

'And so I took up residence': The experiences of family members of people with dementia during admission to an acute hospital unit

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journals.sagepub.com/home/dem**Kay de Vries**

School of Health Sciences, University of Brighton, UK

Jenny Drury-Ruddlesden

Graduate School of Nursing, Midwifery & Health, Victoria University of Wellington, New Zealand

Chris Gaul

Nursing, Nelson Marlborough Institute of Technology, New Zealand

Abstract

It is estimated that a quarter of acute hospital beds are in use by older people with dementia at any one time. Little empirical research has been carried out that has specifically examined the day-to-day input of family members into the care of people with dementia during an acute hospital admission. In this article, we present the results of analysis of interviews with 26 family members of people with dementia about their experiences of supporting an admission of a person with dementia to an acute hospital unit in New Zealand. For all family members, the desire to support the person with dementia during their admission was at the forefront and was their primary focus. The theme, 'And so I took up residence', exemplifies fully the experiences of all of the family member participants. This study provides evidence that family members are a resource that may be unrecognised, untapped and unsupported in the event of hospitalisation of people with dementia.

Keywords

dementia, acute hospital, family members, dignity, neglect

Introduction

The National Audit of Dementia care in general hospitals (2012–2013) in the UK report that a quarter of acute hospital beds are in use by people with dementia at any one time (RCP, 2013).

Corresponding author:

Kay de Vries, School of Health Sciences, University of Brighton, Westlaine House, Falmer, Brighton BN1 9PH, UK.

Email: l.k.devries@brighton.ac.uk

Research in the UK has shown that up to 42% of older people admitted to an acute hospital have dementia and this percentage increases with age (Sampson, Blanchard, Jones, Tookman & King, 2009). In the UK, people with dementia have longer stays in hospital with more re-admissions and higher mortality rates than older people without dementia (Alzheimer's Society, 2009; Care Quality Commission, 2014; Connolly & O'Shea, 2015).

In New Zealand, the prevalence of dementia is known to be underestimated by the Public Health Intelligence (PHI) unit of the Ministry of Health data, as it is determined by contact with specific data systems. Only 45% of people with dementia are identified in the PHI data (Alzheimer's New Zealand, 2008). The number of discharges from hospital for people with dementia in the PHI data is comparable with the New Zealand Health and Information Service (NZHIS) data where dementia is one of up to 20 diagnoses (but not necessarily the primary diagnosis) in a hospital admission (Alzheimer's New Zealand, 2008). Similar proportions are found in some European countries and North America.

In the UK, patients aged 60 years or over account for 23% of attendances to the Emergency Department (ED) (Bannerjee, Conroy & Cooke, 2012). Older people are more likely to arrive by ambulance, have more investigations done and spend a longer time in the ED than younger people (Bannerjee et al., 2012). Hospitalisation can be traumatic and fraught with complications for any older adult particularly if they have cognitive impairment (Bridges, Flatley & Meyer, 2010; Glover et al., 2014; Tadd, Hillman, Calnan, Bayer & Read, 2011). Admission to hospital leads to many challenges for people with dementia predominantly due to communication difficulties and distress experienced at being in an unfamiliar environment (Alzheimer's Society, 2009; Care Quality Commission, 2014). These challenges not only impact on the person with dementia but also on their family members and the hospital staff.

There is a growing body of evidence that shows that health care professionals have poor recognition of cognitive impairment among older patients (Lyketsos, Sheppard & Rabins, 2000; Torisson, Minthon, Stavenow & Londos, 2012) and are unskilled in communicating with people with dementia (Bamford, Hughes & Robinson, 2007; de Vries, 2013). This absence of skills has been shown to lead to poor person-centred care and people with dementia being neglected and treated with a lack of dignity and respect (Kitwood, 1997), demonstrated, for example by people with dementia not being assisted to eat and drink; and being administered antipsychotic medication as a means of managing difficult behaviour (Alzheimer's Society, 2009).

Admission to hospital increases the risk for people with dementia of institutionalisation on discharge (Alzheimer's Society, 2009; Gruber-Baldini et al., 2003; Morrison & Siu, 2000; RCP, 2013); accelerated morbidity and mortality (Andersen, Lolk, Martinussen & Kragh-Sorensen, 2010; Baker, Cook, Arrighi & Bullock, 2011; Freedberg, Dave, Kurth, Gaziano & Bludau, 2008; Gruber-Baldini et al., 2003; Härlein, Halfens, Dassen & Lahmann, 2010; Larson et al., 2004; Mecocci et al., 2005; Rait et al., 2010; Sampson et al., 2009); and often they die with inadequate pain control or without the benefits of hospice care (Birch & Draper, 2008; Frampton, 2003; Sampson et al., 2006, 2009).

Few people with dementia are admitted to hospital as a result of their dementia; admission is generally as a result of an exacerbation of an existing co-morbidity or an acute event that may or may not be related to the dementia, with infection and fractures the most common reasons for admission (Natalwala, Potluri, Uppal & Heun, 2008; Rudolph et al., 2010; Tuppin et al., 2009). In a study carried out in Crete, Greece (Samonis, Giannousi, Varbobitis, Sardi & Falagas, 2009) found that during hospitalisation family

members may provide a considerable amount of informal care and support for this patient group and that for an older person, being single and having no children were proven risk factors for neglect. Family member capability and preference on how much involvement in care they may undertake varies considerably and it has been shown that many are eager to help if given the opportunity (Li, 2002, 2005; Nichols & Heller, 2002). Furthermore, they often feel responsible for supervision of the quality of care (Li, Stewart, Imle, Archbold & Felver, 2000; Lindhardt, Bolmsjo & Hallberg, 2006; Lindhardt, Nyberg & Hallberg, 2008). However, poor communication between staff and relatives of frail older people in acute wards may inhibit full participation in care (Li, 2002) and relatives have rated collaboration with nurses as poor in regard to decision-making and facilitating opportunities for social interaction (Alzheimer's Society, 2009; Lindhardt et al., 2008).

There has been sparse empirical research conducted that has specifically examined the day-to-day input of family members into the care of people with dementia during an acute hospital admission. In this article, we present the results of the analysis of interviews with 26 family members of people with dementia about their experiences of supporting a person with dementia during admission to an acute hospital unit in New Zealand.

Methodology

The research presented in this article was part of a larger mixed method study. The first two phases of the study were conducted at five District Health Boards (DHBs) in New Zealand; two in the South Island and three in the North Island. In Phase 1, a retrospective case note review of all people over the age of 65 admitted to acute medical and orthopaedic wards during three separate periods of one month, to capture seasonal differences, during 2012 was carried out. Phase 2 involved the administration of the 'Approaches to Dementia Questionnaire' (ADQ) (Lintern & Woods, 2001) and focus group interviews with staff providing care on the wards identified. Phase 3 (reported in this paper) involved 26 interviews with family members of a person with dementia who had experienced one or more admission to an acute hospital ward within the last five years. Ethical approval was gained from Central Ethics Committee, New Zealand.

The objective of this phase of the study was to explore the experiences and challenges encountered by family members of people with dementia during an admission to an acute hospital unit. Participants had no direct connection to the five DHBs within which Phases 1 and 2 had been conducted. The inclusion criteria for taking part in the study was that the participant was a family member of a person with dementia who been a patient in an acute hospital unit within the last five years. We had no exclusion criteria.

The interviews were conducted from self-selected convenience samples (Suri, 2011) where we advertised for participants in local newspapers, at Alzheimer's Conferences and other venues such as caregiver support forums or through contacts of participants, that is using a Respondent-Driven sampling approach (Heckathorn, 1997; Penrod, Preston, Cain & Starks, 2003). Semi-structured interviews were conducted by all three authors in environments that were negotiated between the interviewer and the participant. Some were conducted at the participants own home; some were conducted in private spaces during conferences; and some in the researchers' workplace. Interviews lasted from 45 to 100 minutes. They were audio-recorded and transcribed by a professional confidential transcriber.

Every story that was shared by the caregiver was individual and varied. The detailed, complex and challenging situations that each one had faced, particularly in relation to the death of the person with dementia, stand alone as individual stories and are reported as such elsewhere. For the purposes of this paper, we were specifically interested in the experiences of the hospitalisation events and have examined these events in light of our study objective. Data were analysed by the first author following a conventional content analysis process (Hsieh & Shannon, 2005) using a coding scheme developed following line-by-line coding conducted on several transcripts by all three authors. This approach was used as there was limited research literature on the phenomenon under investigation. All three authors then agreed the emergent themes across transcripts.

Findings

The majority of participants (22) were women (Table 1). Of those, 12 had a mother with dementia; one had a mother-in-law with dementia. Four participants had a father with dementia; one a stepfather. A further five had a spouse with dementia, of these only one participant was the husband of a wife with dementia. The remaining participants consisted of a brother of brother (with dementia), sister of a sister, son of mother and niece of her uncle.

Ten of the people with dementia were already resident in a care home facility and 12 of them were admitted from their own home to hospital but discharged to a care home facility. Only four of them were still resident in their own homes at the time of the study. Eight had multiple admissions. Pseudonyms are used for all participants.

‘And so I took up residence’

The theme, ‘*and so I took up residence*’, exemplifies fully the sentiments expressed by all of the family members. Embedded in this theme were the complexities that encompassed the positions that family members took in making sure they were present to attend to the needs of the person with dementia and are represented in the following three subthemes: *assertive advocacy*; *the need to be present*; and *dealing with humiliation, neglect and loss of dignity*.

And so I took up residence, well I’d gone up with enough clothes for four days and took [person with dementia] to see the doctor. They admitted her acutely, I didn’t go home for 48 hours after that and yeah she came, she had the anaesthetic it wasn’t a problem you know. And then we started active treatment. . . One of my biggest issues was you’ve put [person with dementia] into an environment she doesn’t know and she’d get confused and if you break the routines that she’s used to it’s going to add to the things. You’re going to have all sorts of problems. Here you’ve got a person with Alzheimer’s reasonably continent. . . is continent. . . and you don’t want to be messing anything up with that with routines. I took over and I just wrote up a big care plan, big piece of paper and put it on the wall [person with dementia] daily routine, you know. (Elaine [sister] 111–123)

For all family members, the desire to support the person with dementia during their admission to an acute hospital unit was at the forefront and was their primary focus. All of the family members had some type of influence over the care practices that they encountered in the acute environment. In some cases, they were deferred to and listened

Table 1. Participant demographics.

Family member pseudonym	Relationship to person with dementia	Reason for admission	Place of residence of person with dementia	Outcome of admissions	Deceased Yes/No
Tilly	Daughter/mother	Assessment for dementia	Home	Care home admission; died shortly after	Yes
Alice	Daughter/mother	Fractured hip; multiple admissions	Home	Home	Yes
			Home	Care home admission	
			Care home	Discharged back to care home	
Kate	Daughter/mother	Renal failure; multiple admissions for infections	Home	Home	No
Jill	Daughter/mother	Fractured pubic rami	Home	Care home admission	No
Judy	Daughter/mother	Paranoia – for medication reviews	Care home	Care home admission	Yes
Kathryn	Daughter/mother	Multiple admissions; infections; injuries	Care home	Discharged back to care home	Yes
Rhonda	Daughter/mother	Vomiting and diarrhoea; fractured hip; multiple admissions	Care home	Discharged back to care home	Yes
Jenny	Daughter/mother	Stroke	Home	Home	No
Linda	Daughter/mother	Fall	Home	Care home admission	Yes
Noleen	Daughter/mother	Falls; constipation	Home	Care home admission	No
Bonnie	Daughter/mother	Extreme agitation	Care home	Discharged back to care home	No
Gail	Daughter/mother-in-law	Assessment for dementia	Home	Care home admission	No
Sue	Daughter/father	Breathlessness	Home	Home	No

(continued)

Table 1. Continued.

Family member pseudonym	Relationship to person with dementia	Reason for admission	Place of residence of person with dementia	Outcome of admissions	Deceased Yes/No
Betty	Daughter/father	Falls; multiple admissions	Care home	Discharged back to care home	No
Kathleen	Daughter/father	Assessment for dementia	Home	Care home admission	Yes
Denise	Daughter/father	Seizures; multiple admissions	Care home	Discharged back to care home	No
Juliana	Daughter/stepfather	Multiple admissions; cardiac	Home	Care home admission	No
Graham	Son/mother	Leg ulcers	Home	Care home admission	No
Elaine	Sister	Weight loss	Care home	Discharged back to care home	Yes
Holly	Wife	Chest infection; asthma; multiple admissions	Home	Home	No
Edna	Wife	Strangulated hernia	Home	Care home admission	Yes
Sheila	Wife	Acute agitation	Care home	Discharged back to care home	No
Helen	Wife	Acute reaction to first time use of risperidone that had been administered in the care home	Care home/dementia unit	Discharged back to care home/dementia unit	Yes
Ben	Husband	Fall	Home	Care home admission	Yes
Rose	Uncle	Fall/assessment	Home	Care home admission	No
Mark	Brother	Stroke	Care home	Discharged back to care home	No

to with respect by the hospital staff, in others they needed to be assertive to achieve the level of attention that they believed was not forthcoming from the staff.

Assertive advocacy

Family members were passionate in their desire to ensure good care for the person with dementia. This ‘assertive advocacy’ demonstrated how their approach was more than just being an advocate. Family members demonstrated this assertiveness in a number of ways. Some took almost complete control of the care regime for the person with dementia as their concerns centred on maintaining routines and in most cases, at some stage, the family member was actively involved in providing care. In many situations, it was the assertiveness of the family member that ensured attention to health issues were dealt with comprehensively. They set the care perimeters, on some occasions, even going so far as to write a plan of care for the person with dementia and making sure this was adhered to by staff (see Elaine’s quote above).

If the person with dementia had specific medication regimes they were vigilant in making sure these were adhered to by staff and all family members were observant of any indication that the person with dementia was experiencing pain and in many cases made assertive requests for analgesia when they felt it was necessary:

She never complained but you know I mean involuntary groans and grunts just indicated that she was feeling pain alright.

Interviewer: So they noticed if she was in pain by movement?

Well they should have known anyway, yes.

Interviewer: And did you tell them if you saw that she had pain?

You bet I did, yes. I said can you do something about it. (Graham [son] 126–144)

As well as expressing concerns about under medication to staff, family members also had concerns about ‘over medicating’. This was a significant issue for a number of participants at some stage during the admission, particularly sedating medications that impacted on the alertness of the person with dementia. Almost all family members demonstrated that they had some knowledge of issues regarding frailty and medication dosage for older people and of the effect of antipsychotic medications and were vigilant about the side effects or efficacy of these:

[Following medication with Clonazepam] so then she slept for the next twenty-four hours so we couldn’t do anything except... I was able to wake her enough to feed her and to keep the pain relief and everything up. Then she became a little bit vocal so they gave her some more Clonazepam. So in the end I had to ask them not to give her Clonazepam because I said you know she’s got to be given a chance of rehab here. (Jill [daughter] 83–120)

She was in the hospital and I observed her at close quarters eight hours a day for five days and I noticed they were giving her this drug called Quetiapine so I said to the nurse, could I have a look at the file. And the nurse said oh you can’t look at that, I said hand it over, this is my mother we’re talking about give it to me so she did. (Alice [daughter] 250–253)

All admissions were through the ED, and in most cases involved an ambulance transfer from place of residence to the hospital. Eight of the people with dementia had repeated admissions to hospital – always via the ED – and in some cases, the admission only went as far as the ED as a result of assertiveness and advocacy demonstrated by the family member. This was

because either prior experience, or the situation they were facing at the time, was so disturbing and stressful for both the family member and the person with dementia that they insisted on taking the person home rather than have them admitted:

So that was the same process, ambulance and I thought oh no are you sure he needs to go and they [care home] said yes we're really concerned and so he went in and he perked up quite soon and I was very clear with them, I'm taking him out, I'm taking him now.

Interviewer: So he only got to ED again?

He did. Yep.

Interviewer: And were they better that time?

I wasn't going to give them any chance, so I very much managed it. Yep. I wasn't going to go through that again. (Denise [daughter] 145–153)

The reverse also occurred when the medical team wanted to send the person with dementia home and the family member considered that the person needed to be admitted. The determination not to back down was also extremely distressing for family members to the point of, at times, reducing them to tears:

So I brought her in and they assessed her and they sort of said oh well you know it probably is a nose bleed and I said well I don't care, I want her admitted. Well then I got this feisty little house surgeon who wanted to send her home the next day and I said no she's not coming home, she needs an assessment. . . I want her assessed and she argued black and blue. . . I said she deserves more than this and actually I ended up in tears in this room and one of the doctors came in and said to me, what's going on and I said they want to send her home. (Gail [daughter-in-law] 87–103)

For a number of family members, the time spent in the ED was the most difficult. This was an environment in which they found they needed to be particularly firm regarding gaining attention from staff. They were often left waiting for long periods and in some cases only received attention when they assertively approached staff:

And finally at eleven o'clock I went and said that unless they could see us now I was going to take him home and she said don't do that because you know he could get septic which was very true actually. And so she went in and more or less commandeered a bed for him. Well that was about eleven o'clock when I said it then, when we finally got in there and then we had to wait of course for him to be seen. I think he was seen about one o'clock in the morning. (Holly [wife] 31–46)

Family members of those that had repeated admissions did not find any improvement with each admission and became even more vigilant about how staff managed the transition through the ED.

Assertiveness was also required in some cases in relation to discharge plans. It required a strong measure of confidence for family members to ensure that the person was not discharged too early or without sufficient systems being put in place to support the person at home:

He had the surgery and they rung up and said come and take him home and I said no, the understanding was, he's had an anaesthetic he's got dementia, he's staying in for 24 hours at least. They weren't very happy but they did keep him till the next morning. (Edna [wife] 362–365)

Family members wanted to ensure that the person with dementia was actually ready to be discharged and that while they were on the unit that consideration was given to rehabilitation or at least to maintenance of their current level of functioning:

And she's really getting stressed, all she wants to do is go home but I can't let her go home until I know if she can boil the billy safely and pour hot water. You know it's all those little things. So I just said that the systems not geared around dementia patients. It's bad enough having a stroke but when we've got two combinations in there she got all the attention in the first few days, the critical stage till she's medically cleared and then it all stops. She's just sitting vegetating. (Jenny [daughter] 13–32)

For others, assertive approaches were taken when they believed that staff were not attending to the needs of the patient. Although family members frequently did not feel knowledgeable about the subject of dementia, they were prepared to take a stand over what they believed was the right approach to treatment:

I said she needs a dressing changed. 'Oh I'll be there soon'. So finally [the nurse] came and I said oh she's also got a blister on her heel now. She never had that earlier. When I talked to somebody the next day they said oh it would be friction. I said no. I said she didn't move. She can't move her left leg. I said that is just pure pressure. Then they were going to put her on a pressure relieving mattress, waited another two days for that. (Jill [daughter] 175–180)

An assertive position was also taken at suggestions that the person with dementia might not be resuscitated:

[Person with dementia had had four strokes] the last one in 2012 was a bad one. They say he nearly died. They got me down at the hospital and tried to get me to sign papers to say not to resuscitate him, and I said no I'm not doing that, you're the doctors you'll do your best. (Mark [brother] 10–12)

Other ways in which family members established their assertiveness was in situations where staff demonstrated poor understanding of how the symptoms of dementia manifested, particularly in relation to communicating with the person with dementia. There were instances when the medical professional completely disregarded the family member's input into history taking and assessment processes. In the following extract, this daughter had explained to the doctor that her father was unable to communicate but the doctor ignored her and proceeded to interview her father:

And I just sat there. I couldn't look at him I was [so] angry and, and then he said after a while [of attempting to assess the person with dementia] he said oh it's quite clear that your father can't communicate to me. And I was like 'really!' (Denise [daughter] 73–75)

In all cases, at some time during the admission, the person with dementia expressed the desire to 'go home'. A number of family members felt that staff took this cry to 'go home' too literally, due to their lack of understanding of how some of the symptoms of dementia manifest:

[Family member] would have staff telling him that [person with dementia] wants to go home. Well we knew that. And they're insisting that we set things in place so that he could go home because he had friends in Australia that he wanted to visit and you know I said to one of the staff nurses one day, well do you know that it's twenty years since he's actually seen these people.

You know it was all in his mind it was a distant memory and it was very difficult and I understand that this is difficult because [person with dementia] was so plausible in his speaking that when you're having a conversation with him it's easy to believe everything he said. (Rose [niece] 164–174)

Other examples where family members became assertive were where staff '*talked over*' the person with dementia, or wanted to discuss details about their care or condition '*in front*' of the person with dementia without including them in that conversation:

They asked me if I knew he had dementia, oh I said yes and the registrar came and said I want to talk to you about his condition. And I said well I'm not talking to you here.

Interviewer: Was it because he was there and you didn't want to talk in front of him?

Yes. And it was the same with [one family member], with [another family member]. She said don't talk about him in front of him. Either talk to him or take me somewhere and that's how I felt... the same. (Edna [wife] 330–334)

After assertively fighting their corner and being successful in achieving their aim of getting appropriate attention, some family members experienced residual frustration and anger that they had had to fight for the service and felt that they needed to convey this. In some cases, they followed up on their concerns by returning to the hospital and expressing their dissatisfaction about the outcome of the admission:

When I went back, well, actually I made a bit of a, you know, I had a bit of a... 'discussion' shall I say. At which case they said, well perhaps, no it wasn't the most logic thing to send her home, perhaps they should actually at least wait until they had some sensitivities back and so on. (Kate [daughter] 123–126)

All family members felt that they needed to be vigilant throughout the admission, and be ready to be an advocate for the person with dementia. In most cases, this required them to be present for as much time as possible during the admission.

The need to be present

Family members tended to spend a large amount of their time at the hospital, at the bedside of the person with dementia; some spending as much time as they could at the hospital during the period of the admission: '*I went most days*'; '*I went every day*'; '*Well most days I got there mid-morning and I left just after tea time*'; '*I sit with her till she sleeps every night pretty much*'; '*Yeah so I'm in here all the time*'.

This was, in some cases, due to a sense of duty and obligation:

Like he's at the hospital and you feel you've got to visit him every day at least when he's at home I know Mum will call me or text me if there's something wrong, whereas when they're in the hospital you feel that you need to go every day. (Sue [daughter] 143–147)

Or devotion:

It was a case of you know for better for worse as far as I was concerned. I took it seriously. (Ben [husband] 141)

There were a variety of reasons why family members felt that they needed to be present, such as making sure the person with dementia was getting one-to-one attention, particularly if

they were distressed or manifesting behaviours for which the family member had well-established strategies for managing:

It was the only thing to stop his levels of distress escalating was to keep moving with him. And then after an hour I thought you know he might look okay but he's actually not, this is really tricky so I sort of caught a nurse's attention or somebody passing and I said look my father has dementia this is quite stressful and I don't know how long I'm going to be able to do this for you know and she said look we'll get to you as best as we can. Well two and a half hours later they'd watched me go round in front of their office I don't know how many times. (Denise [daughter] 36–42)

They also wanted to be present so that they could make sure they were fully informed about the progress of the person with dementia. Family members would regularly make sure they were present for a 'medication rounds' and 'doctors round' so they could ask questions, give their opinion regarding progress and assist in care activities whenever they could:

I go every day around lunch time to help feed or talk her into having her pills or whatever they were really good and they kept me right informed of what was going on and I requested some things and got them you know. (Graham [son] 118–121)

All of the family members knew the particular personal habits, anxieties and behaviours of the person with dementia and had strategies to manage these in the best interests of the person. Consequently, their desire to be present was also to ensure that a safe environment was maintained for the person and they found, from experience, that knowing how to approach the person with dementia could make a significant difference between the person being distressed and, consequently, in some instances, the distress leading to aggressive behaviour:

[Spent all day at the hospital] well for safety sake because he's quite unsafe, he was wandering away and he did escape quite quickly even though he's got a walker and he uses a wheelchair they don't know how he gets out onto the main part of [name of hospital], so my stepmother talked to him and said did you know that every time you go away (he's trying to get home) that the person in charge here might lose her job if anything happens to you and he stopped doing it. So he had some insight but he just didn't want to be there I don't think. And he kind of thought he was [at home], he used to go into other people's rooms because he thought he had three rooms... so he would go and make three different beds. (Betty [daughter] 49–61)

Family members were very aware that their presence had a therapeutic effect on the person with dementia. They observed that the person with dementia felt much safer and more secure and that as a consequence of their presence would be more cooperative with care interventions. On some occasions, this required innovative approaches to creating security for the person with dementia that were supported by hospital staff:

So we actually ended up having to take her to the emergency room at the hospital and the only way they could really calm her down was to put her in the same room as Dad [husband was a patient in same hospital]. So she was in the bed in the same room with Dad and she was quite happy when she was there next to him. (Judy [daughter] 46–51)

Family members were not only vigilant regarding care interventions and approaches during the hospital admissions. One of the greatest anxieties expressed by all participants was how much they wanted to ensure that the dignity of the person with dementia was maintained.

Dealing with humiliation, neglect and loss of dignity

A number of the family members experienced considerable distress when they observed care practices that they felt were humiliating and reduced the dignity of the person with dementia. This made them all the more determined to stay by their side during the admission. In many cases, this was not only in respect of their own family member. They also witnessed lack of respect and dignity toward other people with dementia within the acute units. This was demonstrated in a number of examples such as dressed in inappropriate clothes, exposure when changing continence pads and not closing curtains properly during care interventions. During the interviews, many of the family members were reduced to tears when they described in detail some of what they termed as '*undignified*' events they were witness to or involved in during the hospital stay:

It was awful seeing. . . my poor husband staggering around in the middle of the room with only the diaper on, he was naked and I just thought you know if I could just go back in time I would make sure the curtains were pulled because of the open door. . . Anyway I grabbed a towel and said put this on him. She [nurse] said oh yeah I'm sorry and she did apologise. (Sheila [wife] 57–64)

In some instances, the distress of the person with dementia culminated in extreme demonstrations of the agitation, aggression and violent behaviour. Interventions by hospital staff, to manage the situation, and were witnessed by family members, were extremely distressing for them. They recognised the helplessness that was experienced by staff but the horror of the event also left them with a sense of powerlessness at their failure to protect the distressed person with dementia:

[Person with dementia] had just gone berserk. . . they didn't know really how to handle it. . . they had all security guards there and they had doctors there and they wanted to give him this injection and so my daughter got there before me. . . she said when she got there the doctors were saying we're going to give him this injection it takes twenty minutes to work and oh you know but you, we might have to hold him down and you might not be happy about seeing that and she said, you won't have to hold him down, so they gave him the injection. And it didn't work. And he was abusing everybody, it was awful. Absolutely horrible and I was in tears, my daughter was in tears and they put a catheter in and I said to the nurse, um, I asked her if they could give him something else. . . and she said no we can only give him only one of those injections. (Helen [wife] 3–25)

Some also felt strongly that if they were not present the person with dementia was at risk of not receiving adequate care and, in some cases, this was seen as a very obvious act of neglect. For example, for almost all family members, at some time, the issue of neglect at meal times was reported as a source of concern. For a number of them, one of the primary reasons for maintaining a presence at the hospital was to ensure that the person with dementia actually received food and fluid:

When we were in the ward, nobody had sort of said well she's got dementia so they would come, this lady came, they came and gave her her food, she didn't eat it so they took it away. . . She couldn't get up. I don't think they did because that was what [family member] was angry about. . . so they just plonk food down. . . I suppose I was up there most of the time and I'd brought her lots of energy drinks. (Kathryn [daughter] 212–222)

I just wonder if she'd get fed if I didn't go up at meal times. Because they were really busy the other night and so I'd fed Mum and I said look I'll feed the lady next door if you like because I knew her because she's also from the same rest home that Mum was in. Also a fractured femur... and so I did that but it was just that you know by the time they would've got back to feed both [another resident from care home] and Mum their meals would've been stone cold. (Jill [daughter] 189–196)

Family members provided a substantial amount of care when at the bedside. Aside from assisting at meal time this included shaving, dressing, taking the person to the toilet and assisting with showering. They undertook these care activities as part of the desire to maintain the dignity of the person with dementia by making sure they were presented at their best, clean and dressed appropriately – even if in nightclothes – in the manner in which they knew the person would have taken pride, given the choice:

So when he was in hospital I'd go in during the day, I was still working but I think I was off then and you know I shaved him and things like that because his electric razor hadn't come so the nurses don't like using hand razors, so I don't mind, I'm used to it. I made sure he looked nice and probably the most worst thing of the whole experience was the body pads. (Sheila [wife] 48–53)

There was also a perception that staff lacked understanding of what people with dementia were actually capable of doing for themselves. Family members witnessed a range of approaches that they deemed inadequate to meet the complex needs of people with dementia:

I think they expected for her to do more for herself. They'd ask her to lift her arm up to something and she would take a while to comprehend what they were saying. 'Lift your arm up [person with dementia]' and she'd be looking at them and lift it half way up and put it down again not sure if she was doing the right thing. I think she didn't have comprehension of what they were doing. (Rhonda [daughter] 346–350)

However, some family members were sympathetic towards the staff and did not perceive it as an issue or neglectful if, for example, the person with dementia was not being assisted with meals. They saw it rather as an organisational problem and due to work pressures and time constraints that they believed the staff were under:

I think that is one of the problems probably in a hospital situations is that the staff haven't got the time to sit there patiently trying to coax them to eat. (Judy [daughter] 202–204)
I mean it was a lot of work for them... the staff... because of having to do the personal cares and everything. Supervise eating. If I hadn't been there would have been a lot of work for them. (Holly [wife] 447–449)

The final two quotes capture the essential issue of why family members felt they needed to be present, to be vigilant and watchful and to actively provide care for the person with dementia when admitted to an acute unit. They all had personal experience of providing care and were well aware of how much time and one-to-one attention was required to undertake this and to do it well.

Discussion

The aim of this study was to explore the experiences of family members of people with dementia during admission to an acute hospital unit. Little empirical research has been

carried out that has specifically examined the day-to-day contribution of family members to the care of people with dementia during an acute hospital admission. There is a large body of research literature on caregiver and family member contribution to care in acute units for frail older people (see Bridges et al., 2010; Clissett, Porock, Harwood & Gladman, 2013; Digby & Bloomer, 2014; Li et al., 2000; Li, 2002, 2005; Tadd et al., 2011); however, specific challenges for family members of patients with dementia are not often made explicit within these studies.

Of note, Jurgens, Clissett, Gladman and Harwood's (2012) study on dissatisfaction of family carers of people with dementia with general hospital care on geriatric and general medical, and orthopaedic wards of a large English hospital, upholds many of our findings. The researchers developed a model explaining dissatisfaction with care where they identified a *cycle of discontent*. Events (or 'crises') were associated with expectations which, when unmet, caused family members to become uncertain or suspicious. The uncertainty identified by Jurgens and colleagues led to a period of 'hyper vigilant monitoring'. Hyper vigilant monitoring involved family members seeking out evidence of poor care, which then led to challenges and conflict with staff similar to the experiences of family members in our study. This behaviour also supports the work of Lindhardt et al. (2008) who found that *standing guard* was important for family members. Standing guard or being hyper vigilant concurs with our study where family members adopted a controlling behaviour, and closely monitored any treatment delivered to the person with dementia including medication regimes. Jurgens et al. (2012) found that this hyper vigilant monitoring could lead to family member withdrawal, a factor that did not feature in our study. On the contrary, 'taking up residence' and staying vigilant at the bedside of the person with dementia was a constant feature.

All admissions in our study were through ED, and in most cases involved an ambulance transfer from place of residence to the hospital. As in our study, Jurgens et al. (2012) found that family members gave negative accounts of the admission experience through ED. The experiences of our participants demonstrated the need for considerable improvement within the ED (Clevenger, Chu, Yang & Hepburn, 2012) particularly in knowledge about the symptoms of dementia; the psychosocial needs of people with dementia and their family members; how to communicate with people with dementia; and support strategies for family members.

The assertiveness demonstrated by family members in this study was similar to that which an advocate may offer or provide. However, family members revealed a personal passion and fierceness that went over and above being simply an advocate. This was likened to that of a relational approach to care as suggested by a number of authors (see Bridges et al., 2010; Nolan et al., 2002). Family member concerns were primarily centred on the wellbeing of the person with dementia and a determination that optimum care was provided at all times but also in collaboration with the staff if possible. The small body of research that has examined family member experiences of time spent at the bedside of a person with dementia in acute hospitals upholds our findings in respect to believing that the person would be neglected if a family member was not present (Samonis et al., 2009), and ensuring attention is given to general physical care, including assisting with meals (Alzheimer's Society, 2009).

Following their systematic review on older people's and relatives' experiences in acute care settings, Bridges et al. (2010) concluded that it was apparent that those older people who were at particular risk of negative experiences of care were people with dementia,

delirium and communication difficulties. Tadd et al. (2011) also found that the reasons for poor attention to the dignity of older people in acute hospitals was due to a lack of knowledge about the needs of people with dementia and the lack of training in relation to the provision of dignified care. There is a wide-ranging body of literature where attempts to define and clarify the concept dignity have been made (see, for example, Edlund, Lindwall, von Post & Lindström, 2013; Nordenfelt, 2004; Tranvåg, Petersen & Nåde, 2014). The term is in common usage in many documents and health policies, professional codes of practice and research literature related to dementia care provision. The position that the family members were coming from was that of dignity as a spectacle where they witnessed the person with dementia being exposed to what they felt were humiliating and undignified situations (Radley, 2004). Radley (2004) presents dignity as both a spectacle and an achievement, a status which is accorded by its appearance. Dignity, as a 'spectacle', refers to suffering (indignity) that is witnessed. The judgements made by family members on the dignity of the person with dementia fit a concept of dignity as a spectacle, where the dignity status was determined by the 'spectator(s)' (Radley, 2004) and revolved around the exposure of the body and the gaze of others (Walsh & Kowanko, 2002). Undignified exposure of the bodies of people with dementia; and talking over the person with dementia as though they were not present; have been identified as indications of lack of person centred care (Clissett et al., 2013; Kitwood, 1997). Family members were determined to maintain the dignity, autonomy and agency of the person with dementia and believed that their presence was essential to facilitate this, a position upheld in the work of Li (2002, 2005) and Lindhardt et al. (2008).

Limitations

The limitations to this study are significant inasmuch as the interview data were collected from self-selecting participants. All wanted to tell their story because they had some concerns about the care the person with dementia received. However, the mixed method design and our data from the case-note review (reported elsewhere) corroborate the stories and upholds many of the concerns raised by the family member participants.

Conclusion

This is one of the few studies that has specifically examined the day-to-day contribution of family members to the care of people with dementia during an acute hospital admission. The role of family members is recognised as making an important contribution to care within the acute healthcare environment. This study provides evidence that family members are a resource that may be unrecognised, untapped and unsupported in the event of hospitalisation of people with dementia. The experiences described here by family members could inform the basis of an approach to care suggested by Lindhardt et al. (2008). That approach suggests developing collaboration between family members of older people with dementia and acute care staff where relatives can become recognised as *competent collaborative partners in care* (Lindhardt et al., 2008). They propose that such a model of care offers family members a role as partners in care provision and decision-making that has the potential to decrease the powerlessness that family members frequently experience; and furthermore, this may ultimately increase satisfaction for family members, the person with dementia and hospital staff.

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Kay de Vries is Deputy Head of School and Head of Centre for Health Research at the School of Health Sciences, University of Brighton, UK. She is an active researcher in the areas of end of life, old age and dementia care, in acute, community and care home environments.

Jenny Drury-Ruddlesden is a full time researcher at Victoria University of Wellington, New Zealand. Her research interests include dementia care and end of life care. Her current

research focus is using computers gaming technology to improve the quality of life for people with dementia.

Chris Gaul is an Academic Staff member with the Health Programmes – Nursing at Nelson Marlborough Institute of Technology, New Zealand. Her research interests are in promoting aged care and health of older people in undergraduate education.