

# The experience of family carers of people with dementia who are hospitalised

Dementia

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## Abstract

Hospital admission of a person with dementia can have a significant impact on the family carer, who temporarily relinquishes caring to health professionals. A descriptive qualitative design using in-depth interviews with a conversational approach was used to elicit data. Adjusting to the change in the carer's role can be challenging and result in feelings of helplessness, loneliness, loss of control and being undervalued. Family support can assist with the transition but family conflict increases anxiety. Good communication between clinicians and the carer is vital. The carer should be included in decision-making as the 'expert' in the care of the person with dementia. This article discusses findings of a larger study specifically related to the emotional support required for the carers of people with dementia, who are admitted to hospital. The carer and the patient must be considered as a dyad in relation to discharge planning.

## Keywords

family carer, dementia, hospital, emotional support, carer

## Introduction

Dementia is one of the biggest global public health challenges facing our generation (Prince, Prina, Guerchet, & Alzheimer's Disease International, 2013) and in Australia, dementia poses a significant challenge to health care delivery. While an estimated 298,000 Australians had a diagnosis of dementia in 2011, population projections suggest that the number of people with dementia is expected to triple between 2011 and 2050, with as many

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as 900,000 people expected to be affected by 2050 (Australian Institute of Health and Welfare, 2012). The impact of dementia on Australian health care services is significant, with recent Australian statistics demonstrating that 1 in every 100 hospitalised patients had a diagnosis of dementia; people with dementia aged 65 years and over had substantially higher average number of health conditions than those without dementia (Australian Institute of Health and Welfare, 2012), thus requiring more care and support.

Around half of all people with dementia need some personal care (Prince et al., 2013) but equally, family carers of people with dementia also need support. While there are several definitions of 'carer', the Australian Institute of Health and Welfare describe a carer as someone who provides ongoing informal assistance to a person living in the community who cannot care for himself/herself, excluding paid workers (2012). In the case of people with dementia, carers are often integral to the person with dementia, managing their daily life and remaining in their own home and community (Roy & Gillespie, 2011). Many people with dementia require more than one carer, with the greatest majority of carers being family members, females, over the age of 65 years and providing co-resident care (Australian Institute of Health and Welfare, 2012).

While caring for someone with dementia can be rewarding and many family members choose to take on the carer role because they see it as a family responsibility (Australian Institute of Health and Welfare, 2012), it can also be very stressful (Roy & Gillespie, 2011). The burden of caregiving is higher among those caring for a person with dementia than those caring for a person with other chronic conditions (Kim & Schulz, 2008). There is significant concomitant psychological, social and financial impact on carers of people with dementia (Alzheimer's Society, 2007; Elvish, Lever, Johnstone, Cawley, & Keady, 2013), with some research suggesting that carer distress is significantly under-reported in this population (Neil & Bowie, 2008).

What is known is that each relationship between a person with dementia and their carer is different and thus their needs for care and support are also different (Prince et al., 2013), with numerous factors influencing this. One of the most significant issues is the lack of a person-centred approach to care and support for the carer (Elvish et al., 2013; Nilsson, Lindkvist, Rasmussen, & Edvardsson, 2013a; Prince et al., 2013). In a recent systematic review of psychological interventions for carers of people with dementia, Elvish et al. (2013) concluded that interventions tailored to meet the needs of individual carers were most likely to assist to address the psychological needs of carers of people with dementia.

When a person with dementia is admitted to the acute hospital setting, not only is the admission likely to be confusing for the person with dementia, resulting in behavioural change, but also his/her care may be compromised due to a dementia-specific knowledge deficit among acute hospital staff (Elvish et al., 2014; Galvin et al., 2010). Galvin et al. (2010) found that knowledge was low and so was staff confidence in their ability to care for patients with dementia.

Hospitalisation is also likely to impact upon the needs of the carer as well. The carer can face challenges in adjusting to the new dynamic of 'patient' and 'visitor', as clinicians plan, coordinate and deliver the primary care. This is particularly evident when hospitalisation creates a new tension between efficiency-driven care (Nilsson, Rasmussen, & Edvardsson, 2013b), the person's acute care needs in response to illness and ensuring person-centred dementia care (Dewing & Dijk, 2014). Despite evidence to state that the standard patient-professional relationship needs to be replaced by a 'triad' relationship that includes the carer of

people with dementia (Jurgens, Clissett, Gladman, & Harwood, 2012), this is not always the case. No longer is the carer primarily responsible for the person with dementia, rather they are expected to relinquish their carer responsibilities to nursing and medical staff, who have no existing relationships with the person with dementia or their carer. Carers often have a negative experience with hospital care (Jurgens et al., 2012) and can feel overwhelmed and under-noticed by the system and the teams of clinicians who work within it (Haesler, Bauer, & Nay, 2007).

The aims of this study were to explore the experience of carers of people with dementia through hospitalisation, rehabilitation and transitioning into residential care – findings that are reported elsewhere. Although not the primary focus of the study, the experience of carers while the person they care for is in hospital was repeatedly identified by participants as significant, highlighting how carers prioritised their carer role and how hospitalisation impacted upon them. The purpose of this article is to explore the carer's experience when the person he/she cares for is an inpatient in hospital.

## **Method**

### *Study design*

A descriptive qualitative design using in-depth interviews with a conversational approach was conducted. Family caregivers of people with dementia, who had been admitted to hospital were interviewed about their experience when the persons they care for are in hospital and of the change in their role from primary caregiver to visitor as a result of the hospitalisation of the persons with dementia.

### *Setting*

The setting for this study was a 60-bed geriatric evaluation and management facility that forms part of a health service network in Melbourne, Victoria. The facility focuses on the rehabilitation of older people over the age of 65 years, most of whom have multiple co-morbidities that may include orthopaedic and neurological conditions, respiratory and cardiac problems, malignancies and diabetes. The majority of the patients are admitted from acute hospital settings following an acute injury or event, with the goal of optimising mobility and function and determining future care needs. The average age of patients is 85 years and dementia is a common co-morbid diagnosis. The average length of stay is 23 days and approximately one-third of patients are discharged to residential care. The majority of the remainder return to their previous place of residence, often requiring an increase in services and support.

### *Participants*

The study was approved by the Human Research Ethics Committees of both Monash University and the health network (ID HREC/13/PH/2). Potential participants who met the inclusion criteria of being a primary family caregiver for a person with dementia, over 18 years of age and able to have a conversation in English were initially identified purposively by one of the members (RD) of the research team from the hospital records. The clinical team was then consulted to ensure that there were no reasons to exclude a particular carer from the study, such as poor health or fragile emotional state. The nominated carers were invited to participate and one member of the research team spent considerable time

explaining the study and encouraging the potential participants to ask questions and consider their involvement. It was made clear that participation was entirely voluntary, the results would be anonymous and the findings relayed to the clinical team in that fashion. All the carers who were approached agreed to participate and none withdrew during the course of the study.

After obtaining informed consent, participants were interviewed individually in a private, quiet location within the facility for up to 45 min. Two of the participants brought another relative with them for support and neither had much involvement in the interview. The interviews were digitally recorded and professionally transcribed verbatim. The interviews were conducted using a 'conversational' approach in which the family caregiver's experience with his/her relative (with dementia) transitioning through the hospital system was discussed. Examples of questions used are as follows:

*Please tell me a little about your relative with dementia.*

*How involved were you with your relative's care before hospital?*

*Can you tell me what your experience has been like with your relative in hospital?*

*How has dementia impacted on your relative's hospital experience?*

*How involved do you feel relating to decisions regarding your relative's care?*

*Can you tell me some of the experiences since your relative has been hospitalised?*

*What are the things that have affected your ability to cope during your relative's hospitalisation?*

*What things do you think are most important to discuss about your relative's care?*

### Data analysis

Analysis of qualitative data in nursing research has been conducted in various ways, which have been attributed by Graneheim and Lundman (2004) to diversities in historical perspective and partly to the differing beliefs of the nature of reality that are held by researchers. It is possible to find multiple meanings in any qualitative text and the interpretation will always be influenced by the researcher's background and history (Graneheim & Lundman, 2004). In this study, researcher bias was offset to a degree by the involvement of multiple researchers in the process of analysis.

The digitally recorded interviews were transcribed verbatim and examined for thematic analysis. The audio recordings were initially listened to by all the members of the research team and the transcripts were read and re-read to gain a good understanding of the material. The text was then coded using an 'open coding' technique to compare the differences and similarities of the described events, actions and experiences identified by the participants, looking for patterns and themes as outlined below (Liamputtong & Ezzy, 2005).

In order to analyse the data, each recording was listened to and then each transcript was read right through by each member of the research team several times to gain an overall sense of the content. The transcripts were then re-examined and meaning units (words, sentences or paragraphs containing aspects related to each other) were identified. The meaning units were condensed into shortened versions while preserving the foundation meaning. These condensed forms of the meaning unit were then given a label so that they could be understood in relation to their context. Common threads were then examined and categories and sub-categories identified. The themes were discussed and reflected on by the research team until all members of the team were in agreement.

### Rigour

Guba and Lincoln (2011) describe the application of rigour in qualitative research as having two main perspectives: first the rigour associated with the application of the method and the second related to the salience of the interpretation of results. In order to maximise the consistency of the experience for the 20 individual participants, the same researcher conducted all the interviews in the same room using an aide-memoir for guidance. The nature of the conversational style precludes using the questions in a regimented way; however, they guided the interviewer when the natural course of the conversation slowed. With regard to interpretive rigour, it has been reported that researchers often find that they can lack confidence in their own interpretation of the findings (Liamputtong & Ezzy, 2005). In this instance, to improve interpretive rigour, the researchers constantly referred back to the interview transcripts during the analysis to ensure that the themes reflected the tenor of the conversations that had been recorded. The research team met monthly throughout the research and minutes were taken to record the ideas raised by the participants and the team. After the analysis was complete, these minutes were compared with the themes to check for consistency of analysis and there were no major discrepancies identified.

### Results

Twenty carers of people with dementia, who transitioned through the acute hospital to rehabilitation with a view to placement in a residential aged care facility were interviewed. Carers included spouses, adult children and friends of the persons with dementia, ranging in age from 34 to 92 years, with the majority in the 70s and 80s. There was an even gender distribution including six husbands, eight wives, two daughters, one son, one daughter-in-law and two male friends. Sixteen of the 20 participants were co-residing with the person with dementia prior to the hospitalisation. Interviews lasted between 14 and 43 min and were digitally recorded (mean interview time 25 min).

A strength of this study was the ability to interview a heterogeneous group of caregivers; participants ranged in age from 34 to 92 years and there was nearly equal representation from each gender and different relationships between the participant and the person with dementia that added to the richness of the data.

While the primary findings of this research focussed on the carer's transition from primary caregiver to 'visitor' when the person with dementia required residential care, the experience of carers while the person they care for was an inpatient in hospital is equally significant. Family carers were interviewed about their experiences of their relative being in hospital and how they felt about it. A number of them said during the conversation that it was a relief to talk about their feelings in a confidential and safe space with a person who was not involved in the situation, as they had not had this opportunity previously. Family and friends are not always suitable as confidantes as they are stakeholders who often have an already established view and the health professionals focussed on the care of the patient, whereas the researcher was an independent person with no pre-existing knowledge about the patient or carer and the interview was a safe space. One participant said that it was a relief to be able to talk confidentially about her feelings to someone external and that '*Noone had asked her how she felt before*'. Another who was crying intermittently throughout the interview was asked by the researcher whether she would prefer to stop the discussion. She responded '*No, it's a relief to get this all off my chest*'.

The interview data revealed that the admission of the person with dementia to hospital was a highly emotive and challenging experience, with five core themes emerging. These themes were: (a) feeling helpless and lost; (b) losing control; (c) family support and conflict; (d) feeling undervalued and (e) opportunities for improvement.

### *Feeling helpless and lost*

The admission of the person with dementia into hospital was described as an emotional experience, not just because of the illness or injury that the person with dementia was suffering but also because the carer's role as primary caregiver had been significantly impacted. For carers, their role and responsibilities can account for a significant proportion of their life and when they are not required to perform this role, even temporarily, it can lead to carers feeling helpless, lost and lonely. Several participants described this feeling.

*Well, it's been stressful for me. Well, I sort of feel lost at home by myself. I come up - there's only one day I've missed coming up ever since she's been here, and that's because I was going to come up on the bus instead of driving up, and I couldn't be bothered with that bus and it finished me. But - But you know, no, it's - well, I feel a bit lost at home and things like that [Interview 3(3)].*

*The house is empty. I just don't know what to do with myself. I just feel a bit depressed [Interview9(5)].*

For other carers, despite the workload associated with caring for a person with dementia, they reflected on how they missed the person and their caring responsibilities when the person was in hospital:

*But this was the worst thing. I'd go home and I had nothing to do. [Interview 5(4)]*

*I've been - something's been wrong with me, which I'm not used to . . . Well, I'm lost without her, I'll put it that way. I'm lost without her, even though she couldn't always do a lot of things but she was there. [Interview 1(8-9)].*

### *Family support and conflict*

The primary carer is generally part of a larger family group and commonly other members of the group have their own views on what the course of action should be taken with the person with dementia. In some cases, the caregiver can find comfort in the support provided by family for difficult decisions. In the following instance, a woman in her 80s had been caring for her husband with dementia at home with increasing difficulty over a period of years but when he was admitted to hospital with a chest infection, her sons encouraged her to place their father in residential care. Despite the anguish she felt in doing this, she felt that her sons were there to support the decision and help her with the practicalities.

*Because I think, you know, he has his good days, and I think, oh, you know, should I put [him] there or shouldn't I? And it gets me a bit upset, but they (the three sons) said, well, you know, it'll only be worse when he gets home. They made (the decision) for me and had to talk me into it. But I agree entirely. It's just that I - I just feel terrible doing it, that's all [Interview 14(12)].*

In other cases the carer and family members can be in conflict over decisions made in regard to the care of the person with dementia. One participant decided to take her mother with

dementia home to live with her and her family. However, this was not supported by the carer's husband and there was significant marital conflict about this decision, which was ultimately over-turned.

*It's a different thing when Mum was living with us. He just didn't handle things, and I was between the devil and the deep. I didn't want to - Mum needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly [Interview 19(12)].*

Another participant who was the primary carer for his mother had some disagreements with his sister who lived interstate and felt that he was making the wrong decision about the care of their mother who had been falling frequently and had had numerous admissions to hospital in the previous year.

*One of the problems is I've got an elder sister who lives in Queensland and she only comes down sporadically. Between you and I, and I'll just be honest with it, she's not of much help in the whole situation, even when she is here. To be honest, I prefer that she stay in Queensland most of the time because she has some rather strange ways of thinking that she's helping [Interview 7(6)].*

The decision to place a person into residential care is known to be difficult for many carers and most continue caring at home while they are still able to manage. Enlisting the support of family and friends to help consider all the alternatives is an important step in the process that can trigger guilt, grief and depression in the caregiver (Caldwell, Low, & Brodaty, 2014). Family conflict about the decision-making can augment an already stressful situation for the primary carer (Heppenstall, Keeling, Hanger, & Wilkinson, 2014).

### ***Losing control and feeling undervalued***

Hospitalisation of the person with dementia was also described as a challenging time. Carers may have taken responsibility for all of the caring, believed they knew the person and their needs most intimately and taken responsibility for decision-making; however, when the person with dementia is admitted to hospital, the carer is usually no longer primarily responsible for these things and he/she can experience an acute loss of control. In addition, vulnerable family caregivers can feel disempowered by the health care system, especially when they are not recognised as the expert in the care of their relative and not appropriately included in decision-making (Bauer, Fitzgerald, Haesler, & Manfrin, 2009) or involved in treatment decisions.

*Yes, the only thing I would like to know is exactly if he's been on any new medication, but then I can find that out probably from our own doctor. I'm wondering if our own doctor would probably have information from the hospital, that John has been taking this while he's been in our care [Interview 19(9)].*

Similarly, others described feeling undervalued by clinicians

*That they will not really listen to you when you understand the person better than they do [Interview 10(12)].*

*They're telling her things and she doesn't understand. She says "the doctor's come in and told me this" and she says "I don't know what's going on". She said, "They should be telling you". She said, "My brain's gone", which it has. So I think that's caused more stress, to be honest, because you're thinking to yourself "I'm not being told what's going on" [Interview 2(10)].*

This was a source of frustration for some carers, who felt that even while the person with dementia was in hospital, they could still contribute to care

*... to me, I look at it not as a job but not as a liability either but just to be there and know I can help her a bit. That makes me feel better and I think it makes her feel better having someone around too [Interview 6(10)].*

### Opportunities for improvement

When asked to consider how the process of hospitalisation for the person with dementia could be done better, several participants suggested that there was little improvement needed, other carers suggested a variety of actions that would improve their experience:

*I'm not getting any information from anyone... medical feedback, yes... the medication what she's on and this sort of thing... Honestly, that's the only thing that I think could be improved, I mean, as far as everything else goes, it's ideal. It's perfect [Interview 3(10)].*

*I'd like to be informed more what's happening. You don't get any information. Like, even in here, she's been put in here, but how long can she - no one said that she could stay in here for, you know, a month... until she gets into - moved to a home. We've no idea. We've never spoke to a doctor here. Nobody tells you anything. Of course, I mean, I don't get here 'til about this time every day, and the doctors have gone [Interview 9(13)].*

Another participant suggested that when a person with a carer is admitted to a hospital, clinicians need to also consider the needs of the carer and the dynamics of the relationship between the patient and the carer when planning the patient's care. One wife, who was carer for her husband commented:

*I'm thinking "What am I going to do? How am I going to manage this?" Well really, getting the right information and obviously when - see, they're only working on him and they got to work on the family [Interview 5(21)].*

Health professionals can make incorrect assumptions about the relationship between the person with dementia and the carer, who may or may not be prepared to continue the role that he/she has been playing previously. One carer, who had been in the caring role for a period of years, expressed the concern that she was not going to be able to manage unless the person's condition improved significantly.

*... Well, when they were talking about sending him home, I had the horrors because there's no way I could do any more than what I was doing. So that was a bit of a worry for a few days. You know, I'm thinking "What am I going to do? How am I going to manage this?" and I put - I know I couldn't and that's all there is to it" [Interview 5(8)].*

Another was concerned less about the standard of care, but how her loved one was spoken to, indicating that given his dementia, the staff needed to be more patient:

*But it was just a couple of the nurses that screamed at him so, so, so bad. I do think that they should try to understand the person. They're elderly, you know, even different ones in there, the way they are. Look, I know the nurses have got to have enormous amount of patience. But the way that he was screamed at was terrible [Interview 10(14)].*



## Discussion

The ageing of the population has led to a rise in the incidence and prevalence of dementia in Australia and globally (Australian Institute of Health and Welfare, 2012), bringing with it an increase in the need for support for families in the care of people with dementia in the community. The needs of carers must be considered as a high priority, including emotional support when the person with dementia is in hospital, as the outcomes for patients and their family carers are very closely linked.

When a person with dementia is admitted to a hospital, the focus is on improving the person's immediate health status with standard care process driven and designed to ensure efficiency (Dewing & Dijk, 2014; Nilsson et al., 2013b). For someone who has been cared for at home, the inpatient care process must consider the dyad of carer and patient, as they are often tightly entwined. This study examining the experience of family caregivers when a person with dementia transitions through the health system highlighted the fact that emotional health of carers is not generally well supported by the health service, as the focus of care is understandably on the patient. The carers who coped well with the experience tended to be more pragmatic or had good support from family and friends to cope with decision-making and the experience of relinquishing care to the hospital staff. Others found that conflict within the family augmented the difficult decision-making experience and contributed to the mixed emotions that they were feeling.

Participants in this study reported that it was essential for them that they felt that their relative was being cared for empathetically and that the staff understood their needs while they were in hospital, a finding reflected elsewhere (Dewing & Dijk, 2014; Jurgens et al., 2012). Having previously provided most of the care themselves, they had a high emotional stake in the patient's well being. The carers were often used to making the decisions and doing most of the cognitive work for the patients and they worried that the patients might be misunderstood or neglected without the carer present to speak for them. A number of carers mentioned that the clinicians didn't seek their opinion about the care of the patient although the carer considered himself/herself to be expert in the care of that patient.

The viewpoint of family carers, health professionals and the patient have been demonstrated in previous studies to be frequently divergent, with the family carers focussing on emotive issues, the patients generally wanting to maintain independence and the clinicians concerned primarily with patient safety (Denson, Winefield, & Beilby, 2013). The needs of the carer have not been adequately considered in many instances and it has been identified in this study that emotional support during the hospitalisation of the patient is a neglected area.

## Conclusion

The hospital care of people with dementia, who have previously been supported by their families at their homes, is complex. The patients generally have cognitive difficulties that preclude them from independent decision-making and they may have a reduced understanding of the situation. Family carers, especially older spouses, have a high-stake interest in the outcome of the hospitalisation, both for their relative and for themselves, as their situations are closely linked.

Family caregivers have few opportunities to talk freely about their feelings about the patient's care and how the hospitalisation affects them personally. It is important that they are well supported and given the opportunity to talk about their issues in a safe space.

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### Conflict of interest

None declared.

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**Kimberley Crawford** is involved solely in research within the School of Nursing and Midwifery at Monash University. She has a strong scientific background, commencing her research career in the laboratory investigating proteins related to the development of the pregnancy-related disorder, pre-eclampsia. Her current role at Monash University involves developing nursings' research capacity with a focus on chronic illness and medicine adherence. She has experience with quantitative, qualitative and mixed method research methods.

**Heather Tan** has a strong background in grief and bereavement counselling, spiritual care in the healthcare context and qualitative research involving particularly vulnerable people such as palliative patients and their family members, aged people and their carers and other end-of-life issues. She is currently the Manager of Education and Research for a peak organisation focused on the integration of spiritual care into the healthcare system.

**Allison Williams** is committed to quality research that will ultimately improve the lives of people and their families. Her research interests are in chronic illness management and reflect priorities in terms of patient well-being and safety. Her scholarship is person-centred, and is characterised by a strong commitment to engagement with interdisciplinary teams and consumers to improve practice.