

Relatives may notice inadequacies in care when a relative with dementia is admitted to hospital. This study gathered views of carers to indicate how care can be improved

# Improving acute care for patients with dementia

## In this article...

- Risks and outcomes of patients with dementia in acute care
- How patients with dementia can be challenging for staff
- Areas in which hospital care can be improved

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People with dementia are more likely to experience a decline in function, fall or fracture when admitted to hospital than the general hospital population. Informal carers' views were sought on the care their relative with dementia received in hospital. Participants were concerned about a lack of essential nursing care, harmful incidents, a decline in patient function, poor staff communication and carers' needs not being acknowledged. Care can be improved through further training, more effective communication, consideration of the appropriate place to care for people and more use of carers' knowledge.

Two thirds of people with dementia are still able to live in the community, while the remaining third live in care homes (Alzheimer's Society, 2007). For those living in the community, care is usually provided by informal carers who experience high levels of stress and physical illness as a result (Mannion, 2008).

Dementia is a generic term indicating diseases that involve a loss of cognitive function. Approximately 850,000 people live with dementia in the UK (Knapp et al, 2014). Age and vulnerability mean that they are more likely than the general population to be admitted to hospital. Admission to hospital can be a frightening and stressful experience; research has shown that, compared with other patients, people with dementia have added risks and poorer health outcomes (Box 1).

## Literature review

A broad search of the literature revealed that well-designed primary research on the subject of dementia care is scarce, particularly for non-specialist hospital environments.

Professionals caring for people with dementia have reported finding it challenging and feeling they cannot always care for patients in the way they would like; they feel the hospital environment is not appropriate for these patients and that their ability to provide person-centred, dignified care is sometimes compromised by safety issues (Borbasi et al, 2006; Boaden, 2016; Nolan, 2006). Research by Fukuda et al (2015), Gandesha et al (2012) and Alzheimer's Society (2009) found that nurses in general hospital wards did not feel adequately trained to care for patients with dementia.

The limited studies that investigate the patient experience describe hospital admission as distressing, with staff often unable to provide optimal care (Boaden, 2016; Cowdell, 2010; Alzheimer's Society, 2009; Norman, 2006). In research, informal carers consistently expressed concerns about their experiences of hospital care and reported significant physical and psychological stress as a result of caring for someone with dementia (Cascioli et al, 2008; Mannion, 2008; Douglas-Dunbar and Gardiner, 2007).

## Aim and method

I decided to research the experiences of people with dementia when in hospital by exploring their carers' views about the care that their loved ones received when admitted to hospital.

I used a qualitative approach involving simple, semi-structured interviews.

## 5 key points

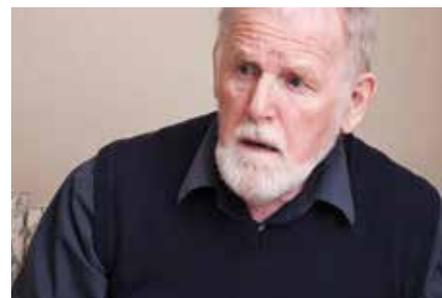
**1** Demographic changes mean the number of patients with dementia in hospital is increasing

**2** Informal carers have a wealth of knowledge – nurses need to gather information from them about the best way to care for patients

**3** Nurses in general hospital wards often do not feel adequately trained to care for patients with dementia

**4** People with dementia are more vulnerable than the general hospital population

**5** Dementia care can be improved through training and better communication



Memory problems can hinder patients' ability to communicate their care needs

Participants were recruited in three ways. Local carers' organisations sent out letters to potential subjects, I attended a local carer support group and leaflets were left in a local day centre. Inclusion criteria are outlined in Box 2.

Interviews were conducted from January to June 2009, transcribed, and all data was anonymised. Once transcribed, a thematic analysis was completed and common themes identified. Study findings were completed in 2010. Although family commitments led to a delay in publication, the Francis report in 2013 and an increased national awareness of the issue of dementia made me realise the continued relevance of this research.

## Results and discussion

The seven interviews – in participants' homes – took 45-70 minutes. One carer had cared for two relatives with dementia and so the data relates to eight patients.

### Patient wellbeing

#### Actual or potential harm

Five participants described incidents in which their relative came to actual or potential harm while in hospital. Two described how their relative escaped from the ward, one getting as far as her home, while one carer recalled how her relative was not supervised properly:

Carer 3: "She seemed to be able to wander in the hospital and go and do what she liked."

In another incident a patient had a fall while on the ward. Participants felt that incidents such as these indicated a lack of supervision and awareness that people with dementia are unable to protect themselves. Two patients contracted a hospital-acquired infection during their stay.

#### Losing property

Three participants described how property went missing during their relative's stay. Dentures, spectacles and slippers were lost, which affected patients' ability to eat and mobilise safely:

Carer 6: "At the end of the day, if she's not got her bottom teeth, she's not going to eat because she can't chew, but there was no consideration for that."

Most of the patients were too unwell to monitor their own possessions; when these are lost they can be difficult to replace and are another source of stress for carers. Such incidents were directly linked with ward moves, and left participants with the impression that their relative was not being cared for adequately.

## BOX 1. RISKS/OUTCOMES

Compared with the general hospital population, patients with dementia are more likely to experience:

- Delirium
- Incontinence
- Pressure ulcers
- Inadequate nutrition and hydration
- General functional decline

(Boaden, 2016; James and Hodnett, 2009; Borbasi et al, 2006).

Patients with dementia also have a two-to-threefold risk of falling compared with people who are cognitively healthy, and are three to four times more likely to sustain a fracture (Härlein, 2009).

### Decline in patient function

Five participants (71%) mentioned feeling that their loved one declined while in hospital, a finding that correlates with previous research (Alzheimer's Society, 2009; James and Hodnett, 2009; Cascioli et al 2008). The participants also seemed to feel an assumption was made that their loved one would not be able to walk, eat or get to the toilet unaided and therefore were not encouraged to do such activities:

Carer 6: "They were feeding her to begin with and there was no need for that. I told them: 'No, she can eat, she's fine'."

Two participants felt patients were not encouraged to mobilise and that the hard work they put in at home to keep their loved ones active was lost when they went into hospital. Three participants stated that staff did not speak to them to discover what their relative could do and had low expectations about people with dementia.

### The wellbeing of other patients

Participants described how their relative's behaviour affected other patients on the ward: some got into other patient's beds, took their property, tucked patients into bed and sang all night. They felt such actions could be stressful for other patients, many of whom may never have had experience of dementia.

Carer 3: "Some found her strange. She bemused them because she would start folding their clothes for them and put them away, interfering with what was going on."

Two relatives had been upset by comments or complaints made by other patients: Carer 7: "They said that she was wandering, tucking some of the patients in, and one patient had complained."

## Staff knowledge and nursing care

### Essential care

All participants could recall occasions when the essential nursing-care needs of their relatives were not met in a timely manner during their hospital stay. These included attention to hygiene and nutritional needs, slow response to call bells and leaving food and medicine in front of patients.

Participants noted that:

Carer 1: "They would leave his medicines in a pot and not oversee that he took them."

Carer 3: "She just wanted to go to the toilet and they didn't come when she rang."

### Dementia knowledge

During the interviews it became clear that participants felt some nursing staff did not have adequate skills or knowledge to manage the care of patients with dementia on the wards. Some staff treated them in the same way as other patients and did not seem to recognise that they have different needs and vulnerabilities. Three participants mentioned feeling that nursing staff wrote people with dementia off more quickly than other patients:

Carer 5: "When they are dealing with mental illness, they think they are dealing with ignorant people. He was a marvellous mathematician and had a very good job."

Despite criticisms of nursing care and management of the patient's behaviour, 85% of participants were quick to acknowledge pressures such as staff shortages and the needs of other, acutely ill patients. They had a great insight into the complexities of caring for those with dementia and had a lot of sympathy and understanding for staff, even when critical of care:

Carer 6: "You've got some nice nurses and they got her better. I just think they are busy and haven't got time for individuality."

Carer 3: "It's a lot for the hospitals to take on, dementia, a hell of a lot, and I understand where they are coming from."

### Good care

The participants were able to identify care they felt was more positive – for example, one mentioned that consistency of care was good when their relative was sent back to a ward he had been to previously:

Carer 1: "They decided to put him on the same ward as before as they had experience of him. I felt he was welcomed by staff."

Two participants mentioned care that went deeper than essential care and could be viewed as nurses' attempts to provide a more person-centred approach:

Carer 1: "They did try to meet his individual needs, for example, letting him go into the office as he has been accustomed to working in an office, and getting him a newspaper."

### Communication issues

People with dementia are often unable to give accurate information due to memory problems, and it is important for carers to receive feedback from hospital staff. Five participants felt frustrated by the level of information about their relative they were given by hospital staff. Some encountered problems speaking to the right person, others felt they were denied information because of confidentiality.

Another issue was the way in which poor communication seemed to affect patient care. Participants were not asked about their relatives' individual needs and capabilities and, in some cases, nursing staff chose to ask the patient, which led to inaccurate information being given:

Carer 6: "She had told them that she couldn't walk and used a wheelchair, and it was three days before a nurse asked me and I told her that she can walk and has never used a wheelchair."

### The carer's experience

When describing their experiences, several participants conveyed a lack of trust in the hospital and concern about what would happen to their relative during admission. This led to their:

- » Choosing to stay with their relative for long periods;
- » Worrying that they would not be cared for properly if they left them;
- » Feeling a responsibility to supervise their behaviour.

As one commented:

Carer 1: "I did not feel I could leave him there safely. He was a nuisance. What were they going to do with him?"

Participants described several examples of how nurses involved them in helping with care and seemed to see them as an extra pair of hands when busy. This led to them feeling they had to come in to help out.

Carer 5: "They even said to me, 'Can you take him to change his pad?'"

While it is vital to build relationships with carers and involve them if they want to be involved, it is not acceptable to expect them to deliver the care that is the responsibility of the nursing team. Many carers are older people themselves and are often physically and mentally exhausted by their caring duties. Carers can require support

## BOX 2. STUDY CRITERIA

Participants had to fulfil the following criteria for inclusion:

- Be caring for, or have cared for in the recent past, a friend or relative who had dementia
- The person for whom they cared had to have been admitted to acute hospital for a non-dementia related health problem at some point

and care themselves at such a stressful time, and in one interview, a participant expressed how much it meant to her when a doctor made her a cup of tea.

### Service developments

Much work has taken place since the dementia strategy was launched (Department of Health, 2009) to improve dementia care nationally. Locally, the large teaching trust has made huge advances by:

- » Improving staff training by including dementia care in induction days and mandatory training, as well as offering study days;
- » Implementing documentation that better captures patients' individual needs such as About Me, dementia pain assessment tools;
- » Cohorting vulnerable patients together, so they can be continuously supervised.

National initiatives, such as Caring around the Clock, should also make it less likely that the care needs of people with dementia are missed.

### Conclusion

Although a small-scale piece of research, the results of this study have much in common with others (Cowdell, 2010; Alzheimer's Society, 2009). Most recently, in January 2016 a large study by Alzheimer's Society (Boaden, 2016) had very similar findings, showing that there is still a long way to go to improve dementia care in hospital. Demographic changes mean the number of patients with dementia in hospital is increasing and it is likely that the issues raised in the study are still relevant, in particular where there are staff shortages.

To improve practice and the confidence of nursing staff, clinical leaders need to recognise the issues and firmly embed regular teaching about dementia in pre- and post-registration training. More dementia specialists to support staff on the wards would also be useful.

Consideration must be given to where people with dementia are cared for,

particularly when ward transfers are necessary, and there must be improvement in communication between professionals and with families. It is essential to offer more opportunities for the voices of carers – and, where possible, the patients themselves – to be heard. Work also needs to be done to develop ways of capturing feedback from patients with dementia – a task that would require time and creativity. **NT**

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