The liminality of the patient with dementia in hospital

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Aims and objectives: The aim was to explore the experiences of people with dementia in subacute geriatric rehabilitation hospitals to critically evaluate the care received by such patients.

Background: Globally, the number of people with dementia is growing and is expected to impact progressively more on health systems. People with dementia can become deconditioned and deteriorate in cognitive function while in hospital. The unfamiliar environment and people can cause the person to become disorientated, which then leads to behavioural symptoms which complicate care.

Design: Critical ethnography.

Methods: Methods included observation with field notes and 30 audio-recorded conversational interviews with patients with dementia in an Australian subacute care setting. Data were collected in May–December 2014, transcribed verbatim and analysed using thematic analysis.

Results: The central theme identified that patients with dementia described a liminal experience and felt like outsiders in the hospital environment. This was supported by the subthemes of not understanding why they were being kept in hospital, feeling lost in the space, bored, anxious about discharge plans and lacking intersubjective relationships. Many felt imprisoned by the locked wards. There was little evidence of nursing care delivered in an empathetic person-centred way. Nurses were busy and engaged with the patients only superficially.

Conclusions: People with dementia can have a liminal experience and feel like outsiders in this environment, which does not cater for the specific needs of this patient group. It should be acknowledged that people with dementia require additional resources. A caring nurse–patient relationship is fundamental to the patient experience. Nurses require further support and education about dementia in order to deliver quality care to this patient group.

Relevance to clinical practice: These findings will influence nurse leaders to advocate for improved resources for nurses to provide appropriate care for patients with dementia in subacute geriatric hospitals. The clinical practice of nurses needs to be supported with education, psychological and material support to improve the therapeutic environment for patients with cognitive impairment resulting from dementia.

KEYWORDS
adult nursing, dementia, geriatric, nurse–patient relationship, nurses, person-centred care, qualitative study
1 | INTRODUCTION

The global incidence and prevalence of dementia is predicted to rise from 46.8 million people in 2015 to an estimated 131.5 million in 2050 worldwide (Prince et al., 2015). People with dementia have more hospital admissions than the general population due to the complex needs and morbidity associated with the condition (World Health Organisation, 2012), and the financial and social cost to the community is estimated to exceed that of cancer, heart disease and stroke (Prince et al., 2015).

People with dementia can have a poor experience in hospital, often becoming deconditioned and deteriorating in cognitive function (Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2011). There is an increased incidence of patient falls, complications of care such as infections, malnutrition and dehydration and a longer length of stay (Bateman, 2012; Digby & Bloomer, 2014; Jurgens, Clissett, Gladman, & Harwood, 2012). Part of the problem is that hospitals often have unsuitable infrastructure which is alienating and sometimes harmful for people with dementia who commonly have spatial disorientation and a reduced ability to express needs (Bridges & Wilkinson, 2011).

Additionally, the experience of being in a strange environment without familiar carers or routine can cause the person with dementia to become anxious, agitated, aggressive or depressed leading to behaviour which complicates care (Backhouse, Killett, Penhale, Burns, & Gray, 2013). The therapeutic relationship between the patient and the nurse is therefore pivotal to the experience of the patient who is without the familiar presence and reassurance of their usual caregivers. Nurses require appropriate interpersonal skills, empathy and emotional intelligence to have a positive impact on the patient (Digby, Lee, & Williams, 2017).

Dementia is more commonly a comorbidity than an admission diagnosis in hospitals, and accordingly, the person generally has an acute health problem which requires treatment (World Health Organisation, 2012); however, the emotional and psychological state of the patient can impact negatively on outcomes (Brooker, 2003). Society stigmatises people with dementia in the community (Blay & Peluso, 2010), but it is important that hospital is a safe space where people are treated appropriately regardless of comorbidities (Digby et al., 2017). More work is needed to develop a culture of equality for all patients in hospital despite the challenges in an environment driven by biophysical and budgetary priorities (Clissett, Porock, Hardwood, & Gladman, 2013; Dewing & Dijk, 2014). Comprehensive literature reviews examining the experiences of people with dementia in hospital have previously highlighted the deficits in care for this patient group (Dewing, 2013; Dewing & Dijk, 2014; Digby et al., 2017; Moyle, Olorenshaw, Wallis, & Borbasi, 2008).

This study discusses the key findings of a study in which people with dementia were interviewed about their experiences in hospital and described feelings of liminality and being outsiders in the environment.

What does this paper contribute to the wider global clinical community?

- The incidence and prevalence of dementia is increasing globally and is expected to impact progressively more on health services. This paper highlights that subacute geriatric rehabilitation hospitals are not currently adequately prepared to manage the care of people with dementia.
- The experiences and opinions of the patients are an important factor in tailoring care to their needs. People with dementia have been asked to comment on hospital care on few occasions previously to the detriment of our understanding. This research provides a unique opportunity for the voice of the person with dementia to be heard.

2 | BACKGROUND

For many people, receiving a diagnosis of dementia introduces the beginning of a series of losses (Clare, Rowlands, Bruce, Surr, & Downs, 2008), often starting with deterioration in memory, thinking, comprehension and judgement, and gradually progressing to include multiple higher cortical functions (World Health Organisation, 2012). The failure to be recognised as a person with the same rights as others is a further loss incurred when the person with dementia is not assigned the same status in hospital accorded to others with intact cognition (Clare et al., 2008). A demonstration of this occurs when a person with dementia is denied access to the same services as others, or unnecessarily confined or scrutinised while in hospital, highlighting difference (Moyle et al., 2011).

Person-centred care principles were espoused in the vision and values statements of both hospitals in this study. The principles emphasise the formation of a therapeutic relationship between the patient and the clinical team to ensure that the needs of the person are understood and met in accordance with their social, cultural and individual identity, rather than physical care alone (Victoria State Government, 2015). The challenges in translating the principles of person-centred care into everyday practice have been well documented (McCormack, 2004; Nilsson, Rasmussen, & Edvardsson, 2013; Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011) and require an enthusiastic, skilled workforce in a supportive environment to be successful (Ross, Tod, & Clarke, 2015).

Cassel (1982) believed that separating the mind and body to treat only physical illness caused suffering due to the denial of personhood. In hospitals, it is not uncommon for the patient to be treated as a collection of symptoms however Cassel (1982) suggested that the extent of the person’s relationship with others determines the degree of suffering that they will experience. The idea of person-centred care has been explored and expanded extensively by others including (Kitwood, 1988, 1993, 1997; Kitwood & Bredin, 1992) who
proposed that failing to recognise personhood was a form of abuse capable of accelerating dementia and which he termed “malignant social psychology” (Kitwood, 1997, p. 45). The definition of personhood used by Kitwood (1997, p. 8) is “…a standing or status that is bestowed upon one human being, others, in the context of relationship and social being. It implies recognition, respect and trust,” although there are other definitions in current use (McCormack, 2004; Nay, Fetherstonhaugh, & Winbolt, 2014; Røsvik, Brooker, Mjorud, & Kirkevold, 2013).

Despite extensive discussion of this issue (Brooker, 2003; Dewing, 2008; Doyle & Rubinstein, 2014; Edvardsson, Winblad, & Sandman, 2008; Feo & Kitson, 2016; Hill, Roberts, Wildgoose, Perkins, & Hahn, 2010; McCormack, 2003, 2004; Røsvik et al., 2013), support from government (Victoria State Government, 2015) and the introduction of guidelines (AHMC, 2006; Dignity in Care Network, 2013; Laver et al., 2016) incorporating the concepts of person-centred care for people with dementia in hospital continues to fall short of the recommendations.

3 | THE STUDY

3.1 | Aim

This study reports one of the findings from a larger study which aimed to critically evaluate the reasons behind the reported poor care received by such patients in subacute geriatric rehabilitation hospitals.

The central research question of the study was “What are the factors which impact on the care of people with dementia in subacute geriatric rehabilitation hospitals?”

3.2 | Design

A qualitative design was undertaken using a critical ethnographic approach to facilitate an understanding of the way that the participants understood their experiences. Critical ethnography is focussed on determining the power relationships and revealing hidden agendas within organisations or situations to determine appropriate solutions to the problems (Carspecken, 1996). The dialogue and behaviour of the participants were examined to understand any social or material disempowerment underpinning the situation (De Laine, 1997; Harrowing, Mill, Spiers, Kulig, & Kipp, 2010).

3.3 | The setting

The rehabilitation facilities of two large metropolitan general teaching hospitals were selected for this research. Five wards were nominated by senior hospital staff as most suitable for inclusion in the study. There was a range of architectural styles with a variety of patient accommodation. All the wards required keypad exit, and one had an additional four-bed locked area within the locked ward where patients with dementia who were likely to wander or abscond were accommodated.

3.4 | Participants

Purposive sampling was used to recruit 30 in-patients with dementia from five wards in two health services. The inclusion criteria were that the patient had a diagnosis which included any type of dementia, able to have a conversation in English, medically stable, and agreed to participate.

The participants ranged in age from 68–99 years with an average age of 82.9 years. Thirteen men and 17 women participated. Recruitment ceased when data saturation was reached. All the participants had dementia; however, in 50% of cases, the specific type of dementia was not mentioned in the patient progress notes, and dementia was commonly a comorbidity to an acute diagnosis. The shortest patient interview was 5.55 min, the longest 59.51 min, the median 13.34 min and the average 18.93 min.

3.5 | Data collection

The data were collected through conversational interviews with the patients with dementia and 120 hr of nonparticipant observation in which the researcher watched the participants with their knowledge, but without taking an active part in the situation in the five wards in Melbourne, Australia, between May–December 2014. Health and demographic information about the patients was accessed through the medical records. Audio-recorded conversational interviews were conducted mainly in the patient bedrooms. The questions were open-ended and semi-structured, starting with the general broad question “Can you tell me what it is like being a patient in this ward?” More specific questioning followed depending on the issues raised by the participant. The researcher brought a list of predetermined topics to the interviews, but the conversations were largely driven by the issues which the participants wanted to talk about. An aide-memoire was used as a prompt to facilitate conversation if required.

3.6 | Ethical considerations

Approval to conduct the study was gained from the human research ethics committees of the university and the hospitals involved. The clinical team on the wards identified potential participants according to the inclusion criteria, and the senior medical officer determined the person’s capacity to consent. For those who lacked the capacity to formally consent on their own behalf the next of kin signed the consent form. Assent was gained from all the participants at the outset in addition to the formal consent process and was closely monitored during their involvement by ensuring that the person continued to respond positively to the researcher and stay engaged in the conversation.

3.7 | Data analysis

The data from the interviews were analysed using thematic analysis as described by Braun and Clarke (2006). Thematic analysis is a
method for identifying, analysing and reporting patterns or themes within data using six phases: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming the themes, and producing a report. The transcripts of the interviews were read and re-read while listening to the audio files. This information was then compared to the data from the field notes and observation of the physical environment, routines and social and power dynamics which had been noted during the observation periods. Themes relevant to the research question were then identified.

3.8 Rigour

Rigour has been defined as “the criteria for trustworthiness of data collection, analysis, and interpretation” and has been compared to reliability and validity in quantitative research (Prion & Adamson, 2014, p. e107). In this research, rigour was demonstrated by the liberal use of researcher reflexivity throughout the results, and consistency between the research aims and the methodology. Credibility has been demonstrated by the validation of the results and involving experienced researchers in the review of data coding and the meanings assigned to the results. The research team (RD, SL and AW) had regular meetings to review the themes together until a consensus was achieved, referring back to the recordings for verification when required.

4 FINDINGS

Analysis of the data revealed a key theme related to the patient experience “I don’t belong here: the patient perspective.” There were a number of factors which contributed to the patients’ sense of not belonging including the unsuitable environment which was unfamiliar and difficult for patients with dementia to understand or navigate, and there was no meaningful activity provided for the patients who consequently felt that they lacked purpose. Additionally, the patients described being excluded from discussions about their discharge plans and there was a general feeling of uneasiness in the patients who feared that they were destined for residential care. The sub-themes which will be illustrated in the following section include not belonging, being lost in the space, boredom, anxiety about discharge plans and intersubjectivity.

The participants are referred to by randomly chosen pseudonyms to protect their anonymity.

4.1 I don’t belong here: the patient perspective

Many of the participants described feeling confused by the hospital environment, unaware of why they were being kept there and not consulted about the plans for their care or discharge. The reasons for not knowing could be related to poor short-term memory, but there were also a number of cases where families of participants were applying for residential care placement and it was documented that this had not been discussed with the patient. The concept of being an outsider was illustrated by the participants in a number of ways including expressing anxiety about the discharge plan, pacing with a view to escaping the ward and resigned sadness.

Ines could not understand why she was being kept in hospital and was continually pacing around the ward because of her frustration and anxiety:

I hate it [in here]. First of all I’m not sick. Number one…Three doctors have said to me ‘You seem 100% perfect. What are you doing in here?’ [Laughs conspiratorially] I don’t know myself what I’m doing in here – there’s nothing wrong with me! . . .

(ines, patient)

Feelings of homesickness, sadness and longing for the familiar were common and were often the cause of anxiety and agitation. Lena was worried because she could not understand why she was in hospital and what was going to happen next:

I don’t know why I am here. Why can’t I do what I was doing?! I think maybe I’m older. [How old are you?] Err, in my nineties I think. The space between when I was alright and doing the garden, and nothing, is just killing me! . . . I don’t know, maybe I’ll get better I hope. That’s what I hope [looks upset].

(Lena, patient)

Some of the patients described feeling imprisoned in the locked hospital wards. Bob expressed his frustration with not knowing why he was being kept in hospital when he had important work to do at home. He was unaware that his case was awaiting a guardianship hearing because his friend had been taking financial advantage of him, and Bob had been deemed incompetent to make decisions on his own behalf. Not knowing or understanding his circumstances caused Bob a great deal of anxiety:

I can’t understand why they’re keeping me here. I’ve got commitments. I’ve got commitments at home! I’m a chaplain by profession!

(Bob, patient)

One of the patients was upset about what she considered to be imprisonment. She grabbed the portable phone from the nurses’ station to ring the police:

There was a disturbance in the ward and I saw Gina being led back to her room. She was shouting at the nurses and looked very agitated. I asked the ward clerk what had happened and she said that Gina had taken the phone and rung the police to report that she was being kept imprisoned.

(Field notes, Ward B)

The feeling of being an outsider was augmented for Larry (patient) who realised he was not included in the physiotherapy sessions with the other patients. He felt shunned by the physiotherapist and
excluded from the patient group, adding to feelings of not belonging. It had been decided that physiotherapy was no longer necessary for Larry because he was going to residential care; however, he was unaware of the reason:

... that physio he goes from room to room asking whether you want to do physio. Nobody asked me... Everybody do this or that and I'm not asked [Larry looked very downcast, shoulders slumped, looking down]. (Larry, patient)

Excluding patients from therapy reinforced division and the perception of not belonging and could lead to resentment, and in this case sadness.

Food is an important element for people to feel comfortable and relaxed, and a focus of activity for the patients, however few made favourable comments about the food in the hospital, with many feeling that it was a factor which increased their feelings of not being at home:

I don't mind most of it but I don't like vegies that are not cooked properly... I don't mind crunchy but when you start cooking them -- boiling or whatever they’re going to do -- sometimes people take them off in the middle and they’re neither one or the other kind of, I like nice vegies. I don’t like them if I don’t like them. (Emma, patient)

The alienation described by the participants speaking about other aspects of care was mirrored in their comments about the food. The unfamiliar taste and presentation of the meals confirmed the feelings of estrangement:

Oh, the food's alright but it doesn't matter what hospital you go to hospital food is hospital food. There's a taste about hospitals that somehow gets into the food and it has that hospital taste about it. I have good meals at home. (Bob, patient)

There was no provision made for the cultural diversity of the patients. Patients who were used to a highly spiced diet suffered through the blandness of the food in hospital:

Well, it's not my food. My food is curry and all that sort of thing. I eat it, when I'm hungry. It has no taste... the food is nothing. Boil, boil, boil, boil, boil... No spice, no nothing in it. So we just eat it to stay alive. (Lena, patient)

Feelings of being an outsider and not belonging in the hospital environment were further augmented by not understanding the environment and continually feeling lost.

4.2 | Being lost in the space

Spatial disorientation was common in the participants who sometimes did not understand where they were, often confusing hospital with home. Emma (patient) could not differentiate between the two places and blurred her recollections to encompass both. She was discussing her day in the hospital then included information about going shopping which was an activity she only did when she was at home:

Oh well we went down and played some type of bingo... Yeah, that was good and then we had lunch and then physio so I thought it was a good ole day here yeah... [sometimes] I have quiet days because I don't do much unless someone's going up the street I might go with them -- that's about all. When I say up the street I mean up the shopping centre -- I'm not so far from Kmart [a large shopping centre]. (Emma, patient)

At the time of the interview, Martha had been in hospital for 26 days and despite walking around the ward repeatedly every day could not understand the environment:

Martha No, no I have my meals upstairs. I am upstairs aren't I?
Interviewer Actually it's all on the same level.
Martha The same level?
Interviewer Yep, mmm. So you don’t go into that room? [the dining room]
Martha I don’t think so, I don’t think so. No... see I could be saying all the wrong things! (Martha, patient)

Spatial disorientation and the unfamiliar food and environment aggravated some patients and led to unsettled and at times aggressive behaviour. This was further hindered by the lack of meaningful activity provided.

4.3 | Boredom

Having very little occupation in the hospital was a frustration for some of the patients, many of whom complained of boredom and described a sense of wasting time. The therapy in these wards was prioritised for those returning to the community, so some patients spent many days, sometimes weeks sitting all day in a chair:

Interviewer What do you do during the day?
Greg Very little. But that’s er... The food comes as I mentioned before... I shower.
Interviewer And then what?
Greg Then nothing. (Greg, patient)

Mary reported that she was involved in some activities in the hospital but she felt removed from them because they were not relevant to her:
I just feel during the day there's nothing in it...not nothing going on, but the things you are doing, they can't contribute to what your life's going to be like. You just go along and have your shower or your bath or whatever and chat away to whoever... (Mary, patient)

The limited schedule and lack of activity was reported by another patient as being depressing and out of her control:

You go mad with boredom. You get bored when there's nothing available that's interesting. Actually, it would depress any person... well there is a television in that living room down there but you can't control it. The latest person that comes into the room is apt to switch it off or change it to something else. (Harriet, patient)

Many of the patients, especially those did not attend therapy, rarely left leave their rooms:

I've been here all day and only one of the patients in this 5-bed bay has left the room except to go to the bathroom. They are all sitting next to their beds where they have been since they were showered in the morning. (Field notes, Ward A)

The lack of meaningful activity gave the patients more time to worry about their situation, especially in regard to the plan for discharge.

4.4 | Discharge anxiety

Many of the patients felt that they had very little power to influence their discharge plan and were left out of pivotal discussions about their own welfare. Anxiety about discharge destination was widespread among the participants. Suspecting that decisions were being made by others served to increase feelings of being excluded.

The patients in this study almost universally feared residential care placement which was considered the ultimate denial of freedom. Bertha (patient) was worried that the hospital clinical team would determine that she required residential care, and she mistakenly trusted that her children would not let this happen. It was noted in the progress notes that Bertha had been assessed by the neuropsychologist and deemed to be unable to make complex life decisions and therefore assessed as unsafe to return home. The team and the family had agreed that she needed permanent care. Not knowing what was going to happen, but suspecting that residential care was being considered caused Bertha intense anxiety:

My son said 'I'm taking you home when the time comes Mum'... he knows how I feel about going home and that. They wouldn't lie I mean if they thought I wasn't looking after myself or I was in danger he would be the first to admit it. They're not silly. (Bertha, patient)

Marco, a 100-year-old participant wanted to go back to his own home, his friends and community despite opposition from the clinical team. He knew that he was not going to live for many more years and he was prepared to accept the risks in order to go back to the place where he felt he belonged:

I stay here for a while, they look after, but if I go home, I'm sure 100%... if something happen to me, what's happen to me? I'm 100 years [old]. I pass away – you pass away... eh?! (shugs) ... Nobody no talka to me [here]. If I go home, everybody knows me! (Marco, patient)

Another patient, Harriet, was unaware that her four adult children planned to place both Harriet and her husband in residential care because they were considered to be unsafe at home due to impaired cognition. Harriet was able to articulate the problem with residential care as she saw it:

I feel that I could be spending it more profitably at home, even if it cut my life shorter. But in the health industry, especially for the aged, the opposite of health is sickness, that's the enemy. Well, sickness is not the worst enemy. Total boredom and the mental suffering that that causes, the feeling of uselessness and the fear of the – which is with all people of my age – the large industry of nursing homes. (Harriet, patient)

4.5 | Intersubjectivity

The participants wanted to feel that the nurses cared about them as individuals and that they had a two-way relationship in which both were contributors. Certain behaviour of the nurses alienated the patients and caused feelings of being ignored or of low importance:

Oh most of them are very good. They can't do enough for you... then they fall away to nothing really...you're supposed to ring the bell to go to the toilet, but I got tired of waiting for them and I'd end up going on my own. Of course I'd be balled out then for going on my own. (Alex, patient)

Another participant could see that the nurses prioritised administrative tasks ahead of their caring duties and that the hospital was being run like a business:

Well er, it's the first time I've been in hospital where it's work to a criteria of quality control... the way they do
things here are similar to standards criteria, how to run a business... times have changed where nursing was nursing and now a percentage of the day is nursing and putting procedures in place, adding data so one doctor will have a group of nurses all cross referencing down on paper etc etc. (Arthur, patient)

The attitude and manners of the nurses was criticised by Esme (patient) who believed that the majority of the nurses considered the patients to be a nuisance and an interruption:

They literally charge in. Very rarely announce themselves let alone explain what they are or who they are... I think that they don’t want to know you because you’re going to be a nuisance, you’re going to be a bother, you’re going to want something, you’re going to ask something of them, expect something, and they don’t want to know. (Esme, patient)

A lack of warmth and caring by the nurses was noted by Jenny who observed that many of the nurses did what was required on a practical level but failed to engage with the patients personally:

Some of them [the nurses] are a bit grumpy, but they don’t really mean it... [some are] more understanding perhaps. If you’ve perhaps got a down day they try to cheer you up and things like that. [And the others?] They do their job but don’t sympathise with you. (Jenny, patient)

The lack of engagement between the nurses and the patients was a major source of anxiety for the patients who felt that they were being ignored. Elements of the hospital experience including the unappealing food and unstimulating routine added to feelings of alienation. Discharge planning was a source of great anxiety especially when the patient felt that plans were being made without their input.

5 | DISCUSSION

5.1 | The liminal experience of the patient with dementia in hospital

Lupton (2013) defined liminality as a state in which a person was transitional between one world and another and therefore considered to be a stranger or an outsider. As a consequence, a person who is not part of the norm may be treated more harshly and allowed fewer rights (Lupton, 2013). The resulting marginalisation and stigmatisation can lead to the person having a liminal experience which can include feeling isolated, depressed and unsupported (Hall, Stevens, & Meleis, 1994).

The term “liminality” refers to being an intermediate state, phase or condition (Merriam-Webster Inc, 2012) and was first used in anthropology to describe the state of being in-between one stage and another such as adolescence which separates childhood from adulthood, or the state between initiate and priest (Kelly, 2008). However, the term has also been used to denote “otherness” and applied to people who are strangers or outsiders and considered different from the mainstream and therefore anomalous (Lupton, 2013). A person whose diagnosis falls outside the majority can therefore be treated with lower priority and can consequently feel like an outsider in the system.

Previously liminality has been discussed in the literature from the perspective of people with mental health disorders (Warner & Gabe, 2004), schizophrenia (Barrett, 1998), physical disability (Lupton & Seymour, 2003; Murphy, Scheer, Murphy, & Mack, 1988), cancer (Little, Jordens, Paul, Montgomery, & Phillipson, 1998), chronic pain (Jackson, 2005) and AIDS (Kelly, 2008). The common features of these illnesses are that the prognosis is uncertain, and for those in the mainstream, there is an element of risk or fear about the person with the condition. In terms of those with a mental illness, the person may seem dangerous and potentially violent, or lacking in the essential human qualities of reason and introspection (Barrett, 1998). Douglas (1992) suggested that individuals who upset the social and cultural boundaries were considered threatening to people who had a stake in maintaining these boundaries. The “others” who pose the threat were then treated as outsiders and blamed for disturbing the status quo (Douglas, 1992).

The patients in this study reported feeling excluded from pivotal discussions about their discharge plans, unsettled by the unfamiliar environment, uninformed and poorly supported. In their view, the nurses did their job but were not caring or reassuring and showed little warmth. Anxiety about residential care placement is not confined to people with dementia. Patients with intact cognition also express sadness and reservation about a change in living arrangements and can have a deep sense of loss about their previous life (Chivers, 2015; Pirhonen & Pietilä, 2015), however in the case of people with dementia understanding the situation becomes more complex because of a reduced cognitive capacity and more so when the person is not included in discussions.

The patients, despite not using this term, described a liminal experience when they spoke about feeling lost in the environment, baffled by events around them and bewildered as to what would happen next. Some of these responses could be attributed to the effects of dementia which causes poor short-term memory, and problems with thinking and reasoning (World Health Organisation, 2012, p. 7); however, there were also factors which were imposed by the nurses which contributed to the patients feeling estranged. The nurses augmented the problem by failing to adequately communicate with the patients in a way which enabled them to understand and be reassured. In addition, spatial disorientation was not addressed and no extra environmental guidance was offered.

Excluding patients with dementia awaiting residential care placement from therapy is based on budgetary restrictions which have led to the prioritisation of patients returning to the community. Patients
with dementia also have legitimate needs and can be at significant risk of physical and mental deconditioning in hospital (Draper, Kar-

mel, Gibson, Peut, & Anderson, 2011). Patients who spend most of their time in a chair, quickly lose physical fitness, balance and strength. Failing to deliver the necessary therapy to ensure that the person leaves hospital in the best possible condition regardless of their diagnosis is regrettable, however the effect that the lack of activity and engagement has on mental health and mood has largely been ignored.

Nurses have the ability to mitigate some of the negative experi-
ences by establishing a close therapeutic relationship with the patients. Initiating conversation not based on practical matters, and ensuring that the person has an opportunity to be part of the con-

versation show that the person is recognised as an equal and valid contributor. Person-centred care principles have been defined previ-
ously as “the need for a recognition of, and a connection with, the person, a focus on the person’s strengths and goals, an interdisci-

plinary approach, and recognition of the centrality of relationships” (Nay et al., 2014, p. 138). Making a personal connection not only improves the patient’s sense of security and empowerment, but the experience of the nurse is also improved (Finfgeld-Connett, 2008).

The difference between delivering care in a task-focussed way and engaging with the patient during the completion of tasks is negligible in terms of time but immeasurable in terms of the outcome for the patient. It has previously been reported that patients with dementia who experience a close therapeutic relationship with the nurses are more settled and satisfied with care (Edvardsson et al., 2008). The importance that the nurse-patient relationship plays in the psycho-

logical state and coping mechanisms of the patients with dementia deserves to be emphasised.

Nurses who focus on tasks but decline to engage with the patient could be considered to have separated the mind from the body of the person. Cassel (1982) described this as a denial of per-

sonhood and a contributor to personal suffering. When a person’s integrity is threatened and the essence which makes that person themselves is overlooked, suffering which goes beyond the physical self can occur (Cassel, 1982). Focussing on the physical to the exclu-

sion of the mind depersonalises the patient, threatens their integrity and denies the reality of their experience (McCormack, 2001). Priori-

tising patients with intact cognition ahead of people with dementia has a moral component in that there is a distinction made between the deserving and undeserving recipients of care. There is also evi-

dence of treachery as described by Kitwood (1997) in the use of de-

ception and manipulation of the person to force compliance. As demonstrated in this study, people with dementia can feel rejected and ignored by health professionals who fail to engage on a personal level with the patient.

Kelly (2008) described the concept of "living loss" as the grief response experienced by people with dementia as they gradually lose their abilities, their connection with others, and their relations-

ships. The uncertainty already felt by people with dementia is amplified by the realisation that the community including the staff in hospitals, consider them to be outsiders and not deserving of the same care and treatment as the cognitively able. A form of personal grief can be experienced by the patients who retain enough insight to see that they are being treated differently. Many of the patients in this study expressed feelings of real sadness about their situation about which they had little control and received little support. The connection with the nurse is of vital importance to the patient in terms of maintaining a sense of self.

All people find meaning and identity from their experiences and interactions with others in a process known as intersubjectivity (Crotty, 1998; Leeds-Hurwitz, 2009). Furthermore, a close therapeu-
tic nurse-patient relationship has been shown to benefit both the patients who develop a greater sense of empowerment and security, and the nurses who experience an increased sense of satisfaction with their role (Finfgeld-Connett, 2008). For the patient in hospital, a connection and engagement with the nurses is a fundamental right of personhood (Dewing, 2008) and a major factor in facilitating a calm and secure milieu. The intersubjective connection between the nurse and the patient facilitates feelings of inclusion. Brannelly (2016) described the breakdown of the nurse-patient relationship as a denial of citizenship, and a demonstration of the oppression of patients with dementia as a marginalised group. Kitwood (1997, p. 46) wrote about what he described as “malignant social psychology” which he maintained was the detrimental psychological effect expe-

rienced by people with dementia when denied positive interpersonal relationships with others. According to Kitwood (1993), the course of the disease was not only influenced by the neurological degener-
ation of the brain but also by the person’s experiences and their dealings and relationships with others. In this study, there was clear evidence of the malignant social psychology described by Kitwood (1997) in the treatment of patients with dementia who were often denied the opportunity to contribute to the extent of their abilities (Kitwood, 1997). The effect of the nurse-patient interaction as an indicator of the patient experience is therefore significant and deserves to be better supported.

In summary, the patients with dementia in this study described a liminal experience in the hospital ward which was fuelled by the nurses’ lack of engagement and their failure to adapt practices to cater to the needs of people with cognitive impairment. The patients described feeling marginalised and not belonging in that environ-

ment: a situation which may have been eased by a more caring and connected relationship with the nurses.

5.2 Study limitations

There were some limitations in this study. The clinical team were the gatekeepers who identified the patients they considered were suitable participants for the study. They may have excluded patients with an alternative view. Patients with advanced dementia were excluded however eliciting the opinions of this patient group would be valuable should it be methodologically possible. People who were unable to have a conversation in English were excluded which meant that information about being in a foreign-language environment was not captured.
CONCLUSIONS

This research found that the patients with dementia frequently felt like outsiders in the hospital ward because of their inability to understand the environment and identify with the activity around them. Failing to include the patients in discussions about their own care and discharge planning contributed to feelings of being marginalised and not belonging. Additionally, the patients felt that the nurses were busy and did not foster the intersubjective relationship, preferring to focus on completing the tasks required. The extra care necessary for these patients was not acknowledged. As a result, the patients with dementia in this study experienced stigmatisation, boredom and sadness and described the liminal experience of being outsiders in the hospital environment.

It is clear that the incidence and prevalence of dementia is increasing and is likely to continue to increase in the coming decades. Provision needs to be made for hospitals to adapt and provide appropriate care for this patient group. Importantly, the model of nursing care requires review to ensure that nursing care adapts to the growing number of patients with dementia requiring hospital care. Further study is required to identify ways to expand education and appropriate support for nurses in this area, and to continue to include the voices of people with dementia in the discussion about care.

RELEVANCE TO CLINICAL PRACTICE

This study found that patients with dementia felt like outsiders in the hospital environment. This is of great significance to nurses who have the power to mitigate this by treating patients with dementia more inclusively. Care practices must be implemented in ways which acknowledge the additional resources required by this patient group. Awareness of stigmatised must be raised and nurses appropriately supported to care for this patient group in a person-centred way.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

CONTRIBUTIONS


REFERENCES


