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Dementia published online 8 June 2011

DOI: 10.1177/1471301211407790

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Dementia

0(0) 1–7

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DOI: 10.1177/1471301211407790

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Abstract

This study reports on the experiences of 25 family carers of the hospital discharge planning process for their family member with a dementia. Analysis of the data indicates that the needs of family carers were not always addressed in the hospital discharge process and that discharge planning and execution is in need of improvement.

Keywords

dementia, discharge planning, family, hospital, older person

Background

The rapidly growing elderly population and the decreased number of inpatient bed day stays, along with the increased acuity and complexity of in-patient care, means the importance of assisting the transition of people from hospital back home, or to an aged care facility, has grown (Cummings, 1999). In the case of people with dementia, the discharge practices of hospitals have become critical in preparing family carers to receive their family member back into the community, or to assist the transition (or return) to long term care.

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An investigation of discharge planning by the Australian Health Care Agreements Reference Group (2002) showed that the discharge planning process continues to vary markedly from hospital to hospital and that there is general dissatisfaction with the quality of discharge planning. Cummings (1999) has noted that a sizable proportion of patients with dementia are discharged without adequate aftercare plans which causes them to be at a greater risk of readmission to hospital. Inadequate communication on the part of health care professionals, insufficient information sharing (Naylor, Stephens, Bowles, & Bixby, 2005), and the absence of adequate emotional support in response to the pressures associated with discharge of the patient from hospital (Weber & Bailey, 2005), are problems frequently cited by family.

Health professionals' assessment of the families' willingness and ability to undertake the caregiver role, including their needs for material, educational and other support services, are critical elements in the overall success of the discharge planning process (Cummings, 1999; Naylor et al., 2005; Renbarger, 1991). Family care givers express an acute need to be more included in the hospital discharge planning process and report that they have little involvement in the decision-making process for the discharge of their family member (Cox, 1996). Nay, Fetherstonhaugh, Pitcher, Closs, & Koch (2004) found that in the transition from hospital to family care of the frail elderly including those with a dementia, caregivers had several pre-discharge needs that included information on the older person's health condition, education on the medications being taken and symptom monitoring/management, help with the mastery of personal care skills and care delivery, emergency management, how to handle the person's emotions and manage their compliance with care, how to set up continuing services and emotional and 'manpower' support.

The evidence suggests that a continuum of care model, where the discharge process commences on admission and continues throughout the hospital stay and beyond is a good model to assist caregivers, yet no evidence has been identified that caregivers currently experience this type of discharge planning for a family member with dementia (Australian Health Care Agreements Reference Group, 2002).

A review of the literature shows that little research has examined the discharge needs of patients with a dementia and their family carers (Bauer, Fitzgerald, Haesler, & Manfrin, 2009) and even less has considered the complexities of hospital discharge for this group and how the quality of the discharge process impacts on the ability to care after discharge.

Aims

This study sought to explore the question of whether caregivers who take the responsibility for caring for a family member with a dementia receive, as part of the hospital discharge planning process, the physical and psychosocial support they need to continue their caring role. This paper reports on one aspect of this study, namely family carers' perceptions of hospital discharge planning and preparation.

Method

A qualitative research design was used to explicate the views of family members. Twenty-five principal family carers of people with a dementia were recruited by means of a flyer displayed at hospitals, the same flyer mailed to family who were members of Alzheimer's Australia (Victoria), and referral by hospital staff. Family members who consented to participate were

interviewed about their experience of the preparation for and execution of hospital discharge, within six weeks of the patient being discharged from the hospital. Patients had been discharged from both metropolitan (public and private) and rural hospitals in Victoria, Australia, back to home-based care, as well as to residential aged care facilities. For a few families, it was their relative's first admission to a residential aged care facility. Interviews were semi-structured and took between 20 and 60 minutes. The study received ethics approval from the university and participating hospitals where recruitment occurred.

A constant comparative method of thematic data analysis (Lincoln & Guba, 1985) was used to explicate issues. This inductive approach develops theoretical propositions that accurately reflect the participants' views on the topic. The study aimed for in-depth understanding of the issues rather than generalizability to specific families or hospitals.

Results

An analysis of the data indicates that the needs of family carers of people with a dementia who participated were frequently not being met, and the discharge practices of nurses and other health professionals is in need of change. Common concerns relating to the discharge planning and preparation for older people with a dementia and their family prior to discharge that were identified include:

1. Family carers perceived discharge planning to be *ad hoc* and in some cases a discharge plan was not apparent.

A couple of times I went in [to hospital] and her suitcase was packed and she was going home that day and then it changed. They couldn't get the timing right obviously, so she stayed an extra day and an extra day...there was no discussion really. (Husband)

We only ever found out [about discharge] because my brother was there one day and one of the nurses said, 'Oh, she'll probably be going home tomorrow'. (Daughter)

I was told that I'd be given 24 hours notice before she was coming home...because I thought I had 24 hours I made an appointment for myself. I got rung up on the day and they said 'Well, can you come and get her now?' I said, 'I've got an appointment myself'. I thought that was settled until the following day and then they rang me up in the middle of the appointment again and said 'Can you come and get her?' I said 'No, I'm sorry, we've already been through this. I'll pick her up first thing tomorrow morning'. So the next day we went off and got her. It seemed a bit odd...I saw one of the nurses who said 'Well, she's ready to go'. I was a bit surprised that nobody spoke to me. It wasn't till later that night when I took her pants off that I realized she had a huge hematoma on her right leg... now nobody said anything to me... we're still having repercussions from that... This was one hell of a thump. She's got a lump the size of an egg a month later you know. I was upset that she was sent home like that. (Daughter)

2. Information that family carers identified as important to their role was often not provided.

I need to be kept informed when she's in hospital... kept informed about what's happening. Kept informed if there are any ideas that maybe she won't be able to continue the kind of care that she's been getting and those sort of things. (Daughter)

It's a fabulous facility, it's a beautiful hospital. But I was never told that there was a little quiet room where we could have gone and have a chat. (Husband)

3. The family carers' expectations of communication by nurses and other health professionals about both the care received in hospital and the care needed after

discharge, frequently fell short of what they considered necessary to meet their caregiver role.

Sometimes it was a bit frustrating to try and find who's looking after her and where is that person... unless you actually caught somebody at the bedside, we didn't have a lot of information. (Daughter)

I would have liked to have one person I could go to. They [the hospital] didn't have anybody that I could just say well, I'll ask the question of this person... I just didn't get the communication happening... (Husband)

I suppose if I'd really wanted to ask something they would have helped me... but they certainly didn't come to me and say, 'Now this is what is happening'. (Wife)

4. The care provided to patients with a dementia in hospital frequently did not meet family members' expectations and there was limited engagement of family by health professionals in planning both hospital care and post discharge care.

I must have gone out to the toilet or to get a cup of coffee or something and somebody from the Aged Care Assessment Service had come to see her and decided she needs to be in residential care. She shouldn't be in a hostel (assisted living facility), but that discussion didn't take place with me, which I think it should have, particularly as I was there. People knew I was there, my stuff was still in the room that she was in. (Daughter)

... you really need family there to articulate what's going on. She can't advocate for herself, or explain you know. She can't say, 'I'm different to normal', or if she's more agitated, or normally this drowsy. (Daughter)

Discussion

The inadequate levels of hospital support for family members of older patients, including those with a dementia, which have been highlighted in past research, are reflected in the present study. The family carers that participated in this study frequently perceived the discharge planning in hospital to be ad hoc, and information, communication and care standards they expected were often not provided. A coordinated and team approach to discharge was often not apparent and in some cases there appeared to be no discharge planning or preparation evident. There was often insufficient consideration given to the needs of the family both in hospital and post-discharge. As a result of their experience, many of the family carers interviewed held negative views about the hospitals where their family member was treated.

Although dementia is now an important health care issue and in Australia has been identified as a national health priority (Department of Health and Ageing, 2008), this and other research (Douglas-Dunbar & Gardiner, 2007; Hegney et al., 2002) has been consistent in the finding that family carers believe that hospital health care professionals, including nurses, remain unaware of the needs of the older patient with a dementia. Family carers themselves can experience considerable anxiety about the reasons for their relative's hospitalization, the progress of the illness including prognosis, and the eventual discharge arrangements (Bradway & Hirschman, 2008; Proctor, Morrow-Howell, Albaz, & Weir, 1992). Health care professionals often fail to recognize that older family carers themselves may be vulnerable to the stresses of providing care (Douglas-Dunbar & Gardiner, 2007; Grimmer, Moss, & Falco, 2004) and yet this understanding is critical if the family are to receive the support they need.

Poor communication and information sharing between health care professionals and family remains an enduring theme in this and other research which has examined the role of the family in the hospital setting (Haesler, Bauer, & Nay, 2007). Communication forms the basis for effective discharge planning and it is the role of the health care professional to inform family carers about discharge processes and empower them to participate in the discharge plan (Department of Veterans' Affairs, 2005; Douglas-Dunbar & Gardiner, 2007). Equally, it is the role of the health care organization to encourage family centred care through the provision of appropriate education and support to its staff (Fisher et al., 2008). To take into account the special needs of older people, hospitals must have formal policies on discharge planning and preparation which are specifically aimed at this group (Clark, Steinberg, & Bischoff, 1997) and the family carers.

Good discharge planning focuses on the continuity of care and supports both the patient and the family carer, by recognizing that family are integral to the development and execution of discharge plans (Department of Veterans' Affairs, 2005). While hospitals have a responsibility to discharge people in a way that ensures there is continuity of care, this research showed this is not always the case. Family carers have a great deal of insight into the needs of the older person with a dementia and discharge practices should recognize the unique knowledge that the family have at their disposal and involve them in the discharge plan.

A number of discharge planning principles which have been identified as essential for each episode of hospital care and beneficial for older people and the family carer (Bauer et al., 2009; Hedges, Grimmer, Moss, & Falco, 1999) include:

- ongoing and effective communication between family, health care professionals and community health services;
- a collaborative and multidisciplinary approach to planning discharge;
- a designated person to ensure that all stages of the discharge plan are fulfilled;
- commencing the discharge plan on, or even before admission;
- consulting and sharing information with the patient and family carer throughout the planning process; and
- ensuring that the discharge is timely and linked to appropriate support services in the community.

Discharge planning should be a routine and integral part of hospital health care; however, the indications from this research are that hospitals are yet to realize best practice with regard to the discharge of older people with a dementia and their family, and that in some cases discharge planning is considered to be ineffectual.

Conclusion

Hospital health care professionals, including nursing staff, should be aware of the needs of older people with a dementia and their family carers. An awareness of how the execution of the hospital discharge plan is perceived by the principal family carer of the person with a dementia will allow health professionals involved with the discharge process to better reconcile the family caregivers' needs and expectations with the discharge process. An important aim of discharge planning is to facilitate a positive transition from hospital to residential, or home-based care. If this is poorly executed, family carers will become disappointed with the standard of health care delivered.

Limitations

It cannot be concluded that the views expressed by the 25 participants in this study will be shared by other family carers of a person with a dementia that have experienced hospitalization. The participants in this study all volunteered and agreed to share their experiences. This could be a form of 'elite bias' where only those family members who wanted to convey problems with the discharge experience agreed to participate in the study (Sandelowski, 1986). However, given the consistency of views that were expressed about hospital discharge planning and execution and the consistency of the findings with previous research, the study suggests that the issues raised are indeed significant ones that warrant serious consideration by hospital administrators and health care staff alike.

Note

1. This project was funded by Alzheimer's Australia Research.

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Dr Susan King was a research officer on this project. Her research has focussed on the experience of chronic illness from the individual and carers' perspectives, including people diagnosed with motor neurone disease, Type 1 diabetes and anorexia nervosa.