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“They rush you and push you too much... and you can’t really get any good response off them”: A Qualitative Examination of Family Involvement in Care of People with Dementia in Acute Care

Abstract

Aim To explore the role and needs of the family carer across different acute care contexts and their level of involvement in the care of their relative with dementia in this setting.

Method A pragmatic, exploratory-descriptive qualitative approach. A convenience sample of 30 family carers across three sites completed semi-structured interviews.

Results Family carers want to be involved in the acute care of their family member with dementia. They acknowledged the importance of a central source of information, educated staff, guidelines on roles and processes, positive communication, as well as respect from staff for the carer’s knowledge of the older person and their needs. They also highlighted the need for medical staff to discuss with them the family member’s treatment and care.

Conclusion There is a need for family focused interventions to improve communication and involvement of family in the care of family members with dementia in the acute setting.

Keywords: dementia, family caregivers, hospital services, qualitative research, relationship centred care

Introduction

The need to deliver high quality services for the growing number of older people with dementia and their carers poses a substantial challenge to acute care systems. An estimated 298,000 Australians had dementia in 2011 and, based on projections of population ageing and growth, this number will reach around 900,000 by 2050 [1]. As a result the number of people with dementia requiring acute care will continue to increase and it is imperative that we have a healthcare service that works for all involved.

It is clear from the literature that questions remain regarding the management, needs and preferences of people with dementia in acute care [2]. Care of the older person with a confusional state presents acute care staff with special challenges, in particular the management of behavioural and psychological symptoms of dementia. Such behaviours add to the challenge of caregiving and can result in the use of physical and chemical restraint [3]. Given the potential of family carers to enhance the care experience of the person with dementia, improving our knowledge of family carer involvement during an episode of acute care hospitalisation is a priority.

Family involvement in the care of people with dementia can result in a reduction in hospital readmission, shorter hospital stays, and greater satisfaction with the healthcare experience [4]. Developing a quality acute care service for people with dementia requires an understanding of the views of key stakeholders. This paper explores the role and needs of carers whose family member with dementia was cared for within one of three major acute hospitals in Australia.

Method

The study used a pragmatic, exploratory-descriptive qualitative approach [5]. Participants were English-speaking primary family carers (spouse, family member, partner or friend) of a person with a confirmed or suspected diagnosis of dementia who had been admitted for medical or surgical intervention or assessment in the Emergency Department. Key personnel in each setting identified family carers who met the inclusion criteria relevant within each site. An information sheet explained the study and written informed consent was obtained. Ethical approval for the study was gained from participating hospitals and associated university human research ethics boards.

Thirty family carers who were directly involved in the care of their relative with dementia in one of three large acute care hospitals in Australia participated. To encourage maximum variation in the narratives, participants were interviewed at different stages of the acute care continuum and within different contexts of acute care. Interviews took place in:

- Queensland during hospitalisation in either the acute delirium, surgical or medical wards (11 participants)
- Tasmania as close as practical to a presentation to the Emergency Department, either in the ward setting if the person had been admitted, or in the community within one week of discharge if the person returned home (9 participants).
- Victoria as close as possible to the day of discharge or within one week of discharge following a surgical or medical intervention (10 participants).

Qualitative Interviews

Individual semi-structured, face-to-face, digitally recorded interviews with the family carers focused on five key areas (see Table 1).

Data Analysis

Interviews were transcribed verbatim. Although participants often spoke more broadly than the research focus, the analysis focused only on the data that was relevant to the acute care experience. A purposeful analysis of the interview transcripts by research questions followed the process of becoming familiar with the data through reading the transcripts, generating initial codes across the whole data set, identifying themes from the codes, checking, discussion and renaming of the themes [6].

Findings

The following sections present the findings in relation to the specific areas of interest.

Family carers' role

Carers reported that their main role was to provide emotional, and to a lesser extent physical, support. This could be in the form of providing reassurance and familiar presence, talking to and taking the patient for a walk. For example, one carer stated, “*Visiting her. I’ll take her for a walk and that. Sit and talk to her and keep her happy.* (QLD husband, 87 yrs).” Carers believed these activities helped the person with dementia to feel cared for, reduced psychological distress and provided social stimulation, and, as a result, relieved their boredom and loneliness. Some carers also reported they liked to carry out personal care, such as feeding, bathing, and bringing clean clothes for the person. In the Emergency Department carers talked about their additional role orientating the person to the hospital and ensuring their basic needs were met, such as the location of toilets and access to drinks. In addition to providing this support, carers also perceived their role was to liaise with the medical practitioners and, in particular, to inform them of the person’s social and medical history. One carer stated, “*I think our main role is to actually liaise with the doctors as Mum has no*

recall of memory. Basically, just to inform the staff of what I know about her care and [what] her needs are. Then for them to follow on as best as they can. (QLD daughter, 54 yrs)."

Carers also reported that their involvement was important to make sure that the person received the best care and the staff appropriately looked after them.

Family carers' needs

The needs of family carers related to a need for information, being valued as part of the team and the need for psychological support.

Information. A majority of the carers indicated information as the highest priority need for them, in particular as the person with dementia was often unable to relay information that had been discussed when the carer was not present. Carers reported that they needed to be kept updated in regards to the person's medical condition and their plan of care and discharge. For example, one carer stated that, "*Information. That's the big thing. We need to know that information just to see how she is, her mental health, plus her physical health, her medical health. (QLD, daughter, 53 yrs).*" Across the three settings, most carers felt that they received limited information, which led to feelings of confusion, tension, and uncertainty. One carer (VIC, son, 37 yrs) spoke of his disappointment and frustration with the limited information he received from the medical staff, "*I believe the information is sketchy. It's just nowhere near enough. They're introducing new tablets. They're introducing new medicine. There's been very rare consultation, explanation why, zero. Very disappointing.*"

Access to information was made more difficult by a perceived lack of access to the medical staff. Carers expressed frustration, as they were not informed of the time the doctors did their rounds, and therefore they found it difficult to coordinate a time to speak to the doctor.

However, even when there was time the doctors appeared to be in a hurry and rushed the conversations. As one carer said, *“Always in [a] hurry. And there’s things you want to ask but they rush you and push you too much and you can’t really get any good response off them. (TAS, son, 55 yrs).”*

Carers emphasised the importance of having one central source of information. The busy environment of the hospital was confusing and overwhelming, and the constant staff shift changes made the two-way flow of information even more challenging. However, carers who stated that they received information also noted that the doctors provided information in complicated medical terms that they were unable to comprehend. One carer stated, *“I am an engineer. All these medical terms mean nothing to me. (VIC, husband, 90 yrs).”* Carers therefore felt unable to inform other family members and friends of the condition of the person with dementia. Prior to admission to the acute care setting the carer perceived they were the advocate for the person. The lack of involvement in regards to information sharing had taken this advocacy role from them.

Being valued as part of the team. Carers wanted to be seen as a team member. Being part of the team meant being valued as a source of information. They expressed their disappointment and frustration that medical staff often did not acknowledge the importance of the carer’s role in information gathering. The following quotation is typical of many of the carers, *“I am no medical practitioner. I am no expert but I am caring for this person, I’m living with the person. I know exactly when this person starts hallucinating (VIC, son, 37 yrs).”* Many carers also believed that if they were included in the information gathering process, staff would get more reliable and personalised information, and a lot of potential problems could be anticipated, and in some cases prevented. Many carers reported that they enjoyed feeding,

bathing, and taking the person for a walk, and saw it as a way to spend quality time with them. As the main carer before hospitalisation, carers felt the need for their involvement to be acknowledged. Carers also expressed a need for information about their role expectations, as they were often unclear about what was expected of them in the acute care of their family member. Some just *‘improvised’* and *‘copied what other family carers did’*. Role ambiguity hindered carers’ involvement and created tension between the staff and carers when there was a misunderstanding about each other’s role. For example, one carer said *“They said please leave the room when providing care... I was really only trying to help them.* (TAS, daughter, 58 yrs).”

Psychological support. Carers often found the hospitalisation of the person with dementia to be a distressing and exhausting experience when they were already often feeling vulnerable as a result of their ongoing caring role. However, the psychological needs of the carers are usually sidelined as the main focus is on the patient, although some carers felt that the psychological needs of the person with dementia also received minimal attention from staff. Carers reported that it would be helpful to have someone to talk to and to support them emotionally throughout the journey.

Needs of the person with dementia

Meeting psychosocial needs. Carers commented that the acute care setting can be *‘boring’* for the person with dementia and meeting the person’s need for companionship and social interaction rested solely on the family carers and visitors. To complement their involvement, carers suggested that the acute care team should organise activities for patients in the unit. They also spoke about how helpful it would be to have psychologists, diversional therapists

or volunteers look after the person's psychological and social needs. As one carer said, *"Mary, I think she is a diversional therapist. She was very much able to attend to those emotional needs. She got him doing activities; she started music therapy, or got him listening to music and things like that to help settle him. (VIC, daughter, 33 yrs)."*

Being valued as a person. Carers expressed the need for medical staff to value and treat the patient as a person, rather than a medical diagnosis. Carers really appreciated it when the staff showed genuine interest in patients and interacted with them in more personalised ways. For example, one carer said, *"It was not just a patient. It was the interest towards him... They had a bit of fun with him and enjoyed it. (TAS, son, 55 yrs)."* This person centred approach helped the carers feel more relaxed because they felt that their family were under the care of people who cared about them.

Increasing effective family involvement

Carers talked about the importance of guidelines, staff education and access as potential strategies to increase their effectiveness.

Guidelines. Most of the carers thought that information or guidelines to help them navigate the processes from admission to discharge was needed. Guidelines could include orientation to environment, the roles of the parties involved in care, the stages of the hospitalisation process, and the role expectations of family carers at each stage. As an example, one carer explained, *"Just a set of guidelines to say, okay, a family member with dementia is in here. This is the expectations. This is the role of the staff. This is their expectation of you... and where everything fits in. (QLD, son-in-law, 60 yrs)."*

Staff education. Carers described dementia as a condition unique to each individual and the need for special attention when providing care. Some commented how staff (especially those outside of the aged care ward) had a poor understanding of the condition and therefore failed to provide appropriate support. As a result some staff made insensitive comments. They suggested all staff should have a general understanding about dementia and of how to care for people with dementia, “*One of the most important things I see is that all staff know what dementia is, and what are the problems involved, and what are the behaviours involved.* (TAS, daughter, 57 yrs).” Such comments suggest that the family carers’ confidence in the expertise of health professionals is important in promoting a collaborative relationship.

Hospital access. For carers who were themselves older and frail access to, and therefore involvement in, the acute setting, could be problematic. Some carers commented on the long walk to the ward and difficulties they had to find parking when they visited. A good service and infrastructure in the hospital was seen to help carers’ life and reduce unnecessary stresses.

Discussion and conclusions

This study was undertaken across three settings and with a wide range of participants. The study uncovered concerns that, with targeted interventions, could improve family involvement in acute care. The study is limited by the focus on the views of the family carer; however the majority of people with dementia were too ill to participate in the study.

The study supports the findings from previous research that indicates family carers believe that hospital staff remains unaware of the needs of the older patient with dementia and indicates the need for staff to partner with family in care provision [7-10]. In truth, family are

often focused on caring and can be fearful of leaving loved ones in hospital because of well-publicised risks, such as medication errors and malnutrition, and of their developing untreated delirium that inevitably leads to greater dependency by the time of discharge [11].

Overall the family experiences were highly critical of the acute situation and one of the most enduring themes was poor communication and information sharing. Part of being responsive to another person is to listen; this requires attending to that person and attempting to understand the message being given [12]. Staff education and training focused on relationship centred care [13] is needed to reduce misunderstanding and conflict. Furthermore, medical staff should take a person centred approach to care.

Carers felt they had an important role in advocacy, companionship, support and information sharing. They perceived they had invaluable insight into the needs of the person with dementia and despite sharing this information with the healthcare staff, they often felt they were excluded from decision-making and discussion on prognosis, especially when the person with dementia was unable to accurately recall information. When carer knowledge and insights about the person are used by staff meaningful timesavings can occur [14,15] and it would be prudent for staff to pay attention to this.

When carers identified gaps in care or observed poor clinical practices, they stepped in and provided the individualized care themselves. In each case where this occurred, the carer reported feeling their contribution was not valued by health professionals, which, as recognised by others, can make for a difficult and sometime tense relationship [7]. The carers were relieved and appreciative when involved, but disappointed when they thought that they were not understood and neglected. It is important that a team culture of active relationship

building and collaboration with the carers is developed, one where there is a sharing of information and support [16,16]. Establishing a clear expectation of each party's role could prevent any misunderstanding. The suggestion of simple guidelines and one central source for providing families with information may offer opportunities for settings to implement and trial. This provision of practical information for carers will help to promote more active and effective involvement of family carers in the acute care setting and at the same time demonstrate a valuing of families in care provision.

Carers also expressed the need for emotional support as they can experience high levels of emotional distress [18-20]. Health care professionals often fail to recognize that older carers may be vulnerable to the stresses of providing care [10] and yet this understanding is critical if the family are to receive the support they need [21]. Providers of formal services such as acute services may be another source of emotional support for carers when they offer, in addition to practical help, much needed 'human contact' to carers who are often socially isolated [22].

Older people with dementia are most likely to be cared for by other older people, predominantly spouses, who will be at increased risk of stress-related health problems themselves. The carers' concern about getting to the hospital and to and from a car park that is often at a distance from the ward is a reality that should be considered with access taken into consideration alongside an ageing population. Improving the quality of the hospital's infrastructures by providing handrails, drop off areas that are close to the entrance, seating and designated parking areas may help carers to be more involved in the care of people with dementia. Volunteer drivers using golf carts for example, may also assist with getting family to and from the car park while furthering a positive human contact experience.

Finally, the need for health professionals who work with older people to be better educated about dementia and dementia care has been previously reported [23,24] and this remains a priority area in need of further improvement. According to the Alzheimer's Society [25], only one in five nurses receives any level of dementia training, but carers tend to assume that nurses know more about the subject than they do. The Australian Dementia Training and Study Centres have the task of health professional dementia education and their recent focus on acute care may well improve the current situation.

Key Points 3-4 key points

- Family carers want to be involved in the acute care of their family member with dementia.
- Information sharing, communication that uses lay terms, guidelines to inform roles and processes that values the person with dementia and the family carer role may support family and the patient.
- Set time is allocated for family carers to meet with medical staff.
- The time is ripe for targeted family involvement in care interventions to improve acute care of older people with dementia.

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