et al, 2012) which limits in-depth exploration of how cultural, organisational and staffing contexts within care units contribute to shaping family involvement practices.

2.7.2 Data collection

Data collection is often limited to the use of interviews (e.g. Douglas-Dunbar & Gardiner, 2007; Bauer et al, 2011a & b; de Vries et al, 2016; Bloomer et al, 2014), which limits the inclusion of people with dementia to those with mild-moderate dementia who are able to take part in an interview and recall their experiences. Interviews are always at one point in time, usually after discharge (e.g. Douglas-Dunbar et al, 2007; Bauer et al, 2011a&b; de Vries et al, 2016), sometimes up to 8 weeks (Bauer et al, 2011a&b) or even 5 years (de Vries et al, 2016) afterwards which raises the possibility of recall bias, especially for participants with dementia. Lengthy periods between the hospital admission and one-off interviews also prevents longitudinal exploration of family engagement across the often protracted and variable course of hospital admissions for people with dementia, including key junctures such as admission, assessments and care planning meetings and the discharge process. Interviews can be brief in length (e.g. 14-43 minutes in Bloomer et al, 2014; 20-30 minutes in Boltz et al, 2015b) precluding in-depth exploration of hospital admissions which can often last weeks or even months. The only study using methods which provide better access to the perspectives of people with dementia is Porock et al (2015) (and related papers) who use observations alongside interviews to explore participants' experiences and interaction between arms of the care-giving triad. However, the approach used still has limitations as the authors state they used non-participant observation which prevented researchers from maximising the potential of this method to include the views of people with dementia by interacting with participants during observation sessions to check and explore their perspective. As a result, as recognised by the authors, "the findings relating to experiences of people with dementia involve the greatest level of interpretation as it was not possible to ask the patients themselves what was happening or why they were behaving in a particular way" (p46, Porock et al, 2015). Porock et al (2015) go on to cite "the reliance on observation to reveal the patient's experience rather than interviewing the patient while in hospital" (p55) as a key limitation, citing concerns over adding the burden of an interview to an acutely unwell person, although brief conversational style interviews have been used with

success in other studies of acutely unwell people with dementia (e.g. Cowdell et al, 2008).

With the above design limitations in mind, the following section summarises what these nine studies tell us about the engagement of family carers in the general hospital care of people with dementia. Some studies contribute less to this discussion than others due to greater limitations in their design and data. The themes identified by the nine studies are augmented at times by broader literature on family engagement on geriatric wards (i.e. not specific to people with dementia) and family engagement with people with dementia in care home or psychiatric settings; literature which informed the initial study design given the extreme lack of topic specific studies available at the time. However, as this wider literature does not explicate the particular challenges of involving family members of people with dementia (de Vries et al, 2016), and most studies of family engagement in elderly acute settings actively exclude participants with dementia (e.g. Li et al, 2003; Lindhardt et al, 2006; Walker & Dewar, 2001), care has been taken to focus on the themes identified by the nine studies specific to family engagement in acute dementia care. Alongside discussion of the content of existing studies, attention will be drawn to gaps in their content which this study could aim to address. After these findings have been discussed, the chapter will conclude by discussing how the existing literature, and its limitations, have shaped the design, methods and focus of this study.

2.8   The content of existing studies

The following sections discuss the key themes that arise from existing studies in the topic area of this thesis, as well as highlighting limitations in their content. Understandings gained from the wider care-giving literature have informed the exploration and critique of these studies, for example in drawing attention to the degree to which studies consider the range of care-giving roles that families could undertake, relationships between and within different arms of the care-giving triad,

variation in care-giving relationships and the temporal nature of hospital care-giving.

2.8.1 Experiences of families of people with dementia in general hospitals

Most but not all of the nine studies report experiences of hospitalisation for families of people with dementia, but typically exclude the perspectives of people with dementia or staff on the involvement of families in care. Only three studies include the experiences of people with dementia and only two studies include the perspectives of staff (See Table 1). Hospital admission caused disruption from both families and people with dementia's normal lives, previous routines and care-giving support networks (Porock et al, 2015; Boltz et al, 2015b). For families, the additional demands of regular visits to maintain vigil on the person with dementia's well-being, coupled with additional strain and demands both prior to and during the admission itself, significantly disrupted their normal lives and levels of burden (Boltz et al, 2015b; Jurgens et al, 2012). Worries about the experiences and quality of hospital care for their relative were commonplace, in relation for example to their relative's distress, unmanaged pain, risk of falls, premature discharge, bed moves and deterioration in physical and cognitive function (Boltz et al, 2015b; Jurgens et al, 2012). Families expectations regarding quality of care were not always met (Jurgens et al, 2012) and both families and people with dementia experienced a lack of control, for example over care provision, care-giving roles and routines, decision making, the care environment and access to it (Bloomer et al, 2014; Porock et al, 2015). However, it should be noted that studies were largely focused on family perspectives, overlooking the extent to which people with dementia were involved or excluded from aspects of their hospital stay such as care provision, discharge planning and decision making, an area which remains largely unexplored.

2.8.2 The roles undertaken by families of people with dementia in general hospitals

Studies that report on care-giving roles often concentrate on families' involvement in task focused roles such as feeding, washing and dressing (de Vries et al, 2016), a finding reflected in wider studies on family involvement in elderly acute care (e.g. Li et al, 2000). These roles were often instigated by families who felt compelled to be with the person with dementia to ensure that their care needs were met (Douglas-Dunbar & Gardiner, 2007; de Vries et al, 2016). Aside from care provision, some studies make reference to other ways in which families might be involved in care. These actions include advocating for the person with dementia, trying to manage their care, ensuring adequate discharge arrangements, providing warmth and occupation, promoting mobility, maintaining valued relationships and links with normal life and sharing their knowledge of the person with staff (de Vries et al, 2016; Douglas-Dunbar & Gardiner, 2007; Tolson et al, 1999; Boltz et al, 2015; Porock et al, 2015b).

2.8.3 Focusing on the use of families' knowledge

Families were seen to hold valuable knowledge about the background, needs, preferences, typical behaviours and functioning, baseline status and sources of anxiety of people with dementia, as well as strategies for dealing with these behaviours and connecting emotionally with the person (Boltz et al, 2015b; de Vries et al, 2016; Bray et al, 2015). Such knowledge is a crucial component of person centred care and decision making, making families a critical part of planning for future care (Gladman et al, 2012), providing their knowledge is sought and used. Families are therefore a valuable source of knowledge if the person with dementia is unable to provide information about themselves, the potential for which is greater in general hospital settings due to ill health and the potential for associated confusion.

Although personal knowledge was identified by some studies as having a central role to play in the delivery of person centred care (Bray et al, 2015), it's use and impacts during the hospital care of people with dementia has received little research attention (Thompson, 2016). A small unpublished study exploring the impacts of personal profiles for people with dementia in hospital settings (interviews with n=13 staff) suggests that using personal knowledge can promote person centred acute care, improve experiences of care by reducing distress and promoting communication, increase understanding and acknowledgment of the person and promote relationships with people with dementia and their families (Thompson, 2016). This small study suggests that personal knowledge, including that obtained from families, could enhance experiences of hospital care for people with dementia but little is known about how personal knowledge is current sought, valued or used in the acute care context.

2.8.4 Competing knowledge, expertise, priorities and roles

Advocating recognition of families' knowledge and expertise leads to questions about how that expertise fits with the knowledge and expertise of hospital staff. Competing claims to knowledge and expertise between formal and informal caregivers are occasionally cited in the wider care-giving literature (e.g. Allen, 2000) but have not been explicitly explored in relation to families of people with dementia in general hospital settings. However, the different types of knowledge, perspectives and priorities reported by families and staff hint at the potential for competing claims to expertise, and the wider care-giving literature suggests that attempts to integrate the 'local' knowledge of family carers with the contrasting 'global' knowledge of staff (Nolan et al, 1996) has the potential to lead to significant tensions (Allen, 2000). However, no studies have focused on the different types of knowledge held by families, staff and people with dementia, whether and how knowledge is exchanged and used to inform care, or how the tacit knowledge of families fits with professionals' conceptions of people with dementia.

Hospitalisation may also create tensions as the dynamic of the family caregiving relationship changes and aspects of the family care-givers role, such as the coordination and delivery of care, are handed over to ward staff. This means relinquishing responsibility and control for care to staff whom lack relationships with, or knowledge of, the person (Bloomer et al, 2014). Concerns about the quality of care that might be provided in such circumstances can make relinquishing care to unfamiliar staff particularly difficult for families. In addition, general hospital settings frequently create tensions between requirements for efficient, routinized care, the meeting of physical needs and the delivery of person centred dementia care (Cowdell, 2010; Dewing & Dijk, 2016). Whilst families' concerns may centre around the well-being and optimal, individualised care of the person, and maintenance of their relationship with their relative (Bloomer et al, 2014; de Vries et al, 2016; Tolson et al, 1999; Jurgens et al, 2012), high workloads, bed pressures and a medically oriented approach mean staff often feel compelled to focus on cure, task-oriented care provision and discharge preparation (Bronson & Toye, 2015; Porock et al, 2015; Jurgens et al, 2012). As a result, affective aspects of care such as connecting emotionally with people with dementia, which are often highly valued by families, are not typically seen as integral to acute care provision (Tolson et al, 1999).

With these tensions present, the priorities of families, health professionals and people with dementia may diverge, although this possibility has not been a focus of previous studies. The priorities, preferences and involvement of people with dementia in decision making in particular are overlooked and little is known about how decisions are made or how the knowledge of different stakeholder groups contributes towards decision making. The wider care-giving literature suggests the possibility of divergent priorities within care-giving triads, with families in other care settings or situations concerned with individualised and emotive care, staff primarily focused on patient safety, and patients concerned with maintaining their independence (Denson et al, 2013). In circumstances where expertise, knowledge, priorities and power are in competition, questions are then raised over whose perspectives and expertise are valued and used to inform care and decision making.

2.8.5 Relationships and communication within the care-giving triad

Evidence of conflict around knowledge, expertise, priorities and control suggests the potential for negative relationships between hospital staff and families of people with dementia. This suggestion is corroborated by several of the studies in this review, where poor communication and negative relations between staff and family carers, and between staff and people with dementia, were reported (e.g. Jurgens et al, 2012; Douglas-Dunbar & Gardiner, 2007). Families reported failures by staff to engage with them about their relative and the care-giving situation, and so a failure to acknowledge and provide support for the difficulties they may be facing, some of which could jeopardise continuation of care-giving. Failure to engage with families is one of several reported precursors to negative staff-family relationships, which are also suggested to stem from negative prior experiences of hospitals and staff, or from conflict as a result of families' dissatisfaction with care (Jurgens et al, 2012). Conversely, high levels of family involvement in hospital care are also suggested to create conflict and tension in relationships with staff (Bauer et al, 2011b).

The unmet expectations of family carers regarding care is cited by one study as a major precursor to negative relationships and conflict (Jurgens et al, 2012) with a lack of communication between staff and families meaning that families expectations may not be understood or met by staff. Continued failure to meet families' expectations can have particularly negative consequences, resulting in a cyclical process of increasingly deteriorating staff-family relationships and mistrust, anger, confrontation and complaints (Jurgens et al, 2012). Chapter 1 identified problematic relationships between staff and people with dementia, the literature presented here suggests that hospital admissions have the potential to result in negative relationships between staff and both arms of the care-giving dyad.

The quality of relationships within the care-giving dyad, and the potential for negative relationships, has received almost no attention. Whilst the wider care-giving literature cites numerous problems and conflict in relationships with staff, most of the nine studies reviewed presume that family relationships (i.e.

relationships with the person with dementia and relationships within informal care networks) are unproblematic. Care-giving research has been criticised in the past for taking a narrow and ideological view of family care-giving as invariably based on deeply affective and positive relationships, denying the possibility of dysfunctional family relationships or family involvement in care that is detrimental to the well-being of the cared for person (Dupuis & Norris, 1997). The studies reviewed here conform to this stereotype, painting an almost uniformly positive picture of family relationships and care-giving actions and presenting a largely negative impression of relationships and care-giving actions involving staff. This highly dichotomous view may not reflect the likely range in the quality of actions, interactions and relationships amongst all three arms of the care-giving triad. Only a couple of papers make brief references to conflicting perspectives within family care networks (Jurgens et al 2012; Bloomer et al 2014) or to difficult relationships between people with dementia and their families (Porock et al, 2015). Dysfunction in these relationships is suggested to create challenges for staff (Porock et al, 2015) and stress for families (Bloomer et al, 2014) but the nature of family-person with dementia interactions and relationships in hospital settings remains largely unexplored, particularly in relation to their impact on people with dementia. A further limitation is that only one paper considers relationships between all three arms of the care-giving triad - the series of papers by Jurgens et al (2012) represent the only study to consider findings from each arm of the triad, although some of these discussion take place across several papers which precludes an in-depth exploration of some of these between and within group interactions, and their impact. For example, little is written in any papers about interactions within the multiple players that can make up the staff and family arms of dementia care-giving triads.

2.8.6 Current family engagement practices

Whilst existing studies suggest numerous ways in which families might contribute to hospital care, many families that want to be involved in care, and the potential for

multiple benefits from this involvement (Boltz et al, 2015b), existing studies suggest that family involvement in care is highly variable and is not a routine component of general hospital dementia care (Boltz et al, 2015b; Bloomer et al, 2014; Douglas-Dunbar & Gardiner, 2007; Bauer et al, 2011b). For example, despite an often regular presence on the wards, families report that their knowledge of relatives with dementia is not valued or used and they often feel excluded from, and poorly informed about, care-planning and decision-making (Bloomer et al, 2014; Bauer et al, 2011a&b; Douglas-Dunbar & Gardiner, 2007). Decision making involvement have been criticised for being opaque and tokenistic with decisions made elsewhere (Walker & Dewar, 2001), and families' knowledge of the person is reported to be poorly valued and used (Douglas-Dunbar & Gardiner, 2007).

Levels of family involvement are frequently below families' expectations (Jurgens et al, 2012) with involvement reported to be subject to the assertiveness of family members (de Vries et al, 2016). Families employ strategies to try and assert their input - for example visiting strategically to coincide with key knowledge exchange and care provision opportunities such as ward rounds, medication rounds and mealtimes (de Vries et al, 2016). 'Hyper-vigilant monitoring' (Jurgens et al, 2012), or close variations on this theme (e.g. de Vries et al, 2016; Boltz et al, 2015b), are repeatedly cited and involve families managing concerns about care quality and their potential lack of involvement by closely monitoring the person with dementia and the quality of their care. If families' expectations are not met they can interject assertively and at the risk of creating conflict, to try and ensure their relative's health, safety and well-being and to minimise any deterioration or distress (Douglas-Dunbar & Gardiner, 2007; Porock et al, 2015; de Vries et al, 2016). Reports of sustained, strategized and repeated efforts to infiltrate care suggest families can feel under-involved and may view hospitalisation as a potential threat to their control over the care and well-being of their relative. This threat extends to life after hospital, with families reporting fears that in-hospital departures from normal care routines will threaten post-discharge re-establishment of their prior ways of managing and care-giving (Bauer et al, 2011b; Porock et al, 2015). The overall impression from the limited existing evidence is of family engagement practices that do not accord with

policy or theoretical assertions of the importance of triadic care-giving relationships or the need to involve and see families as equal partners in care.

However, these findings must be interpreted with caution given the many limitations of these studies – limitations which are highlighted here and in Section 2.7. In particular, existing studies do not explore the effects of varying degrees of family input on experiences or outcomes of care from the perspective of people with dementia. And whilst some studies identify a lack of family involvement in decision making they typically do not expand upon this to explore how decisions about people with dementia are made, whether people with dementia themselves are involved, or how families' involvement in decision making impacts upon outcomes of care for people with dementia.

2.8.7 Understanding and explaining variation in family engagement

Although previous studies suggest limited and variable engagement with families, they do not explore in any depth the reasons for this variability or what factors affect the degree to which families' knowledge and expertise is used to inform care and decision making. Whilst we can hypothesise potential reasons - staff workload, carer strain or ill health, geographical proximity of carers, lengths of stay, conflicting claims to expertise and negative staff-family relationships being potential contenders - little actual exploration of the barriers or facilitators to greater family engagement has taken place. Other potential influences on degrees of engagement include family preferences, with substantial heterogeneity in the degree to which families want, expect or feel able to give active physical or emotional care during hospitalisation (Jurgens et al, 2012) and staff recognition of stress in family carers. For example, whilst greater involvement may relieve burden, families can find pressure to make difficult decisions stressful (Jurgens et al, 2012).

Insufficient understanding of why family engagement varies, the conditions or approaches required to facilitate engagement, and the impacts of variability in

family engagement, seriously hamper policy makers' and campaigners' efforts to increase families' involvement in acute dementia care. The lack of guidelines for engaging families of people with dementia in acute care (Boltz et al, 2014) means that hospital staff, managers, campaigners and policy makers have little evidence or guidance on how to effectively engage families in general hospital dementia care.

2.8.8 Potential impacts of family engagement

Many studies stop at describing the extent to which family engagement takes place and do not explore the impacts of engaging, or failing to engage, families of people with dementia in hospital care. In particular, the impacts of family engagement from the perspectives of people with dementia and staff are poorly understood. Family involvement is often presumed to lead to improved experiences and outcomes without actually engaging with people with dementia to explore their experiences of having relatives involved in, or excluded from, their care. Whether family engagement is actually beneficial for people with dementia, their families and staff has not been established, nor have the processes through which beneficial impacts might be achieved. For example, Boltz et al (2015b) conclude that family knowledge is essential to guiding treatment and decision plans but they do not explore how these benefits might occur in practice.

The limited evidence on impacts suggests that a lack of involvement in discharge planning and decision making may affect families abilities to undertake care-giving roles (Bauer et al, 2011a) and could result in discharge arrangements that fail to meet the family or person with dementia's needs in terms of timing and level of service provision (Bauer et al, 2011b). Families report that failure to use their knowledge of the person leads to lower standards of care as well as distress, frustration and disappointment for families (Bauer et al, 2011b). In addition, negative or absent relationships with staff and the stress of the admission are suggested to impact on the well-being of both the carer and the person with dementia (Douglas-Dunbar & Gardiner, 2007). The only study which specifically refers to the impacts of

family involvement on people with dementia is a feasibility study of a family-centred, function focused acute dementia care intervention (Boltz et al, 2014; 2015a). This study suggested some benefits in function (in activities of daily living, walking and delirium prevalence) for people with dementia whose families were involved in care provision, as well as improvements in families' levels of anxiety and preparedness for care-giving. However, as this was a feasibility study it was not sufficiently powered to detect a difference between intervention and control groups and does not provide reliable evidence of impact.

2.9   Summary of existing studies and their limitations

In summary, existing research has begun to explore some aspects of the involvement of families in general hospital dementia care, but several important areas remain unexplored or poorly understood. Studies indicate that hospital admissions can have multiple negative impacts for family members as well as people with dementia. Disruption from prior lives, concerns about care quality, and a lack of involvement in care are reported and have the potential to increase families' burden and stress to a point where it threatens continuation of their care-giving role *(*Douglas-Dunbar & Gardiner, 2007; Porock et al, 2015*)*. Most studies portray negative impressions of staff as providing substandard care and holding negative relationships with people with dementia and their families. In contrast, relationships between families and people with dementia, and the impacts of involving families in care, are presumed to be positive and remain largely unexplored, particularly from the perspective of people with dementia. Studies often focus on families' involvement in physical care, largely overlooking the range of ways in which families might impact upon the experiences and outcomes of care for people with dementia and, in particular, how families' knowledge and expertise could help to effect more person centred care and decision making. No studies have explored the different types of knowledge held by each arm of the care-giving triad, decision making within care-giving triads, or the nature of interactions between and within all three arms of the triad. In addition, most studies rely on interview data (often collected

after discharge), exclude one or more arms of the care-giving triad, and do not collect data longitudinally across the course of the hospital admission, with these design combinations particularly poorly suited to maximising opportunities for people with dementia to take part and contribute their views and experiences.

Although the majority of the studies reviewed had not been published when data collection for this study was designed and conducted, similar limitations were noted in the two published studies at the time (Tolson et al, 1999; Douglas-Dunbar & Gardiner, 2007) and the wider literature on family engagement in elderly acute care. Similarly, for example, this wider literature relied heavily on single interviews and largely excluded people with dementia (e.g. Lindhardt et al, 2006; Walker & Dewar, 2001; Li et al, 2000; 2003), and thereby focused on the experiences of elderly acute patients without dementia and their families, often focusing primarily on the views of family members. The following section discusses how the content and limitations of existing studies have shaped the design, focus and methods of this study.

2.10 Building on existing studies and their limitations

2.10.1 Developing the Research Questions

The reviews of existing literature in Chapters 1 and 2 have led this study to focus on research questions relating to areas of family engagement in general hospital dementia care that previous studies have overlooked. The literature reviewed in Chapter 1 highlighted how experiences and outcomes of hospital care can be particularly problematic for people with dementia and Chapter 2 highlighted a need to understand more about how families' knowledge and expertise impacts upon experiences and outcomes of care for all three arms of the care-giving triad, with a particular focus on the impacts of family involvement for people with dementia. In order to address these priority areas, the final research question was as follows:

"How does families' knowledge and expertise, and the ways in which it is sought, valued and used, impact upon experiences, outcomes and decision making in the general hospital care of people with dementia?"

To answer the above research question this study explores the use of families' knowledge and expertise in actions and interactions between all three arms of the dementia care-giving triad in general hospital settings. The methodology and methods used to do this are described in the following chapters.

2.10.2   Developing the design, methods and focus of the study

The content and limitations of previous studies were used to guide the design, methods and focus of this study, leading this study to:

- Focus on the views and experiences of all three arms of the care-giving triad in relation to the involvement of families in care, in particular those of people with dementia
- Include a focus on families with multiple care-givers
- Use multiple data collection methods to provide flexible opportunities for people with dementia to take part
- Collect data longitudinally to explore fluctuations in families' involvement, and the impacts of this involvement, across the course of the hospital admission and at key junctures (such as admission, discharge planning, and discharge)
- Focus on data from two hospital wards in two different care trusts to enable in-depth exploration and comparison of cultural, organisational and environmental factors that influence the engagement of families in care

Chapters 3 and 4 describe the study's methodology, methods and design, and illustrate how these have been shaped by the research questions and by the findings and limitations of previous studies, as described above.

Chapter 3

Research Methodology

3.1   Introduction

Chapters One and Two provided a review of the research and theoretical literature that has guided this study. In particular, theoretical perspectives on dementia care, and the design and content of existing studies on family engagement in general hospital dementia care, have shaped the design, methods and focus of the study and emphasized the importance of exploring triadic relationships between people with dementia, families and staff in hospital settings. As summarised at the end of Chapter 2, this study therefore explores interactions and relationships between people with dementia, their families and hospital staff in order to understand how the use of families' knowledge and expertise impacts upon experiences and outcomes of hospital care for people with dementia.

The purpose of this chapter is to introduce and justify the methodology chosen to undertake this study. The chapter begins by discussing the philosophical approach underpinning the research methodology (Interactionism) before exploring how the chosen methodology (Ethnography), together with the theoretical viewpoints and previous research explored in Chapters 1 and 2, have shaped the research methods used and provided an in-depth account of interactions and relationships between people with dementia, families and hospital staff. Chapter 4 will then explore how these approaches to data collection and analysis were enacted in practice.

3.2   Epistemology and ontology in qualitative research

A qualitative rather than a quantitative approach was necessary to provide the in-depth exploration of triadic actions and interactions required for this study. Qualitative research has developed from a range of philosophical underpinnings which hold a variety of competing views about the nature of reality (ontology) and how knowledge of the social world can be generated (epistemology) (Blaikie, 2007; Mason, 2002). This has resulted in diverse ideas about the extent to which empirical research can tell us anything meaningful about the social world, and how it might do this (Mason, 2002). As different approaches will lead to the use of fundamentally different research questions and methodologies, and may produce different research outcomes (Blaikie, 2007; Henwood, 1996) the approach used must be identified and justified.

3.2.1 Linking epistemology, ontology, methodology and methods

Clear consideration of the philosophical basis of research is essential to ensure a congruent design and relationship between ontology, epistemology, methodology and methods (Carter and Little, 2007; Proctor, 1998). These facets inter-relate and contribute to qualitative research practice via a cyclical process through which epistemology and ontology determine the nature of knowledge and so guide methodological choices which, in turn, shape the methods used to generate and analyse research data and produce knowledge (see Figure 1: Carter & Little, 2007). The following sections therefore explore the epistemological and ontological approach used in this study before considering how these have influenced the methodological approach and so shaped the research methods used. Chapter 4 then considers how the research methods employed in this study have shaped the data that have been produced.

Figure 1: The relationship between epistemology, methodology and method

Figure 1
The Simple Relationship Between Epistemology, Methodology, and Method
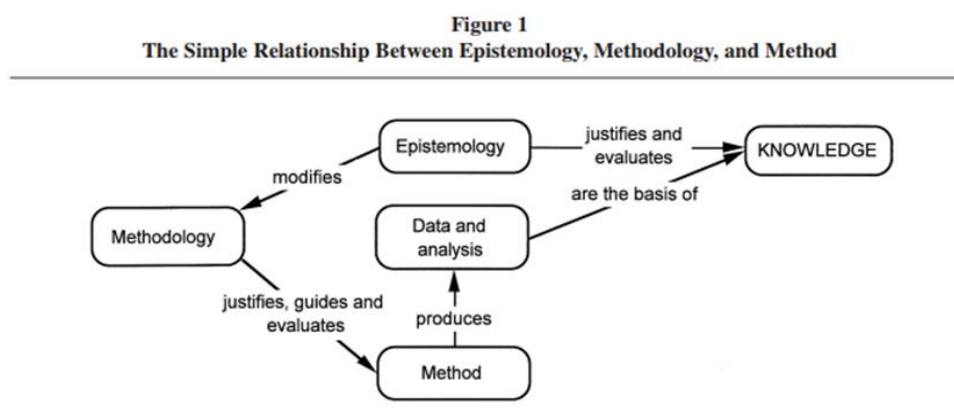
(Carter & Little, 2007, p3)

3.2.2 The Philosophical Approach underpinning this study

There is an extensive literature on the range of approaches to social enquiry and their strengths and weaknesses (Blaikie, 2007). There is not space or significant merit in using this chapter to revisit the range of theoretical approaches available, and so instead I describe and justify below the approaches which have informed this study.

Qualitative research is primarily concerned with experiencing, observing, describing and analysing various facets of social behaviour as they occur in natural, real life contexts (Brewer, 2003, Bowen, 2006). This naturalistic approach to data collection lends itself well to the principles of Interpretivism, a philosophical perspective focused on understanding the social world as it is interpreted, and so constructed and reproduced, by the people within it (Blaikie, 2007). The focus is on how people interpret social situations and behaviour, and in doing so develop meaning and understanding of the social world around them (Blaikie, 2007). Symbolic interactionism, from which ethnography developed, draws on these principles and sees people as active in shaping their world (Herman & Reynolds, 1994) and 'reality' as developing through interaction with others and in response to the meaning

participants ascribe to those interactions and the social world around them. Thus people exist on the basis of social relations and interactions, defining themselves through social roles, expectations and perspectives cast by society and those in society (Mead, 1962) and individual concepts of self are constructed and changed through social interaction with others (Blumer, 1969).

These views accord with the theoretical approaches to dementia discussed in Chapter 1 (Person Centred Care and Relationship Centred Care) which build upon interactionist ideas about social worlds and a person's sense of self being constituted through action, interaction and relationships with others. By prioritising the relational, these theoretical and philosophical approaches all imply that observations, accounts and analysis of relationships between participants can be used as a means of understanding how they make sense of their experiences, connections and the world around them (Peacock, 2015). Taken together, the theoretical and research literature discussed in Chapters 1 and 2 and the interactionist principles behind ethnography clearly direct attention towards understanding interactions and relationships between people with dementia, their families and staff within care-giving triads; perspectives which, as Chapter 2 identified, have received little previous attention in relation to the general hospital care of people with dementia.

3.3   Methodological approach to data collection

The logical symbolic interactionist approach is to undertake research within naturally occurring social contexts, where people are more likely to behave as they usually would, and to focus on exploring interactions, actions and relationships, and the meanings implicit within these behaviours (Nelson, 2009). Focus is placed on facets of the social world such as communication, inter-relationships and community through attempts to enter into the perceptions, attitudes and values of a community or social group (Crotty, 2005). To do so therefore requires methodology and methods capable of accessing and exploring the meanings participants ascribe to

the social setting under study and the actions, interactions and relationships experienced within it. Ethnography as a methodology involving immersion in others' social worlds, and its associated methods of participant observation, conversations, interviews and documentary evidence, is particularly well suited to achieving these aims.

3.3.1 Ethnography

In keeping with an Interactionist approach to enquiry, Ethnography focuses on the social and interactional processes that make up people's daily lives (Emerson et al, 1995). It studies the perceptions, actions and interactions that occur within groups, teams, organisations and communities (Reeves et al, 2008). The focus is on understanding what groups and individuals see as meaningful and important; how they see the world, live their lives and carry out daily activities (Emerson et al, 1995; Hammersley, 1992). To do this, ethnographers attempt to 'get inside' and immerse themselves in social settings over a prolonged period of time (Hammersley, 1992).

Attempts to access and document this 'inside' perspective take place through extensive fieldwork which requires the researcher to be personally immersed in the ongoing social activities of the individuals or group under study (Wolcott, 1995). The primary method through which this is achieved is participant observation, which involves spending extended periods of time participating in, observing, and writing accounts of the everyday lives of the participants. The 'participant' element of these observations means that, alongside observations, ethnographers interact with participants through conversations 'in the field' and formal interviews (Whitehead, 2004), as well as collecting and examining other forms of information such as documents, artefacts and media coverage related to the subject under study (Denzin, 2001).

Collectively ethnographic methods allow researchers to gain rich insights into the culture, perspectives, practices and actions of people in natural social settings as well as the nature (e.g. sights and sounds) of the location they inhabit (Reeves et al, 2008;

Hammersley, 1992). In doing so they generate understandings of culture through representation of the emic perspective; the insider's point of view (Hoey, 2014). However, whilst ethnography talks about gaining access to the 'insider' perspective, what it offers are unique opportunities for up close *insights* to this perspective, it would be naive to think that participating in others social experiences equates to fully understanding those experiences (Wind, 2008). Nonetheless, ethnography facilitates a closer understanding of many emotive and important experiences, such as those of illness and suffering, than other research methods are typically able to offer (Long et al, 2008).

In classical ethnography, immersion in the field meant 24 hours a day, 7 days a week for an extended period of time (a year or more) typically in cultures and settings far removed from the researcher's own. In more modern, 'local' ethnographies such extreme immersion may not be possible, for example in hospital settings such as those where this study is situated, but considerable time must still be spent in the setting at different times of the day, week and year. In doing so the researcher not only becomes familiar with the spatial dimensions of the research setting and it's socio-cultural dynamics, but also how those dynamics may change over the course of days, weeks, months or even years (Whitehead, 2005).

3.3.2 The use of Ethnography in Medical Sociology

Ethnography has a long history in Sociology which goes back to British sociologists Sydney and Beatrice Webb's observations of miners in the 1920s and the Chicago School practitioners who located themselves within various social settings to understand how group members lived their lives (Charmaz & Olesen, 1997). Within Medical Sociology, developed in the 1950s and 1960s, ethnographic methods have played a key role in deepening understandings of actions and meanings in illness and disease and given voice to the often muted experiences and perspectives of patients and their families (Long, 2008; Charmaz & Olesen, 1997). One approach to doing so is to focus ethnographies on facets of health and illness such as patient or

family interactions with healthcare professionals and how people live with and conceptualise illness inside medical settings (Long at el, 2008; Charmaz & Olesen, 1997).

The ability of ethnography to represent difficult to access 'insider' perspectives is particularly relevant to people with dementia experiencing significant ill health in unfamiliar hospital settings; a situation where the emic perspective may be especially muted. By providing access to disadvantaged and difficult to reach emic perspectives, ethnography has dispelled myths about people with dementia being socially unaware and incompetent and also thereby illustrated the extent to which these conditions are socially created (Charmaz & Olesen, 1997). An ethnographic approach therefore has close ties with person centred theorising of dementia which emphasizes the perspectives of people with dementia and espouses that dementia is a partially socially constructed condition.

3.3.3 Locations and contexts for ethnographies in Medical Sociology

Within Medical Sociology, ethnographies have taken place in a variety of clinical settings including hospital wards, intensive care units, operating theatres, nursing homes and mortuaries and across various points in life and illness cycles (Long et al, 2008). Hospital ethnographies have provided a rich source of data on both the culture of hospital wards and relationships between patients, families and healthcare staff. For example, previous ethnographic studies have generated new understandings of the social organisation and hierarchical structure of wards, the nature and negotiation of care-giving roles, and the clashes, bargaining, and power struggles that can occur between patients, families and staff (van der Geest & Finkler, 2004; Charmaz & Olesen, 1997). As these and other studies have shown, ethnography is uniquely placed to understand and interrogate the complexity of hospital environments and the myriad of relationships within them (Long et al, 2008). Over the last decade, ethnographic methods have been increasingly used to

explore the experiences of people with dementia in general hospital settings. Several studies identified in Chapters 1 and 2 (e.g. Cowdell 2010; Gladman et al, 2012) have used participant observation, interviews, conversations, and documentary evidence to document experiences of care and care-giving interactions involving people with dementia in general hospital settings.

3.3.4 The suitability of an ethnographic approach for this study

As previous sections have identified, an ethnographic approach was well suited to the aims of this study, enabling an in-depth exploration of actions and interactions between people with dementia, their families and staff in general hospital environments. Ethnographic methods facilitated a rich and nuanced interpretation of the daily lives, experiences, behaviours, routines and perspectives of people with dementia, families and staff, with a focus on how the involvement of families' knowledge and expertise influences these facets of social experience.

The use of an ethnographic approach afforded several additional benefits over other methods. Firstly, the observations produced data that may not have been available through interviews alone; previous studies have found that staff often express verbal support for family involvement but do not necessarily translate this into their clinical practice (Haesler et al., 2007). Secondly, extensive time in the research sites enabled the experiences of people with dementia and their families to be explored longitudinally across the hospital stay. Thirdly, ethnographic methods greatly facilitated the involvement of people with dementia in the study. Eliciting the views of people with dementia was one of the main challenges of the study, particularly as ill health, delirium and the unfamiliar environment compounded communication difficulties, but the extensive fieldwork greatly aided the development of relationships with, and access to the views of, people with dementia. Extended time in the field built trust and familiarity with participants and their communication habits whilst also enabling data collection to be scheduled, or re-scheduled if necessary, to suit fluctuations in participant's health or communication abilities. This

flexibility was beneficial not only for people with dementia, but also for families and staff who could have limited time availability or be called away on other tasks. The variety of data collection methods also enabled data collection to be tailored to the communication abilities and preferences of individual participants (Bond & Corner, 2001), with people with dementia contributing their views in a range of ways including formal interviews, casual conversations, and their words and actions during periods of observation. How the research methods and design enabled people with dementia to take part is explored in more detail in Chapter 4.

3.4   Methodological Approach to Data Analysis

The approach to data analysis used in this study has been guided by Grounded Theory methodology, which is one of many approaches to qualitative data analysis. As Grounded Theory is underpinned by a symbolic interactionist perspective (Annells, 1996) it fits well with an ethnographic methodology and accordingly is often utilised by anthropologists and sociologists (Bowen, 2006).

Ethnography and Grounded Theory approaches to data analysis share the same guiding principles, with Grounded Theory providing the processes through which these principles can be realised (Charmaz, 2012). As ethnography prioritises the emic 'insiders' perspective, it requires an approach to data analysis that emphasises the emergence of categories and meanings from ethnographic encounters rather than imposing these from existing models (Hoey, 2014). Ethnography therefore, like traditional Grounded Theory, espouses an inductive approach to discovery, making inferences, and continuing inquiries in an attempt to achieve emic validity (Whitehead, 2004; Bowen, 2006). This iterative approach is a central component of Grounded Theory, where theoretical ideas develop from data analysis and subsequent data collection, guided by the emergent theoretical concepts. Grounded Theory's symbolic interactionist underpinnings mean that it focuses on developing explanatory theory about patterns of social life (Annells, 1996) and so, as with

ethnography, it is concerned with understanding and explaining patterns of social interaction and relationships.

3.4.1 Grounded Theory

Grounded Theory was developed approximately 50 years ago by two sociologists (Glaser & Strauss, 1967) as an approach for enabling new theory to be developed from data to avoid an over-reliance on ideas derived from existing theories (Willig, 2008). As with many forms of analysis, it initially involves applying codes to lines of data, before identifying and focusing on key codes from which to begin generating analytic categories. Open coding thereby develops into more focused coding on topics of particular interest in order to deepen understanding and begin generating major categories and theoretical concepts (Emerson et al., 1995; Charmaz, 2012; 2006). The main analytic strategies of Grounded Theory, many of which set it apart from other data analysis methods, are coding data from the start of data collection, using comparative methods, writing memos and conducting theoretical sampling to fill out emerging theoretical categories and make them robust (Charmaz, 2012). The constant comparative approach to analysis is particularly emphasized, which involves frequent comparisons across the data to develop, modify and extend theoretical propositions (Emerson et al., 1995) including comparison with negative cases (Willig, 2008). More specific details of the processes involved in Grounded Theory data analysis are provided as part of the descriptions of how the data analysis was undertaken in Chapter 4.

3.4.2   Variations in approaches to Grounded Theory

Grounded Theory has developed from its symbolic interactionist roots (Bryant, 2009; Charmaz, 2003) to be used and interpreted in a variety of ways. Criticisms of Glaser and Strauss' traditional approach to Grounded Theory have led to different versions of the method (Mills et al, 2006) and disagreements between its founders over how

it should be practiced (Willig, 2008), indicating a need for researchers to go further than saying they will use Grounded Theory to explain and justify which form they are subscribing to.

The traditional approach to Grounded Theory (Glaser & Strauss 1967; Glaser 1978) and the 'evolved' approach of Strauss and Corbin (1994; 1998) have been criticised for being overly inductive and ignoring or not sufficiently addressing the influence of the researcher on the data collection and analysis process (Mills et al, 2006). Grounded Theory was originally conceptualised as 'discovering theory from data', implying a positivist approach where data is 'discovered' (Willig, 2008) with Strauss and Corbin's developments retaining post-positivist references to 'recognising bias' and 'maintaining objectivity' (Mills et al, 2006). These approaches have been criticised for preventing existing theory from enhancing the research process and for paying insufficient attention to the role of the researcher and their influence on data collection and analysis. Kathy Charmaz, a key proponent of these criticisms, argues that it is impossible for researchers to avoid imposing categories of meaning onto the data (Charmaz, 2006). She asserts that categories and theories do not just emerge but are constructed by the researcher through their interaction with the data and any preconceptions held in relation to the data, the research topic or participants (Willig, 2008). Hammersley & Atkinson (1995) also take the view that data analysis is rarely a purely inductive approach, as Glaser and Strauss imply, with theoretical ideas, expectations and stereotypes likely to play a role in data analysis and holding the potential to facilitate identification of surprising, interesting and important features.

3.4.3   Selecting an approach to Grounded Theory for this study

To counter these limitations, Charmaz has led the development of a constructivist and so more reflexive approach to Grounded Theory which views knowledge as co-produced and encourages recognition of how this production of knowledge has occurred and recognition of the multiple standpoints of participants as well as the

researcher (Charmaz, 2006); an approach particularly well suited to studying the many and often conflicting viewpoints found within triadic care-giving relationships. Constructivist approaches to Grounded Theory also emphasise the centrality of grounding observations within the contexts that have generated them, providing a detailed and nuanced description of the phenomena (Willig, 2008), an aim shared by the ethnographic methodology employed in this study. In addition, Charmaz's approach to Grounded Theory permits existing theories to influence the research process (Charmaz, 2012) which fits with the use of existing research and theoretical literature in this study to inform the research questions, interview and observation guides, and approaches to data collection and analysis. For these reasons, the approach to data analysis used in this study has been based on Charmaz's Constructivist approach to Grounded Theory. How this method of data analysis was employed in practice is described in Chapter 4. In keeping with the emphasis on reflection proposed by Charmaz and the Interactionist perspective, Sections 4.11-4.14 of the Methods Chapter and Section 8.5 of the Discussion chapter reflect on my influence on the process of data collection and analysis.

3.5   Limitations of the theoretical and methodological approaches used

As with any research study, there were limitations to the theoretical and methodological approaches used in this study, which are discussed below. The limitations of the study methods and implementation are also discussed in Chapter 8.

3.5.1   Limitations of a Symbolic Interactionist approach

Critics of Symbolic Interactionism argue that it can fail to see the 'bigger picture' - the larger, macro issues of society – by overlooking the influence of social forces and institutions on individual interactions. For example, Snow (2001) suggests that

attention can be diverted from topics such as social structure and culture by focusing empirical and analytic attention on meaning and interpretation. Interactionism thereby had the potential to simultaneously illuminate and obscure by directing the researcher's gaze to some aspects of social action over others, although Snow (2001) also suggests that this criticism could in fact be levied at most seminal conceptions of theoretical perspectives.

In the context of this study, the implication of this limitation would be a failure to consider what impact higher institutional forces, such as hospital organisation and policy, have on interactions between families, staff and people with dementia. Care was therefore taken to include attention to organisational influences in the data collection, with these included as a topic of conversation in interviews and in the observations through attendance at some higher level organisational meetings and observation of the contents and impacts of organisational policies and pressures from a higher 'hospital level' on participants behaviour and patterns of family engagement. The choice of research sites also enabled comparisons to be made between different wards and different NHS Trusts in terms of the organisational influences at both a ward and institutional level.

3.5.2   Limitations of an ethnographic approach

Taking an ethnographic approach to data collection and analysis also has potential weaknesses and pitfalls. For example, the naturalistic approach to capturing the social world can lead researchers to try and be everywhere at once and to stay in the setting as long as possible, resulting in large volumes of unfocused data with little time for reflection on its significance (Hammersley & Atkinson, 1995). The way in which Grounded Theory encourages comparison and integrates data collection and analysis from the start can help to counter these problems by encouraging researchers to reflect and focus their data collection from early into the research process (Charmaz & Mitchell, 2001). These processes direct the ethnographic gaze and help the researcher to focus and structure the research process (Charmaz &

Mitchell, 2001). Various strategies were used to focus the ethnographic data collection in this study; regular reference to the observational framework, regular supervision to discuss progress, and using early data analysis to hone the focus of subsequent data collection. However, despite these efforts, the time consuming nature of the data collection was a significant challenge, as was retaining a focus on events and data related to the core aims of the study. It was easy to lose focus and difficult to decide when to leave to write up the fieldnotes, with so many varied and interesting events taking place on the wards. The large volume of interesting data that resulted from the observations, and the inclusion of multiple perspectives and types of data, also complicated and protracted the data analysis process, making determination of the key themes and messages from the data a time consuming and challenging process.

3.5.3   Limitations of a Grounded Theory approach

Some of the criticisms of more traditional approaches to Grounded Theory were discussed in Section 3.4.2. Disagreements remain about the potential conflict between the Grounded Theory principal of being inductive and the use of existing theory to inform research design, methods and analytical processes through avenues such as sampling strategies, observational guides or conceptual frameworks. Some commentators argue that Charmaz's approach of using existing theory to inform such processes turns Grounded Theory from an inductive, data led approach to a rigid, deductive process (Willig, 2008). However, others contest this argument and claim that fear of violating the inductive process has led to researchers ignoring the findings of others and impeding the development of their own work (Morse, 1994), with a deductive element espoused for sensitising researchers to how codes and categories may inter-link and helping to ensure important considerations are not overlooked (Willig, 2008). The integrations between data collection and analysis used in this study illustrate one way in which the inductive element is not lost – the focus of elements such as the sampling strategy, observations, and interviews were significantly shaped from what was seen

in earlier stages of data collection and so developed inductively, alongside valuable deductive influences from existing research and theoretical literature, as is discussed in Chapters 1, 2 and 4.

The integration of data collection and analysis leads to another potential pitfall of the Grounded Theory approach. The interaction between data collection and analysis is not an easy process to achieve and ethnographers often fail to reflect sufficiently on this approach, failing to collect data crucial to checking interpretations or the comparative cases necessary for developing and testing emerging sets of analytic ideas (Hammersley & Atkinson, 1995). Sections of Chapter 4 describe the ways in which I attempted to counter these limitations. For example, I describe how I wrote memos about emerging analytic ideas and used these to refine my interview and observational guides and the sampling strategy, thereby enabling me to further these ideas in subsequent data collection and through comparison across research settings.

3.6   Summary of the methodological approach to the study

In summary, this study is shaped by a symbolic interactionist perspective and utilises an ethnographic approach to data collection underpinned by a grounded theory approach to data analysis. All of these perspectives see interactions and relationships, and the meaning attached to them, as central to understanding the social world. This focus on relationships, along with support for such a focus from the research and theoretical literature reviewed in Chapters 1 and 2, has set triadic interactions and relationships between people with dementia, families and hospital staff as a central focus for the study, through which the influence family knowledge and expertise has on these relationships can be explored. Chapter 4 describes how Ethnographic and Grounded Theory methods were used to answer the research questions.

Chapter 4

Research Methods

4.1 Introduction

Having justified the use of ethnographic and grounded theory approaches to data collection and analysis in Chapter 3, the following chapter focus on how these methods were enacted in practice, using examples from the data collection and analysis to illustrate their use. Alongside these descriptions, details are provided of the procedures use to recruit and seek consent from participants, including the care taken to involve people with dementia in the research process wherever possible. The chapter then discusses the ethical and reflexive considerations that arose from the study, including my influence on the research process and how this affected the data collection and the interpretations presented in this thesis. The chapter concludes by discussing the trustworthiness of the data collection and analysis methods.

4.2 Summary of the ethnographic approach used in this study

In keeping with the typical approach to ethnographic research described in Chapter 3, multiple methods of data collection were employed - participant observations, unstructured conversations, in-depth interviews, and documentary evidence. These multiple methods of data collection took place in two elderly care general hospital wards where a large proportion of patients had dementia or cognitive impairment. To facilitate immersion in the research settings and to explore experiences longitudinally, data collection took place over a period of 7-9 months in each site. Data collection in each site took part in two stages - orientation observations of the

routine patterns of behaviour at a ward level (Stage 1) followed by in-depth case studies of individual patients, families and staff (Stage 2). These methods facilitated an in-depth exploration of actions and interactions between people with dementia, families and staff within the context of general hospital care, with a focus on the use and impact of families' knowledge and expertise within these actions and interactions. How the research methods were used, and so led to production of the data that has informed this thesis, is explored below.

4.3   Sampling

4.3.1 The Research Settings

The research took place on an elderly care rehabilitation ward in one NHS Trust and a general hospital elderly care ward in another NHS Trust. The rehabilitation ward was chosen as patients were admitted directly from all of the local hospital's elderly care wards, thereby providing an opportunity to explore experiences of these wards as well as experiences on the rehabilitation ward itself. Given that the focus of the ward was on rehabilitation, and so on enabling people to return to their previous caregiving and living arrangements where possible, this seemed a setting from which exploration of instances of engagement with families would be possible. The second research site, an elderly care ward in a large general hospital, provided an in-depth insight into the practices and challenges of caring for people with dementia and engaging with their families in the context of a busy general hospital setting. This setting also enabled exploration of how factors such as acute illness and concurrent delirium were likely to impact upon patient experiences and outcomes as well as levels of engagement and knowledge exchange with families.

The choice of two different Trust and ward settings allowed comparisons to be made between family involvement policies and practices in different NHS Trusts, at different stages of the hospital trajectory, settings with different care environments

and routines, staff with varying degrees of expertise in dementia care, and patients with different physical needs, thereby enabling comparisons to be made at group, organisational and cultural levels. There was a high prevalence of people with diagnosed or suspected dementia on both wards (often around a third of patients in Site 1 and half of patients in Site 2 would have a documented or suspected cognitive impairment), but exact prevalence was hard to gauge due to the lack of a formal diagnosis and the presence of delirium induced confusion in many people coupled with inaccuracies in the recording of people's cognitive states in hospital records.

4.3.2 Description of the settings

Site 1

The ward environment:

The elderly care rehabilitation ward was an 18 bedded unit which contained 10 single bedrooms, two four-bedded dormitories, and two communal areas; a large day room and a separate dining room. Rooms were typically light and bright, with communal areas featuring large windows, pictures and brightly patterned curtains. The dining room contained round tables and chairs laid out with place mats, vases of flowers and salt and pepper pots, and the dayroom contained around 20 blue armchairs and several coffee tables arranged to create two seating areas. One seating area in the day room focused around a TV (which was often loudly playing) and the other focused around a fish tank and a flip chart featuring the date and the ward name. Bed spaces were uniformly decorated, each featuring a bed, a chair, and a bedside cabinet. Furnishings and features in the bed spaces were predominantly focused around physical care (including oxygen connections, sanitising hand-wash dispensers, sinks, and posters covering a variety of topics including hand-washing techniques, cleaning services, and correct use of the bins) with limited features of interest for patients.

Entry to the ward, through a set of double doors, was gained by pressing and speaking into a buzzer on the wall. The doors opened directly onto the reception area which featured a large reception desk with a seating area off which the communal areas were situated, with the bedrooms, staff room, therapy room and other clinical areas being up a corridor to the side of the reception area. There were no designated meeting rooms. Various posters stuck to the outside of the doors advertised the 'rules' of the ward, including a zero tolerance policy to abuse and a request for no visits during mealtimes due to the protected mealtime's policy. A poster also advised visitors that an appointment could be made with the matron to discuss their relative's care.

Ward and work routines:

The unit was situated on a separate site away from the general hospital which patients were transferred to the ward from. The unit was predominantly nurse led – managed by a matron (not typically included in the nursing numbers) supported by two ward sisters – and staffed by a mixture of nurses, nursing assistants, a physiotherapist, an occupational therapist, therapy assistants and a ward clerk. The four consultants were not based on the ward but visited for set sessions; typically one ward round & one Multi-Disciplinary Team (MDT) meeting each per week. The therapy staff held community roles alongside their ward work and they typically provided ½ day sessions to the ward, usually in a morning. Visiting times were initially 11-8 but excluded mealtimes (so effectively 11-12, 1.30-4.00 and 5.30-8.00) but were reduced during the study to two two-hour blocks, with the end of a visiting block sometimes indicated by the ringing of a bell to tell visitors it was time to leave. Most visitors came in the afternoon or evenings; some visited in the lounge whereas others took their relatives up to the greater privacy of the bedroom areas. The typical admission length was 10 to 20 days, although this was longer for some participants with dementia, allowing plenty of time for participants to be recruited and to take part in the study.

Site 2

The ward environment:

The general hospital elderly care ward was a 24 bedded unit which was part of a large general hospital with numerous other elderly care wards in close proximity. The ward was laid out along a long central corridor off which flowed three six-bedded dormitories and six single bedrooms as well as numerous clinical or staff-only rooms, toilets and bathrooms. Buzzer-operated double doors marked the entrance to the ward and were adorned with various notices imparting instructions or hospital policies to visitors, including 3 notices about infection control and 2 notices about protected mealtimes. Once inside the ward, the first room off the corridor was the first of the 6 bedded dormitories, with the sluice room and other clinical areas opposite. The very small reception desk was situated in a small space a quarter of the way down the corridor and the only 'communal' space was a very small dayroom situated further down the corridor from the reception desk. This was approximately the size of one of the single bedrooms and contained around six tightly packed chairs, a couple of pictures on the walls, an intermittently-functioning television set, and some books and games. There was a small staff room near the reception desk and a doctor's room at the end of the corridor, past which a bend in the corridor took you round to a few additional clinical rooms and the end of the ward, marked by a pair of (usually) locked doors. The rest of the single bedrooms and shared dormitories flowed off the main corridor at various points along its length.

The ward corridor felt quite cluttered, containing equipment such as portable monitoring devices, the medication trolleys, and hygiene equipment such as hand-wash dispensers and disposable gloves and aprons, with the walls adorned with various posters and pieces of information. The dormitories and bedrooms were decorated with predominantly white walls, pale curtains around the beds, with a bed, chair and bedside cabinet provided for each patient. A whiteboard above the bed indicated each person's bed number and the name of their consultant, and the walls were adorned with various predominantly clinical features such as oxygen tubes, call alarms, hand-washing facilities and information posters for staff. There were no

pictures, TVs or features of interest in any of the dormitories – some side rooms had a portable television set that could be wheeled between rooms.

Ward and work routines:

Alongside the environmental differences, the staff mix and managerial arrangements were different to the first ward. Two consultants were based on the ward and so were present most days, conducting twice weekly ward rounds and weekly MDT meetings, and were supported by two Registrars and a team of junior doctors. Nursing leadership came from a senior sister (who regularly undertook an active role on the ward including some provision of care and engagement with families), supported by a sister and a team of nurses, nursing assistants, a ward clerk and ward-based physiotherapists. In addition, there were various non-ward based staff such as occupational therapists, speech and language therapists and social workers who visited the ward either for set sessions or to visit particular patients under their care. Visiting times were 2-4pm and 6-8pm, although a flexible approach to visiting meant that some visitors spent time on the ward outside of these times. Family visits nearly always took place by bedsides as the dayroom was too small to accommodate more than one family and was rarely used. The typical admission length was similar to the first site although again admission rates were longer for many of the participants in the study. The turnover of patients was higher at Site 2 and there was a greater pressure on beds, with regular phone-calls from bed managers to identify beds that were soon to become available.

4.3.3 Research Participants

The first stage of data collection at each site involved orientation observations – these entailed recording routine patterns of action and interaction at a ward level. Due to their general nature, these observations included many patients, families and staff. The second stage of data collection involved in-depth case studies of dyads of people with dementia and their families who, along with the staff involved in their

care, gave permission for me to observe and interview them about their experiences during the person with dementia's hospital stay. Descriptions of the procedures used to recruit and consent participants are given in Section 4.10.

Six patient and carer dyads were included from each site, resulting in twelve patient-carer dyads overall. This number was deemed small enough to enable the collection of in-depth and detailed data whilst being large enough to include a diverse range of participants whose experiences and perspectives were likely to differ. Where more than one family member was heavily involved in the person with dementia's care, data and consent to collect this were obtained from multiple relatives. A larger number of staff members were observed and interviewed to gain a range of staff experiences in relation to the dyads involved and to explore general views on the involvement of families and their knowledge in care. This led to twenty three staff members consenting to take part in the in-depth interviews.

4.3.4 Descriptive summary of the patient-carer dyads

Attempts to produce a table summarising the characteristics and situations of each dyad proved too identifying, requiring such substantial alteration to make it anonymous that it rendered the information of limited value other than to provide a general sense of the range of people's circumstances. I therefore decided to summarise participants' characteristics and circumstances instead, as detailed below.

The 12 case studies comprised of a mixture of men (n=5) and women (n=7) with various stages of dementia, ranging from those with suspected but unconfirmed earlier stages of dementia to people with diagnosed and/or advanced dementia. They had been admitted to the hospitals for a range of reasons including increased confusion or delirium, infections (e.g. UTIs or chest infections), falls, fractures and a suspected stroke. Participants had been living in a variety of circumstances prior to admission. Apart from one person who was admitted from a care home, all were living at home; roughly half on their own and the rest with one or more family members, usually a spouse or occasionally one or more adult children. Their lengths

of stay in hospital were highly variable, ranging from 13-41 days[1] at Site 1 and 15-78 days at site 2. The median length of stay was 24 days overall and was very similar between sites (23 days at Site 1 and 24 days at Site 2). Seven participants were discharged to a care home (six of these were new admissions), and four returned to their own homes with new or increased support from home care services. Three people sadly died during the latter stages of data collection, one in hospital and two shortly after their discharge to a care home.

Every patient participant had been receiving some level of support from their family prior to admission. This support ranged from 'lighter' activities undertaken on several occasions throughout the week, such as providing meals or food, shopping, cleaning, companionship and managing aspects of the person's life or care, to the daily provision of more intensive hands on assistance including helping the person to get out of or into bed, assistance to mobilise, help with person hygiene, daily companionship and other aspects of daily living. For two-thirds of participants this support was provided by a network of family and occasionally also friends, with support in the remainder of cases primarily provided by one person. Daughters were the most common type of participant (involved in 8 cases), and often took a primary carer role, but in 7 cases husbands (n=2), sons (n=2), granddaughters (n=2), wives (n=1) or friends (n=1) were significant primary or secondary carers (networks of carers leading these numbers to total more than 12). The majority of these family carers were regular visitors to the wards, typically visiting at least a few times a week or daily in many cases (sometimes between network members). Visits were less frequent from family members with their own health or mobility issues, competing roles or those who lived a greater distance away, with these family members more often part of a network of carers as a result. Some people with dementia were, or had recently been, providing reciprocal care to others in their care network.

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[1] Calculations of lengths of stay at Site 1 did not include the portion of the admission spent at the nearby general hospital prior to transfer to Site 1. Depending on their health, people with dementia typically spent between a few days and 1-2 weeks at the general hospital prior to transfer to the rehabilitation ward. At Site 2 lengths of stay included days in the admission ward at the same hospital prior to transfer up to Site 2.

4.3.5 Sampling technique

Theoretical sampling (Charmaz, 2006) was used in Stage 2 to include a diverse range of people with dementia, families and staff with characteristics likely to influence the use of families' knowledge and expertise to inform care. Initial sampling decisions were influenced by the previous literature in Chapters 1 and 2 but theoretical sampling proceeded throughout the study and was also determined by the ideas that emerged. For example, previous literature and the orientation observations highlighted the importance of including staff with varying professional backgrounds (nurses, medics, allied health professionals, healthcare assistants and ward clerks) and differing levels of experience and dementia training to explore how these varying characteristics influenced their use of families' knowledge and expertise. Efforts were made to include patients with suspected as well as diagnosed dementia, patients with a range of physical complaints, family members who rarely visited the hospital, variations in the nature of caregiver/cared for relationship (e.g. spouse, adult child, grandchild, friend etc.) and people from different ethnic and cultural backgrounds. The observations at each site were very useful in contributing to ongoing decisions about which characteristics to sample for to add depth and richness to the data.

4.3.6 Inclusion and Exclusion Criteria

People with dementia and their families

Patients and their families were eligible to take part in Stage 2 if the patient:
- Had a confirmed or suspected diagnosis of dementia
- Was expected to remain an inpatient for at least 7 days (to allow for data collection)
- Had at least one identifiable family member or close friend

Patients and their families were excluded from Stage 2 if the patient:

- Was in need of palliative care

- Was severely medically unwell or unconscious

- Was due to be transferred or discharged imminently from the ward

- Declined to take part in the study on a previous admission

Patients and family members were also excluded if neither were able to give informed consent or could speak English; the latter because, based on the orientation observations, undertaking observations was too difficult if family members and the person primarily communicated in a language other than English.

Ward Staff

All staff working on participating wards were eligible for inclusion in both stages 1 and 2. Staff were excluded if they were working on the ward as a student or on a temporary basis as agency staff.

4.4   Data collection process

Data collection took place from November 2011 - August 2012 at Site 1 and December 2012 – July 2013 at Site 2. As stated earlier, data collection in each site began with a period of 6-8 weeks of orientation observations to familiarise the researcher with the general patterns of ward activity and interaction on the ward. This was followed by a much longer period of 6-7 months of more focused observations, conversations, in-depth interviews and documentary data collection which followed, at each site, six dyads of people with dementia, their families and the multiple staff involved in their care throughout the hospital stay. In total 46 tape-recorded interviews were completed (further details of these are provided in Section 4.8) and 400 hours of observation took place across the two research sites.

In line with the methodological approach described earlier, sampling, data collection and analysis followed an iterative process through which each informed the other, as illustrated in Figure 2 below. In addition to the integration displayed in Figure 2, data collection and analysis from Site 1 fed into the sampling, data collection and analysis at Site 2.

Figure 2: The integration of data collection and analysis at each research site

Stage One:
6-8 weeks — Orientation Observations – ward level

Theoretical Sampling

Stage Two:
6-7 months — Observations, interviews & documentary data collection: 6 case studies of people with dementia & their families

Analysis

Iterative process of final analysis and writing up
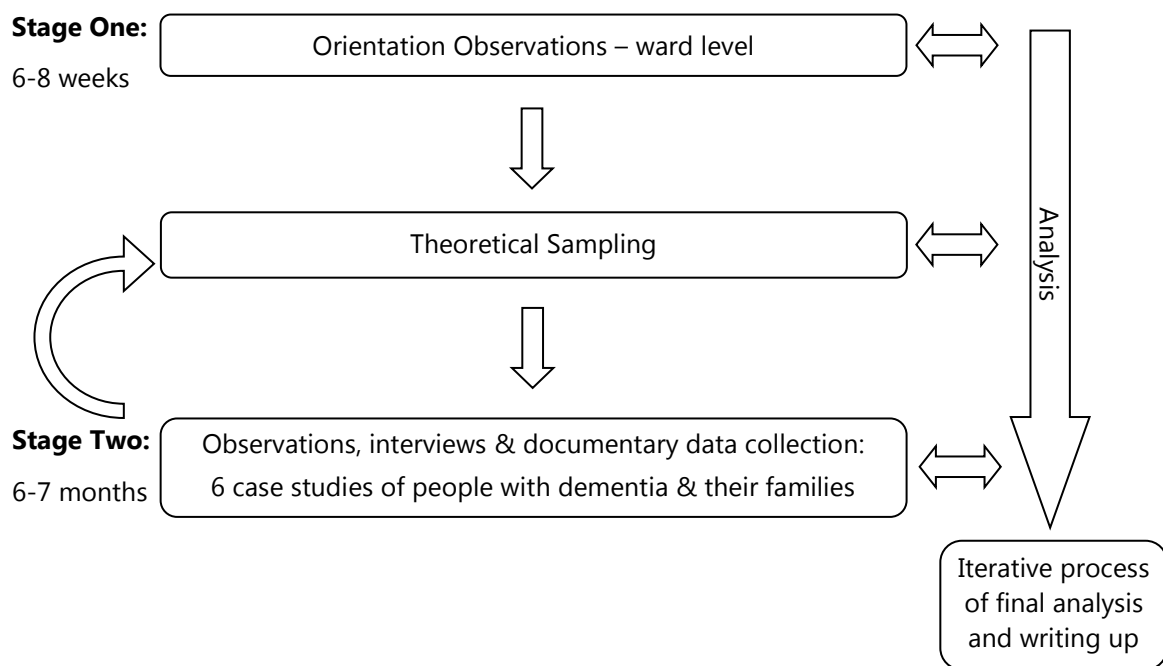
4.4.1 Stage 1 - Orientation observations

Orientation observations were the first stage of data collection used in both sites to develop understanding of the organisational and social context of each ward. The focus of these observations was on describing and understanding general patterns of ward activity and interaction between patients (with and without dementia), families and staff. For example, observations were made of the ward environment, routines, working practices, typical care experiences, and the typical timing, patterns and content of interaction between staff, patients and their families. The observations took place over a period of 6-8 weeks (8 weeks at Site 1 and 6 weeks at Site 2), at various times of the day and on varying days of the week (including evenings and weekends), in order to capture the range of activities and interactions

that took place. Such orientation observations are a common initial step in qualitative observational studies and are routinely used to orientate the researcher, and later the reader, to the context in which the research took place. They also provided a useful introduction into observation, particularly in the first site where additional time was utilised to practice the process of observing, using the observational framework and writing fieldnotes.

The understandings gained from these observations were used to inform and add depth to the second stage of data collection (detailed case studies of patient, carer and staff triads). Data from the orientation observations directed recruitment towards participants who would bring further depth and variability in experiences, identified the most opportune times and locations and forums for observing or discussing family engagement, and enabled the development of trust and rapport with staff which was essential to undertaking the in-depth involvement in ward life required for the data collection in Stage 2. Data from these observations were later used to situate the data analysis within the context of the ward settings, to understand any contextual factors that explained patterns of engagement between staff, families and people with dementia (and variations in these patterns), and to ensure that the recommendations for practice made at the end of this thesis took into account organisational, social or other contextual factors that may prevent or facilitate a change in practice.

4.4.2 Stage 2 - Detailed observations, unstructured conversations and interviews

The data gained from the orientation observations were used to inform longer periods of detailed observations, conversations, and in-depth interviews. This involved detailed case studies that followed triads of people with dementia, their families and staff throughout a hospital admission. Data collection involved extensive observation of participants' experiences and interactions with each other. Conversations took place alongside these observations with all three stakeholder

groups to ask questions about the events that were observed and to seek to understand the meaning of these events for participants. These conversations proved a particularly useful means of eliciting the views of people with dementia who were not able to participate in a more formal interview process.

Alongside the observational data collection, in-depth interviews were conducted with family members and with some staff. Interviews with family members took place on two occasions; early into the admission (typically within a week) to capture experiences of the admission process and early days on the ward, and within 2 weeks of discharge to explore experiences over the course of the hospital admission. One staff interview was conducted at the end of the admission with a staff member who had a high level of involvement in the care of the person with dementia, with additional interviews conducted with other staff to explore more general patterns of engagement with families. Short formal or conversational interviews took place with some people with dementia, depending on their communication and comprehension abilities.

The observations, conversations and interviews were focused on gaining a detailed understanding of the patterns of behaviours, relationships and interactions that took place between people with dementia, their families and staff. The main focus was on understanding those patterns in relation to the involvement of families in care – for example, understanding what actions and interactions families undertook in relation to the care of their relative, routine practices for engaging with families and variation from those, and the impact of varying degrees of family engagement on experiences and outcomes of care. Through the focus of the sampling strategy, data collection and analysis, these factors were explored across variation in contextual features such as the nature of the illness affecting the person with dementia, care-giver characteristics, the nature of the care-giving relationship (spouse, adult-child, grandchild, positive and less positive relationships) and changes in behaviours and needs across the course of the hospital admission. Additional data were collected from documentary evidence contained within hospital policies, ward posters, hospital records, assessments and care plans, within which were details of approaches towards family carers and people with dementia, the actions,

interactions and knowledge that were generated, valued and used within each care-giving triad, and decisions made regarding the current or future care of people with dementia and the rationale for those decisions.

4.5   Observational Framework

Emerson et al's (1995) and Spradley's (1980) guides to the content and structure of fieldnotes, along with the priorities established from the research, theoretical and methodological literature discussed in Chapters 1-3, were used to create an observational framework for the study to help focus the observations and the resulting fieldnotes. The framework was a fluid document which was further developed over the course of the data collection in response to emerging themes and the early data analysis. The framework had two sections; a guide for the orientation observations which focused on generating understandings of routine practices and experiences on the ward, and a guide for the more detailed second stage of observations which focused on exploring the actions and interactions that took place between people with dementia, their families and staff. This included, for example, a focus on understanding the range of ways in which families were involved in care, how their knowledge and expertise was talked about, valued and used, variations in the involvement of families (e.g. between wards, staff members or over time) and its impact upon the care experiences and outcomes of people with dementia. A copy of the observational framework can be found in Appendix 1.

Alongside the observational framework, Spradley's (1980) guide for structuring ethnographic observations was used as an additional general guide as it encouraged focus on areas that I otherwise tended to overlook, such as the emotions associated with particular events. Spradley suggests making notes about a range of facets of the social world being observed in order to gain a rich and contextual picture of the setting, as can be seen in Table 2 in which his guide has been adapted to suit the focus of this study.

Table 2: Spradley's Observational Framework adapted for this study

FACET	EXAMPLES (In the context of this study)
SPACE	Layout of the physical setting; rooms, communal areas, entrance, meeting rooms, sight of others, etc.
ACTORS	The names (pseudonyms) and relevant details of the people involved (background, previous experiences etc.)
ACTIVITIES	The actions and routines of the various actors
OBJECTS	Physical elements: furniture, equipment etc.
ACTS	Specific individual actions between arms of the care-giving triad
EVENTS	Particular occasions e.g. meetings, ward rounds, visiting times
TIME	The sequence of events, developments over the course of admissions
GOALS	What the various actors are attempting to accomplish
FEELINGS	Emotions in particular contexts

Adapted from Spradley (1980)

This summary of Spradley's guide, along with the study specific observational framework, was used to shape the observations to gain an in-depth picture of the ward context as well as the patterns of action and interaction between triadic members on each ward. To aid this process, along with the observational framework, a summary of Spradley's guide was taken to the ward and summarised at the top of the electronic fieldnotes template, with these two guides regularly consulted to prompt breadth and depth in the observations.

4.6 Conducting the observations

Observations at both stages of data collection took place across different times of the day and different days of the week, including some evenings and weekends. At

Site 1 the earliest observation session commenced at 8am and the latest finished at 8pm, and at Site 2 the earliest start and latest finishing times were 9am and 9pm respectively, reflecting slight variations in the working patterns of staff and patterns of activity between the two wards. In total, 400 hours of observation were undertaken; 196 hours at Site 1 across 67 days spread over 9 months, and 210 hours at Site 2 across 71 days spread over 7 months. At both sites observation sessions were typically 2-4 hours long, but ranged from half an hour to 6 hours.

Observations on both wards initially took place mainly in communal areas and in meetings that were routinely attended by staff, such as Multi-Disciplinary Team (MDT) meetings. Over time, and as my relationships with staff, patients and families developed, I gained increasing degrees of access into less public arenas such as consultations with patients and families, provision of care (excluding acts of personal care such as washing and toileting), and meetings about the care of people with dementia. Although intimate acts of care, such as help with washing and dressing, were not observed, I was able to hear some interactions during these activities from behind curtains and included some details of these conversations, if they were relevant to the study, in my fieldnotes. For example, the talk, or lack of talk, that could be heard from behind curtains during the provision of personal care formed an important part of illustrating variability in the degree to which staff used opportunities to effect connections with people with dementia during care provision, as discussed in Section 5.5.1.

Observations were undertaken in a variety of ways and with varying degrees of participation in the events being observed. 'Observing' ranged from sitting in meetings and communal areas such as dormitories and day rooms and reception or corridor areas largely, but not entirely, watching and taking notes as events unfolded, to greater levels of participation and retrospective note-taking in events such as ward rounds, assessments, and conversations with people with dementia, their families and staff. For example, I would often sit in communal areas during visiting hours so that I could observe actions and interactions involving families of people with dementia and I would also spend time talking to the people I was observing to get to know them, to find out what was happening in their hospital

journey, and to ask about their experiences on the ward in the preceding days and weeks. In MDTs and ward rounds I was often treated akin to a medical student – this meant that people's backgrounds were explained to me, I accompanied consultants on some of their rounds around the wards, I met and talked with patients, and I had the opportunity to ask questions. Events were recorded with a mixture of note taking at the time and retrospective note writing. Multiple events were usually observed during a period of observation, with the type and level of my participation in events often changing many times during one observation period, for example in moving from meetings to conversations to participation in assessments to observing communal areas. The flexibility permitted by the use of observations and accompanying conversations was particularly well suited to capturing the experiences of people with dementia and enabled tailoring of data collection to the abilities and preferences of individual participants. Experiences and challenges related to the conduct of the observations are further explored in Sections 4.11 - 4.13.

The focus of the observations and the observational notes were directed by the observational framework and developing analysis, and centred around observing and asking questions about how families' expertise and knowledge were utilised during hospital admissions and discharge planning for people with dementia. To explore this focus, the fieldnotes included descriptions of the environment and how it was utilised and experienced by different stakeholders, patterns of activity on the wards, the actions, interactions and specific words used by participants (to each other and to me), and the way in which these interactions were delivered and responded to.

4.6.1 Writing Fieldnotes

Observational and conversational data were recorded in handwritten field note diaries – these were small notebooks which were carried with me at all times. Notes were usually written as events happened, or immediately afterwards if note taking

was not appropriate at the time (e.g. if it felt likely to curtail further interaction or was impossible due to walking alongside a participant). Relevant extracts from documents such as medical records, visiting policies and posters were also recorded in these fieldnote diaries. All participants were given pseudonyms to anonymise the fieldnotes as much as was possible although by their in-depth nature they could contain potentially identifying information. The location, date and times of each period of observation were always recorded, including the timing of events to give the fieldnotes a sense of time and to maintain a chronological order. In both the handwritten and subsequent electronic versions of the fieldnotes, efforts were made to capture detailed descriptions to enable the reader to understand and become immersed in the events that had been observed. In order to achieve this I tried hard to note and remember features of the interactions observed that would convey the feeling and nature of events to others, such as the way in which things were said - the body language, tone of voice, and facial expressions used - and the reactions given to others' actions and interactions. These descriptions helped to convey a sense of the emotion and meaning in the actions and interactions observed.

The handwritten fieldnotes were typed up and expanded into fuller fieldnotes as soon after the period of observation as possible, usually the same day and often whilst still on the hospital site (via a laptop) to aid recall. Space was allocated in a column directly alongside the typed up fieldnotes to reflect upon my participation in the observations, what had been observed, and emerging thoughts and questions to pursue in subsequent data collection and analysis. Recording these reflections immediately alongside the piece of data they referred to, as recommended by Charmaz, maintained strong links between the data and emerging analytical thoughts. Space was also allocated at the end of the fieldnotes to record any similar reflections in relation to the period of observation or my participation in general. All fieldnotes contained these features and were documented in Microsoft Word files as shown in Figure 3 below.

Figure 3: Example of typed up fieldnotes

Date: 26/1	Time: 8:00-10:40	Location ID:	

Descriptive 'facts':

(Description of: participants, physical setting, sensory impressions, events/activities, quotes/conversations, actions, interactions (others & mine), diff. perspectives, reactions, responses, effects, emotions/feelings, routines, patterns).

10.00 O is making phone calls from behind the desk. She asks for the person by name when they answer and then tells them who she is and that she is calling from the hospital and that there is 'nothing wrong' but that she 'just has a few questions about *patient name*' who is a new lady that was admitted to the ward yesterday. 'Is now a good time, is now alright?' she asks, making sympathetic noises when she hears the response. She says that she'd like to 'ask a few questions about home, so that me and the physio have a bit more idea about normal functioning' She asks about the lady's housing, double checking that she lives in a ground floor flat, and asks about rails, steps, the warden, careline and homecare. She also asks 'Are you her main carer?' and 'What do you do for her?' and tells her that they are 'trying to get her used to the stick and work on her balance' and asks how she normally mobilises.

10.05 P (A lady with dementia) is still in the dining room sat by herself (she has been there since at least 9.15am when I first came to sit behind the desk, and probably before then as she was no longer eating or drinking by the time I arrived). She is sat doing nothing. The phone conversation with O continues. 'Do you know why she sleeps on the sofa?' asks O. She says that she can transfer ok here so it's not the transfer, and suggests that maybe it's fear. She asks 'What kind of chair' the lady has. They talk a bit more, and there is a brief discussion about confusion which I don't manage to capture. She asks about equipment at home, e.g. for the toilet and 'What about getting washed and dressed? Does she do that herself apart from you helping with the bath?' which, after the reply, is followed by 'What about meals and things? Does she normally do her own meals?' then 'Where does she eat?' asking if she has a table and chairs. Then O says 'I think that's everything I wanted to check, what she normally does at home and what we need to do to get her back home'. She then listens for a while to what the person on the other end of the phone says before asking 'Do you think you'll want some support?' adding 'It's something we can discuss with yourself and with *patient name*. We can refer to social services, give you a bit of a break'. Confusion, mobility and balance then gets mentioned but I can't hear properly because other people are talking near by. O then says 'We'll keep you informed of the discharge date' and the conversation finished soon after.

10.20 D starts going round to ask people what they want for lunch. She asks P (the lady with dementia) first and then leaves her to ask others in the day room. P remains sat alone in the dining room. She sits doing nothing, then picks up a cup, looks at it, and puts it back down again. She sighs, as if she is fed up and grimaces as if she might be in pain. She rests her head to the side a lot, and shifts around in her chair several times as if she is trying to get more comfortable. She then starts lifting her bottom up off the chair just enough to take the weight off it by pushing up from the chair arms, as if she is trying to relieve pain in her bottom.

10.25 P looks around and over towards the desk and where I am sitting. She looks for a little while but no one looks up or comes to her. There is only O behind the desk and she has her head down writing up notes. The lady looks away again after a while. Soon after N and R meet by the desk and chat about where they are at with getting patients up and dressed. N says that there are 'two double ups to do' One is a 95 year old man who is 'not really eating. I've not really looked after him, have you?' N asks. 'No' says R.

10.35 N says, partly to herself 'Does P take two to move? And then repeats this again, followed by again to herself 'I don't know these people'. She comes with a wheelchair and goes to P saying 'right' and 'go sit in the dayroom for a while'. I presume P says that she wants to go somewhere else, perhaps to her room as that is where she wanted to go yesterday. N says in response that she should go in the dayroom first 'for a little while, in case the therapists want to see you'. She transfers into the wheelchair and is wheeled into the dayroom.

Responses to the descriptive 'facts':

(Thoughts, feelings, assumptions, attitudes, ideas, reflections, participant's interactions with me, methods used).

The information O collects over the phone sounds very functional and focused on AoDL and equipment. I wonder if this is because of her profession or if most information collected from family is typically of this nature. Is information ever collected about the patient as a person (Carer 1 complained it wasn't) – e.g life history, likes/dislikes, behaviour, etc. Perhaps this kind of information is collected more from people who are unable to provide it themselves? This doesn't appear to be the case with this lady though, from what I have seen & heard of her so far.

Support needs of the carer talked about, after O listens to the carer for a while, so presumably in response to what the carer says, perhaps she sounds as if she is struggling? O says support will be discussed with family and the person with dementia, giving the impression that the families' needs will not override the person's preferences. Is that always the case?

P spends a long time alone, with almost no interaction or activity – at least 1 hour 20 mins left in a room by herself.

Reflective summary:

(Overall impressions of the observation, new questions/ideas provoked, how does above supplement my knowledge, emerging patterns/themes, future points for clarification, anyone's voice missing, reflections on my involvement?)

The above example shows how questions such as the types of knowledge valued and sought from family caregivers began to emerge from early examination of the data and were highlighted as requiring further exploration in subsequent data collection. These notes also demonstrate how several different events might be observed concurrently; a phone call and the experiences of a nearby lady with dementia in this instance. Furthermore, they also identify why recording not just

interactions involving families but also the wider ward context was important; failure to do this would have missed this example of how long people with dementia could spend unoccupied and without interaction and also of how busy the ward staff were with the routine work of the ward, which went some way to explaining the lack of connections made with people with dementia at times. This early identification of important aspects of ward life via analytic memos enabled these to be explored with increasing depth in subsequent observations and interviews. This illustrates how, despite previous literature helping to shape the focus of the research, data collection and analysis remained inductively developed from the data in line with grounded theory and ethnographic approaches.

Analytic reflections such as these were subsequently summarised and expanded upon in memos as part of the data analysis process, as described in Section 4.9.5. Reflections on my participation in ward life and influence on data collection were summarised and expanded upon in a word processed reflexive diary. Further details of this diary, and the reflections documented within it, are provided in Sections 4.11-4.14.

4.7   Interview Topic Guides

Separate interview topic guides were developed for people with dementia, staff and families. Examples of the topic guides can be found in Appendix 2. The topic guides were developed based on the research questions and the existing research and theoretical literature described in Chapters 1 and 2, and refined following the orientation observations (fieldnotes from the orientation observations were read to pick out key themes well suited for further exploration in the interviews) and through listening back to the initial interviews. The interview guides thereby went through many stages of careful development.

As well as exploring key topics, the interview guides were personalised for each triad, with some questioning specific to understanding individual situations and

events that had been observed in relation to that triad, and exploring the meaning behind those events. In order to identify events to explore in greater in detail, I re-read the observational notes for each case prior to the interview so that any events requiring further exploration were fresh in my mind. These processes enabled linking up of interview and observation data and allowed me to deepen and check understandings gained during the observations. To gain deeper insights, specific examples of events, including events I had been unable to observe, were sought from interviewees, for example through questioning such as 'Could you talk me through what happened/an occasion when that happened?' Events that I had not managed to observe were also explored, for example, Carer 1 had a meeting with a social worker that I wasn't able to attend and so I built questions about that into her interview guide. Prompts were also used during the interviews to follow up and elicit further information about the topics raised by participants.

4.7.1 Topic guides for families

Two topic guides were developed for family members; one for the initial interview and one for the post discharge interview. The guides focused on understanding important contextual information such as the background to the person with dementia's admission and memory problems and typical life and relationships within the dyad, before focusing on understanding the story of the hospital admission. Understanding each dyads' hospital story centred around understanding both the general context of the admission and elements specific to the research questions. This included families' experiences on the wards, their involvement with care provision and decision making, the nature of any knowledge exchanges that took place with staff, and the general nature and content of their interactions and relationships with staff. Alongside further exploration of some of these topics, the post-discharge interviews reviewed families experiences of the whole admission and their involvement in it, how they would have liked to have been involved, and their relative's well-being since discharge.

4.7.2 Topic guide for staff

The topic guide for staff focused on views and ideals surrounding hospital care for people with dementia, experiences of the involvement of families and their knowledge in care and decision making, and perceived barriers, facilitators and impacts from the involvement of families. The intention was to also explore staff experiences of being involved in the care of the people with dementia who were being followed as case studies, including staff knowledge of the person and their experiences of interactions, knowledge exchange and care provision involving the person's relatives. In reality, staff members recall of specific people with dementia and families and the events surrounding their admission, even those they had been heavily involved with, could be limited, especially if the interviews had to be re-scheduled or occurred much after the person had been discharged due to staff shortages or availability.

As a result of recall problems, even when interviews were conducted sooner, some staff interviews focused more on general experiences of caring for people with dementia and involving and exchanging knowledge with families. However, staff would still often discuss examples of specific cases which brought additional depth to the interviews, even if these examples did not always relate to the case study participants. Staff perspectives on the case studies were often gleaned instead from the many conversations that took place during the observations.

4.7.3 Topic guides for people with dementia

Very flexible topic guides were developed for participants with dementia which focused on understanding their experiences of hospital, their relationships with staff, and their experiences of the visits and roles undertaken by their families during their hospitalisation. Under each of these headings were various simply constructed example questions that asked in different ways about each topic. For example, for experiences of hospital: "What is it like here?" or "How much choice do you have over what happens here?" However, although conversations and interviews with

people with dementia were loosely based around the topic guide, they very much followed the flow of the person's conversation and picked up on cues and words they used to talk about their experiences of hospital and of having their families involved in care and decision making. So, for example, if family members were mentioned the conversation could then be steered towards talking about when family visited, what families did when they visited, and the impact these visits had.

A few participants with dementia were able and happy to participate in a more formal interview format, and so these interviews more closely followed the example topic guide. However, most people with dementia could not participate in such a structured process and so many interviews were much more conversational, as in the example above, and often took place over a series of visits rather than at one point in time. This meant that conversations and interviews could also be timed, where possible, to happen soon or immediately after events of interests (such as visits from families or discharge planning meetings, which had often also been observed) in order to best capture the person's experiences and recall of the event.

4.8   Conducting the interviews

In-depth, tape-recorded interviews were conducted with 38 people; 4 people with dementia, 11 family members and 23 members of staff. In addition, numerous conversations took place during the observations, including tape recorded conversational-style interviews with some people with dementia. As many, but not all, family members were interviewed twice, this lead to a total of 46 tape recorded interviews plus additional recordings of conversation extracts with some participants with dementia.

Ward-based interviews with family members, people with dementia and staff were conducted in private rooms, apart from some conversations with people with dementia which had to take place by their bedside due to poor mobility and the absence of alternative spaces to use. Follow up interviews with families (at which the

person with dementia was sometimes also present) usually took place outside of the hospital in the place of residence the person with dementia had gone to after discharge. This could be their own home or a quiet room within a care home. One family member was interviewed at work and one in a cafe, both at their request. Interviews with family members usually took place in one go, but interviews with staff and people with dementia more often took place in several bouts in order to accommodate interviewee preference, concentration and other demands on their time.

Interview data sheets were completed for each interview which recorded the pseudonym and ID number of the participant and the time, date and location of the interview. All in-depth interviews with families and staff, and some interviews with people with dementia, were audio-recorded and transcribed, as were some of the brief conversational interviews with people with dementia, if they were happy for the conversation to be tape recorded and spoke with sufficient clarity to be understood on tape. Where either of these were not the case, hand written notes were made either during these conversations, or occasionally immediately afterwards, depending on the preferences of the person. Due to the highly involved and time consuming nature of the data collection, the majority of taped recorded interviews were transcribed by University transcribers but were checked by the researcher against the original tape for accuracy. Interviews were pseudonymised at the point of transcription.

4.8.1 Improving the interview technique

I listened to early interview tapes to review and improve my interview technique. I noticed I talked too much and did not allow silences; several times my interjections cut off the interviewee just as they were about to speak. I also didn't listen enough to, and follow up on, cues to probe further. On reflection, these unexplored cues were often related to the emotion and meaning behind hospital admission for families, something it could be difficult to elicit from the observations. In future

interviews I spoke less and attended more closely to such cues and to following them up. The result of these changes was interviews that contained far more of the participant's words than mine, and words that were richer in meaning and emotion due to the use of prompts to follow up on meaningful cues. I also tried to include a focus in interviews on the feel of interactions and relationships between families and staff to avoid making assumptions from my observations about the feelings participants attached to events. I initially struggled with how to build the observations into the interviews, finding it awkward to probe interviewees about events we both knew I had observed; over time I developed comfortable ways of bringing up events I had observed and encouraging interviewees to talk about them in more detail.

4.9   Data analysis process

Electronic versions of all of the data (fieldnotes, interview transcripts, conversations and handwritten notes on details from medical records and policy documents) were entered into, and analysed, using the qualitative data analysis software Atlas.ti (2015, Version 7).

In keeping with the grounded theory approach to data analysis described in Chapter 3, data collection and analysis formed an iterative cycle in which data analysis took place alongside data collection, with the immerging analysis influencing and focusing subsequent data collection and sampling decisions. Data analysis therefore began early in the process of data collection, beginning alongside analysis of the orientation observations before moving on to analysis of the in-depth case study interviews, observations and documentary data. The supervisory team and their expertise were involved at every stage of the data analysis to provide expert input into the generation of the analytic understandings. The strategies used to analyse the data, in line with the processes and principles of grounded theory, are described below.

4.9.1 Integrating data collection and analysis

Initial data coding began early into data collection in order to integrate data collection and analysis. Through this cyclical process data analysis repeatedly guided further data collection with hunches, analytic notes and codes feeding into the data that was subsequently sought and analysed, as described by Hammersley & Atkinson (1995). This integrative approach is central to grounded theory as it is through this process that data collection becomes increasingly focused on answering analytic questions and helps to test and sharpen ideas (Charmaz, 2012). An example of this 'funnelling' approach was the increasing focus in data collection and analysis on the valuing and use of families' knowledge, and how this knowledge interfaced with professional conceptions of people with dementia.

4.9.2 Familiarisation with the data

Interviews and fieldnotes were first read on paper to become familiar with the data and to gain a sense of the key events and topics. Fieldnotes were read in the order they were collected to begin identifying changes over time and reoccurring patterns of action and interaction, as well as potential explanations for these patterns. For example, from early into the data collection and analysis it became apparent that the different levels and types of knowledge held about patients with dementia by different arms of the triad were of central importance and so 'forms of knowledge' became an early focus. Exploration of this topic through consecutive fieldnotes identified different understandings of people with dementia and reoccurring patterns of poor knowledge exchange and the impacts of these patterns on discharge planning. Initial reflections, ideas and comments on key themes such as these were written in the margins of the transcripts and fieldnotes. This process of familiarisation and immersion in the range and diversity of the data lead onto the process of open coding – the identification of themes and analytic ideas.

4.9.3 Open Coding

From the point of open coding onwards, data analysis was conducted electronically, using Atlas.ti, but with reference back to the initial reflections and notes recorded on the paper versions of the fieldnotes and interview transcripts.

Open coding in Grounded Theory, as with many analysis methods, initially involves coding data line by line to capture all ideas and themes and to begin identifying patterns and variations in the data. Segments of data were 'coded' by writing alongside the data phrases or words which identified the analytic ideas drawn from the data. The focus of coding, in-line with the focus of the research, was on identifying themes, patterns, variations, and explanations for patterns and variances in relation to actions and interactions between families, people with dementia and staff. As is typical of a Grounded Theory approach, coding thereby focused on the conditions and constraints each arm of the triad faced in their everyday lives and paid attention to identifying the mundane as well as the exceptional (Mills et al, 2006). To set the context for the research and remain open to all possible analytic directions, initial coding also captured ideas outside the core focus of the research.

To stay close to the data and emphasise the focus on action, as recommended by Charmaz (2012), gerunds (action words) and participants own words were used in codes wherever possible in order stay close to participant's experiences (Mills et al, 2006). For example, one of the early codes developed in relation to the topic of knowledge was "Knowing the person" which was generated from the words used by a family member in an interview to identify a type of knowledge often held and valued by families but less so by staff – personal knowledge of people with dementia. A further example of gerund coding was the central theme of 'effecting connections with people with dementia', a theme which is discussed in Chapter 6.

4.9.4 Focused coding and creating categories

Charmaz (2012) recommends that line by line coding stops once key codes have been identified and that these codes are then taken and examined in other data sources and through the questions asked in interviews, of documents and through observations. This stage therefore involved identifying and focusing on key codes from which to begin generating more analytic categories. Thus open coding developed into more focused coding on topics of particular interest in order to deepen understanding and begin generating major categories and theoretical concepts (Emerson et al., 1995; Charmaz, 2012; 2006). Codes from the open coding which were of particular interest were pursued as part of a more focused analysis. Through more intense, detailed analysis and re-examination, codes from earlier stages were developed, amalgamated and expanded into categories, with categories often subsuming several related codes. For example, further examination of the key codes related to knowledge exchange revealed that discrepant knowledge was a key element across many of these codes and so this was raised to category status.

As Charmaz (2012) suggests, components of these categories were then developed and refined by further sampling, shaping of the questions asked in interviews, of documents and through observations, and increasingly focused analysis that concentrated on developing understanding of aspects of these key categories. An example of this increasingly focused data collection and analysis was a developing focus on what factors influenced the degree to which families' personal knowledge was valued and used by staff. Relationships between categories were also explored, for example to identify links between the various elements of disconnection which are discussed in Chapter 5.

4.9.5 Memo writing

Memo-writing is a crucial component of grounded theory which prompts data analysis from the early stages of data collection (Charmaz, 2006). Theoretical memos were written alongside data collection and data analysis in order to capture and

explore ideas about the data. Initial memos were written about many thoughts, ideas and hunches, becoming more focused over time as analysis and understanding of the data developed and thereby helped to expand analytical thoughts and ideas in relation to specific codes and categories. These memos enabled further development of emerging insights, comparisons, connections and analytic themes and began the process of building a lengthier analytic account of the data, with later memos forming a basis for writing up the data analysis. As recommended by Charmaz (2012), memos were directly linked to codes and categories, and so to the data to which these codes and categories were linked, through a feature in Atlas.ti which enabled this linking and thus helped to keep participants' voices and meaning present in the emerging analysis.

4.9.6 Constant Comparison

The grounded theory process of constant comparison also facilitated the development of categories by comparing and contrasting data from different participants, settings and points in time. A constant comparative approach encouraged searching between and within data, codes and categories for similarities or differences (Willig, 2008). This process was used to further explore patterns and variations within the data (Boeije, 2002) and so to develop and extend the development of categories and build up a more nuanced understanding. For example, from this comparative approach a core category was developed around 'discrepant knowledge' which explored the different ways in which people with dementia were understood and how the different stakeholder groups generated, held, valued and used their version of knowledge about the person with dementia. Constant comparison between different actors and settings enabled this understanding to develop, with a more nuanced understanding gained through exploration of the characteristics, situations, actions and interactions of members of each triadic group who held, valued or used knowledge in ways that were different to others in their group. Comparison between different types of data and between and within the perspectives, behaviours and experiences of each stakeholder group

also developed deeper understanding of patterns and variation in the data. For example, a constant comparative approach was used to compare and contrast the experiences of people with dementia, their families and hospital staff in relation to knowledge exchange and decision making, the results of which are discussed in Chapter 7.

Negative case analysis is another form of comparison which encourages vigilance for exceptions that do not fit, encouraging the generation of more elaborate, deeper theory that captures the complexity of the situation (Willig, 2008). An example of the exploration of negative cases involved comparison between cases and instances where connections with people with dementia were present or absent to different degrees, in order to identify the factors associated with these variances. The outputs of this form of analysis feature throughout Chapters 5 and 6 in, for example, discussion of the circumstances under which connections with people with dementia were effected or prevented.

4.9.7 Generating and writing analytic understandings

In relation to developing theory Charmaz (2006) highlights how different methodological approaches conceptualise 'theory' in different ways, which thereby affects the form of the theoretical offerings produced. In relation to a symbolic interactionist perspective, Charmaz refers to 'interpretative theorising' which gives priority to showing patterns and connections in the data. She suggests that researchers raise the categories that render the data most effectively and carry the most analytic weight to theoretical concepts which carry the analysis forward via their theoretical reach, incisiveness, power and relation to other concepts and categories (Charmaz, 2006). In this study, several categories fitted this definition and so were raised to a more conceptual level and subjected to further analytic refinement, including exploration of the relationships between them; for example, 'Dimensions of disconnection' and 'Creating connections' which form the central focus of Results Chapters 5 and 6 respectively.

The final stage of the analysis was writing a final analytic account of the data and linking that back to existing research and theoretical literature. All of the processes above fed into the writing of the final analytic account, which continued to develop during the writing process. Development of theoretical ideas did not stop therefore at the end of the data analysis process, but continued into the writing up; a process of collating and relating ideas and arguments which further tests and extends the ideas and theories that have emerged from the analysis. Writing is therefore seen as a key strategic element of grounded theory, requiring a writing style that provides both a conceptual analysis of participant's stories and a sense of their presence in the final text (Mills et al, 2006; Charmaz, 2000; 2001). Keeping participants' accounts sufficiently visible for the reader to make connections between analytical findings and the data from which they are drawn is a delicate balancing act (Fossey et al, 2002); multiple revisions of the results chapters were required in order to try and get this balance right.

The accounts of the results presented in Chapters 5 to 7 are the product of the approach to data analysis described above, with multiple and careful attempts at writing and re-writing required to get the content of these chapters right. The final stage of the constant comparative approach, which involved comparison of the final analytic account with relevant theoretical and research literatures, is a process which is undertaken in the discussion in Chapter 8.

4.10 Ethical issues concerning the collection and analysis of data

This section describes the recruitment and consent procedures that were approved by the ethics committee, and the main ethical issues involved in the conduct of the study.

Ethical issues included the potential for intrusion of privacy during observations, the discussion or observation of negative aspects of care, the challenges of maintaining

participant anonymity amongst such in-depth and detailed data collection, and identifying, consenting and including people with dementia in the study, especially those who lacked capacity. Careful consideration was given to addressing these issues, including careful development of appropriate recruitment, consent and data collection processes. Ethical approval for the study was provided by Bradford Research Ethics Committee, Ref: 10/H1302/49. A copy of the approval letter is provided in Appendix 3.

4.10.1   Identifying, recruiting and consenting people with dementia

Identifying, recruiting and collecting data from people with dementia was particularly ethically challenging and so careful consideration and expert input was given to how best to undertake these processes. Whilst it was not anticipated that using observational research methods with people with dementia would be especially problematic given that such methods are commonly used with this group (e.g. Dementia Care Mapping), careful consideration was given to involving people with dementia in the data collection. Previous sections of this chapter have already described how the data collection methods were designed to enable people with dementia to take part wherever possible. As discussed in Section 4.6, the observational methods used had many benefits for participants with dementia, enabling people whose cognitive impairment may otherwise prevent research participation to contribute their views and experiences.

4.10.2   Recruitment and Consent Procedures

4.10.2.1   Consent – Stage 1: Orientation observations

Due to the general nature of the orientation observations (focused on collecting data about routine patterns of ward life rather than specific data about individuals),

and in line with similar studies (e.g. Cowdell, 2008; Allen, 2000) and the ethical approval granted, permission for the orientation observations was sought at a ward level from the ward manager rather than via individual written consent. However, patients, visitors and staff were made aware of the observations through discussions with the researcher (through visits to the ward and attendance at staff and handover meetings) as well as through the display of REC approved posters and staff information sheets (given to all staff) which explained the study. All participants were made aware that they could opt out of the observations if they preferred, with information of how to do so provided on the information leaflet for staff and made clear in discussions with participants. Copies of the poster and information sheet are provided in Appendix 4. Verbal consent for the observations was always sought from patients, families and staff.

4.10.2.2   Recruitment and Consent – Stage 2: Detailed observations, conversations and interviews

Recruitment Procedures

In Stage 2, people with dementia and their families were approached for consent to take part in in-depth observational and interview case studies, and staff were approached for consent to take part in the interviews. A key ethical issue was the recruitment and consent of hospitalised people with dementia who could be acutely unwell or have fluctuating or insufficient capacity to consent. Careful consideration was therefore given to developing recruitment and consent procedures that met the many potential needs of patient participants. The processes through which participants were identified, approached and gave consent to take part are described below.

4.10.2.3 Identifying participants

Identification of potential participants with dementia was not limited to those with a documented diagnosis of dementia because this would have excluded many potential participants. Only around 50% of general hospital patients with dementia have a documented diagnosis at the time of admission (Sampson et al, 2009) - including only those with a documented diagnosis would therefore have excluded a large proportion of people with dementia and their families who may have differed in important ways from those with a documented diagnosis. For example, those without a documented diagnosis may have less severe dementia, they and their families may be less likely to have received support or information regarding dementia, and their family carers may be at earlier stages in the care-giving trajectory, all factors which could impact on the person's hospital care needs, experiences and outcomes, as well as their family's knowledge, abilities and preferences for involvement in care. Patients (and their families) that were approached for inclusion in the study therefore included people with a suspected as well as a documented diagnosis of dementia, although all patient participants have been called 'people with dementia' for ease in the writing up of this thesis.

Potential patient participants (and so their families) were identified by nursing staff through consultation of patient records for cue words indicative of dementia (such as "dementia" "confused" "cognitively impaired" or "memory problems") and through their own knowledge of each person's cognitive state. To avoid approaching patients when it was inappropriate, for example due to personal circumstances or particularly poor or terminal health problems, advice was also sought from staff on whom it would be appropriate to approach. Patients or ward staff were asked to identify an appropriate relative or close friend to approach. Of the patient and family dyads identified as eligible, decisions were then made about who to approach in line with the sampling strategy described in Section 4.3.5.

Potential staff participants for the in-depth interviews were identified through my knowledge of which staff had made the most significant contributions to the care of

each person with dementia, and in line with the sampling strategy's aim of including staff with a range of professional backgrounds and expertise.

4.10.2.4   Approaching potential participants

People with dementia and their families identified through the above process were asked by staff if they were happy to speak with a researcher about a research project running on the ward (to do with the care of people who might experience difficulties with their memory, PPI consultation having identified memory problems as a preferred term to dementia). All introductory conversations with people with dementia took place face to face. Some initial conversations with families were by phone but all family participants were met with in person at some point during the recruitment process. I approached staff participants directly.

4.10.2.5   Recruiting participants

Once eligible patients and family members had been identified by ward staff and had agreed to speak to a researcher about the project, I approached them directly to check they were happy to spend some time talking about the research. An initial explanation of the research was then given before showing potential participants the information leaflet and holding a discussion based on the information in the leaflet in a way that was appropriate to the person and their communication abilities. Information was presented as clearly and simply as possible in order to maximise understanding.

Through these initial conversations it was possible to establish not only willingness to take part in the study but also to clarify further, sometimes from family and sometimes from the person themselves, whether those with suspected dementia had longer term memory problems indicative of dementia. This conversational and staff guided approach to identifying people with suspected dementia is similar to that

used by other studies and the simple questioning process that has been used by the Dementia CQUIN to identify people with suspected dementia (NHS England, 2012).

Potential staff interviewees were given an explanation of the interviews followed by an information leaflet and a fuller explanation if they were willing to consider taking part. The participant information leaflets and consent forms for all three groups can be found in Appendix 5. All participants who agreed to take part signed a consent form or, in the case of some people with dementia, had an assent form signed on their behalf. Further details about the processes used to explain the study to people with dementia and to seek their consent are given below.

4.10.2.6   Consent procedures for people with dementia

The consent procedures were carefully planned to take the needs of people with dementia into account and were developed in discussion with PPI advisors (several relatives of people with dementia) and researchers with considerable experience of involving people with dementia in research, including some with experience of conducting observations with people with dementia in hospital settings. The consent procedures and participant information leaflets were based on those used by these researchers, several of whom kindly provided copies of their information leaflets and met with me to discuss the best ways of engaging people with dementia in consent and data collection. The resulting information leaflets and consent processes were reviewed and further improved by the PPI advisors. The consent procedures were also developed to adhere to the Mental Capacity Act (Department of Health, 2005) and its accompanying Code of Practice.

4.10.2.7   Assessing capacity in people with dementia

The consent procedures were carefully planned to enable people with dementia to make, and to continue to make, their own decisions about taking part wherever possible. Capacity to consent to the research was assessed for all potential patient

participants. Careful consideration was given to the best ways to ascertain capacity and seek consent. Assessment of capacity took place during my first conversation with potential participants; as a trained mental health nurse I already had experience of assessing capacity and undertook additional training on capacity assessments specifically for the study with a local Liaison Psychiatry Department. In line with the Mental Capacity Act (Department of Health, 2005), capacity to consent was assessed by ascertaining the ability of the person I was speaking with to understand, retain, and respond in a manner indicating their understanding, to a brief conversation about the project followed by a fuller conversation based on the written participant information leaflet, and to use the information we discussed to make a decision about taking part in the study. These conversations sometimes took place in conjunction with a family member or at other times just between myself and the person with dementia. Capacity was always presumed until it was proven otherwise and so attempts were made to introduce myself and explain the study to every potential participant. Below are some examples of the ways in which people with dementia indicated their level of understanding of the research:

> A person with dementia demonstrating understanding of the study and of being in hospital:
>
> *'I'm doing a study on what it's like to be in hospital' I explain to a potential participant. 'It's terrible!' she replies loudly and matter of factly. I comment something along the lines of that she doesn't like it. 'I needed the toilet for ages but there was no one here' she replies.*

> A person with dementia demonstrating on-going recall of the study:
> *Emmett remembers what I do - I don't have my notebook with me as I have just popped in very briefly and so he asks me about my notebook and pen, demoing scribbling down with his hands as he does so.*

> A person with dementia demonstrating insufficient understanding to consent:
> *I use my two sentence summary of the study to preliminarily assess Sybil's capacity (two simple sentences that summarise what I am doing which I have written down on paper). She seems to retain and understand some of what is on the paper when we talk about it immediately afterwards, but not all of it. I don't feel that she retains or understands enough to make a decision about taking part but she seems happy to talk to me and happy with the bits that she does understand. I decide to try another time to make sure and, if she cannot consent, to speak to her husband to see if he is happy to provide assent.*

These notes illustrate how some participants indicated their understanding of what the research involved and gave their agreement to take part with these understandings in mind. They also illustrate how, if the person lacked capacity to consent, their willingness to take part was still ascertained wherever possible, including any signs indicating acceptance or unhappiness with my presence during initial meetings or at any point during the subsequent data collection. Therefore, attempts were made to ask all potential participants if they would like to take part in the study, with everyone approached (i.e. families and staff as well as patients) given the option to take time to consider their decision and discuss taking part with others. In line with other studies involving people with dementia, assessing capacity and obtaining consent was not a one off procedure but rather an ongoing process through which the wishes of people with dementia were repeatedly sought (Cowdell, 2008, Norman, 2006, Hubbard et al., 2003). I regularly checked whether people with dementia were still happy to be observed or to talk to me and also monitored for any signs of loss of capacity, distress caused by their participation or unwillingness to take part.

4.10.2.8   Assent procedure for participants lacking capacity

Due to the focus of the research on family involvement, only patients with a contactable relative or close friend were included and so there was always a "consultee" available to advise on the inclusion of people who lacked capacity to consent. In such instances, the consultee was approached to discuss the study and given an information leaflets explaining the research and their role as a consultee. If the consultee advised that the person would be willing to take part in the study, and signed a 'consultee declaration form' to this effect, the person with dementia was included, providing they showed no signs of unwillingness to take part (for example becoming distressed, upset or anxious due to my presence or when discussing the study). See Appendix 6 for the consultee information leaflet and declaration form.

4.10.3   Maintaining dignity and privacy and dealing with negative events during observations

The observations were conducted as sensitively as possible. I monitored for signs of distress caused by my presence and responded to distress in individuals who found the hospital experience upsetting. Intimate acts of care, such as help with washing and dressing, were not observed and care was taken to maintain participant's dignity and safety (for example, ceasing observations and seeking help if staff were unaware a participant had been incontinent or was at risk of falling). If any negative examples of care were observed which had the potential to be deemed to be serious or untoward these were discussed either with the PhD supervisors or with senior clinicians on the participating ward, as appropriate. If further action had been necessary, University and NHS procedures for reporting such incidents were available. If a participant (person with dementia, family or staff) became upset or distressed I provided reassurance and checked whether or not they wished to continue with data collection or the study. I carried details of relevant support agencies with me and provided these to several family carers during the study who felt they were in need of further support.

4.10.4   Maintaining participant anonymity

Maintaining the anonymity of research participants in an ethnographic study is hard to achieve, even when personal details have been removed and pseudonyms created. The richness and depth of data collected, whilst an inherent strength of the method, creates unique challenges when trying to anonymise such detailed social accounts (Kaiser, 2009). Given the depth and detail of the data collected in this study, maintaining confidentiality in the reported findings was difficult. Throughout this thesis, efforts have been made to report data and case studies in ways that do not reveal the identity or expressions of individual participants. In order to obscure

participants' identities, all participants have been given pseudonyms, the names and locations of the services involved have been removed and, in common with other ethnographic studies (Gullion, 2016), some identifying descriptions and characteristics of participants have been altered. When more detailed excerpts of data have been presented, some identifying details of these cases have been altered, in ways which do not impact the findings of the data analysis, in a further attempt to protect the anonymity of the research participants. As recommended by Gullion (2016), the characteristics that have been altered have been carefully chosen to mask participants' identities whilst retaining an authentic account of events and any unique characteristics with research relevancy.

4.10.5   Data security and confidentiality

All of the data collected during the study were securely stored, with identifiable data stored separately from the anonymised research data. Participant's personal details were recorded in a password protected file on a University of Leeds server and were only used for the purpose of linking participants to consent forms or contacting participants (for example to arrange interviews). Consent forms and field note diaries were stored in locked filing cabinets in a locked room at the University. The nature of the field note diaries – predominantly speedily written shorthand notes - made them largely unintelligible to anyone other than the researcher.

The only link between personal and research data was via an ID number unique to each individual. Only the researcher had access to these ID numbers and participants' personal data. Names were removed from interviews at the point of transcription.

4.11 Reflections on my impact on the research process

The purpose of reflexivity is to offer the reader a means to understand the researcher's relationship to the participants and the data collected in a study (Emerson et al, 1995). It is widely accepted that the ethnographer's self influences how ethnography is produced (Hammersley & Atkinson, 1983); ethnographic fieldwork is shaped by personal and professional identities and by the researcher's own experience, characteristics, background and perspectives (Moore, 1988). This means the "I" in fieldwork and analysis must be acknowledged; it must be made clear where you stand in relation to the process of your fieldwork and the subject of your study. Any judgments, preconceptions or attitudes held in relation to your subject will affect the process and so the product of your work; how you capture and interpret data and how you represent the lives of others, and so must be examined and included in your account of your fieldwork (Hoey, 2014).

Methods of participating in and finding out about daily lives determine what the ethnographer sees, experiences and learns; what is found out is inherently connected to how it is found out (Emerson et al, 1995). In his landmark ethnography Street Corner Society, Foote-Whyte (1993) identified how his acceptance in the field depended most on the personal relationships he developed; the very concept of immersion into a social setting denies impassivity. Ethnographers will undoubtedly interact with and have an impact on those being studied, and fieldwork will be influenced by the researcher's perspective, meaning they are likely to engage with some activities and relationships over others (Emerson et al, 1995). Symbolic Interactionism similarly sees knowledge as co-produced and 'reality' as developing through interaction with others (Herman & Reynolds, 1994), implying that the data in this study is a product of specific interactions and relationships between myself and the participants. Researchers following an interactionist approach must therefore play close attention to their influence on the process and outcomes of the research by continually reflecting on, and being transparent about, their role in the research process and the nature of their subjectivity to enable readers to make judgments about it (Carter & Little, 2007).

As the findings of the study were contingent on the circumstances of their discovery, these circumstances were recorded alongside the fieldnotes and in a reflexive diary. I regularly recorded details of my actions, thoughts and emotional responses to the situations and participants I encountered, keeping an account of my influence on the data collection and analysis process. This included my conduct of the fieldwork and the roles I undertook, my relationships with the people I observed and spoke to (e.g. how I interacted with and felt about them), who I chose to observe, and my preconceptions, experiences and reactions in relation to the data collection and data analysis. Key reflections from these notes are discussed below, starting with my early experiences in the research sites.

4.12 My relationships and roles in the research settings

4.12.1 Introductory roles and relationships

Developing trust and establishing roles began before I even entered the hospital, from the first careful negotiations required with senior staff who had the power to grant or refuse my access to the ward. Such care is most definitely needed; ethnographers have experienced defensiveness and hesitation from hospital authorities approached for permission to observe in their services (van der Geest & Finkler, 2004) with the close scrutiny of the ethnographic gaze viewed as unwelcome by staff or patients (Inhorn, 2004). In fact, one ward did decline my initial request to take part due largely to some clumsy wording in my introductory email.

Similarly to Foote-Whyte (1993) I found my first task on actually entering each setting was simply to try and find a place and role for myself, to explain what I was doing, and to begin forming relationships with the staff as gatekeepers to the ward and to knowledge about it. I gave a great deal of consideration to where and how to position myself and how to establish roles in each site, beginning with how I introduced myself to staff. I began justifying my interest in the topic to others by

explaining that I used to work as a nurse with people with dementia. However, reflecting on the interactions that followed identified that this introduction positioned me as a potential expert in the subject I was hoping to learn more about and had the potential to inhibit the responses I got from staff and cause confusion over my role. For example, in one instance I was subsequently asked to perform a mental capacity assessment on a patient. Following this event I realised I needed to explain my research role more clearly and often only told people my background if they asked or if it came up in conversation, trying instead to position myself as wanting to learn from those I was talking to.

Whilst not stating my background initially felt uncomfortable, Spradley (1979) has commented that ethnography is not so much about studying people as learning from them, which implies that ethnographers must become comfortable with appearing unknowledgeable of the world about which they are learning (Whitehead, 2004). Subsequent introductory conversations with staff where I did not immediately discuss my nursing background seemed to result in far greater initial disclosures of information, to the point where the volume of information was sometimes difficult to recall as I rarely used my notebook during initial introductions. Despite the aforementioned focus on 'fitting in', I was surprised and remain very grateful at the degree to which I was welcomed onto both wards, allowed to play a part in ward life and for the numerous occasions the busy staff took time to talk to me, answer my questions and show me their work, as well as to the patients and families who accepted my regular presence during their hospital stays.

4.12.2   Roles and relationships as the research developed

Finding a role as a participant observer in hospital settings with participants who require or provide skilled clinical care creates a particular set of problems. The central premise of ethnographic research - immersion and participation in the setting, daily activities and lives of the people under study – becomes difficult given the presence of significant ill health and the risky, complex and skilled nature of the

actions and roles of hospital staff (Wind, 2008). The assumption that it is possible to participate in the lives of the people you are studying and to attempt to become one of 'them' is challenged (Wind, 2008). In addition, the distinctly different roles of patient, staff or visitor require choices to be made about which role(s) you adopt as a participant observer and the version of the world gleaned from the research as a result (van der Geest & Finkler, 2004; Wind, 2008). My positioning in relation to the different groups of actors on the wards therefore required careful consideration. A key challenge was how, or whether it was even possible, to position myself in a way that would provide access to the perceptions and experiences of all three arms of the triad under study. For example, van der Geest and Finkler (2004) suggest that undertaking a role that positions you alongside doctors or nurses will lead to research which may represent the professional's view point over that of patients or visitors. This dilemma raised repeated questions about whether and how I could locate myself alongside and access groups with such differing perspectives and locations without creating distance from, and so threatening the development of trust and relationships with, some of those groups.

My initial focus on fitting in with and befriending staff by locating myself in 'staff' areas (such as behind the nurses station), coupled with wearing an ID badge, firmly positioned me as a member of staff. This was evident when families visiting the ward questioned me about their relative as they presumed I was a member of staff, as is evident from this extract from my reflexive diary:

> *"Today several relatives tried to ask me questions presuming I was a member of staff as I was sat behind the desk in what is clearly 'staff space'. I also noticed some of my behaviours mimic those of staff; today I answered the door on numerous occasions as I was nearest the buzzer and I sat behind the desk reading notes and talking to staff whilst wearing an NHS ID badge. Am I unintentionally positioning myself as a member of staff? I feel that I have to 'fit in' with staff to do this work, but in doing so will I affect the way other participants see me, how they behave towards me and what they tell me? Several times when Carer 1 visited after our interview I was sat behind the desk & it felt awkward speaking to her. It felt awkward that she had been very honest with me about the staff and now here I was sitting behind the desk laughing and joking with the very people she had been talking about. I felt as if I had betrayed her, or that's how she might see it at any rate."*

I quickly realised that expecting patients and families to trust me or speak honestly about their experiences on the wards whilst so firmly positioning myself in the 'staff' corner of the triad was highly problematic and I began testing out alternative locations and ways of positioning myself, for example spending more time in patient areas. Testing out these alternative positions lead me to realise that I would need to repeatedly re-position myself during the research process in order to try and access the perspectives of the different groups I was following. I therefore varied where and how I located myself depending on whose perspective I was trying to follow. For example, by sitting with patients to share their views and experiences, spending visiting times with families or engaging in staff only activities such as working at the desk, being part of the ward round or attending multidisciplinary team meetings.

This fluidity of roles, positions and degrees of participation fits with the continuum of participation referred to by Spradley (1980) and the approach of Wind (2008) who, in recognising the difficulties associated with aligning primarily with one arm of the patient-visitor-staff triad, suggests the concept of 'negotiated interactive observation'; a constant negotiation of when and how observation and interaction takes place. My interpretation of this was to try and interact with, and experience as much as I could of, the different roles and perspectives of people with dementia, families and staff, whilst trying not to overly align myself with one position over the others. Under the circumstances, this seemed the only approach to the ethnographic principle of finding a role with the best opportunities for building trust and rapport with the kaleidoscope of different participants I encountered.

4.12.3   Variability in the participant observer roles undertaken

4.12.3.1 Variation between settings

There was variability between the wards in whom I became more closely aligned to resulting from differences in the culture, social hierarchy, routines, and layout of each ward. The orientation observations provided an ideal opportunity to test and

reflect upon where best to position myself to achieve the most insight into ward life and the experiences of its members. For example, in the nurse-led facility middle and junior level staff (sisters, nurses, therapy staff and nursing assistants) led and undertook much of the care and contact with families and so I primarily aligned myself with these staff as the gatekeepers to accessing this activity. At the other site, family engagement work was primarily shared between medical, therapy and qualified nursing staff, with the approach led by the senior staff from those groups, and so I aligned myself more closely to those staff, in particular the senior staff, in order to access and understand their approach to family engagement. These choices had implications for the data collection; for example, I had less relationships with and understanding of the experiences of the medics at the first site and nursing staff and nursing assistants at the second site, and saw less of their interactions with families.

Differences in ward layouts also affected my relationships and observations of participants - people with dementia and their families in particular. At the first site patients and relatives could spend time in the communal lounge or in the mostly single bedrooms and so I could less easily observe and develop relationships with participants who chose to spend most of their time away from communal spaces. At the second site there were less single rooms and so most activity unfolded in the 6 bedded dormitories or the corridors where it was easier to spend time with and observe people with dementia and their families, but less easy to build relationships with some staff due to limited communal and desk space.

4.12.3.2 Variation in roles

I have already alluded to taking up different roles at different times. In relation to the care-giving triad, Wind (2008) suggests that hospital ethnographers take on a fourth position of 'researcher' but I found that my role was more nuanced and varied that that single role heading implies. Whilst I definitely was 'a researcher', my extensive time in the field and close contact with many of the participants meant that I also took on, or was given, other roles. 'Researcher' is such an apparently un-functional

role, especially within highly practical hospital settings, that it felt impossible to maintain only that role whilst interacting with participants over such an extended period of time. As a result, I took on or was assigned a variety of roles during my time on the wards, the most common of these being 'expert', 'friend/advocate' and 'ward assistant'. These roles were interesting to examine in their own right and also because they could conflict with my researcher role. Examples of these roles are given below, before considering the impact they had on the research process and the knowledge they enabled me to gain.

4.12.3.3 Expert role

I have already referred to some examples of when I was seen to have particular expertise by staff on the ward. The influence of my position as a potential expert returned throughout the fieldwork, particularly in the first setting where I had initially been explicit about my mental health nursing background, and with participants at both sites who got to know me and my background better. At times throughout the fieldwork I was drawn into activities and requests for my opinion that I would have preferred not to have given or which had the potential to further elevate my 'expert' status. For example, I was asked to help undertake an environmental dementia audit which involved leading a team of lay assessors around the ward and I was specifically asked to attend an adult protection meeting for one participant; this request due primarily to my level of knowledge of the participant and her family which I was told was greater than that of the ward staff. Families who knew or felt I had some understanding of dementia would also ask me for information about dementia and it's progression, having sometimes been given little or no information about this previously or being unable to recall what they had been told. This had impacts on data collection, for example turning conversations from me learning from participants to participants learning from me. To deal with this I usually responded with the information requested but tried to retain a focus on discovering what the participant knew of the topic and returning to a role of 'learning about' as soon as was possible.

4.12.3.4 Friend/advocate role

The level of involvement and relationships I had with participants clearly shaped the knowledge I gained. This was often most apparent in the 'friend/advocate' roles I was drawn into with some people with dementia or family members. For example, the close relationships established with some participants with dementia meant that they sometimes drew me into the heart of events I had intended to observe, for example asking me to explain things they did not understand or seeking me out for comfort or interaction during assessments or meetings. An excerpt from my reflexive diary reveals the dilemmas these situations could cause:

> "*I have become particularly close to Ailsa because understanding her complex case and communicating due to her deafness takes more time. After the meetings I have attended and conversations I have had with her and her family, I have become one of the people who knows her and her complex situation best on the ward. There is no hiding this from the staff as they know I have sat in on meetings they have not been able to and Ailsa openly recognises me and knows my name. In addition, she can sometimes understand me but not the staff, meaning I occasionally end up translating between them. Another difficulty is that sometimes she seeks me out for reassurance, specifically using my name and looking to me when she feels uncomfortable or upset, and so I become involved in the situation, thereby helping to more actively shape it and less able to 'observe' it. In these circumstances there is a play off between wanting to observe and the stronger pull of not wanting to ignore her distress or requests for help, meaning I comfort her, answer her questions and try to explain what is happening. From then on I am involved in the situation and, once involved, cannot easily withdraw back towards observer.*"

4.12.3.5 Ward Assistant role

I have already referred to one example of actions which positioned me as a 'ward assistant' – answering the door buzzer. There were many ward tasks which I sometimes undertook or were asked to assist with. These included getting drinks for people, very occasionally feeding patients, aiding people at risk of falls who were walking very unsteadily when no staff were around, getting staff attention for

patients when they asked me to, and answering basic questions from patients and visitors to the ward. I was also asked to undertake some specific tasks that staff did not have time for, such as an environmental audit (referred to in Section 4.12.3.3) and friends and family questionnaires the wards were required to ask families to complete.

4.12.4   Reflecting on the impact of the roles undertaken

Dilemmas over the roles and levels of involvement I should have were on-going. The roles I undertook clearly conflicted with my researcher role at times. For example, unhelpfully positioning me as akin to a staff member (as discussed earlier) or meaning there were occasions where I did not see what would have happened if I hadn't interjected, for example by preventing a participant from falling or by getting them a drink. Initially, primarily from a research perspective, I felt uncomfortable about some of my interjections and how they conflicted with my research role, but, on discussing this dilemma with ethnographer colleagues and realising the opportunities for deeper involvement and understanding these interjections also offered, I became more comfortable with my involvement. I also read around this area and discovered that other participatory researchers with clinical backgrounds have undertaken similar levels of participation in research settings (for example, Brown-Wilson, 2007; Cowdell, 2008). I also felt strongly that I could not knowingly ignore someone at risk of falling or making a direct appeal for help, and felt that responding humanely was the only option my conscience would allow.

Whilst dilemmas over my involvement proved challenging at times, the ways in which I was involved on the wards also provided valuable insights into the research topic. For example, my invitation to attend the adult protection meeting revealed how staff could have limited knowledge of people with dementia and their families, and being sought out by distressed people with dementia over staff revealed the lack of relationships between some people with dementia and staff and the potentially distressing nature of ward life. Being involved to a greater degree than I

had originally envisaged was also beneficial in providing deeper access to ward life and to events I may not otherwise have seen. Being sought out repeatedly in such situations gave me a keen insight into how bewildered and alone people with dementia could feel amongst the routines and practices of the wards and how much difference the presence of a familiar face could make, even if it was the face of a researcher they had recently met rather than a much closer family member. My involvement in these events also illustrated that, with time, repeated contact and knowledge of the person from family, it is possible to build trusting relationships with acutely unwell people with dementia in hospital settings.

A further unintended benefit was that some of my roles aided my integration and acceptance by participants as well as giving me opportunities to access other parts of the ward or adjacent spaces. For example, I sometimes filled water jugs at people's requests – as the nearest source of drinking water at one site was an adjacent ward this gave me some exposure to practices on an additional ward with a stricter approach to family involvement. If I filled a water jug just before 2 o'clock I would pass the queue of family members waiting outside for 2pm to arrive so they would be allowed onto the ward, a level of strictness I never witnessed on either of the wards I was involved with.

4.12.5   Negotiating multiple roles

The adoption of multiple roles was a very fluid process, I could move repeatedly between roles during a period of observation or even within an individual interaction. A consequence of taking these multiple positions and becoming increasingly involved in ward life was having to make choices about what and who to observe and what to miss. This would have been the case anyway in a setting with so much concurrent activity, but was heightened by trying to follow multiple participants at the same time and taking on multiple and increasingly involved roles. There were times where two or more events of interest coincided and it was not always easy to choose what was most pertinent to observe, and my lack of

confidence and preoccupation with being accepted by staff meant I did not observe what I wanted to. For example, on one occasion a member of therapy staff offered for the third time to let me observe a therapy session (I had declined the previous offers due to observing a concurrent event). Again the timing was not good, I was observing a relative's visit at the time, but I broke this off to attend the therapy session as I felt repeated declining on my part may discourage her or other staff from offering to include me in the future.

It was of course always going to be the case that I was not able to observe everything – the fieldwork required daily time away from the ward to write up the fieldnotes and I undertook the data collection on a part-time basis (luckily my day away from both wards was a day of reduced activity; a cleaning day when visitors were not permitted on one ward and a meeting free day on both wards). Here the multiple methods of data collection proved invaluable as I was able to use hospital records, conversations and interviews with those attending events I was unable to, to establish what I had missed. As I was given unrestricted access to the wards I was also often able to time my data collection to coincide with key events. These methods enabled me to understand the series of events, interactions and discussions that characterised each person's hospital stay, despite not being present for every event.

4.13 The influence of my perspectives, prior experiences and preconceptions

Alongside the records kept of my positioning and conduct of the fieldwork, I also wrote reflexive notes examining my attitudes, preconceptions and judgments in relation to the research topic and participants. I expected to find that, having been a nurse myself, I might be overly sympathetic in my opinions and portrayal of the nursing staff but quickly realised that in fact the opposite was the case. My background, training, priorities and skills as a mental health nurse were quite different to many of the medically orientated staff on the wards and I found I had a

tendency to view the very clinically focused wards and staff in negative terms. On reflection, I realised that the experiences of people with dementia being admitted to general hospital from my previous nursing role were also predominantly negative. Conversely, if I found a staff member that seemed to share my views and approach to caring for people with dementia and their families then I tended to protect them in my fieldnotes, as this extract from my reflexive diary indicates:

> *"I am aware when I am writing these notes up of an urge to represent Staff 10 in a positive light. She is my favourite and most admired nurse; I wonder if the fact that I found nursing difficult creates an extra tendency to appreciate those that do it, in particular those that do it well or how I would like to have done it. I also wonder if Staff 10 is a bit like me - eager to please - she often goes the extra mile, ends up staying late and does more than she needs to. This admiration for Staff 10 makes me want to defend her, both in my notes and in my actions on the ward. I wonder if part of the reason I say more in the meeting I go to with her than I otherwise would is to help her as I know she feels she doesn't know the situation [of the patient] as well as she might."*

I also quickly noted strong tendencies to protect and defend people with dementia in both my actions during observations and also my writings about them. I perceived, both prior to and during data collection, their situation in hospital as incredibly vulnerable and I cannot think of an example where I viewed or portrayed a person with dementia in a negative light. This view stemmed largely from my former nursing role in a team which placed person centred care and so the individual with dementia at the heart of the care provided. This instinct to protect can be seen in the way I frequently put aside my data collection in order to ensure people's comfort and safety.

My attitude towards families was more mixed, shaped again largely by my prior experiences of working with families of people with dementia during which I had encountered mixed experiences of the quality of families' input and actions. I found that I tended to evaluate families, and also sometimes members of staff, quite dichotomously, often on the alert for whether I should categorise family members or staff as 'good or bad' and whether or not they were acting in the best interests of

the person with dementia. This was stimulated by encountering instances where families had clearly not acted in the person's best interests:

> *"I nearly cry today whilst talking to a nurse about a lady who has been neglected*
> *by her family."*

The nurse and I later reflected, on finding out more about the family's situation, how the ward, and both of us, had automatically marked the family down as 'bad'. Previous hospital ethnographies have unintentionally demonised staff as a result of advocating so strongly for often muted patients and families (Long et al, 2008); dichotomising in this way discouraged exploration of the nuanced behaviour of both staff and families, and explanations for these behaviours, and was something I was keen to avoid. As recognised in Chapter 1, criticisms of staff and the hospital care provided to people with dementia is a common theme in previous studies of general hospital dementia care without sufficient consideration of the degrees of variation in practice and positive examples of care, or the reasons for variability in care practices. Once I recognised my tendency to dichotomise I attempted to counter against it by looking for variation and nuance in my data collection and analysis and, if making negative judgments, stopped and checked whether these were grounded in the data collected. My supervisors also watched for overly simplistic or negative interpretations and alerted me to occasions where this may have been the case. For example, the first draft of one of my results chapters gave a very negative perception of staff without sufficiently considering the many constraints placed upon their behaviour at cultural and organisational levels or the way in which some staff overcame these constraints and so I was encouraged to revisit this section and the supporting data.

Prior to undertaking this PhD, I had limited qualitative experience and had never undertaken ethnographic data collection which added to my initial nervousness in undertaking an unclear and potentially controversial role in unfamiliar hospital settings with unfamiliar people. My natural tendency to worry about what others think and to avoid conflict led to very careful negotiations into the field. My initial lack of confidence and fear of not being accepted stopped me from asking

questions and observing events which I perceived as more sensitive intrusive or intrusive to observe. I was so focused on fitting into the ward that asking about these more awkward events, in interviews or conversations, felt difficult and meant I initially missed out on some potentially rich information. For example, after hearing a difficult telephone conversation between a nurse and Case 1's daughter, of which I obviously only got a partial impression, I barely asked the nurse about it afterwards, even though I had the opportunity, due to the potential awkwardness of probing about a negative interaction with a family. Over time however, I became more comfortable with the setting, participants and my role, increasingly venturing into situations and conversations that I initially avoided.

I also felt unconfident in asking participants about feelings and found it difficult at times to recognise and describe emotions in participants' behaviours. I wanted to be careful to avoid falsely attributing emotions and so tried not to put a feeling to an event unless I was fairly sure I had interpreted emotion in a similar vein to how the participant had felt it. However, not including content about the emotions attached to people's experiences would have reduced the richness of my observations and interview data. From reading literature around the writing of fieldnotes, I soon realised the key to conveying emotions was to provide vivid descriptions of the ways in which things were said, the body language used, the tone, speed and nature of the voice, and the reactions to it, to convey rather than interpret the emotion attached to an event.

4.14 Reflexive Summary

This reflexive section, and the preceding descriptions of the research methods, have provided insights into the ways in which data were produced and interpreted in this study, and my influences on the research process. Providing the reader with such insights is one approach to enhancing the credibility of a study (Bourdieu, 2001). Further steps taken to enhance the trustworthiness of the study are considered below in the concluding section of this chapter.

4.15 Maximising the trustworthiness of the study

This study aimed to produce high quality contextual data collected via a range of over-lapping methods that might lead to credible interpretation of actions and interactions at the research sites. According to Guba and Lincoln (1985) the trustworthiness of qualitative research has four components – credibility, transferability, dependability and confirmability – how each of these criteria were attended to in this study is considered below.

4.15.1   Credibility

Credibility refers to the 'truth value' of a research project (Seale, 2012; Silverman, 2006), the demonstration of which entails providing an account of the research that satisfies others that the data have not been invented or misrepresented (Shenton, 2004; Mason, 2002). The accounts presented in this chapter of the data collection and analysis processes and logic, and the data provided in Chapters 5 to 7, aim to provide sufficient detail of the methods used to clearly demonstrate how the claims made by the research were reached and to enable readers to judge the credibility of the data and the interpretations made. In addition, other methods of maximising credibility have been used, including; developing familiarity with the research setting and its culture (Shenton, 2004) and prolonged engagement between investigator and participants (Erlandson et al, 1993) in order to develop trust with, and understanding of, the organisation and its participants. Credibility of the findings and interpretations was enhanced by utilising one of the PhD supervisors and a local ethnographic expert as 'critical friends'. Encounters with these experts were used to discuss, seek advice and gain further insights into the data collection and recruitment methods, ethical challenges, and interpretations of data.

Triangulation of data through a range of data collection methods, types of participants, settings and phases in the fieldwork further enhanced trustworthiness by guarding against the limitations of single data collection methods and enabling individual and site specific viewpoints and experiences to be verified against others.

Whilst diverse pieces of data leading to the same conclusions created confidence in those conclusions, differences between data sources and respondents also created a more complex, nuanced and illuminating account of the phenomenon under study (Hammersley & Atkinson, 1995). Negative case analysis involved re-examination of some events and cases to establish whether the properties of the emergent themes were applicable to all cases and to encourage more nuanced understandings of the data. For example, in some cases, elements of engagement with families differed from the norm and so these cases were further explored to establish explanations for this divergence and so to deepen the analysis.

As data analysis took place alongside data collection, I was also able to seek and so explore discordant cases in later stages of recruitment. For example, I purposefully recruited a family where initial information indicated that the ward's routine engagement practices were likely to be especially problematic, a case which added further depth to my data analysis. Confirmatory similarities and differences between participants, practices and settings are explored in the Results Chapters, and detailed descriptions of the settings, participants and their interactions are used in order to convey a thorough sense of the situations and contexts explored and how these were interpreted to reach the conclusions drawn by the study. The congruence of the findings with past studies is explored in Chapter 8.

4.15.2   Transferability

Transferability refers to the extent to which the findings of one study could apply to other settings or situations. The reader's judgment of transferability is facilitated by the provision of detailed descriptions of aspects of the research such as the context, research settings, sampling and data collection procedures. In addition, the discussions of the guiding theoretical, research and methodological literature presented in Chapters 1 to 3 convey how the research was intellectually situated. Critical examination of my roles and perspectives in Section 4.13 and how this may have influenced the research further situates the research data and analysis within

the context in which it was collected and analysed. Collectively, these detailed descriptions "of all the contextual factors impinging on the inquiry" (Guba in Shenton, 2004, p70) enable readers to judge whether transferability to other situations and contexts is possible.

4.15.3   Dependability

Dependability refers to reporting the study in sufficient detail to enable future researchers to repeat the work, although not necessarily to gain the same results. Credibility, transferability and dependability thereby have close ties, with demonstration of the former going some way to ensuring the latter. The above references to the detailed sections devoted to various aspects of the research design and implementation, and critical reflections on the advantages and limitations of the research process (provided in this Chapter and Chapter 3), enable readers to develop a thorough understanding of the methods and their effectiveness. Dependability was also enhanced by ensuring I had the skills required to undertake the level of in-depth and varied qualitative work required for an ethnographic project. To ensure this, I undertook advanced training in qualitative methodologies, including a two week summer school in interviewing and qualitative data analysis, a week long ethnography school, a two day ethnography masterclass, and a MSc module in qualitative research.

4.15.4   Confirmability

Confirmability in qualitative research refers to the extent to which the researcher admits and addresses his or her own predispositions (Miles & Huberman in Shenton, 2004, p72) and the extent to which research findings are the result of experiences and ideas of informants or due to researcher preconceptions and judgments (Shenton, 2004). The detailed reflexive account provided in this chapter deals with how my preconceptions and perspectives may have influenced the research process.

The methods of triangulation referred to earlier also play a key role in addressing confirmability. In addition, detailed hand-written fieldnotes, including verbatim accounts of participants' words and actions, the checking of interview transcripts after transcription to amend inconsistencies, and discussing and developing the data analysis in conjunction with my supervisors helped to ensure authentic accounts of the words, actions and perspectives of participants were the focus of this thesis.

4.16 Chapter Summary

This chapter has provided a detailed account of the methods used to answer the research questions, including details of how these methods of data collection and analysis were employed, my impact on the research process, and the steps taken to maximise the trustworthiness of the study. The methods chosen and their use have been justified not only in terms of their theoretical and methodological appropriateness, but also due to the opportunities they offered to engage with people with dementia and follow the development of actions and interactions between care-giving triads across the course of hospital admissions. The following results chapters detail the findings that developed from the use of the research methods and processes that have been described in this chapter.

Chapters 5-7: The Results Chapters

Chapters 5, 6 and 7 present the findings of the study. Chapter 5 explores experiences of hospital care for people with dementia, focusing on the degree to which connections were established with the person and their pre-hospital life. Chapter 6 explores variability in the extent to which families' knowledge and expertise was used to create connections with people with dementia. Chapter 7 concludes the results chapters by considering the interface between families' knowledge and the knowledge-exchange and decision making practices on the wards.

Chapter 5

Experiences of hospital care - Moving from disconnection to connection

5.1 Introduction

During the data collection and analysis it became clear that the frequency and quality of connections with people with dementia were vary variable. People with dementia regularly experienced varying degrees of disconnection – from pre-hospital routines and care-giving relationships as well as the unfamiliar environments, staff, routines and activities encountered in hospitals - all of which could be compounded by the effects of dementia, delirium or physical ill health. This chapter begins by exploring how these different elements of disconnection arose before moving on to consider the circumstances under which more positive and meaningful connections were effected. As a result, the chapter begins with predominantly negative examples of care experiences before moving on to consider

more positive examples of care. Chapter 6 then considers how families' contributions of their knowledge and selves as resources formed a crucial element of delivering more person and relationship centred care experiences and connections.

Specific examples in the form of interview and observational quotes are provided throughout the results chapters in order to illustrate and support the analytic points that are being presented.

5.2 Experiences of care

5.2.1 Dimensions of disconnection

Experiences of hospital for people with dementia were often characterised by varying degrees of disconnection from one or more elements of their life prior to admission which could be compounded by further disconnections experienced on the wards. This included disruption to elements of pre-hospital life such as familiar routines, habits, relationships, surroundings and belongings - compounded by unfamiliar hospital environments, staff, clinically focused daily routines and knowledge exchange and decision making forums on the wards. How these various facets of disconnection arose and affected people with dementia is explored below.

5.2.2 Disconnections from pre-hospital life

Disconnections from pre-hospital life primarily involved disruption to the person's usual care-giving relationships, routines, and levels of functioning as well as families' care-giving roles, knowledge and control - as described below.

5.2.2.1 Disconnections from prior care-giving relationships

Care-giving connections between families and people with dementia were often disrupted during hospital admissions. Prior to hospitalisation, many people with dementia had close emotional and relational bonds with family and friends, many of whom had been providing a high level of support to help the person manage the challenges of living with dementia:

> *Interview Site 1, Carer 3: "I've been looking after him for the past 4 years now. Fighting his battles for him and fighting his corner and making sure he's got plenty of everything. A lot of things I do on the sly so that he doesn't realise. Like I'll, if I know he's low on tea bags I will get him them and I'll stock them up and make sure that he has got food in and everything else... ...I haven't really got a lot of say in the matter because I'm the only person that really gives, that really gives a shit to be fair... ...He won't take 'owt from my sister, he won't let her do 'owt whereas I'll do the same thing my sister were going to do and he'll let me! There are even certain things he won't let my mum do that he prefers me to do! It's what he's comfortable with really and its, I'm like his bloody cardigan! I just said to him now, I said, well there's no getting rid of me is there Granddad? He went 'No! Whether I like it or not you're in for it aren't you?' 'Yes! Sorry pal!'"*

> *Interview Site 2, Carer 25: "For five years I looked after my Mum..." Interviewer: "And what sort of things were you doing for her then? It sounds like a lot?" Carer 25: "Everything. Cleaning, cooking, washing, bathing my Mum, everything. Taking her to and from hospital. I mean we didn't have any home help or people, you know, going in."*

The relationships from which these care-giving roles had developed were often close and longstanding (such as spousal, child, grand-child or sibling relationships), and were of great importance to both parties. Families frequently spoke of valuing and trying to retain what they could of their relationships with relatives with dementia, and people with dementia often talked about their significant others longingly and with fondness, displaying a level of animation that was uncharacteristic of many of their other hospital interactions:

Fieldnotes Site 2: A daughter talks about how cruel dementia is, telling me she doesn't want her mum to forget her and not recognise her 'Don't want her not to recognise me'. She looks close to tears for the first time as she says this. Her mum smiles over at her and chatters at her unintelligibly.

Fieldnotes Site 2: Ophelia is frequently concerned about her husband and being with him; it is her main topic of conversation every time we meet. She is concerned when she wakes up that she might have slept through his visit, asking me immediately on wakening if he has visited.

Disruptions to family relationships could be keenly felt by both families and the person with dementia. Even people who were very confused or had limited speech often made references to their families and to missing them, with some people repeatedly searching or calling out for family members. Outside of visiting times some people with dementia would repeatedly seek or shout out for family members, with some people displaying overt signs of distress if they could not be found:

Fieldnotes Site 2: Kitty searches for, and enacts imaginary scenes involving, her daughter Wilma with whom she is very close. She repeatedly calls out 'Where's Wilma?' looking around as she does so as if she is looking for her. Then 'Do you want to sit down? Come on then' gesticulating for imaginary Wilma to sit down and share a cup of tea with her. Soon afterwards she asks out to the room 'Do you know where Wilma's gone?' before getting up on her feet, pushing her table away and walking towards the end of the bed. 'Wilma?' she calls out a couple more times as she starts reaching out and forwards into the air.

Dementia exacerbated these feelings of disconnection, for example when people struggled to recall that their relatives had visited or to recall even basic details about them such as their names:

Fieldnotes Site 1: I get talking to Ailsa, who usually lives with her son and daughter. She says 'my son and my daughter' and then pauses, screwing up her face and then saying their names slowly and falteringly, as if she is struggling to remember them. She cries a few times during our conversation when she talks about missing her daughter (Clara) and her son (Mark), wailing loudly at one point when she talks about how much she misses them. Later, when her daughter visits, she says 'I miss you anyway, I'll tell you that. But I'm forced to do'. Later she cries 'I miss you and Mark' repeating this followed

by 'Are you alright you and Mark?' 'I love you both' she continues and cries 'I do'
through her tears, sobbing 'I'd like to come home'.

Fieldnotes Site 2: When I talk to Emmett he talks about his daughters and how he 'Can't
get a message to them' and he 'Can't get up' – indicating towards his falls sensor which
goes off every time he tried to stand up. He pleads with me 'Can you help?'

These valued relationships with families were already vulnerable, often having undergone stress or substantial change over the course of the person's dementia, particularly in the lead up to hospitalisation, and were further disrupted by the person's admission to hospital. By temporarily disconnecting people with dementia from familiar faces, activities and routines, and from the understandings of each other that came with them, hospital admissions caused disruptions to these highly valued relationships. Although contact with families during visiting hours meant these disconnections could be transient, most people with dementia spent large periods of the day without contact with their significant others, often incomprehensibly so to them, at a time when they were particularly vulnerable to additional confusion and distress. This was particularly the case for people such as Kitty, Emmett and Ailsa, all of whom usually had extensive daily contact with one or more of their family members. Hospital also threatened more permanent disconnections from family members as some patients, both with and without dementia, faced the prospect of being unable to return to the level of connection they had previously held with their loved ones:

Fieldnotes, Site 2: Ophelia is concerned she might be going to a care home, telling me
how she wants to go home to her husband. She tells me how they met when she was
just 16 and he was 22. She says he is the only man she has ever dated and he wants her
to come home too.

5.2.2.2 Disconnection from care-giving roles and control

Families also spoke about the disconnect they felt from their usual care-giving roles and their knowledge and control over their relative's care and well-being. This disconnect could be compounded by problems reliably ascertaining their relative's

well-being in hospital, particularly if lack of recall was an issue for their relative, and the many hours spent apart when the person was in hospital. This was especially the case for families used to a high level of input with their relative:

> *Interview Site 2, Carer 23: "When I rang up every morning to find out how Kitty had been, that must have be a bug bear as well, relatives phoning up every few minutes. But you do if you're a relative, you're worried, and some of them went away to find out what Kitty's night had been, others just said she's been alright she's in bed, and that, she's eaten her breakfast. And that has to do then, until you get there at two o'clock for visiting… …I'm not saying that they concoct it but the number of times when I was told that 'oh yes she's settled', and later in the day on visiting I find that she's been up and about, which isn't settled."*

> *Interview Site 2, Carer 25: It's like anybody that is hurt, anybody that is vulnerable you want to put your arms around them and you want to protect them. You want to take everything away that's hurting 'em and that's the same. Interviewer: Yes. But you couldn't? Carer 25: No I couldn't because it was out of my control."*

Families' usual care-giving roles and control over care-giving could be taken away as 'ownership' of the person's care and well-being was handed over to the hospital, either entirely or for the long periods of the day where families and friends weren't on the wards. Families could have to transition from carer roles to the much less active role of visitor when their access to their relative and their connections with them and their care was restricted. Organisational policies around areas such as infection control, visiting hours and protected mealtimes could place particular restrictions on families' roles. The restrictive effects of these policies could be mediated or enhanced depending on the ethos of the ward and its staff, especially senior staff, towards visitors and visiting times:

> *Interview Site 1, Staff 10: "Some staff'll say 'oh gosh you know, you can't walk with them', which is exactly what they'd be doing if they were at home (laughs) 'We'll do it'. And that's maybe then taken away isn't it."*

> *Fieldnotes Site 2: (Daughter talking to her father) 'No one will come tomorrow. It's cleaning day, so they won't let us in tomorrow'.*

Interview Site 2, Carer 20: "You're a visitor aren't you - you can't even sit and have a cup of tea with them. It's just a cup of tea and a bit of normality into your life… …we feel like a bit more involved in his life (in the care home her dad has now moved to) rather than just being a visitor to him you know".

Interview Site 2, Staff 20: "…I think sometimes they [relatives] feel helpless. They come in and their relative is just sat there. They're undergoing all this medical treatment, the nurses keep them clean and give them their drugs and we get them up and walking, and then they (relatives) come in and they're just sat there for 2 hours well, they feel a bit useless you know".

Several of these quotes demonstrate how families and friends often had limited visitor rights and roles on the wards. These roles restricted their opportunities to maintain anything near to their usual level of connection with the person with dementia and their care, as well as impeding the forming of connections with the staff who had taken on care-giving for their relative.

5.2.2.3 Disconnection from prior routines and levels of functioning

Alongside a lack of familiar people, the lack of recognisable routines meant that daily life on the wards could feel very unfamiliar and impersonal to people with dementia. A culture of routinized care could leave little room for trying to maintain connections to elements of the daily routines, behaviours and levels of functioning that people with dementia had been used to prior to hospital:

Interview Site 2, Carer 20: "Even if they just got dressed every day and did something that were a normal routine, if they just got dressed and, and sat 'em in a room… …that looked like a lounge with a television on and, made 'em just do a little bit of daily things every day rather than just there… there's your bed, there's your chair, there's your bed, there's your chair, never getting out of the pyjamas or anything."

Interview Site 1, Staff 12: "It's like in a morning… …they get everybody up, washed and dressed and in the dining room, and for me why do you do that? And they've all got to be done by ten o clock so they can all have their break. Well, it's getting them in to the mind-set that actually Mrs Smith might want to have a lie in bed for an hour, and as

long as she's safe, she's clean and she's continent and blah blah blah, why can't she stay in bed for an hour… Does she want to have a bath after breakfast or before breakfast or in the afternoon? …but again it's around culture and historically what they've always done… … it's not around individual patients is it?"

Ward routines were primarily designed to deliver the high volume of care required with the limited time and staff available rather than to meet the preferences of individual patients. De-personalised daily routines seemed particularly common amongst people with dementia who (from the orientation observations and staff interviews), more often lacked the ability to influence their care or how they spent their time. These impersonal routines could have important negative impacts; disrupting connections to usual behaviours, routines and levels of functioning, exacerbating confusion, and causing people with dementia to lose, through lack of practice, connections with valued abilities:

Interview Site 1, Staff 7: "…with someone with dementia… …if you take away their functional ability by give, by somebody else just doing it, they're gonna deteriorate quicker."

Interview Site 1, Staff 12: "…if they've a set routine or they go to bed early and we're completely doing what they don't normally do at home it makes it worse, and the fact that they've come here and they might have already been moved a couple of times, we're just confusing them even more…"

Interview Site 1, Staff 1: (Speaking about Mavis) "Everything's out of her normal routine so once she goes home it may be she's going home quite different from how she was…"

Although worsening health could explain losses in function, these quotes indicate that impersonal daily routines and difficulties maintaining connections to usual levels of functioning were also contributory factors. The comments from these staff also indicate that reductions in function were potentially irreversible for people with dementia, leading to a requirement for increased care post-discharge or even, in some examples, care home placement (an example of this is provided in Section 6.7), thereby causing further disconnections from people's previous lives. Examples such as this of escalating disconnection, where one dimension of disconnection leads to further disconnections, can be found throughout this chapter.

Alongside highly pressured ward routines, a lack of attention to information about the usual or preferred routines and habits of people with dementia also contributed to a lack of focus on maintaining connections to usual life:

> *Interview Site 1, Carer 1: "I had explained to them regarding her meals. They kept trying to give her cereal, well she wouldn't eat cereal. Just give her a slice of bread, no butter and jam. And she'd be fine. Make sure she has a cup of tea. Don't bother with fruit juice, just a cup of tea one sugar, a slice of bread with jam. That's not difficult. But nobody would listen, they still wanted to put a cereal by her and a bread roll... ...She can't even open the bloody bread roll to put butter on or to put jam on. And then they are getting upset because she's not eating. She won't eat because she can't eat it... ...And I wrote it down, no cereal, no fruit juice... ...A cup of tea, one sugar... ... Alright she might say no I don't want it. When you've got out of the room she'd pick. And even if she'd only had half a slice, it's summat."*

This quote touches again on some of the effects of failing to maintain connections to usual habits and routines, a reduction in food and drink intake in this instance, again demonstrating how disconnection from usual routines could have important consequences. It also demonstrates how, even if information about someone's usual routine was conveyed to staff, this did not ensure that it was used. The influence of the valuing and use of families' knowledge on the ability of staff to connect with people with dementia and provide more individualised care is explored in Chapter 6.

5.2.3 Disconnections from hospital life

The beginning of this chapter has explored how hospital life could exacerbate disconnections from pre-hospital life. In addition to these disconnections, the hospital environment and life on the wards could create additional disconnections, as are explored below.

5.2.3.1 Disconnection from ward environments

Ward environments were highly unfamiliar and often bewildering worlds for people with dementia to inhabit; their design often inhibiting connections with others. Patients often spent much of their time sat alone, either by or in their beds (or in the communal lounge in the case of Site 1), in spaces that offered limited or no sight of staff or the rest of the ward:

> *Staff 12 Site 1, Interview: "I think the layout of the ward isn't good, you can't see patients because it's a very long corridor."*

The often unfamiliar activity and sounds of ward life, which could be heard but rarely seen, creating a further sense of disconnection:

> *Fieldnotes Site 2: John says 'Don't know what the hell I'm doing'. He talks about the people (staff) that 'Come out of there' referring to the door way into the corridor and says 'must be nice, some of them' adding 'Bloody this' waving his arms around the room as he says it.*

> *Fieldnotes, Site 2: A few staff come into the room and talk and it is suddenly quite noisy. A gentleman with dementia exclaims 'I don't like all this', indicating with his hand towards where the noise is coming from and turning his head away from it.*

Bed spaces reflected the primary purpose of the ward and were typically highly clinical and unengaging environments, largely or entirely devoid of any recognisable features people with dementia could make connections with. The wards contained a wealth of clinical equipment and signs that people with dementia often found confusing and difficult to make sense of, to the point of causing distress at times. Even everyday items such as taps and toilets often had unusual mechanisms and were not easy to identify or locate:

> *Interview Site 1, Staff 4: "I think it is for most patients with dementia, it's really distressing being in hospital. And then here it's quite, you know, it's very clinical isn't it and you know there's a long corridor and it's, but I do, I think it's really distressing. There's nothing familiar at all really, and then you can find yourself in a room on your own in a strange environment on a night and, but equally I think it's distressing if*

they're in the four bedded bays as well, it's, it's… …I just think it's just really distressing… …I think it's a lot to do with the environment."

Fieldnotes Site 2: I talk to Ruby who is quite bothered about her feet being in a pool of water, thinking that the two blue wires holding her notes onto the end of her bed are taps and water is pouring out of them; they are shaped a bit like taps and, if they were taps, water would be pouring out of the bottom of them directly onto her legs. She reverts many times to worrying about her feet during our conversation and not being able to lift her legs up out of the way, repeatedly preoccupied by the supposed 'taps'.

Fieldnotes Site 2: The falls sensor Emmett is sitting on goes off loudly each time he tries to get up. He sits back down again each time he hears the noise, looking around and seeming puzzled by why an alarm sounds every time he moves. Soon he stands up again, resulting in another loud blast from the alarm. James comments from the bed next door 'That bloody thing frightens me every time it goes off!'

The decoration and furnishings of bed areas were mostly uniform and bland, lacking any individualised features (such as a variety of colours, pictures or furnishings) to connect people with dementia to the environment or to 'their' space on the ward. On Site 2 patients were usually without their own clothes, and were instead dressed alike in hospital nightwear, and on both wards people with dementia were usually without personal belongings such as handbags, wallets, photographs and familiar bedding. Such impersonal surroundings and clothing, and a lack of belongings, created anxiety for people with dementia and negatively affected their sense of security, belonging and identity:

Fieldnotes Site 2: James is talking on the ward phone to a relative. He starts talking about all the things he has at home 'Furniture, photographs…' 'Where's it gone to?!' 'Who's give it away?!' He starts to sound upset. Shortly afterwards he says 'You want to see the mess I'm in'. He talks at length about his wallet, bank card, post office card and the money he has on it and how he doesn't have it with him.

Fieldnotes Site 1: A lady with dementia tells me that she doesn't know where her money is, and that she was going to give some to her great granddaughter to get her a new bed, but that she doesn't know if that is happening now. She says several times 'I don't know' and 'I don't know why it's all gone wrong'.

A lack of personal belonging also reduced people with dementia's ability to make connections with their surroundings or to convey a sense of themselves to others, thereby inhibiting the formation of new connections – a topic discussed in more detail later.

Many ward spaces, particularly in site 2, lacked stimulating or orientating features such as pictures, calendars, clocks, televisions, radios, or sight of staff or the rest of the ward. This meant that people with dementia, who struggled to source their own activity, spent much of their time unoccupied and with limited means of connecting with and making sense of the unfamiliar world in which they found themselves:

> *Fieldnotes Site 1: Ailsa often looks frightened and confused; I repeatedly notice her looking around the dayroom from side to side with an alarmed expression on her face, as if she is unsure or frightened of her surroundings. She says to herself tearfully 'I'm not stupid but where am I? I just can't see where I am'. When I talk to her she keeps screwing her eyes up and looking around, asking repeatedly 'Am I alright here?' as if she is unsure whether or not she is in a good place.*

> *Interview Site 1, Staff 7: "I mean at the moment we've got a lot of patients on the ward that have got dementia and that aren't engaging in anything particularly other than sitting in the day room. And yes there's the fish tank to look at, there's books available, there's TV but with quite a lot of patients with dementia, they're not gonna engage themselves, they need somebody to say 'oh do you want to come and have a look at the fish' or 'let's have a look out of the window'…….. I think that's, that's the problem, there's no engagement because there isn't the time because there isn't the staffing for it."*

As the last quote demonstrates, the few potentially engaging features that were present, particularly in the less clinical environment of site 1, were of limited value if they were not accompanied by interaction with people with dementia to facilitate their connection with these features. The lack of interaction with people with dementia at times, which is explored below, contributed further to creating confusing and unengaging environments containing many features that challenged people's abilities to connect with and make sense of the world around them.

5.2.3.2 Disconnections from staff and fellow patients

The disconnections produced by unfamiliar ward environments and routines were compounded by the large amounts of time people with dementia spent without anyone to connect with or alleviate their concerns. For much of the day, due partly to the restricted visiting times, staff or other patients were often the main potential sources of interaction. Whilst some patients would chat to and assist each other, interaction between patients was often limited. The distances created between people (beds, chairs, curtains or side rooms often separating one patient from the next), ill health, fatigue, deafness and poor sight could limit opportunities for connection with fellow patients, especially when confusion and muddled or incoherent speech was also a factor:

> *Interview Site 2, Carer 20: "…and I think it was a bit awkward for him, with him being deaf. He couldn't shout across to the other people or the man in the next bed, even if they were alright to talk to, because he's so deaf."*

> *Fieldnotes Site 1: There is a curtain hanging next to Mabel's chair that separates her bed space from the bed space next door – the curtain isn't drawn but it is hanging down next to her chair, obscuring her view of one of the windows and the lady who is sat the other side of the curtain. As they can't see each other I imagine it would be difficult for them to have a conversation, if they wanted to.*

> *Interview Site 1, Staff 12: "…'cause we're all too busy and whilst they're all sat in the lounge, they all, always look lonely because they're not talking to one another…"*

As this last quote demonstrates, opportunities for connection between staff and people with dementia were limited by the closed design of the wards and the volume of work and clinical priorities of staff. Apart from times when staff were providing care to patients in the immediate area, they were often out of sight undertaking work on other parts of the ward - caring for patients in other rooms or behind curtains, or at the nurses' station, or in meetings. As a result, people with dementia could spend large amounts of time without making a connection with anyone:

Interview Site 1, Carer 3: "They put him in his own room, that's it. People just used to come in briefly and come out but he would be left for hours do you know, just by his self... ...he didn't like it, he did not like it. And he'd just dwell on things, and he'd just do, there was nought for him to see'.

Interview Site 2, Carer 25: "The last thing that people with dementia need is isolation. And what happens when they go into hospital? It is isolation. Especially when you're in a side room because the nurses, the doctors, people that are serving the lunches, people that serve the teas, don't have to go into that room unless they have got a job to do, so they don't go into that room at all. So what you're doing is your putting somebody with an illness like that into further isolation."

Interview Site 1, Staff 7: "That's the problem, there's no engagement because there isn't the time because there isn't the staffing for it... "

Interview Site 2, Carer 20: "They don't have the means for it, to look after 'em properly (speaking about people with dementia). It's 'We're too busy seeing to patients that are ill and need the attention', whereas there's nothing wrong with your organs or anything like that, it's just, 'So we'll just sit you there and leave you there'... ...just as though they are patients, but ignored as patients."

Staff often recognised the lack of interaction they were able to provide to people with dementia and spoke of the uncomfortable conflict between their clinical priorities and the time required to make connections with people with dementia, especially for those who were distressed or anxious:

Interview Site 1, Staff 7: "I find it very hard to walk past somebody that's obviously trying to get your attention and all you can say is 'oh right' and then carry on because you don't have time, you know that if you get stuck there, you're gonna be stuck there for twenty minutes, half an hour because he's not gonna understand that you don't have the time to spend, and that's really hard..."

Interview Site 1, Staff 10: "Obviously the healthcare's get bogged down with everything else and then that (interacting with patients) gets shoved to the last doesn't it of the, they've got to prioritise what they're doing. But it would be nice to see more going on really I think... ... just to give a bit more stimulation."

Lacking the time to connect with people with dementia was such a regular occurrence that some staff had developed strategies such as 'tactful ignoring' and 'putting somebody off' which they reluctantly used to avoid getting into conversations that they did not have time for:

> *Interview Site 1, Staff 7: "…it's that professional tactful ignoring that's just, it's not right at all, but you have to do it to be able to do your job, you don't have time to spend like, like that unfortunately. It's really hard, it is hard with somebody that's so anxious… …. the bit that makes me cringe a lot is the putting somebody off 'oh it'll just be five minutes, somebody'll be with you in five minutes' and it's because you don't have time to say 'what is it that you want?' "*

The above quotes reveal how connecting with people with dementia was not necessarily considered a core part of ward work. Even when patients were displaying signs of anxiety or distress, getting through the volume of 'clinical work' often had to take priority as wards were staffed for physical need and not for the extra time required to connect meaningfully with people with dementia and to meet their need for interaction:

> *Fieldnotes Site 2: A lady with dementia confined to her bed is repeatedly banging items in her room against the metal frame of her bed. A staff member says she just wants someone to sit with her and that she has told her that she has 'no time to talk to you'.*

> *Interview, Staff 7: (Talking about how staffing levels are determined) "It's all well and good looking purely at mobility or transfers, somebody with dementia may well be independent to get themselves out of bed and walk around but that doesn't tackle the issue of them needing the support in different ways. And that's the problem, they staff for physical ability not cognitive deficit."*

> *Fieldnotes Site 2: The daughter of a lady with dementia tells me that the staff are nice here but that they haven't got the time to sit with her mum.*

As dementia is an incidental feature of patients in general hospitals (the purpose of the wards being the care of acutely unwell people or those transitioning to home), it may be unrealistic to expect regular connections to be made with people with dementia. However, as identified in Section 4.3.1 many patients on both wards had

dementia or cognitive impairment, making the care of these patients a daily feature of ward work, and the quotes above identify staff who felt that making the connections needed by people with dementia was something they should be given time to effect. However, as Section 5.5 will explore, time was not the only limiting factor, connections also depended on the extent to which staff used opportunities available to them to effect connections within the constraints of ward work.

5.2.4 Disconnections due to dementia, delirium and ill health

Earlier quotes have already illustrated some of the challenges for ward staff when it comes to making connections with people who have dementia. Alongside time, clinical and environmental constraints, the presence of dementia could create additional challenges to making connections, even for staff with dementia knowledge and expertise. Physical ill health and delirium, coupled with unfamiliar surroundings and people, meant that people with dementia could be more confused than usual and could be difficult for staff, especially those unfamiliar with the person, to understand and connect with:

> *Interview Site 2, Carer 25: (Speaking of her mum who was more confused than usual) "They didn't understand her and she didn't understand them... ...She was frightened because she didn't know what was happening to her."*

> *Interview Site 1, Staff 7: "There's some (people with dementia) that it's very difficult to engage with"*

The confused and muddled talk and actions of some people with dementia could be particularly difficult to understand, for example if they had had more advanced dementia, hearing impairments or a first language other than English:

> *Interview Site 1, Staff 4: "It's difficult really with her hearing because you try and explain things and you just find that you're getting louder and louder and actually she's still not grasping, you know... ...I think that's probably more of a problem, I think she's probably not as confused as we think she is, I think the problem is that she can't hear what we're saying and she misinterprets what we've said to her."*

Fieldnotes Site 2: Muhsin repeatedly mutters and talks to me and the staff in language we can't understand, with odd words of muddled English thrown in.

Interview Site 2, Staff 32: "(it is) often really difficult if you've got somebody with dementia and there's a language barrier. That is, that's really hard. Really, really hard."

Making sense of difficult-to-interpret interactions and behaviours was particularly difficult for staff who were unfamiliar with the person and his or her usual ways of communicating and making connections. As will be explored in more detail in Section 6.9, staff could hold limited personal knowledge about individuals with dementia due to the challenges of gaining this information from the person and a lack of personal knowledge seeking from families. This meant that staff could lack valuable knowledge of conversation starters or topics that would be likely to engage individuals with dementia, and knowledge of the person's communication habits and needs, which could further limit the already restricted opportunities for making connections:

Interview Site 1, Staff 4: "A lot of time you just see written down retired but you don't know what. Obviously they've retired, they're in their eighties, doesn't take Einstein to work that one out. But no, no job title. So you don't know what they used to do." Interviewer: "Does it make a difference when you do know?" Staff 4: "I think it does because if somebody's quite wound up, if they're confused, you can normally, if you start to talk about their home life then that sorts, you know it kind of brings them back down to Earth and realise where they're at and things, whereas if you can't you're digging really aren't you? And it's not the best time to be digging when somebody's really confused and aggressive."

Interview Site 2, Staff 33: "One of the things you find is, a patient may come into hospital that's got dementia, that won't take tablets for you. Will become quite agitated if you try to wash them or toilet them. And you don't know anything about that person to, to try and put them at ease."

These quotes begin to indicate how proactively sought personal knowledge was an important means of facilitating connections with people with dementia and how the

degree of personal knowledge held about people with dementia could influence the extent to which connections were made with them. The last quote also illustrates how a lack of connection with people with dementia can affect both care provision and the person's experience of care, impacts which are explored in more detail below.

5.3 The effects of disconnection on people with dementia

A lack of connection with people with dementia could have multiple impacts upon the person and their care. These impacts, which are explored below, included negative effects on the person's emotional and physical well-being through negatively affecting their sense of self and self-worth, their levels of stress and agitation, and the provision of safe, timely and effective personal and clinical care.

5.3.1 The effect of disconnection on emotional well-being and care provision

A lack of connection was often cited as affecting the emotional well-being of people with dementia, exacerbating symptoms of dementia, such as agitation, distress and fear, and significantly affected the ability of staff to provide care to the person:

> *Interview, Carer 25: "It [making a connection] would have made a difference to me because then my Mam wouldn't have been as agitated as she was, she wouldn't have been as upset, she wouldn't have been as frightened. The fear in somebody's eyes was not nice. And then you've got to alleviate that fear and a lot of times, you know, you feel as though you're lying because you say it's not going to happen again and you know for a fact it's going to happen again because nobody bloody learns from what you've said… And no matter how much, you know, you say these things [how to engage with her mum] and it doesn't help because they don't put it into practice. Then my Mam's upset, she's agitated, she's frightened. You've got staff that are refusing to go in and help her. What is the point of that? When all of that could have been stopped?"*

> *Interview Site 1, Staff 7: "I know we've had somebody relatively recently that got quite agitated with the staff and again that's about the time that you can spend... ...as long as you explained why you wanted to do something or you know what was next or you know what you were expecting, he was absolutely fine. But because the staff don't have time for that and their aim is to get somebody washed and dressed, it's very difficult to kind of manage somebody that doesn't understand what's going on or wants to do something their own way... ...and that's where you get agitation or aggression or, you know, just general issues."*

The first quote also demonstrates how failure to use the knowledge of families could contribute to failures to connect with people with dementia and improve their experiences of care. The impact of a lack of meaningful connections on well-being could be most clearly seen for people such as the lady described above who were distressed or anxious and had a particularly high need for connection with others. Staff often tried hard to interact with people who were distressed, with some staff displaying extraordinary levels of patience, kindness and continued responses to those who were repeatedly distressed. However, the staffs' lack of time and knowledge of how to reduce distress and forge meaningful connections with some individuals could mean their responses, whilst often warm, could be brief and impersonal. Such interactions did not fully connect with the needs or anxiety the person was expressing, and did little to reduce the person's distress. As a result, the person could cry out again soon afterwards, or even as the staff member was leaving, creating a feeling amongst some staff that their efforts to connect with people with dementia had little effect.

The negative effects of disconnection could go beyond stress and agitation to adversely influence the sense of self, worth and hope of some people:

> *Fieldnotes Site 1: A lady with dementia tells me that being here is 'a nightmare' and that it is 'desperate'. She says that nothing happens and that they just 'sit all day' and this is 'no way to live'.*

> *Fieldnotes Site 1: John comments out loud that he is a 'doddery old bugger' and says twice 'Don't let me die'. A staff member is stood over him when he says this but says nothing in response. He also says that he'll 'probably die' and another staff member*

replies 'Try not to'. On a different occasion, after a staff member has ignored John's attempts to initiate interaction, he comments to himself that he is 'Useless' 'I'm sorry' and 'I want to be dead'.

These negative impacts were particularly apparent for people who were already distressed and had higher levels of need for interaction, such as John who was already struggling with feelings of low mood and poor self-worth. This meant that people who were quieter and did not exhibit overt signs of distress (or other signs indicating a need for interaction) could risk their need for interaction being overlooked whilst staff focused instead on responding to people who called out for help or more clearly indicated a need for attention.

5.3.2 The effect of disconnection on physical well-being and care provision

As some of the above quotes have already indicated, disconnection also affected the provision of care and the maintenance of physical well-being. For example, staff highlighted how disconnection and any resulting agitation could lead to an increase in the risk of falls:

> *Interview Site 1, Staff 7: "…when you don't have the staff you can't do that (engage with people with dementia) and therefore they become a falls, more of a falls risk and also like they get agitated cause you're constantly telling them to go and sit back down, and they don't want to go and sit back down, so yeah you end up with conflicts because of that."*

How disconnection could lead to an increased risk of falls was apparent from examples of frail people with dementia who would start trying to get up or deal with problems themselves if they could not locate or connect with anybody to help them:

> *Fieldnotes Site 2: Lynette starts mumbling, calling out and shuffling down the bed. Her feet near the bottom and side of the bed before starting to hang off the bed. She shuffles and mumbles to herself for about 5 minutes before more clearly calling out that she wants to go to the toilet 'Take me to the toilet'. She sits herself up shakily, grabbing*

onto the bed rail, and then carries on mumbling whilst lying back down and shuffling further down the bed so that eventually, after a few minutes more, her thighs are hanging off the bed. She calls out as people walk past the corridor outside her dormitory. I don't think they are members of staff and no one stops for her. I wonder how much longer to wait before acting so she doesn't fall off the bed. As I am about to get up a domestic comes in to collect tea cups, sees what is happening and goes to get a member of staff. I go to Lynette as she starts shuffling even further down the bed, talking about her tummy and putting her hands down her net knickers. The domestic comes back saying she couldn't find anyone and presses Lynette's call bell before carrying on with what she is doing. Lynette pulls her hands back out of her knickers covered in runny faeces. She starts grabbing hold of the bed rails, smearing poo around and moaning repeatedly 'in a mess'.

Fieldnotes Site 2: A patient calls out 'Nurse' from one of the side rooms. She repeatedly calls out in a long moan 'Nuuurrrse', thirteen in times in total, accompanied by a few calls of 'Hello?' when no one comes.

Fieldnotes Site 1: A lady with dementia starts tapping her fingers on her chair arm repeatedly. She continues to tap before suddenly gripping tightly onto the chair arms with her hands, her grip so tight that the skin on her fingers stretches and changes colour. She looks around and mutters 'Come on. I want the toilet'. She mutters something, turning to look at the other patients in the room but no one responds. She moans and then pushes hard on the arms of the chair as if she is trying to stand up. She lifts up shakily before sinking back into the chair with the effort and shouting 'Hello!' A patient sat near her jolts awake and shouts 'Hello?!' in response. She says 'Hello' again, followed by 'I need a nurse'. There are no staff in the room and none in view in the corridor.

These examples begin to demonstrate how disconnection impeded the ability of staff to meet the care needs of people with dementia; in these examples the absence of staff, who were more than likely busy elsewhere, delayed the identification of a need for care.

Providing physical care to people with dementia came with many challenges for staff which were exacerbated by the difficulties they experienced in making connections with the people they were caring for. An unavoidable lack of staff presence at times, coupled with difficulties understanding the expressed needs of people with

dementia, could mean that even basic care needs were not always met. This was not routine, there were many examples of staff trying hard to meet the nutrition, toileting, mobility and hydration needs of people with dementia, and doing so with warmth and kindness – examples of which will be provided shortly - but there were also occasions when the lack of connection between people with dementia and staff obstructed the provision of care. People with dementia could struggle to articulate when they needed the toilet or a drink, were in pain or hungry, or required help in some other way. And failures to connect with individuals with dementia prior to attempts to provide care could lead to refusals to accept personal care, examinations, treatments, food or drink:

> *Interview Site 2, Carer 25: "If they could just take that couple of minutes, don't just go in the room get the gloves on without saying owt, try and make a little bit of a joke with 'em. They need to get that person's confidence because if not you're on a road to nothing. It's going to make their job a lot harder because that persons going to feel threatened, going to show aggressive behaviour to the nurse or the auxiliary that's there trying to help them... ...So it's just that little connection they need first before they do anything... ...and, you know, try not talk over them either, try and include them when you're talking."*

> *Interview Site 2, Staff 33: "...a patient may come into hospital that's got dementia, that won't take tablets for you, will become quite agitated if you try to wash them or toilet them. And you don't know anything about that person to try and put them at ease."*

More specialist care tasks, such as physiotherapy and occupational therapy and clinical assessments, could also be time consuming and difficult to undertake with people with dementia, especially when their recall was poor or it was difficult for staff to explain to the person why the activity was necessary or what they needed to do. As a result, requests made of people with dementia to do seemingly strange activities such as to get in and out of bed for no apparent reason or to recall specific details of their home or care needs were often met with confusion, poor quality information or a refusal to engage with the task:

> *Interview Site 1, Staff 7: "A lot of our patients we would go at half past ten, eleven and say 'right, let's have a look at you getting on and off the bed'. If you do that with some*

of the patients with dementia they don't want to do it because they don't understand why you're making them go to bed, even though you're not."

Fieldnotes Site 2: Emmett's daughter says a social worker has spoken to her Dad and said he was really confused, but she wonders if he isn't as confused as the staff think and whether it is because he can't hear them and what they are asking him.

As the last quote demonstrates, if staff did not know the person and so lacked knowledge of their communication needs and how best to communicate with him or her, then it was particularly difficult to encourage participation with such activities.

5.4   Cumulative disconnections

Facets of disconnection did not exist in isolation from each other. They could accumulate, with the potential for one element to intensify over time or give rise to further disconnection. Disruption from prior routines was an example of this process, with disruption to these routines having the potential to effect longer term, or even permanent, disconnections from pre-hospital life, levels of functioning and relationships:

Interview Site 1, Staff 7: "Some patients with dementia, if they have a physical injury and they can't stick to their routine, their normal walking aid, that kind of thing, they lose the ability to stand themselves up even though they physically are able."

Interview Site 1, Carer 1: "She has slid back an awful lot this time… Interviewer: In what sort of ways? Carer 1: Disorientated in her own flat… …Not wanting to do anything. I think because she is sat watching that television. She thinks she is sometimes still back at the hospital, in the lounge watching tele, because that is all they did… …And I have said Mum, come on let's try walking into your kitchen, you have not been in for 5 weeks. But no, no, she does not want to…" …Interviewer: "Is that different than before she went to hospital?" Carer 1: "Yes. Yes, she would potter about yes… …I mean, when I brought her washing up she would have a little potter, a little walk around with me…. Or we would go and sit on bench, or things like that. Whether it is her confidence that has gone I don't know."

These quotes demonstrate how temporary disconnection from familiar others, routines and levels of functioning in hospital could lead to more enduring disconnections in these areas which persisted after discharge. A more extreme example of cumulative disconnection is provided in Section 6.7 in relation to John who loses his ability to transfer independently whilst he is in hospital, due to a lack of practice according to his daughter, which results in discharge to a care home and thus to more permanent disconnections from his prior life and from the significant others with whom he previously lived.

Cumulative disconnection was also apparent in the lack of involvement of people with dementia and of their families with events on the wards (such as ward rounds and assessments), which could lead to one or both parties experiencing disconnection from the knowledge-exchange and decision making forums that contributed to determining the future care of the person. Similarly, when families' connections with people with dementia and their care were disrupted, so too was their in-depth understanding of the person. Physical ill health, increasing time in an unfamiliar and bewildering setting, and disconnection from familiar people, places and routine could create changes in the person with dementia's cognition and abilities. This process was often hidden from families because they rarely saw their relatives undertaking functional assessments or acts of daily living on the wards. This lack of knowledge of the person as they are now inhibited families' abilities to make well-informed contributions to decisions about the future care needs of their relative, as is revealed in the following excerpt:

> *Fieldnotes Site 2: Emmet's wife and daughter meet with the social worker to discuss whether he can return home. The social worker reads off a list of his care needs and asks his wife whether she can manage with that at home. There is a pause and then Emmett's daughter says quite sharply and sounding stressed "We don't know" and 'We can't answer that" because "We don't know what he'll be like 'til we get him home". She asks 'Can he walk upstairs?' and goes on to say that they 'Can't even answer' because they have 'not seen' what he is like. She explains to me later that they have 'not seen him walking' and have only seen him sat in a chair.*

This quote clearly shows the escalation from disconnection with the person to disconnection from knowledge about them, leading to difficulties when making decisions about future care needs and the family's ability to meet those needs. These important impacts of disconnection on knowledge and decision making for families and people with dementia will be further explored in Chapter 7.

5.5   Moving from disconnection to connection

The data presented so far have demonstrated how hospitalised people with dementia could experience disconnection from familiar pre-hospital life and from the unfamiliar routines, environments, activities and staff on hospital wards. Connections were not, however, simply present or absent. For example, disconnection from pre-hospital life could be transient and there was great variability in the degree to which staff utilised available opportunities to make connections. The following sections explore the degree to which connections with people with dementia could vary, and begins to explore some of the circumstances under which staff were able to effect more meaningful interactions. In order to do so, examples along this 'continuum of connection' are explored, beginning with instances of disconnection at one extreme of the continuum before considering examples of increasingly meaningful interactions and the circumstances under which these were effected.

5.5.1 Overlooking and disregarding opportunities to connect

Although the time available for staff to spend with patients was clearly limited, even when staff were present it did not ensure that connections with people with dementia were made. Due to time constraints, episodes of clinical care constituted the majority of opportunities for interaction with people with dementia, but these opportunities were not always utilised and the quality of engagement with people with dementia during clinical tasks was mixed. At one end of the continuum

interaction was almost entirely absent, with tasks completed almost in silence or at the same time as conversations with colleagues to the total exclusion of the person with dementia:

> *Fieldnotes Site 1: Two members of staff stand either side of Mavis and help her up. Mavis walks supported between them. Her feet stutter as she walks, taking small steps and lifting up onto her tip toes as she goes. The staff members talk to each other over Mavis' head about when one of them has some days off - they continue to chat with each other all the way to the toilet. They then take Mavis into the toilet and leave her there. After five minutes or so a member of staff goes back round into the toilet and five minutes later she comes out of the toilet with Mavis and they walk slowly back towards the day room. There is no conversation between them.*

> *Fieldnotes Site 1*:

> *4.16pm*: *A staff member goes behind Jean's curtains. She tells Jean she is going to change her nightie and then asks her to 'stand up for me darling'. There is no more talking heard after that. I hear the tap running for a little while as if she is getting water to wash Jean with.*

> *4.20pm. The staff member is still with Jean but has said nothing further to her until now when she says one sentence which I don't quite catch.*

> *4.25pm. The member of staff comes out from helping Jean. She has been with her for 9 minutes but has only said two sentences to her.*

Very occasionally, people with dementia were even ignored despite making efforts to initiate conversations with staff:

> *Interview Site 2, Carer 25: "Sometimes she used to say something and they used to dismiss what she said and not follow it up."*

> *Fieldnotes Site 1*: *James is in the dining room, a staff member is sat at the same table. She isn't talking to him, she is looking down at her handover sheet and writing things on it. 'No one likes me, especially not you' says James. The staff member stares away around the room and doesn't say anything. James says a few more things – I can't always hear what they are but each time the staff member says nothing and doesn't acknowledge him speaking. She sits still, staring ahead, and gives a big yawn. James fiddles with something on his jumper, pulling at it with his hands and asking what it is.*

'It's just the pattern on your jumper!' she exclaims, sounding exasperated. James says several more things which the staff member ignores, then she gets up and leaves the room, leaving James sat alone. After she has gone James comments to himself that he is 'useless' 'I'm sorry' and 'I want to be dead'.

These examples demonstrate how opportunities to effect connections with people with dementia were not always acted upon by staff. However, there were also examples of staff who did use the limited opportunities available to them to interact with people with dementia and include them in conversations. In these examples, the degree of connection that was established was determined by the content of the interaction rather than by whether or not it took place, leading to variability in the degree to which meaningful connections were made. Many of the tasks observed did involve some level of interaction but, whilst often delivered with kindness and warmth, some of these interactions, not always out of necessity, consisted mainly or entirely of talk related to the task:

Fieldnotes Site 2: A staff member exclaims in surprise to find a lady with poor mobility left on a commode behind her curtains 'What you doing Leila! Could have fallen!' adding really to herself but as if she is saying it to Leila, 'Don't think you should be left on your own on toilet'. She goes on to help the lady onto the bed 'Push up the bed Leila' and 'Leila push up the bed darling' before moving back and forwards around the bed area. I hear noises as if she is tidying things up and moving things around. She doesn't say anything else to Leila, pulling back the curtains soon afterwards and leaving in silence.

5.5.2 Moving towards connection

During tasks some staff would expand conversations to include topics outside of the task being undertaken or would take the time to exchange pleasantries and greetings with patients outside of tasks, as they passed by or undertook a task with someone else, meaning they made connections with patients even when there wasn't a specific need for them to do so. These exchanges were again often

conducted with warmth although they could be brief and limited to fairly general topics of conversation, thereby conveying little knowledge of the person:

> *Fieldnotes Site 2: An NA comes in and says as she passes says 'Emmett hello!' and 'Love your slippers!'*

> *Interview Site 1, Staff 7: "...certainly with some, like Ray that's been on a while you know, we'll always make an effort to say hello. We might not be seeing him but we'll say hello to him, and we'll make sure we have a bit of a chat and a, you know, a smile with him."*

> *Fieldnotes Site 2: The staff that come into the dormitory whilst I am in there talk to and say hello to all the patients, even those they have not come in to see.*

> *Fieldnotes Site 1: A couple of people pass John because of where he is sat (in the corridor) and talk to him. One says 'Hiya John' and strokes his hand. 'Yeah you alright' replies John. Another says 'Are you all ready for off?' 'Are you all ready for going?' followed by 'Soon. Think bus is coming for you soon'.*

There were many examples of warmth and kindness in interactions with people with dementia, although these conversations often remained relatively superficial and brief because staff did not have the time or know enough about individuals to engage with them in more personally meaningful ways. These examples indicate how connections were not simply present or absent, but were also dependant on the quality of the connections made.

5.5.3 Increasingly meaningful connections

Whilst connections at the lower end of the continuum could be relatively superficial and brief, the other end of the continuum was characterised by examples of increasingly meaningful interactions where staff used the opportunities, resources and knowledge available to them to create more personalised connections and gain or convey a sense of the person and their life:

Interview Site 2, Staff 29: "You usually get talking to them, cos we are so busy sometimes. But it's usually when we wash people cos you have at least 10 minutes to, well 15 minutes, and you say "Oh, were you ever married then? How many children have you got?" And they are like, they will tell you if they can, sometimes they can't remember, but most of them they can. Then they will just spout off about something, sort of hear about their life and you're just sort of "Oh yes" So you do get to know in that sense. They will just talk and talk!… …I think, if you didn't ask them they wouldn't initiate. But I do ask."

Interview Site 2, Carer 20: "I know he'd been talking when, when I came yesterday the nurse said 'Ooh he's had a right good chat today with…' uh, I thought she said a doctor, about when he was in the navy."

Interview Site 1, Staff 9: "One patient she'd got a bit of dementia… …and she was sat in the dining room on her own, eating and I though oh! So I went and sat with her and had my break. I ate with her. I had something to eat with her and she were, we were both chatting away."

The above staff demonstrated how, in different scenarios, it is possible to find opportunities to connect with people with dementia on acute hospital wards. These staff, and others like them, demonstrated that creating meaningful connections with people with dementia is possible within the constraints of busy and minimally staffed hospital wards. The following sections explore the circumstances under which meaningful interactions were created, before Chapter 6 focuses in more depth on the role families and their knowledge could play in effecting such connections.

5.6   Explaining the connection continuum

As has already been described, circumstances such as busy clinically orientated routines and environments and more challenging communication needs affected the degree to which connections were established. Alongside these factors, the extent to which connecting with people with dementia was valued, particularly by senior staff, was an important factor in determining how often interaction took place. Some staff saw making connections as important and beneficial to both staff and people with

dementia, whereas others did not view engaging with patients as real work - a view that they sometimes imparted to more junior colleagues by chastising them for spending time talking with patients instead of 'working':

> *Interview Site 2, Staff 20: "I'll often bring people to the therapy room who I could treat at the bedside but I just think, you know, let's get them off the ward! Let's give them you know 45 minutes of just, like a really nice environment where they can, where we can, you know, have a bit of a laugh. Because although you've got to be professional, you know, you can have a really nice conversation and just try and you know ask people what they used to do, what they used to work as. And it's amazing what they can remember about their job!... ...I've had people saying 'Oh I've really enjoyed that! That was so nice. Are you coming tomorrow?'"*

> *Interview Site 1, Staff 12: "...sometimes when patients are agitated, it might only be somebody sat with them for a while and talking to them... ...But it's the time to do that because they haven't, because they're still doing lots of cares and other things, and it's letting them feel confident to be able to sit down and not feel guilty of talking to patients, and sometimes it is just about talking and having a conversation..."*
> *Interviewer: "And you said staff might feel guilty if they talked to patients?" Staff 12: "I think they do. And we have had staff that have sat down and have been told by the qualified nurse, questioned what you're doing. Or they'll find them a job. Well they're doing a job." Interviewer: "But it's not seen necessarily as one?" Staff 12: "And that, again, is around education."*

These quotes highlight how much the value attached to connecting with people with dementia could vary between staff and how the influential values of more senior staff- alongside staffing levels, a lack of time, other care priorities, and dementia education and expertise (including personal experience) – affected the extent to which connections between staff and people with dementia were made. As the quote above suggests, compared with those who had received post-qualification dementia training, staff with little or no training or expertise in dementia care often knew less about, or placed less value on, making connections with people with dementia and the benefits of doing so:

Fieldnotes Site 2: An NA tells me that 'Dementia training would be nice' and tells me that only one of the NAs on the ward has had any. She tells me that she doesn't know what to do with people who have dementia or how to handle them.

Interview Site 1, Staff 4 (Senior member of staff): I've got no background caring for people with dementia… …it's not that's it's not been something that's never interested me but it's, you know, it's not at top of me agenda for things that I needed to get more information on really. It's only when you speak to like Staff 12 and Staff 10 who have obviously done extended training now, that you realise there is a lot more to it than you know, just re-orientating people."

In contrast, staff with greater knowledge and expertise (of which Staff 12 on the previous page was an example) placed much greater value on meaningful engagement and possessed more of the skills, understanding and confidence required to initiate the kind of interactions that really connected with people with dementia. An example of this can be seen in the instance below where Staff 12 takes an agitated lady back to an era of her life that could be used to establish a connection that had sufficient depth to assuage possible distress:

Interview Site 1, Staff 12: "…So like I had that lady once who was insistent on going home, she was adamant she was going home, she kept getting up and going to the door. But actually 'cause I had the time to sit with her and we ended up talking about how she left her home country to escape the war, took her mind completely off it. And actually it saved time in the long run because staff weren't having to keep getting her from the door".

This last quote demonstrates again just how much the quality and meaningfulness of interactions with people with dementia mattered, and not just whether opportunities for making connections were utilised or missed. Connecting with this lady on a topic that was meaningful to her took her away from the distress she was experiencing and indicated how taking the time to connect meaningfully with people with dementia could have positive impacts for both staff and the person - in this instance, staff 12's interaction reduced both the lady's agitation and the subsequent workload of staff. This event begins to demonstrate the role that personally meaningful connections could play in improving experiences of hospital

care for people with dementia. However, whilst the above member of staff had the time to effect a lengthy connection with a lady who was able to communicate a great deal of knowledge about herself, this combination of time and communication abilities was not always present. As well as staff characteristics, the characteristics of people with dementia, as described in Section 5.2.4, also influenced the ease with which connections were made; people with communication barriers from dementia, language or hearing impairments consistently proved more difficult for staff unfamiliar with the person to interact with. In these instances in particular, time and a willingness to engage were not sufficient to overcome the challenges to creating connections; knowledge about the person and tips for communicating with them and stimulating conversations were, if sought and used, a valuable means of overcoming the challenges of creating connections:

> *Interview Site 1, Staff 7: "If you know from the family tree what relatives they've got, you can ask specifically, if you're asking a really broad question about something, they might not be able to answer you. If you can say 'I know that you like to do this', they might go 'Oh yeah, I really do' and talk to you about it. If you say 'What do you like to do?' they might not be able to tell you anything, so if you've got prompts on, about that person it makes it a lot easier to gauge your questioning to be specific to them… …because you've already given them a little clue and then they can build round it so yeah, in the sense that it's, it's much more specific to them, and therefore they'll engage with it more, but also it means that you get more out of them so it's much easier to do your own job."*

This quote begins to demonstrate how the degree of knowledge staff held about people with dementia played a central role in determining the extent to which staff were able to create meaningful connections. How personal knowledge, often available from families if the person was not able to communicate it themselves, could be used to provide a valuable means of facilitating and expediting connections with people with dementia will be explored in more detail in Chapter 6, as will the benefits that these more meaningful connections could bring.

5.7   Chapter Summary

This chapter has demonstrated how hospitalised people with dementia can experience disconnection on many levels: from both pre-hospital and in-hospital life, the latter focused largely on the core business of delivering clinical care and not on forming connections with the people to whom that care is provided. Opportunities to connect with and seek comfort from the familiar – the routines, relationships, and ways of functioning and communicating that characterised pre-hospital life – were limited by environments, routines, staffing and professional training which did not encourage a focus on maintaining these connections.

Connections with pre- and in-hospital life were not simply present or absent, but existed on a continuum with great variability in the extent to which staff used opportunities to effect connections with people with dementia. Whilst elements of disconnection were common, there were also examples of staff members, especially those with dementia training, grasping the opportunities and using the knowledge available to them to effect more meaningful connections, with personal knowledge a key enabler of these connections. Chapter 6 takes this focus on personal knowledge forwards by exploring how the knowledge, expertise and involvement of families could play a central role in facilitating the connections that formed a crucial component of providing more person and relationship centred care.

Chapter 6

Creating meaningful connections with people with dementia – using families' knowledge and expertise

6.1   Introduction

This chapter considers how families' knowledge and expertise could be used to create meaningful connections with people with dementia, connections which formed a crucial element of delivering more person and relationship centred care experiences. Data are presented here that demonstrate how involving families and their knowledge in care could enable more individualised connections with people with dementia which, in turn, could enhance identification and meeting of their individual care and communication needs. The variable nature of engagement with families, despite the benefits their knowledge and expertise might bring, is then explored. The chapter concludes by considering some of the barriers to working with families and why the involvement of families, although often beneficial, did not uniformly lead to enhanced connections and care for people with dementia.

6.2   Creating connections with ward environments

Staff recognised the need to enhance hospital environments for people with dementia, but faced financial, cultural and organisational barriers when attempting to do so themselves. These barriers included a lack of funding, the inability to alter non NHS-owned buildings, and staff resistance to the making of decorative and furniture alterations that would make ward spaces more interesting and individual bed spaces more recognisable, and thereby encourage interaction with the environment and those in it. Although some staff tried to overcome these challenges and make environmental enhancements for people with dementia, some of the most

effective improvements to hospital environments came from family members. Families who visited and brought personal items to the wards, such as photographs, favourite activities, bedding and gifts or cards, gave their relative a sense of familiarity, belonging and identity, thus generating a connection with their sense of self, in an otherwise highly impersonal environment. These personal items similarly created for staff a sense of the person's individual personality, interests and significant others, thereby providing a stimulus for more meaningful connections between staff and people with dementia:

> *Fieldnotes Site 2: (During a ward round) Staff 27 speaks kindly to the lady and introduces himself. He doesn't lurch straight into business, instead picking up a card with a picture of her granddaughter on it and talking about that, saying that she is a bonny looking lass and asking what her name is. The lady falters as she can't remember her granddaughter's name. Staff 27 asks her again but she still can't remember - instead tells him other information about her family such as the name of her son."*

> *Interview Site 1, Staff 7: "Getting them [families] to bring things in like pictures and stuff like that would be helpful, cause… … if you're saying 'oh, tell me about your family, who are these people?' and they can still recognise the pictures and tell you about them, you know it's an easier way for staff to engage with a patient about something that they're specifically gonna be interested in."*

> *Fieldnotes Site 1: The photographs up on Mavis' wall are our main source of conversation; discussing them is the only time she really lights up and contributes to our conversation. She tells me about a photograph of her grandson, going on to recall her grandchildren's names and how they were all here to see her at the weekend, joking that they were 'crammed in!'*

As seen in the above quotes, personal items could also stimulate meaningful connections beyond the items in question. Some conversations started around these items and moved on to other topics that revealed further details about the person and their life. Another advantage of using personal items to stimulate meaningful interactions was the possibility of these items being used as conversation starters by successive staff without the need for prior knowledge of the person, thereby avoiding the difficulties of conveying personal knowledge amongst large groups of

staff. However, the above quotes also show how personalisation of the environment needs someone to interact with the person in relation to these personal items in order to achieve the most benefit from them. Given that connections with people with dementia were often limited, some opportunities to utilise environmental features to stimulate more personal interactions with people with dementia were inevitably missed. On the other hand, personal items, if available, were particularly important in creating shortcuts to more meaningful interactions during the limited opportunities for interaction that did arise.

As well as stimulating interaction with others, personal items could also provide stimulation and maintain connections to familiar activities if the items brought in were related to hobbies undertaken outside of hospital; examples of this included regular games of dominoes instigated by the wife of someone with dementia and continuation of a photography hobby initiated by a granddaughter bringing in her grandad's favourite camera. These activities also became talking points for staff with the person with dementia thereby facilitating further connections with them.

6.3   Creating connections with care or ward routines

Personal knowledge from families, when it was sought and used, helped staff to create and maintain connections to the usual routines of people with dementia by personalising aspects of their care-routine on the ward. Information from families also enabled staff to identify and meet individual care-needs and to recognise deviations from routine behaviours which could indicate changes in the person's health or well-being that required further exploration:

> *Interview Site 1, Staff 12: "It's understanding the routine because we just, it's trying to treat patients individually isn't it, so you know, if they've a set routine… …it's giving them that understanding that she doesn't go to bed till nine, ten o clock, it's those little things that help their patient experience, and they settle down more if they're in that routine, they do settle down quicker." Interviewer: "So if you know that about someone, you know they've got a particular routine during the day, can you slot that into the*

ward routine or…?" Staff 12: "Yeah, we, we should, we try, I don't say it's always right but we do try… …they'll say, you know 'my dad likes to get up at this time', they like, they prefer this, and I think that's really helpful… …if staff, particularly the health cares, if they know what somebody's routine is, what they normally do, then, we shouldn't have as many problems…"

Interview Site 1, Staff 10: "we had a lady the other day, she was an amputee, and they were worried 'cause she was on the floor in the morning… And when I spoke to the daughter she said 'don't worry about it, that's what she does if she gets out of bed, she can't put her limb on so she will shuffle on the floor'. And it's knowing simple things like that that that's, that's why she's displaying that sort of be…. you know behaviour, she obviously, she couldn't put her leg on so she had to get on to the floor and shuffle around, whereas everybody else was thinking 'oh my goodness, she's fallen out of bed'. And that was just normal for her. So it's knowing what's, you know, what their patterns are at home and if any changes are in that, you know, why it may be, and it gives you a whole insight into everything really, I think, so you can look after them more effectively, better."

These examples show that staff who sought and used personal knowledge of the routines and behaviours of people with dementia were better able to recognise changes in the person and maintain connections to aspects of their usual care routines; connections that helped the person feel more settled in otherwise unfamiliar surroundings. However, more personalised routines, although recognised as beneficial by some staff, remained difficult to implement within the constraints of the busy, fixed and clinically focused ward routines. Families could counter some of the difficulties that staff faced in creating connections via personalised routines by undertaking some of this personalisation themselves. During visiting hours, family members often had the time and knowledge of the person's habits and usual routines required to help the person retain connections with aspects of familiar pre-hospital life and routines:

Interview Site 1, Carer 1: "I used to put me mum her nighty on and see to her and do her teeth and tuck her in before I came home. I suppose I felt that she were in bed and alright and…" Interviewer: "Could you talk me through what you were doing?" Carer 1: "Well, undressing her, helping her undress and go to toilet and change her pads and things and her teeth. Take her teeth out and put them in her Sterident thing and make

> *sure she was comfortable". Interviewer: "What sort of difference did it make?" Carer 1:*
> *"I am not sure because they would have done those things, I am sure they would. But I*
> *think my mum felt better... ...I think she felt better me doing that. Yes. Being there... ...I*
> *think it was more like being at home you know when she stays with me. She goes up to*
> *bed and I tuck her in and see to her."*

The familiarity created by these activities, and the familiar people who undertook them, seemed to bring a sense of comfort to people with dementia, helping to detract from the otherwise highly unfamiliar ward environments, routines and faces, and helping to maintain connections to previous routines, abilities and care-giving relationships.

6.4   Creating connections with people

6.4.1 Using personal knowledge to create connections

Meaningful connections were often forged when staff used opportunities that became available during or between tasks to interact with people with dementia. Doing so using knowledge of the person, often sourced from families, to understand and connect with individuals with dementia enabled staff to convey a comforting sense of knowing something about the person. These moments of personal connection showed that it was possible for busy hospital staff to elicit and make use of personal knowledge and that doing so produced connections with people with dementia that were more individualised, better met the person's needs, and lessened some of the challenges of caring for them:

> *Interview Site 2, Staff 20: "...there's a lady, just recently, who even if you just mentioned*
> *her husband and that he'd be wanting her up and wanting her walking and be really*
> *proud of her if she would be up and walking... ...that was the only way she would walk!*
> *And if you were to go and not mention her husband's name then she'd say no! And she*
> *refused for quite a few sessions actually until I found this out! ...So just that small*
> *difference and she'd, she'd walk, I don't know, 20 odd metres with us!"*

Fieldnotes Site 1: A ward Sister tells me about a man with dementia who struggles to speak. She tells me how she knows what his actions mean, using examples such as when he points to the door he is asking when his wife is coming, and when he points to his pocket he means he wants a tissue. A nearby health support worker exclaims that she didn't know that, and that if he had pointed to his nose she would have been able to work out he was snotty but not if he pointed to his pocket. The Sister explains that his pocket is where he normally keeps his handkerchief, although today he doesn't have a pocket in his shirt so it is even less obvious to people who don't know him what he means when he points to his chest.

These instances of more personalised connection often, but not always happened with staff who were more senior or had dementia training or experiential expertise and knew something about the person; characteristics which tended to give them greater autonomy, skills, and confidence to try and engage with people with dementia or their families. For example, the Sister above was a senior member of staff with expertise and training in dementia whereas the health support worker had less experience and no formal dementia training. What was perhaps most striking however was the Sister's personal knowledge of the gentleman and the impact this had on her ability to interpret and respond to his actions, which, as the health support worker points out, were so individual to him they were largely incomprehensible to anyone without such knowledge. The Sister had gained expert knowledge of this gentleman from nursing him previously and coming to know him and his wife well enough to have learnt some of his communication habits and mannerisms. Personal knowledge such as this, when it was sought and used, could play a vital role in helping staff to overcome some of the challenges of connecting with people with dementia.

Personal knowledge could also stimulate more meaningful conversations by providing conversations topics and prompts that were familiar, interesting and understandable to the person and thus more likely to stimulate a response:

Interview Site 1, Staff 11: "...it [personal knowledge] makes it easier to engage with that person in conversation."

Interview Site 1, Staff 7: "...If you've got prompts on, about that person it makes it a lot easier to gauge your questioning to be specific to them rather than just generalised, where they might not be able to tell you anything... ...because you've already given them a little clue and then they can build round it so yeah, in the sense that it's, it's much more specific to them, and therefore they'll engage with it more, but also it means that you get more out of them so it's much easier to do your own job."

Interview Site 2, Staff 32: "Sometimes when they've got dementia you know it's like you don't know them! And you can't get to know them because sometimes they don't communicate with you. So then it's like when you, when you're doing something quite intimate like helping them to have a wash or something, and it's like, you feel a bit, it's awful cos you become a bit detached because you don't know them. But then once you, you see a photo or you speak to the family about what they used to do, then sometimes you can talk to them about that because they can talk about things from the past. So you can say to them "Oh I heard you used to work at the mills" and then you'll find, then they'll go, we'll be talking about the mill then for half an hour, and then you feel like you've made a connection because when you're doing that you can see the delight, emotion or whatever in them... ...they must feel a bit better and think "Oh! She knows a little bit about me!" ...just something as simple as knowing their son's name or their daughter's name, and then you can often start a conversation like that and they'll start telling you about when they were little and things like that. So it's just making that connection with them."

These quotes demonstrate how the weaving of personal knowledge into interactions enabled people with dementia to connect with and take part in conversations, care and therapy activities in ways they would otherwise have been unable to. Each staff member above cites personal knowledge as the key to creating more meaningful interactions, in sharp contrast to the generic approaches to conversations and questioning which had to be used when personal knowledge was not available and which could be difficult for the person to understand and respond to. The last quote illustrates how this personal knowledge did not need to be in-depth, even simple trigger words such as the names of familiar others or previous workplaces could be enough to stimulate prolonged periods of interaction

6.4.2 Families' directly creating connections

As well as families' offering their personal knowledge to staff, they were often able to directly connect with people with dementia in ways that could be more meaningful and engaging than the connections that staff were able to effect:

> *Interview Site 1, Carer 1: "It's like the same thing over and over, and I know what words to say to trigger, or to get her interested in what she's saying and what will come next… …Because she hasn't done anything (in hospital), and it's all the past".*

> *Fieldnotes Site 2: I explain to Emmet that it looks like his wife is visiting him (I can see her coming down the ward) and I ask if it makes a difference when she visits and he says 'Yeah' and 'Otherwise you're just sat gawping'. On another occasion several of Emmett's family visit; although he remains difficult to understand he is regularly included in their conversation. At one point he recites riddles he made up for his daughters in childhood which have unusual answers which they respond with, such as 'quarter of an old bun'. His daughter and sometimes wife join in with the rhymes and prompt him when he gets stuck and then he carries on again and they all laugh at the end of each one. He mumbles some of the words so that I can't make them out but his daughter recognises what he says because of her familiarity with his rhymes, repeating or reciting them for him when he can't find the words.*

These quotes demonstrate again how key bits of personal knowledge, such as trigger words and knowledge of the person's past, were a highly effective stimulus for engaging with people with dementia. Whilst some of this knowledge could be conveyed to staff, ensuring it was shared and used by the large and busy care teams could be challenging. Although families also faced challenges connecting with relatives with dementia, their in-depth knowledge of the person and his or her life could help to overcome these challenges and enable connections even with people who had limited language, advanced dementia or very impaired communication abilities, as seen with Emmet in the last example above.

6.5   Maintaining connections with significant others

Maintaining connections with family during hospitalisation was often a key concern for people with dementia. Ailsa regularly demonstrated this, using her daughter's visits to check repeatedly on her welfare and that of her housebound son (with whom they lived), by repeated questioning of her daughter during her visits:

> *Fieldnotes Site 1: 'Ooo how's Mark? asks Ailsa with her typically wobbly voice that often sounds close to tears. Clara doesn't reply. 'What day is it?' she then wails gently, followed by when she doesn't reply 'When did I last see ya?' 'Yesterday' says Clara. 'Oooooer' says Ailsa appreciatively, adding with even greater appreciation 'And you came to see me yesterday as well!!' 'How's Mark?' she asks again soon afterwards. 'Alright' says Clara. Their conversation repeatedly comprises of Ailsa seeking reassurance or asking questions about how Clara and Mark are.*

Many people with dementia appeared to attach great value to their connections with significant others and the opportunities that visiting times offered to maintain connections with these close relatives and friends. Visits from families, and the opportunity to reconnect with them, could be so valued that these often seemed the highlight of their day:

> *Fieldnotes Site 1: I ask Ray if it makes a difference when he gets visitors. He says it 'brings a smile to my face' and that when his lady friend came he didn't know she was coming and 'it made my day'. He tells me how he has one granddaughter who lives nearby. He says she is visiting tonight, adding that he hopes she brings his great grandson, a broad smile spilling across his face as he says this.*

People with dementia could appear visibly more relaxed when their families were present, or even just when engaged in conversation about them, in contrast to the repeated searches and questioning made by some people (as described in Section 5.2.2.1) when these familiar faces were not present.

Families also valued connecting with their relatives and maintaining relationships with them so highly that creating and maintaining connections with the person, connections which relatives often suspected were otherwise largely absent, could form one of the key aims of their visits:

Fieldnotes Site 1: A grandson tells me that he and his mum come to see his grandma who has dementia every day to chat as otherwise she is 'staring at the four walls'.

Fieldnotes Site 1: Ray's daughter tells me about the visiting rota she arranges for her dad, which mirrors the visits from close family he gets at home as much as possible. She tells me that she always tries to get someone to visit, later talking her dad through who is coming to see him and when, mentioning his sister, daughter, granddaughter and lady friend. She tells me the lengths she has taken to ensure there is someone to visit and spend time with him at each visiting time.

Much of the focus of families visits was on maintaining the person's connections with significant others and familiar life, with families bringing news or photographs of family life and happenings outside of the hospital, helping people with dementia to maintain connections to their usual world. The effort that went into maintaining some of these connections, such as the visiting rota above, indicated the degree of value and importance families attached to them.

6.6 Better connections creating better care: The use of families' knowledge in staff led care

Utilising families' knowledge or their direct involvement on the wards could go beyond effecting better connections to improving the care provided to people with dementia. When families imparted to staff knowledge about how to connect with their relative, by describing the person's unique communication habits and the meaning behind their words or actions, it could make the difference between whether or not staff could identify and meet even the most basic of care needs. Without such knowledge staff could be unable to understand people with dementia's behaviours or expressions of need:

Interview Site 1, Staff 10: [speaking about how family knowledge affects care] "…the whole care really, you knowing their needs. I think with people with dementia it's all key about if they're doing cer…, you know acting in a certain way, or certain behaviours that they may be, you know, expressing that they need something. It's usually a lack of

needs… …and if you've liaised with the family, the more information you have. They might say 'well actually when they do this at home it's because they need the toilet'… …I'm sure a lot of the healthcare's we've got on then would understand if they spoke to families who are, you know caring for someone, what maybe it's like and maybe we'd appreciate it more, and understand the behaviours and not, and think well actually the person might want, need the toilet or whatever, I think it'd be quite good all around really... … it's just simple things like that isn't it? Knowing just, just key things really."

Interview Site 1, Staff 11 and 12 (Different interviews but speaking about the same person): *Staff 12*: *"…like that gentleman we had the other week who used to say no instead of yes, he'd say no and he meant yes. And it wasn't until his son told us and he'd been here a few days and he'd been asked if he wanted extra meals and he was saying no, and he was hungry." Staff 11*: *"'Do you want some more dinner?' and he'd say no, so he wouldn't get anymore! But actually then he would be telling his son he was really hungry! … …That's a massive thing… …Cos anything, 'Do you want to go to the toilet?' 'No'."*

These examples show how families could hold valuable pieces of knowledge about how to connect with the person that were crucial to interpreting his or her actions and interactions and so to identifying any needs they were trying to express. Conversely, not knowing or understanding these communication habits, as identified earlier, could prevent identification of even very basic care needs such as hunger, pain or needing the toilet. Alongside improved provision of basic care, knowledge from families could also enable staff to engage people with dementia in more complex care activities such as assessments or therapy tasks:

Interview Site 2, Staff 20: "If you can spend … quarter of an hour talking to … a patients' relatives or somebody, you know, spouse, then it gives you so much, it gives you a better picture. They sometimes give you tips on how, what motivates them and then so the next day, they'll come back and be, even if you see them for half an hour, you can be a lot more productive with that half an hour having held the conversation."

Families connections with and knowledge of their relative could also help to establish how the person with dementia was presenting compared to their usual levels of functioning, health, and well-being.

When changes in the person's health or care needs were difficult for staff unfamiliar with the person to identify or for people with dementia to convey, family members could often recognise signs suggesting their relative was different to usual, unwell or in need. This could be the case even when the person had advanced dementia and their means of communicating verbally was much reduced, as these series of interview quotes from the son of someone with advanced dementia illustrate:

> *Interview Site 1, Carer 2: "….there's always a build up to these infections, it just doesn't happen overnight. He'll start getting more agitated or he'll stop eating or he'll start swearing a lot at my mum and so we know it's building up."*

> *"….if he's really bad, when we was, for a couple of days in the hospital, er, then I can tell because he'll be swearing at me and telling me I've never been to see him and what an awful son I am, I mean, he goes through all this when he's really bad… ….usually, the last thing that he starts doing different is refusing to get out of bed because he says he's too weary, he's too tired."*

> *"….now that he can't do much I can't say 'well he's no longer doing this and he's no longer doing that' because he can do very little for himself anyway, so he's been virtually as good as he's going to be. Again, coming back to yesterday, you can tell though when something's amiss."*

This example demonstrates how nuanced changes in the behaviour of people with dementia, including how they connected with familiar others, could indicate changes in their health or care needs which would be difficult for staff unfamiliar with the person to recognise. Whilst these indicators of change might be obvious to families, they might not be recognised by or revealed to staff during their limited connections with people with dementia, particularly if the signs involved differences in how the person interacted with significant others.

As changes in connections and behaviour sometimes indicated unmet needs or worsening health it was not only important that family were able to recognise and convey these signs to staff, but also that staff valued and responded to this information. Failure in any of these steps could reduce the quality of care, health, functioning or well-being of people with dementia. However, as will be explored

further in Chapter 7, knowledge from families was not always sought, valued or used, either at all or in a timely manner. Failures to act upon family's knowledge were especially likely if staff had questions over the family's credibility or held an opinion that differed from that of the family:

> *Fieldnotes Site 2: MDT Meeting: Emmet is described by the doctor as a 'delightful' man who has come in with a now treated delirium superimposed on dementia. He says his wife was concerned that over the weekend he was a bit more confused than normal but 'I'm not sure if that is the case' followed up with 'I don't think that's the case', as if he doesn't agree with Emmet's wife. A member of the therapy team then says that she did stairs practice with Emmet today and he 'nearly fell multiple times' and that he is 'more confused today'. 'Ah' says the doctor, 'So he is more confused'. The doctor then suggests they could 'throw a chest x-ray into the mix and suggests that it could be 'another superimposed delirium'.*

This example illustrates how a family's knowledge needed to be sought, valued and used - acted upon in this instance - in order to improve the care of the person with dementia. Failure in any of these steps could lead to delayed or missed opportunities to identify aspects of the person's care needs. For example, failure to value and respond to the signs of infection identified by Emmett's family could lead to a delay or failure to treat an infection and a resulting delirium which could cause deterioration in the health and cognition of an already frail older person. Therefore it was not only connections between families and people with dementia that facilitated better care, but also connections between families and staff, through which knowledge about the person could be conveyed and used to inform care decisions and delivery. The use of families' knowledge to inform decision making is explored in Chapter 7.

6.7 Better connections creating better care: The use of families' expertise in staff led care

When families were more directly involved in care, their connections with the person meant they were often able to encourage, explain to and relax people with dementia

in ways that staff could not. Families' presence could thereby enable people with dementia to take part in care and therapy activities that they might otherwise find confusing or incomprehensible and so struggle or be reluctant to engage with:

> *Interview Site 2, Staff 20: "…cos they might do more when family's there! I often do, I find patients who, when there's a familiar face there, somebody that they know and recognise and almost relate… being able to walk with that person! They can do a lot more, they've may be got more motivation or they are more orientated."*

> *Interview Site 1, Staff 2: "We often find with patients that have got severe cognitive issues, is family members can be very useful to help kind of get the best out of the patient."*

> *Fieldnotes Site 2: The staff nurse comes along again and I ask her if Jessie has eaten anything today for them and she says she hasn't, she has only had one sip of Lucozade. She says she is better for her daughter.*

Notably, the staff who provided the interview quotes above were therapy staff or more senior nursing staff, with dementia expertise (professional or personal), who appeared to more readily appreciate the value of family knowledge and engagement for people with dementia, having sought or used such knowledge to enhance the care they delivered. However, even these staff did not typically elicit personal knowledge or engagement with family members at the start of an admission. Knowledge-seeking from families, particularly about the person, was neither a focus of the wards' admission or subsequent paperwork nor a priority for many staff. The need for consultation with family was often not obvious until a diagnosis of dementia became apparent or when an MDT meeting (with senior and often more family-focused staff present) highlighted a collective lack of knowledge about aspects of the person and their care needs.

The following extracts of data from one of the case studies (John) include examples of the presence and the absence of engagement with his son, thereby illustrating the value of timely engagement with families and the problems that could arise when family involvement was not sought. The data illustrate how, when families were involved in care, they could facilitate connections with people with dementia which

helped to engage them in care and therapy tasks - and to retain connections to their remaining abilities and ways of functioning. In contrast, failures to involve families in care and rehabilitation could contribute to difficult-to-reverse disconnections from prior abilities and levels of functioning, leading to increased care needs after discharge. John, who had advanced dementia and often struggled to communicate with staff, provides a good example of this phenomenon. Data from across his admission illustrate how the challenges of maintaining his connection to one of his few remaining abilities, transferring independently, were largely overcome when his son facilitated his connection with rehabilitation sessions. However, during the long periods of time that passed without the involvement of his son, John lost the ability to transfer independently; an ability which his return home relied upon. Maintenance of this ability had formed the primary reason for his referral to the rehabilitation ward, from his son's perspective, and he was discharged to a care home as a result:

> **8/5** *Medical notes from admission ward: "Therapy assessment with son present. Chair to bed with hoist and assistance of two. Bed leaver put in place. Transferred bed to wheelchair with banana board with assistance of 1 and support of 1 and then back to bed. Good use of bed leaver."*

> **11/5** *Medical Notes from rehabilitation ward: "Initial Therapy assessment - Unable to fit bed leaver to bed. Transferred with banana board, managing banana board extremely well, minimal prompting required."*

> **14/5** *Medical Notes: "Refusing to use banana board."*

> **15/5** *Interview 1, John's son: "The idea (of him coming to rehab) was to see if they could get him to use his banana board... ...That's his only means of moving on his own cause he hates the hoist... ...I've just been told now that they're not using it here... ...I'm quite surprised that they seem to have abandoned the banana board at such an early stage... ...I saw him do it in acute ward name with no trouble at all. When they're clear what's happening they'll tell me! ...The problem with my dad is he feels totally useless... ...cos everything he does is in someone else's hands. He can't go to bed until they come, he can't get up until they come... ...He can't wash himself, he can't go to the toilet on his own... ...the one thing he can do at the moment is shuffle on his bum from a bed to a wheelchair... ...to me the only advantage of coming here, was to make him a bit stronger to be able to do that. And it would appear that that's not happening."*

> **15/5** *Fieldnotes: The nurse tells the physio they have been 'having to hoist him'. The physio replied that she's 'only seen him once' and he was 'able to use the banana board'*

but that he had 'difficult with lie to sit'. They mention the bed leaver he doesn't have and the physio says she has 'got down to see him tomorrow morning''.

16/5 *Medical Notes: "Therapy assessment. Assistance x3 lie to sit. Unable to use banana board. If still needs assistance of 3 may need placement."*

24/5 *Fieldnotes: MDT - The physio talks about rolling John in bed, saying it 'needed 3-4' and that he is 'so scared he can't retain or understand what's happening', explaining that he was 'anxious and distressed' and that it's 'unfamiliar surroundings' and that he was like that 'even with someone constantly reassuring him'. She then says 'I think we've missed the window of opportunity with him' going on to describe him as 'more disabled now' and that she will 'try to catch the family and give them a bit of a courtesy call. Say what we've been doing in therapy'.*

30/5 *Medical Notes: "Seen with son. Agreed to attempt patient sitting out of bed to wheelchair with banana board. Struggled lay to sit as unable to fix bed leaver as is at home due to cot sides. Needed assistance of three throughout lie to sit, slides and banana board transfer. Son gave lots of verbal encouragement. John limited by lack of bed leaver – used at home for a long time and son confirmed bed mobility would be improved with this in situ. Ward beds not compatible with leaver. Improved today from last transfer as son very helpful in helping patient feel calmer."*

Interview with Staff Member: [speaking of the therapy session involving John's son] "I think his son just kind of chatted with him if that makes sense… …according to the son he knew the football stadium... …And his son was trying to encourage him to kind of sit up and look out of the window that way and kind of keep his dad's interest really in what we were doing. And of course John was kind of going "oh no, no I'm not doing any of that, I'm not, I'm not doing that." And his son would be like "Come on Dad, I know you can do it!" And he was really good at encouraging him, and with that encouragement John was a lot happier and he was smiling. He seemed a lot less distressed. He wasn't clinging on to things or on to people. He was a lot happier. He was actually following instructions better from us with being a bit more settled and calmer as well."

31/5 *Fieldnotes: MDT – Staff member says she had a 'joint session with son yesterday. Did actually manage to get him using the banana board' but that he still needs three of them now. She says he's 'used to using a bed leaver but we can't fit it here due to the beds. Might be if beds at care home can have his leaver fitted....' She continues about the nursing home 'expect they'll still hoist him' and comments 'He did manoeuvre himself better round the bed' and that his 'son was really good'. She says it is difficult as he's 'so stiff and can't roll' and that his 'son was keeping him happy so he was relaxed' and so he moved better.*

31/5 *Medical notes: "Carry over limited, mainly hoisted for his and staff safety. No further input required."*

Post-discharge Interview with John's son: *"I still believe, rightly or wrongly and I'm no expert, I still believe if the handle that he had on the bed at home would have fit on the bed here with a little bit more effort, he could've banana boarded. I honestly believe that. But the handle wouldn't fit on the, if he'd nothing to hold on to when he sat up he was petrified that he was going to fall and wouldn't do it, the handle wouldn't fit the bed so they abandoned banana boarding. Again I can understand why but I do believe he would still be able to do it…"* Interviewer: *"Yeah. Did you, am I right in thinking that you came in at one point as well to help them with…?"* Carer Two: *"Yes. And that's when I realised that they weren't putting the handle on the bed"*. Interviewer: *"Right, I see, so before that you hadn't known that then?"* Carer Two: *"No. I thought he just couldn't banana board. And at that point I told them, I said there's no way he will do it, if he hasn't got that handle on the bed you're just wasting your time. I assumed, wrongly, that it fit on and he was failing, you know, he was failing to do it even with that on… …I suppose the message comes from here (the hospital) to the officer in charge of the home, he can't banana board therefore he's hoisted, full stop."*

This example illustrates the difference that a family's presence can make to the delivery of care. Families' connections with people with dementia could increase the ability of staff to deliver care and to work effectively towards the regaining and retaining of previous abilities and levels of functioning. It also demonstrates how failed or untimely engagement with families could contribute, alongside physical ill health and a lack of familiar equipment and opportunities to practise familiar routines, to the loss of highly valued abilities and independence. The delay of 22 days in engaging John's son in therapy activities meant that his input came at a time when the "window of opportunity" to retain John's crucial ability to transfer independently had already been "missed", resulting in discharge to a care home where he would be permanently hoisted. This episode illustrates how failures or delays in connecting with families and people with dementia could contribute to negative outcomes following hospital admissions. Delays in connecting with families could also leave them initially unaware of deterioration in their relatives usual functioning, giving these deteriorations time to establish and reducing families' opportunities to try and reverse deterioration. Once again this points towards the need to forge connections with both people with dementia and families, and to do so in a timely matter if the benefits of family engagement are to be maximised. In John's case, the lack of timely and consistent engagement with his son contributed to a lack of recognition and focus from staff on retaining a connection to John's

remaining abilities, thereby affecting his ability to remain living at home. Instances such as this - of divergent priorities between staff, families and people with dementia - will be explored in more detail in Chapter 7.

John's case illustrates an inconsistent approach to working with families; engagement with John's son varied from absent to high levels of engagement, although not optimally timed to benefit John's care. Such inconsistencies were seen with other families too and meant that the ability of some families to provide valuable knowledge about their relative, and to connect with and encourage their participation in care, was not regularly recognised nor used as a resource despite the many benefits the engagement of families could bring:

> *Fieldnotes Site 1: The grandson of a lady with dementia who does not speak English tells me he is happy to come in and help the staff having given them his number and offered to help three weeks ago. He says they haven't asked him up until now, telling me that he is coming in tomorrow for the first time to help with a therapy session. He says it is like you have to keep saying the same thing and that he has told them repeatedly he will help and then when he comes in and asks how it is going they say that it is difficult but haven't asked him to help. He says that when he asks why it has been difficult they don't know because they haven't been able to talk to his Grandma. He tells me how when he accompanied her for an x-ray the staff couldn't get her to do what they needed, but that when he explained that she needed to cross her arms and lay still she understood and was able to do it. He says an interpreter wouldn't be able to understand her either because of her confused answers and the confused way she talks, giving an example of how they might ask a question and she might talk about going to get her shopping instead and that an interpreter would obviously just feed that back to the staff and they wouldn't know what to do with that, but that he would understand where she was going with that, and what she was talking about, and respond accordingly.*

6.8 Better connections creating better care: families directly providing care

As well as supporting staff to undertake care and therapy activities, some families provided high levels of hands-on care to their hospitalised relatives. These included family carers who took on significant care-giving roles that would usually have been performed by staff:

> *Interview Site 1, Staff 10: "We had a lady in who, who wanted her daughters to come in everyday and help her to get, do all her personal care, she didn't really want the staff to do it."*

> *Interview Site 2, Carer 25: "they used to ring me up sometimes and say you know "she won't take it" or this, that and the other so I used to go down and I used to give her the medication three or four times a day when she needed it. When they wanted to wash her and change her they couldn't do it, so again they used to have to ask me."*

> *Interview, Carer 3: "I have mopped him up if he were sick, I've helped the nurses if his bed needed changing or if he wanted hitching up the bed a bit. I helped him wee in those little pots. I've helped him go to the toilet, wash him down if he needed. Do you know I did quite a lot and I think the nurses were quite appreciative of me being there because I did a lot, I did what I could anyway, what I knew." Interviewer: "And how did that come about do you remember did they kind of ask or did you just think or?" Carer 3: "No. He just, he were lying in bed and he said oh I need the toilet and I were like well oh shit what do I do, what do I do, and I were like Oh my God and he were like Toya quick, quick! So I just grabbed the thing and then it just started from there. I thought I'm, I, I took a step back and thought I'm capable here of doing a little bit more... ...So, I just, I just did it. It, it were just, it needed, do you know, it needed doing and I took that step and I did what I had to do really ...I mean I was scared at first I mean er do you know physically lift him because I didn't know whether I was going to hurt him or whether I was going to make things worse. Whether do you know, but I did it, I think instinct kicked in really and I just, I did what I thought he, he needed doing so."*

These examples of high levels of involvement in care indicate the great variability that existed in the degree to which families were engaged with by staff and involved in the care of relatives with dementia. They also begin to explain some of the reasons for this variability; these instances typically involved family members who

had a close connection to the person with dementia and were initiated in response to the person refusing care or preferring to receive care from someone familiar, or by relatives wanting to ensure that care was given. Explanations for the variation in engagement with families are explored in more detail below.

6.9   Variability in connections with families

As with connections between staff and people with dementia, varying degrees of connection were noted between staff and families. Although there were many examples of engagement with families having benefits for people with dementia, such engagement was not routine. Families received varying information and responses regarding their involvement in care, which ranged from discouragement and restrictions to their input (on both wards in the study) through to receiving permission and being invited and welcomed to contribute their knowledge or participate in care.

Varying degrees of engagement with families were present at a ward level. Wards within the same hospital Trust differed in their approach to visiting hours; whilst some wards strictly enforced visiting times others did not, with the senior staff (sisters and consultants) particularly influential in shaping the ward's approach to visiting times and ward clerks (the principal gatekeepers) instrumental in conveying their understanding of the ward's visiting ethos to families:

> *Interview Site 2, Staff 32: "Cos our wards doing that (being more flexible about visiting times) and then the other wards aren't! But it's like, I don't, well why isn't it ok really? Do you know what I mean! It's their relative and they're vulnerable because they've got dementia so locking them out and saying you can't come in till 2 o'clock, what does that, what does that say?"*

> *Interview Site 2, Staff 20: (Who regularly rotates wards, speaking of what influences the focus on family engagement on the ward) "It's the sister. But then the sister employs the nurses so she'll look for people who are, you know, think along the same lines as her... ...You definitely tend to like adopt the kind of, the general feeling of the ward and*

you do things as everyone else does… …And I suppose the, I mean the junior doctors follow the instructions of the consultants so, although they haven't been chosen, it does feed down I think quite a lot."

Fieldnotes Site 2: Staff 21 (a senior member of staff) says she sees visiting times as 'guidelines not rules' but they are treated as rules on other wards she has experience of from her senior role. I comment on how there are only metres between this and the opposite ward and yet their approach to visiting times seems different and she comments that it is 'down to me', going on to say that it is also down to their ward clerk, talking about a ward clerk on another ward who wouldn't let visitors in until 2pm so a row of visitors would build up at 5 to 2. She also talks about a consultant on another ward who refuses to meet with families.

Strict interpretations of visiting and protected mealtime policies could limit opportunities and encouragement for families to spend time with their relatives to undertake care-giving roles and spend time with people with dementia:

Fieldnotes, Site 1: "A gentleman is buzzed onto the ward. He comes in and starts walking straight towards the day room. The ward clerk says 'Excuse me!' at him and he stops and says 'Visit'. She tells him pointedly 'Visiting hours don't start until eleven' to which he replies 'Just 5 minutes'. She says sternly 'I'll have to check with the ward sister'. The man says 'He's just there' and points into the dayroom at the man he has come to visit. After discussing the issue with another staff member she says to the gentleman '5 minutes' and 'In future come at the correct time'.

Fieldnotes Site 1: A girl comes onto the ward and says that she has come to see a patient and 'sit in her room whilst she eats lunch'. She tells this to an NA who then speaks to a more senior member of staff who tells her 'we have a protected mealtimes policy' and says it will be 'alright for today' but that it isn't something she can do normally.

Interview Site 1, Staff 10: "I think sometimes it's a bit restrictive isn't, like 'ooh, the doctors are coming and…' and even our visiting times have become a bit restrictive now… … but I think if we were more flexible, why not let someone come in and feed their relative at lunchtime if they needed help."

Notably, the majority of references to restricting and enforcing visiting times came from Site 1 where there was less of an ethos from senior staff towards a flexible

approach to visiting hours and to the involvement of families in care. On Site 2, the regularly present senior staff held, modelled, and repeatedly conveyed support for the seeking and use of families' personal knowledge. This support created a greater cultural expectation that some family engagement would take place, and more conversations and knowledge seeking from families were observed. Some staff at Site 2 identified the support from more senior staff as instrumental in giving them the confidence to initiate conversations with families:

> *Fieldnotes Site 2: Staff 21 tells me that she feels confident in speaking to families because she is supported by the consultants and their communication is good so they know what is going on and can pass that on, meaning they are not nervous of speaking to family on here, but that nurses on other wards can be.*

Differing approaches to family engagement between wards could also be seen in the way different wards within the same hospital could give quite different responses to the same family member's efforts to become involved in care. Carer 3 for example, after having been extremely involved on one ward in providing hands on care outside of visiting hours to her grandad, was told to adhere to visiting hours on the ward he subsequently moved to, which significantly restricted the time and level of input she was used to having with him:

> *Interview, Carer 3: "11 o'clock is such a crap time. And then I've got to disappear for when he goes for his dinner cos I'm not allowed to be there when he eats his dinner! ... And then it's like I might as well just go home then, just see him for an hour! ...I've not said 'owt because I know he's alright and I've felt comfortable in saying "Yes alright then I'll stick to your visiting hours" instead of demanding that I can come and be with him every day".*

These differing responses to the same caregiver illustrate how much responses to families could vary between wards. Carer 3's response also indicates how families' adherence to visiting rules was dependant on the well-being of their relative in hospital; with defiance against visiting restrictions more likely in circumstances where the care or well-being of the person with dementia was felt to be under threat.

Variations in responses to families' involvement were also seen within the same ward, with individual staff holding and enforcing quite different views on the extent to which families, including the same family members, should be present on the ward and involved in their relative's care:

> *Interview Site 1, Staff 12: (in reference to a gentleman with dementia who was often distressed and anxious to see his wife) "We did have one patient where his wife used to like, spend a lot of time here, and she used to play games and dominoes and things, and actually some of the staff were quite resistant to that and thought she was spending too much time, 'oh well it's visit... visiting's finished now.' Well, yes you know, and if we had all eighteen patients with all their relatives here, yeah it would be a problem, but actually she was keeping him occupied."*

As this quote demonstrates, not all staff agreed with restrictions placed on families and their involvement in care whether at a staff, ward or organisational level and there was great variability in staff responses to families. More flexible and positive responses to families were often explained by the care-giving context in which they occurred. Some staff would bend the rules to permit families to have greater access to their relative in response to special circumstances such as when family were visiting from far away or their relative was terminally ill. There were other good reasons for not adhering to the official 'rules'; when families had especially close care-giving relationships or were insistent of their need to visit more often, or when staff were struggling to care for the person with dementia due to challenges such as distressed behaviour or refusal to eat or take medications:

> *Interview Site 2, Staff 28: "I think we've had open visiting for some, I think if they're not settled on the ward and they're quite agitated and they're not settling and things like that."*

> *Interview Site 1, Staff 2: "Erm, sometimes if someone is struggling to eat, I know the nursing staff will get family members to come in, if the family are happy to do that or are wanting to do that... ...And if someone is getting quite distressed or what have you, they will allow them to come on if it keeps the patient settled and calmer and happier and the family are wanting to do it. Erm, I don't really know of any other ways that, if I'm honest, I don't really think they encourage too much else."*

Interview Site 2, Carer 25: *"…it was apparent that there was, you know, that there was problems because the nursing staff used to actually ask me to do things because they thought that they couldn't do it."*

Interview Site 1, Staff 10: "We had a lady in who wanted her daughters to come in everyday and help her to get, do all her personal care, she didn't really want the staff to do it. That's fine by me."

Fieldnotes Site 2: During a telephone conversation a nurse tells a daughter that her dad has 'absolutely, blankly refused to have a wash with us' and that she 'thought if you were coming in you might be able to persuade him'.

These quotes demonstrate how more flexible approaches to families' involvement existed but often happened when staff were struggling to meet the patient's needs, meaning that people with dementia with less overt or challenging needs could be given fewer opportunities to maintain care-giving connections with their significant others. Initiating engagement with families was often in response to a particular need rather than a routine occurrence; other reasons to engage included a need to discuss bad news, a complex case or to undertake a specific assessment:

Interview Site 2, Staff 27: "What I tend to do is, you see, well, see anybody who asks to see me, see families where there appears to be some centre policy decision we need to make, to be made, and those where there's a particular slant to the management you want to convey, and particularly if there's, you know, bad news. It's hard to see them all, and do the other things, but I don't know, in an ideal world I would like to see them more."

Interview Site 2, Staff 22: "You have a two hour span where every relative wants to speak to you and it's not always that easy, so you have to prioritise… …if you've got a ward full of relatives, even if you spend five minutes with every relative, your two hours is gone, and quite often the conversations aren't five minutes…"

Interview Site 2, Staff 28: "If they've been in for a while and they've been really poorly the doctors will phone the families for a chat just to keep them updated."

As these quotes indicate, the time required to undertake these conversations precluded them from becoming routine. As a result, some families felt they had

been kept informed and consulted with, whereas others felt excluded from decision making and unclear about their relative's current or future care needs:

> *Interview Site 2, Carer 23: [Speaking about a conversation with a doctor) "It was very helpful, yes, he explained it. That's why I hung, I knew the meter was ticking in the car park but I was so interested in what he was saying because he was explaining, as much as he knew, about it the condition. And that's what I wanted to know… …he explained it was permanent and there was at least I was finding something out… …I wanted to know what I was dreading… at least we were in the picture… …you could start then planning, from then on."*

> *Interview Site 2, Carer 21: "We weren't told about it (the care planning meeting), I think it was their notice board, and I saw 'JCM', and I thought what's that, so I asked somebody at the nurses' station and they said 'Oh it's a meeting that we're having on Wednesday, alright, you're invited if you want to come', and then I had to ring round the family and say we're having this meeting and everybody goes to it and this is what happens, you know. And it was sort of right at the last minute, I think the ward could have sort of involved us a bit more, really."*

The variability in responses to families between and within wards points to the lack of any standard approach to supporting the involvement of families in care or in the maintenance of family or care-giving connections. Even when a ward or an individual staff member did take a more flexible approach, this was not the advertised or routine approach so many families still adhered to the advertised visiting hours and rules (e.g. not to visit at mealtimes or cleaning days) which were often clearly displayed at ward entrances or passed on verbally by staff. The lack of an agreed approach to engaging with families meant that conversations with families about their options for involvement were often absent or reactive; instigated in response to complex patient needs or to concerns about potentially risky family involvement rather than proactive negotiations about how families could helpfully contribute to care. This inconsistent approach seemed to be at least partly responsible for a lack of clarity around what activities or care-giving roles families could undertake whilst a relative with dementia was in hospital:

Interview Site 1, Carer 1: Interviewer "You said you didn't know what was expected of you. I wondered if you could say what you mean by that?" Carer 1: "Em, how far I could go with my mum, what was expected of me or what I wasn't expected to do or touch or get involved in. Or leave to them, leave it to them… …it was things that I should be doing. I mean I did not even know if I was allowed to take her to the toilet or to, what things, you know, you can do and other things you can't… …You don't know what, what you're supposed to do, or what their thing is, I mean you don't want to be interfering with them."

Due to the lack of information, written or conversational, about opportunities to become involved in care, families who felt that greater involvement was warranted sometimes simply began to undertake such activities and waited to see whether there were any repercussions:

Interview Site 1, Carer 3: Interviewer: "You said you weren't sure, because you had been helping a lot at the other hospital, how much you were allowed to do here?" Carer 3: Yes I went to pick him up and do you know just to haul him out of his wheelchair and into his chair and a woman came up to me, she went "How did he?" I said "Oh I put him in there", she went "Oh no, no you are not allowed!" I went like why? She went because you're not, I'm not, not insured and if he falls then it's on my, do you know it's on my head. And I'm like no, well… nobody's ever do you know said that I'm not allowed to be hands on with him. So I had to take like a step back and think well this is a bit, I don't know whether I can do, you know, not be hands on with him."

Whilst this carer's attempt to 'haul' her relative out of his chair does not represent ideal practice, the lack of discussion with family members such as Carer 3, who was expecting to undertake a significantly increased care-giving role when her grandad left hospital, suggests that opportunities to teach care-giving skills to families who will be providing care after discharge are being missed. Reproaches, such as the one above, to families' attempts to involve themselves reveal how, despite the significant support families could provide for their relatives outside of hospital, people with dementia were often thought of in individual terms rather than as part of a care-giving dyad. Despite the variations in practice noted earlier, families were not typically viewed as potential partners in care, despite policy assertions that this should be the case, and the care-giving relationships that many people with

dementia and their families had outside of hospital were not routinely recognised within the hospital. Relatively little attention, at a ward, environmental or organisational level, was paid to understanding, maintaining or consulting with these care-giving dyads:

> *Interview Site 1, Carer 1: "I think they don't take into consideration, they don't consult the visitors, they just think patient. I know it's about them, but see the big picture, you know, visiting day after day after day."*

The lack of knowledge exchange with some families (including information about the roles they could undertake), and organisational policies that restricted families' access to the wards, created a sense that the hospital wards were predominantly staff domains. Families' claims to expertise were further questioned by practices which appeared to value knowledge exchanges between staff over exchanges with families. For example, staff could make extensive efforts to exchange knowledge with other professionals without making similar efforts to engage with families, and families were not always given access, either at all or in a timely manner, to valuable information held by staff, such as details of assessments, diagnoses (including dementia) and discharge plans:

> *Fieldnotes, Site 1: Carer 2 (who provides daily care for his dad) speaks to a member of staff about his dad's discharge date: "Right, well I'm not here that day, I've just told them that. No one told me anything". Later he explains "The homecare staff told mum he was coming home on the 23rd and I knew nothing about it".*

Such practices suggested that less value was ascribed to families' expertise, care-giving roles, and need for knowledge, despite the valuable knowledge and expertise that family members (such as Carer 2) could possess. The lack of engagement observed or reported between some families and staff, even with longer or more flexible visiting hours, argues against approaches to families that significantly restrict their access to hospital wards. The data presented in this chapter suggest a need for more proactive discussions about families' and patients' preferences for the involvement of families in care.

Suggesting that families' involvement should be encouraged implies, however, that connections and care provision involving families is uniformly positive. Although difficulties in interactions and relationships between staff and people with dementia were set out in Chapter 5, relationships between families and people with dementia have largely been presented as unproblematic. But, as with relationships with some staff, negative interactions between families and people with dementia were sometimes evident and had the potential to detract from the person's well-being. This chapter therefore concludes by exploring examples of less positive care-giving and connections between families and people with dementia, and the impacts of these negative behaviours.

6.10 Concerns about the involvement of families in care

Although the data collected in this study implies that greater family involvement could benefit patients, staff and families, the effects of families' involvement were not uniformly positive. Concerns about the care-giving abilities of some families suggest that a standard open approach to involving families as caregivers could be difficult. Not all families had the knowledge, skills or physical ability to help their relatives to a professionally acceptable and safe standard. Concerns about the risks and legal liabilities when families were allowed to provide care meant that staff routinely undertook or supervised tasks, creating further variability in approaches to families' involvement:

> *Interview Site 1, Staff 2: "If the patient is quite independent and quite ok, it depends on the family member that is supporting them. Cos some family members think they can do all these weird and wonderful things and you look at them and you think you can barely walk yourself. It's not safe for you to assist someone. So we tend to, it's a matter of clinical reasoning and judgement call. It's, I tend to say is always make sure a member of staff is with them. Just cos then it covers our backs if anything God forbid happens to the patient... ...cos sometimes family members don't always supervise or assist the way that we would want them to. And you can't expect them to cos they are not obviously trained to know how to assist them with their walking if they are far from*

their normal so we do tend to suggest take a member of staff with them. But I know sometimes you catch the odd family member like I caught a gentleman walking down the corridor with his wife and I kind of intervened like but, you know it's, it's just keeping an eye on those things really."

Interview Site 1, Staff 10: [Speaking of families trying to help patients] "Yeah they will try and help them, I think sometimes it's tricky that isn't it in the hospital environment, sometimes we'll be saying 'oh you know, we'll take them if the falls risks and things cos, we'd be in a bit of a stump I think if something happened and the relatives were taking them. So that's probably an area that could be looked at, cos from an insurance point of view, I think there are issues there. Some staff'll say 'oh gosh you know, you can't walk with them', which is exactly what they'd be doing if they were at home (laughs) 'We'll do it'. And that's maybe then taken away isn't it… …I mean I tend, if they're fairly steady mobilising and what have you, but if they are a huge falls risk sometimes you do, I've probably done it myself actually, take over thinking 'oh gosh', especially if the person's frail themselves. If they fall over and knock them over, erm, they'll be thinking we'll be getting sued through the roof. But that's wrong isn't it, but that's the nature of how everything's going, you're always thinking of claims aren't you…"

Alongside concerns about the ability of some families to provide safe care, caution was voiced by staff at both study sites about the negative impacts they felt that the involvement of families could bring. These concerns primarily centred around disruptions to care-giving and the additional workload visitors could cause for staff - concerns that had contributed to both wards reducing their visiting hours (one in recent years and one during the study) so that official visiting times at both sites by the end of the study were in two 2-hour blocks per day:

Fieldnotes, Site 2: Staff 21 tells me their directorate's visiting hours 'were 12-8' but they changed it several years ago because the patients weren't getting any 'down time'. She later says they changed visiting hours to reduce infection and reduce the throughput of visitors though the hospital and that it 'has made a difference I think' looking questioningly towards a more junior member of staff who nods in agreement. She tells me that she would have visitors here every other day if she could and that they do advise that visiting is 2-4pm, and to be honest it is lovely on a Wednesday when it is cleaning and no visitors come, and they have time to care for patients properly and give

the care they want to. She goes on to describe how visitors are 'at you' at the desk all
the time and it never stops.

This quote encapsulates various concerns that staff voiced regarding families, including their potential to conflict with care provision or infection control, suggesting that engaging with families was not viewed as a core part of ward work. Comments by other staff members indicated similar caution regarding open encouragement of visitors; there seemed to be a threshold level of engagement past which the involvement of families became viewed as encroaching on the work of the staff. Reductions in visiting hours, however, did not seem to alleviate the concerns that staff voiced about the demands or effects of visitors, or meet the engagement needs of families and staff. The more limited opportunities for families and staff to interact caused by the shorter visiting hours at Site 2 sometimes led to several families waiting at the desk to speak to staff during visiting times or to families and staff being unable to connect with each other:

Interview Site 2, Staff 20: "We obviously only catch the first visiting hours you know 2 till
4, so a lot of patient's relatives we'll never see. Cos if they work at all then they are
going to work till, for the afternoon and then come in 6 till 8."

Interview Site 2, Staff 22: "I've worked places where it (visiting) has been kind of an all
afternoon type thing and... ...you're not having to cram in eight different family
conversations into two hours."

6.11 Families creating disconnections

Although many examples of positive connections between families and people with dementia were observed, relationships between people with dementia and their families were not uniformly positive and family involvement was not always beneficial for people with dementia. The presence of families could contribute to disconnections by diverting interactions away from the person, who might thereby become excluded from discussions and decision making about their future care and lives. For example, some family members answered for people with dementia, or

staff automatically interacted with or sought information from families instead of the person:

> *Interview Site 1, Staff 7: "I think unfortunately it's very easy sometimes to just think I'm not, never going to get anything out of them, I better ring the family, and to a certain extent that's fine, it gets you to the end point but you don't know that patient then and that's the problem, it's quite difficult".*

> *Fieldnotes Site 2: A staff member asks Emmett's wife and daughter, who are sitting near him, 'Has anyone mentioned people coming in for a couple of days when he goes home?' His wife doesn't seem sure, so the staff member mentions that it would be to help out a bit and Emmett's wife says she thinks so. The staff member explains that they will come two times a day to see if he is getting on ok, and if he needs help with anything, giving examples of helping him to get up and dressed. She says that if he is managing ok it will just be for a few days, or if he needs a bit more help they will stay for longer and arrange homecare if needed. They talk at the end of the bed for about 5 minutes about the care Emmett will need. I'm pretty sure that Emmett, with his hearing difficulties, cannot hear any of it. I stay crouched down by Emmett listening, and he says to me after a while 'Can you tell what they're saying?' and so I tell him that they are talking about his stairs at home. The staff member and his family do not include him in the conversation at any point.*

> *Interview Site 1, Staff 10: sometimes families do say 'oh you know, you're better getting it from us, they don't really know themselves' but if you actually sit with them, it's surprising that they'll tell you a lot about themselves so I prefer to do it with them… …I think there's a lot of presumption that, that people can't really tell you what they want and they can." (Staff member with dementia training)*

Further negative consequences of family involvement for people with dementia could arise due to strained past relationships or the stress of caring for someone with dementia, especially around the time of a hospitalisation. Interactions between families and the person with dementia, or with ward staff, could be fraught and irritable as a result. In addition, families did not always know how to respond to their relative's confusion and could express overt frustration at repeatedly going over the same conversations:

Interview Site 1, Staff 11: "Sometimes if they have reached crisis point, it's an ideal opportunity for them to take a step back and not be involved! …You can see their irritation levels with that person are obviously very high by that point. They are trailing in, you know getting 3 buses to get here and things like that. I mean it's not beneficial for anybody then when they are irate with each other in the day room or whatever. Interviewer: Right. So that happens then does it? Staff 11: Oh yes. Yes! It can do because the person with dementia is saying 'you've never visited me' and they've only been there 3 hours ago! You know and you can see them sort of (upset voice used) "I do everything and I'm always here!" And yes, yes, it's hard!"

Fieldnotes Site 1: A daughter is loudly explaining to her father why he is in hospital, telling him 'you're not fit to be at home on your own!' She tells him loudly what to do 'Don't blow it!' and again, with an accusatory tone, 'You're making it worse!' She is referring to his nose, in which he has a nose bleed. She repeatedly makes comments with a critical tone, sounding frustrated and stressed, 'It's running again, your nose!' 'Hold it up to your nose!' 'It's going everywhere!' followed by a barked re-iteration of 'Hold - it – up – to – your - nose!' and a 'You're making it worse!' After a while a staff member comes over in response to the noise 'Hello Sir' he says. 'I don't know what it is' exclaims the daughter adding 'I've <u>told</u> him'. Later they talk about his lunch coming and he says in response to discovering she won't get lunch 'I'll pay for it out of my brasses'. She responds with exasperation 'Of course you don't pay for it here! You're in hospital!'

High levels of expressed emotion between relatives and people with dementia created negative connections which were not beneficial for either party and detracted from the person with dementia's well-being. Families' emotions and concerns at what was invariably a difficult time could also negatively affect people with dementia:

Interview Site 1, Staff 2: "it tends to be more the anxious family members that are really overly anxious that tend to be a little bit more difficult cos they kind of over-worry themselves or over complicate things which can of, as I said, that ends up passing on to the patient. The patient then starts worrying about everything unnecessarily."

Connections between families and people with dementia could also be problematic because family members were not uniformly skilled in understanding and responding to their relative's confused talk and actions, particularly if the person's

communication abilities or behaviour were different to usual. Families did not, therefore, invariably know more than staff about how best to connect with their relative. Although staff typically lacked in-depth prior knowledge of the person, they could understand more than families about the person's current communication and cognitive abilities. It is staff who have clinical training and experience (sometimes including dementia expertise), access to the person throughout the day, and privileged access to the person's hospital records, all of which can leave them better equipped than some families to understand and respond to distressed, difficult and challenging communication and behaviour:

> *Fieldnotes Site 2: A relative comes up to the desk looking anxious. She says to Staff 21 that 'he is holding a water jug in his hand' and 'seeing red' and she is worried he is going to throw it. Staff 21 says he is 'not as bad as yesterday' to which the relative exclaims 'Oh gosh!' as if he must have been really bad yesterday. Seeing that the lady still looks worried and anxious Staff 21 softens her voice and says sympathetically 'It's just difficult, really hard isn't it, when you're not used to that?' She continues that she is 'coming down in a minute' and 'I'll come to you first'. 'If you could' replies the lady adding 'I daren't take it off him, I'm worried that he's going to throw it'. After she's gone Staff 21 says of the lady 'I've just told her he's delirious' as if the lady should then understand why her relative is behaving the way he is.*

> *Fieldnotes Site 2: I talk to Staff 21 about a lady with dementia who shouts out a lot. She tells me that her daughter has been in and said 'She's always been like this love' and 'She'll do your head in, she does my head in'. Staff 21 says that the daughter 'doesn't understand' and 'I knew the first I met her, she won't soothe her'.*

These examples illustrate the potential for staff to have greater expertise in connecting with confused people than family members, Staff 21 above for example being a senior member of staff with many years of experience in elderly care.

Inconsistencies in the quality of relationships and care-giving skills of families suggest that wards may be justified in showing variable and ambivalent approaches to involving families. It would plainly be better, however, if variability in the degree of family involvement was in response to proactive consideration and discussion of the person with dementia and the families' needs and preferences rather than the

piecemeal and reactive arrangements that often occur in practice. The poor understanding of some relatives about dementia and their relative, together with the stress and strain many families were experiencing, are all opportunities for staff, particularly those with dementia expertise, to intervene to educate and support family members or to model how to interact with a confused person. Families' negative relationships and poor care-giving skills or knowledge are not reasons for staff to avoid engaging with them. Instead, such families might need to be engaged more rather than less in order to upskill them for their current or future care-giving roles. In this study, however, the knowledge and support needs of families were not always met. Some families received very little information about their relative's current health, functioning, abilities, and cognitive state - in some cases not even having been told that their relative had dementia. The types and degrees of knowledge held by families, staff and people with dementia, and the influence of these different knowledge pools on care and decision making will be explored in Chapter 7.

6.12 Chapter Summary

Chapters 5 and 6 have demonstrated how disconnections from pre- and in-hospital life were not simply present or absent, but existed on a continuum with great variability in the degree to which staff used opportunities to effect connections with people with dementia. Whilst disconnection was a common experience, there were also examples of staff members using the opportunities and knowledge available to them to effect more meaningful connections, with the involvement and knowledge of families playing a central role in facilitating connections that formed a crucial component of providing more person-centred care.

The intention of this thesis is not to criticise staff who were typically trying hard to care for people with dementia in challenging circumstances and where under-staffing and highly demanding, time-limited workloads were common. But the data suggest that the delivery of more person-centred care in hospitals requires hospitals

and staff to use the knowledge and resources of families more effectively. The data also indicate that better engagement with families in isolation is unlikely to be effective without addressing factors that do not prioritise or actively detract from connecting with people with dementia and their families - such as the environment, staffing levels, staff education and expertise, and cultural and organisational priorities and policies.

Although family engagement did not uniformly benefit people with dementia, most examples of the presence or absence of such engagement suggested that when families contributed their knowledge or expertise, it often helped to ameliorate disconnections experienced by people with dementia. It was also apparent that staff who engaged with families viewed such involvement, and the knowledge it produced, as beneficial: aiding work such as information gathering and cooperation with care, and improving the quality of care and the quality of interactions with people with dementia. These potential benefits point towards practices in which conversations with families about their desire and capability to contribute their knowledge and skills become a more routine component of hospital care. Although a more uniform approach to broaching the involvement of families and their knowledge could be considered, this cannot, however, equate to an assumption that all family involvement is beneficial; the merits of involving each family may need to be considered on a case-by-case basis with equal consideration given to the preferences of, and impacts on, the person with dementia.

While a few published studies have recognised benefits to the involvement of families of people with dementia in care provision, little attention has been paid to the use of families' personal knowledge, or how this intersects with the knowledge and perspectives of the other arms of the care-giving triad: people with dementia and staff. The following chapter will focus on how families' knowledge intersects with the other forms of knowledge that are valued and used in hospital settings, and how the different types of knowledge held about people with dementia impact upon decision making about their current and future care.

Chapter 7

The interface between staff and families' knowledge and its impact on decision making

7.1   Introduction

Chapter 6 identified the value of families' personal knowledge and expertise in enhancing connections and care for people with dementia. It also introduced the idea that families and staff can have different understandings of people with dementia. This chapter further explores knowledge exchanges between and within arms of the care-giving triad to explore the different types of knowledge that are accessible to and valued by families, people with dementia and staff, and how divergence in these understandings can affect decision making and discharge planning.

7.2   Routine understandings of people with dementia

As with all patients, gathering information about people with dementia was a central part of their hospital stay. Broadly speaking, all of the stakeholders involved (people with dementia, families and staff) aimed to establish or convey how the person was prior to admission, how they were now, and how they were likely to be in the future; information that determined much of their care in hospital and after discharge. But although there was overlap in the knowledge that different stakeholders used to build a picture of the person, there was also considerable divergence, between and even within stakeholder groups, in access to information and the ways in which the person and their care needs were understood.

7.2.1 Professional perceptions of the person

7.2.1.1 Knowledge of physical health and function

The primary purpose of the wards, and a central focus of knowledge exchanges for staff, was the provision and transfer of care - getting patients physically and functionally well enough to be safely discharged:

> *Interview Site 2, Staff 23: "A lot of our job is information gathering, and actually finding out 'Ok what's this persons' base line?' and then we can start, that's half the battle working that out. Because we're an acute service, our goal is to get the person back to where they were the day before admission... ...facilitating safe discharge is our goal."*

This central objective of 'moving on' was evident in encouragement to begin planning for discharge soon after the person was admitted. This could be seen in practices such as early agreement of potential discharge dates and early referrals to social services to prevent delays in moving on. Timely transfers of care were strongly emphasised by hospital management to deal with ever-present bed pressures. There was an emphasis from admission onwards on generating knowledge about the person's physical health, function and risk to determine how these could be improved to a point where they were either close to normal or sufficient for the patient to be moved on to another care setting. The focus of the staff's knowledge-seeking was accordingly centred around these priorities:

> *Fieldnotes Site 1: Staff 1 makes the ward's first contact with Mavis' daughter by telephone, explaining 'I've just seen your mum this morning and wanted to check a couple of things'. She asks questions about various aspects of Mavis' usual physical functioning, for example confirming that Mavis lives in a 'warden controlled ground floor flat' has 'pull cords' and is 'independent' and has a 'stick'. She asks if there is a 'step into the shower?' and a 'stool there?' before confirming that 'you do the shopping and housework?' and asks 'Are you happy with continuing on with that?' followed by 'As long as you are aware that there are services out there'. She repeats 'Goes to memory clinic' and then confirms 'Does frozen microwave meals' and 'Prepares her own food then?' followed shortly by 'I presume she makes drinks and things?' The conversation finishes soon afterwards with Staff 1 saying 'That's brilliant. Gives us a clear picture of exactly how she was before'.*

Organisationally, the focus on physical and functional knowledge was apparent in the content of routine admission paperwork, assessment tools and referral forms and was also evident at a ward level in the content of MDT meetings, nursing handovers and other staff discussions, which collectively directed staff attention towards the core business of physical health and function. Risk minimisation and patient safety was a dominant theme throughout hospital records, mandatory paperwork, discussions and decision making. This focus was encouraged at an organisational level through hospital policies, practices and notices focused around risk reduction (e.g. infection control policies and close monitoring of falls data) and reinforced by a culture where staff faced the threat of being held personally accountable if they did not adequately address the physical health and risk of individuals under their care. Staff referred to a culture of accountability and felt compelled to assess closely and monitor for signs of risk, which led to risk-related knowledge receiving a high profile in documentation, discussions and decision making. Extensive notes were written documenting and exonerating staff or the service if risks were present and there was a strong culture of minimising risk and, often closely related, the likelihood of complaints:

> *Interview Site 1, Staff 7: "If, you know it's documented that… …it was only a week ago, you've discharged that person, you've said they were safe to go home, and they're back in hospital they're gonna be asking questions on why they went home in the first place. If you've documented clearly that you have registered they are a high falls risk, you've had this conversation, you've put this in place, then obviously it can't, there's less likelihood of it coming back on you as being an unsafe decision… … if you happen to forget that you've said that to somebody and you've not documented it then it could come back on you for not registering falls risks."*

> *Interview Site 2, Staff 20: "…if you were to say they're independent and then they were to fall, it would be totally our fault! …So I said to the nurses he needs somebody at all times because I, because I knew he was unsteady. But honestly with his furniture at home, not as wide open spaces as in here, I think he'd probably be all right… …I'm dreadfully over-cautious! I can't! It's just the thought of you know coming in the next day and someone had fallen because she's said "Oh they're fine!" "They're fine on their feet. They can get up whenever they want!" And then they've fallen and they've*

broken a hip and they're in for 2 months or something... ...It would be awful! And then you might get a complaint as well because it could come back legally on you. You said they were independent and they've fallen!"

The attention that was focused on risk, physical health and function meant that the person and their situation could be largely characterised and understood in these terms. Failure to attend adequately to other aspects of the person - such as their usual routines, care preferences and social or emotional needs - was less likely to cause ramifications for staff and was less of a priority organisationally. In addition, most of the staff's pre- and post-qualification training and experience had been focused around medical or physical care which further reinforced a focus on knowledge-seeking in these areas.

As described in Chapter 5, the layout and content of ward spaces reflected the primary focus on physical care provision, with most resources, equipment and furnishings devoted to this focus. Wards therefore contained little in the way of features to encourage sharing of personal knowledge or to facilitate interactions between staff, families and patients. Ward layouts of long corridors, side rooms and a lack of communal spaces mean that people with dementia and their families were often out of the sight of staff, and spaces to meet with families were either limited or non-existent. These layouts reduced opportunities for staff to observe and interact with people with dementia and their families to learn more about the person. Staff who wanted to hold conversation with families often had to do so in public areas due to the lack of any private spaces for family meetings:

> *Fieldnotes Site 1: Staff 13 agrees to feedback to Evan's granddaughter and suggests that they find somewhere more private to go. Staff 14 says that there isn't anywhere, a social worker is in the dining room, the therapy room is in use and staff are having their breaks in the staff room, but that they could sit in the corner in reception and that would be a bit more private. Staff 13 says they need somewhere more private and they go up the corridor to find somewhere. They return soon afterwards, having been unable to find anywhere, and talk by the reception.*

7.2.1.2 Personal knowledge

Only a few staff had dementia training or experience (professional or personal) that might encourage recognition of how personal knowledge of usual routines, behaviours, communication habits, preferences, and life histories might enhance care provision. Staff with this additional expertise were more often seen to seek personal knowledge and weave it into: the picture of the person being created on the ward, the person's care, communication with the person, and decisions that were made about their care. For example, staff with experiential or formal dementia expertise were more likely to balance concerns about risk and physical function against concerns for the well-being, quality of life and preferences of the person:

> *Fieldnotes Site 2: The MDT talk about a lady with dementia who was living at home but is being discharged into 24 hour care. 'Is she? Does she know that?' asks Staff 30 (A senior and experienced member of staff). Another staff member says she is vulnerable at home and that the family are 'all in agreement'. 'Is she happy with that?' asks Staff 30. Later they discuss another lady who won't get out of bed. 'Anyone know what she's like at home?' asks Staff 30. A nurse reads from the nursing notes that say she was mobilising until a few weeks ago. Staff 30 then asks 'No one spoken to the family? Has anyone?' 'No' comes back the response.*

The degree to which staff sought or used personal knowledge depended on their professional and organisational status as well as their dementia expertise. Staff with less flexibility in their workload (such as junior nurses and nursing assistants) had less autonomy or time to undertake personal-knowledge work themselves. In contrast, consultants, ward sisters and therapy staff worked more autonomously, giving them greater flexibility to build engagement with families and seeking of personal knowledge into their work. Senior staff could also encourage, model or request seeking of personal knowledge and encourage more attention to this from others:

> *Interview Site 2, Staff 20: "It all feeds down from the consultants really, in terms of, they are always keen for you know collateral [collateral history from families]... ... I'll often see in the plan like, the ward round plan, kind of meet with family, and I meet the*

family… …you definitely tend to like adopt the kind of, the general feeling of the ward and you do things as everyone else does."

Interview Site 2, Staff 22: "Some wards are very strict about visiting… …I think they're run very differently… …Other wards I've had consultants I've worked for 'I don't speak to relatives, that's a junior's job' and will wash their hands of relative discussions unless you're reaching a point of complaint".

These quotes illustrate the variability present in the degree of engagement with families - variability that was influenced by the views of senior staff towards families. At site 1, where there was less emphasis from senior staff on family engagement, there was also less cultural expectation that seeking of personal knowledge would take place. There was less emphasis too on paperwork for collecting personal knowledge, and visiting hours were more tightly policed. However, the greater emphasis on personal-knowledge seeking at Site 2 did not ensure this filtered down to all staff:

Interview Site 2, Staff 31: [Speaking about personal knowledge] "How is that relevant to a doctor who is very busy? We're always overworked and understaffed, we're always, so how is knowing like my patient used to play golf in the sixties will help me manage him, manage his dementia… …What if I want fish on Monday, sorry there is no fish, there is something else, no I want fish, so this is irrelevant. Right, what's your favourite colour? This is irrelevant. Because we cannot act on it… …definitely not of any use, definitely… …we're not social workers, we are doctors so I'm sticking with the fact I should know your baseline, how is your performance status, how can you communicate, whom should I call in case you deteriorate and leave the rest for me. I know because I studied in medical school and I've done a few other exams and I know how to sort the rest out."

This quote illustrates how knowledge-seeking from families could be limited to topics the staff member involved thought were of importance - which did not necessarily include the seeking of personal knowledge even when senior staff tried to encourage this.

Unlike the systems for generating knowledge about physical health and function, neither ward had routinely used tools or paperwork for inserting knowledge about the person and their care routines and preferences into care planning and decision

making - making it more difficult to collect, share and use such knowledge routinely. This is not to say that this knowledge was not given any value; attempts were made to use paperwork to collect personal knowledge from families of people with dementia at both sites, but the use of this paperwork, and the information from it to inform care planning and delivery, was not routine:

> *Interview Site 2, Staff 27: "As you know we've recently introduced the Know Who I Am document… …The problem is that, even on my ward where I feel quite passionate about it for obvious reasons, it's still not being used routinely… …I'm sure that it wouldn't get used if I didn't prompt them on [ward name], and I'm the biggest fan of them, you can imagine what's happening a lot on other wards… …I think it's just pressure of work and bit of time…"*

> *Interview Site 1, Staff 10: "I mean there, there is this new thing isn't there? This See Who I Am document that we hand out and we get that (personal) information, but I do think you need to, it's alright giving them a sheet and saying you go away and fill that and bring it back and we'll put it in the notes, it's sort of how many people actually get time to sit down and read that?"*

> *Interview Site 2, Staff 23: "I think people have tried these 'Who Am I' sheets. I've not really seen them around on this ward much and I don't know whether it makes it a bit more of a paper exercise again, and sort of do people really look at it?"*

Although the introduction of this document indicated that personal knowledge was being given value, the greater need to understand physical health and function took priority, leaving the seeking and use of personal knowledge an often unrealised ideal rather than a routine focus. The volume of physical care required, together with minimal staffing created a need for knowledge seeking and routines orientated around the core business of providing physical care, reducing the time available to seek personal knowledge and to build it into the care provided.

7.2.2 Families' perceptions of the person

Whilst staff often focused primarily on knowledge about physical health and function, the types of knowledge held by families were more variable, with inconsistencies in the degree to which different types of knowledge were accessible to and understood by families. As highlighted in Chapter 6, varying degrees of knowledge exchange with families were reported and observed, with some families receiving limited access to the knowledge held by staff about their relative.

7.2.2.1 Knowledge of physical function and health

Families could share with staff a focus on physical health, functioning and risk. However, their understanding of these areas came largely from before the hospital admission and could differ from the knowledge of staff. Once the person with dementia was in hospital, an understanding the person's functioning and health was restricted to what could be understood from conversations with the person and with staff, the limited notes kept by patients' beds, and potentially unreliable judgments made from observing their relative during visiting times:

> *Interview Site 1, Carer 6: "It's guess work because I don't know because they are not giving me, they are not saying to me your Dad's done this today."*

> *Interview Site 2, Carer 20: "When my dad's in hospital all the time and he's taken out of bed and into a chair, we don't really see what he's capable of, you don't see... ...we don't really know how much help he needs... ...they never explained as to what he can do, so you don't really know... ...I used to flick through that book myself, but it doesn't tell you enough in that book as to really give you picture as to how they've gone on."*

Gathering knowledge of the person's function and health was hampered by the presence of dementia, the limited information routinely provided to families, restricted visiting hours, and the lack of activity seen during visiting times - which were typically spent sitting by the bed or chair of the person. A lack of opportunities to observe relatives undertaking activities of daily living or to engage with the busy staff to ask about physical health or functioning could limit a family's knowledge of

their relative's current health and abilities and judgments of their likely care needs after discharge.

7.2.2.2 Biographical and embodied knowledge

As described in Chapter 6, families held forms of personal knowledge about people with dementia that staff did not. This information included in-depth biographical knowledge of the person's life history, key relationships, values, interests, routines, and usual behaviours, as well as whether or not their current presentation was representative of their usual state. As Chapter 6 demonstrated, some families had also developed expert 'embodied' knowledge of how to care for and communicate with their relative, sometimes including the development of individualised care routines, strategies for dealing with care challenges, and ways of understanding and responding to otherwise difficult to comprehend verbal and non-verbal communication. Embodied and biographical knowledge were found to be closely interlinked, with each contributing to understanding of the other. Biographical knowledge enabled greater interpretation of the words and bodily communications of people with dementia, by understanding the context in which words or communications were made. Embodied knowledge enabled greater communication with people with dementia and greater opportunities to gain further biographical knowledge of the person.

Embodied and biographical knowledge was much commoner among families than among staff - due to the level of relationship and contact with the person required to develop these understandings, and the lack of routine seeking of such knowledge from families. Whilst it was possible for staff to hold some embodied knowledge - if, for example, they had cared for the person previously or extensively, or sought this knowledge from families - the questions that staff asked of families often conveyed a sense that only physical and functional knowledge was relevant to hospital care. This restricted range of questioning discouraged exchanges of biographical or embodied knowledge. There was also potential for aspects of families' embodied and biographical knowledge to be temporarily disrupted during admissions. Limited

opportunities to interact with relatives with dementia, and to continue prior activities with the person, could make it difficult to judge whether they had retained the ability to undertake previous activities, relationships and ways of communicating.

7.3 Discordant understandings of the person

Although not a completely uniform finding, there was clearly a tendency for staff to know more about the person's current physical health and functioning and for families to hold far greater levels of biographical and embodied knowledge, alongside information about the person's past physical health and functioning. Exchanging these different understandings was clearly beneficial to both parties but could be a difficult process, and it happened to varying degrees in practice (as Section 6.9 has already identified). Chapter 6 explored how differing understandings of people with dementia between staff and families affected experiences of care; the following sections will explore how knowledge-sharing practices between and within stakeholder groups exacerbated discordant understandings amongst these groups. The chapter will conclude by exploring how these different understandings impacted upon decisions about the person with dementia's future care.

7.3.1 Discordant understandings amongst staff

When personal knowledge was sought by staff, it formed a small part of an expanse of information recorded about patients' health, risk and functional ability amongst which pockets of personal knowledge from families could be easily lost or overlooked. This flaw was just one component of the wider problems of trying to share large quantities of information through sizeable and varied groups of staff and extensive record keeping systems. As knowledge relating to the core business of physical health and function could be mislaid or overlooked, it was not surprising to find that this was also the case for less routinely recorded information such as

personal knowledge. Sharing knowledge across wards and organisations (such as social services and care homes) amplified the challenges:

> *Interview Site 2, Carer 20: (Speaking about a document collecting personal knowledge) "We got that quite late on, I don't remember them asking for it back, I don't remember them pushing it at all. We filled in but I think, I'm sure I gave it in on the day, but it didn't seem as though it was used anywhere or anything like that. Or it didn't feel like it was."*

> *Interview Site 1, Staff 7: "Obviously we do have a copy of the medical records but we don't have time to look through all of that, really it tends to be based on the most recent notes from where they've come from… …It can be quite difficult sometimes to work out whether somebody actually has a diagnosis of dementia or it's just that somebody's put 'query dementia' in some notes somewhere and that's been copied across as being fact… …we use paper notes still and obviously sometimes they're not the best notes in the world because you can't guarantee a bit of paper hasn't been lost."*

A further challenge to knowledge exchange, as the last quote demonstrates, was the potential for information from hospital records to be conflicting or incorrect. As searching through extensive records to establish the reliability of information was usually not feasible, the reader could be unaware of this problem. Such inaccuracies were particularly problematic for patients with dementia who could struggle to confirm or deny the validity of the information held about them:

> *Interview Site 1, Staff 12: "Sometimes it (dementia diagnosis) comes on the referral form, but I think experience has shown that actually that isn't always the right, it might not have been a confirmed diagnosis. So that's an issue as well 'cause I think we've been burnt a couple of times with, you know, them saying 'this patient has dementia' and actually when you dig into the notes, there's never been a confirmation, it's just maybe been mentioned and then, and then that's it then, they're labelled, they've got dementia… …we try and dig deeper but we can't always do that cause we haven't always got the time… …and the patient's not always appropriate to ask."*

The difficulties of sharing written or verbal knowledge about patients in an accurate and complete form was one of several reasons that partial, discordant or incorrect understandings of people with dementia could be found amongst staff. Contrasting

perceptions amongst staff of people with dementia were exacerbated by the different ways and times of day that different professional groups came into contact with patients. For example, doctors and therapy staff often only saw patients at certain times of the day or to undertake specific tasks whereas nurses and support workers saw patients throughout the day and night, leading to the potential for the same person to be viewed quite differently by different groups of staff:

> *Interview Site 2, Staff 20: "We (staff) can disagree! I think in a way physio is probably the one, well no, physio and doctors, often dis, well not often, sometimes, initially disagree with the nursing staff because we don't ever see the patients as the nurses do! We never, first of all we never even see them on a night time. We never see them outside the hours of 8 and 4… …we don't have to go and clean them. We don't have to wash them. We don't have to give them help with like the general day to day things that they need to do to be able to go home."*

> *Interview Site 2, Staff 28: "On the ward round we'd be like oh this patient's been really confused and really aggressive and playing up and what not, so then the doctors will go and see them and they're nice as pie. But then I'm like are they're just doing that cause it's the doctor… …I think as well because we see them a lot and spend more time with them than the doctors, they only see them or are with them for like 10 or 15 minutes or however long they're with them, so I think it is different… …we do different things with the patients so I think they act differently with us."*

Whilst the difficulties in knowledge generation cited above were true for all patients, generating knowledge about people with dementia was beset by additional complexities. The detrimental effects of unfamiliar hospital environments on the person's usual behaviour and functioning meant that gaining an accurate picture of their current and future care needs was often difficult and was a further cause of partial, discordant or incorrect knowledge:

> *Site 1, Staff 7: "You take them out of their environment they can't do anything, they can't find the toilet, they can't, you know, but actually at home they function very well… …it is very difficult working in a ward environment 'cause you don't, you're not getting a clear picture with people with dementia. They function generally so much better in their own environment, so taking them out of their own environment, they're bound to have more issues than they would at home and its being able to try and judge what's the*

environment and what's their actual cognitive state and that's quite difficult
sometimes… …so you end up on a bit of a guessing game sometimes with some of
them."

This 'guessing game' created significant difficulties in accurately judging the functioning and well-being of people with dementia. Attempts to seek information directly from people with dementia about their previous health and functioning could also be difficult due to confusion or communication difficulties, which could be exacerbated by physical ill health, delirium, and the unfamiliar surroundings and people. As a result, staff were sometimes unable to gain essential information from the person or found themselves uncertain of the reliability of the information provided:

> *Extract from Ailsa's medical notes: "Assessment – attempted to ascertain previous*
> *functional level – unable. Pt muddled and slightly disorientated – distracted easily."*

> *Interview Site 1, Carer 1: Interviewer: "I wonder then if the staff are getting a true*
> *understanding of how your mum is?" Carer 1: "They are not. They are not. That is what I*
> *said before, they are not… …You can't really blame them for it, anything really, because*
> *they are only going by what my mum says."*

> *Interview, Site 2, Staff 20: "It's a lot more difficult to get a history from the patient*
> *themselves… …and you can be given, not false but inaccurate information."*

The difficulties of determining essential hospital knowledge around previous levels of functioning and health was often magnified if staff had not managed to contact families, with MDT meetings often including references to missing information from either the person themselves or their family members:

> *Fieldnotes, Site 1: MDT meeting. The nurse says that Ailsa was 'incontinent plus plus*
> *plus plus last night' commenting that she is 'not sure what her usual continence is' and*
> *'that it is 'a bit hard to determine what she was like' as they 'can't get in touch with the*
> *family'. The doc says 'her hearing is appalling' and that you 'can't get a clear detailed*
> *answer'.*

Limited opportunities for staff to spend time liaising with each other as well as with patients or families meant it could also take a while for discrepant knowledge to be revealed and corrected:

> *Interview Site 1, Staff 7: "Usually when the physio and OT do separate assessments and the nursing staff do a separate assessment, because one person'll go and talk to them and get certain information, another person'll go and talk to them and get different information, and you won't, unless we sit down and have our MDT meeting or have a bit of a brief chat about somebody, you don't always add those things up. So I went to see a patient once that appeared perfectly fine… …when physio had gone to see him, he'd told a completely different story, but each time it was completely believable, everything added up. So until you have that conversation with other professionals or other family members, you don't always get a clear picture."*

During the time it took to identify and correct dissonant understandings, false or conflicting information could be transmitted to other staff or organisations (such as social services or care homes), creating further spread of mismatched versions of the person.

7.3.2 Discordant understandings amongst families

The problems of reliably ascertaining the previous and current health and functioning of people with dementia showed the need to liaise with families wherever possible and how this connection could help to build a more complete and reliable picture of the person:

> *Interview Site 2, Staff 22: You get a completely different story from a relative to what you get from a patient, particularly if they're just really good at confabulating. And they will tell you lots of things, I mean we've all been taken in. I had a patient tell me all sorts, and it sounded quite plausible that he had a little scooter and he went off down to the shops and did his own shopping on his scooter… …and it was only when you actually delved a bit deeper and spoke to his relatives that they were like no, he hasn't done that for years."*

As identified in Chapter 6, knowledge from families, when sought and used, could help to unravel discrepancies between the presentation of people with dementia in hospital settings and their usual level of functioning. Information from families could not, however, always be relied upon to be accurate. Multiple family members, when involved, might not share the same levels of relationships, usual contact, or care-giving input with the person with dementia. Consequently, family members did not always share consistent knowledge or understanding of the person and, depending on which family member was spoken to, staff could be given differing views on the person's capabilities and needs:

> *Interview Site 2, Staff 20: "One day you will see one family member who, you know, tells you a long story about what they think should happen! And then the next day you've got the opposite!"*

> *Fieldnotes Site 2: Emmett's wife she says she thinks that he is back to his normal self. His daughter says that he is a bit confused still, and that 'he has said a few things today' which his wife seems surprised about, seeming not to have noticed this 'What's he said?' she asks her daughter.*

> *Interview Site 2, Staff 27: "A patient of mine's daughter is coming tomorrow, that you're aware of, where one family member felt strongly and the others didn't, and you got dissent there, and sometimes the decision you know isn't clear cut."*

Family members did not always get on, communicate with each other, or agree on what care would be best for their relative. Conflicts of opinion could occur, which staff had to identify and then carefully negotiate in order to facilitate a decision being reached that represented a shared understanding about the person and their future care. Dissonant views could have a significant impact on decision making, which is a topic that will be explored in more detail in Section 7.4.

As with staff, families could also experience difficulties in judging or getting information from their relative about their functioning and well-being, particularly under the dual negative influences of ill health and unfamiliar surroundings:

> *Fieldnotes, Site 2: John is sitting with his wife. She asks him 'Did you eat your dinner?' repeating her question when she doesn't get a response. 'I don't know' admits John*

falteringly. Later she asks 'How did you get into here?' adding 'Into wheelchair?' 'Don't know' replies John. 'Is it with that banana board thing?' she pursues. 'Don't know' says John again. Soon afterwards he seems to continue this conversation, saying 'You get to know about it. They come to you' and 'Get there now and again. But we're alright'.

Whilst in the example above it was clear that John was unable to provide the information being requested, the potential unreliability of information from relatives with dementia was not always as obvious:

Interview Site 2, Staff 20: "I think patients can often… not want to admit themselves and so they sometimes talk to their relatives and tell them that they're a lot better, they're managing a lot better, than they actually are. So the relatives, it's not any fault of the relatives because they are just taking it, they are trusting their, the person that's in, but sometimes they, whether they can't remember that they've needed help or they're not really willing to admit it, so they push it aside and they cover it up with this social face… …sometimes they do tell a bit of a story to their relatives! And then they think well they're fine!"

This quote highlights yet another potential source of dissonant understandings between families and staff, misunderstandings that were unlikely to be revealed until conversations between the two parties took place. Although efforts were made to engage with families and exchange knowledge with them when there was a particular need to do so, it was not uncommon for families to feel that they didn't have enough contact with staff or information about their relative's care. Relatives were often not privy to the array of information staff held about their relative and they could struggle to gauge, or be unaware of, their relative's well-being, physical health and functioning on the ward, professional discussions, assessments and tests that had taken place, or discharge plans:

Interview Site 2, Carer 20: "Nobody's really spoke to us and we… …From what we'd seen of him we didn't think he could manage at home, but as I say they never explained as to what he can do, so you don't really know."

As will be explored in Section 7.4, this lack of knowledge created particular difficulties when families were asked to make decisions about their relative's future

care, or to undertake or resume care-giving roles on discharge, without the knowledge with which to understand what these roles might entail.

Interestingly, whilst conversations between staff and families could help to unravel discrepant understandings, these conversations could also be the source of dissonant knowledge. Conflicting knowledge could spread from staff to families as different members of staff could provide different information about patients and the plan of care:

> *Fieldnotes Site 2: I talk to a doctor who tells me that because a lot of their patients are confused, families can't find out from them what is happening and so they have to ask staff. She tells me that they don't have enough nurses to regularly have one on the ward round and so the families get conflicting information fed back to them and mixed messages as the doctors will tell them how things are from their point of view and then the nurses will tell them separately from their point of view. She gives an example of the doctors saying that someone is doing well but the person actually being unsettled at night (when the doctors aren't around) and so the nurses will say that they've been really unsettled. She says that the nurses don't know what the plans are from the doctors' point of view, and that the doctors don't know what the nurses are thinking or what they know because communication between them is not good. She says that the nurses will get a line of a handover, if that, about a patient.*

As this quote demonstrates, the transferring of discordant knowledge from staff to families was less likely with better staff-to-staff communication so that the various professionals involved had more of a shared vision of each person's admission and discharge plans.

Restrictions in families' access to their relatives could also create discrepant understandings between families and staff. Visiting outside of the key activities of the day, such as mealtimes and washing and dressing, meant that many families rarely or never saw their relative undertaking daily tasks. During visiting times people with dementia were largely sat in beds or chairs, whereas staff more regularly saw the person attempting to undertake daily activities. As a result, it could be difficult for families to gain a sense of the person's current physical functioning and any changes in their care needs:

Interview Site 2, Carer 20: *"When my dad's in hospital all the time and he's taken out of bed and into a chair, we don't really see what he's capable of, you don't see… …it's better to have a ward where they get them up and they get them dressed and you can see them, we know whether he's capable of getting dressed or how much help he needs, we don't really know how much help he needs"*

This quote reveals how the 'guessing game' involved in trying to establish the abilities of people with dementia in hospital environments extended to families as well as staff. Conflicting perceptions could also be created between families and staff because the presence of familiar family members could prompt people with dementia to exhibit a level of animation that was not evident in their interactions with others, thus creating an impression of greater well-ness than that seen by staff:

Interview Site 1, Staff 11: "People with dementia respond to their relatives in a different way than they do to us."

Interview Site 2, Staff 20: "There's quite a few where you're shocked because visiting time, it's quite sheltered visiting times! And the patients just seem to come to life in visiting times! Because you see your family and you want to put on a good show. Even, you know, being with dementia, you know you almost never see them as orient or alert and orientated as when their family come in! For that 2 hours every, they are not calling the buzzer because their family can pass them things and they are not, it's sometimes easier for them to stay continent whilst, because they don't, because they know their family are there! And so the family see a very sheltered picture of what they're like and they think "Oh you know of course she could go home! She's chatting to us. She's not the, you know, she's fine!" But when it comes to like night times and when they're not there… … it's not saying that our picture of how we see them is how they are really. When they are in their familiar surrounding I am sure they are a lot more like when their relatives are here. But it doesn't stop the fact that they're sometimes needing actual physical, they need somebody there to do things, who might not be there at home".

This last quote highlights the difficulties faced by both staff and families in trying to determine the ongoing care needs of people with dementia in an environment and situation which so negatively affected their functioning and well-being. This was one of the central problems faced by all three arms of the care-giving triad: that the presentation of people with dementia in hospital was unlikely to provide an accurate

representation of their abilities and functioning outside of a hospital environment, creating real difficulties in determining what level of discharge arrangements would provide the best balance between meeting needs and minimising any risks. These challenges provide further support for the importance of trying to maintain aspects of normality for hospitalised people with dementia, through the encouragement of familiar visitors, routines, and levels of functioning wherever possible, in order to enable a closer to reality picture of the person.

7.3.3 Discordant understandings amongst people with dementia

Up until now, this chapter has focused on the types of knowledge that were held and valued by staff and families. The understandings that people with dementia had of their current and future care needs could, however, also differ from the perspectives held by family members or staff. Differences between the person's view of their situation and the view of others was sometimes due to difficulties understanding or retaining information about his or her care:

> *Interview Site 1, Staff 4: (Speaking about Ailsa) "It's a very similar conversation every morning that you have, that she doesn't have any tablets and she doesn't know why she's taking them. And then she'll ask if she's ok and if she's poorly. So then you explain to her what's been happening... ...It's difficult really with her hearing because you try and explain things and it just, you just find that you're getting louder and louder and actually she's still not grasping. I just say to her you're ok... ...you're fine, you're safe and you're well at the moment and we're just trying to get you moved on. But she'll, again forget quite quickly what you've said so it's difficult."*

It was not uncommon for people with dementia to be unsure of what was wrong with them, unaware of why they were in hospital, or unclear about the events that had led to their admission:

> *Fieldnotes Site 2: I talk to Emmett who tells me that he doesn't know why he is here, that he can't remember, but he has no complaints and they are looking after him fine.*

Fieldnotes Site 2: David tells me he can't remember what happened to him or why he ended up in hospital, saying that someone brought him here and 'Here he is'. I comment that he looks like he's been in the wars a bit, pointing to his bruised and cut hands, and he agrees, rubbing at his wounds but remaining unsure about what has happened to him.

When people with dementia were unaware of potentially concerning reasons for their admission, such as the fall that had taken place in the last example above, they were left unaware and thereby unconcerned by risks that might be a key concern for staff or family members. People with dementia could also view their current abilities differently to others people's assessments, with some patients believing that they could carry out activities and tasks that families or staff questioned their ability to perform or knew they were no longer able to manage:

Interview Site 2, Staff 20: "I've had a number of people say 'oh yes I was walking to the shops last week' when actually they have been bed bound for a, for you know a few months."

Alongside the difficulties that dementia could cause in understanding and retaining information about care, a lack of access to information could also limit people's understandings of their own care needs. People with dementia were often not privy to information that was held about them by staff, or to some of the discussions that took place amongst staff or with their families regarding their future care. For example, care planning meetings between staff and family members could take place without the person present. Although these exclusions could be due to good intentions, such as to enable frank discussions to take place without causing distress, there were instances where people with dementia were aware that conversations were taking place about their future lives without their involvement:

Fieldnotes Site 2: When I ask David he doesn't seem to know how long he'll be here 'Don't tell you 'til you're going'.

Fieldnotes, Site 1: Joan tells me that her daughter has said they are having a meeting this week to decide where she is going to go, as if she may be going into care. I ask her if anyone has asked her where she wants to go and she says 'no'. She isn't invited to the meeting.

The conversation with Joan indicates how some people who were excluded from meetings or discussions about their care understood enough of their situation to comprehend the focus of the discussion that was taking place without them. However, overcoming the challenges of conveying information understandably to people with dementia was not as simple as ensuring their physical presence in discussions. In some instances where people with dementia were involved in conversations about their care, they were unable to understand the way in which information was conveyed to them:

> *Interview Site 1, Carer 1: (Speaking about the general hospital) "The anaesthetist came while I was there and my son was there, and she was talking to my mum and I kept thinking, well, she's not even understanding what you're talking about. And she must have known, cause it's on her notes that she, you know dementia and, but I thought well she'll ask me surely, but no. It was a form to sign you know to say that, and she explained both things, 'Do you want an epidural or general anaesthetic?' Me mother doesn't even know what an epidural is, she hadn't a clue, yet she were talking to her, and I was a bit angry with her over that."*

> *Fieldnotes, Site 2: Ophelia calls me over and says 'Can you answer a question for me?' She asks me what a 'kick' bed is, saying that she has been told she is going to one and she is worried she is going to somewhere where she is going to get 'knocked about'. Her voice wobbles as she asks and she sounds genuinely worried. I ask her if they explained what is was and she says no and so I tell her what it stands for (CIC - Care in the Community - bed) and that it means it is a bed in a smaller place that isn't a hospital. She sounds relieved, saying she was quite upset when 'they just came along and said it'.*

Both these examples illustrate how careful attention was required as to how to involve each person with dementia in conversations and meetings about their care. Conversations did not always take place in ways that were sufficiently sensitive to the person's understanding or communication needs, with the first example above also illustrating failure to draw on family as a resource to help translate information and maximise the person's understanding. Attempts to involve the person could even lead to distress if they were unable to follow proceedings, such instances being particularly distressing if the person understood enough to realise that the conversation involved decisions that did not accord with his or her wishes - such as

discharge to a care home. This was the case in the following example of Ailsa who found her inclusion in a meeting with staff from her future care home highly distressing due to the focus of the discussion, an unwanted and unclearly explained transfer to a care home, and her inability to follow proceedings sufficiently to understand the conversation in relation to this unwanted decision:

> *Fieldnotes Site 1: Two members of staff from Ailsa's new care home come to the ward to assess her. One of the ladies tries to talk to her and explain where she has come from whilst the other asks a student nurse questions about Ailsa. As they start to talk Ailsa starts sobbing and asking if she can go home. The lady tries to comfort Ailsa but doesn't speak loudly enough for her to hear and Ailsa gets repeatedly upset over the 20 minute discussion, crying and asking can she go home, where are Clara and Mark, and are they are ok. She repeatedly seeks reassurance from me during this time and is so upset at one point that her nose pours as she cries, with her exclaiming 'Ooh heck' as so much mucus streams out of her nose and down to her hand it is too much for even her hanky to hold.*

This conversation illustrates how failure to involve people who had awareness of their situation in conversations about their care - either at all, or in a way that catered for their understanding and emotional needs - could result in distress, a lack of understanding of events, and potentially missed opportunities to reach a more shared understanding of the issues involved. There were some staff, usually with dementia expertise, who appreciated the value and potential for including people with dementia in conversations and meetings about their future care:

> *Interview Site 1, Staff 10: "Everybody tends to talk about them and around them (people with dementia) rather than address the issue with the person themselves… …it'd be good to sit down as a nurse with the family and the person and discuss it, and discuss the risks. And often I've found the more the person is realistic about the risks themselves, I'd one lady who said, 'I realise I've huge risks if I go home', and they all scooted around her really at first, 'and if I can't manage this time I will then go into placement', a lady with dementia and she clearly said what she wanted. And they'd been messing about for weeks, and you think 'gosh, why didn't somebody just ask her in the first place'."*

This example shows that there were instances where people with dementia were wrongly assumed to be incapable of understanding and taking part in conversations and decision making about their care. These instances demonstrate the importance of trying to include people with dementia in conversations about their care wherever possible, with attention to doing so in ways that maximise their understanding of the situation, and enable them to play a part in the decision making process wherever possible. The roles people with dementia, families and staff took in decision-making processes, and the impact of discrepant understandings on decision making, are explored in more detail below.

7.4 Impact of discordant understandings on decision making

When it came to making decisions about the person with dementia's future care, discordant views between and amongst stakeholder groups could lead to differing opinions on the person's future care needs. This was by no means always the case and there were times where families, staff and people with dementia agreed on the best course of action. But there were also occasions where views on the most appropriate discharge plans showed a division in perspectives between or within stakeholder groups:

> *Interview Site 2, Staff 20: "We can disagree! Often the doctors will say, you know, right so this person's doing much better, right can we try and, shall we aim to get them back to the residential home or something. Or aim to get them home by the end of the week? And then they (nurses) will just, or I'll say actually this person hasn't walked since they've been in here! They can't stand up! So we are not going to get them home! ...So they, I've found they often get a very different picture to us. Or to the nurses especially. So we have to, we have to try and put together a picture just between us, never mind family!"*

> *Interview Site 2, Staff 22: "There are often disagreements about where people should go... ...There's been disagreements like 'oh mum always wanted to be at home, I can't*

believe you want to put them in a care home' and the other family going 'but we're reaching the end of the tether'.

Interview Site 2, Staff 26: "I think it was two or three daughters plus a couple of granddaughters, and none of them could seem to agree on just what they should be doing, which quite often happens."

These quotes demonstrate how discrepant knowledge and views between or even within stakeholder groups created problems and delays with decision making. Differences in the understanding and knowledge of care needs between staff and families, and the difficulties this caused with decision making, are illustrated in the following excerpts from a care planning meeting between Emmett's family and a Joint Care Manager (JCM):

Fieldnotes, Site 2: The JCM starts by talking about what help Emmett might need at home, saying she has read the notes (she hasn't met Emmett yet) and seen that the family want him home. I look to the family to see if this is right, as I am not certain that this is what they want. The JCM explains services can provide care during the day but 'not overnight' and asks Emmett's wife whether she can manage with that at home. There is a pause and then Emmett's daughter says quite sharply and sounding stressed 'We don't know' and 'we can't answer that' because 'we don't know what he'll be like 'til we get him home'. The JCM explains that the 'referral I got was for him to come home' and that it 'said that was your wishes'. Daughter replies that of course it is 'everyone's wishes for their family to come home' but that they don't know what he will be like and whether or not her mum can manage. Later in the conversation Emmett's daughter reiterates in relation to him going home that they 'can't even answer' because they have 'not seen' what he is like.

As well as illustrating the lack of knowledge families might have of their relative's current abilities and care needs, the above extract illustrates how some staff who were regularly involved in decision making, in particular non-ward based staff such as JCMs or social workers, could also show limited or incorrect knowledge of people with dementia and their care-giving situation. The JCM above, for example, was operating under the false understanding that Emmett's family had agreed to support him at home and was discussing plans for Emmett's future care without even having met him, which she reveals during her conversation with the family:

> *Fieldnotes Site 2: "I will need to speak to him' says the JCM, going on to talk about capacity and how she will need to see if he is able to 'make a decision' and 'if he said he wanted to go home' it is a 'difficult scenario'. Later she tells the family how they (JCMs) "only get basic info" about patients.*

The lack of information that was sometimes exchanged between ward and external staff could limit both the external assessor's knowledge of the person with dementia and internal staff's knowledge of the decisions that had been made. This was particularly problematic given the regularity with which external staff were involved in arranging discharge plans.

As many of the above quotes illustrate, decision making often involved negotiating the different understandings, priorities and perspectives between and within stakeholder groups. Perceptions of levels of risk were a particularly powerful influence on decision making, with balances regularly needing to be sought over recognition and perceptions of acceptable levels of risk between each stakeholder group:

> *Interview Site 1, Staff 4: "You can see that there's grave concerns from the daughter really. And you know, Mavis is quite blasé about it, and possibly a little bit, well, I don't think she realises the risks that are there at all really."*

> *Interview Site 1, Staff 7: "The problem quite a lot of the time is that some patients with dementia don't necessarily recognise when they're putting themselves at risk… …they don't understand why you're not letting them go home… … We might have an elderly wife or husband or carer or partner that we wouldn't really view as being a capable person but they feel they can manage and again that's very difficult because you end up in a situation where realistically they probably may have been managing before and they may well manage again but the risks are high… …it depends completely on the professionals involved on whether they go home again with the risk that they're gonna come straight back in or we put our foot down and say 'right, they don't have capacity. All the time we've been allowing you to make these decisions for them but now their risk is too high, they are gonna come back in, we have to overrule you and go for a best interest decision without using the family decision'."*

Fieldnotes Site 1: Staff 15 (a nurse) says about Ailsa 'I hope she goes home. It'll kill her' adding she is 'so upset, she just wants to go home'. 'Is it her house?' she asks. No one seems to know. She continues 'If it is and she's got capacity and wants to go home then we've no choice' and comments that she was 'tearful today. I wonder if she knows something's happening'. Staff 2 (a therapist) then joins our conversation saying 'she's not safe at home' mentioning 'clutter' and 'needs two stair rails' and that they 'don't know if they look after her, interact with her' adding 'It's a relief she's going to placement'.

The last two quotes reveal how perceptions and acceptable levels of risk could differ between professionals and how staff had individual risk thresholds above which they considered the risks to be too great for the person, or the care-giving dyad, to continue with. The threat of repercussions for unsafe decision making were influential here, with staff required to demonstrate careful consideration of risks and the safety of their decisions - to avoid negative repercussions for themselves or the person with dementia.

Several of the above quotes also reveal the significance that decisions made in hospital could have for the future lives of people with dementia and their families, which magnified the challenges of balancing differing perspectives and potential conflicts between risk and the person's emotional well-being. Decisions to put somebody into residential care, particularly against their will, were particularly emotive examples of this conflict:

Interview Site 2, Staff 20: "It is difficult and people can get really understandably upset when they are told, or even at the mention of being put into some kind of care."

Interview Site 1, Staff 10: "We get a lot of families coming to us saying 'Oh gosh, they really can't go home' because they're so worried about the risks, rather than seeing the broader picture, where would they be more happy? And sometimes the risks outweigh the happiness."

Interview Site 1, Staff 4: (Speaking of the decision for Ailsa to go into residential care against her will) "It's quite a relaxed hospital environment and it's been quite distressing her, so I can imagine it's gonna be the same in a residential home really for her... ...I mean for her safety it's a good thing, for her mind, it doesn't sit well. And I said,

I, I think that maybe the CPN should of made the effort to maybe take her to visit her son before she went in, but then I don't know how distressing it would be for her going to her home address and then being taken away again. But it's just not, it's not nice to think that she may not see her son ever again."

These quotes indicate just how much impact decisions made in hospitals could have on the lives and emotional well-being of people with dementia. In the (rather unusual) previous example, discharge to a care home meant that Ailsa would never see her housebound son again, permanently disconnecting her from a family member she had been repeatedly distressed at being apart from during her hospital admission. This decision was by no means taken lightly, and was only decided upon after extensive discussion about the very significant risks of her returning home, but it was taken without any discussion about whether or how Ailsa could retain a connection with her son. Ailsa's escalating distress at her unwanted discharge to a care home could be heard loudly throughout the ward by the day of her discharge:

> *Fieldnotes Site 1: I arrive in time to see Ailsa before she is discharged to a care home. As I enter the ward I can hear her sobbing from the dining room. I have never heard her crying so loudly before and her eyes and the skin around them are very red, as if she has been crying profusely. Staff 8 passes Ailsa's table, Ailsa looks up at her and states loudly 'I want to go home' 'I want to go home'. She initially gets no response from Staff 8 so she repeats three more times 'I want to go home. I want to go home. I want to go home'. Staff 8 puts her hand on Ailsa's shoulder and rubs it as she continues to supervise a lady to her chair. A little later I see Staff 16 who tell me Ailsa has been 'awful' and 'really upset' and how you could 'hear her from right down the corridor'. Staff 16 says 'she knows what's happening, that she doesn't want'.*

Both Ailsa's and other examples above highlight the potential for strongly held and differing views on discharge arrangements for people with dementia, including the potential for discharge arrangements that were explicitly against the person's wishes:

> *Interview Site 2, Staff 20: "There have been people go home still refusing to go to a care home, and they've been discharged with that mind set and taken from hospital to a care home. Because, I mean it's, people with quite advanced dementia and they, you know, I think they've tried all of that but still not been able to get the patient on board".*

In the examples above, judgments of the person's capacity often determined the extent to which they were able to influence decisions about their care. Many staff gave examples of discharge arrangements, often care home admissions that were made against the wishes of people who lacked capacity. In circumstances where the person's capacity was called into question, decision-making power often shifted strongly away from the person towards staff and families. Decisions in these circumstances were made in what was considered to be the person's best interests, which was not necessarily in accordance with the person's wishes, especially as staff and family opinions could differ from those of people with dementia:

> *Interview Site 2, Staff 20: (Speaking about people with dementia wanting to go home and their families wanting them to go into a home) "Yes! Yes! That happens quite a lot. So then you delve deep into things, looking at capacity, don't you. I think now the consultants have the authority to say whether someone has capacity to make or whether the decision has to be made in their best interest... ...Quite a high proportion of people who come into us from home and then go to a care, some form of nursing or care home, quite a high proportion of those, their family wants a care home but the patient said they don't."*

> *Interview Site 2, Staff 23: "It [capacity] can have big consequences because it often just means that that persons' opinion, just all of sudden, becomes so much less important. And it's like should that be up to us?"*

Although staff could hold strong and persuasive opinions, families often also held strong positions when it came to shaping the decisions that were made about their relative's future care, particularly in circumstances where the person lacked capacity:

> *Interview Site 1, Staff 7: "It's really down to whether or not the family agree or not. Because if somebody hasn't got capacity to make the safe decision themselves, you're making a decision in their best interest. But if the family disagree, you kind of have to go with what the family are saying cause they're next of kin and realistically, if they're not willing to take the risk, then they're gonna have to go into some kind of residential care home, even if it's against what the patient is wanting to do."*

> *Interview Site 2, Staff 20: "You can't then send them in a home just because they haven't got capacity, doesn't mean you have to send them into a home cos their family*

wants them in a home. You do whatever is professionally best. But then almost

negotiated with the family… …If they need anything else and if they do deteriorate, it's

the family that then has to go in and sort all that out. So you do have to sometimes

think well this person could manage at home for a very short period at the moment but

realistically, you know, if the family's happy, wants 24 hour care, we can think more

long term. And be realistic and think ok this would be the best option cos we are going

to get there very soon anyway. But yes it has a huge, I mean what family want for a

patient has a huge influence on what happens I think some of the time."

These quotes reveal some of the challenges of trying to balance conflicting views and they illustrate the potential power staff and families can have over decisions about discharge arrangements for people with dementia. In contrast, the bargaining positioning of people with dementia was much more variable, dependant on their ability to assert their views, their degree of involvement in decision making forums (which, as identified earlier, was variable), and the extent to which they were deemed to have capacity to contribute to decisions about their future care. Judgments by staff of a person's capacity were vital determinants of the person with dementia's ability to influence their future life and care arrangements. However, the process and quality of the assessments that determined a person's capacity, and so their decision making power, was sometimes questioned by staff and families, particularly when judgments were made at one time point by someone who had not previously met the person with dementia:

Interview Site 1, Staff 4: It's a sticky wicket is capacity really. It's on the day and who's

doing it really. I think it can be quite, not subjective as such, but I think a lot of it is, it

tends to be the people you think won't have capacity have, and the ones you think

won't… …On more than one occasion I've been absolutely amazed by the decision that's

come out. And then on the flip side of it people that you think 'oh they'll know, they'll be

fine', 'they'll be you know, they'll have capacity' and it comes back that no actually

today they haven't… …I think they'll say 'Do you want to go home?' and 'Do you

understand that you'll fall if you go home?' If the patient says 'I won't fall, I'll be fine'

and they've fell millions of times at home they've not got capacity. But that's quite

subjective isn't it really… …I mean I could be wrong, my knowledge on it's not that great

but it does seem to be very, very ropey really… …And it's quite a big decision as well you

know. I always think it's people who spend five minutes with patients who make these

decisions and yet family, although they'll be very one sided, or the nurses, staff who spend you know, seven hours a day, five days a week some of us or twelve and half hours that day I've spent with that person don't, aren't able to make assessments on the capacity."

Interview Site 2, Staff 22: "Capacity's huge, and it's really hard to assess. It's not an easy thing to say, cos at the end of the day you might be taking someone out of their home and putting them into care home which is not what they want. So you have to be careful. And it's often something that you get multiple opinions on, so we might look and I might say yes, I don't think they've got capacity, and then ward round, a consultant will have a chat, and then may or may not agree. And if it's really complex, we get psychiatrists involved."

Interview Site 2, Carer 21: "There was all this thing about power of attorney and that, and the consultant deemed that she couldn't make that decision. But actually I think she could, you know, because if you said to my mum who's going to look after your finances, who do you want to look after you finances - there's four of us - she'd immediately pick my brother, every time, no matter who asked that question. So I do think that she has got that capacity to do that really."

Determining capacity was made more complex by the potential for the capacity and capabilities of people with dementia to be negatively affected and highly variable whilst in hospital, making it particularly challenging to determine both the person's capacity and what discharge plans were in their best interests. The significance that decisions made in hospital could have for the future lives of people with dementia meant that understanding the person, their wishes, and their capacity was all the more crucial:

Interview Site 2, Staff 28: "If they're moving into 24 hour care we're changing their whole life."

Interview Site 2, Staff 23: "People are referred to as 'Bed Three'... ...knowing something about them makes them much more human and much less Bed Three-ish. And makes these big decisions that you're making on behalf of, well not on behalf of them but you know what I mean, a lot more of a deal. Because Bed Three oh she needs to go to a residential home. Right ok, but oh Joe Blogs is a doctor, very independent, he loves his house, he bought it when he was twenty... ...knowing these kind of things it makes it

more of thing. Like 'wow we're really changing someone's life now', we should at least know who they are... ...we are capable of re-housing someone or putting someone in a residential home. And they could have been a gardener and it's their only passion and it's the only thing keeping them going since they lost their spouse or something. And we've put them in a first floor sheltered accommodation flat."

The potential for divergence of opinions, power imbalances, and difficulties determining the person's capacity and capabilities, alongside the significance of discharge decisions for people with dementia and their families, required attempts to bring together differing views and mutually agree discharge arrangements wherever possible. Meetings or conversations between staff, families, and sometimes people with dementia, were usually the means through which divergent perspectives and understandings between groups were identified and attempts made to bring them closer together:

Interview Site 1, Staff 7: "If there is a strong disagreement from the side of the professionals, thinking that it would be better for them to be at home, and the family members thinking it wouldn't, we would normally have an MDT meeting for everybody to put their points across."

Interview Site 2, Staff 20: Interviewer: "When that happens, so say the family are thinking that they should go into a home but the person doesn't want to, how do you get to the decision about whether they will go into a home or not?" Staff 20: "It's quite, it's a long process. When patients go from home into a care home they tend to be, looking back, the longer hospital stays because of this process of getting discussions with their family about what they think is best. Discussions with the patient to try and, to try our best to you know give them a bit of insight into how, how would you manage at home? They'd say well I'd be fine and then you say, just delve a bit deeper and you'd try and get beneath the surface and say but you're needing a lot of help with this. And we're having to give you help with this and, you know, we're not going to be there if you were to go home. Would you be able to manage? We don't think you'd be able to manage." It's difficult but I think it, you do have to make sure."

Such discussions often narrowed or even brought to a close the divergence between the groups involved, although multiple conversations were sometimes required to

navigate strongly divergent views, with significant proportions of time needed to undertake these important discussions and make such challenging decisions:

> *Interview Site 2, Staff 27: "It's a very difficult decision for people, I think everyone needs to ensure they're doing the right thing, for whatever reasons. It takes a bit of time, and you do see people oscillating between what they want, some people oscillate, others it's very clear cut, but a significant proportion of people are chopping and changing. And I think no matter how you know the health service view is well it'd be really nice if they could just make their minds up so you can plan appropriately, you know this is a really difficult thing, it's a very difficult stressful emotional time, you can't really make these sort of decisions easily or lightly and you know they, you sometimes have to give the process the time it needs really, but it's hard… …and it's hard when you receive an email every day from managers saying beds are tight, beds are tight, which is what the usual subject box says, you know, it's hard. But you've just got to kind of do the right thing sometimes. You have to be mindful of the, you know, the fact that it's a very difficult decision and these things take a bit of time, but we are under significant pressure at times, to keep the system ticking over, that's hard."*

This quote highlights not only the additional time required to bring differing stakeholder views into alignment, but also the complications and organisational pressures that occurred when these views had not been aligned and discharge arrangements were still pending. These extended decision-making processes were one cause of lengthy stays for people with dementia. The time required to make these difficult decisions, particularly when there were dissonant views or delays in the instigation of discharge discussions, could delay decision making and extend lengths of stay, resulting in people with dementia spending longer than necessary in hospital:

> *Interview Site 1, Staff 4: "If you had that extra member of staff who could go and spend time with the family and discuss where we're up to and where we're heading and any concerns and then you wouldn't get to the day before discharge and all the problems come to light like it normally does."*

> *Interview Site 2, Staff 20: "I know there have been a few weeks where you're kind of rehashing the same information (In MDT meetings) because families and the person stay here. Even though they are like medically stable because there's on-going issues*

with different family members wanting different things for someone… …it does happen quite a bit that relatives disagree. And then you feel it definitely prolongs the hospital stay because you're spending a lot of time going between the two and it's difficult to get everybody together."

The last quote illustrates the power that families could exert over decision making and the potential for conversations and decision-making processes to focus on gaining agreement from families. In contrast, although staff could speak of needing to recognise and incorporate the views of patients into decision making, people with dementia were often absent from the forums where decisions were made about their future care and lives:

Interview Site 1, Staff 10: "I think people sort of do override over the person and go straight to ask the family what they would want… …the families' main concern is to protect them straight away so it's like 'gosh, get them into placement' and it's not what the person's wanting. But people don't always ask the person, I've even found in some of the big MDT meetings that I've been in, you'll say 'Shall we get, you know, the patient to come and sit in?' And it's like 'Oh no' and you think oh gosh, that's really not good, everybody's making these decisions for you, and the person's sat in the day room or, and they're not being that involved really."

Interview Site 2, Staff 28: Interviewer: "What happens when it comes to deciding about whether or not somebody with dementia gets to go home again or where they go?"
Staff 28: "Depends if they've got family, if they've got family we'll just kind of do a best interest meeting with the social worker and one of the nurses, family."

The absence of people with dementia from the discussions about their future, together with the pressure from families sometimes to push for outcomes that are contrary to the person's own wishes, mean that staff need to assess family motives carefully – and sometimes move towards a position of advocacy on behalf of the person with dementia:

Interview Site 2, Staff 27: I think it's also fair to say you know the degree of acceptance of the arrangements can vary from family to family… …I think one factors that view (the family's view) into the planning, whilst at the same time safeguarding the interests of the individual, and so ensuring that one is acting in their best interest and that we're

taking every step to ensure that's the case regardless of what the family's view is...

...They (families) can be driven by a variety of factors, sometimes I think it's fair to say not always for the best reasons for the individual, sometimes it's clear there's been a climate where people did financially assess it, and sometimes it will be financial reasons, and you have to ensure why people, as far as you can, why people are taking the decisions they're taking."

Interview Site 2, Staff 20: "The family sometimes, although it's hard to say it, sometimes have an ulterior motive, they might want them to go into care, it might be too much stress for them, they're putting a lot of effort into keeping them at home, they can't do it anymore, which is understandable. But actually they might be able to return home with homecare and then that's taken the pressure off the family, they're still getting to go home, you know, there's other ways round it."

These efforts to respect the interests of people with dementia illustrate how, as with the involvement of families discussed in Chapter 6, families' involvement in decision making was not uniformly in the best interests of people with dementia:

Interview Site 1, Staff 1: "We naturally think that next of kin is going to be, the family members or friends are going to be a positive influence and helpful, but they're not always."

Whilst it was clearly important to ensure families were provided with information and involved in decision making about their relatives care, the data presented here also clearly demonstrate a need to ensure that staff and family involvement in decision making does not result in the involvement or wishes of people with dementia being overlooked. There is clearly potential for staff or families to overrule the wishes of the person with dementia, particularly if the person is absent from decision-making forums or is found to lack capacity. Decision-making should, therefore, be contingent upon thorough assessments of capacity and on the inclusion of the views and wishes of people with dementia, either by their presence in discussions or by someone advocating on their behalf, to ensure the person's wishes are heard and acted upon wherever possible.

7.5   Chapter Summary

This chapter has explored knowledge sharing and decision-making practices between staff, families and people with dementia, and identified how understandings of people with dementia can differ between and within stakeholder groups. The value placed on assessing physical health, function and risk contributes to variability in the extent to which families' knowledge of the person is valued and used to inform care and decision making. Inconsistencies in knowledge exchanges with families and people with dementia, coupled with challenges in accurately assessing the person's functioning in unfamiliar hospital settings, create the potential for discordant understandings of the person and their care needs between and within stakeholder groups. The time and difficulties involved in reconciling these different understandings can extend lengths of stay and, particularly if power imbalances are present, lead to the views of one or more stakeholder groups being overlooked. The absence of people with dementia from decision making forums, or an assessment indicating they lacked capacity, places them at particular risk of decision-making which does not accord with their range of needs or wishes. Proactive engagement with families and people with dementia enabled more timely identification and bringing together of differing views on the person, and facilitated shared agreement on discharge plans.

Chapter 8

Discussion and conclusions

8.1 Introduction

This final chapter begins by bringing together the findings from Chapters 5 to 7 and discussing how they relate to the previous research identified in Chapters 1 and 2. To aid interpretation of the findings, the limitations, strengths and challenges of the research are then discussed, followed by my influence on the results and their interpretation. The chapter concludes by considering the implications of the study's findings for future research and clinical practice.

8.2 Summary of the key findings

The aim of this study was to explore how families' knowledge and expertise affects experiences of care and decision-making for hospitalised people with dementia. Taken together, the results chapters identify the highly variable nature of ward staff's connections with people with dementia and their families in hospital, and how the use of families' knowledge and expertise can help to effect more meaningful connections and care. The lack of consistent engagement with families reduced opportunities to improve experiences of care, and to bring together the variety of perspectives and knowledge held by staff, families and people with dementia. Different understandings of the person and his or her situation could lead to delays and difficulties in agreeing discharge arrangements that best meet the needs of both the person with dementia and their family.

Chapter 5 explored the circumstances under which opportunities to effect connections with people with dementia were missed. In these circumstances, people with dementia experienced varying degrees of disconnection from pre-hospital life as well as disconnection from the unfamiliar ward environments, routines, staff and knowledge and decision-making exchanges. These multiple facets of disconnection were interrelated; with a lack of connection in one area having the potential to impact negatively on connections in other areas. Disconnection had the potential to reduce emotional and physical well-being (negatively affecting physical functioning, recognition and meeting of care needs, and levels of distress, fear and loneliness) and could contribute to longer term disconnections from pre-hospital life (including more permanent disruptions to prior levels of functioning and aspects of prior care-giving roles and relationships).

Chapter 6 explored the circumstances under which more meaningful connections were made with people with dementia. These data demonstrated how the knowledge and expertise of families played a central role in facilitating connections that formed a crucial component of providing more person- and relationship-centred care. For example, knowledge from families about the person's usual routines and behaviours, and strategies for engaging them in conversation and care tasks, provided a valuable means of enhancing connections and experiences of care. These examples illustrated first how person-centred connections and care are possible despite the constraints of busy hospital settings and, second, the circumstances under which these connections are best effected. Attempts to use families' knowledge and expertise to provide more person-centred care depended on the degree to which circumstances such as ward environments, routines, staffing, staff expertise, and cultural and organisational priorities and policies encouraged or inhibited engagement with people with dementia and their families. Variations in these circumstances meant that the knowledge and expertise of families was not routinely sought, valued or used - with inconsistent approaches evident among individual staff and wards.

Chapter 7 explored knowledge sharing and decision-making practices between staff, families and people with dementia, and identified how understandings of people

with dementia can vary between and within stakeholder groups. The over-arching value placed on assessing physical health, function and risk contributed to variability in the extent to which families' knowledge of the person was valued and used to inform care and decision making. A lack of consistent consultation and knowledge exchange with families or people with dementia, together with challenges in accurately judging the person's functioning in the unfamiliar hospital surroundings, created the potential for discordant understandings of the person and their care needs between and within stakeholder groups. The time and difficulties involved in reconciling these dissonant understandings could extend lengths of stay and, if power imbalances were present in the decision-making process, lead to the views of one or more stakeholder groups being discounted or overlooked. People with dementia who were deemed to lack capacity were particularly at risk of having decisions made about them which did not accord with their range of needs or wishes. Earlier engagement with families and people with dementia enabled more timely identification and bringing together of differing views on the person and the most appropriate discharge plans.

Despite the advantages of involving families in care, Chapters 6 and 7 identified that family involvement was not uniformly beneficial. Families had the potential to contribute to disconnecting people with dementia, for example by diverting conversations away from the person, speaking over or for the person, and creating negative interactions with the person. The potential power afforded to families, particularly when the person's capacity was questionable, was another example of how the involvement of families was not unwaveringly positive. Most examples of the presence or absence of family engagement indicated, however, that drawing the knowledge and expertise of families into care and decision making often helped to improve the quality of connections and thereby care and decision making. Staff who engaged with families also viewed their involvement as beneficial to their tasks - aiding work such as information gathering, care delivery and decision making - and helpful to people with dementia, by improving the quality of care and interactions with them. These potential benefits make a case for engagement with families becoming a more routine component of hospital care for people with dementia. This

suggestion cannot, however, equate to an assumption that all family involvement is beneficial; the merits of involving each family must be balanced against the preferences, involvement and needs of the person with dementia.

8.3 Relationship of the key findings to previous research

This section discusses the relation between the key findings of this study and the previous research referenced in Chapters 1 and 2, with further references made to additional literature, where appropriate.

The first results chapter, which focused on the many facets of disconnection that people with dementia could experience, upholds the findings of Porock et al (2015). In the most in-depth prior study in this area they identify disruption from pre-hospital relationships and life as a central component of hospital experiences for people with dementia. Hospitalisation caused disruption to the familiar surroundings, routines and relationships of people with dementia, disruptions which could begin prior to admission due to the onset of illness, deterioration or an accident as the precipitating reason for admission. There is great overlap between Porock et al's concept of 'disruption' and the facets of disconnection from pre-hospital life referred to in this thesis, both of which are used to refer to the interruptions people with dementia experience to their usual lives as a result of a hospital admission.

The use of the term disconnection rather than disruption was purposefully chosen in this thesis to draw in the additional forms of disconnection that people with dementia experience during hospital admissions which do not involve disruption to *prior* lives. These disconnections included a lack of connection with busy, task-orientated hospital staff and with knowledge exchange and decision making processes. The consideration of disconnections from in-hospital as well as pre-hospital life in this thesis therefore builds on the work of Porock et al by establishing a wider range of ways in which people with dementia have the potential to

experience disconnection during hospital admissions. The term disconnection also creates the alternative possibility of exploring connections or re-connections, and so also enabled the exploration in Chapter 6 of the ways in which connections could be created or maintained.

Porock et al's (2015) focus on disruptions to 'normal' life raises interesting dimensions of disruption which have not been a core focus of this thesis. The primary difference is their extension of the concept of disruption to consider how other stakeholders within the care-giving triad (families, staff and co-patients) are also disrupted by the admission of the person with dementia. For example, they pay significant attention to disruption caused to family care-givers' lives, including the emotional disruption caused by uncertainty around the person's future prognosis and care needs. Such disruptions are heightened for families who usually care for the person with dementia at home or for families who are concerned that hospital admission will disrupt familiar and effective community support arrangements. Other studies (e.g. Bloomer et al, 2014; Boltz et al, 2015b; Lindhart et al., 2006; Li, 2005) similarly identify disruption and stressors for families, including uncertainty and anxiety around both their ability to continue care-giving and their relatives' in-hospital experiences, well-being and care. The threat hospitalisation poses to maintaining prior ways of managing and to the continuation of care-giving roles (e.g. Bauer et al, 2011b; Douglas-Dunbar & Gardiner, 2007), provides a further example of the potential for 'disruption' or 'disconnection' for families. In support of these prior findings, many (n=8) of the families included in this thesis experienced significant disruption to, or more permanent disconnection from, their pre-hospital care-giving roles -through new home or residential care arrangements post-discharge, or through the death of their relative. This supports Porock et al's (2015) claims that disruptions continue after discharge until both the care-giver and the person with dementia re-adjust to changes in the care-giving situation. Alongside these more dramatic changes in roles, disruption to the care-giving roles, relationships and control of families, which corroborate the findings of Porock et al (2015) and others, are implicitly and explicitly referred to repeatedly in this thesis. For example, the results chapters discuss how families and people with dementia are

disconnected from each other during hospital admissions and the potential for families to experience reductions in their claims to expertise and power through reduced involvement in knowledge exchanges, care and decision making during hospital admissions.

Porock et al (2015) also consider how people with dementia disrupt the usual care routines of ward staff (although they identify their staff data as limited) and co-patients with whom people with dementia share ward spaces. Disruption to staff routines and to the balance of power is also identified by Allen (2000) in relation to the involvement of families on hospital wards, with 'expert carers' particularly likely to challenge nurses' retention of power. Although this thesis did not focus on co-patients' experiences or extensively explore disruptions or disconnections in relation to staff, there are examples within Chapter 7 of disconnections between staff members. These include the limited transfer of knowledge between staff and disruptions to their usual work caused by the difficulties of gaining knowledge about people with dementia and time required to engage with their families. These findings thereby support and extend those of Porock et al (2015) and Allen (2000) on the disruptions to staff caused by caring for people with dementia.

Chapter 6 moves on from concepts of disruption and disconnection to consider the conditions required to effect meaningful connections with people with dementia, highlighting families' knowledge and expertise as crucially important. The concept of a connection continuum is presented to demonstrate variability in the extent to which connections were forged with people with dementia. This variability is supported by examples from previous studies of varying degrees of connection with people with dementia in hospital settings (e.g. Tolson et al., 1999; Norman, 2006; Clissett et al., 2013). Previous studies have suggested, as I have here, that hospital staff do not grasp all opportunities available to them to create more person-centred care connections (e.g. Clissett et al, 2013; Douglas-Dunbar, 2007; Tolson et al, 1999; Norman, 2006). They have also pointed out some of the negative impacts of features such as unfamiliar and clinical environments and task-oriented routines on the quality of connections and care (e.g. Clissett et al, 2013; Tolson et al, 1999).

The value of using families' knowledge and expertise to effect connections echoes a finding from Nolan (2006) and Stenwall et al (2007) who identified challenges for nurses in developing relationships with people with dementia without the information required to deliver person-centred care, and the consequent value of seeking this knowledge from families. Porock et al (2015) corroborate the value of connecting both with families and people with dementia by suggesting links between disruptions to pre-hospital life and distressed and disengaged behaviours in people with dementia. Previous studies give examples of some of the ways in which families can improve hospital experiences for people with dementia; the data in these studies bear similarities with the findings of this thesis. For example, families are described as ameliorating some of the distress, disruptions and gaps in the care experienced by people with dementia by providing knowledge and strategies for managing the person's anxieties and behaviours: maintaining links with normal life, advocating for the person, and using their knowledge of the person to influence care (De Vries et al, 2016; Gladman et al, 2012). What this literature does not provide are specific details of how some of these changes in practice and care are effected by families within the constraints and practices found within general hospital settings. These studies also do not explore how families' involvement in care is experienced by, and affects, people with dementia (e.g. De Vries et al, 2016; Gladman et al, 2012). And, rather than exploring how families' knowledge and expertise can be used to effect more person-centred connections and care in hospital settings, studies tend to focus on the problems that arise when staff do not engage with families (e.g. Stenwall et al, 2007). This thesis therefore builds on previous studies by setting out some of the conditions and approaches through which person-centred connections and care with people with dementia can be created in busy and physical care-oriented hospital settings.

Despite the potential benefits of family involvement, Chapter 6 identifies variability in the use of families' knowledge and expertise to inform hospital care for people with dementia, a finding supported by several previous studies (e.g. De Vries et al, 2016; Boltz et al, 2015b; Bauer et al, 2011b). Some studies (De Vries et al., 2016; Boltz et al, 2015b) identify strategies used by families to insist on some input to their

relative's care, such as asserting their knowledge and expertise, 'taking up residence' or 'keeping vigil', and strategic visiting to coincide with key opportunities for input (such as mealtimes and ward rounds). These studies, however, tend not to explicitly identify the range of ways in which families might be encouraged to contribute their knowledge and expertise to improve care.

Chapters 6 and 7 identify multiple aspects of hospital care that influence the extent to which connections are made with people with dementia and their families and shape their involvement in knowledge exchange, care and decision making. Negative influences include unfamiliar and highly clinical environments, busy physical-health orientated routines, knowledge seeking focused on physical concerns, minimal levels of staffing, limited dementia expertise, and a variety of care priorities at organisational, ward and staff levels that all tend to inhibit connections with people with dementia and their families. It is necessary to read across previous studies to find prior recognition of these factors affecting the degree to which person- and family-centric care, decision making and knowledge exchanges occur in hospital settings. For example, separate studies identify: the influence of dementia training or expertise on the degree to which individual staff feel equipped to provide person-centred care (Nolan, 2007; Norman, 2006); conflicts between task and person focused care (e.g. Clissett et al, 2013; Cowdell, 2010); the challenges of focusing on individuals with dementia and families amidst highly pressured time-limited workloads (Doherty & Collier, 2009; Borbasi et al, 2006); and an over-arching focus on discharge processes (Bronson & Toye, 2015).

Other studies have identified the crucial role of senior ward staff in shaping cultures of care delivery (e.g. Lindhardt et al., 2008) and how person-centred approaches to care, including the seeking and use of personal knowledge, often occur in 'pockets', as a result of individual practitioners' influence rather than a routine approach across services (Clissett et al, 2013; Royal College of Psychiatrists, 2011; Nufer & Spichiger, 2011; Borbasi et al, 2006). Judgments about the legitimacy of family members' roles in their relatives care have also featured in previous studies, with Collier & Schirm (1992) reporting that staff did not involve 'undesirable' care-givers such as those who were abusive, disagreed or wanted the person in a care home. Although staff in

the current study were similarly cautious around families with negative or potentially abusive relationships, their responses to disagreements seem to counter those reported by Collier & Schirm (1992); conflicting opinions were sometimes a specific reason for engaging rather than avoiding families. Chapters 6 and 7 therefore support and build upon the findings of previous studies by providing an in-depth exploration of a range of potentially modifiable explanatory factors that shape the degree to which hospital staff engage with families and people with dementia and families' knowledge and expertise is used during episodes of hospital care.

Chapter 7 explored knowledge-sharing and decision-making exchanges within dementia care-giving triads, and the potential for these exchanges to be shaped by divergent understandings of people with dementia. The differing types of knowledge held by professional and informal carers are also identified by Harvath et al, (1994) and Smebye & Kirkevold (2013) who compare the personal or 'local' knowledge of families with the general or 'cosmopolitan' knowledge of staff in care settings other than hospitals. Dissonant understandings and perspectives on decision making within hospital care-giving triads have also been recognised in studies that examine how families, staff and patients without dementia bring different definitions of the situation, different knowledge, and different goals (e.g. Rosenthal et al, 1980; Allen, 2000). Interactions within hospital care-giving triads involving people with dementia have received less attention, although Bloomer et al (2014) identify the potential for conflicting views between family members of people with dementia and decision making dilemmas when families do not agree. Naylor et al (2007) describe hospital staff giving contradictory recommendations to families of people with dementia, and discrepant perspectives between families and staff are suggested by De Vries et al (2016) and Jurgens et al (2012) in their references to staff who do not share, or are unaware of, families' philosophies and expectations of care. Although none of these studies explores in any depth the concept of dissonant understandings in relation to the hospital care of people with dementia, they collectively lend support to the claims made in this thesis about divergent perspectives. By focusing on discrepancies between staff and families, these previous studies also inadvertently suggest, but do not explore, the finding reported here -

that people with dementia are often excluded from decision making about their own care.

Both Chapters 6 and 7 identify that family engagement is not uniformly beneficial for people with dementia, a finding which appears to have received relatively little previous attention. Discussions around relationship-centred care appear to largely overlook the potentially negative effects of engaging with families, and none of the 9 studies of family engagement identified in Chapter 2 pays much attention to this downside to involving families in care. De Vries et al (2016) make very brief reference to the presence of families as a catalyst for unintentional bad practice, such as staff attempting to talk to families above the head of the person with dementia, and the partial or complete exclusion of the person from discussions about his or her own care. Porock et al (2015) describe how various stakeholders act to gain a sense of control but do not consider whether attempts to gain control by one stakeholder or group impacts on the sense of control of other groups. The power differentials at play between arms of the care-giving triad have been recognised in studies outside of general hospital dementia care. These studies have recognised the potential for families or health professionals to control conversational agendas and dominate decision making (e.g. Smebye et al., 2012), thus limiting the participation of people with dementia (Tyrell et al, 2006). Smebye et al's (2012) findings support claims made here of families having the potential to draw decision-making power away from people with dementia. The power imbalances identified in this thesis, and by Smebye et al, counter conceptions of triadic relationships that portray stakeholder groups as inwardly homogenous and mask the dissonance and power differentials that can occur both between and within these groups.

In recognising dissonance between stakeholder groups it should, however, not be presumed that all conflict is a bad thing. Constructive responses to conflict are recognised by this and other studies, including an appreciation and accommodation of the other's perspective, an impetus to discuss legitimate concerns, and recognition of misunderstandings or previously unaddressed needs (Breen et al., 2001). It should not be assumed, however, that experiences of conflict and power differentials in patients without dementia (e.g. Breen et al, 2001; Rosenthal, 1980;

Allen, 2000) reflect the additional marginalization likely to be experienced by people with dementia, particularly by those who are deemed to lack capacity. The quality of decision making about those who lack capacity, including judgments of capacity itself, is questioned both in the present study and by others (e.g. Emmett et al., 2013), with preoccupations about risk minimisation particularly likely to outweigh consideration of happiness and emotional well-being when it comes to determining discharge plans for people without capacity (Laird, 2014). The potentially life-changing effects of hospital discharge decisions for people with dementia (Sheehan et al, 2009) point first to a need for balance in the power and priority differentials that can drive decision-making processes and, second, the importance of involving people with dementia and their views in decisions about their own care. Whilst input from families is often positive, the potentially detrimental effects of family engagement identified in this thesis run counter to the widely expressed view that family engagement is unwaveringly positive and uniformly desirable for people with dementia. This suggests a need for further research on this specific topic as well as the development of family-involvement practices that give precedence to the needs, wishes and involvement of people with dementia.

8.4 Limitations, strengths and challenges of the study

8.4.1 Limitations and strengths

In interpreting the findings from this research, it should be borne in mind that this study, as with any research, has a number of limitations, as discussed below.

The choice of research sites may have limited the degree to which I observed what might be considered 'typical' experiences of people with dementia and their families. As the research sites comprised a rehabilitation ward and an acute ward, each with

senior staff who had dementia expertise, it is possible that I saw a picture of family involvement practices that was better than average. From the information I was given about other wards, practices elsewhere seemed less supportive of family involvement, illustrated by the examples of bell-ringing to tell visitors to leave, queues of visitors waiting to be allowed access, differences between wards in the care permitted by families, and reports of senior staff on some wards refusing to engage with families. However, discussion of these alternative experiences highlighted both their presence and an opportunity to explore reasons for these variations, which contribute to the findings discussed in Chapter 6.

Despite efforts to recruit a varied sample, and the inclusion of translation costs in my PhD fellowship application, there was a lack of minority ethnic and non-British participants. The time consuming nature of the data collection meant that recruitment was restricted to people admitted at the times when I had capacity to follow up a new participant. The admission of minority ethnic and non-British participants was unexpectedly limited at both sites during the data collection, despite one site being located in an ethnically diverse area, and the occasional admission of more ethnically diverse participants unfortunately did not coincide with my capacity to take on a new participant. Exploration of family engagement in ethnic minority groups and amongst families or people with dementia who do not speak, or are not fluent in, English would form an interesting future study.

Recent encouragement for more open hospital visiting for families of people with dementia from John's Campaign (Jones & Gerrard, 2014) and financial incentives in the 2016/17 CQUIN (NHS England, 2016a) have led, since these data were collected, to many hospitals or individual wards changing their approach to families of people with dementia. These advances do not, however, render the data here outdated because the limited data available from these changes indicate that uptake remains patchy and dependent on the practices of individual wards (NHS England, 2016; Imperial College Healthcare NHS Trust, 2016). There is little available guidance, either in the CQUIN or more widely, on strategies for implementing closer working with families or for the incorporation of their knowledge and expertise into the hospital care of people with dementia. For example, the CQUIN documentation

(NHS England, 2016b) refers only to involving families in care and makes no reference to balancing families' involvement against the need to involve and consider the wishes of people with dementia - a finding strongly emphasized in this thesis. Although practice in this area has undoubtedly advanced in recent years, research and guidelines on family involvement remain limited and, from the data presented here, there remains much to be learned about the processes and implications of involving families in care.

Ethnography as a method also has limitations. Although the method provided unique access to the perspectives of all three arms of the care-giving triad, and interactions between them, the limits of participant observation must also be recognised. Caution is required in interpreting the findings of any ethnography, or any research, as reflecting and understanding the experiences of 'the other' (Wind, 2008), particularly perhaps here, where substantial interpretations were made of the meanings behind the apparently confused talk and actions of some participants. The combination of methods and lengthy data collection used here have, however, provided what I believe to be a more in-depth and nuanced understanding of the experiences of people with dementia and their families than would have been possible with other methods, including those used in previous studies. Detailed accounts of the data collection and analysis methods and detailed extracts of data have been provided in order to enable the reader to judge the interpretations that have been made.

Despite the above limitations, the study also has significant strengths. The length of time spent, deeply immersed within both wards, and the multiple data collection methods have provided rich and nuanced data, including attempts to represent the experiences and perceptions of people with dementia, which are missing from many published studies. It is unlikely that alternative methods would have afforded these benefits. Despite recent advances in practice in the involvement of families of people with dementia in hospital care, this remains the most in-depth multi-methods study to date of approaches towards, and experiences and impacts of, family involvement in this area. The study also explores aspects of families' involvement that have been overlooked by previous studies, including experiences across the course of a hospital

admission and interactions between and within all three arms of the care-giving triad.

8.4.2 Challenges arising during the research

Collecting such in-depth data over extended periods of time with acutely unwell participants with dementia posed particular challenges, as discussed below.

Data collection took far longer than anticipated, due predominantly to some participants having lengths of stay far exceeding estimates. Before the start of data collection, lengths of stay had been estimated by several clinicians to be around 10-14 days but in reality problems determining discharge arrangements and the more complex nature of ill health and recovery for people with dementia meant that some participants spent months rather than weeks on the wards. As a result, data collection took far longer than had been anticipated which increased the likelihood of missing parts of the admission due to my inability to attend the ward on occasions or participants moving to different wards (due to worsening or improving health). For example, one participant temporarily moved to a different hospital due to ill health, during which time I was unable to follow her. I was, however, able to keep checks on her whereabouts via staff who worked across hospital sites or had been in contact with her new ward, and via contact with her family. Fortuitously, she was later transferred back to the research ward and I was able to continue following the latter part of her admission. I was also able to understand something of her experiences during her time away, and those of other participants when I wasn't present, through conversations with participants, families and staff, and via the hospital notes. Extended lengths of stay also meant more choices had sometimes to be made between who to observe - as interesting events could be happening for more than one participant at the same time - which resulted in some data being missed.

Ward closures were a further challenge. Both wards were closed for 1 to 2 weeks during data collection due to outbreaks of infection, with access to the wards and participants dependent on the ward's approach to visitors during closures. On

arriving at one site to find a large closed sign and all patients confined to their rooms, I was asked not to visit until the ward re-opened, a request which I agreed to whilst repeatedly wondering how patient's experiences were affected by their confinement and lack of visitors (even therapy staff) for over a week. At the other site, other visitors and I were allowed to continue visiting at our own risk, providing we abided by the strict hygiene rules. As I had previously entered isolated rooms on this ward, at the invitation of staff members and with full instructions in the hygiene procedures, other visitors and I continued to visit this ward during its closure.

At the first site I experienced problems in securing second interviews with some relatives post-discharge. Although families were typically keen for me to spend time with their relative on the wards and to complete the first ward-based interview, it was harder to arrange second interviews once participants had left the wards. Despite speaking to, leaving messages and re-contacting relatives as many times as felt appropriate without unduly hounding them, I was unable to secure second interviews with three out of six relatives from Site 1. One relative did not attend our arranged interview and a further two agreed to an interview in principal but I was unable to confirm arrangements for these interviews to take place. I later reflected that the assertion in my research protocol that I would try to interview relatives separately from the person with dementia within 2 weeks of discharge was logistically awkward for families, especially if they were adjusting to changes in the care arrangements or needs of their relative post-discharge. A separate interview also unintentionally implied a lack of on-going interest on my part in their relative, which was at odds with my close prior contact with them and again potentially off-putting. At Site 2 I approached arrangements for the follow up interviews more flexibly and also developed closer relationships with relatives, perhaps due to my increased confidence and the more open ward layout, which seemed to contribute to the success of the follow up interviews as all six took place.

A further challenge to follow up was the death of three of my participants, one during data collection and two after discharge but before the final interview with their family. Whilst I was careful not to approach or recruit anyone who was terminally or seriously ill, the risk of unexpected deterioration in this patient group

meant that the health of these three participants unexpectedly worsened some time after recruitment to the study. In all three cases, I had come to know the person and their relatives well by this point, after several months of regular observations, conversations and a home visit in one instance. Due to the length of time these participants had been involved, after much deliberation and discussion with my supervisors and the ward staff, I decided to simply ask each set of relatives what they would prefer to do, giving them multiple and easy opportunities to state that they would no longer like to take part. I expected all three groups to decline to take part any longer, particularly the family of the participant who became terminally ill during the observations. Instead, all were insistent that they wanted to continue and spoke of a value to being able to continue sharing their story and, in the latter case, to having a familiar face around during the weeks ahead. I did, however, change my approach to data collection in all 3 instances. For example, final interviews were significantly delayed and included discussions of happy memories of the person, and my observations were largely limited to popping in briefly to say 'hello' and ask after the family rather than to observe, although this regularly resulted in lengthier conversations as the family seemed to value the opportunity to talk to someone. In all 3 instances data collection only continued at the repeated assurance of the participants that they wanted to continue taking part.

8.5 Reflexive summary of my influence on the results and their interpretation

My influence on data collection has already been discussed in Sections 4.11-4.14 so here I provide a brief additional reflection on my influence on the interpretation and analysis of the data I collected. In Section 4.13 I referred to my tendency to dichotomise participants as good or bad and a predisposition from my previous clinical role to protect people with dementia. Representing and making sense of the (sometimes) opposing perspectives of people with dementia, families, and staff was a significant challenge - particularly when those perspectives diverged. In trying to

interpret and present such complex triadic relationships it is possible that I have insufficiently represented them. For example, my efforts to present the perspectives of the most marginalised individuals in this study – people with dementia – may have led to insufficient or negative representation of the experiences and positions of families or staff. I made efforts to avoid these prejudices throughout the study, for example by reflecting regularly on how my preconceptions might be influencing data collection and analysis, by using verbatim accounts of participants' words, and by involving my supervisory team in interpretation of the data. In addition, detailed excerpts of data have been included alongside the interpretations presented in Chapters 5-7 to allow the reader to judge the quality of the interpretations made.

Sections 4.12 and 4.13 described the extent of my involvement with participants. I was lucky enough to be welcomed and involved in life on both wards. Whilst this greatly aided data collection it created repeated dilemmas concerning my level of involvement and when to step out of my researcher role and give a purely 'human' response to situations, knowing this would affect the data I collected. As a result, there were times when I did not capture, or therefore analyse, the full extent of the difficulties experienced by people with dementia or their families because I intervened in the situation, either at their request for information or comfort or because I was unprepared to witness the events unfolding without intervening. As described in Section 4.11-4.14, my presence and intervention thereby inevitably influenced the data that were collected and analysed to produce the findings presented in Chapters 5 to 7. These findings therefore need to be interpreted in light of my influence on both the data collection and its analysis.

8.6   Implications for future practice

As no guidelines currently exist for involving family caregivers in acute care (Boltz et al, 2014) and research in this areas is limited (Porock et al, 2015; Boltz et al, 2015b), this thesis provides much-needed evidence to inform practices around the involvement of families of people with dementia in hospital care. This is particularly

apt given the recent impetuses for greater family involvement set out in the 2016/17 CQUIN (NHS England, 2016a&b*)* and John's Campaign (Jones & Gerrard, 2014) which have increased the engagement of families but have little evidence on which to base their recommendations.

The study focused on experiences of people with dementia and their families but many of the problems and challenges highlighted may also apply to other patients and families. In particular, the findings may be relevant to other potentially vulnerable patient groups who may struggle to express their needs - such as people who have experienced a stroke, have learning disabilities, brain injuries or delirium. Staff engaging with families of people with dementia also potentially have much to learn from areas that already implement high levels of family engagement on a regular basis, such as children's wards, and countries where families' input to hospital care is a cultural expectation (for example in some countries in Europe and Asia).

The findings of this study demonstrate how families' knowledge and expertise can effect connections with people with dementia, supporting a growing assertion that person-centred care is possible in general hospital settings. It is clear to see how these findings link back to the concepts of person and relationship-centred care discussed in Chapter 1. The focus on creating and maintaining connections with people with dementia, and using families as resources to effect these whilst maintaining a focus on the involvement, wishes and needs of the person with dementia, echoes the key concepts of these interlinked theoretical perspectives on dementia care. By directing specific attention to how connections with people with dementia can be effected in hospital settings, this study sets out some of the circumstances and approaches through which hospitals and their staff can deliver person- and relationship-centred care to people with dementia. The findings also demonstrate how families can contribute to improving the often poor experiences and outcomes of care highlighted in Chapter 1. Families can, for example, help to improve care provision, engage with care and rehabilitation tasks, assist with retention of previous functioning, and be more involved with decision making, all of which have the potential to contribute to improved discharge outcomes, providing

their involvement is balanced against the needs, involvement and wishes of people with dementia.

Evidence from this thesis could contribute to the development of future guidelines to support the involvement of families in general hospital care by. For example, the finding point to the need to ensure that ward conditions (staffing, staff training, senior support, visiting policies, and the like) support engagement with families and people with dementia. The findings provide examples of the range of ways in which families might be involved in care, and the need to maintain a focus on involving and considering the views of people with dementia alongside those of families. The data also provide insight into what person- and relationship-centred care might look like and how it might be effected within general hospital contexts as opposed to in the long-term care settings where these concepts were originally developed.

8.7   Implications for future research

Several largely unexplored areas requiring further research have been identified by this thesis. Although this study has focused on the involvement of families in the hospital care of people with dementia, this remains a largely unexplored general topic area, as identified by Chapter 2 and other recent literature reviews (Boltz et al., 2015b; Bauer et al., 2011; Porock et al., 2015). This study identifies specific areas within this field which would benefit from further enquiry, such as: understanding and balancing power differentials and dissonant understandings within dementia care-giving triads, exploring and ensuring quality in capacity assessments, the potential for negative impacts of family engagement for people with dementia, and further exploration of discharge decision-making processes within dementia care-giving triads. The data (from this study and others) indicate that the problems and challenges of hospital care and engaging with families may be heightened by dementia, although comparison with the experiences of patients without dementia and their families was largely outside the scope of this thesis. This would, however, provide an additional useful focus for future research.

A further potential progression from the findings of this study is the development and testing of an intervention to involve families in the general hospital care of people with dementia. The current study forms part of the development work required for such an intervention, in line with the intervention development stage of the MRC framework for developing and evaluating complex interventions (Craig et al., 2008). The current study contributes to developing a more robust evidence base for a future intervention, providing in-depth data relevant to the design and content of the intervention. The data here also provide a detailed understanding of the opportunities, challenges and benefits of implementing such an intervention in complex and dynamic general hospital settings.

Literature on social and care networks was referred to in Chapter 2. The addition of formal (in this case hospital) care as a component of 'social' or 'care' networks is under-explored (Rutherford & Bowes, 2014). These theories appear to offer a useful framework from which to consider the complexities of interactions between formal and informal caring networks in future studies, with data from the present study helping to broaden understandings of care networks beyond informal care. Social network theory may therefore provide a useful framework for identifying the components of the family involvement intervention described above and contribute to building a logic model to identify the mechanisms of action through which an intervention might improve experiences and outcomes of hospital care for people with dementia, families and staff.

Finally, in demonstrating that it is possible to seek and elicit the perspectives and experiences of acutely unwell people at various of stages of dementia and in complex hospital settings, this study adds to the call for researchers and funders to ensure that future studies are designed to maximise the involvement of people with dementia wherever possible. Research practice remains inconsistent with regards to the inclusion of people with dementia; several recent studies in the area of this thesis (e.g. Bloomer et al, 2014; Boltz et al., 2015b; Bauer et al., 2015a & b) have excluded people with dementia despite their successful involvement in other studies. This represents an undesirable mirroring of the way in which some people with dementia are excluded from knowledge and decision making about their care.

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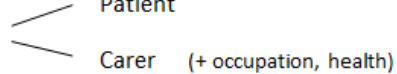
Appendices

Appendix 1: Observational Framework

Appendix 2: Interview Topic Guides

Interview Guide: Families, Interview 1

Background info

- Home - Where live & who with? — Patient
  Carer   (+ occupation, health)

History of memory problems

Typical day at home

- Memory problems?
- Help needed?
- Who provides help?
- Strategies that help)
- **Effects on carer** (how is it for them, effects on day to day life, relationship with the person)

Admission story

- Ask for admission story   (Home → A&E → ward(s)

- How has _____ seemed since been here?
  - Getting help they need?
  - Any worries?
  - Anything difficult due to memory problems?

- Hopes for outcome of the admission?   Person... Yours...

Talk me through typical visit to the ward:

- What do
- Describe typical conversations with staff:

  - How did it start?

  - What talk about? (person? how they are usually?)

  - How do you feel conversation went? (How were staff with you?)

  - Outcome of conversation (effect, how info used)

- How easy is it to get to speak with staff?

- What sort of information has been shared? ⟨ With carer / With staff

  Personal info?

  Do you/how do you get a sense of how relative is doing?

  Talk in person/on phone?

'Involvement' in care:

- Any other ways have been 'involved' in the admission?
  - e.g. Admission, Assessment, Physio, Nurses, Doctors, planning
  - When/Why?
  - How did this happen?
  - What difference has it made? (to patient, carer, staff/care)

- In ideal world, how would they like to have been 'involved'?
  - Conversations? Things like to do?
  - When/why
  - What difference would it make? (to patient, carer, staff/care)
  - Why hasn't it happened?

Focus on outcomes & decision making & person centred knowledge – what personal knowledge they have & what is sort from them. If ward were going to welcome families doing and passing on more how would they want this to be introduced/explored with them. N.B. ask for example, 'talk me through what happened', repeat key words, explore feelings in more detail, ask why,

Interview Topic Guide – Families, Interview 2

Overall Experience:

- Patient
  - How seemed?
  - Get help needed? - Anything could have been better?
  - Did staff understand how to be with relative because of memory problems? (How well did staff know your relative?)
- Carer — How felt for you?

Visiting:

- Describe typical visit
  - What did you do for ????
  - Why
  - Reaction from/negotiation with staff
  - Impact on selves & patient

Conversations with staff:

- Typical conversation with staff?
  - What about? (person?)
  - How feel conversation went?
  - Effect of conversation?

- How find speaking with staff?

- Enough contact with staff? *Before quick chats at reception*

Other Involvement?

- Information sharing
  - Shared with you?
  - You shared with staff?

- Social services assessment?

- Memory assessment?

- Discharge planning?

- What difference did the above involvement make? —— You / PwD / Staff/care

Ideal involvement:

- Anything like to have done during visits but didn't?
    - What
    - Why
    - Why didn't they do it?

- What contact would you like to have had with staff?

- Talk me through, in ideal world, how liked to have been involved in your ????'s hospital care, starting with when 1st admitted?

    - When?

    - Why?

    - What difference would it make? (to patient, carer, staff/care)

    - Why didn't it happen?

How is your ???? now?

- Memory?

Interview Topic Guide: Staff

Patient's background:
- Memory problems & effect
- Personal knowledge (home, how managing, family, life history, interests)

Patient's admission story:

- Ask for admission story
  - Why admitted
  - Care needed since admitted (rehab & routine care)

- Difficulties of providing that care alongside memory problems?
  - e.g. communication, understanding, memory, pain, emotions
  - Anything that has helped?

- Experience of being in hospital for _____?
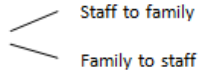 - How seemed?
  - Anything that has helped?

Visitors:

- Describe typical visits - *Ask for examples*
  - What would they usually do?
  - Who talk to?
  - Reasons why?
  - Effects on patient? …..relative? ……..staff/care?
  - Visits different at different points in admission?

- How typical is above for:
  - Visitors of people with memory problems
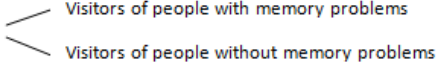 - Visitors of people without memory problems

Conversations with family:

- *Think back to when admitted, talk me through what contact had at diff points....*

  Describe a typical conversation
    - How did it start
    - What talk about *(Person?)*
    - Why
    - Conversations useful? *(how info used? any effects on care?)*

- How have family seemed during conversations?

- How have you found talking with them?

- What sort of information has been shared? — Staff to family / Family to staff

Relatives' involvement in care

- Any other ways family have been 'involved' in the admission
    - e.g. Social services, Assessments, Therapy, Nursing care, Doctors, Planning, Discharge
    - How did this happen?
    - When?
    - Why?
    - **To what effect? (patient, carers, staff)**

- How typical is above for: — Visitors of people with memory problems / Visitors of people without memory problems

- How should relatives of people with memory problems be involved in care?
    - When
    - Why?
    - What would be the effect? (benefits/downsides to patient, carer, staff/care)
    - Does this happen now?
    - How could it happen?

At end: time on the ward, experience/training dementia

Interview Topic Guide – People with memory problems

Experience of hospital: *(May ask these questions more than once)*

- What is it like here?

- Do you like it here? / How do you feel about being here?

- Are you well looked after here?

- How much choice do you have over what happens here?

Relationships & connections with staff: *(Ask when staff have recently been around)*

- How do you get on with the other people here?

- Do people here talk/listen to you/spend time with you?

- Do people know you well here? / know much about you here?

Family involvement: *(Ask when family have recently been around)*

- Ask about person's family
- Do they come to see you here?
  - What do they do when they are here?
  - What is it like when they are here? / Do you like having them here?
  - What would you like them to do?

- Do they talk to the staff?
  - What about?
  - Do you mind?

- **Could ask – would you like your family to be here more? Why? What would you like them to do?**

Appendix 3: REC Approval Letter

Bradford Research Ethics Committee
Yorkshire & Humber REC Office
Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Telephone: 0113 3050166
Facsimile:

23 July 2010

Mrs Rachael Kelley
NIHR Doctoral Research Fellow
University of Leeds
Leeds Institute of Health Sciences
Charles Thackrah Building
University of Leeds, Leeds.
LS2 9LJ

Dear Mrs Kelley

Study Title:	**Improving hospital care for people with memory problems: Working with informal carers to improve experiences and outcomes of hospital care**
REC reference number:	**10/H1302/49**
Protocol number:	**2**

Thank you for your letter of 01 July 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

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).

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. I will write to you again as soon as

one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at non-NHS sites.

Conditions of the favourable opinion

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

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

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 (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice 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:

Document	Version	Date
Investigator CV	R Kelley	
Investigator CV	J Young	
Protocol	2	01 July 2010
Letter from Funder		28 August 2009
REC application		18 May 2010
Summary/Synopsis		
Interview Schedules/Topic Guides	Carers	
Interview Schedules/Topic Guides	Staff	
Advertisement	1	
Participant Information Sheet: Patients	1	28 April 2010
Response to Request for Further Information		01 July 2010
Participant Information Sheet: For Relatives/ Friends	1	05 May 2010
Participant Information Sheet: Staff: In Depth Interviews	1	05 May 2012
Participant Information Sheet: Staff: Interviews Following Observations	1	05 May 2010
Participant Information Sheet: Staff: Observational Data Collection	1	05 May 2010
Participant Information Sheet: Consultees	1	05 May 2010
Participant Consent Form: Patients	1	05 May 2010
Participant Consent Form: Consultees	1	05 May 2010
Participant Consent Form: For Relatives/ Friends	1	05 May 2010

Participant Consent Form: Staff	1	05 May 2010
References		
Observational Framework	2	01 July 2010
Evidence of insurance or indemnity		08 October 2006
Referees or other scientific critique report		

Statement of compliance

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

After ethical review

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

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

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

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

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1302/49	**Please quote this number on all correspondence**

Yours sincerely

Professor Alan Roberts
Chairman
OBE, TD, DL, MPhil, PhD, DSc, LLD, DTech.

Email: laura.sawiuk@leedspft.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Mrs Rachel E De Souza*
                  Faculty Research Office
                  Level 10, Worsley Building

Appendix 4: Poster and Information Leaflets – Stage 1

INFORMATION POSTER

'Improving hospital care for people with memory problems'

I would like to let you know about a research project that will be taking place on your ward. Thank you in advance for your help with the project.

Why is the research taking place?

The aim of the research is to improve our understanding of experiences of hospital care for patients and their carers. I am particularly interested in the experiences of patients who may have memory problems (for example, people with dementia), as they may find being in hospital especially difficult or upsetting.

What will happen?

I would like to spend some time observing the experiences of patients and carers on the ward. I would also like to speak to some patients, carers and staff to help me understand these experiences in more detail.

When will I be visiting the ward?

I will be visiting the ward over the next few weeks to explain the study to staff. I will be very happy to answer any questions you may have. At a later date I will also be speaking to patients and carers to ask them if they would be willing to help with the study.

In the meantime, if you have any questions or concerns please feel free to get in touch. I can be contacted on: (0113) 3431892 or r.s.kelley@leeds.ac.uk.

I look forward to meeting you soon.

Rachael Kelley (Researcher)

Leeds Institute of Health Sciences, 101 Clarendon Road
University of Leeds, Leeds, LS2 9LJ

UNIVERSITY OF LEEDS

STAFF INFORMATION LEAFLET

"Improving hospital care for people with memory problems"

I would like to let you know about a research project that will be taking place on your ward. This leaflet explains more about the research. I will also explain the study to you, and will be happy to answer any questions you may have.

Thank you in advance for your help with the project.

What is the research about?

The aim of the research is to improve our understanding of experiences of hospital care for patients and their carers. I am particularly interested in the experiences of patients who may have memory problems (for example, people with dementia), as they may find being in hospital especially difficult or upsetting. I am also interested in the experiences of family and friends who visit the ward.

I am doing this research as a PhD project. It is an area I am interested in because I used to work as a nurse with people who had memory problems.

What will happen during the project?

I would like to spend some time observing the experiences of patients and carers on your ward. This will help me to obtain the perspectives of patients who may struggle to talk about their experiences, for example due to memory or communication difficulties. I may ask you some brief questions, to help me understand your experiences of having patients with memory problems, and their carers, on the ward. I will also speak to some patients and carers, to help me understand their experiences in more detail. With permission, I may look in some medical records.

The observations will involve me spending time in communal areas of the ward and taking notes. This may involve me observing some interactions between staff and patients or carers. I will not, however, record information about, or the names of, individual staff. The dignity and privacy of patients will be respected at all times. I will not observe any personal care. I will only observe and speak to patients and carers who have given me permission to do so.

If you would prefer not to be included in the study you will still see me around on the ward. I will not observe you or the interactions you have with patients or carers.

What will happen to the findings of the research?

The findings of the research will be shared with staff who will be asked to identify any opportunities for improving the care of patients with memory problems. A similar discussion will take place with a group of patients and carers.

The research findings will be written up into reports and research articles. If you agree, some of what happens to you and the things that you tell me could be quoted in these reports. All the information I report will be anonymous. I will never use your name or the name of the ward/hospital. If you wish, I can send you a copy of the research findings.

Will taking part be kept confidential?

I will be the only researcher that will know who took part in the study. All the research data will be kept safe. It will be stored in a locked filing cabinet or on password protected computer files. The anonymous research data will be kept for 5 years to help with future research planning.

To help me understand and interpret the research data I will need to share it with my two research supervisors. I could also be asked to show the research data to authorised people from regulatory bodies. They will only look at the data to check that the study is being carried out properly.

Do you have to take part?

If you would prefer not to be included in the observations it is fine to say so. I will be happy to answer any questions you may have. Please feel free to discuss taking part with others, if you wish. You can change your mind about being involved at any time, without giving a reason.

By taking part in the research you might help to improve the care given to hospital patients in the future. There are unlikely to be any disadvantages to taking part. I will keep checking that my presence is not causing any distress to patients. If it is, I will stop observing immediately. I will keep checking that you are still happy to take part in the observations.

Who has given permission for the research?

The details of the research have been checked and approved by the _____ Research Ethics Committee. _____ NHS Trust has agreed that the research can take place on your ward.

What if there is a problem?

I do not expect the study to cause any problems for the people who take part in it. But, if you are worried about the research or have any questions, please speak to me, or to _____ (Ward Manager). If you prefer, you could contact one of my research supervisors.

Thank you for your help.

Rachael Kelley

Researcher and PhD Student - Tel: (0113) 3431892 or Email: r.s.kelley@leeds.ac.uk

Research Supervisors: Mary Godfrey   John Young
                       Senior Research Fellow   Professor of Elderly Care Medicine
                       Tel: 0113 343 3959   Tel: 01274 383400
                       Email: m.godfrey@leeds.ac.uk Email: john.young@bthft.nhs.uk

Leeds Institute of Health Sciences, 101 Clarendon Road, University of Leeds, Leeds. LS2 9LJ

Appendix 5: Information Leaflets and Consent Forms – Stage 2

UNIVERSITY OF LEEDS

INFORMATION LEAFLET FOR RELATIVES AND FRIENDS

"Improving hospital care for people with memory problems"

> A large-print version of this sheet is available on request

I would like to invite you to take part in a research project. Before you decide, it is important that you understand why the research is being done and what taking part would involve. This leaflet explains more about the research.

I will also explain the study to you, and answer any questions you may have.

What is the research about?

My aim is to find out whether and how experiences of hospital care could be improved for patients, and their family and friends. I am particularly interested in the care of people who may experience difficulties with their memory, as they could find being in hospital especially difficult. I am also interested in the experiences of family and friends who visit the ward.

I am doing this research as a PhD project. It is an area I am interested in because I used to work as a nurse with people who had memory problems.

What will happen if you decide to take part?

I would like to spend some time observing the care of your relative or friend. I would like to do some of this observing when you visit the ward. This will help me to understand what the hospital experience is like for you (and for your relative or friend). The observations will involve me spending time in communal areas of the ward and taking notes. The dignity and privacy of patients will be respected at all times. I will not observe any personal care or at times when you do not want me to. I would like to carry out my observations regularly (up to 3-4 times a week).

If you agree, I would also like to talk to you about your experiences on the hospital ward. I would like to talk to you on two separate occasions, if possible. This is to get a picture of your experiences over the course of the hospital admission. I will ask you if it is ok to tape record these conversations. This will help me to remember our conversations in detail. If you do not want me to record our conversation, it is fine to say so. I will be happy to take notes instead.

I will also collect information about your relative or friends care by talking to some of the hospital staff. I may speak briefly with your relative or friend. I may ask if I can look in some of the hospital records belonging to your relative or friend.

If you decide not to take part in the study you may still see me around on the ward. I will not observe you or your relative or friend.

What will happen to the findings of the research?

The findings of the research will be used to suggest how hospital care could be improved in the future. The research findings will be written up into reports and research articles. If you agree, some of what happens to you and the things that you tell me could be quoted in these reports. All the information I report will be anonymous. I will never use your name or the name of your relative or friend. If you wish, I can send you a copy of the research findings.

Will taking part be kept confidential?

I will be the only researcher that will know the names of people who took part in the study. All information about you will be kept safe. It will be stored in a locked filing cabinet or on password protected computer files. If you have given me any personal details (e.g. your name & address) these will be kept separately from the rest of the research data. Any personal details will be safely destroyed after 3 years. Anonymous data will be kept for longer to help with future research planning.

To help me understand and interpret the research data I will need to share it with my two research supervisors. I could also be asked to show the research data to authorised people from regulatory bodies. They will only look at the data to check that the study is being carried out properly.

Do you have to take part?

It is up to you to decide whether you would like to take part. I will be happy to answer any questions you may have. Please feel free to take your time to decide, and discuss taking part with others, if you wish.

If you decide to take part, I will ask you to sign a consent form and give you a copy. You can change your mind about taking part at any time, without giving a reason. This will not affect the care of your relative or friend. I will ask you what you want me to do with any information I may have about you.

I will also ask your relative or friend if they would like to take part in the research. If they are not able to make their own decision I will ask for your advice on whether they would want to take part.

By taking part in the research you might help to improve the care given to hospital patients in the future. There are unlikely to be any disadvantages to taking part. I will keep checking that my presence is not causing any distress to your relative or friend. If it is, I will stop observing immediately. I will keep checking that you and your relative or friend are still happy to take part in the research.

Who has given permission for the research?

The details of the research have been checked and approved by the _____ Research Ethics Committee. _____ NHS Trust has agreed that the research can take place on this ward.

What if there is a problem?

I do not expect the study to cause any problems for the people who take part in it. But, if you are worried about the research or have any questions, please speak to me, or to a member of staff. If you prefer, you could contact one of my research supervisors.

If you are still not happy you could speak to the _____ Patient Advice and Liaison Service (PALS) on _____ or via pals@_____.nhs.uk. PALS is a free, confidential service for patients, relatives and friends. If you wish to make a formal complaint, you can do this by asking staff for details of the NHS Complaints Procedure.

Thank you for taking the time to read this leaflet.

Rachael Kelley

Researcher and PhD Student

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UNIVERSITY OF LEEDS

PATIENT INFORMATION LEAFLET

"Improving hospital care for people with memory problems"

I would like to invite you to take part in a research project. Before you decide, it is important that I explain why the research is being done and what taking part would involve. This leaflet explains more about the research.

What is the purpose of the study?

I would like to find out whether hospital care could be improved for patients, and their family and friends. I am particularly interested in the care of people who may have difficulties with their memory, as they could find being in hospital especially difficult. I am also interested in the experiences of family and friends who visit the ward.

What will happen if you decide to take part?

I would like to spend some time observing the care of patients on the ward. If you agree, I would like to include you in the observations. This would mean that I would watch what happens on the ward whilst you are there. This will help me to understand what being in hospital is like for you. Your privacy will be respected at all times. If at any time you do not want me to observe it is fine to say so. I would also like to talk to you about your experiences of being in hospital. I may ask you if I can look in some of your hospital records. I will also ask you if I can speak to a one of your relatives or friends (you can choose who) and to some of the hospital staff.

I will make notes based on what happens whilst I am on the ward and based on what you tell me. I may ask if it is ok to tape record some of what you tell me. This is to help me remember what you have told me. If you do not want me to tape our conversation it is fine to say so.

What will you do with the findings of the research?

The findings of the research will be used to suggest how hospital care could be improved in the future. The findings of the research will be written up into reports and research articles. If you agree, some of what happens to you and the things that you tell me may be quoted in these reports. I will never use your name. If you wish, I can send you a copy of the research findings.

Will taking part be kept confidential?

I will be the only researcher that will know the names of people who took part in the study. All information about you will be kept safe. It will be stored in a locked filing cabinet or on password protected computer files. If you have given me any personal details (e.g. your name & address) these will be destroyed after 3 years.

Do you have to take part?

It is up to you to decide whether you would like to take part. To help you decide I will explain the research to you, and will answer any questions you may have. You may ask a relative or friend to help you decide, if you wish.

If you decide to take part, I will ask you to sign a consent form and give you a copy. You can change your mind about taking part at any time, without giving a reason. This will not affect your care. I will ask you what you want me to do with any information I may have about you.

By taking part in the research you might help to improve the care given to hospital patients in the future. There are unlikely to be any disadvantages to taking part. I will make sure I respect your privacy whilst I am spending time with you. I will keep checking that you are still happy to take part.

Who has given permission for the research?

The details of the study have been checked and approved by the _____ Research Ethics Committee. _____ NHS Trust has agreed that the research can take place on this ward.

What if there is a problem?

If you are worried about the research or have any questions, please speak to me, or to a member of staff.

Thank you,

Rachael Kelley

Researcher and PhD Student, University of Leeds

Tel: (0113) 3431892

Leeds Institute of Health Sciences, 101 Clarendon Road, University of Leeds. LS2 9LJ

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INFORMATION LEAFLET FOR STAFF

"Improving hospital care for people with memory problems"

I would like to invite you to take part in a research project. Before you decide, it is important that you understand why the research is being done and what taking part would involve. This leaflet explains more about the research.

I will also explain the study to you, and answer any questions you may have.

What is the research about?

The aim of the research is to improve our understanding of experiences of hospital care for patients and their carers. I am particularly interested in the experiences of patients who may have memory problems (e.g. people with dementia), as they may find being in hospital especially difficult or upsetting. I am also interested in the experiences of the relatives, friends and staff who care for these patients. I would like to use the experiences of patients, carers and staff to help us to understand whether and how hospital care could be improved.

I am doing this research as a PhD project. It is an area I am interested in because I used to work as a nurse with people who had memory problems.

What will happen if you decide to take part?

If you agree, I would like to speak to you about your experiences of caring for patients who have memory problems. I would also be interested to hear about your experiences of visits by relatives or friends to the ward.

I will ask you if it is ok to tape record our conversation. This will help me to remember what we have talked about in detail. If you do not want me to tape record our conversation, it is fine to say so. I will be happy to take notes instead.

I will also be collecting information by spending time with, and speaking to, patients and their relatives or friends. The dignity and privacy of patients will be respected at all times. I will not speak to or spend time with patients whilst they are receiving personal care.

What will happen to the findings of the research?

The findings of the research will be used to suggest how hospital care could be improved in the future. The research findings will be written up into reports and research articles. If you agree, some of the things that you tell me could be quoted in these reports. All the information I report will be anonymous. I will never use your name. If you wish, I can send you a copy of the research findings.

Will taking part be kept confidential?

I will be the only researcher that will know the names of people who took part in the study. All information about you will be kept safe. It will be stored in a locked filing cabinet or on password protected computer files. If you have given me any personal details (e.g. your name) these will be safely destroyed after 3 years. Anonymous data will be kept for longer to help with future research planning.

To help me understand and interpret the research data I will need to share it with my two research supervisors. I could also be asked to show the research data to authorised people from regulatory bodies. They will only look at the data to check that the study is being carried out properly.

Do you have to take part?

It is up to you to decide whether you would like to take part. I will be happy to answer any questions you may have. Please feel free to take your time to decide, and discuss taking part with others, if you wish.

If you decide to take part, I will ask you to sign a consent form and give you a copy. You can change your mind about taking part at any time, without giving a reason. I will ask you what you want me to do with any information I may have about you.

By taking part in the research you might help to improve the care given to hospital patients in the future. There are unlikely to be any disadvantages to taking part.

Who has given permission for the research?

The details of the study have been checked and approved by the Bradford Research Ethics Committee.   NHS Trust has agreed that the research can take place on this ward.

What if there is a problem?

I do not expect the study to cause any problems for the people who take part in it. But, if you are worried about the research or have any questions, please feel free to speak to me, or to
(ward manager).

Thank you for reading this leaflet, and for taking an interest in the research.

Rachael Kelley

Researcher and PhD Student

Tel: (0113) 3431892 or email: r.s.kelley@leeds.ac.uk

Leeds Institute of Health Sciences, 101 Clarendon Road, University of Leeds, LS2 9LJ

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CONSENT FORM FOR RELATIVES OR FRIENDS

"Improving hospital care for people with memory problems"

Please tick

	Yes	No
We have looked at the information leaflet and I have kept a copy.	☐	☐
I have had the chance to talk about the study and to ask questions.	☐	☐
I understand that I do not have to take part, and that I can decide not to take part at any time.	☐	☐

_____

	Yes	No
I agree to take part in the study.	☐	☐

_____

	Yes	No
I would be happy for the researcher to tape record our conversations.	☐	☐
I am happy for some of the things I say to be quoted in reports.	☐	☐

Signed _____   Date _____

Name _____

Thank you

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PATIENT CONSENT FORM

"Improving hospital care for people with memory problems"

Please tick

	Yes	No
We have looked at the information leaflet and I have kept a copy.	☐	☐
I have had the chance to talk about the study and to ask questions.	☐	☐
I understand that I do not have to take part, and that I can decide not to take part at any time.	☐	☐

_____

I agree to take part in the study.	☐	☐

_____

I am happy for the researcher to look in my hospital records.	☐	☐
I would be happy for the researcher to tape record our conversations, if necessary.	☐	☐
I am happy for some of the things I say to be quoted anonymously in reports.	☐	☐

Signed _____   Date _____

Name _____

Thank you

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STAFF CONSENT FORM

"Improving hospital care for people with memory problems"

Please tick

Yes   No

We have looked at the information leaflet and I have kept a copy. ☐ ☐

I have had the chance to talk about the study and to ask questions. ☐ ☐

I understand that I do not have to take part, and that I can decide not to take part at any time. ☐ ☐

_____

I agree to take part in the study. ☐ ☐

_____

I would be happy for the researcher to tape record our interview. ☐ ☐

I am happy for some of the things I say to be quoted in reports. ☐ ☐

Signed _____   Date _____|

Name _____

Thank you

Appendix 6: Consultee Information Leaflet and Consultee Declaration Form

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CONSULTEE INFORMATION LEAFLET

"Improving hospital care for people with memory problems"

A large print version of this leaflet is available on request

A research study is taking place at _____ to help improve experiences of hospital care for patients who may experiences difficulties with their memory, and their family and friends. I feel that _____ may not be able to make their own decision about taking part in the study. As a relative or friend, I would like to ask for your advice on whether or not they would want to take part.

Before you decide, it is important that you understand why this research is being done, and what taking part would involve. This leaflet explains more about the research. Please could you read this leaflet and think about _____ likely wishes and feelings about taking part. If you know of any views they have previously expressed about taking part in research, please let me know.

If you do not feel able to give advice on this, it is fine to say so.

What is the purpose of the study?

My aim is to find out whether and how experiences of hospital care could be improved for patients, and their family and friends. I am particularly interested in the care of people who may experience difficulties with their memory, as they could find being in hospital especially difficult. I am also interested in the experiences of family and friends who visit the ward.

I am doing this research as a PhD project. It is an area I am interested in because I used to work as a nurse with people who had memory problems.

What will happen to my relative or friend if they take part?

I would like to spend some time observing the care of your relative or friend. This will help me to understand what being in hospital is like for them. The observations will involve me spending time in the communal areas of the ward and taking notes. The dignity and privacy of patients will be respected at all times. I will not observe any acts of personal care. I would like to carry out my observations regularly (up to 3-4 times a week).

I may also spend some time talking with your relative or friend to help me understand their experiences of being in hospital. I may ask if I can look in some of their hospital records. I will also ask if I can speak to you about your experiences, and will speak to some of the hospital staff.

I will make notes based on what your relative or friend tells me and based on what happens whilst I am observing their care. I may ask if it is ok to tape record some of what they tell me. This is to help me remember what has been said. If you think they would not want our conversation to be recorded it is fine to say so.

If you decide that your relative or friend would not want to take part in the study you may still see me around on the ward. I will not observe the care of your relative or friend.

What will happen to the findings of the research?

The findings of the research will be used to suggest how hospital care could be improved in the future. The findings of the research will be written up into reports and research articles. If you agree, some of what happens to your relative or friend and the things that they tell me may be quoted in these reports. I will never use their name. If you wish, I can send you a copy of the research findings.

Will taking part be kept confidential?

I will be the only researcher that will know the names of people who took part in the study. All information about your relative or friend will be kept safe. It will be stored in a locked filing cabinet or on password protected computer files. If I have been given any personal details (e.g. names & addresses) these will be safely destroyed after 3 years. Anonymous data will be kept for longer to help with future research planning.

To help me interpret the research data I will need to share it with my two research supervisors. I could also be asked to show the research data to authorised people from regulatory bodies. They will only look at the data to check that the study is being carried out properly.

Does my relative or friend have to take part?

Taking part is entirely voluntary. You are being asked to advise on whether or not you think your relative or friend would want to take part in the research. It may help to think about any thoughts or feelings they have previously expressed about research.

To help you decide I will explain the research to you, and will answer any questions you may have. If you are unsure about your ability to offer advice please let me know or feel free to discuss it with someone else.

If you think that your relative or friend would want to take part, I will ask you to sign a form to confirm this and will give you a copy. I will keep you informed about the project so you can let me know if you have any concerns. You can change your mind about your relative or friend taking part at any time, without giving a reason. This will not affect their care. I will ask you what you want me to do with any information I may have about them.

By taking part in the research your relative or friend might help to improve the care given to hospital patients in the future. There are unlikely to be any disadvantages to taking part. I will keep checking that my presence is not causing any distress to your relative or friend. If it is, I will stop observing immediately.

Who has given permission for the research?

The details of the study have been checked and approved by the _____ Research Ethics Committee. _____ NHS Trust has agreed that the research can take place on this ward.

What if there is a problem?

I do not expect the research to cause any problems for the people who take part in it. But, if you are worried about the research or have any questions, please speak to me, or to a member of staff. If you prefer, you could contact one of my research supervisors.

If you are still not happy you could speak to the   Patient Advice and Liaison Service (PALS) on   or via pals@   .nhs.uk. PALS is a free, confidential service for patients, relatives and friends. If you wish to make a formal complaint, you can do this by asking staff for details of the NHS Complaints Procedure.

Thank you for taking the time to read this leaflet.

Rachael Kelley

Researcher and PhD Student

Tel: (0113) 3431892 or email: r.s.kelley@leeds.ac.uk

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Research Supervisors:

Mary Godfrey
Senior Research Fellow
Tel: 0113 343 3959
Email: m.godfrey@leeds.ac.uk

John Young
Professor of Elderly Care Medicine
Tel: 01274 383400
Email: john.young@bradfordhospitals.nhs.uk

UNIVERSITY OF LEEDS

CONSULTEE DECLARATION FORM

"Improving hospital care for people with memory problems"

Please tick

	Yes	No
I _____ [name of consultee] have been consulted about _____ [name of potential participant]'s participation in this research study. I have had the opportunity to ask questions about the study and understand what is involved.	☐	☐
In my opinion he/she would have no objection to taking part in the above research study.	☐	☐
I understand that I can request he/she is withdrawn from the research at any time, without giving any reason and without his/her care being affected.	☐	☐
I agree that the researcher may look in the medical records of my relative or friend.	☐	☐
In my opinion, my relative or friend would be happy for the researcher to tape record conversations with him/her, if necessary.	☐	☐

_____   _____

Name of consultee   Date

_____   _____

Signature   Relationship to participant