The care of older people with dementia in rural Australian hospitals – a case study

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KEY WORDS

Empathy; Health Resources; length of stay; risk management; workload

ABSTRACT

Objective
Investigate how nurses in rural hospitals care for people with dementia.

Design
A case study research design.

Setting
Three rural hospitals in one region of the state of New South Wales, Australia.

Subjects
A purposive sample of 21 nurses who were employed at the study sites.

Main outcome measure
Description of how nurses working in rural hospitals care for people with dementia.

Results
Nurses drew upon their community connectedness to creatively use limited resources to provide person-centred care for people with dementia. The physical environment of the hospital influenced rural nurses' practice, with chemical and physical restraint occasionally used when nurses' were concerned about workload and safety.

Conclusion
Rural nurses used their community connectedness to help them provide person-centred care for people with dementia, but at times, this care was limited by overriding concerns about risk management and patient safety.

INTRODUCTION

In 2015 it was estimated that, worldwide 46.8 million people had dementia and this number would double every 20 years, to 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International 2015). Against this background, increasing recognition is being given to the needs of people who have dementia by governments and non-government organisations internationally (Alzheimer's Disease International 2015). Rural areas are becoming increasingly populated by older people due to a combination of declining fertility rates, out-migration of younger people and in-migration of older people to these areas (Smailes et al 2014). As rural areas age, it is likely that the numbers of people with dementia will rise. An international systematic literature review reported the need for increased formal dementia services for people who live in rural areas (Morgan et al 2011). In Australia, rural hospitals are used for sub-acute care, including dementia care (Alzheimer's Australia 2007).

People with dementia are most commonly admitted to hospital for conditions unrelated to their dementia (Zuliani et al 2012). Hospitalised people with dementia have longer hospital stays than those who do not have dementia (Draper et al 2011; Mukadam and Sampson 2011). In hospital, people with dementia have higher rates of hospital-acquired complications of delirium, pressure injuries, urinary tract infection and pneumonia (Bail et al 2013), with significant costs to the health service (Bail et al 2015).

The hospital environment can increase confusion for people who have dementia (Dewing and Dijk 2016) leading to distress. Qualitative studies based in metropolitan hospital settings suggest that nurses may lack the skills necessary to care for people with dementia (Cowdell 2010), may be unclear on what constitutes a person-centred approach for people with dementia (Clisset et al 2013), and/or may be focussed on risk management rather than on the person (Moyle et al 2011). A person-centred approach encompasses respectful relationships between staff, the people they are caring for and those who are important to them and is enabled in workplaces where staff are empowered to develop their practice (McCormack and McCance 2016). The calm presence of staff has been found to have a positive impact on wellbeing for people who have dementia and are in hospital (Edvardsson et al 2012).

Working in a rural hospital is unique. Nurses are generalists rather than specialists (Mills et al 2010) and may care for people with different diseases or concerns, often on a single shift. The lack of specialist knowledge may negatively impact the way rural nurses are able to provide care for people with dementia (Robinson et al 2010). There are strong interconnections in rural communities, with many overlapping interactions between personal and professional lives, including nurses' lives (Baernholdt et al 2010; Robinson et al 2010). The nature of generalist practice and strong community interconnections are potential challenges for nurses to provide care for people with dementia in rural hospital settings. This study aimed to explore how nurses in rural hospitals cared for people with dementia.

METHOD/METHODOLOGY

In order to study events that were contemporary and outside the control of the researcher, an exploratory case study research design was selected (Yin 2009).

Setting

A purposive sample of three rural hospitals, each with 50 beds or less, was selected in one rural region of New South Wales. Rural hospitals of this size typically have a mix of acute services, as well as dedicated long-term aged care beds (New South Wales Health 2009).

Participants

Nurses who worked at one of the three hospitals were invited to participate in the study. Patient participants were included if they had a diagnosis of dementia and were in a general ward (exclude those in the emergency department or high dependency unit).

Ethical considerations

For the people with dementia, capacity to consent to have their care observed was not assumed. The nurses, who agreed to be observed, initially approached the patients and if necessary, their legal guardians, about the study. If they expressed interest, the researcher (first author) provided a participant information sheet and discussed the study with the patient and the legal guardian. The researcher included the patient in the process of consent however the legal guardian provided final consent for observation.

Ethical approval for the study was secured from the University of Canberra Committee for Ethics in Human Research (Project number 10-156) and the Greater Western NSW Area Health Service Human Research Ethics Committee (HREC/10/GWAHS/41).

Data collection

Two sources of data were collected. Observations of nurses caring for people with dementia were undertaken. Nurses were also invited to participate in a semi-structured interview. Additionally, a reflective journal was maintained to monitor the researcher's thoughts, impressions and feelings regarding the data throughout the data collection phase. Data were collected between June and August 2011. The details of data collected by site is described table 1.

Table 1: Data collection by site

Hospital	A	B	C	Total
Number of nurses interviewed	8	7	4	19
Number of nurses observed providing care	0	7	6	13
Number of patients whose care was observed	0	1	2	3

The first author observed nurses caring for three patients with dementia at two of the study sites. No observations were conducted at the first site visited, because there were no patients with dementia in the hospital at the times scheduled for data collection. At each of the other two sites, observation of practice took place over two days. At the second site the care of one patient participant was observed for seven hours in three periods ranging from 90 minutes to 210 minutes. At the third site the care of two patient participants was observed for five hours in one-hour periods. A total of twelve hours was spent observing care, with the researcher seated in day rooms or ward areas of the hospitals. Intimate care was not observed.

The semi-structured interviews were conducted using an interview guide. Questions focussed on ways of caring for people with dementia in their settings that worked well or didn't work well, important aspects of care for people with dementia, and the impact of rurality on the ways that care was enacted in their facilities. The first author conducted all interviews at the nurses' workplace with one exception, conducted by telephone. Interviews were recorded using a digital voice recorder. In one case, at the nurse participant's request, the interviewer did not record the interview and made detailed notes as soon as the interview was concluded. Interviews lasted between thirty and sixty minutes.

Data analysis

The nurse participant interview recordings, observation recordings and personal field notes were transcribed into word documents. The word documents were read and re-read, with immersion in the data, maintaining

notes of recurring concepts and constructs. Data analysis was an iterative process, carried out by the first author with validation provided by the second author. Concepts were inductively grouped into a hierarchy of categories and then themes, with the aim to capture the most important themes in the data (Franzosi 2004). Study credibility was ensured through data triangulation (Yin 2009). The three sources of evidence, participant interviews, participant observation and reflective field notes were constantly compared to arrive at the final themes.

FINDINGS

Twenty-one nurses participated in the study, with eight participating in the interviews only, eleven in interviews and observations and two in observations only. All of the nurses were female, with half in the 50 to 70 year age range. Basic demographic information of the 19 interviewed nurse participants is provided in table 2. Nurse participants have been given pseudonym names in order to protect their identities.

Table 2: Demographic profile of nurse participants

Qualifications		Age range					Average years of experience
		21-30	31-40	41-50	51-60	61-70	
RN	13	1	2	2	7	1	22.5
EN	5	1	2	-	1	1	18.4
AIN	1	-	-	-	1	-	2

aRegistered Nurse; bEnrolled Nurse; cAssistant in Nursing

Analysis of the data led to the development of three themes, entitled 'watchful wandering', 'risk versus restraint', and 'keeping people close to home'.

Watchful wandering

Wandering within a calm atmosphere was valued to decrease distress for people with dementia. Nurses valued ensuring people were safe, distress was minimised and people were cared for in ways that were respectful of their dignity and personhood. They found creative and simple ways of using the existing resources to safely care for people.

'Watchful wandering' consisted allowing people with dementia to move around the ward, while providing continuous supervision. Nurses were observed to invite people with dementia to accompany them to clean cupboards, prepare notes and write notes. Nurse participants acknowledged the ward environment was not ideal for wandering:

"We try and take them with us when we are working but you can't take them into every room, it depends on whether the other patients are happy for us to do that" (Margaret, EN).

To enhance continual observation during wandering, nurses would accommodate people with dementia in rooms near the nurses' station and put them in shared rooms:

"... if they're [person with dementia] wandering we try to put them in with someone else [who] might notify or ring the bell ... so they can say 'that patient's gone out the door or something" (Ellen, RN).

Observational data confirmed people with dementia were in rooms close to the nurse's station or in a communal sitting room, where staff could easily observe their movements.

Working collaboratively with family members was valued by nurse participants and often nurses would invite family members to stay with the person:

"...We like to have that relationship with the family where we can ring them and they'll come and sit with them and things like that" (Margaret, EN).

Nurses valued keeping the overall ward atmosphere calm and quiet. The interactions between nurses and people with dementia were observed to be calm and respectful. At one site in particular, nurses were observed to speak and act calmly, even during an emergency situation. Several nurses voiced the value of routine:

"Just to keep things routine is so important, basically" (Penny, RN).

"Once [people with dementia] are agitated, it becomes much more difficult to look after them, so if you can maintain calm throughout your shift it makes life much easier" (Mary, RN).

In summary, watchful wandering was achieved through continuous observation. Nurses were focussed on the person and their dignity, maintaining a calm atmosphere in the ward through routines and supporting the people with dementia to wander as much as possible.

Risk and restraint

Nurse participants in this study were very concerned with keeping patients safe and they were particularly concerned patients would fall or go outside the building.

"The layout of the hospital is difficult because of the stairs [leading outside] and you don't have the staffing to supervise them [in the way] you'd like to; it only seems to take a second and they're gone" (Liz, RN).

At each of the sites visited, nurses described the use of restraint, either physical or chemical, to keep people with dementia safe. The use of physical restraints appeared to be limited to those times when the person with dementia exhibited behavioural and psychological symptoms of dementia. The use of physical restraints was confirmed by observational data at one site. The use of restraint was described as being necessary when workloads were heavy and when the physical environment made keeping patients safe difficult. Nurse participants acknowledged these practices could lead to adverse outcomes for people with dementia.

"If we're short staffed or overworked, we have to chemically restrain [people with dementia]...very rarely physically unless it's just with a chair lockup... most people don't like doing that because it just aggravates some people" (Rachel, EN).

Nurses recognised it was preferable to use other ways of managing behaviours, such as trying to keep people with dementia busy with 'helping' tasks, because restraint increases the person's distress.

"If you keep her [person with dementia] occupied, she's quite amenable but [if] you try and restrain her and stop her from wandering, it makes it quite difficult... she gets quite [distressed]" (Ann, RN).

Another form of restraint was used at times, known in Australia as 'specialling'. This is the close supervision, usually confined to the patient room, to prevent wandering. Some nurses described the use of security staff to 'special' people with dementia who were likely to wander when they were busy due to increased workload:

"We get security if we're short staffed; they're very helpful and they'll watch [the person with dementia], especially through the night" (Carol, RN).

However, some nurses saw the use of security staff for close observation as exacerbating distress for the person with dementia. Having family members sit with the person was the preferred option, if this was possible:

"...and then you get the security, so you're bringing another frightening thing at them" (Karen, RN).

"Sometimes you have to get the family to come and sit with [the person with dementia] because you haven't got the time to [stay] and you're very reluctant to use chemical restraint" (Christine, RN).

In a busy ward, nurses may see physical restraint as necessary, but the safe management of restraint also required extra resources:

"Because we have other higher level care [patients]... it is very difficult because you can't go back and take [the person with dementia] out of their restraints every so often, it does make it very difficult" (Emma, EN).

Nurses spoke of the tension between their desire to care for people with dementia in ways that are more person-centred, for example allowing them to wander in order to 'use up' energy, and the need to ensure their safety in older hospital buildings that are not designed for people who are cognitively impaired. Observational data confirmed the physical environments at each site were not safe for unsupervised wandering, with exit doors opening to busy and dangerous roads or, in higher floors of the hospital, to stairwells where dangerous falls were possible:

"The door as you come out of the ward onto the main stairwell [cannot] be locked...if [people with dementia] are wanderers...you can't lock them in their room and it's very difficult ...because we are an acute [hospital setting], and people [with dementia] need to be able to wander...to use up their energy, but we can't actually keep them safe all day and that's my biggest dilemma" (Denise, RN).

Nurses justified the use of restraint on the grounds of potential injury:

"Restraints are probably a very interesting topic to get into, because you say that people have the right to choose, but busted bones [sic] are frowned upon" (Val, RN).

The same nurse participant spoke of the need for a balance between providing idealised care that facilitates freedom for the individual and managing the use of restraint safely:

"So it's always a toss-up... I know the idealists will say you know we shouldn't... restrain them, but the other thing is managing the restraint making sure that you're there to release it and making sure that they go for their walks and all that sort of stuff" (Val, RN).

In summary, nurses occasionally used physical and chemical restraint, as well as 'specialling' of people with dementia to manage perceived risks of injury.

Keeping people close to home

The local hospitals were an extension of the respective communities. The nurses often drew upon their personal knowledge of people with dementia from their local communities for application to their clinical practice. The nurses knew the histories of people with dementia in the community because they had been in hospital previously or were users of services affiliated with the hospital. The nurses also knew about people with dementia through personal networks in their communities. For example:

"...we've been aware of her [person with dementia] for the last couple of weeks. The husband's [has] got to the crisis point where he needs emergency respite" (Mary, RN).

The nurses recognised the importance of connections with family and community for people with dementia, with an established volunteer visiting program in one of the study sites. The local volunteers were observed informally visiting all of the long-term patients in the ward.

Older people with dementia can access government funded care services, either in their own homes or within residential aged care facilities, but must first have their level of care needs assessed by a multidisciplinary Aged Care Assessment Team (ACAT). However, given the rural setting, geographical distance was challenging. For example, one person with dementia lived around 80 kilometres from town, was considered too far for community based aged care services:

"We could have kept her at home a bit longer but you see [her town] is so isolated, there [are very few] services out there." (Ann, RN).

If the ACAT recommends an aged care facility placement, people with dementia would wait in the hospital for a placement. Often families preferred local aged care facility placement, although that was not always possible:

"We always go for their first choice and if that's not available, [we'll aim for] a bed as close as possible" (Rachel, EN).

"Sometimes the family put on a bit of pressure that they only want them to come into the local aged care facility, but if there's a bed [outside of town], they should be taking the bed and then when one comes available in the local facility, they can transfer across. I don't think the family understand that because [the distance is] difficult for family too" (Denise, RN).

As indicated in the previous theme, nurses sometimes know patients as members of their local communities, and can use this knowledge to support the person with dementia in hospital. Where possible nurses endeavoured to keep people with dementia in their local hospitals while they waited for an aged care service or placement and aimed to place people in aged care facilities located in the local community.

Limitations

The data from the three study sites were analysed and reported as a single case, due to concerns about participants and study sites being recognisable. However, this could be a limitation of the study because multiple case study design is acknowledged as a stronger design than single case study design (Yin 2009). The timeframe available for observations, the fact one site had no eligible patients at the time of the site visit, and the small sample size, are potential limitations of the study. The results of the study cannot be generalised to the wider population due to the small sample size and the study being conducted in one region in rural New South Wales.

DISCUSSION

Three themes emerged to describe how rural nurses work with people with dementia in hospital. In describing their practices, the physical hospital environment had an impact on the way that care was provided.

'Watchful wandering' was the preferred way that nurses maintained a calm environment, encouraging people with dementia to engage with their environment. However, like nurses in a metropolitan hospital study (Nilsson et al 2013), rural nurses were frustrated that increased workloads meant they could not provide this care. Keeping the ward atmosphere calm, speaking calmly, not using raised voices and not rushing, in order to avoid worsening confusion or agitation for people with dementia, is also consistent with metropolitan hospital practice (Hynninen et al 2015). However, keeping the atmosphere calm was sometimes challenging within the ambience of a hospital environment.

Nurses in the current study described the simple ways they occupied people when they have time. These interventions can prevent boredom, social isolation and associated agitation (Cohen-Mansfield et al 2010). The nurses were creative in their strategies to engage people with dementia. Other authors have recommended interventions such as art therapy (Peisah et al 2011), exercise such as walking with volunteers (Bateman 2010) and animal-assisted therapies (Bernabei et al 2013) for keeping hospital people who have dementia socially and cognitively engaged.

The majority of nurse participants spoke of patient safety being one of their main concerns when they are nursing people who have dementia. Considerations about the environment influenced nurses' focus on patient safety. Previous researchers have also found that nurses are concerned safety of people with dementia in hospital settings (Dewing and Dijk 2016; Moyle et al 2011). In this study, the nurses used close supervision or 'specials' and physical and chemical restraint when they judged this was necessary to enhance patient safety. The use of 'specials' for supervision of people who are cognitively impaired is well established in hospitals (Kerr et al 2013; Moyle et al 2011; Wilkes et al 2010).

While they preferred continued observation, restraint was used when the ward was busy and continuous observation could not be sustained. The nurses who discussed restraint use did not clearly state an ethical dilemma but this was implied in their descriptions of practice. The use of restraint was justified on the grounds of inadequate resources (staff time) for watchful wandering and the dangers inherent in the hospital environment. While nurse participants in the current study recognised restraint had adverse consequences for patients, they chose the risks associated with restraint over the risks of injury related to falls or absconding.

This finding is disturbing in that restraint reduces mobility and can lead to preventable complications such as urinary tract infection, pressure injuries and pneumonia (Bail and Grealish, 2016). There is also emerging evidence that for people with cognitive impairment, reduced use of restraint is associated with reduced length of stay (Gerace et al 2013; Kwok et al 2012). How rural communities access and enact evidence-based practice in the area of restraint requires urgent attention.

People who live and work in rural communities are often connected in overlapping ways. Lauder et al (2006) use the term "community embeddedness" to describe this interconnectedness (p.75-76). The nurses valued their relationships in the local community; it was easy for them to invite family members to assist with a person with dementia who was distressed in the hospital environment. In contrast a study in a large metropolitan hospital found that the nurses infrequently requested family members be involved in the care of people with dementia in hospital (Moyle et al 2011). The interconnectedness in rural communities can enhance the ability of nurses to provide high quality care (Baernholdt et al 2010), with relationships enhanced and patient care improved (Pesut et al 2012).

Nurses in this study recognised older people needed to remain in their local communities to enable the continuation of lifelong connections. Having to move outside of their own communities to accept an aged care bed has been likened by older rural people to being exiled (Bernoth et al 2012). Nurses in this study worked to reduce separation of the older person with dementia from their community.

CONCLUSIONS

This study has found that despite unsuitable physical environments and multiple competing demands on the time of the nurses, rural nurses found simple ways to maintain person-centred care. Maintaining a calm atmosphere required creativity and thoughtfulness, and drew upon the nurses' personal connections with their rural community. However, when the ward was busier and resources were scarce, there was an increased focus on risk management, often with significant clinical implications for the person with dementia. There is a need for further discussion and clarification between nurses and health care managers about the meaning of risk, and clarifying whose interests are being protected when chemical and physical restraint are used. Contesting the idea of risk of injury for people with dementia in the rural hospital contexts is worthy of further research.

The nurses recognised the value of the community-based relationships with the family members of people with dementia and with other service providers and used the information gathered through these relationships to provide better care for people with dementia. Working collaboratively with family members is a strategy that could be adopted by nurses in urban and rural hospitals in Australia and globally in order to improve care for people with dementia who are hospitalised.

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