UNIVERSITY OF LEEDS

This is a repository copy of *The impacts of family involvement on general hospital care experiences for people living with dementia: An ethnographic study*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/145142/

Version: Accepted Version

Article:

Kelley, R orcid.org/0000-0002-8838-0313, Godfrey, M orcid.org/0000-0002-2408-534X and Young, J (2019) The impacts of family involvement on general hospital care experiences for people living with dementia: An ethnographic study. International Journal of Nursing Studies, 96. pp. 72-81. ISSN 0020-7489

https://doi.org/10.1016/j.ijnurstu.2019.04.004

© 2019 Published by Elsevier Ltd. Licensed under the Creative Commons Attribution-Non Commercial No Derivatives 4.0 International License (https://creativecommons.org/licenses/by-nc-nd/4.0/).

Reuse
This article is distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND) licence. This licence only allows you to download this work and share it with others as long as you credit the authors, but you can’t change the article in any way or use it commercially. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

White Rose
university consortium
Universities of Leeds, Sheffield & York

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

Title:

The impacts of family involvement on general hospital care experiences for people living with dementia: An ethnographic study

Funding:

The lead author was supported by a National Institute for Health Research Fellowship. This article presents independent research funded by the NIHR. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Acknowledgments:

We thank all of the participants for generously giving up their time and sharing their experiences.

Conflicts of interest:

We have no conflicts of interest to declare.

Abstract:

Background:
A quarter of people in general hospitals have dementia. Limited existing studies suggest that hospital care experiences of people living with dementia, and the involvement of their families in care, may be suboptimal.

Objectives:
The objectives of this study were to explore how family involvement impacts upon experiences of hospital care for people living with dementia.

Design:
A qualitative ethnographic study.

Methods:
Ethnographic data were collected from two care of older people general hospital wards. Data were collected via observations, conversations and interviews with people living with dementia, families and staff. In total, 400 hours of observation and 46 interviews were conducted across two 7-9 month periods.

Results:
People living with dementia could experience 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 to involve families in improving connections and care. When used, the knowledge and expertise of families played a crucial role in facilitating more meaningful interactions, demonstrating 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. Care was required to ensure that family involvement did not override the needs and wishes of people living with dementia.

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

Keywords: Acute care; General Hospitals; Nursing; Dementia; Family Caregivers; Qualitative Research; Ethnography

Contribution of the Paper:

What is already known about the topic?

- Experiences of general hospital care are often poor for people living with dementia
- Working with families of people living with dementia may help to improve care
- Research is needed to understand how families of people living with dementia are involved in care and the impacts of their involvement

What this paper adds?

- People living with dementia experienced disconnection from pre- and in-hospital life in many different ways
- Families could play crucial roles in facilitating more person-centred connections and care but their involvement was not routine, varying between and within hospital wards
- Family involvement was not uniformly positive for people living with dementia; careful attention is required to ensuring family involvement does not override the needs or wishes of the person

Anonymised manuscript:

Background and Objectives

Considerable numbers of people living with dementia are admitted to general hospitals. For example, in the UK, one in four hospital patients have dementia and up to one in two may have some form of cognitive impairment (Alzheimer's Society, 2016, 2009; Royal College of Psychiatrists, 2005). Their care needs are multifaceted and diverse due to the combination of cognitive impairment and a wide range of co-morbid medical problems (Porock et al., 2015; Knopman et al., 2003), some of which may exacerbate symptoms of dementia. These complex needs are often poorly met in general hospital settings (Dewing & Dijk, 2016). Outcomes of hospital care for people living with dementia are often poor, and include longer lengths of stay and higher rates of malnutrition, dehydration, delayed discharges, care home admissions and mortality than people without dementia (Dewing & Dijk, 2016). A growing body of research exploring hospital care from the perspective of people living with dementia suggests that experiences of care are also poor (e.g. Featherstone et al, 2019; Porock et al., 2015; Cowdell, 2010). Positive examples of care exist (Scerri et al., 2015; Cowdell, 2010; Tolson et al., 2009), but hospitals are often viewed as distressing and bewildering environments (Porock et al., 2015; Cowdell, 2010), where interactions are limited or dominated by routinized clinical care at the expense of interactions on a personal level (Featherstone et al., 2019; Moyle et al., 2011; Cowdell 2010). Staff and families also identify care concerns, including inadequate support with eating and drinking, communication problems, insufficient social interaction, and difficulties managing distressed behaviour (Boltz et al., 2015; Alzheimer's Society, 2009). The possibility of a causal relationship between poor care quality and poor outcomes (Featherstone at el, 2019; Sampson et al, 2009) highlights the importance of improving care quality.

One approach through which hospital care for people living with dementia might be improved is the involvement of families and friends in care planning and delivery. Outside hospital, people living with dementia are often supported by families and friends, who represent a potential source of knowledge and expertise in relation to their relative's care. For example, they may hold in-depth knowledge of the person and their usual levels of functioning, or have a repertoire of skills and strategies to help care for them, such as familiar care routines or bespoke communication techniques (Bray et al., 2015; Nolan et al., 2002; Redfern et al., 2002). Such expertise, if conveyed to hospital staff or employed in hospitals by families and friends, could help to improve care.

Whilst not all relatives and friends are able to provide such input, some carers welcome opportunities to help improve care (Cowdell, 2008). However, despite widespread support for family involvement from campaigns, reports and policy initiatives (e.g. Jones & Gerrard, 2014; National Federation of Women's Institutes, 2016; Royal College of Nursing, 2011), limited guidance or research is available on how families of people living with dementia can be involved in general hospital care (Bauer et al., 2011a; Boltz et al., 2015; Kelley, 2017; Porock et al., 2015). The few available studies paint a negative picture of family involvement practices, where families' expertise is often not recognised or sought by hospital staff (Cowdell, 2008; Nolan et al., 2002; Douglas-Dunbar & Gardiner, 2007) and families are excluded from knowledge exchanges, care planning and decision making (Jurgens et al., 2012; Bloomer et al., 2014; Bauer et al., 2011a; Walker & Dewar, 2001; Douglas-Dunbar & Gardiner, 2007; Care Quality Commission, 2014; Department of Health, 2009). However, there are several limitations to these studies; the processes and impacts of family engagement is poorly understood, people living with dementia are often excluded, and data collection is often restricted to interviews conducted after discharge, further limiting the involvement of people living with dementia and longitudinal exploration of families' involvement. As a result, there remains much to be understood about the processes, challenges and impacts of involving families in general hospital dementia care.

To address these evidence gaps, this study explored the processes through which families are involved in general hospital dementia care, and the impacts of their involvement on care experiences. The methodological limitations of previous studies were avoided by collecting data from all three arms of the care-giving triad (people living with dementia, families and staff) over the course of an admission (to explore family involvement experiences longitudinally) and using multiple data collection methods to maximise the involvement of people living with dementia.

Research Design and Methods

Data collection

Data were collected from people living with dementia, their families, and staff in two care of older people hospital wards in the north of England. Data were collected by the lead author over two 7-9 month periods between 2011 and 2013. An ethnographic approach, involving participant observations, informal conversations, and in-depth interviews, was used to explore experiences of care and the involvement of families in those experiences. Ethnographic methods were well suited to the achieving the study's aims, enabling exploration of actions and interactions between members of the care-giving triad and of how family involvement is enacted in practice. Extensive fieldwork enabled relationships to develop with participants and facilitated timing and tailoring of data collection to the communication abilities and preferences of participants, in particular those living with dementia.

Observational Data Collection

Data collection began with a period of general observations to explore routine patterns of care, and to allow the researcher to become familiar with the ward environments and staff. These were followed by in-depth case studies (involving participant observations, conversations and interviews) with 12 dyads of people living with dementia and their families (6 per site). A larger number of staff were observed and interviewed to gather a range of experiences in relation to each dyad, and to explore general views on care experiences and family involvement.

400 hours of observation were conducted by RK; 190 hours over 67 (non-consecutive) days at site 1 and 210 hours over 71 days at site 2. Observation sessions were typically 2-4 hours long, but ranged from 30 minutes to six hours depending on the activity being observed, encompassing different days and times of the week, including mornings (from 8am), evenings (until 9pm) and weekends. Observations took place in various wards locations (e.g. bed spaces, communal areas, meeting rooms) and involved conversations with participants as well as observations of events. From initial observations and review of the literature, a sensitising framework was developed to guide the observational data collection, guiding attention towards the nature of families' involvement and how it impacted upon experiences of care. Handwritten fieldnotes were made during observations,

or shortly afterwards, and typed into fuller versions later. Notes were also made from accounts of families' input in hospital records.

In-depth Interviews and informal conversations

Alongside the observations, in-depth interviews and informal conversations with case study participants were used to further explore experiences of care and of families being involved in care. Informal conversations occurred throughout the data collection period and were recorded in fieldnotes. These provided a valuable means of including the perspectives of people living with dementia who were unable to participate in a full interview. In addition to these informal conversations, 46 in-depth semi-structured interviews were conducted. These interviews were audio-recorded and took place with 23 staff, 11 family members (1 declined an interview), and 4 people living with dementia. Follow up interviews were conducted with 8 of the 11 family members after discharge to explore experiences across the course of the admission.

Separate interview topic guides were used for people living with dementia, families and staff, shaped by the research aims, existing literature and observed events. All audio-recorded interviews were transcribed verbatim. Interview length varied from shorter conversations with some people living with dementia (around 30 minutes) to in-depth discussions with relatives and staff (up to 1.5 hours). Most interviews were conducted in private spaces on the wards, but some interviews occurred by bedsides due to poor mobility or a lack of alternative options. Post-discharge interviews with families usually took place in the family or person's own residence. Interviews sometimes took place in stages to accommodate interviewee preference, concentration levels or time constraints. A reflexive diary was used to document and explore the researcher's influence throughout data collection and analysis.

Sampling

The research took place on two care of older people acute hospital wards in two cities in the north of England: an 18 bedded rehabilitation ward and a 24 bedded general hospital ward. These settings were purposefully selected to explore practices and policies across different organisations and care environments and patients with varied medical needs. Purposive sampling was used to include a diverse range of case study participants; for example, people with a range of physical complaints, degrees of dementia, and care-giver relationships, and staff with varying professional backgrounds, training and experience.

People living with dementia (and their families) were eligible for inclusion in the case studies if the person had a confirmed or suspected dementia diagnosis, was expected to remain in hospital for at least 7 days, had at least one identifiable family member or friend, was not seriously or terminally ill, and communicated predominantly in English. Further details of case study participants are provided in Figure 1. All ward staff, apart from students and agency staff, were eligible for inclusion. Staff participants included doctors and nurses (with varying degrees of seniority), healthcare assistants and therapists (physiotherapists, occupational therapists and therapy assistants).

Figure 1 about here

Recruitment and consent

Permission for the orientation observations was sought verbally from senior ward staff, patients, families and staff, who were made aware of the observations through discussions and posters. Written consent was sought for the patient-carer case studies and staff interviews. Case study participants were identified by nursing staff from cues in hospital records suggesting dementia (e.g. 'memory problems' or 'cognitive impairment') and their knowledge of each person's cognitive state. Case study participants were asked by staff if they were happy to speak with the researcher before direct approaches were made. One family decided not to take part after the initial approach due to their relative becoming seriously ill. Staff interviewees were approached directly from the researcher's knowledge of who was most involved in each participant's care.

Care was taken to explain the study in an understandable way to enable people living with dementia to make their own decisions about taking part wherever possible. Capacity to consent was assessed during these conversations. Written informed consent was obtained from participants with capacity, and the advice of a personal consultee sought for people who lacked capacity in accordance with the Mental Capacity Act (2005). Obtaining consent was an ongoing process through which the willingness of people living with dementia to take part was repeatedly ascertained, either verbally or by monitoring for any signs of unwillingness to take part, such as reluctance to speak to the researcher or anxiety caused by her presence. Ethical approval for the study was provided by Bradford Research Ethics Committee (Ref: 10/H1302/4).

Data Analysis

Data collection and analysis were informed by a Constructivist Grounded Theory approach (Charmaz, 2014). Grounded Theory was chosen as a complimentary and widely used analytic approach in ethnography which supported the study's focus on exploring patterns of social interaction (Annells, 1996). A constant comparative approach was used to integrate data collection and analysis (Charmaz, 2012). Interview transcripts and fieldnotes for each case study were initially read through and coded line-by-line, with reflections and ideas noted in analytic memos. Key codes were identified and developed via further coding and data collection. Simultaneous data collection and analysis, and constant comparison (across different data sources, participants, settings and time points), was used to test and refine emerging analytic ideas and to inform subsequent data collection and sampling decisions. All authors were involved in the analysis, with RK repeatedly sharing and discussing transcripts and the emerging themes with the co-authors. The data were analysed using Atlas.ti (2015)

Results

The results begin by summarising experiences of hospital care for people living with dementia, to provide some context for exploring how family involvement impacted upon those experiences.

Experiences of hospital care for people living with dementia – from disconnection to connection

Hospital care for people living with dementia could involve multiple disconnections – from pre-hospital care-giving relationships and routines as well as the unfamiliar people, routines and environments encountered in hospital. However, connections were not simply present or absent but existed on a continuum. First, we summarise the features of disconnection before considering how increasingly meaningful connections were made, the crucial roles families could play in creating these, and the impact of these connections on care quality.

Disconnections from pre-hospital life

Disconnection from prior care-giving roles and relationships

Care-giving relationships were often disrupted during hospital admissions. Prior to hospitalisation, many people living with dementia had close emotional and care-giving bonds with family members:

> *Interview Site 1, Carer 3: "I've been looking after him for the past 4 years now… making sure he's got plenty of everything… It's what he's comfortable with really, I'm like his bloody cardigan!"*

Disruptions to these care-giving roles and relationships were often keenly felt by both parties. People living with dementia often made references to missing close family and friends, sometimes repeatedly searching or calling out for them:

> *Fieldnotes, Site 2: Kitty repeatedly searches for her daughter Wilma, with whom she is very close. 'Where's Wilma?' she calls, looking and walking around with outstretched arms, 'Do you know where Wilma's gone?'*

Families spoke of the disconnect they experienced from their usual familial and care-giving roles, including difficulties determining their relative's care and well-being in hospital and in maintaining care-giving or social relationships with their relative:

> *Interview Site 2, Carer 23: "I rang up every morning to find out how Kitty had been… the number of times when I was told 'Oh yes she's settled' and… on visiting, I find that she's been up and about, which isn't settled."*

> *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."*

Usual care-giving roles, and control over these, were taken away as care 'ownership' transferred to the hospital, leaving many families to transition to the much less active role of visitor.

Organisational policies - such as protected mealtimes, restricted visiting hours and infection control - could further limit opportunities for families to undertake care-giving roles:

> *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.'*

Disconnection from prior routines and levels of functioning

Alongside temporary absences of familiar people, the lack of recognisable routines meant that ward life could feel very unfamiliar to people living with dementia. Routinized care cultures left little room for maintaining connections to usual routines and levels of functioning:

> *Interview Site 2, Carer 20: "Even if they just got dressed every day and did something that were a normal routine… rather than just there's your bed, there's your chair… never getting out of the pyjamas or anything."*

> *Interview Site 1, Staff 12: "They get everybody up, washed and dressed… by 10 o'clock so they can all have their break… actually Mrs Smith might want to have a lie in… it's around culture and historically what they've always done… it's not around individual patients."*

Prolonged disruptions to familiar routines and levels of functioning could have important consequences for people living with dementia; exacerbating confusion and causing the person to lose, through lack of practice, connections to valuable abilities:

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

Irreversible functional decline could lead to increased care post discharge (including residential care), thus causing further disconnections from previous life.

A lack of attention to information about preferences and routines could also limit connections to usual life:

> *Interview Site 1, Carer 1: "I had explained to them about her meals… Just give her bread, no butter, and jam… a cup of tea… But nobody would listen… and then they are getting upset because she's not eating."*

This highlights again how failure to maintain feasible aspects of usual life could have important consequences - a reduction in food and drink intake in this instance – indicating the potential value, if used, of families' knowledge for enhancing care provision.

Disconnections from in-hospital life

Disconnection from fellow patients, staff and the ward environment

Disconnection from familiar people was compounded by the large amounts of time people living with dementia spent without anyone to interact with or alleviate their concerns. As visiting times were restricted, other patients or staff were often the main potential sources of interaction. Whilst some patients chatted to each other, interaction was often limited by confusion, ill health, deafness, poor sight, or distances between people (with beds, chairs, curtains or side rooms separating people). Opportunities for interaction with staff were also limited by closed-ward designs (for example, bed areas not visible from 'staff' areas) and the volume and prioritisation of clinical work; when staff were not providing care in the immediate vicinity, they were often working out of sight elsewhere. As a result, people living with dementia could spend long periods with limited interaction with others:

> *Fieldnotes Site 2*: *Mabel is in a side room repeatedly banging objects against her bed frame. A staff member says she wants someone to sit with her and she has told her she has 'no time to talk to you'.*

> *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, just by his self."*

As these quotes reveal, the levels of engagement required by people living with dementia could not always be accommodated during busy, task-focused ward routines. Despite high numbers of people living with dementia on both wards, staffing was often not perceived by staff or families as sufficient for the time required to meet their needs. In addition, physical ill health, delirium, and hearing impairments created further challenges to making connections, particularly if staff were unfamiliar with the person and their usual ways of communicating.

In addition, ward environments were unfamiliar and often bewildering places for people living with dementia. Bed spaces were typically clinical and unengaging, largely devoid of recognisable features, with equipment and signs that could be difficult to make sense of, even causing distress at times:

> *Fieldnotes Site 2: Ruby voices repeated concerns that her feet are in water, thinking the blue wires holding her notes onto her bed are taps of pouring water. They are shaped like taps and, if they were taps, would be pouring water directly onto her feet.*

A lack of interaction, and stimulating or orientating features (such as pictures, clocks, televisions, radios or sight of staff or the rest of the ward), could mean people living with dementia had limited means of making sense of their unfamiliar surroundings:

> *Fieldnotes Site 1: Ailsa looks frightened and confused, staring around with an alarmed expression, saying tearfully 'I'm not stupid, but where am I? I just can't see where I am?'*

The effects of disconnection on care quality

Disconnection had numerous negative impacts, highlighting the value of creating connections and of engaging families' help to do so.

A lack of connection with staff could obstruct care provision; people living with dementia could refuse care or struggle to articulate their needs, particularly when staff were out of sight or knew little about the person and how to interact with them:

> *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 distressed 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."*

A lack of connection could also affect the emotional well-being of people living with dementia, exacerbating symptoms such as agitation, distress and fear:

> *Interview Site 2, Carer 25: "It [making a connection] would have made a difference… because then my mam wouldn't have been as upset as she was… she wouldn't have been as frightened."*

People who were distressed or anxious had a particularly high need for connection with others. Staff often tried hard to interact with them, displaying patience, kindness and continued responses to repeated distress. However, a lack of personal knowledge and time could mean these attempts failed to alleviate the person's distress. A lack of staff presence or time to interact was also linked to an increased risk of falls:

> *Interview, Site 1, Staff 7: "When you don't have the staff you can't do that [engage with people living with dementia] and therefore they become a falls, more of a falls risk… they also get agitated cause you're constantly telling them to go and sit back down."*

> *Fieldnotes, Site 2: Lynette starts mumbling, calling out and shuffling down her bed, her feet beginning to hang off the bed. She shuffles and mumbles for 5 minutes before shouting 'Take me to the toilet!'. She continues shuffling and calling out as people walk past outside. A housekeeper enters, sees what is happening, and tries unsuccessfully to find a nurse. She presses Lynette's call button before continuing her work. Lynette shuffles further off the bed, pulling her hands out of her knickers, covered in runny faeces, moaning 'In a mess.'*

Creating connections

Despite the challenges of connecting with people living with dementia in acute settings, there were many circumstances under which connections were made. These connections ranged from brief or task focused to personalised and meaningful, with personal knowledge from families, or their direct involvement, often enabling the latter.

Using opportunities to connect

Although care was occasionally delivered almost silently, or alongside conversations with colleagues, many staff used the opportunities care tasks presented to interact with people living with dementia. Whilst care was often delivered with warmth and kindness, interactions could relate mainly or entirely to the task:

> *Fieldnotes Site 2: A staff member finds Leila, who has poor mobility, alone on a commode behind curtains – 'What you doing Leila! Could have fallen! Don't think you should be left on your own on toilet.' She helps Leila onto the bed - 'Leila push up the bed darling' - before tidying around the bed. She doesn't say anything else to Leila, pulling back the curtains soon afterwards and leaving in silence.*

Some staff expanded conversations during tasks to include other topics, or took the opportunity to engage with people living with dementia as they passed:

> *Fieldnotes Site 1: A staff member passes John [he is sat in the corridor] and says 'Hiya John', stroking his hand gently. 'Yeah, you alright' replies John.*

> *Interview Site 2, Staff 29: "We are so busy sometimes, but it's usually when you wash people, cos you have at least 10 minutes… you say "Oh were you ever married then? How many children have you got? …Sometimes they can't remember, but most of them they can... They will just talk and talk! …If you didn't ask them they wouldn't initiate. But I do ask."*

These quotes demonstrate that it is possible to find opportunities to make meaningful connections on busy acute wards, and the value of seeking and using personal knowledge to create meaningful connections.

The roles of families in creating connections

The personal knowledge of families, and their expertise and involvement in care, could play numerous crucial roles in facilitating the connections required to provide more person-centred care.

Using personal knowledge to create meaningful connections

Personal knowledge, often available from families if the person could not communicate it themselves, provided a valuable means of facilitating and expediting connections. Even simple conversation triggers, such as the names of familiar people or places, could be used to stimulate prolonged interactions:

> *Interview Site 2, Staff 32: "You become a bit detached because you don't know them. But once you see a photo, or you speak to the family about what they used to do… you can say to them 'Oh I heard you used to work at the mills'…we'll be talking about the mill then for half an hour, and …you've made a connection."*

> *Interview Site 1, Staff 7: "If you're asking a really broad question… they might not be able to answer you… If you've got prompts about that person, it makes it a lot easier to gauge your questioning to be specific to them… you've already given them a little clue and then they can build around it… and therefore they'll engage with it more."*

Personal knowledge, in the form of conversation prompts or communication techniques, enabled people living with dementia to participate in conversations, assessments and care activities in ways they would otherwise have been unable to.

Creating and maintaining connections with the person

As well as providing personal knowledge, families could find it easier to connect meaningfully with their relatives than staff:

> *Fieldnotes Site 2: Emmett recites riddles made up in his daughters' childhood. His daughter and wife join in, prompting when he gets stuck, laughing with him after each one. He often mumbles, his words unclear, but they still recognise his rhymes, reciting them when he can't find the words.*

Although families, as with staff, could face challenges connecting with people living with dementia, their in-depth knowledge of the person often helped to overcome these.

Maintaining family connections during hospitalisation was a key concern for people living with dementia, many of whom attached great value to these relationships and the opportunities visiting times offered to maintain them:

> *Fieldnotes Site 1: Ray says visitors bring 'a smile to my face', describing how his lady friend's visit 'made my day'. He says his granddaughter is visiting tonight, adding he hopes she brings his great grandson, a broad smile spilling across his face.*

Creating and maintaining connections with hospitalised relatives was also a key aim for many families:

> *Fieldnotes Site 1: Ray's daughter describes the visiting rota she has arranged, which mirrors the visits her dad gets at home. She describes the lengths she has taken to ensure visitors at each visiting time.*

A focus of family visits was often on maintaining the person's connections with familiar life, with news and photographs brought in to maintain connections to the outside world. These examples, alongside further ones below, illustrate how disconnection was not constant or inevitable.

Creating connections with ward environments

Families who brought personal items to the wards (e.g. favourite photographs, activities, blankets and clothes), also provided their relative with a sense of familiarity and identity, and thus a connection to their sense of self, in an otherwise highly impersonal environment. These items also stimulated personalised interactions with staff:

> *Fieldnotes Site 2: A staff member speaks kindly to Betty, introducing himself. He picks up a picture of her granddaughter, asking her name. Betty falters, forgetting her granddaughters name, recalling other family members instead.*

Conversation starters involving personal items also had the ability to be used by successive staff without prior knowledge of the person, avoiding some of the difficulties of sharing personal information amongst large staff groups. Items related to hobbies and interests could also provide stimulation and maintain connections to these activities. Examples included regular games of dominoes instigated by one gentleman's wife, and continuation of a photography hobby via a granddaughter bringing in her granddad's favourite camera, which also created talking points with staff.

Creating and maintaining connections with care routines

Information from families could help maintain connections to the usual routines of people living with dementia, by informing personalisation of care routines. Information from families could also help to identify and meet care needs, and to recognise deviations from routine behaviours which could indicate important changes in health or well-being:

> *Interview Site 1, Staff 12: "It's understanding the routine… it's giving them [staff] that understanding that she doesn't go to bed until 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… if they [staff] know what someone's routine is, what they normally do, then we shouldn't have as many problems."*

Personalised routines, although beneficial, were sometimes difficult to implement within the constraints of busy, clinically-focused ward routines. Families could counter these difficulties by undertaking some of this personalisation themselves:

> *Interview Site 1, Carer 1: "I used to put me mum her nighty on [in hospital] and see to her and do her teeth and tuck her in before I came home… I think she felt better me doing that… It was more like being at home, 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, appeared to bring a sense of comfort, lessen the unfamiliarity of ward environments and routines, and helped maintain connections to prior routines, abilities and care-giving relationships.

Better connections creating better care

The impacts of families' involvement went beyond enhancing connections to improving the care provided. For example, when families imparted knowledge about how to communicate with their relative, it could make the difference between whether or not staff could identify and meet even basic care needs:

> *Interview Site 1, Staff 11: "Like that gentleman… he'd say no and he meant yes. And it wasn't until his son told us… he'd been asked if he wanted extra meals and he was saying no, and he was hungry."*

These examples show how families could hold crucial information for interpreting the needs of people living with dementia. Families' knowledge could also help staff engage people living with dementia in activities such as assessments and therapy tasks:

> *Interview Site 2, Staff 20: "[speaking to relatives] gives you a better picture. They sometimes give you tips on how, what motivates them, and so the next day… you can be a lot more productive… having held the conversation."*

Families could also recognise signs that their relative was more unwell or in need, even when the person had significant communication difficulties:

> *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'll know it's building up."*

Whilst these indicators of change could be obvious to families, they were not necessarily recognised or revealed during limited staff interactions. When directly involved in care, families could also explain to, and encourage, people living with dementia in ways that staff could not:

> *Fieldnotes Site 2: I ask a member of staff if Jessie has eaten anything today and she says she hasn't. She says she is better for her daughter.*

In some cases, families were providing particularly high levels of care to their hospitalised relatives:

> *Interview Site 2, Carer 25: "They used to ring me up… 'She won't take it'… So I used to go down and I used to give her the medication 3 or 4 times a day… When they wanted to wash and change her, they couldn't do it. So again they used to have to ask me."*

Variability in the involvement of families

Although family involvement could have numerous benefits, it was very variable and far from routine. Involvement of families was sometimes in response to 'special' circumstances, such as when the person was refusing care (as above), distressed or terminally ill, or when families had especially close care-giving relationships or wanted to ensure care was given:

> *Interview Site 1, Staff 2: "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… and if someone is getting quite distressed… they will allow them to come on if it keeps the patient settled… I don't really think they encourage too much else."*

Other reasons to engage with families included bad news or a complex case, meaning that families of people with less overt or complex needs were often less involved in care. Disparities in family involvement were also explained by inconsistent information and responses given to families regarding their involvement. Responses ranged, between and within the two wards, from invitations to contribute to discouragement and restrictions on families' input. Wards in the same department could have differing approaches to visiting hours, creating confusion when people moved between wards. Some wards strictly enforced visiting hours whilst others did not, with senior and administrative ward staff particularly influential in shaping approaches to visiting times. Strict interpretations of protected mealtimes, visiting and infection control policies, by individual staff or at a ward level, could limit opportunities for families to become involved in their relative's hospital stay:

> *Fieldnotes Site 1: A visitor says she has come to 'sit in her [relatives] room whilst she eats lunch'. A senior staff member replies 'We have a protected mealtimes policy' and that it will be 'Alright for today' but that it isn't something she can do normally.*

Notably, these policies were interpreted in ways which limited family involvement more often in the site with less encouragement for family involvement from senior staff. At the other site, the more regularly present senior staff repeatedly conveyed support for families' input, creating a greater expectation that family engagement would take place:

> *Fieldnotes Site 2: A staff member says she feels confident 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 to families.*

However, varying responses to families' involvement were also seen within the same ward, with individual staff holding quite different views on the extent to which families, including the same family members, should be involved on the wards:

> *Interview Site 1, Staff 12: "We did have one patient [a gentleman with dementia who was often distressed] where his wife used to 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… but actually she was keeping him occupied."*

Variability in responses to families between and within wards points to a lack of any standard approach to supporting the involvement of families in care. Even when a ward or staff member did take a more flexible approach, many families kept to the advertised visiting hours, which were clearly displayed at ward entrances or conveyed by staff. The lack of an agreed approach meant that conversations with families about their involvement were often absent or reactive; in response to complex patient needs rather than proactive discussions. This inconsistent approach created a lack of clarity around what activities or roles families could undertake:

> *Interview Site 1, Interviewer: "You said you didn't know what was expected of you…?" Carer 1: "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… You don't know what you're supposed to do, or what their thing is."*

Concerns around the involvement of families

A final but important finding was recognition that family involvement was not uniformly positive and not all families had the knowledge, skills, or physical ability to help their relatives to a professionally acceptable standard. Concerns about the negative impacts of involving families included disruptions and additional work for staff and falls, infection control and litigation risks:

> *Interview Site 1, Carer 3: "I went to pick him up… haul him out of his wheelchair… and a woman came up to me… 'Oh no, no, you are not allowed!' I went like 'Why?' She went 'Because you're not, I'm not insured, and if he falls then it's on my head.' "*

> *Fieldnotes, Site 2: A staff member tells me visiting hours were reduced because patients weren't getting 'down time', and to reduce infection and visitor throughput. She describes how visitors are 'at you' at the desk all the time.*

However, shorter visiting hours at one site did not appear to alleviate concerns around visitor demands, or meet the engagement needs of families, with families queuing to speak to staff, some of whom were unavailable, during the limited visiting hours.

Other potentially negative impacts included the potential for family involvement to result in the involvement of the person living with dementia being overlooked:

> *Fieldnotes Site 2: A staff member talks for 5 minutes at the end of Emmett's bed with his wife and daughter about what care he will need when he goes home, including help with washing and dressing. Emmett, with his hearing difficulties, cannot hear any of it. After a while, Emmett says to me 'Can you tell what they're saying?' The staff member and his family do not include him in the conversation at any point.*

There was also concern about negative relationships between some people living with dementia and their families. For example, carer strain, or a lack of understanding of how to respond to a confused relative, could result in negative interactions:

> *Interview Site 1, Staff 11: "If they have reached crisis point… you can see their irritation levels with that person are obviously very high… it's not beneficial for anybody when they are irate with each other in the day room."*

Families did not invariably know more than staff about how best to connect with their relative. Negative interactions between family members, at an understandably difficult time, were not beneficial for the well-being of either party. Stress, negative relationships, and limited care-giving and dementia expertise are, however, not reasons to discourage engagement with families. These families could benefit from engagement with staff to establish their needs, provide support and, if necessary, upskill them for any current or future care-giving roles. However, the findings clearly show that careful attention is also required to the needs and wishes of each person living with dementia when considering the involvement of their families in care.

Discussion and Implications

The findings of this study highlight the highly variable nature of connections between hospital staff and people living with dementia, and with their families, and illustrate how families' knowledge and expertise can create more person-centred connections and care. Providing the most in-depth exploration of this issue to date, the findings set out a range of ways in which families can contribute to improving hospital care for people living with dementia. For example, families can provide valuable information about the person, aid communication between staff and people living with dementia, encourage engagement with care, assessments and rehabilitation, provide social interaction, personalise ward environments and conversations by providing personal items from home, and identify important changes in the person's health or well-being. But an inconsistent approach to engaging with people living with dementia and their families results in missed opportunities to improve hospital care for people living with dementia.

The elements of disconnection experienced by people living with dementia in this study expand upon the findings of Porock et al (2015) who identified *disruption* from pre-hospital relationships and life as a key consequence of hospital admissions for people living with dementia. Some of these disruptions preceded hospitalisation, including general deterioration, accidents or the onset of illness (Porock et al, 2015). In this study, the overlapping term *disconnection* is used to incorporate disconnections experienced during hospital admissions which do not involve disruption to prior lives, such as disconnections from busy staff and unfamiliar environments. Porock et al extend the concept of disruption to consider how other stakeholders in the care-giving triad (families, staff and co-patients) are also disrupted by the admission of the person with dementia. Some studies also identify sources of disruption and stress for families of hospitalised people living with dementia, including uncertainty and anxiety around their ability to continue care-giving roles and prior ways of managing post-discharge (Boltz et al., 2015; Bloomer et al., 2014; Bauer et al., 2011b; Douglas-Dunbar & Gardiner, 2007).

Many previous studies present a largely negative picture of hospital care for people living with dementia. The findings presented here suggest that disconnection is neither inevitable or unremitting, illustrating how meaningful connections can be created with people living with dementia in acute hospital settings and the crucial roles families play in creating these. These findings support those from other studies reporting variability in the degree to which people living with dementia (e.g. Featherstone et al., 2019; Clissett et al., 2013; Norman, 2006) and their families (de Vries et al., 2016; Boltz et al., 2015; Bauer et al., 2011b) are engaged with by staff. It is, however, necessary to read across previous studies to find prior recognition of the factors collectively identified here as affecting connections with families and people living with dementia; for example, the influence of dementia training (Nolan, 2007; Norman, 2006), task-orientated care routines (Featherstone et al., 2019; Clissett et al., 2013; Cowdell, 2010), and pressurised workloads (Doherty & Collier, 2009; Borbasi et al., 2006). The suggestion that hospital staff may not grasp all available opportunities to create more person-centred connections and care has recently been suggested elsewhere (Featherstone et al., 2019; Clissett et al., 2013), but the use of families' knowledge and expertise as a crucial means of creating meaningful connections has not been a focus of previous studies. Whilst families are suggested to ease some of the distress and gaps in care experienced by people living with dementia (de Vries et al., 2016; Gladman et al., 2012), how families might create changes in practice and care has not previously been explored in any depth. The findings of this study suggest that many problematic points for people living with dementia in standard acute care routines, such as mealtimes, medication rounds and personal care (Featherstone et al, 2019), have the potential to be improved through liaising with, and involving, family members.

Finally, an important but typically overlooked finding is recognition that family involvement is not uniformly beneficial for people living with dementia. Care-giving research has been criticised for ideological views which presume relationships between families and people living with dementia are unproblematic, denying the possibility of dysfunctional family relationships or family involvement that is detrimental to the cared-for person's well-being (Dupuis & Norris, 1997). Despite this, two recent reviews on acute care for people with dementia identify problematic relationships between staff and families or people living with dementia, but not the potential for relationship difficulties between people living with dementia and their families (Beardon et al., 2018; Dewing & Dijk, 2016). In the current study, we found some examples of family involvement that did not appear to benefit the person with dementia or their family, such as negative interactions or talking over the person. These findings suggest that care is needed to ensure that family involvement is enacted in ways that meet the needs of each person living with dementia and their family.

Strengths and limitations

Limitations include a predominantly white British sample despite efforts to recruit a diverse sample, and the possibility that participants' experiences were not 'typical' of usual practice. Some senior staff on both wards had dementia expertise, and reports of family involvement practices on other wards were more negative (including queues outside wards prior to visiting times, bell-ringing to signal visitors should leave, and refusals to speak with families). Since these data were collected, UK-based campaigns for open visiting (Jones & Gerrard, 2014; National Federation of Women's Institutes, 2016) have led to changes in approaches to family involvement on some wards. However, recent reports indicate that family involvement remains patchy and dependant on individual ward practices (National Federation of Women's Institutes, 2018; NHS England, 2016; Imperial College Healthcare NHS Trust, 2016) suggesting the findings of this study remain current.

To the best of our knowledge, this study provides the most in-depth exploration available of family involvement practices in the hospital care of people living with dementia. Strengths include the length, depth and multiple methods of data collection, which were vital to capturing the experiences of people living with dementia missing from many previous studies. In addition, data collection from two wards in different hospitals enabled exploration of different family involvement policies and practices, patient groups, environments, and cultures. However, the focus on two different types of ward from different NHS Trusts meant it was difficult to disentangle whether some differences between the wards occurred at a ward or Trust level. Future research would benefit from exploring differences in family involvement practices within as well as across Trusts, to establish why involvement practices vary and how barriers to effective involvement could be overcome.

Conclusions

As no guidelines currently exist for involving family caregivers in hospital care and research in this area is limited and (Boltz et al., 2014; Boltz et al., 2015; Morrow & Nicholson, 2016), this study provides much needed evidence to inform family involvement practices in the acute care of people living with dementia. The findings demonstrate how families' knowledge and expertise can help to effect connections and improve hospital care for people living with dementia. The variable nature of engagement with families suggests a need for more proactive planning and discussion around the involvement of families in care. In particular, there is a need for: ward environments and cultures that encourage families input; supportive senior staff; a review of policies which may conflict with family involvement; clarity and information around the roles families can undertake; methods for effectively sharing and using personal knowledge from families; a workforce educated on dementia and the importance of proactive family involvement; and approaches for inserting greater personalisation and interaction into ward routines. Finally, it is vital to ensure that family involvement does not lead to the needs or wishes of people living with dementia being overlooked.

References

Alzheimer’s Society. (2009) Counting the Cost: Caring for people with dementia on hospital wards. London: Alzheimer's Society.

Alzheimer’s Society. (2016) Fix Dementia Care: Hospitals. Alzheimer's Society, London.

Bauer, M., Fitzgerald, L., Koch, S., & King, S. (2011a). How family carers view hospital discharge planning for the older person with a dementia. Dementia, 10 (3) 317-323.

Bauer, M., Fitzgerald, L., & Koch, S. (2011b). Hospital discharge as experienced by family carers of people with dementia: a case for quality improvement. Journal for Healthcare Quality, 33 (6) 9-16.

Beardon, S. Patel, K. Davies, B. & Ward, H. (2018) Informal carers’ perspectives on the delivery of acute hospital care for patients with dementia: A systematic review. BMC Geriatrics, 18 (23).

Bloomer, M., Digby, R., Tan, H. Crawford, K., & Williams, A. (2014). The experience of family carers of people with dementia who are hospitalised. Dementia, 15 (5) 1234-1245.

Borbasi, S., Jones, J., Lockwood, C., & Emden, C. (2006) Health professionals’ perspectives of providing care to people with dementia in the acute setting: toward better practice. Geriatric Nursing, 27 (5) 300–308.

Bray, J., Evans, S., Thompson, R., Bruce, M., Carter, C., Brooker, D., Milosevic, S., Coleman, H., & McSherry, W. (2015). Understanding the needs of people with dementia and family carers. Nursing older people, 27 (7) 18-23.

Boltz, M., Chippendale, T., & Galvin, J. E. (2015). Anxiety in family caregivers of hospitalised persons with dementia: contributing factors and responses. Alzheimer's Disease and Associated Disorders. 29 (3) 236-241.

Boltz, M., Resnick, D., Chippendale, T., & Galvin, J. (2014). Testing a Family-Centered Intervention to Promote Functional and Cognitive Recovery in Hospitalized Older Adults. Journal of the American Geriatric Society, 62, 2398–2407.

Care Quality Commission. (2014) Cracks in the pathway: People’s experiences of dementia as they move between care homes and hospitals. Care Quality Commission.

Charmaz, K. (2014) Constructing Grounded Theory. London: Sage.

Clissett, P., Porock, D., Harwood, R., & Gladman, J. (2013) The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families. International Journal of Nursing Studies, 50 (11) 1495-1503.

Cowdell, F. (2008). "That's how we do it.... we treat them all the same" An Exploration of the Experiences of Patients, Lay Carers and Health and Social Care Staff of the Care Received by Older People with Dementia in Acute Hospital Settings. Thesis submitted for the degree of Doctor of Professional Practice, University of Bournemouth.

Cowdell, F. (2010). The care of older people with dementia in acute hospitals. International Journal of Older People's Nursing, 5 (2) 83-92.

Department of Health. (2009) Living Well with Dementia: A National Dementia Strategy. London, Department of Health.

de Vries, K., Drury-Ruddlesden, J., & Gaul, C. (2016). 'And so I took up residence': The experience of family members of people with dementia during admission to an acute hospital unit. Dementia, 0 (0) 1-19.

Dewing, J., & Dijk, S. (2016) What is the current state of care for older people with dementia in general hospitals? A literature review. Dementia, 15 (1) 106-124.

Doherty, D. & Collier, E. (2009) Caring for people with dementia in non-specialist settings. Nursing Older People, 21 (6) 28-31.

Douglas-Dunbar, M., & Gardiner, P. (2007) Support for carers of people with dementia during hospital admission. Nursing Older People, 19 (8) 27-30.

Dupuis, S. L., & Norris, J. E. (1997) A multidimensional and contextual framework for understanding diverse family members' roles in long-term care facilities. Journal of Aging Studies, 11, 297-325.

Featherstone, K. Northcott, A. & Bridges, J. (2019) Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences. International Journal of Nursing Studies, DOI https://doi.org/10.1016/j.ijnurstu.2018.12.009

Gladman, J., Porock, D., Griffiths, A., Clissett, P., Harwood, R., Knight, A., Jurgens, F. et al, (2012) Better Mental Health: Care for Older People with Cognitive Impairment in General Hospitals. Final report NIHR Service Delivery and Organisation Programme.

Imperial College Healthcare NHS Trust. (2016) Staff survey - One year after the implementation of John's Campaign at Imperial College Healthcare NHS Trust. Imperial College Healthcare NHS Trust, London. Available at: http://johnscampaign.org.uk/#/inspiration

Jones, J., & Gerrard, N. (2014). John's Campaign: for the right to stay with people with dementia: for the right of people with dementia to be supported by their family carers [online]. John's Campaign, Chelmsford. Available at: http://johnscampaign.org.uk/#/about

Jurgens, F. J., Clissett, P., Gladman, J. R., & Harwood, R. H. (2012) Why are family carers of people with dementia dissatisfied with general hospital care? A qualitative study. BMC Geriatrics, 12 (57) DOI: 10.1186/1471-2318-12-57.

Kelley, R. (2017) “Knowing the person” – The use of families’ knowledge and expertise in delivering care and valued outcomes for older people with dementia on acute wards. PhD Thesis, University of Leeds.

Knopman, D. S., Boeve, B. F., & Petersen, R. C. (2003). Essentials of the Proper Diagnoses of Mild Cognitive Impairment, Dementia, and Major Subtypes of Dementia. Mayo Clinic Proceedings, 78, 1290-1308.

Morrow, E., & Nicholson, C. (2016) Carer engagement in the hospital care of older people: an integrative literature review. International Journal of Older People Nursing, 11, 298-314.

Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R., & Gracia, N. (2011). Acute care management of older people with dementia: a qualitative perspective. Journal of Clinical Nursing, 20, 420–428.

National Federation of Women’s Institutes. (2018). Dementia care in hospitals: From the perspective of carers. National Federation of Women’s Institutes, London. Available at: https://www.thewi.org.uk/__data/assets/pdf_file/0006/286539/NFWI-report-2018-Dementia-care-in-hospitals.pdf

National Federation of Women’s Institutes. (2016). 'Carer's Welcome' campaign. National Federation of Women's Institutes, London. Available at: https://www.thewi.org.uk/campaigns/current-campaigns-and-initiatives/carers-welcome

NHS England. (2016). *NHS En*gland CQUIN 2016/17. Implementing a policy on welcoming carers and family members of people with dementia according to patient's needs and not restricted by visiting hours. NHS England, Leeds.

Nolan, L. (2007). Caring for People with Dementia in the Acute Setting: A Study of Nurses' Views. British Journal of Nursing*,* 16 (7) 419-422.

Nolan, M., Ingram, P., & Watson, R. (2002). Working with family carers of people with dementia: negotiated coping as an essential outcome. Dementia, 1 (1) 75-93.

Norman, R. (2006). Observations of the experiences of people with dementia on general hospital wards. Journal of Research in Nursing*,* 11, 453-465.

Porock, D., Clissett, P., Harwood, R., & Gladman, J. (2015) Disruption, control and coping: responses of and to the person with dementia in hospital. Ageing and Society*,* 35 (1) 37-63.

Redfern, S., Norman, I., Briggs, K., & Askham, J. (2002). Care at home for people with dementia: Routines, control and care goals. Quality in Ageing and Older Adults, 3 (4) 12-23.

Royal College of Psychiatrists. (2005) Who cares wins: Improving the outcomes for older people admitted to the general hospital. London: Royal College of Psychiatrists.

Royal College of Nursing. (2011). Dignity in Dementia; Transforming General Hospital Care Project. www.rcn.org.uk/development/practice/dementia/rcn_dementia_project

Scerri, A., Innes, A., & Scerri, C. (2015). Discovering what works well: exploring quality dementia care in hospital wards using an appreciative inquiry approach. Journal of Clinical Nursing*,* 24, 1916–1925.

Tolson, D., Smith, M. & Knight, P. (1999). An investigation of the components of best nursing practice in the care of acutely ill hospitalized older patients with coincidental dementia: a multi-method design. Journal of Advanced Nursing, 30, 1127-1136.

Walker, E., & Dewar, B. J. (2001). How do we facilitate carers' involvement in decision making? Journal of Advanced Nursing, 34, 329-37.

Figure 1: Characteristics of case study participants

Characteristics of case study participants living with dementia (n=12)

Purposeful sampling ensured case study participants with a range of characteristics, as follows:

Gender: A mixture of men (n=5) and women (n=7)

Stage of dementia: suspected but unconfirmed earlier stages through to diagnosed or advanced dementia

Reasons for admission: included increased confusion/delirium, infections, falls, fractures, and suspected stroke

Pre-admission living arrangements: mainly living at home or sheltered housing (n=11), 1 person was living in a care home. Half lived with one or more family member, the rest living alone

Length of stay: ranged from 13 to 78 days (median 24 days)*

Discharge destination: 4 people returned home with new/increased support, 7 were discharged to a care home (6 were new admissions), and 1 person died before discharge

*length of stay data for the rehabilitation ward excluded time spend at the associated general hospital prior to transfer to the rehabilitation ward

Characteristics of relative/friend case study participants

Characteristics of relatives and friends, and the they support offered, were as follows:

Types of pre-hospital support: Varied from 2-3 times weekly support with activities including shopping, meals, cleaning, companionship and care management to more intensive daily support including assistance to mobilise, wash, dress, eat and drink, and daily companionship

Care networks: Support was often provided by a 'network' of family (and occasionally friends). Less commonly support was primarily provided by one person

Relationship to person living with dementia: Daughters were the commonest participant (n=8). Other care-giving relationships included husbands (n=2), sons (n=2), granddaughters (n=2), wives (n=1) or friends (n=1), care networks leading these numbers to total more than 12

Hospital visiting: The majority of relatives/friends were regular ward visitors, typically visiting between a few times a week and daily. Visits were less frequent when relatives/friends had their own health issues, competing roles (e.g. work or childcare) or lived a distance away