MONASH University

The patient with dementia in sub-acute geriatric rehabilitation hospitals: a critical ethnography

by

Robin Digby

RN, MN (Nursing)

Monash University

Faculty of Medicine, Nursing and Health Sciences

School of Nursing and Midwifery

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'Nothing's lost forever. In this world, there's a kind of painful progress. Longing for what's left behind, and dreaming ahead.'

Tony Kushner, *Angels in America Part 2 Perestroika, Ozone monologue.*

"Men die as trees die, slowly, and frequently at the top first".

George Miller Beard*, Legal Responsibility in Old Age,* 1874.

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Dissemination of the findings

Publications:

Digby, R., Williams, A. & Lee, S. (2014). Nursing people with dementia in hospital *Australian Nursing and Midwifery Journal*, 21(7), 39-40.

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Conference presentations:

R Digby, A Williams, S Lee. (31 October- 2nd November 2016) *"The worthy patient in rehabilitation hospitals"* Alzheimer Europe Conference, Copenhagen, Denmark
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R Digby, A Williams, S Lee. (2-3 May 2014). "*Interviewing people with dementia using photo-elicitation techniques*". TQ2U 'Thinking Qualitatively' conference Melbourne

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Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Name: Robin Digby

Signature:

Date: 16 November, 2016

Declaration

Abstract

Introduction

This study investigated the care of people with dementia in sub-acute geriatric rehabilitation hospitals. Sub-acute care encompasses rehabilitation, palliative care, geriatric evaluation and management (GEM) and psychogeriatric care (Australian Institute of Health and Welfare, 2012b, p. 13) and is known as intermediate care in the United Kingdom (Nancarrow, 2007). The patients in sub-acute geriatric rehabilitation facilities have complex needs associated with chronic medical conditions related to ageing, and treatment is delivered by a multidisciplinary team. It has been previously reported that people with dementia can deteriorate cognitively and physically while in hospital are poorly supported by the hospital system (Australian Institute of Health and Welfare, 2015), have a negative experience of care (Cowdell, 2010b), and that nurses find caring for people with dementia a stressful experience (Griffiths, Knight, Harwood, & Gladman, 2014).

Aims

The aim of this study was to explore the experiences of people with dementia and nurses in sub-acute geriatric rehabilitation hospitals in order to offer a critical perspective of the widely reported poor care received by such patients. A further aim was to focus attention on the cultural and organisational factors which influenced care.

Method

This study used a qualitative design employing critical ethnography as the methodology. The data was collected in five wards in two metropolitan hospitals in Melbourne, Australia in 2014. Conversational semi-structured interviews were conducted with 30 inpatients with dementia and 29 nurses who volunteered to participate. In addition 120 hours of observation took place in the wards and patient progress notes and documentation was examined.

Findings

The findings of this study indicated that patients with dementia felt alienated in the hospital environment, were bored, homesick and often did not know why they were there. Nurses reported feeling over-worked, poorly supported and under-prepared educationally for the role. Nurse and patient participants described the efficiency-driven organisational focus as having a detrimental effect on caring practices. This view has also led many nurses to see patients with dementia as unworthy, and the patients themselves to feel alienated.

Conclusion

As the number of people with dementia in the community continues to rise, a focus on supporting patients and the nurses who care for them in sub-acute care is critical in order to concurrently improve the outcomes for patients and job satisfaction for the nurses.

Acknowledgements

I was motivated to explore the experiences of people with dementia in the hospital system by my involvement with many patients during my years of working in sub-acute rehabilitation facilities. The older patients with dementia are an almost forgotten group, and I see this thesis as a small step towards changing the culture of stigmatisation that is currently present in many hospitals.

I would like to take the opportunity to thank some of the people who have encouraged, supported and mentored me during my PhD.

Firstly and most importantly I wish to acknowledge and offer heartfelt thanks to my supervisors, Associate Professor Allison Williams and Associate Professor Susan Lee for the many hours of guidance, endless patience and encouragement they have provided during this PhD journey. I have the utmost respect for their knowledge and professionalism. Without their expertise, mentorship and belief in me, this would not have been possible. I am eternally grateful.

I also wish to thank Monash University for awarding me the Maxwell King scholarship and the Faculty Postgraduate Excellence Award which provided me with the opportunity to study full-time.

I would also like to sincerely thank the nurse managers, patients and nurses in the five wards where the study was conducted. I trust I have represented their views in a way that does them justice.

Finally I would like to thank my wonderful family for their continuing love, encouragement and patience.

Declaration

PART A: General Declaration

Monash University

Declaration for thesis based or partially based on conjointly published or unpublished work

In accordance with Monash University Doctorate Regulation 17.2 Doctor of Philosophy and Research Master's regulations the following declarations are made:

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes 3 original papers published in peer reviewed journals. The core theme of the thesis is 'The patient with dementia in sub-acute geriatric rehabilitation hospitals'. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the candidate, working within the School of Nursing and Midwifery under the supervision of Associate Professor Allison Williams and Dr Susan Lee.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapters 2 and 3 my contribution to the work involved the following:

Thesis chapter	Publication title	Publication status*	Nature and extent of candidate's contribution
2	The experience of people with dementia and nurses in hospital: an integrative review	In press	80% - Concept development and writing
2	Nurse empathy and the care of people with dementia	published	80%-Concept development and writing
3	Interviewing people with dementia in hospital: recommendations for researchers	published	80%-Concept development and writing

I have renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Signed:

Date: 16 November, 2016

Keywords

- Dementia

- Nursing

- Sub-acute care

- Experience of care

- Critical ethnography

- Geriatric rehabilitation

List of abbreviations

AD   Alzheimer's Disease

ANUM   Associate Nurse Unit Manager

BPSD   Behavioural and Psychological Symptoms of Dementia

EN   Enrolled Nurse

GEM   Geriatric Evaluation and Management

NOK   Next of Kin

OT   Occupational Therapy

POA   Power of Attorney

RN   Registered Nurse

VaD   Vascular Dementia

Key terms

Assistant in Nursing (AIN) - staff who have completed the Certificate III in Health Services Assistance in order to support registered nurses (RN) and enrolled nurses (EN) in the delivery of general patient care (Australian College of Nursing, 2014a).

Associate Nurse Unit Manager —a Registered Nurse who within the guidelines and practices established by the Nurse Unit Manager, assists in the overall clinical and administrative management of a ward or unit and deputises for the Nurse Unit Manager when required (Australian Nurses Federation Victoria, 2012).

Clinical supervision - is the process of two or more professionals formally meeting to reflect and review clinical situations with the aim of supporting the clinician in their professional environment (Fowler, 1996).

Code Grey - A code grey is a hospital-wide coordinated clinical and security response to actual or potential aggression or violence (unarmed threat) (Victoria State Government, 2014).

Critical ethnography - A form of ethnography incorporating a change orientated approach in which hidden agendas and power relationships are uncovered in order to identify ways to improve a situation (De Laine, 1997) .

Director of Nursing - A Registered Nurse appointed as the principal nursing executive officer, responsible for the nursing service (Australian Nurses Federation Victoria, 2012).

Empathy - is the capacity to understand or feel what another person is experiencing from within the other being's frame of reference (Halpern, 2003).

Enrolled Nurse (EN) - nurses who have completed hospital training or a Certificate or Diploma in Nursing. The course is currently delivered through the Vocation Education and Training (VET) sector (AHPRA, 2016).

Geriatric Evaluation and Management (GEM) services provide care in which the primary clinical purpose or treatment goal is improving the functioning of a person with multidimensional needs. These needs are associated with medical conditions related to ageing. They include falls, incontinence, reduced mobility, delirium and depression (Victoria State Government, nd-a).

Nurse caring - Nurse caring, for the purpose of this study has been defined according to Kostovich (2012, p. 169) as 'an intersubjective, human connectedness shared between the nurse and the patient'.

Nurse Unit Manager - The Nurse Unit Manager (NUM) is a registered nurse with responsibility for a ward, unit, service or team. The position combines leadership, management, clinical and teaching roles and is integral to the ability of the healthcare system to achieve quality patient care outcomes (Australian Nurses Federation Victoria, 2012).

Person-centred care: person-centred care is a central tenet underpinning the delivery of nursing care and health care generally. Person-centred care means: treating each person as an individual; protecting a person's dignity; respecting a person's rights and preferences; and developing a therapeutic relationship between the care provider and care recipient which is built on mutual trust and understanding (Australian College of Nursing, 2014b).

Photoelicitation - an interviewing technique in which photographs are used to stimulate a response in research participants (Hansen-Ketchum & Myrick, 2008)

Registered Nurse (RN) - nurses who have in most cases graduated from a university and met the requirements of the Australian Nursing and Midwifery Federation for registration (AHPRA, 2016).

Specials or Continuous Patient Observers (CPOs) - staff, often nurses or assistants in nursing who are assigned to spend the shift observing and monitoring a patient when there is a demand for increased level of observation and care. In GEM facilities this is often related to behavioural and psychiatric symptoms of dementia including when there is a risk to the patient or others, or increased risk of the patient falling or absconding (Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2011).

Sub-acute Care - The rehabilitation, palliative care, geriatric evaluation and management and psychogeriatric care facilities in which specialised multidisciplinary care is delivered to patients for whom the primary need is optimisation of functioning and quality of life (Victoria State Government, nd-b).

Volunteer – A person who voluntarily works in the hospital without getting paid. In the sub-acute geriatric rehabilitation wards volunteers are variously employed in patient contact and non-patient contact under supervision (Bateman, 2012).

Chapter 1 Introduction and background

Introduction to the study

This chapter provides an introduction to the study and the aims and objectives of the research. The background section provides insight into the details of dementia and the reasons from a neurological and cultural perspective why people with this condition have difficulties in the hospital environment. This chapter will present an overview of dementia including the syndrome progression, history of care and treatment, the government policies and guidelines which influence care practices, and the behavioural and psychological symptoms which often beset those admitted to hospital. This is crucial to understand the issues which patients and nurses who are the focus of this study confront. Beginning with an examination of the global incidence and prevalence of dementia, this chapter will outline the key background issues relevant to the care of patients with dementia in the Australian hospital system.

The media and the literature abound with reports that the incidence and prevalence of dementia is escalating and is expected to impact progressively more on health and welfare systems globally. The world population is getting older, increasing the number of people who have chronic conditions such as dementia related to advancing age (Knapp, Comas-Herrera, Somani, & Banerjee, 2007). The World Health Organisation (WHO) estimates that 35.6 million people across the world are living with dementia and the rate of diagnosis is accelerating with 7.7 million new cases identified each year (World Health Organisation, 2012). In Australia it is estimated that there are 298,000 people with dementia of whom 62% are female, however this number is considered conservative as dementia is often unrecognised or under-reported (Australian Institute of Health and Welfare, 2012a). The reasons for the increased incidence of dementia in women is due, in part to increased longevity. However it has also been suggested that brain metabolism may be affected by

falling oestrogen levels at menopause, leading to dementia (C. Carter, Resnick, Mallampalli, & Kalbarczyk, 2012). Dementia is the leading cause of death among women in the United Kingdom, and women are twice as likely to develop dementia as breast cancer (Savitch, Abbott, & Parker, 2015). The estimated mortality risk for people with dementia high-income countries is more than double that of people without dementia, and even larger relative risks have been recorded in studies from Nigeria and Brazil (World Health Organisation, 2012).

Dementia is defined as:

> *'...a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement'* (World Health Organisation, 2012, p. 7)

Dementia is the chronic condition that has been projected to show the greatest disease burden by 2023 (Low, Gomes, & Brodaty, 2008) and be one of the most costly (R. Cohen, 2013). Reasons for the potential increase in prevalence of dementia include an increase in life expectancy from birth, and improved medical and social care, which means that people are living longer with chronic conditions. However there is evidence that individuals are tending to develop dementia at a more advanced age and are being diagnosed at an earlier stage of the condition (Dening, 2013). There has been recent speculation that the incidence of dementia might not remain constant as first thought due to improvements in preventative health, diet, and education which increases cognitive reserve (Matthews et al., 2013). The situation is complex and not confirmed, although the fact that dementia rates are modifiable is important (Sachdev, 2014).

It is well-documented that people with dementia do not fare well in hospital from a range of perspectives (Moyle et al., 2011) and that nurses find caring for people with dementia stressful (Eriksson & Saveman, 2002). The purpose of this thesis is to critically evaluate this

situation by examining the evidence and coming to a final conclusion based on the most important factors uncovered in the data.

Dementia

Alzheimer's disease (AD) accounts for at least half of all cases of dementia and there is evidence that there is also an overlap between Alzheimer's disease and vascular dementia, with the aetiology of most cases being far from clear-cut (Peters, 2006). Recently however it has been recognised that vascular dementia is more common than previously thought and may be on the rise (Korczyn, Vakhapova, & Grinberg, 2012). Alois Alzheimer who first described the condition in 1906, identified that there was degeneration of the smaller cerebral blood vessels at a cellular level and a co-occurrence of plaques and neurofibrillary tangles in people with dementia on autopsy (van Norden et al., 2012). Although there is still much to be known about the biological causes of Alzheimer's disease a genetic component is rare, accounting for up to 5% of cases (H. Bartlett, Gray, Byrne, Travers, & Lui, 2006). Diabetes is a major risk factor for the development of Alzheimer's disease (Halling & Berglund, 2006; Wolozin, 2006) especially when combined with the other components of the metabolic syndrome which include hypertension, obesity and high cholesterol (Hughes & Ganguli, 2009).

It has also been argued by some that dementia is not merely a neuro-physiological condition but is instead a physical problem which combined with societal attitudes and management cause a person to develop in a certain way (Kitwood, 1997a). Kitwood has maintained that "a malignant social psychology may actually be damaging to nerve tissue (and that) dementia may be induced in part, by the stresses of life" (p 19) although this claim has not been proven. The culture of care which focuses on the biomedical aspects may be misplaced, as in some cases the lived experience and the subjectivity of the person are not adequately considered when the focus is on the physical illness of the person (Kitwood, 1997b). If Kitwood is correct, then expert, holistic, person-centred empathetic nursing care is very important to these patients.

People with Alzheimer's disease initially show signs of memory deficits which gradually progress to global cognitive impairment leading eventually to death, however the course that the condition takes in individuals is variable (Lopez & Becker, 2004). In comparison to other forms of dementia, the progression of Alzheimer 's disease can be relatively slow with short-term memory loss and difficulty with language gradually becoming more severe over a period of years (H. Bartlett et al., 2006).

Vascular dementia (VaD) is the second most common cause of dementia and is due to cerebral atherosclerosis caused in part by small infarctions in the brain which lead to a chronic reduction in blood flow (Jellinger, 2008). The development of dementia is shown in the presence of vascular risk factors, transient ischaemic attacks, strokes, and white matter ischaemic changes on Magnetic Resonance Imaging (Kirschner, 2009), however pure VaD is relatively rare and most patients diagnosed with the condition also have evidence of AD on autopsy (H. Bartlett et al., 2006).

Other forms of dementia include Lewy body dementia in which accumulations of a protein called alpha-synuclein in abnormal spherical structures (Lewy bodies) cause the degeneration and death of brain nerve cells (Leyhe, Darreh-Shori, Laske, Mielke, & Maetzler, 2013). Recurrent complex visual hallucinations are present in up to 80% of patients, with postural instability and gait disturbance also prominent symptoms (H. Bartlett et al., 2006). Many people with Parkinson's disease develop a similar type of dementia and the reason for this is unknown (Leyhe et al., 2013).

Fronto-temporal dementia is the name given to a group of less common dementias including Pick's disease affecting the frontal or temporal lobes of the brain leading to progressive non-fluent aphasia. Pick's Disease is a relatively uncommon type of dementia which has an uncertain aetiology and is characterized by early onset and frontal lobe-type changes resulting in grossly insensitive behaviour and disinhibition (Thompson, 2006). The symptoms of frontal lobe damage are mainly related to personality and behavioural

disturbances including disinhibition, distractibility, and inertia, while the temporal lobe changes can result in severe expressive language disorders (H. Bartlett et al., 2006). The different types of dementia result in a range of variable symptoms hence it is important that nurses and other clinicians have a good understanding of the type of dementia affecting the patient as the behaviour can be significantly different between diagnoses.

Behavioural and psychological symptoms of dementia

Behavioural and psychological symptoms of dementia (BPSD) is a term used to describe some behavioural issues commonly found in people with dementia which are potentially disturbing to the person and their carers, including aggression, agitation, anxiety, depression, sleep disturbance, wandering and psychosis (Backhouse, Killett, Penhale, Burns, & Gray, 2013; Gustafsson, Sandman, Karlsson, Gustafson, & Lövheim, 2013). BPSD are evident in 50-80% of people with dementia and are an important focus of treatment and management as they can severely impact on the quality of life of the person and the burden experienced by caregivers (Lü et al., 2013). The reason that people with dementia exhibit these symptoms is thought to be due to their reduced capacity to interpret and understand their environment and manage stressors, in addition to the effects of neurological damage associated with the condition (K. Moore, Ozanne, Ames, & Dow, 2013). Changes in the environment (for example when a person is admitted to hospital) can trigger serious behavioural disorders and disorientation because of an increase in the activity of the hypothalmo-pituitary-adrenal axis (Fauth, Zarit, Femia, Hofer, & Stephens, 2006). Most people with dementia will experience at least some BPSD over the course of the condition particularly when cognitive and functional decline is advanced (Hort et al., 2010).

Management of BPSD is initially focused on non-pharmacological strategies, however using this approach is more common in the community where carers are typically close relatives and have a greater moral investment in caring for the person in this way. Strategies such as redirection, physical activity, identifying and avoiding triggers for BPSD, accepting and learning to work around the symptoms, validation or going along with the person's reality,

are often used by family carers (K. Moore et al., 2013). However in the hospital environment it is more difficult for nurses and other staff to identify triggers for BPSD and to manage the patients in these often successful but time-consuming ways (Ervin, Cross, & Koschel, 2013). Additionally, understanding the patient, their specific health and psychological needs and the impact of the environment is complex and may be beyond the capacity of some staff (Aberdeen, Leggat, & Barraclough, 2010). Nevertheless person-centred care which respects and acknowledges the basic human needs of the individual and personalises treatment and care to meet these needs has been shown to be successful and is recommended (Kitwood, 1997a).

Progression of dementia

People with dementia have an increased mortality which is influenced by not only the neurodegeneration associated with the various conditions but also by other factors such as co-morbidities, age, ethnicity, gender and education (Todd, Barr, Roberts, & Passmore, 2013). Alzheimer 's disease is the most common form of dementia and is considered a terminal chronic neuropathological illness (Appleby & Cummings, 2013). Dementia of all types is incurable however the exact mechanism of why this is the case is not well understood (Australian Institute of Health and Welfare, 2012a). Commonly the reduced survival rate is related to complications associated with severe cognitive decline such as malnutrition, pneumonia and other infections (Todd et al., 2013). Death typically occurs after a long period of disability complicated by a high rate of comorbidity (Brown, Sampson, Jones, & Barron, 2013).

History of care and treatment for people with dementia

In the 19th century, people described as having dementia, some of whom actually had schizophrenia, (also known as dementia praecox), or an acquired intellectual deficit, were cared for in asylums along with other people with mental health conditions described as mania, melancholia and moral insanity (S. A. Hill & Laugharne, 2003). The inmates of such asylums were viewed as deviants rather than people with treatable health conditions and the

care was custodial rather than therapeutic (Kobrynski & Miller, 1970). Senile dementia was not described as a discreet condition until the turn of the century (S. A. Hill & Laugharne, 2003).

In 1906 Alois Alzheimer presented the first case of the condition which is now called Alzheimer's disease (Jay, 2013). Dr Alzheimer followed the case of Auguste D., a 51 year old woman who developed cognitive problems in 1901, until her death in 1906, at which time he examined her brain for pathological evidence. This showed many abnormal plaques and fibrils indicating that the condition was related to deterioration of the brain matter and in fact was a distinct disease (Maurer, 2006).

In the 20th century attitudes slowly changed, however the person with dementia was still considered by some to be a shell of their former self that was gradually eroded in a process described as 'an unbecoming' (Fontana & Smith, 1989, p. 37) or dementia as a 'death which leaves the body behind' (Kitwood, 1990). The person with dementia was often described as the victim, the sufferer (Heston & White, 1983) or 'the demented' (Jorm, 1987, p. 12; Wells, 1979, p. 45), reinforcing the 'otherness' and exclusion of people with this diagnosis (Sabat, Johnson, Swarbrick, & Keady, 2011). Naue and Kroll (2009) point out that labelling someone a 'demented patient' rather than a 'patient with dementia' is using the adjective to describe the person themselves and thus reduces their identity to being defined by the condition; a demented other. Additionally the word 'demented' as described in the dictionaries of last century means 'madness, insanity, irrationality and strangeness', not specifically dementia (Sabat et al., 2011, p. 284).

The focus of most of the last century was on the burden and cost to the community, the relatives and carers, and very little consideration was given to what it was like for the person with the condition. The person with dementia was situated as the cause of the problem and largely ignored as an individual (Marshall, 2001). As a result people with dementia were not treated as persons, but instead were confined by rigid rules and boundaries which satisfied

the needs of the institutions rather than the individual (Clare, Rowlands, Bruce, Surr, & Downs, 2008). The view of dementia as being an erosion of the self and personhood has implications for care-giving. Quality person-centred care is not possible if nurses believe that the patient with dementia is a non-person.

The concept of person-centred care for people with dementia was first described by Kitwood (1995) who maintained that there had previously been a disproportionate emphasis on the pathology of dementia with a resultant neglect of other aspects of the person such as relationship, emotion and sensation. The idea of 'malignant social psychology' was a way of explaining the harmful effect that treating a person with dementia as an empty shell or a non-person had on the progression and effects of the condition (Kitwood, 1997a, p. 45). The implementation of person-centred care for people with dementia in hospitals and residential care has since been championed by Dewing (2010), McCormack (2003) Røsvik, Brooker, Mjorud, and Kirkevold (2013), Poole (2009) and others including the Victorian government (Victoria State Government, 2015).

Biophysical care

 The dominant paradigm in Western hospitals remains the rational, analytic biomedical model which is based on the premise that ill-health is caused by identifiable physical abnormalities which are treated according to the results of examination and tests (Feo & Kitson, 2016). This model dominated throughout most of the 20th century despite the efforts of Engel (1977) to introduce an holistic alternative known as the biopsychosocial model. Engel (1977) proposed that the biomedical approach was excessively narrow and that illness was caused by a combination of not only physical, but also psychological and social factors which each needed to be addressed in order to improve the health of the patient. This perspective was contrary to the concept of the "body as a machine" which had been the prevailing standard until that time, and championed the idea that the subjective experience of the patient had a measurable effect on health (Borrell-Carrió, Suchman, & Epstein, 2004, p. 577).

Despite this, there remains a view that curing and caring are a dichotomy in which the curing is managed by the doctors and the caring administered by the nurses. Through the elevation of curing as most important and the devaluation of caring (which historically was considered to be women's work and of lesser value), medicine maintains power in the healthcare hierarchy (Treiber & Jones, 2015).

Dementia as a gendered issue

Women are not only disproportionately represented in the population who develop dementia (World Health Organisation, 2012), but 70% of family caregivers (C. Carter et al., 2012) and the majority of paid carers are women (R. Bartlett, Gjernes, Lotherington, & Obstefelder, 2016). R. Bartlett et al. (2016) observed that despite this obvious gender bias there is very little reference in the literature or indeed the national dementia strategies, to the issue of gender in dementia, with most authors using gender-neutral terms such as *people* with dementia.

The issue of gender is relevant in this thesis both from the perspective of the nurses and the patients. Nursing is historically a female occupation dependent on the social construction of nursing as 'women's work' (Simpson, 2011). Furthermore despite women forming the majority of the health workforce, they are under-represented in managerial and decision-making positions in hospitals and thus the specific problems faced by women patients and nurses may not receive due attention (World Health Organisation, 2010).

Person-centred care for people with dementia

Person-centred care for people with dementia was a concept first described by Kitwood (1997a) to describe an approach which embraces the personhood of the individual despite cognitive impairment. The key features being that the person experiences a sense of attachment, inclusion, identity, occupation and comfort, and they are respected and valued as a social being (Clissett, Porock, Harwood, & Gladman, 2013a) rather than a technical problem in need of medical and behavioural management (Kitwood, 1988). The central tenet

was that not being recognized as a person caused the ill-being rather than the cognitive impairment per se (Røsvik et al., 2013). In Kitwood's view the problem was not due only to the neurological condition, but "...the process of dementia is also the story of a tragic inadequacy in our culture, our economy, our traditional views about gender, our medical system and our general way of life" (Kitwood, 1997a, p. 41).

Kitwood (1997a) has been credited with being the first to describe the concept of person-centred care for people with dementia. He did this in response to the reductionist biomedical view of dementia in which the person is viewed as the sufferer of a neurodegenerative disease, for which there is no cure and consequently no need for consideration of the person's experience. Person-centred care was described by Røsvik, Kirkevold, Engedal, Brooker, and Kirkevold (2011, p. 156) in the VIPS practice model as having four major elements:

> V - A value base that asserts the absolute value of all human lives regardless of age or cognitive ability;
>
> I – An individual approach, recognising the uniqueness of the person living with dementia;
>
> P – Understanding the world from the perspective of the person living with dementia;
>
> S – Positive social psychology in which the person living with dementia can experience relative well-being.

These principles can be applied in any situation and are not about the details of the tasks, but the way that the tasks are approached by the nurse which make them person-centred or not (Røsvik et al., 2011). More specifically, interactions with people with dementia should move beyond the focus on the technical to recognise that all human life including that of people with dementia is intersubjective or grounded in relationships (L. Hill, Roberts, Wildgoose, Perkins, & Hahn, 2010).

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Developing a culture of care in acute hospitals which embraces people with dementia in social relationships and meaningful activity is not without significant challenges. Person-centred care is tailored to meet the needs of the person with dementia rather than the needs of the staff, the routines of the hospital or assumptions made about the person (Surr, Smith, Crossland, & Robins, 2016). Nurses who see their primary role as caring for people with acute physical illnesses are not well placed to take this view. Staff may have difficulty seeing their actions as therapeutic especially in late stage dementia and hence they may consider practice change to be futile (Smythe, Bentham, Jenkins, & Oyebode, 2015)

Current treatment of dementia

In general there are two main approaches currently used in the treatment and management of dementia.

1. Non-pharmacological therapies which aim to improve cognitive function and behaviour using techniques grounded in psychotherapy or complementary medicine, and

2. Pharmacological treatment which uses medications to either improve cognitive functioning or modify behaviour.

The New South Wales (NSW) Health and Royal Australian and New Zealand College of Psychiatrists (RANZCP) (2013) prioritizes the application of non-pharmacological interventions for the management of agitation and aggression in the first instance. They stress that the physical needs of the person must be addressed before further treatment is considered, as the behaviour may settle with these measures alone. Since all forms of dementia are considered incurable, the focus of treatment is generally on slowing the progression of the condition and stabilising symptoms (Hort et al., 2010).

Non-pharmacological treatment

It has been established that empathetic care in which people with dementia are treated in a person-centred way leads to fewer episodes of behavioural symptoms (Edvardsson, Sandman, Nay, & Karlsson, 2008). Therefore the use of a holistic philosophy of care which involves the interdisciplinary team and family members, and adapts the environment and the care principles to the needs of people with dementia are both better for the patients and can result in fewer episodes of BPSD, a reduction in staff stress and a decreased length of stay in hospital (Edvardsson, Nilsson, Fetherstonhaugh, Nay, & Crowe, 2013). Patients with dementia being cared for by overworked staff who do not believe that the patients have the capacity to engage in personal interactions is a common occurrence and leads to a focus on the physical tasks (Hopper, 2003). Protests from the patients are then seen as problem behaviour (Marshall, 2001) or a symptom of the disease rather than a function of being treated in dysfunctional ways (Sabat et al., 2011).

Complementary treatment including aromatherapy (O'Connor, Eppingstall, Taffe, & van der Ploeg, 2013), snoezelen therapy (Klages, Zecevic, Orange, & Hobson, 2011) and acupuncture (Kwok et al., 2013) have been applied in some instances with a variety of results but are not widely used in hospitals. The evidence for the use of other complementary therapies including gingko biloba, vitamin E, melatonin, light therapy and hormone therapy to slow the progression of the condition or stabilise symptoms is inconclusive (H. Bartlett et al., 2006).

Pharmacological treatment

Increasingly pharmacological treatment especially antipsychotics are used to control BPSD in hospitals and residential care facilities where human resources are in demand and the knowledge and education of the staff about dementia management strategies may not be sufficient (Ervin et al., 2013). It is important to identify and treat physical symptoms such as pain, cold, discomfort, or neglect and consider the side effects of other pharmaceutical treatment such as anti-cholinergics and cholinesterase inhibitors which may trigger

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hallucinations and BPSD and are relatively easy to rectify before antipsychotics are considered (Fauth et al., 2006). The use of psychotropic drugs for the control of BPSD is controversial because of the high risk of adverse effects such as extrapyramidal symptoms, stroke and falls, and the potential for accelerated cognitive decline in older people (Gustafsson et al., 2013). Nonetheless, these medicines are a popular choice in residential care facilities (Backhouse et al., 2013).

Haloperidol is a neuroleptic which is often used to control agitation in people with dementia by modifying dopamine receptors, despite the potential for side effects such as tardive dyskinesia, over-sedation, parkinsonian manifestations such as rigidity and tremor, and malignant neuroleptic syndrome (Lonergan, Luxenberg, Colford, & Birks, 2002). A Cochrane systematic review was unable to identify a justification for routine use in people with agitation because of potential side-effects in some patients (Lonergan et al., 2002).

Many people with dementia are prescribed anti-depressant medication however these drugs have been shown to increase verbally disruptive and attention-seeking behaviour in some individuals and may also worsen depression and increase mortality (Gustafsson et al., 2013). The rationale for the use of anti-depressant medication use is that many facilitate serotonergic neurotransmission known to be reduced in Alzheimer's disease and the restoration may result in an improvement in behaviour, although the justification for their use is poor (Seitz et al., 2011).

Pain can be present in people with advancing age due to medical conditions such as musculo-skeletal conditions, vascular disease, wounds or malignancy. People with dementia may be unable to communicate their symptoms due to limited language, memory or ability to reflect, however it may present as agitation, aggression, apathy or depression and lead to pharmacological treatment designed to address those disorders instead of the underlying pain (Husebo, Ballard, & Aarsland, 2011). It is therefore important to perform thorough pain

assessments on people with dementia who have BPSD before medication commences, as it may be analgesia that is required (Husebo et al., 2011).

Guidelines for the care of people with dementia in Australian hospitals

Clinical practice guidelines (CPG) for the care of people with dementia in the community, residential care and hospitals in Australia have recently been released to improve the consistency of the information and support for the workforce and families engaged in care relationships (Laver et al., 2016). The guidelines have 109 recommendations based on person-centred principles. Central to these are the individual needs and preferences of the person with dementia and their carers and family based on a systematic approach to assessment and care. The guidelines endorse and promote the 10 principles of dignity in care (Dignity in Care Network, 2013). Recommendations relevant to this study include that health professionals should receive comprehensive role-appropriate training (attitude, knowledge and skill development) based on established programs which have been shown to optimise the care and treatment of people with dementia, focussed on teaching staff how to understand, communicate and respond to the person. It is recommended that behavioural and psychological symptoms of dementia are formally assessed and treated without the use of antipsychotic medications. Independence, strength and mobility should be maintained with regular exercise and support (Laver et al., 2016).

The Australian CPG was yet to be published when the current study was conducted, however other guidelines including the VicHealth document 'Keys to person-centred care: Person with dementia' (Victoria State Government, 2015) had many similar recommendations. These include that the person with dementia must be cared for as a whole individual with a unique social, cultural and individual identity, not just in terms of physical care. The importance of support and education for staff was emphasised.

The Australian Government Department of Health, Ageing and Aged Care developed a National Framework for Action on Dementia 2015-2019 which extended the work done on a previous framework developed by the Australian Ministers' Advisory Council in 2006 (AHMC, 2006). The original 2006 document outlined the broad parameters of care which included that people with dementia had specific needs to be considered throughout all aspects of care including the community, hospital and aged care. A particular focus was the comprehensive assessment of the requirements of the person and their carers and family, and an individual rather than a generic response (AHMC, 2006). A well-supported workforce was considered essential to the outcomes (AHMC, 2006).

The recently updated and expanded framework Australian Government Department of Health and Ageing (2015) proposed that in hospital settings the carers and family of the person with dementia should be consulted and included in care planning, and that the behavioural and psychological symptoms of dementia should be viewed as symptoms of the person's unmet needs. The targeted education and training of health professionals was stated to be an integral component of implementing appropriate care for people with dementia in hospitals.

The United Kingdom-based NICE (National Institute for Health and Care Excellence) guidelines (National Collaborating Centre for Mental Health, 2006) on which the expanded Australian framework was based additionally suggested that dementia training should be incorporated in all undergraduate and postgraduate health professional programs. The NICE guidelines offered advice based on the principles of person-centred care for dementia.

The common features of these papers include the recommendation that person-centred care must be the priority for people with dementia, underpinning all encounters with both the person and family carers. This is supported by appropriate training programs for staff so that they have the ability to recognise, prevent and manage behavioural and psychological symptoms and translate person-centred principles into practice. None of the guidelines included suggestions for funding models, budgets or specified nurse-patient ratios.

Sub-acute geriatric rehabilitation

Geriatric Evaluation and Management (GEM) wards care for a large proportion of patients with dementia who undergo a period of therapy to improve mobility and function and determine the most appropriate discharge destination (Australian Institute of Health and Welfare, 2013b). The majority of patients with dementia are initially admitted to an acute hospital with an acute health problem in which dementia is a co-morbidity rather than the reason for admission, but because of the physical and mental frailty associated with dementia they require a period of GEM care following the acute episode (Australian Institute of Health and Welfare, 2012a). The term 'subacute care' was first used in Australia in 1992 to describe patients whose use of hospital services was better predicted by their functionality than by their principal medical diagnosis (Poulos & Eagar, 2007). Sub-acute care is defined as 'rehabilitation, palliative care, geriatric evaluation and management (GEM) and psychogeriatric care' (Australian Institute of Health and Welfare, 2012b). The patients in GEM facilities have complex needs associated with chronic medical conditions related to ageing, and treatment is delivered by a multidisciplinary team. In other parts of the world comparable care facilities exist, including in the United States where it is more loosely defined to include a broad range of medical and rehabilitative services and settings that provide care to post-acute patients (U.S. Department of Health and Human Services, 1994). Similarly in the United Kingdom 'Intermediate Care' provides a range of services to this patient group including community-based, hospital in the home, and hospital facilities (Nancarrow, 2007).

The focus of this thesis will be the care of people with dementia in sub-acute care as there are specific problems associated with the care of this patient group that require redress. The issues differ significantly from acute care because the length of stay in sub-acute care is considerably longer and the focus changes from addressing the acute reason for admission to maximising mobility and function and planning for the future. The poor outcomes for people

with dementia have been extensively documented previously, but very little research has investigated the reasons for this situation in sub-acute geriatric rehabilitation hospitals.

In Victoria, Australia where this study is set, nurse staffing in public hospitals is governed by the Nurses and Midwives (Victorian Public Health Sector) (Single Interest employers) Enterprise Agreement 2012-2016. For GEM beds, the nurse–patient ratio for morning shifts is 1:5 plus in-charge, for afternoons it is 1:6 plus in-charge and at night it is 1:10 (including in-charge). A registered nurse has completed a university degree in nursing or hospital-based training, whereas an enrolled nurse has a diploma-level qualification in nursing, commonly from the Vocation Education and Training sector or is hospital-trained (Australian Nurses Federation Victoria, 2012). The proportion of enrolled and registered nurses on a shift varies, but there must always be an Associate Nurse Manager in charge of the ward. The exact skill-mix, which is the proportion of different levels of nurse (Jacob, McKenna, & D'Amore, 2015) is not specified. In contrast the nurse-patient ratios in acute care are 1:4 plus in charge for the morning and afternoon shifts and 1:8 at night, and the target skill-mix is 1/3 registered nurses with over 3 years' experience and up to 20% enrolled nurses (Australian Nurses Federation Victoria, 2012).

This study

Little research has occurred which examines the care of people with dementia in subacute geriatric rehabilitation facilities where a large number of patients are transferred after an acute hospital stay. This study has investigated the experience of people with dementia and nurses in order to add to the existing information already known.

Study aim

The aim of this study was to explore the experiences of people with dementia and nurses in sub-acute geriatric rehabilitation hospitals in order to offer a critical perspective of the widely reported poor care received by such patients. A further aim was to focus attention on the cultural and organisational factors which influenced care.

Study objectives

The objectives of the research were to:

1. Understand the viewpoint of patients with dementia and nurses in sub-acute geriatric rehabilitation facilities

2. Determine the dominant influences affecting nursing practice in this area.

3. Draw conclusions about the relationship of hospital culture and processes on the experiences of patients with dementia and nurses.

The central research question is:

"What are the factors which impact on the care of people with dementia in sub-acute geriatric rehabilitation hospitals"?

Scope of the study

The scope of this study was to explore the experiences of the patients with dementia from their own viewpoint. In the past it was thought that people with dementia could not have a valid opinion because of cognitive deficits, however it has since been established that this is not the case, and the person is often able to comment on the issues affecting them (Dewing, 2002).

Significance of the study

This study provides a unique insight into the institutional and cultural factors which influence the experience of people with dementia and the nurses caring for them in sub-acute facilities. The study is significant because of the increase in the number of people with dementia and the need for quality care in hospital. This study provided a critical evaluation of the forces shaping care in this context shown through the intersubjective experiences of the participants.

Overview of the study

This thesis is formatted in seven chapters. In chapter one, the background describes the global situation of increasing incidence and prevalence of dementia and the current treatment being offered. The nature of sub-acute care in Australia and the characteristics of the model of nurse staffing employed in these facilities has been added for context. A section on behavioural and psychological symptoms of dementia provides additional perspective.

Chapter two provides a literature review of the issues involved for people with dementia and nurses. There is very little written specifically about sub-acute care, so in order to have a broad examination of the topic, an integrative review was conducted to include studies set in either acute or sub-acute hospitals and elicited the direct viewpoint of either people with dementia in hospital or the nurses caring for them (Digby, Lee, & Williams, 2016a). Residential care was excluded as the issues in care homes are different because it is the person's permanent place of residence and the staffing profile is dissimilar. Further literature examining other issues relevant to this topic was added to this chapter in addition to the published integrative review in order to broaden understanding. Additionally a published article 'Nurse empathy and the care of people with dementia' (Digby, Williams, & Lee, 2016) provided further insight into the topic.

Chapter three describes the methodology issues and research design, and chapter four outlines the methods employed. A qualitative design was undertaken in order to facilitate an understanding of the way that the protagonists understand and construct meaning in their world (Liamputtong & Ezzy, 2005). Critical ethnography was chosen in order to piece together the experiences of both parties to build a cultural critique of the forces which contributed to this scenario. Ethnography shares epistemological foundations with constructionism in that both see reality as being a construct or based on the intersubjective shared meanings created by people in their interactions with each other (Crotty, 1998). A critical perspective takes into consideration the power relations that are inherent in hospital hierarchies. An explanation of the ethics procedures, interview techniques, and population,

recruitment process and research settings is outlined, followed by an account of the data collection and analysis process.

The outcome of the data analysis is discussed in chapter five. During analysis themes were derived from the transcribed interviews with the nurses and patients with the aid of Nvivo 10 software (QSR International Pty Ltd, 2012) and further information gained from extensive observation periods and examination of documents. Finally three main themes with a number of sub-themes were identified. These themes were further discussed in chapter six delving deeper into the meaning behind the findings and referring to the work of others.

Chapter seven draws together the major conclusions and recommendations of the study and proposals for further research in this area.

Chapter summary

Dementia is increasing globally and the repercussions for health services are significant. An increasing number of patients admitted to sub-acute geriatric rehabilitation facilities have dementia as a co-morbidity, and specific needs which are a result of this cognitive impairment. Currently nurses have a limited understanding of dementia, and hospitals in Australia are not well placed to accommodate these patients.

This study uses a critical ethnographic methodology to explore and understand the factors contributing to the experiences of the participants and develop a cultural critique of the forces affecting the care of people with dementia in sub-acute care. There is no known critical ethnography which has previously focussed on this group in sub-acute geriatric rehabilitation facilities.

In the following chapter a literature review will be presented which seeks to identify information about the care of people with dementia in hospitals from the perspective of patients and nurses.

Chapter 2 Literature review

Introduction

This chapter examines literature related to the experience of people with dementia in hospital, in response to the research problem identified in chapter one. The purpose of this chapter is to identify what contributions have already been made towards understanding the research topic and to identify the gaps in research to date.

There are three parts to this chapter. Firstly, the publication *The experience of people with dementia in hospital: an integrative review* (Digby, Lee, et al., 2016a) is presented. This review identified and examined the existing research that has explored how people with dementia and the nurses caring for them viewed the experience of care in hospital. An integrative review was considered the most appropriate approach because the technique of reviewing, critiquing and summarising the literature on the topic facilitated the identification of areas which required further research (Whittemore & Knafl, 2005). As there is very little literature which is set in sub-acute care, the search was expanded to include acute hospitals because of the similarities with the sub-acute setting. Both acute and sub-acute hospitals have a relatively short patient length of stay and the staffing profile of these facilities is mainly registered and enrolled nurses. This is unlike residential care which is permanent long-term accommodation for the residents, and is staffed by assistants in nursing supported by some registered and enrolled nurses (Australian Nurses and Midwifery Federation, 2015).

The strong viewpoint of the nurses about the care of people with dementia identified in the integrative review lead to further exploration on the topic of empathy and lead to an additional publication 'Nurse empathy and the care of people with dementia'.

Publication 1: The experience of people with dementia and nurses in hospital: an integrative review

The experience of people with dementia and nurses in hospital: an integrative review

Authors:

Ms Robin DIGBY,

RN, MN.

PhD candidate

Monash University

PO Box 190

Sorrento, VIC 3943

+61 400892518

rdig1@student.monash.edu

Dr Susan LEE

PhD, MBioeth, BAppSci (Nsg Ed)

Director Research Degrees

Nursing and Midwifery

Monash University

Peninsula Campus

PO Box 527

Frankston, VIC 3199 Australia

Publication 1: The experience of people with dementia and nurses in hospital: an integrative review

+61 9904 4204

susan.lee@monash.edu

Associate Professor Allison WILLIAMS,

RN, PhD, MN

Director, Monash Nursing Academy

Monash University

Clayton Campus

Room 323, 35 Rainforest Walk

Wellington Road

Clayton, VIC 3168 Australia

+61 3 9904 4377

allison.williams@monash.edu

Abstract

Aims and objectives:

To identify and examine existing research exploring how people with dementia and nurses

view acute hospital care.

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Background

Admission to hospital can be traumatic for a person with dementia due to an inability to cope with unfamiliar environments, faces and routines. Adverse behavioural and health outcomes can result. Dementia adds complexity to patient care. Inability to deliver appropriate care is a source of stress and frustration for nurses.

Methods

Integrative review of the literature 2005-2015 reporting the experience of people with dementia and nurses caring for them in an acute hospital setting (n= 24).

Results

Hospitals focus on acute medical care; consequently people with dementia are considered low priority and a disruption to normal routine. Risk management often takes priority over patient dignity.

People with dementia are stigmatised. Families have significant roles to play in the care of a person with dementia in hospital but are often excluded.

Nurses struggle to complete even basic patient care, and focus on tasks often at the expense of specific patient needs. Support for nurses is lacking. The job satisfaction of nurses caring for people with dementia is poor.

Conclusions

Nurses require improved education and support to care for patients with dementia. Hospitals must focus on genuine caring concurrently with rapid discharge requirements, risk mitigation and fiscal restraint. More research is needed to inform the development of appropriate care for people with dementia in hospitals.

Relevance to clinical practice:

Nurses must understand the complex needs of people with dementia in hospital. Nurse education about dementia, practical support, strong clinical leadership and role-modelling is needed. Empathy for patients regardless of diagnosis must remain a core attribute of nurses. Current hospital culture requires wider system review to mitigate against stigmatisation of patients with dementia.

Summary Box

What does this paper contribute to the wider community?

- People with dementia often have a poor experience in hospital due the inability of the hospital system to accommodate the specific needs of this patient group. Enhancing awareness of this problem is a positive step towards rectifying it.
- This paper highlights the deficits in education and support for nurses caring for people with dementia in hospital.
- Stigmatisation of people with dementia has been identified and must be remedied.

Key words: Dementia, care experience, nurses, hospitals, integrative literature review.

The experience of people with dementia and nurses who care for them in hospital: an integrative review

Introduction

The number of people with dementia is increasing world-wide presenting a major challenge to health systems which must adapt to the needs of the many patients who will be admitted with this condition as a co-morbidity (Prince *et al.* 2015). A person with dementia can find admission to hospital a traumatic experience due to a limited ability to cope with a strange environment, faces and routines (Eriksson & Saveman 2002). This can result in a range of adverse behavioural and health outcomes which can be distressing for the individual, their

families and the staff caring for them, and may unnecessarily extend the person's length of stay in hospital (Moyle *et al.* 2008).

Dementia and the related behavioural issues add another layer of complexity for nurses caring for patients on a busy ward. In the majority of cases people with dementia admitted to the hospital system have dementia listed as an additional diagnosis rather than the principal reason for admission, and in some cases the person may have dementia but be undiagnosed (AIHW 2012). Nurses consequently report a number of challenges which include feeling ill-informed or unprepared to deal with patients with dementia and the associated behaviour in an environment which is already under pressure because of inadequate resources and pressure to increase patient throughput. Being unable to deliver the most appropriate care is a source of stress and frustration for nurses (Byers & France 2008).

The World Health Organization (WHO 2012) advise that people with dementia and their caregivers have a significant and unique perspective on this situation and therefore should be involved in formulating policy, plans and services which relate to them. People with dementia have traditionally been omitted from direct participation in research, although family carers have been included to a limited extent (Moore & Hollett 2003).

The reason for this exclusion is because the deterioration in cognitive and verbal skills associated with the condition have led to the view that the input of this group is not valid (Nygård 2006). However this attitude is neither person-centred nor legitimate as it has been demonstrated that people with dementia can contribute to research and can add significantly to the body of knowledge about care and treatment (Beuscher & Grando 2009, Dewing 2002). Accessing the opinions of people with dementia is fundamental in order to reframe dementia through personal narratives and take the spotlight away from the biomedical focus on loss and burden. If people with dementia are not viewed as having a valid contribution to make they can be ignored (Beard *et al.* 2009) and the barriers which prevent the inclusion of their opinions in care planning will remain (Webster 2011). Older people with dementia have

rarely been asked to discuss their experiences of hospitalization, to the detriment of our understanding (Atwal *et al.* 2007).

Similar reviews in relation to this topic have been undertaken previously. Dewing and Dijk (2016) published a literature review which was wide-ranging in scope, discussing and comparing the results of peer-reviewed journal articles, reports, policy documents and theses on the subject of the acute care of older people with dementia in general hospitals. Dewing and Dijk (2016) used the review of Moyle *et al.* (2008) who examined the theoretical and research-based literature related to the management of people with dementia in hospital as a baseline and focussed on literature that had been published more recently. Turner *et al.* (2015) conducted a meta-synthesis of the literature focussed on the experience of staff caring for patients with dementia in general hospital settings. This review contributes a new perspective which is primarily based on the direct feedback of the key players, namely the patients with dementia and the nurses who care for them in hospitals.

Aim

The aim of this literature review was to identify and examine the existing research that has explored how people with dementia and the nurses caring for them view the experience of care in hospital.

Methods

An integrative review is a method of reviewing the literature on a topic by reviewing, critiquing and summarising that which has been written in the literature previously about a particular issue in order to form a more comprehensive understanding and generate new perspectives (Torraco 2005, Whittemore & Knafl 2005). In addition the integrative review method is useful for identifying the gaps in current research (Russell 2005). An integrative review was determined to be an appropriate method to explore the literature on this topic as nurses and patients have issues which are separate but closely intertwined because of their

interdependent relationship. In this paper the views of the two groups will be investigated and the results integrated in a discussion.

The questions that are the focus of this review are as follows:

- What impact does dementia have on the experience of patients in hospital?
- How do people with dementia perceive the attitude of staff to their illness?
- What is the experience of nurses caring for people with dementia in hospital?

Search strategy

An extensive literature search was conducted using the databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid Medline and Scopus. The literature dated 2005- 2015 was searched for relevant material using Boolean technique in which two or more terms were searched and combined with AND, OR and NOT. The literature of the past ten years was considered to be appropriate for this review in order to reflect recent issues arising from pressures of an aging population on health systems. In addition, the bibliographies of significant articles were hand-searched for further relevant articles using an ancestry approach. A search of author names from major studies was conducted to determine if the author had written other work on a similar topic.

The criteria for inclusion was that the main focus was on the care of people with dementia in hospital, and the research was based on the direct viewpoint of either people with dementia or nurses caring for them. Only primary qualitative studies published in English in peer-reviewed journals during 2005 – 2015 were considered. Quantitative research was excluded in order to ensure that the direct opinions of the nurses and patients were the focus.

Articles were excluded if the main focus was residential or community care or the information was the opinions of others such as family carers or students. Theoretical articles, literature reviews, surveys and articles written from a biomedical viewpoint were also excluded.

The key search terms and MeSH terms used were as follows:

Dement*, Alzheimer's disease, cognitive impair*, hospital, ward.

Staff, nurs*, patient, person.

A flow chart of the search strategy can be viewed in Figure 1.

Figure 1

Critical appraisal

Each identified article was critically appraised using the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (CASP International Network 2013). The CASP appraisal tool uses 10 questions which are designed to assist the researcher to think about the articles systematically, particularly in regard to the following three broad areas: 'Are the results of the review valid?', 'What are the results?', and 'Will the results help locally?' (CASP International Network 2013). The 10 questions commence with two screening questions which determine if it is worth proceeding further, and these are followed by more specific questions which assist in establishing the quality and strength of the research.

After screening with the CASP tool, the main identified weaknesses of the articles were that they were conducted in one specific setting with a small number of participants (Arnold & Mitchell 2008, Byers & France 2008, Cowdell 2010a, b, Digby & Bloomer 2014, Digby *et al.* 2012, Edvardsson & Nordvall 2008, Edvardsson *et al.* 2012, Harrison & Zohhadi 2005, Moyle *et al.* 2011, Nolan 2006, Norman 2006) which limits the transferability of the results. Ethical issues were not discussed in three of the articles (Atkin *et al.* 2005, Griffiths *et al.* 2014, Nolan 2007) and discussion of the relationship between the researcher and the participant was omitted from 11 of the 24 articles (Arnold & Mitchell 2008, Atkin *et al.* 2005, Borbasi *et al.* 2006, Byers & France 2008, Edvardsson & Nordvall 2008, Fukuda *et al.* 2015, Moyle *et al.* 2011, Nilsson *et al.* 2013, Nilsson *et al.* 2015, Nolan 2007, Scerri *et al.* 2015) Additionally

the participant demographic details provided were either limited or not specified (Arnold & Mitchell 2008, Atkin *et al.* 2005, Borbasi *et al.* 2006, Byers & France 2008, Harrison & Zohhadi 2005, Hynninen *et al.* 2015, Moyle *et al.* 2011, Nilsson *et al.* 2013, Scerri *et al.* 2015) although in the case of Borbasi *et al.* (2006) inclusion of demographic details was mentioned, but the authors deemed it to be unnecessary. There was a predominance of studies which used participants from the same ward or site, making the transferability of results limited (n=15). One study included the demographic information of patient and family carer participants, but not of the formal carers whose opportunistic conversations were quoted in the results (Clissett *et al.* 2013). In some cases the discussion of the results was very brief (Atkin *et al.* 2005, Byers & France 2008, Digby *et al.* 2012, Scerri *et al.* 2015).

The main strengths identified in the included articles was that the impact of participation for patients with dementia was considered (Cowdell 2010a, b, Digby & Bloomer 2014, Digby *et al.* 2012, Porock *et al.* 2015), the data was obtained from multiple sites (Clissett *et al.* 2013, Fukuda *et al.* 2015, Porock *et al.* 2015), or the discussion incorporated good use of the evidence identified in the study (Edvardsson & Nordvall 2008, Goldberg *et al.* 2014, Harrison & Zohhadi 2005, Moyle *et al.* 2011, Nilsson *et al.* 2013, Nilsson *et al.* 2015, Nolan 2006, Norman 2006, Porock *et al.* 2015). The strengths and weaknesses of the articles are outlined further in Table 1.

The results discussed in the identified articles were analysed using the thematic analysis method described by Braun and Clarke (2006). To begin with, each one was examined, and the themes and ideas which had been identified by the authors during their research were extracted and tables created. Broad codes were developed based on the recurring concepts, and the prevalence of certain themes was determined. Discussions were conducted between the authors in order to come to a consensus on the most appropriate structure and names for the themes. Six recurrent themes were identified: priorities of care, nurse education, stigmatisation of people with dementia, risk management in the ward environment, the input

of family carers, and nurse job satisfaction. The themes related to both patients and nurses are discussed below in narrative form.

Characteristics of the included studies

Despite the 1270 articles initially located, after screening the titles and abstracts for relevance and removing duplicates, 24 articles remained for inclusion for full CASP appraisal (CASP International Network 2013).

The country of origin of the articles was weighted strongly to the U.K. (n=10), followed by Sweden (n=4) and Australia (n=4). Single examples were identified from the U.S., Japan, Finland and Malta, and two from Ireland.

Sixteen articles were identified which primarily examined the perspective of nurses and eight studies reported the perspective of patients, although because of the closely entwined issues there was some overlap. Of the 24 articles, four used focus groups to explore the viewpoint of nurses (Arnold & Mitchell 2008, Atkin *et al.* 2005, Fukuda *et al.* 2015, Harrison & Zohhadi 2005) and eight articles used observational methodology which included opportunistic conversations with participants (Clissett *et al.* 2013, Cowdell 2010a, b, Edvardsson *et al.* 2012, Goldberg *et al.* 2014, Nilsson *et al.* 2013, Norman 2006, Porock *et al.* 2015). Two studies used data drawn from the same study and had a major component of observation followed by interviews with patients and/or family care-givers conducted in their homes following discharge (Clissett *et al.* 2013, Porock *et al.* 2015), one study included interviews with both patients and nurses (Cowdell 2010a) and one augmented a long period of observation with formal interviews with nurses (Nilsson *et al.* 2013). Twelve articles were primarily based on the results of interviews with either patients or nurses (Borbasi *et al.* 2006, Byers & France 2008, Digby & Bloomer 2014, Digby *et al.* 2012, Edvardsson &

Nordvall 2008, Griffiths *et al.* 2014, Hynninen *et al.* 2015, Moyle *et al.* 2011, Nilsson *et al.* 2015, Nolan 2006, 2007, Scerri *et al.* 2015).

In three cases, more than one article was written using the data from the same studies although there were some slight differences in interpretation in each article (Cowdell 2010a, b), (Nolan 2006, 2007) and (Clissett *et al.* 2013, Porock *et al.* 2015). In the case of data being referred to in more than one article, the data was counted only once for each study in the review.

Table 1: Overview of included studies investigating the experiences of people with dementia and nurses in hospital.

Priorities of care

Three articles reported that the patient with dementia was considered to present a disruption to the normal routine and an obstacle in the delivery of medical care to other patients (Atkin *et al.* 2005, Clissett *et al.* 2013, Harrison & Zohhadi 2005). Despite the increasing prevalence of patients with mental health conditions nurses continue to believe that physical treatment is their primary concern (Atkin *et al.* 2005, Clissett *et al.* 2013, Moyle *et al.* 2011) and patients with dementia are a low priority in comparison to those with acute health issues (Griffiths *et al.* 2014, Harrison & Zohhadi 2005, Moyle *et al.* 2011, Nilsson *et al.* 2013, Nilsson *et al.* 2015), although Fukuda *et al.* (2015) reported that in Japan, a higher priority is given to patients with dementia in order to prevent liability issues. Acute hospitals are fast-paced, inflexible, disease-orientated and driven by budgetary constraints in an environment often unsuitable for patients with dementia (Borbasi *et al.* 2006, Moyle *et al.* 2011, Nilsson *et al.* 2015). The unrealistic workload and inadequate staffing contribute to poor quality care for patients with dementia (Byers & France 2008, Hynninen *et al.* 2015, Nilsson *et al.* 2013, Nilsson *et al.* 2015, Scerri *et al.* 2015).

Eight articles reported that nurses tend to focus on tasks rather than care which is centred on the specific needs of a patient (Arnold & Mitchell 2008, Atkin *et al.* 2005, Borbasi *et al.* 2006, Byers & France 2008, Cowdell 2010b, Goldberg *et al.* 2014, Harrison & Zohhadi 2005, Moyle *et al.* 2011). The delivery of routine physical care such as hygiene, medication administration and toileting often takes up the majority of nurses' time and is frequently delivered in a functional manner with very little personal engagement (Goldberg *et al.* 2014, Griffiths *et al.* 2014, Moyle *et al.* 2011). Nurses may respond to their own feelings of anxiety and uncertainty by avoidance and depersonalisation of patients (Harrison & Zohhadi 2005). Goldberg *et al.* (2014) noted that patients were often ignored and staff did not introduce themselves as they delivered routine care such as delivering food trays, checking charts and tidying up. Borbasi *et al.* (2006) described situations such as this as a suspension of the patient's personhood and was also demonstrated in situations where the nurse ignored patient requests, was unsympathetic to their distress or unfairly prioritised the care of others. Remaining distant and disconnected from the patient was interpreted as the nurse gaining control and prioritising their own needs ahead of those of the patient (Borbasi *et al.* 2006). In some instances nurses appeared to have suspended compassion for the patients with dementia in the quest to get the work done rather than finding ways to overcome the difficulties they face (Moyle *et al.* 2011), however nurses who were able to summon patience and calm were more likely to make the experience for patients with dementia a favourable one (Scerri *et al.* 2015).

In a study set in the UK, (Cowdell 2010a, b) patients with dementia when directly asked about their interactions with the nurses, reported that the care was ~~perfunctory~~ done in a routinised way that satisfied the requirements, but was not centred on the person's needs. A patient described an example of an uncaring nurse-patient interaction: '...I felt terrible, nobody come to see you and said to you what's the matter or nothing... they didn't care, so long as they come in and you see 'em and they see you, that's all that matters' (Cowdell 2010a). Cowdell (2010b) and Clissett *et al.* (2013) described instances where patients

suffered and showed obvious distress during care delivery but staff ignored their protests and specific needs in order to get the work done. Similarly in the study conducted by Edvardsson and Nordvall (2008) in Sweden, the nurses conveyed their lack of concern for the patients by their haste and manner. An Australian study (Moyle *et al.* 2011) also found that the interactions between patients and nurses were almost entirely focused on tasks, delivered with very little compassion. However for the patients, the quality of the care is the most important component of being in hospital, above the quality of their surroundings and other factors (Digby & Bloomer 2014).

The hospital admission of a person with dementia has a disruptive effect on the patient, their family and the staff; the reactions of each influencing the others (Fukuda *et al.* 2015, Porock *et al.* 2015). The psychological environment of the hospital ward is a complex interplay of interactions between the different groups, with the staff acting as catalysts for the emotional climate (Edvardsson *et al.* 2012, Porock *et al.* 2015). Staff who delivered care in a task-focused way without engaging with the patients risked marginalising the patients and prompting agitated or aggressive behaviour. In contrast staff who were available and engaged with the patients, involving them in conversation and meaningful activity had the opposite effect on the psychological climate of the ward and the patients' experiences (Edvardsson *et al.* 2012).

Education of nurses

Lack of education about mental health conditions was discussed in ten of the articles, in relation to nurses reporting that they felt under-prepared and lacking in the skills necessary to care for people with dementia (Arnold & Mitchell 2008, Atkin *et al.* 2005, Borbasi *et al.* 2006, Cowdell 2010a, b, Fukuda *et al.* 2015, Griffiths *et al.* 2014, Harrison & Zohhadi 2005, Hynninen *et al.* 2015, Norman 2006). The education that nurses in acute health have received both in general terms, and specifically related to cognition, has a direct bearing on

their ability to care effectively for people with dementia (Borbasi *et al.* 2006, Eriksson & Saveman 2002, Griffiths *et al.* 2014, Moyle *et al.* 2011). Acute care nurses tend to lack specific knowledge about dementia and may not understand the difference between acute and chronic confusional states, resulting in care that is superficial and generalised for an older person rather than specific to the condition (Moyle *et al.* 2011). Atkin *et al.* (2005) reported that the nurses in their study considered that caring for such patients was outside their competencies and that they needed ongoing training and role-modelling. In the United Kingdom the general nurse training curriculum contains only a small mental health component which is apparently inadequate to prepare nurses for the care of such patients (Arnold & Mitchell 2008, Griffiths *et al.* 2014). Participants in the study by Arnold and Mitchell (2008) reported that few had received any mental health education since obtaining their nursing qualification, and that the doctors were in a similar position. Education during training and subsequently was focussed almost entirely on physical care, contributing to the hospital emphasis on treatment of physical illness as the priority (Arnold & Mitchell 2008).

Nurses who have had previous experience in caring for people with dementia can be a significant asset to the ward team and support more appropriate care (Borbasi *et al.* 2006, Griffiths *et al.* 2014). In contrast, lack of education, in-services and experience in managing mental health issues lead to the provision of sub-optimal care for people with dementia in acute wards (Fukuda *et al.* 2015, Griffiths *et al.* 2014).

Harrison and Zohhadi (2005) discussed the problem of a lack of preparedness as being divided into resources which were internal to the nurse such as skills, knowledge and time, and external including inadequate access to training, support, and clinical supervision. They also reported that there was a perceived lack of understanding and unrealistic expectations on the part of the hospital management. Education was seriously lacking and in some cases this led to professional distress for nurses who felt inadequate and ill-equipped to deal with patients with mental health problems (Borbasi *et al.* 2006, Griffiths *et al.* 2014, Harrison &

Zohhadi 2005). Support for the well-being of nurses was described as vital but not always apparent in health systems (Hynninen *et al.* 2015).

To understand patients' actions and deal with challenging behaviours including aggression, nurses need to understand confusion and the underlying conditions (Griffiths *et al.* 2014). In some instances, a lack of education and knowledge led to nurses using physical force or chemical restraint in order to complete tasks for uncooperative patients (Nilsson *et al.* 2015). Nurses described the frustration and guilt they felt when this was the case, attributing the poor care to their lack of skill (Nilsson *et al.* 2015).

Nurses often relied on their own philosophies of care, personal experience and ward culture rather than education or standardised guidelines to influence their care practices (Cowdell 2010b, Fukuda *et al.* 2015, Nilsson *et al.* 2013). Nurses reported being more confident delivering physical care and had difficulty dealing with emotional issues or behavioural symptoms (Cowdell 2010b).

Stigmatisation of people with dementia

Fifteen of the 21 articles representing 13 studies, discussed the stigmatisation of people with dementia, mainly in reference to the different treatment received by this patient group in relation to other patients (Arnold & Mitchell 2008, Borbasi *et al.* 2006, Clissett *et al.* 2013, Cowdell 2010a, b, Digby *et al.* 2012, Edvardsson & Nordvall 2008, Goldberg *et al.* 2014, Harrison & Zohhadi 2005, Moyle *et al.* 2011, Nilsson *et al.* 2013, Nilsson *et al.* 2015, Nolan 2006, Norman 2006, Porock *et al.* 2015). Categorising a person as having a mental health condition can lead to labelling and singling people out for different treatment, as a result of nurses not looking for the person behind the condition (Arnold & Mitchell 2008, Atkin *et al.* 2005, Borbasi *et al.* 2006, Clissett *et al.* 2013). Some of the nurses in these studies considered that people with dementia should be cared for in other facilities because acute hospitals are ill-equipped to deal with behavioural symptoms (Borbasi *et al.* 2006, Harrison & Zohhadi

2005, Moyle *et al.* 2011). This may also be because staff consider patients with dementia to be a nuisance or an inconvenience in the acute setting where staff are struggling to keep pace with even routine care (Moyle *et al.* 2011). As a consequence, the negative attitude of nurses to the patient with dementia turns the attention away from addressing their needs to looking for ways to move the patient out of the ward (Moyle *et al.* 2011). Additionally the nurses working in acute wards who do not see the care of patients with dementia as part of their job may feel that the presence of such patients devalues their role (Borbasi *et al.* 2006, Cowdell 2010a, Moyle *et al.* 2011, Nilsson *et al.* 2013). Importantly nurses have a significant impact on the ward culture and the general attitude to patients with mental health diagnoses (Borbasi *et al.* 2006, Edvardsson *et al.* 2012).

Patients with dementia who are quiet, cooperative and happy to remain seated are deemed acceptable in the acute ward but often receive less time than other patients who are more challenging (Cowdell 2010a, Nilsson *et al.* 2013, Nilsson *et al.* 2015, Norman 2006) however those who are confused, demanding or resistant to care can trigger feelings of anger and inadequacy in nurses (Nilsson *et al.* 2015). Nurses often view these patients as reduced to their parts which require specific action in a reductionist manner of a biomedical model (Norman 2006). As a consequence of minimal engagement and a focus on routine tasks, patients frequently report feeling devalued and bored (Edvardsson & Nordvall 2008).

Stigmatisation of people with dementia was also found to occur when nurses labelled patients according to their diagnosis or behaviour especially the behaviour that disrupted routine care delivery (Arnold & Mitchell 2008, Atkin *et al.* 2005, Norman 2006). Stereotyping is entrenched in some areas and staff frequently fail to see the person behind the illness (Borbasi *et al.* 2006). Dementia was downplayed as a diagnosis by a nurse quoted by Atkin *et al.* (2005) who said disparagingly "You don't die of confusion", suggesting that the nurses' priority belonged with the care of others who were more physically unwell.

Shift handovers can perpetuate the labelling of patients (Arnold & Mitchell 2008). A patient who has been described as confused by one nurse can carry the label of confusion throughout

their hospital stay, with little regard being paid to mitigating factors such as the change in environment or the part that staff behaviour plays in the way patients react (Arnold & Mitchell 2008). It has been observed on occasion that nurses labelled patients according to their behaviour, discriminated against people with dementia and treated them differently, even cruelly (Atkin *et al.* 2005, Digby *et al.* 2012, Griffiths *et al.* 2014). Instances of nurses panicking, shouting or avoiding patients were noted (Griffiths *et al.* 2014). Similarly Clissett *et al.* (2013) observed that nurses sometimes put their own needs before those of the patients, chose not to engage with them despite the opportunity arising, or assumed an officious curt manner. Such behaviour was attributed to the nurse seeking to gain a sense of control in the face of a disruption to the work environment. Mockery and unsympathetic response to a distressed patient were cited as examples of unprofessional behaviour (Clissett *et al.* 2013).

In five articles it was reported that nurses made derogatory remarks about the patients either directly to them or within earshot, or the nurses discussed the patient in front of them as if they weren't there (Cowdell 2010a, Digby *et al.* 2012, Edvardsson *et al.* 2012, Goldberg *et al.* 2014, Norman 2006). The patronising attitude of the staff was not altogether lost on the patients, some of whom remarked on this (Cowdell 2010a, Digby *et al.* 2012). In the study by Edvardsson and Nordvall (2008) one of the patients felt the stigmatisation acutely: "... they toss me my sandwiches the way you would do a dog". In another study a patient with some insight admitted that he avoided saying that he was confused about something as it would be interpreted by the staff that he had dementia and they would treat him differently (Digby *et al.* 2012). Patronising language is common and contributes to the denial of the recipient's individuality and shows a lack of respect (Digby *et al.* 2012, Norman 2006).

Focus on safety (ward environment)

Hospitals are required to cater to the needs of a wide range of patients and staff but in many instances the buildings are outdated, over-crowded, noisy and unsuitable, even dangerous,

for people with dementia (Borbasi *et al.* 2006, Fukuda *et al.* 2015, Porock *et al.* 2015). Ten of the 24 articles cited the constantly changing, busy hospital environment as a problem to this patient group because it is noisy and unfamiliar and can consequently escalate anxiety and trigger behavioural responses (Borbasi *et al.* 2006, Cowdell 2010a, b, Digby *et al.* 2012, Edvardsson & Nordvall 2008, Fukuda *et al.* 2015, Hynninen *et al.* 2015, Nilsson *et al.* 2013, Nolan 2007, Scerri *et al.* 2015). Porock *et al.* (2015) emphasized the effect that the disruption caused by admission to hospital on the person with dementia, and also the family caregivers, staff and other patients. Porock *et al.* (2015) described the way that the family and the health professionals reacted, as strategies to gain a sense of control for themselves, demonstrated in different ways. For the person with dementia, manifestation of this control could mean purposeful behaviour such as wandering, interfering with other people's possessions or calling out (Porock *et al.* 2015).

Managing patient safety with insufficient resources is a serious challenge for nurses; however the priority given to risk management can lead to some inappropriate and unnecessary interventions which gives primacy to the prevention of falls and infections, and swift discharge at the expense of person-centredness (Clissett *et al.* 2013, Moyle *et al.* 2011, Nilsson *et al.* 2015). Patient dignity can be overlooked in the quest for the safety of the person with dementia or other patients and staff (Moyle *et al.* 2011). Inappropriate interventions can include physical or pharmacological restraint which might prevent the patient from absconding or falling but can lead to other problems such as pressure areas, excessive drowsiness and de-conditioning (Borbasi *et al.* 2006, Moyle *et al.* 2011). In one study, restraint of patients with dementia was routine (Hynninen *et al.* 2015). The focus on surveillance of at-risk patients who need to be constantly checked could also result in less attention being paid to other patients on the ward (Fukuda *et al.* 2015, Goldberg *et al.* 2014, Nilsson *et al.* 2015, Nolan 2007).

Adapting care to cope with patients' behavioural symptoms without additional resources adds to the challenge of delivering safe, dignified care (Nilsson *et al.* 2015). Moyle *et al.* (2011)

described the use of chemical or physical restraint, often with the assistance of security guards, as a method used at times to manage aggressive or violent patients. Despite this being a poor alternative to more person-centred approaches such as looking for the reason for the confusion or agitation, restraint was justified by the staff as a way of ensuring patient and staff safety. Nilsson *et al.* (2015) observed that nurses resorted to physical force at times when they felt that they were unable to communicate with patients yet still had a responsibility to complete care tasks. Acting in a way which is clearly against the patient's will is a form of assault however the nurses stated that they felt justified when they considered that the actions were in the best interest of the patient (Nilsson *et al.* 2015). Hynninen *et al.* (2015) reported that chemical and physical restraint was used at staff discretion, especially when there was no personal nurse supervision available.

Having an additional amount of supervision for patients with dementia often does not result in an increase in meaningful interaction (Moyle *et al.* 2011). When cost considerations permit, hospitals use 'specials' who are staff assigned to continuously observe a patient for the shift to prevent the patient from falling, harming themselves or others, absconding, and to allow staff to deliver care to other patients. However 'special' staff are not specifically expected to deliver care or diversional therapy to the patient with dementia (Moyle *et al.* 2011). The use of 'specials' may result in fewer falls but does not necessarily improve the care for the patient and in fact may lead to an escalation in anxiety if the patient feels that their physical space is invaded (Moyle *et al.* 2011).

Family

The involvement of the family in the care of the person with dementia in hospital was discussed in 12 of the 24 articles (Borbasi *et al.* 2006, Clissett *et al.* 2013, Digby & Bloomer 2014, Digby *et al.* 2012, Fukuda *et al.* 2015, Goldberg *et al.* 2014, Hynninen *et al.* 2015, Moyle *et al.* 2011, Nilsson *et al.* 2013, Nolan 2006, Porock *et al.* 2015, Scerri *et al.* 2015).

In many instances family support is a significant source of comfort to a person with dementia who is in a strange environment. Help with decision-making, and reassurance that someone is acting in their best interest is comforting and may lessen anxiety (Digby *et al.* 2012, Edvardsson & Nordvall 2008). Inclusion of the family can also be important from the perspective of the family who have a close relationship with the patient (Digby *et al.* 2012).

Building a relationship between the staff and the relatives of a patient with dementia is important, as family can be a valuable source of information and assistance (Fukuda *et al.* 2015, Hynninen *et al.* 2015, Nolan 2007, Scerri *et al.* 2015). Family members, which may include a loving life partner, may often have been caring for a person with dementia for many years at home before the person's admission to hospital, and the admission can cause serious disruption to the lives and experiences of the carer (Porock *et al.* 2015). In many cases the person with dementia will be unable to provide personal information; however the family may have experiential knowledge and valuable insight to contribute as an alternative or adjunct (Hynninen *et al.* 2015, Nolan 2007). The family carer then becomes an integral member of the care 'triad' which comprises the hospital team, the family and the patient (Adams & Gardiner 2005). However staff do not always welcome the input of family or welcome their presence despite the additional help and information that the family can provide (Clissett *et al.* 2013, Goldberg *et al.* 2014). The family were generally considered assets to the care of a patient with dementia however there was the potential for conflict between family and staff and within the family, especially in regard to unscrupulous behaviour on the part of family members or a dispute about the discharge destination (Borbasi *et al.* 2006, Nolan 2007). In Japanese culture it is expected that the family will attend to their relative with dementia while they are in hospital, however this situation has the potential to spark conflict when the family and the nursing staff do not agree on goals of care, or if the family are not willing or able to cooperate (Fukuda *et al.* 2015).

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Even though family involvement in care was acknowledged as being beneficial, Moyle *et al.* (2011) found that there was no clear strategy to ensure that hospital staff included the family in discussions. In many instances family involvement was left to the family to initiate, and the focus of the nurses remained with acute medical issues. The family may also have issues such as grief or embarrassment that could be addressed by the staff, however many nurses do not consider supporting the family as part of their role which remains primarily centred on the direct needs of the patient (Nolan 2007).

Job satisfaction

Ten studies revealed that caring for people with dementia could impact negatively on the job satisfaction of nurses (Arnold & Mitchell 2008, Byers & France 2008, Clissett *et al.* 2013, Cowdell 2010a, Fukuda *et al.* 2015, Griffiths *et al.* 2014, Harrison & Zohhadi 2005, Hynninen *et al.* 2015, Moyle *et al.* 2011, Nilsson *et al.* 2015). The reasons for dissatisfaction stemmed mainly from feelings of inadequacy and lack of education in mental health disorders (Arnold & Mitchell 2008, Byers & France 2008, Clissett *et al.* 2013, Cowdell 2010a, Fukuda *et al.* 2015, Griffiths *et al.* 2014, Harrison & Zohhadi 2005, Hynninen *et al.* 2015, Nilsson *et al.* 2015) and the insufficient resources with which nurses are expected to manage people with dementia in the acute ward environment (Arnold & Mitchell 2008, Byers & France 2008, Clissett *et al.* 2013, Fukuda *et al.* 2015, Harrison & Zohhadi 2005, Hynninen *et al.* 2015, Moyle *et al.* 2011, Nilsson *et al.* 2015).

The disruption caused by patients with mental health problems, was a cause of professional frustration for nurses who saw their efforts as exhausting, draining and ultimately futile. If nurses do not believe that their efforts are worthwhile or effective then job satisfaction is generally poor (Harrison & Zohhadi 2005, Nilsson *et al.* 2015). Nilsson *et al.* (2015) described instances of nurses who ignore a patient's screams or constant calls for attention because of the necessity of attending to other duties. The result is poor job satisfaction and avoidance of critical reflection in order to avoid burnout. Nurses can feel offended and

irritated when they are insulted or physically abused by patients and such situations compromise both personal and professional integrity (Nilsson *et al.* 2015).

The time-consuming care of people with dementia places additional demands on nurses who are working in an environment which is already under intense pressure. Because there is inadequate time allocated to administer even routine care, nurses focus on getting the basic work done, and people with dementia are viewed as highly problematic because they absorb additional time resources (Borbasi *et al.* 2006, Goldberg *et al.* 2014, Harrison & Zohhadi 2005). Nurses need to feel that their work is valuable and respected by others but caring for people with dementia is often seen as unskilled, routinised, mundane and not prestigious which may also be a reflection of society's attitudes (Cowdell 2010b).

Discussion

This integrative review examined the existing literature on the experience of care in hospitals as perceived by patients with dementia and nurses. The majority of the articles suggest that the experience of being in hospital is very unsettling to the person with dementia and is poorly supported by hospital staff. A complex array of factors which include in some instances the nurses' lack of interpersonal qualities and education about dementia is blamed for this negative experience. Most of the studies discussed in the reviewed literature were too small to transfer the findings to other situations, however in combination the evidence from these small studies gathers weight (Rozas & Klein 2010).

In many of the articles the actions and interventions of the nurses and other health professionals were reported to have a significant impact on the patients. Interactions with nurses have the potential to be both helpful and stabilising or alternatively increase the patient's feelings of alienation. When nurses focus on tasks with minimal engagement with the patients, and the patients feel largely ignored, an already challenging experience can be made even worse. A consequence of the lack of preparedness of acute hospitals and staff to care for this patient group can be a poor quality experience for the patients and nurses alike.

People with dementia are already stigmatised by society in general (Blay & Peluso 2010); unfortunately this stigmatisation also appears to be prevalent in the hospital environment. An understanding of the part that their approach and attitude plays in influencing patient behaviour would be beneficial to nurses and other health professionals and positively affect the care of patients with dementia. Learning to use appropriate strategies would lead to a calmer environment for staff and patients. Stigmatising those who have this condition, including suggestions that they should be treated elsewhere, is pointless and delays addressing the issues. Nurses must learn to accommodate patients with dementia in general hospital wards, especially in relation to the specific needs created by the patients' compromised ability to understand new environments.

Greater inclusion of families in the care of people with dementia results in a better experience for patients, family carers and nurses (Adams & Gardiner 2005). The presence of family can allay anxiety in the patients and provide helpful information and an additional resource for time poor nurses. More research is needed in this area to identify clear strategies for health services to involve families in the care and support of patients with dementia in a more structured way.

Many nurses feel that they are lacking the skills required to manage patients with dementia and reported receiving very little education about dementia, relying instead on their own philosophies of care based on personal beliefs rather than knowledge (Arnold & Mitchell 2008, Borbasi *et al.* 2006, Moyle *et al.* 2011). Greater confidence in attending to physical care adds to the dominance of the physical rather than psychosocial focus. As a consequence of poor job satisfaction, nurses view caring for people with dementia as unskilled, not prestigious and low on the list of career aspirations (Cowdell 2010b, Griffiths *et al.* 2014). Improving education for nurses about dementia is an important priority which could improve confidence and skill in this area and potentially increase job satisfaction for nurses as well as improving the standard of care for people with the condition. Expecting nurses and other

staff to care for people with dementia who require complex, time-intensive and skilled care without appropriate preparation to equip them for the role is unrealistic and doomed to fail.

Some nurses do not have the personal qualities including empathy and emotional intelligence necessary to meet the needs of people with dementia with complex health and behavioural issues (McPherson *et al.* 2016). There are opportunities for further research on aspects of nurse recruitment, education and support which would both identify ways to recognize staff who are appropriate for this role and then support and equip them during their practice. None of the articles in this review reported that the nurses received any significant mentoring or clinical supervision despite this being identified previously as beneficial (Edberg *et al.* 1996). Tom Kitwood (1997) wrote about the selection and support required for nurses working with people with dementia in his seminal work 'Dementia Reconsidered: the person comes first'. Kitwood pointed out that the staff must be looked after from a material, psychological and educational perspective in order to have the ability to care effectively for people with dementia. Recruitment of appropriate staff for the job should go beyond qualifications, to ensure that the employee has the appropriate attitude and disposition for the work (Kitwood 1997).

Despite none of the articles in this review reporting that the nurses in their studies had regular access to staff with specialist dementia or mental health skills, there is evidence in other literature that including specialist practitioners in the team improves care for people with dementia. Borbasi *et al.* (2006) and (Griffiths *et al.* 2014) advocate for the involvement of a range of staff qualified in this area including gerontology nurse practitioners and dementia-friendly volunteers. Initiatives such as The Dementia Friendly Hospital Initiative Education Program in the United States (Palmer *et al.* 2014) and The Dementia Champions Programme in Scotland (Banks *et al.* 2014) could be applied more widely to improve nurses' understanding and skills related to dementia. Similarly the experience of others in the implementation of specialist cognition nurses in acute hospitals could be consulted in order to improve support for nurses and patients (Elliot & Adams 2011, Griffiths *et al.* 2015). In

some hospitals, initiatives involving the use of ward volunteers have been successful in engaging patients with dementia in conversation and activities, allowing the nurses time to attend to other duties (McDonnell *et al.* 2014).

Some positive experiences were identified in this review. Scerri *et al.* (2015) discussed the importance of supporting the care relationship between the nurse and the patient. Getting to know each other was beneficial to both parties: the nurses felt that they understood the meaning behind patient behaviour and the patients were more relaxed with staff who were known to them. The participants in this study spoke about the staff spending quality time with the patients and in some instances going the extra mile when they carried out actions which were not specifically part of their role (Scerri *et al.* 2015). The organisational determinants were also acknowledged, especially in relation to the additional staffing levels required for this type of care. However this was a barrier for many of the other hospitals in the reviewed articles which were disproportionately focused on discharge planning, risk management and the treatment of acute illness without due consideration or the financial resources for other factors. Whilst it is acknowledged that financial considerations are important it appears that in some instances, efficiency has been misinterpreted to exclude empathetic care.

This integrated literature review has some limitations. Despite being carefully and systematically undertaken, the process may not have uncovered all the relevant literature on this topic. Due to the small number of articles which met the inclusion criteria, and the similarity of methodological approaches, an element of bias may have been introduced.

The majority of the articles in this review were conducted in the United Kingdom, Sweden or Australia, with only one from the United States two from Ireland by the same author using the data from one study, one from Finland, one from Japan and one from Malta. The narrow range of locations makes transferability to other areas problematic. Notably there were no

studies identified which examined the perspective of nurses or people with dementia in central European hospitals where there may be considerable differences in the care of people with dementia in hospital. The exclusion of articles written in languages other than English is a limitation which could have contributed to this omission. It has been reported elsewhere that in Spain, the care of people with dementia is managed largely by the family, although as in other cultures, the last 30 years have seen changes in family living arrangements which have added challenges to these arrangements (Rivera *et al.* 2009). Similarly in Greek society the focus on the close family relationships is reinforced when a parent develops dementia, making the expectation of all parties, that a family care arrangement will occur (Botsford *et al.* 2012). Addressing the issue of family involvement in hospital care more formally and improving the relationship between nurses and families may improve the hospital experience for the patients with dementia.

The experience of Japanese nurses discussed by Fukuda *et al.* (2015) has some parallels with those of nurses in the other studies; however there are some significant cultural differences in Japan which make direct comparisons difficult, notably the expectation of family involvement in the direct care of the patient, and the low nurse staffing levels and status (Fukuda *et al.* 2015). Other Asian countries are not represented in this review.

Conclusion

This review draws attention to the shortcomings of acute hospitals in providing care for people with dementia. Nurses are not appropriately supported by hospital administration, and the required resources are not consistently provided. The review identified that stigmatisation of patients with dementia occurs in hospital settings and that nurses feel ill-equipped to provide care to people with dementia. Furthermore, the fast-paced, noisy, acute hospital environment has the effect of increasing the disorientation and agitation of patients with dementia adding to the distress already caused by the disruption to normal routine.

Additionally the dominant medical model of care is focused on acute illness, and dementia is considered low priority.

Nurses require education and increased support from hospital administrators to better cope with the needs of patients with dementia. It is important that nurses apply the same empathetic care to this patient group as to all others; however dementia is currently a stigmatised condition along with mental illness and older age, and there is insufficient resources allocated to caring for this patient group. Lack of time and a culture unduly influenced by rapid discharge requirements, risk mitigation and fiscal restraint contribute to produce an environment unsuited to caring for people with dementia. Dementia as a co-morbidity is increasing in hospitals due to the aging of the population, thus systems must change to improve education and support for nurses, and improve the culture of hospitals to focus on genuine caring along with the other priorities. There is an urgent need for more research that focuses on this area in order to inform the development of appropriate care which addresses the needs of people with dementia.

Relevance to clinical practice

It is important for nurses to understand the complex needs of people with dementia admitted to acute hospital wards. Nurse education on mental health issues is greatly lacking, and the emotional and practical support provided is inadequate. Strong clinical leadership and role-modelling give nurses opportunities for clinical-based education and skill-development. The core values of nursing which include empathy and caring for patients regardless of diagnosis must remain a primary concern. Institutional factors including hospital culture which focuses

on patient throughput, risk mitigation and fiscal restraint to the detriment of genuine caring

is regrettable and requires wider system review.

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Figure 1: PRISMA flow chart of included studies investigating the experiences of people with dementia and nurses in hospital.


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┌─────────────────────┐  ┌─────────────────────┐  ┌─────────────────────┐
│ Records Identified  │  │ Records Identified  │  │ Records Identified  │
│ through data base   │  │ from reference lists│  │ from grey literature│
│ searching           │  │                     │  │                     │
└─────────────────────┘  └─────────────────────┘  └─────────────────────┘
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Initial Citations

N=1298

Duplicates

N= 421

Citations screened on title and abstract

Excluded: 720

Not in English 21

Incorrect topic area 689

Citations screened on full text

N= 157

Excluded: 131

Not in English X 6

Not qualitative data X 22

Incorrect topic area X 78

Incorrect location X10

Citations for Critical Appraisal

N= 26

Excluded: 2

No ethics approval X 1

Citations included in review

N= 24

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Article	Aim	Methodology and sample	Data collection techniques	Results	Weaknesses	Strengths
Patients						
Cowdell, F. (2010) U.K. The care of older people with dementia in acute hospitals	To explore the experiences of patients and nursing staff of the care received by older people with dementia in acute hospitals	Ethnography 11 patients with dementia, 25 Registered Nurses 33 Nursing assistants	125 hours of observation, Field notes, 18 interviews, opportunistic conversations with patients with dementia	Patients - being in hospital is stressful and difficult Nurses - constrained by organisational and environmental factors, lack of support and education. Nurse lack empathy and work within fixed habitus	Only one of the formal interviews was with a patient with dementia	Extensive observation period. Considered the effect of participation on participants
Cowdell, F (2010) U.K. Care of older people with dementia in an acute setting	To investigate the experiences of patients and nursing staff in relation to the care delivered to, and received by, older people with dementia in an acute hospital setting	Ethnography 11 patients with dementia 25 Registered Nurses 33 Nursing assistants	125 of observation, Field notes, 18 interviews	Main themes surround the difficult and stressful experience of patients with dementia in hospital Nurses lack support, education and empathy	A small scale study conducted in one acute hospital	Good, succinct discussion Good explanation of ethical issues
Digby, R., Moss, C. and Bloomer, M. (2013) Australia Transferring from an acute hospital and settling into a sub-acute facility: the experience of patients with dementia	To understand how older patients with mild to moderate dementia experienced the transfer from acute to sub-acute care and the settling-in period	Qualitative description Eight patients with dementia	Eight in-depth semi-structured interviews	Five themes were identified: • Factors in settling in to the new environment. • Staff attitudes to people with dementia. • Loss of control • Family support • Anxiety about the future	Small study conducted in one facility Limited discussion of data analysis technique	Good discussion about interview techniques.
Digby, R. and Bloomer, M.	To elicit the perspectives of inpatients with	Qualitative	Eleven in-depth semi-	Seven themes were identified:	Small study conducted in	Good discussion about the case

(2013) Australia People with dementia and the hospital environment: the view of patients and family carers	dementia, and their family carers, about the environment/ design features of sub-acute hospitals that they believe are necessary for people with dementia and their family carers	descriptive study Seven patients with dementia and four unconnected family carers	structured interviews	• The quality of care is more important than the surroundings • Homeliness • Navigation and way-finding prompts • Privacy • The needs of family carers • Noise factors • Access to garden	one facility Limited discussion of data analysis technique	for inclusion of people with dementia on issues that affect them
Edvardsson, D., Nordvall, K. (2007) Sweden Lost in the present but confident in the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia	To illuminate meanings of being in a psycho-geriatric unit in a hospital	Open-ended research interviews interpreted using a phenomenological hermenuetic analysis Six people with mild to severe dementia	Six open-ended interviews	Four themes were identified: • Appearing lost in the present • Appearing confident in the past • Having one's private space invaded • Understanding the perspective of the person	Small study involving only six participants. Study conducted in one facility. Further exploration of themes.	Good justification of methodology Good discussion of findings
Edvardsson, D., Sandman, P., Rasmussen, B. (2011) Sweden Forecasting the ward climate: a study from a dementia care unit	To explore the psychosocial climate and its influence on the well-being of people with dementia in a psycho-geriatric hospital unit	Grounded Theory 24 beds occupied by patients with moderate to severe dementia	36 hours of observation	Variation in patient well-being was accounted for by staff presence or absence and their engagement with the patients. Staff were the catalysts for the psychosocial climate	No formal interviews with patients. One clinical setting only. Small scale study	Detailed observation and field notes
Norman, R. (2006) U.K. Observations of the experiences of people with dementia on general hospital	To explore how people with dementia are cared for in general hospital wards in the United Kingdom	Observational phase of a grounded theory study Three wards,	Unspecified number of hours of observation	Nursing practice must move away from constraint of patients with dementia towards their realisation Viewing the actions of people with dementia as a method of communication	Interviews with patients not discussed. Observation time unspecified. Small number of	Good discussion of findings Good use of quotes to support findings

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wards		eight patients with dementia			patients(n=8)	
Porock, D., Clissett, P., Harwood, R. H. & Gladman, J. R. F. (2015) U.K. Disruption, control and coping: responses of and to the person with dementia in hospital	To gain insight into the experience of hospitalisation from the perspectives of the older person with dementia, their family caregiver and other patients sharing the ward	Ethnography 35 caregivers, 4 co-patients concerning the experiences of 38 patients	72 hours of non-participant observation on 11 wards,. 39 interviews with family carers and co-patients	Core problem: • Disruption from normal routine leading to difficulty and distress Core process: • Patient with dementia gaining a sense of control through constructive, disengaged, distressed and neutral behaviour	Patients with dementia not interviewed directly. No demographic data provided	Good justification of methodology
Nurses						
Arnold, M and Mitchell, T. (2008) U.K. Nurses' perceptions of care received by older people with mental health issues in an acute hospital environment	To explore a sample of nurses' perceptions of mental health services for older people in the acute care setting	Qualitative Grounded Theory 14 nurses	Three focus groups	Main themes surround stigma of people with dementia in hospital Nurses require more specific mental health education and support. Better team work between disciplines and collaborative working	Data analysis not fully explained. Single site study Demographic details of participants not included	Themes illustrated with pertinent examples from the focus group interviews
Atkin, K., Holmes, J. and Martin, C. (2005) U.K. Provision of care for older people with co-morbid mental	To explore the training needs of general nurses to care for people with co-morbid mental illness	Framework analysis 19 nurses	Three focus groups	Older people with mental illness are identified through their behaviour General nurses lack the skills needed to recognise and manage mental illness Nurses do not believe older people with mental illness get a good service in general hospitals	Demographic details of participants not included Very limited discussion	Good presentation of participant quotes in a table

illness in general hospitals: general nurses' perceptions of their training needs						
Borbasi, S., Jones, J., Lockwood, C. and Embden, C. (2006) Australia Health professionals' perspectives of providing care to people with dementia in the acute setting: toward better practice	To explore, understand, and interpret nurses' and health professionals' experiences of managing patients who have dementia and have been admitted to hospital for treatment of a non-dementia related illness, and to provide a rich description of current practice and perceived better/ best practice	Qualitative, constructivist. 25 healthcare professionals including nurses, doctors and allied health professionals	Semi-structured interviews	The hospital environment is unfamiliar and unsafe Medical model of care focuses solely on patients' acute condition The profile of patients, family and staff. The current management and the ideal management of people with dementia are incongruent There is a need for staff education, dementia-friendly staff, purpose-built facilities, multi-disciplinary approach to care, and volunteers More time must be allowed to deliver care	Diverse skill mix in staff interviewed. Other staff may have different opinions	Three hospitals involved in the study Large volume of data generated Good discussion of the issues raised
Byers, D.C. and France, N.E.M. (2008) U.S. The lived experience of registered nurses providing care to patients with dementia in the acute care setting; a phenomenological study	To explore the lived experience of RNs caring for patients with dementia in the acute care setting	Phenomenology Nine registered nurses	Interviews and field notes	Two themes: • Frustration and emotional exhaustion due to inadequate staffing, and remorse that care was left undone. Lack of time results in a focus on tasks. • Synthesis of unity - nurses carrying work home	Watson's theory of caring has a very specific focus. Long verbatim quotes with minimal commentary/ interpretation. No clear statement of the findings	
Clissett, Porock, Harwood and Gladman (2013) U.K. The responses of healthcare	To explore the responses of healthcare professionals to the admission of people with cognitive impairment to the acute hospital setting	Ethnography 72 hours of observation Interviews with 35 family caregivers	Observation, field notes and interviews	Two themes identified: The admission of a person with cognitive impairment causes disruption to the staff. Responses by the healthcare professionals to the disruption include embracing the personhood of the individual, protecting self without jeopardising personhood, and suspending the personhood of the confused older person	Most of the interviews were with the family carers rather than the person with dementia	Excellent discussion section Good explanation of data collection process and data analysis

professionals to the admission of people with cognitive impairment to acute hospital settings: an observational and interview study						Multi-site study
Fukuda, R., Shimizu, Y. and Seto, N. (2015) Japan Issues experienced while administering care to patients with dementia in acute care hospitals: A study based on focus group interviews	To explore the challenges nurses face in providing care to patients with dementia in acute care hospitals in Japan	Qualitative study 50 nurses working in acute hospitals in western Japan	Eight focus group interviews	Nurses found that the various problems and difficulties interacted in a burdensome cycle and they needed to adapt to the conditions despite feeling conflicted The necessity to care for patients' families and obtain their cooperation	Only one male nurse participant Possible selection bias as the head nurses nominated the nurses to participate	Multi-site study
Goldberg, S.E., Whittamore, K.H., Pollock, K., Harwood, R.H. and J.R.F. Graham. (2014) U.K. Caring for cognitively impaired older patients in the general hospital: A qualitative analysis of similarities and differences between specialist Medical and Mental Health Unit and standard care wards	To compare and contrast the behaviours of staff and patients on the Medical and Mental Health Unit (MHU) and standard care wards and to provide a narrative account that helps to explain the link between structure, process and reported outcomes	Analysis of field notes using the constant comparison method. 90 TEAM trial participants who had been identified as confused	Sixty observations (360 hours) using the Dementia Care Mapping observational tool Detailed field notes	Care in a specialist mental health unit compared to a standard ward improves the experience for the patient, but not their health status. Developing a relationship between staff and the patient with dementia takes time and expertise, and may be impossible Organised activities provide occupation and social interaction for the patients	Study conducted in one English NHS hospital only. Demographic data of patients and nurses/carers not specified	Good discussion of the findings
Griffiths, Knight, Harwood and Gladman (2014)	To explore doctors, nurses and allied health professionals' perceptions of their preparation to care for confused older patients on general wards	Consensual Qualitative Research 60 staff including doctors, nurses	Semi-structured interviews using open-ended questions	Concerns about the quality of care for people with dementia in UK No staff training analysis has been done. Current education and training is inadequate More workplace training, more support from senior staff, and better access to specialist services is required	Participants all from one hospital	Multi-professional perspective Interviews carried out by independent researchers

U.K. Preparation to care for confused older patients in general hospitals: a study of UK health professionals		and allied health				
Harrison and Zohhadi (2005) U.K. Professional influences on the provision of mental health care for older people within a general hospital ward	1. To identify the factors and issues that nurses consider to be of relevance in meeting an individual's mental health needs 2. To provide data that will go on to inform the future stages of the action research process 3. To begin to develop an understanding of how the future practice developments can be achieved 4. To make the insights generated accessible and available to other practitioners	Phenomenology Nine members of staff including a ward manager, staff nurses, student nurses and healthcare assistants	Focus group	Nurses struggle to provide effective and patient-sensitive care The nursing needs are complex and require highly skilled practitioners A focus on providing holistic person-centred care is required	Small study One focus group interview from one unit Planned interviews with patients and carers were not undertaken for financial, time and practical constraints	Findings/ themes presented as a diagram as well as in text, contributed to clarity Excellent justification of methodology Good discussion of data analysis
Hynninen, N., Saarnio, R. and Isola, A. (2014) Finland The care of older people with dementia in surgical wards from the point of view of the nursing staff and physicians	To describe the care of older people with dementia in surgical wards from the point of view of the nursing staff and physicians	A qualitative, descriptive design 19 nurses 9 physicians	Unstructured interviews	The nurses interviewed did not have the skills required to provide good care for people with dementia Nurse education and training needs to be improved Additional resources are required to provide a safe environment Clinical written guidelines are needed	Small number of participants from one facility	Good explanation of data analysis and the trustworthiness of the study
Moyle, W., Borbasi, S., Wallis, M., Olorenshaw, R. and Gracia, N. (2010)	To explore management for older people with dementia in an acute hospital setting	A pragmatic, exploratory qualitative approach	Semi-structured in-depth, face to face audio-taped	People with dementia are not always provided with care that takes into account their individual needs Appropriately skilled staff are needed to provide both person-centred and dementia-	Small number of participants from one facility.	Excellent discussion section

			interviews	specific care Staff education is very important		
Australia Acute care management of older people with dementia: a qualitative perspective		13 staff including a medical doctor, nurses and AINs				
Nilsson, A., Rasmussen, B. and Edvardsson, D. (2013) Sweden Falling behind: a substantive theory of care for older people with cognitive impairment in acute settings	To develop a theoretical understanding of the processes hindering person-centred care of older people with cognitive impairment in acute settings	Grounded theory Patients, family members and staff	110 hours of observation, 100 informal interviews 11 formal interviews with 1 patient, 1 family member and 9 staff	High-quality PCC is difficult to achieve in settings where staff work without consensus, the organisation is disease-orientated and efficiency-driven, and the environment is busy and inflexible These factors contribute to patient suffering, family exclusion and staff frustration	Small study conducted in a 20-bed acute hospital ward	Good explanation of methods Results presented in a table and narrative form Good use of quotes to support results
Nilsson, A., Rasmussen, B. and Edvardsson, D. (2015) Sweden A threat to our integrity - Meanings of providing nursing care for older patients with cognitive impairment in acute settings	To illuminate meanings of caring for older patients with cognitive impairment in acute care settings as experienced by nursing staff	Phenomenology 13 nurses	Narrative interviews	Caring for older cognitively impaired patients in acute settings is a threat to nurses' personal-professional integrity. Nurses must be supported in providing dignified care Nurses need opportunities to reflect on and discuss care and how it impacts on their ethos and integrity and on the health of patients and families	Small study conducted in one hospital. Demographic information not included. Relationship between researchers and participants, not mentioned	Good explanation of data analysis Good use of quotes to illustrate themes
Nolan, L. (2007) Ireland Caring for people with dementia in the acute setting: a study of nurses' views	To explore nurses' experiences of caring for older people with dementia in an acute hospital setting	A thematic approach Seven nurses	Interviews	Environmental constraints and multiple demands on nurses' time make meeting the needs of people with dementia difficult in the acute hospital setting Nurses work hard to meet the needs of people with dementia Skilled, knowledgeable nurses are essential	Small study conducted in one purpose-designed unit of a large hospital not typical of acute wards	Good use of quotes to support findings

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Scerri, A., Innes, A. and Scerri, C. (2015) Malta Discovering what works well: exploring quality dementia care in hospital wards using an appreciative inquiry approach	To explore the quality dementia care in two geriatric hospital wards using appreciative inquiry with formal care workers and family members of inpatients with dementia	Appreciative inquiry 33 Care workers including 16 nurses, 9 nursing aides and clerks, 8 other healthcare professionals and 10 family members	Interviews using open ended questions	Dementia care in hospitals is not optimal although there are positive experiences. Personal attributes of staff, and organisational, environmental and contextual factors influence care practices.	Nurses were not asked to discuss negative experiences, only positive. This has the potential to skew the results.	Good discussion of the issues

Nurse empathy

In response to the findings of the integrative review which determined that the nurse-patient relationship was a key factor in the provision of quality care, an article was written on the topic of nurse empathy related to care of people with dementia and concludes his chapter. Austin (2011) suggested that the relational practices of nurses may have deteriorated not only in response to excessive workload but to the change in culture of nursing as a 'caring profession' to one of a customer/ service-provider model. The focus on customer satisfaction which has its roots in commercialism changed the approach of nurses by directing them to respond to patient needs in ways which satisfied this model rather than from the perspective of caring (Austin, 2011). As concepts such as empathy and compassion are notoriously difficult to measure (Yu & Kirk, 2009) nurses spend their time 'ticking boxes' rather than listening to and comforting the patients (Bradshaw, 2009). Despite these challenges, nurse empathy must be considered an essential component of good patient care.

The article entitled "Nurse empathy and the care of people with dementia" (Digby, Williams, et al., 2016) is presented. This article discusses the factors which influence the delivery of empathetic nursing care to people with dementia, including an organisational focus operational and resource issues.

Nurse empathy and the care of people with dementia

AUTHORS

Robin Digby
RN, MN, PhD candidate
Monash University, School of Nursing and Midwifery,
Peninsula Campus, PO Box 527,Frankston, Victoria,
Australia
rdig1@student.monash.edu

Associate Professor Allison Williams
RN PhD M Nurs BAppSci (AdvNurs) GradDipAdvNurs
(ClinNursEd) FACN
Director, Monash Nursing Academy, Room 323, 35
Rainforest Walk,Clayton Campus, Wellington Rd, Clayton,
Victoria, Australia
allison.williams@monash.edu

Dr Susan Lee
PhD, MBioeth, BAppSci (Nsg Ed), DipAppSc (Nsg),RN
Senior Lecturer, Monash University, School of Nursing
and Midwifery, Peninsula Campus, PO Box 527,
Frankston, Victoria, Australia
susan.lee@monash.edu

KEY WORDS

Dementia, empathy, nursing care, compassion, in-patient, hospital

ABSTRACT

Objective
Empathy is widely accepted as an essential nursing attribute yet the relationship between nurse empathy and the care of people with dementia in the hospital setting has rarely been explored. A number of themes have emerged from the relevant literature regarding the influences which shape a nurse's ability to deliver empathetic care to this patient cohort. These issues include a lack of hospital resources, an organisational focus on operational issues such as patient flow and risk management, and widespread stigmatisation of dementia in society.

Setting
Acute and sub-acute facilities.

Subjects
In-patients with dementia and nurses

Primary argument
Although there is widespread acknowledgment that nurses require empathy to deliver quality care, the complexity of caring for people with dementia in hospital creates further challenges for both nurses and patients. This issue has been discussed previously but there is little evidence that the situation has improved.

Conclusion
This paper details the relevant influences on the ability of nurses to care empathetically for people with dementia in hospital. The recognition that there are distinct factors related to this patient cohort is an important one and may assist nurses and health organisations to identify systemic and individual problems associated with hospitalisation and lead to the implementation of supportive strategies. Appropriate nurse-patient ratios which consider the additional workload attached to caring for people with dementia, clinical supervision and targeted nurse education must be considered to ensure health systems deliver appropriate person-centred care to people with dementia.

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INTRODUCTION

A sign of our ageing population is the increased prevalence of dementia (Access Economics 2009). Dementia is defined by the World Health Organization (WHO) as, '...a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement' (WHO 2012, p7). It is projected that globally the number of people with dementia will nearly double every 20 years to 65.7 million in 2030 and 155.4 million in 2050 (WHO 2012). Despite extensive research, there is currently no cure for dementia and no effective prevention strategy (van Norden et al 2012), making quality nursing care an important component of treatment.

It is not possible for nurses to care appropriately for patients without the vital ingredient of empathy. One description of empathy is "understanding, sharing and creating an internal space to accept the other person, hence helping them to feel understood and not alone" (Cunico et al 2012, p2016). Empathy has been described as a necessary component of all caring relationships (Mercer and Reynolds 2002). If empathy is lacking, nurses are unable to understand the patient's perspective, create trust, and deliver person-centred care (Griffiths et al 2012). May (1990) questioned if it was realistic to expect nurses to be empathetic considering the increasing demands placed on the role. More than 20 years later factors which facilitate nurses to deliver high quality, compassionate inpatient care continue to be debated (Bridges et al 2013).

Patients with dementia are commonly admitted to hospital with acute illnesses and dementia is a co-morbidity to the presenting problem (Hermann et al 2015). Despite many articles being written about the concept of empathy, many that refer to people with dementia are contextually in residential care. People with dementia are more than twice as likely to be admitted to Australian hospitals as those without (AIHW 2013), however there has been very little written about the relationships between staff and inpatients with dementia. The argument presented in this paper is that there are multiple factors which shape nurses' ability to deliver empathetic care to patients with dementia, in particular the work environment, organisational support, economic issues and societal influences. These factors must be addressed in relation to the care of people with dementia. The aim of this discussion paper is to examine nurse empathy in the context of caring for people with dementia in hospitals and suggest strategies for overcoming the barriers to the delivery of empathetic nursing care to this patient group.

DISCUSSION

The concept of empathy

The concept of empathy has been difficult to define but is generally understood to mean that an environment is created in which a person feels understood and accepted, by the demonstration of kindness and warmth (Griffiths et al 2012). An expanded explanation is that empathy involves 'understanding, sharing and creating an internal space to accept the other person, hence helping them to feel understood and not alone' (Cunico et al 2012, p2,016). Compassionate care is then a result of having empathy for another person and responding to their needs with humanity, relieving pain and distress: in other words, compassion implies that we not only understand a person's suffering but that we respond to it (Straughair 2012). To empathise with a person with dementia therefore involves gaining insight into a fragmented and confused world which may be changing, unpredictable and sometimes frightening (Cunningham 2006).

It has been suggested that nurses should work with empathy and compassion but retain a degree of detachment in order to allow the nurse's concern for the patient to be evident but maintain an emotional separateness (Edberg and Edfors 2008). This is to protect the nurse from losing objectivity and may decrease the likelihood

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of burnout (Maslach et al 2001). It is important to recognise that caring empathetically can render the nurse emotionally vulnerable, and consequently the benefit to the patient is not without cost, therefore to be most effective nurses must find an appropriate balance between engagement and detachment (Austin 2011).

Factors influencing empathy with people with dementia in hospital

The specific issues of people with dementia and the relationship with nurses in the hospital setting has received very little attention. Previous research has focussed mainly on residential care facilities where it is estimated that in Australia approximately 50% of the residents have dementia (AIHW 2012) with similar figures in other developed countries (Wimo and Prince 2010). The hospital environment can be noisy, busy and unfamiliar which may exacerbate the person with dementia's problems with spatial disorientation which can worsen anxiety and make care more challenging (Marquardt 2011). People with dementia may have attributes which make connection with other people more difficult because their ability to communicate and understand the needs of others can be impaired (Moreau et al 2015). This may impact on the nurse/patient relationship which is already strained because of time constraints, lack of understanding about dementia and inappropriate ward environment (Turner et al 2015).

Stigmatisation

There is evidence that both old age and dementia are conditions that are stigmatised by society, often in subtle and unacknowledged ways (Phillipson et al 2012). Stigmatisation of people with dementia by nurses and other health care providers, can be apparent although it is less prevalent in those with more education and hence a greater understanding of the condition (Mukadam and Livingston 2012). Despite this, educated health professionals can also demonstrate prejudice against people with mental health conditions including dementia (Blay and Peluso 2010). Judging and labelling patients can perpetuate stigma about people which influence the nurses' attitude towards patients and consequently their care (Scodellaro and Pin 2013). Demonstrations of stigmatisation of people with dementia include insinuating that the behavioural symptoms of dementia are deliberate and in the control of the person rather than a symptom of the condition or a demonstration of unmet need (Mukadam and Livingston 2012). For instance a person with dementia who is shouting 'Brian, Brian!' constantly may be interpreted by a nurse with poor insight into the condition as being wilful and irritating, whereas the person may in fact have a physical need such as thirst or pain which they are unable to express in a conventional way. The media must take responsibility for some of the negative projections of dementia in society including the emphasis on decline and the loss of capacity, and the burden on the community and families, despite the fact that many families actually feel satisfied in their caring role (Van Gorp 2012). The prevalence of these negative attitudes permeates all levels of society, influencing the ability of health professionals to see people with dementia as worthy of person-centred empathetic care (Milne 2010).

Nurse stress

Frustration and emotional exhaustion are common among nurses caring for people with dementia (Griffiths et al 2014). Because of the fast pace in hospital settings the problem is augmented by the complex needs of the patients with dementia and the limitations on what nurses can achieve during a working day (Fukuda et al 2015). Nurses need to be cared for and supported from an organisational perspective to empower them to care sensitively for their patients (Maben et al 2012b). Disharmony can be evident when the hospital environment is at odds with the requirements needed to care for people with dementia sensitively (Sánchez et al 2013). Flawed organisational priorities can also be blamed for the frustration and 'workplace suffering' generated by the gap between what nurses are able to do in terms of care and treatment and what they feel they should do (Biquand and Zittel 2012). Nurses may be distressed by the recognition of the needs of the person with dementia while faced with organizational constraints which prevent them from delivering

appropriate care (Bridges et al 2013). A higher level of stress in nurses is closely linked with their self-efficacy and well-being which in turn impacts on their ability to care empathetically (Austin 2012).

In some cases nurses who have been the victims of violent behaviour from patients can show a high incidence of depersonalisation, burnout and psychological stress which reduces their capacity to deliver empathetic care (Scott et al 2011). Furthermore, a correlation has been demonstrated between nurse working characteristics and patient behavioural symptoms: people with dementia who are cared for by nurses who experience a lower degree of job strain show a lower incidence of disruptive behaviours (Edvardsson et al 2008).

Nurses can experience increased stress levels if patients are aggressive (Scott et al 2011). This aggressive behaviour can make the process of caring effectively even more difficult, however if the nurse is able to see that the patient is not responsible for their behaviour and can contextualise it in terms of the illness, they are less likely to be personally affected and more likely to continue the delivery of appropriate care (Ostaszkiewicz et al 2015). Nurses' Emotional Intelligence (EI) which is a measure of their emotional, personal and social abilities and skills is relevant to their capacity to care for their patients with empathy and compassion. Nurses who have a higher EI score have the propensity to be more empathetic especially when this quality is developed through education and support (Austin 2012).

Furthermore, nurses' stress has been shown to negatively impact on the behaviour of people with dementia (Edvardsson et al 2012), and lead to high staff turnover (Chenoweth et al 2014). It is not uncommon to find that patients with dementia are cared for by overworked staff who do not believe that the patients have the capacity to engage in personal interactions, and who consequently focus on the physical tasks (Blagg and Petty 2015). Protests from the patients are then seen as a symptom of the disease rather than being due to inappropriate treatment (Sabat et al 2011). This unsatisfactory relationship between staff and patient behaviour was termed 'malignant social psychology' (Kitwood 1997, p.45) and is demonstrated by staff who see people with dementia as 'personless' and unworthy of engagement (Penrod et al 2007). Nurses may demonstrate this by treating the person with dementia with dehumanising attitudes such as objectification, disempowerment and stigmatisation (Kitwood 1997). Carers of people with dementia who consider them to be valueless or empty consequently see their work as worthless and futile, which impacts on their ability to empathise with people (Chenoweth et al 2014). Nurses who feel disempowered are similarly unable to relate meaningfully to the patients and instead focus on the technical aspects of care (Terrizzi DeFrino 2009). It is important to note that nurses who are more empathetic and therefore have the ability to understand the person's feelings have greater job satisfaction (Lim et al 2011).

Resources and operational priorities

The nurses' ability to deliver ethical care can be constrained by the diminishing healthcare resources and tight fiscal restraint (Sanchez et al 2015). Nurses can feel that they are treated as a commodity rather than contributing team members in a culture which underplays the role of the nurse and engaged humanistic care (Austin 2011). Quality of care is directly linked to nurse-patient ratios, staff support and staff turnover, with comforting and talking to patients the tasks most often left undone when workload and other pressures increase (Duffield et al 2011). However it has been demonstrated that consistency of staff over a period of time can allow the connection between the staff and the person with dementia to develop and the relational aspects of care are then prioritised above the completion of tasks (Clissett et al 2013). The pressure to increase the flow of patients through the hospital system decreases the opportunities for nurses to develop a connection with patients which interferes with the therapeutic nurse/ patient relationship (Goodrich 2012). Significantly these time pressures can also lead to an increase in medical errors and ineffective care delivery (McSherry et al 2012).

The effect of technology

There has been speculation that empathy in nurses has declined with a rise in the technological and biomedical approach to care due to the decreased focus on the human perspective (Watson 2009). The relationship between the nurse and the patient is changed with the dependence on technology, and it is increasingly difficult (but still possible) to prioritise the human factor in the relationship (Buckner and Gregory 2011). Both the increasing demands of technology and the rise of consumerism put pressure on nurses to practice nursing in other non-traditional ways (Schantz 2007) and the 'softer' nursing qualities such as empathy and listening have also been described as at odds with 'academic' nursing related to technology and biomedical aspects of care (Griffiths et al 2012). It is important that empathetic care is not gradually eroded over time as the nursing culture becomes more technology dependent.

Risk management and relational practices

According to Austin (2011) relational practices of nurses have deteriorated not only in response to excessive workload but to the change in culture of nursing as a 'caring profession' to one of a customer/service-provider model. The focus on customer satisfaction which stems from commercialism reframes the definition of nursing, and scripts nurses to respond to patient needs in ways which satisfy the model often to the detriment of sincerity (Austin 2011). As concepts such as empathy and compassion are difficult to measure (Yu and Kirk 2009) nurses spend their time 'ticking boxes' rather than listening to and comforting the patients (Bradshaw 2009).

Health services across the world, including Australia, have experienced rapid change in the past 50 years however in the light of these changes the essence of nursing has evolved from one in which the first premise is caring, to a new paradigm which has a focus on risk mitigation, accountability and patient flow (Roch et al 2014). There is a danger that the traditional nursing values which heavily emphasised empathetic care and patient comfort are being superseded in a society which values efficiency.

Strategies to improve empathetic care

The two major factors needed to improve empathetic care for people with dementia involve education and support for nurses and other staff (Cunico et al 2012). On-going education about dementia is essential for nurses who care for people with dementia so that they have the knowledge and the required strategies to care effectively for people with dementia in hospitals (Nayton et al 2014). Without a good understanding of the dementia condition, nurses are compromised in their ability to recognise the behaviour and respond to the patients appropriately (Chenoweth et al 2014). Appropriate on-going education improves care but also has a positive impact on nurse retention and improves nurses' job satisfaction as they not only become more masterful in the role but feel valued and supported by their organisation (Chenoweth et al 2014). Furthermore it is important to ensure that the nurses feel well supported by managers and their colleagues when they are caring for those who have concurrent acute medical illnesses as well as dementia, as this creates additional challenges (Clissett et al 2013). Appropriate education can include improving communication between nurses and patients, especially in the case of patients with dementia where communication can be difficult. Empathy must not only be felt by the nurse, but communicated to the patient or it loses its meaning (Webster 2010). It has been shown that nurses can be taught to develop their rapport with patients (Dewar 2011). However some believe that empathy is an innate quality which cannot be learned, although it can be recognised and encouraged (Richardson et al 2015). Nurses who are taught to be more aware of how their own beliefs and values influence their relationship with patients are more likely to change their attitudes positively (Harper and Jones-Schenk 2012). It is recommended that 'relational practices' warrant a higher place on the educational and competency agendas in order to support nurses to deliver appropriate compassionate care (Dewar and Nolan 2013).

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Support for nurses

The need for emotional and practical support is particularly evident in nurses who care for people with dementia. Nurses have been shown to benefit considerably from clinical supervision in which individuals are given the opportunity to meet regularly with more senior or experienced practitioners in order to receive relationship-based support and guidance, and engage in reflective practice (Pearce et al 2013). Nurses who are provided with regular opportunities to discuss their workplace challenges have greater job satisfaction and a lower incidence of burn-out (Kemp and Baker 2013).

Actions which express the concern and support of managers for the nurses is very important in that it shows that there is a team approach to care and the difficulties are acknowledged (Moyle et al 2011). The understanding of the word 'team' can be extended to the whole of the organisation and health system as demonstrated in a study of the United Kingdom National Health Service performance which revealed '...cultures of engagement, positivity, caring, compassion and respect for all – staff, patients and the public – provide the ideal environment within which to care of the health of the nation' (West and Dawson 2012). Nurses who feel they are not alone in the challenges they face (Maben et al 2012a) and who feel valued and supported by the organisation will derive greater satisfaction from their work (Chenoweth et al 2014).

CONCLUSION

Dementia adds complexity to the nurse-patient relationship in hospital and requires specialised understanding in order to enable quality care to be delivered. In this paper empathy has been discussed in relation to the barriers and enablers to caring empathetically for people with dementia in hospital from a nursing perspective.

The barriers are multi-factorial but include society's stigmatisation of people with mental health problems which permeates into the health arena and cause nurses to unwittingly discriminate against people with dementia. The increasing pressure from fiscal restraint, increased patient flow-through and technology experienced by nurses impact on their ability to relate effectively to the people in their care. Lack of time and resources to support nurses leads to dissatisfaction with the role; a problem which is ultimately reflected in the quality of care delivered to the patients.

RECOMMENDATIONS

Health services will continue to care for a greater number of patients with dementia as the population ages. Traditional nursing values which include empathy must be supported despite the challenges of the modern healthcare environment. Nurse empathy has been demonstrated to be a vital ingredient in the provision of quality care for people with dementia in hospital. In order to improve this situation, nurses require organisational backing which includes an understanding of the increased needs of people with dementia reflected in nurse-patient ratios. Organisational initiatives including ensuring there are opportunities for clinical supervision must be implemented and sustained if nurses are to receive the support they need. Targeted education about dementia would increase nurses' understanding of the condition and enable a more objective appreciation of patient behaviour, allowing nurses to maintain an empathetic approach in the face of challenging behaviour. Improving the support for nurses will advance the care of patients with dementia in hospital.

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Additional literature

The second part of the literature review was based on a broad general search of the literature conducted initially in 2012 and further updated in 2016 as work on the thesis progressed. The topic of interest was research in which the direct viewpoint had been sought of people with dementia in research undertaken in non-hospital settings. This literature augmented the integrated review which was narrowly focused on the experience of being an inpatient, by including a broader range of situations and settings to increase understanding of the person with dementia.

Search strategy

Electronic databases, including the Cochrane library, Joanna Briggs Institute EBP database, Ovid MEDLINE, Embase, CINAHL plus, Scopus, PsychINFO, ProQuest central and Google scholar were used to find literature about research relevant to the topic of interest. The search involved several approaches in order to maximize the information obtained. In addition, the bibliographies of significant articles were examined to discover further relevant papers which had not previously been identified.

It can be argued that "the hallmark of good qualitative methodology is its flexibility rather than its standardization" (Popay, Rogers, & Williams, 1998, p. 346) and for this reason a more flexible criteria for inclusion in this section of the literature review was established. The search used a variety of keywords in different combinations - 'dementia OR Alzheimer's Disease OR cognitive impairment', 'patient OR person', 'hospital' and 'interview' as a starting point; however because of the scarcity of literature describing the direct experience of people with dementia a pragmatic approach was undertaken which broadened the search to examine articles set in residential care and the community, and involving people from diverse backgrounds. The search terms 'community', 'aged care OR residential care OR nursing home', and 'diverse background' were applied in various combinations.

Interview-based research involving people with dementia in non-hospital settings

People with dementia have been asked for their opinions about hospital care on surprisingly few occasions, yet they have successfully taken part in direct research about other aspects of their experience (Hellström, Nolan, Nordenfelt, & Lundh, 2007). The recognition of the diagnosis by the person while still in the early stage of the disease has been quite widely investigated perhaps because unlike those with advanced dementia most people in this situation still reside in the community and have largely intact language and comprehension skills (Rudolph et al., 2010). Interviewing people in the early stages of the disease is a relatively straightforward process in that most participants are capable of consenting on their own behalf, and would be able to take part in a conversation which required them to recall events (Caddell & Clare, 2011). Research in which the participants are people with more advanced dementia is more complex and requires greater skill on the part of the researcher in order to extract meaningful data because of the deterioration of both language and cognition (Dewing, 2002).

Direct interviews have been used in a number of studies investigating the coping strategies and life experiences of people with early stage dementia or mild cognitive impairment (Caddell & Clare, 2011; Harman & Clare, 2006; Langdon, Eagle, & Warner, 2007; MacRae, 2008; Ostwald, Duggleby, & Hepburn, 2002). The majority of the participants in these studies were community-dwelling and were recruited through memory clinics or community groups. Some common themes were identified including fear of what the future holds, striving to normalise losses, making the best of the situation, and trying to maintain a sense of self. However the conclusion which is most relevant to this thesis is the significance attributed to the relationships with others. People with dementia (in fact, people generally) gain a sense of self partly as a reflection of feedback from the people with whom they have contact. For those with dementia this has heightened importance (Harman & Clare, 2006).

People with dementia in the community

There are a number of studies in which people with dementia living in the community have been involved in research in which their opinions have been directly accessed. Langdon et al. (2007)

interviewed 12 people who had been diagnosed with dementia to explore the social effects of the diagnosis. They found that participants had negative reactions to the terms 'dementia' and 'Alzheimer's Disease' preferring to call it 'memory loss' and a 'disability ' rather than a disease. Participants commonly felt left out socially and struggled with how to manage diagnosis disclosure. The word 'dementia' was disliked because it is linked to 'demented' and has connotations of 'going mad' which contributed to the participants being acutely aware of the reactions and feedback from others. They were commonly reluctant to share the diagnosis outside their close family and friends and embarrassed if their memory problems became obvious to others. Retaining a sense of self was important despite a loss of roles and social standing, and participants were highly sensitive to the reactions of others to their diagnosis. The participants reported especially disliking patronizing language or being ignored, and preferred people to respond to them honestly and genuinely. Langdon et al. (2007) concluded that people with early stage dementia are capable of presenting 'coherent, meaningful and insightful' accounts of their experiences, however they do not suggest at what stage, if at all, this ceases to be the case (Langdon et al., 2007).

Similar findings were made by Phinney (1998) who interviewed five community-dwelling people with a probable diagnosis of Alzheimer's disease, and their spouses. The participants described fluctuating symptoms including memory loss, conversation breakdown and disorientation, but said that they tried to present as normal by self-monitoring, staying engaged and downplaying their deficits. The ability of the study to produce valid results was initially doubted due to the cognitive impairment of the participants. However after follow-up interviews and a comparison of the data with the researcher's observations, it was concluded that the findings of this study made a valuable contribution to the body of knowledge about the experience of early Alzheimer's disease (Phinney, 1998). The triangulation of data was demonstrated to be an important validation tool (Phinney, 1998). Similarly Sørensen, Waldorff, and Waldemar (2008) found that anxiety about diagnosis disclosure was evident in a study of 11 community-dwelling people in the early stages of the disease. They concluded that individual coping strategies and personal resilience were strong predictors of outcome. People who protect themselves from a decline in

dignity and value by adapting to the consequences (with strategies such as increased self-monitoring and avoidance of complex tasks) coped more successfully (Sørensen et al., 2008).

 The phenomenon of the experience of dementia continues to be poorly understood which can lead to the person with dementia feeling that they are 'accused' of being forgetful, or in some way to blame for the problems. Taking a different approach to the ones described above, Robinson, Giorgi, and Ekman (2012) interviewed one person with early dementia four times over a period of three years and found that the experience of the condition for that person was of continual adjustment to change. The discrepancy between how the person interpreted a situation and the information being received from others was confusing and lead to self-protection strategies and a certain sense of bewilderment, especially when first diagnosed. As the participant did not initially feel very different from previously, her reaction to being told that she had memory problems was largely that of incomprehension. As the disease progressed she relied more and more on the presence of her husband to reassure herself of normality, and in fact being near him became necessary for her to keep equilibrium in her day. However the specific dynamics of their relationship were not detailed in this article and it is therefore unclear in what way the husband responded to his wife's illness or assisted her to come to terms with her situation. The researchers determined that this study demonstrated that personal resilience and the strong support of others were important factors in coping with the early years of the disease (Robinson et al., 2012).

The idea of preservation of self in the early stages of dementia is one that has been extensively explored, mainly through personal interviews with people with the condition (Beard, 2004; Branch Jr, Davis, & Weng, 2012; Caddell & Clare, 2011; Harman & Clare, 2006; Langdon et al., 2007; MacRae, 2008; Morris, 2012; Schantz, 2007; Sørensen et al., 2008; Von Dietze & Orb, 2000). Recurring findings in studies such as these include that there is often a struggle to maintain a sense of normality and understand the changed situation, coupled with feelings of isolation and the need to constantly monitor their own behaviour and interpret the reactions of others. The process of reappraising abilities and making adjustments was on-going and at times exhausting. Feelings of grief, sadness and loss were common.

People with dementia in nursing homes

The experience of living with severe dementia in residential care has been less extensively investigated and is likely to have both similarities and differences to the experiences of people with the condition in hospital settings. Clare et al. (2008) conducted a study in residential care facilities in England and Wales in which participants with dementia were given the opportunity to express their views about the facility in which they lived. The level of cognitive impairment in the participants was demonstrated by the mean Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) of 10.54 which indicated that they had moderate to severe cognitive impairment. The participants reported feelings of uncertainty, fear, loss, isolation and loneliness, and many felt lost or homeless despite secure surroundings. The researchers found that most conversations with staff were task-focussed and that this absence of positive relationships contributed to the residents' distress (Clare et al., 2008).

In an earlier study, recorded conversations with forty-five people with dementia who were residents in a nursing home in the south-east of the United States showed that a sense of self was retained throughout the course of the condition as evidenced by the use of the pronoun 'I' (Tappen, Williams, Fishman, & Touhy, 1999). This directly contradicts previous understanding that the 'self' diminishes as dementia progresses reported by (D. Cohen, 1991) who wrote of the 'death of the mind'. The people with dementia in the study reported by Tappen et al. (1999) were clearly able to comment on their situation as evidenced by the range of topics mentioned; however it was not clear what questions were asked or how the people were engaged in conversation. Tappen et al. (1999) conclude that the problem lies with health professionals who fail to engage with people with dementia because of preconceived ideas that they have 'diminished humanness'. The opportunity to uncover the person that may be hidden behind the disease is then missed (Tappen et al., 1999). Kitwood (1988) previously raised this topic however it continues to be discussed.

The work of Kitwood was referred to by Surr (2005) when exploring the preservation of the self in people with dementia in residential care. In four residential care facilities 14 people with

dementia participated in several unstructured interviews over 6 months. It was confirmed that the person's relationship with others, the broader social context, personal narrative and story-telling have a crucial role in either undermining or maintenance of self. Loss of self may occur if the person with dementia is only permitted to 'receive' rather than also to 'give' in a relationship. There was evidence that social feedback from the community of being part of an undesirable group can result in the person taking on the expectations of the stigma and society's view of themselves (Surr, 2005). In this instance, the researcher was very conscious of ensuring that the participants felt secure and confident in their surroundings before the interviews were attempted. This not only allowed the participants to feel comfortable to open up to the researcher, but also ensured that they maintained their self-esteem throughout the process which can otherwise or risk being daunting. The participants reported that lack of independence and choice was a problem for the people in residential care brought on by a power imbalance between caregivers and residents. A series of losses often resulted in negative feeling and depression in the residents (Aggarwal et al., 2003).

H. Hill (2004) researched the care of people with dementia in a residential care facility but found that in this particular facility it was not possible to interview residents in the traditional manner. Instead, opportunistic conversations and using knowledge of the person and their non-verbal communication to 'fill the gaps' was deemed more effective. The strength of this research lay in the extended time the researcher spent with the participants making a concerted effort to understand the issues and perspectives of the residents. It was established that in this facility there was a failure to treat the residents as unique individuals and only piecemeal attempts were made to introduce positive change. Hill suggested that an organization-wide change process would need to be implemented in order to genuinely provide authentic person-centred care for people with dementia (H. Hill, 2004).

People with dementia with diverse backgrounds

The participants with dementia in published research have been identified as lacking in diversity (Hulko, 2009; Proctor, 2001). Hulko (2009) was concerned by the lack of the direct views of

people with dementia, and particularly that the existing accounts were mainly written about people with early stage dementia who were white middle-class, Anglo-Saxon and heterosexual. To correct this omission research was undertaken using a sociological concept called 'intersectionality' which aimed to understand both marginalization and privilege. To do this eight community-dwelling people with dementia sourced through a hospital outreach program were interviewed using both photography and photo-elicitation to understand their views of what it means to have Alzheimer's disease. The researcher also used observation sessions and focus groups. It was suggested that the reason the experience of people with dementia had been almost uniformly depicted as negative was more to do with societal influences and the analysis of data by health professionals than the actual experience of people with dementia which can be quite diverse (Hulko, 2009). In that research the experience of dementia was reported by the participants as ranging from 'hellish' to 'not a big deal'. The data collection in the study was relatively extensive, with 24 interviews and 17 observation sessions being conducted in a range of settings. It was concluded that past research which focused on middle-aged, well-educated, white married people in the early stages of the disease has resulted in relatively homogenous views shaping service delivery for all people with dementia (Hulko, 2009).

Proctor (2001) was also concerned about the views of marginalised groups especially on the lack of documentation about the experience of women. The assumption was that women were oppressed and disempowered in society along with the disabled, people with intellectual and mental health disabilities, all of whom deserve the right to have their voices heard. Older women with dementia were the focus of the study which aimed to ascertain how the women viewed the services they received and to gain insight into their world view, at the same time understanding the issues surrounding the inclusion of people with dementia in interviews. The conclusion was similar to the previous study (Hulko, 2009) and in agreement with earlier work by Kitwood (1988, 1990, 1997a, 1997b) suggesting that the experience of dementia is shaped only in part by the bio-physiological process, and heavily influenced by limitations imposed on the individual by society's attitudes. Women with mental health conditions were found to be multiply disadvantaged by the addition of gender and ageism (Proctor, 2001).

It is common to approach the topic of living with dementia as though the experience of having dementia occurs in a vacuum independent of socio-economic, cultural and institutional factors (O'Connor et al., 2007). This was addressed by Kitwood (1997a, p. 45) in the seminal text *Dementia Reconsidered: The Person Comes First* in which he described the effect on people with dementia of treatment by others which he termed 'malignant social psychology'. His theory which was revolutionary at the time, placed the physical environment and the relationship between the person with dementia and others as predictors of the course of the disease (Kitwood, 1997a, p. 45). Kitwood challenged the accepted views of the day by rejecting the technical attitude to dementia – to uncover the cause and control it – with the personal attitude where the it was viewed and treated through the eyes of the person with the condition (Kitwood, 1997a).

The idea of understanding the situation through the eyes of the other person described by Kitwood (1997a) is strongly grounded in the concept of intersubjectivity which refers to the mutual interaction between two people (Frie & Reis, 2001). Habermas (1984) described it as a shared understanding which was formed through reciprocal relationships between people. Hence it was decided that further investigation was required into the empathetic relationship between the nurse and the patient.

Nurse empathy

An article was consequently written on the topic of nurse empathy related to care of people with dementia and included in this section. Austin (2011) suggested that the relational practices of nurses may have deteriorated not only in response to excessive workload but to the change in culture of nursing as a 'caring profession' to one of a customer/ service-provider model. The focus on customer satisfaction which has its roots in commercialism changed the approach of nurses by directing them to respond to patient needs in ways which satisfied this model rather than from the perspective of caring (Austin, 2011). As concepts such as empathy and compassion are notoriously difficult to measure (Yu & Kirk, 2009) nurses spend their time 'ticking boxes' rather than listening to and comforting the patients (Bradshaw, 2009). Despite

these challenges, nurse empathy must be considered an essential component of good patient care.

Chapter summary

The evidence in the literature has demonstrated that people with dementia often have a poor experience of care in hospital. While the literature reviewed did provide some information about the problems encountered by patients, and suggested some potential reasons for this, there was little information about the influence of hospital governance on caring practices. Some of the studies provided insight into the patient experience, but most were small samples and there are opportunities to expand what is known about this by focussing more research in this area.

In summary the experiences of people with dementia in hospital or sub-acute care as experienced by the individuals have been minimally investigated to date although some research has been done to understand their experiences through the interpretation of others. People from diverse backgrounds, those with more advanced dementia or in institutions including hospitals and residential care are less likely to have been asked for their viewpoint. However it has been well demonstrated that people with dementia are able to comment on the things that affect them and deserve the opportunity to do so, justifying the relevance of this study. Nurses have been more extensively investigated, and it was identified that nurse education about dementia was generally lacking, consequently leaving many nurses ill-equipped and not having the appropriate skills.

Chapter 3 Research Framework

Introduction

In the previous chapter the research literature was examined which described the direct opinions of people with dementia and nurses about their experiences of care in hospitals. It was demonstrated that very little research had been conducted in which people with dementia had been asked to comment on this topic despite there being a great deal of literature written from the perspective of care-givers and health professionals. The nurse-patient relationship is central to the patient experience, so for this reason the viewpoint of the nurses was also investigated.

This study was conducted using a critical ethnographic methodology in order to investigate what was privileged in the hospital care of patients with dementia in sub-acute rehabilitation facilities. This chapter presents and justifies the methodology used in this study which draws on the principles of critical interpretative ethnography. The literature review found that the problems for both people with dementia and the nurses who care for them are significant in residential facilities and acute health; however there was very limited research set in the sub-acute hospital setting. In previous studies reported in the literature patients have reported feeling distressed and lost in the hospital environment. In this chapter the rationale for the research methodology used to address the research question is described and justified, the choice of critical ethnography is explained, and the research strategy and the ethical foundations of the study is outlined.

The methodology was designed to respond to the research aims and questions. As stated earlier the aim of this study was to explore the experience of care for people with dementia in sub-acute geriatric rehabilitation facilities from the perspectives of the patients and the nurses caring for them with attention to the institutional and social practices that shaped care.

The central research question was:

"What are the factors which impact on the care of people with dementia in sub-acute geriatric rehabilitation hospitals"?

As discussed previously the objectives of the study were to understand the viewpoint of people with dementia and nurses in sub-acute geriatric rehabilitation facilities, determine the dominant influences affecting nursing practice in this area, and draw conclusions about the relationship of hospital culture and processes on the experiences of patients with dementia and nurses.

Ontology

A range of theoretical approaches could be used to meet these research objectives. Initially the question 'how do we know what we know?' must be asked, and a particular theory of knowledge, or epistemology, adopted and embedded in the different theoretical approaches (Crotty, 1998). The ontological stance of the critical paradigm is historical realism in which reality is understood as being shaped by previously established social, political, cultural, economic, ethnic and gender values: in other words socially constructed entities (Guba & Lincoln, 1994). In this paradigm reality is constructed by language and interaction between individuals with a specific focus on the power interactions which take place between individuals and groups (Scotland, 2012). In this study the power relations between the researcher and the participants, the nurses, patients and the hospital as an organisation were examined and analysed.

Epistemology

Crotty (1998) defined four basic elements in the research process starting with the epistemology or the theory of knowledge imbedded in the theoretical perspective. This theoretical perspective or philosophy then informed the methodology or design which underpinned the choice of methods or procedures used to collect and analyse the data (Figure 1).

Figure 1: The relationship between conceptual framework and method

Critical ethnography allowed hidden meanings to be uncovered within this context through the use of close observation and thick description in addition to discussions and interviews with the two groups of participants, and examination of documents. This chapter will begin with a description, exploration and justification of the epistemology and theoretical perspective chosen for this study, followed by a discussion of critical theory and Braun and Clarke's (2006) method of thematic analysis.

Constructionism

Crotty (1998) explained that ethnography shares epistemological foundations with constructionism which is a theory of knowledge in which meaning is not discovered, but rather constructed by the individual as they engage and interact with the realities of their world. What is perceived as a cultural reality is in fact a construct, additionally the description of another culture is not a reflection but an image constructed by the researcher according to their own cultural interpretation (Malewska-Szalygin, 2012; Wilson & Clissett, 2011). In other words, the meaning is not created in a vacuum but is gradually built up and communicated in a culture over time and therefore different people will construct meaning in different ways in relation to the same phenomenon (Crotty, 1998; Liamputtong & Ezzy, 2005). That which is considered valid and real is actually a reflection of social conventions (Segre, 2016). An important component of constructionism is that people rationalise their experiences in coordination with others by creating a model of the social world and how it functions (Leeds-Hurwitz, 2009). Crotty (1998) compares this with a process of sedimentation or layering in which established meanings and truths are built gradually upon each other in an on-going process. Reality is considered to be

intersubjective, or based on the shared common-sense meanings created by people in their interactions with each other. Intersubjectivity was an important element in the decision to use constructionism in this study as it facilitated close scrutiny of the nurse-patient relationship and some clarification of the experience of being a patient in this setting.

Constructionism contrasts to the positivist theories which are appropriate for the study of physical sciences but have limitations when it comes to the study of people. In positivism true knowledge is limited to objective knowledge of which human consciousness can never be a part as it is not accessible to science (Gray, 2009; Guba & Lincoln, 2011). Constructionists view social reality as a complex phenomenon which is produced by the inhabitants of that world and treated as 'real' but is distinct from physical reality (Neuman, 2006; Ryen, 2011). Thus constructionism enables the researcher to understand the meaning of lived reality, the emic perspective, through the actor's definition of the situation. In essence the epistemology of constructionism is based on the premise that meaning and knowledge are not created in a void but are constructed by individuals and groups within their subjective and objective world in a way that is personal to the individual (Crotty, 1998). Hence multiple contradictory but equally valid perspectives can co-exist. "There is no objective truth waiting for us to discover it. Truth or meaning comes into existence in and out of our engagement with the realities in our world" (Crotty, 1998, p. 8).

Society can be considered to exist as both objective and subjective reality meaning that people interact with the social world which influences people to create habit and routine (Berger & Luckmann, 1991). The experience of society as subjective reality comes about through socialisation with those around us who filter the experience of society by what they say and do in a way that is internalised by individuals (Burr, 2003). Conversation is the most important vehicle for maintaining, modifying and reconstructing subjective reality as there is an understanding of concepts and definitions for people within a social group (Berger & Luckmann, 1991) and underscores how the world is interpreted.

A rich description of the social world of patients with dementia and nurses working and caring for them in the sub-acute hospital setting has been built up in this study using multiple informants and perspectives. Hospitals are organisations built on formal power relationships

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and with distinct and authoritative cultures (Manias & Street, 2001). An ethnographic approach facilitated a focus on the social constructions of reality inherent in such an organisation and provided a means of interpreting and describing the culture within it (Keyton, 2005). As this study was focused on the patients with dementia and nurses within sub-acute geriatric rehabilitation facilities, a constructivist approach was considered to facilitate the understanding of how the two groups perceived and interpreted this world and affected care.

Theoretical perspective

Critical theory

Critical theory was formulated in the work of the Frankfurt School in the 1930s and 1940s and first mentioned by the German sociologist and philosopher Max Horkheimer in his article *Traditional and Critical Theory* in 1937 (Horkheimer, 1972). Horkheimer articulated the difference between the two as related to reflexivity: social researchers were understood for the first time to bring their own socially situated awareness and experience to their research, negating the long-held viewpoint that social sciences could be modelled on the positivistic natural sciences (Gray, 2009; McCarthy, 1994). Knowledge and representation as previously understood were then less believable through the new lens of social awareness (McCarthy, 1994). Critical theory of society is hence a model where reflection and scientific knowing are joined to produce knowledge which is both critical and practical (Bernstein, 1995). Carspecken (1996, p. 7) has described this aptly: "Criticalists find contemporary society to be unfair, unequal, and both subtly and overtly oppressive for many people. We do not like it, and we want to change it". The literature review has highlighted the inequity of the treatment of people with dementia in hospital, suggesting that a critical approach was warranted. In this study, the viewpoint of the patients was sought in order to give a voice to a group of people who had previously been given little opportunity to speak on their own behalf. The researcher as a criticalist sought to understand the disadvantage which was experienced by this group as a result of their cognitive deficits.

These ideas were pursued by a number of philosophers in the generation of thinkers including Jurgen Habermas which followed the Heidelberg School. Habermas suggested that the opposition between history and theory was the only legitimate basis for the criticism of the past and present with the crucial feature of considering not only the psychological aspects of conscious experience but communicative action (Habermas, 1984). Pusey (1987) considered that the lifeworld or the characteristics of a person's everyday life which are taken for granted, is a key methodological term in the work of Habermas. From a Habermasian perspective it is not possible to step out of or distance oneself from one's lifeworld; it is the context for every social action and consciousness (Pusey, 1987).

In his work *Knowledge and Human Interests,* Habermas put forward the idea that knowing and understanding are based on ordinary everyday communication and language rather than the philosophical idea of transcendental ego or the conscious self (Habermas, 1972). This was in opposition to positivist philosophy which despite maintaining a legitimate position as a category of knowledge, in Habermas' view was not relevant to philosophical inquiry into the knowing subject: in this case perception was understood to be as important as observation (McCarthy, 1978). Hence critical theory seeks to raise the self-understanding of social groups to enhance their self-consciousness to the point where it "has attained the level of critique and freed itself from all ideological delusions" (Habermas, 1972, p. 55). The idea of emancipation resulting from critical self-reflection is an important Habermasian concept expounded in *Theory and Practice:* "This interest can only develop to the degree to which repressive force, in the form of the normative exercise of power, presents itself permanently in structures of distorted communication - that is, to the extent that domination is institutionalized" (Habermas, 1974, p. 22). Knowledge increases reflection and therefore, self-determination, communicative action and emancipation. Critical theory informs the processes of critical inquiry.

The concept of emancipation is an important component of critical theory according to Habermas and is considered by many to be his most original contribution to modern philosophy (Grundy, 1987). Emancipation requires autonomy and responsibility, independence from outside influences and is primarily an individual experience (Grundy, 1987). The focus is on the

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power relationships inherent in a situation. The individual can go beyond what is considered the norm towards a consciousness in which meaning is examined and reconstructed, resulting in increased self-knowledge (Boychuk Duchscher, 2000).

Critical inquiry

Critical inquiry was based on the understanding that an individual's view of themselves was coloured by social and historical forces as defined by critical schools of thought (Kincheloe & McLaren, 2005). The researcher (or 'criticalist') assumes that all thought is fundamentally driven by social and historical power relations which cannot be separated from the reported facts as they are unstable and subject to change: the research must be connected with an attempt to confront the injustice related to a particular group within society (Kincheloe & McLaren, 2005). Critical researchers question the status quo and discard accepted norms in order to discover new ways of understanding and to guide action, rejecting mainstream research practices as being guilty of reproducing oppressive class, race and gender systems (Gray, 2009).

The power and dominance issues evident in healthcare required a critical form of inquiry in order to understand the reasons behind the poor experience reported by the patients with dementia and nurses in the literature. It has previously been reported that nurses have found the challenge of caring authentically for patients within unsupportive institutions, which have a culture opposing the values that they promote, to be difficult and disheartening (Hutchinson & Jackson, 2015). An aim of critical ethnography is to bring about change in both researcher and participants based on the resultant personal and cultural growth (Smyth & Holmes, 2005) and was consequently chosen for this study.

Methodology

Ethnography

Ethnography has been defined in a number of ways including the process and product of describing cultural behaviour (Roper & Shapira, 2000), and "the study of social interaction and

culture groups" (Reeves, Peller, Goldman, & Kitto, 2013, p. e1366). Ethnography is generally understood to have as a defining principle the close observation of environments which were previously unfamiliar to the researcher in order to understand the perspectives of the people in that environment (Savage, 2000). It has been described as both a methodological approach and an analytic perspective on research (Savage, 2000; Van Maanen, 2011) and involves methods which may include observation, interview and examination of documents, conducted in various ways to facilitate a deep understanding of the situation (Hammersley & Atkinson, 1983). Clifford Geertz was an early proponent of ethnography and argued that it was defined less by the use of specific methods such as observation and interview and more on the result which he called 'thick description' also known as analytical or theoretical description (Liamputtong & Ezzy, 2005, p. 16). According to Geertz, thick description was a link between the description of activities and their interpretation which were 'thickened' by the addition of comments from the researcher to give as much depth of meaning as possible to the situation experienced: the descriptions also functioned as interpretations (Malewska-Szalygin, 2012). However Atkinson and Delamont (2005) warn against assuming that the definition of thick description is that it was "densely constructed with graphic and detailed cultural descriptions" (Atkinson & Delamont, 2005, p. 832). Geertz's idea was that the description captured the essence of multiple perspectives and frameworks and was overlayed with a sense of the numerous possibilities in interpretation and frames that inform social events and actions (Atkinson & Delamont, 2005, p. 832). The focus of thick description is to capture the rhythm of people's lives, the culture of groups and the patterns of meaning extracted during the research in order to formulate an explanation of particular social phenomena (Liamputtong & Ezzy, 2005). Thick description can provide insight into otherwise closed worlds by focusing on the minute detail including the sights and sounds and smells of a situation. It is also notorious for the time and effort involved and the complexity of the analysis because of the large amount of data generated (Liamputtong & Ezzy, 2005).

Ethnography shares some foundations with anthropology in that it is a way of knowing which is based not on data but experience (De Laine, 1997). Ethnography has its roots in cultural anthropology and was first used by anthropologists in the early 20th century who studied foreign isolated communities abroad, exploring and describing a group, culture or community in

order to understand their value systems, rules of behaviour and relationships (Holmes & Marcus, 2008; Mechanic & Meyer, 2000). Before this time, researchers did not engage in fieldwork but obtained their data through the examination of statistics, government archives, archaeological finds and documents rather than by direct observation (Gobo, 2011), a method of data collection which had more in common with empiricism or positivism (Crotty, 1998). For example, anthropologists such as the Englishman Bronislaw Malinowski travelled to unexplored foreign territory to learn from people whose social lives and cultures were unique to them and consequently a curiosity (Liamputtong & Ezzy, 2005). Malinowski's work which came about after he was prevented from returning to Europe from Australia by the outbreak of World War 1 was a turning point in the conduct of research. He spent many months in the Melanesian Trobriand Islands and formulated principles that are still followed by many researchers today (Malewska-Szalygin, 2012). Literally the word 'ethnography' means to write about people or cultures, from the Greek ἔθνος *ethnos* (people) and γράφω *grapho* (to write) (Reeves et al., 2013).

Ethnography first emerged as an appropriate research method for health care in the 1960s as ethnographic participant observation conducted in the natural setting could offer valuable insight into people's experiences which are not obtained through quantitative work (Allen, 2004). The observational principles of ethnography can be applied to any cultural group which has members with a common situation in any setting. The ethnographer in health care seeks to learn from the group under observation and view the condition in terms of the experience of the individual rather than a set of biomedical outcomes (Moser, 2011). Obtaining a deep understanding of people's behaviours in relation to their health facilitates finding ways to help them to improve it (Liamputtong & Ezzy, 2005). It has been pointed out that "we have no direct access to the truth, even the truth of our own perceptions or emotions" (Van Maanen, 2011, p. 227) however, immersing oneself in a culture and obtaining as much information about the viewpoints and motivations of individuals as possible provides the tools to "interpret and shine a light on what people are up to and why" (Van Maanen, 2011, p. 229). However, ethnographers have been criticised for identifying problems but failing to take moral responsibility for the pursuit of solutions (Denzin & Lincoln, 2008). Hence critical ethnography was chosen for this

study in order to not only produce an understanding of the situation, but also to critique and prompt change where it is needed. Critical ethnography will be discussed in the following section.

Critical ethnography

Critical ethnography is one of a number of post-modern research approaches which takes an alternative view to that of ethnography in response to methodological reflection within the cultural paradigm of postmodernism (Gobo, 2008). It originated at the University of Birmingham, England in the 1970s stimulated by the Frankfurt School of social research and the critical social theory of Jurgen Habermas with the purpose of augmenting the awareness of the ways in which lives are constructed, and the influences which come to bear on people (Holmes & Smyth, 2011). Critical ethnography is a change-orientated approach focussing on cultural critique and interpretation, going beyond the quest for knowledge for its own sake (Crotty, 1998; Foley & Valenzuela, 2008). During the 1970s there was a widespread rejection of the positivist concept that ethnographies could be value-free, and consequently some ethnographers turned their focus to the juxtaposition of the powerful and the powerless, producing both theoretical knowledge and local practical knowledge (Foley & Valenzuela, 2008, p. 288). Hammersley referred to it as appropriation and reconstruction of conventional ethnography in order to facilitate human emancipation (Hammersley, 1992). These post-modernists criticised the classical ethnographers for being realist, impersonal and falsely neutral and considered the observation of disadvantaged groups as an infringement on the rights of those being observed (Gobo, 2008). Furthermore critical ethnographers view it as the moral responsibility of researchers that once injustice and oppression are uncovered action must be taken to reach solutions: It is only this which makes the research useful (Denzin & Lincoln, 2008).

The definition of critical ethnography is not clear-cut and there is a limited description of it in the literature (Harrowing, Mill, Spiers, Kulig, & Kipp, 2010). Any definition is unlikely to satisfy all critical ethnographers because of the associated assumption of a particular epistemological stance (De Laine, 1997). However critical ethnographers commonly seek to uncover hidden

agendas and power relationships in order to identify ways to improve a situation (Carspecken, 1996). To do this, critical ethnographers closely scrutinize the discourse and behaviour of the participants to understand the political, social and the material disempowerment inherent in the situation, (De Laine, 1997; Harrowing et al., 2010). For this reason, critical ethnography always has an explicit political purpose and generally focuses on marginalized and oppressed groups (Cook, 2005; Fassin, 2013). In this study people with dementia and nurses can both to an extent be considered as groups which are subject to oppression. The people with dementia are particularly vulnerable when removed from their normal environment without the familiar supports (George, Long, & Vincent, 2013), and nurses have a history of oppression within health organisations (Dong & Temple, 2011). The focus of critical ethnographies is often on the asymmetrical power relationships inherent in social and organizational settings and the critical ethnographer challenges the practices that sustain this inequality: they not only describe 'what is', but they critique and potentially change the situation (Cook, 2005; Harrowing et al., 2010), thus it was deemed to be an appropriate framework for this study. As De Laine (1997) points out, the marginality of certain groups is assumed, but the critical ethnographer is interested in exploring the individual's response to that marginalisation and their understanding of it. Critical ethnography can raise the consciousness of the participants by prompting reflection and setting the scene for the challenge of practices which sustain unequal power relationships within that culture: the aim being empowerment for the participants (Manias & Street, 2001). Both the researcher and the researched have the potential to experience personal growth and be changed by this research process (Smyth & Holmes, 2005). Critical ethnography is an accepted methodology in nursing research as it allows the underlying systems of domination, hidden assumptions and ideologies to be exposed and the situation redefined (Hardcastle, Usher, & Holmes, 2006).

The rationale for the choice of critical ethnography for this study was based on the intention to give a voice to a vulnerable group of patients, and produce information which may be used to inform nursing practice in the future. In this instance the relationship between people with dementia who are a very vulnerable group was examined in the light of the relative position of power that the nurses occupy, acknowledging that the nurses themselves may have a power

imbalance in their relationship with the health service administration. People with dementia occupy a place in society which is relatively powerless and their views are not well represented. Moreover, when in hospital the person with dementia is additionally vulnerable and reliant on the professionalism and skill of the nurses in order to have their needs met.

Emic/ etic viewpoints

It is important to recognise the emic-etic distinction which underpins ethnographic theory. An emic perspective represents an 'insider' view of the culture as experienced by the people being studied (Douglas et al., 2010). The researcher seeks to gain the 'actor-orientated perspective' and understand a vision of the world as seen by the native (De Laine, 1997, p. 45). The etic perspective is a framework or analysis imposed externally by the researcher independently of the participants: a scientific observer's point of view attempting to identify patterns of behaviour (De Laine, 1997; Douglas et al., 2010; Hoare, Buetow, Mills, & Francis, 2013). Anthropologists did not originally source their information from the individuals whose world was being studied, preferring instead to use secondary sources such as statistics gained from government offices, journals or the accounts of people such as missionaries, since the 'natives' were considered to be savages and therefore unreliable informants (Gobo, 2008). This etic approach has been replaced in most ethnographic research in more recent times by a combination of both emic and etic perspectives. The change was led by Malinowski who is attributed with inaugurating the "view from within" which is now accepted as a central part of ethnography (Gobo, 2008, p. 8).

In most ethnographic studies an emic perspective is first sought in order to gain knowledge about the existing rules and patterns present in a culture and grasp the 'natives' point of view, however it is also important to recognise the etic perspective which is gained when the researcher leaves the studied setting and makes sense of it through the collected data. It is important for the researcher to be aware of the dangers of becoming too immersed in the environment, creating rapport which is too familiar and thus losing the detached perspective necessary to evaluate the situation under observation (Hammersley & Atkinson, 1983). This is a realistic fear for nurses researching in an area with which they are already familiar. The challenge for the nurse researcher is to balance the objectivity required as a researcher with the

subjectivity of a participant in the scene (Manias & Street, 2001). However the position of a nurse researcher as both insider and outsider is a privileged one when investigating healthcare as it provides a unique opportunity to enter the world which would be inaccessible to others (Douglas et al., 2010). The researcher in this study had the advantage of understanding the hospital system and sub-acute geriatric rehabilitation but was mindful of remaining an independent observer. This study provides both groups of participants with the opportunity to have their views heard, providing an 'emic' voice to the study; the researcher then overlayed the 'etic' framework to support deeper understanding.

The researcher is a registered nurse who had previously worked in the field of geriatric rehabilitation in another health setting for 20 years and consequently was familiar with the general routine of such wards and the patient demographic group. Working closely with nurses and people with dementia in various roles including bedside nurse, nurse manager and director of nursing gave the researcher insight into the area of inquiry however a major determinant was involvement in previous studies in which the researcher interviewed people with dementia and in some instances the family or nurses caring for them (Bloomer, Digby, Tan, Crawford, & Williams, 2014; Crawford, Digby, Bloomer, Tan, & Williams, 2014; Digby & Bloomer, 2014a, 2014b; Digby, Moss, & Bloomer, 2012). This gave a privileged view in respect to understanding the scenes being observed and the difficulties experienced by people with dementia in hospital. Empathy for the situation being faced by the patients and also the nurses was a motivation for pursuing this line of research. However having never worked in either of the settings in which the study was set, the researcher was unfamiliar with the geography of the sites, had never previously met any of the nurses or patients and did not have an understanding of the local culture. Care was taken to maintain a professional distance and constantly self-monitor reactions to what was being observed. This self-awareness and reflection in the form of written field-notes gave the researcher some confidence that what was being observed and interpreted was not unduly clouded by previous experiences. The researcher in this instance was both an insider and an outsider.

In this study, the views of the people with dementia and the nurses caring for them were initially explored through observation and interviews to gain an emic perspective. This balance between the viewpoint of an insider (as a nurse) and outsider (as a person who was unfamiliar with the wards, patients and staff participating in the study) has been described as the tension between familiarity and distance (Allen, 2004). The data obtained was then framed using thematic analysis (Braun & Clarke, 2006) which will be further discussed in the next chapter.

Accessing the views of people with dementia

The under-representation of the opinions of people with dementia in research leaves a considerable gap in our knowledge (Balfour, 2006; Beard, 2004; Cotrell & Schulz, 1993; Cowdell, 2010b; Nygård, 2006; O'Connor et al., 2007; Proctor, 2001; Roger, 2007; Young, 2002; Zimerman, 2011). R. Bartlett et al. (2016) reported that people with dementia were not being adequately represented as contributors to research as their experiences were not valued to the same degree as that of their caregivers. The majority of articles published to date concentrate on the biophysical and pathology of dementia, medication and other treatments, caregiver burden and control of behavioural symptoms (Beard, 2004; Edvardsson & Nordvall, 2008; T. F. Moore & Hollett, 2003). However when focusing on the biomedical aspects of dementia there is a risk that all behaviour and attributes will be ascribed to the disease process and other relevant influences will be discounted (Nygård, 2006). The person's health, personality, biography and social psychology are increasingly being understood to be influential on the expression of dementia symptoms (Bryden, 2002). Furthermore there is a temptation when relying on the biophysical viewpoint which elevates the 'mind' over the 'body' to define a person by the state of their cognition – a person with dementia as 'cognitively *impaired*' - and discount them as reliable reporters (Beard, 2004).

Recently it has been shown that involvement of consumers in their own care is central to contemporary practice (Penney & Wellard, 2007) however there has been speculation by some that the voice of the service users is often only heard when it reflects the view of powerful others (Cheston, 2000). Accessing the opinions of people with dementia is fundamental in order to reframe dementia through personal narratives and take the spotlight away from the biomedical

focus on loss and burden. If people with dementia are not viewed as "surviving, continuing viable selves" they risk becoming "social invisibles" (Beard, Knauss, & Moyer, 2009, p. 234) and the barriers which prevent the inclusion of their opinions in care planning will remain (Webster, 2011). It has also been observed that older people (with or without dementia) have rarely been asked to discuss their experiences of hospitalization, to the detriment of our understanding (Atwal et al., 2007).

The reason for the failure to seek the direct opinions of people with dementia about their experiences may be that, until recently, it was considered that their view was untrustworthy as a consequence of the condition (Phinney, 2002). Memory in people with dementia is unreliable, and there may be confabulation and confusion in their stories which has raised concerns about the validity of conducting research with this group (Ballard et al., 2001). People with dementia have been viewed as 'diseased entities' rather than people with valuable information to give (Roger, 2007) or seen as the 'living dead' a term which renders them unworthy of participation in research (Beard & Neary, 2012; Ostwald et al., 2002). It is also possible that the focus on the biomedical aspects of dementia may have overshadowed the subjective experiences and inner feelings of the people affected (Hubbard, Downs & Tester, 2003). So far the observations of others such as professional and family caregivers have generally been given greater credence as these people are viewed as more reliable reporters (Beard & Fox, 2008; Droes et al., 2006; MacRae, 2008). Conversely there is another view that people with dementia have the capacity to contribute to decision-making and the traditional competency-based approach is exclusionary as it is based on the biophysical aspect of the condition and is not specific to the circumstances for which consent is being sought (Dewing, 2007).

It has been found in research investigating the accuracy of proxy decision-makers' decisions and opinions that there is often a discrepancy in the viewpoint of the person and their proxy (Droes et al., 2006). This applies to both people with dementia and people in other situations where they are unable to make decisions independently. In research examining the decision to enter residential care (Denson, Winefield, & Beilby, 2013) and decisions about other situations including the provision of prolonged mechanical ventilation in intensive care units (Cox et al.,

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2009) and end-of-life care decisions (Carr & Moorman, 2009; McDade-Montez, Watson, & Beer, 2013), it has been found that the opinion of proxy decision-makers and the person affected can be divergent. Inviting professional and family caregivers to discuss their opinions on the care of people with dementia is useful and complementary, but is not a substitute for asking people with dementia to give their viewpoint directly. Hellström et al. (2007) argue that the ethical and methodological barriers to the inclusion of people with dementia in research are surmountable and should not hinder their participation. According to Parse (2007), only the individual living that life moment to moment is truly qualified to comment on it.

Despite this there are obvious methodological problems associated with the inclusion of people with dementia in research because of the symptoms of the condition which include deteriorating memory, thinking, orientation, comprehension, language, and judgement (World Health Organisation, 2012). These symptoms limit the ability of the person to recall events accurately and relate their experiences in a way that will make sense to the researcher. Perseveration, which is the uncontrollable repetition of words or phrases, dwindling vocabulary, disordered speech patterns, word-finding problems and confabulation add further challenges. Accordingly most people with dementia who have participated in research have been in the mild to moderate stage of the condition before the effects are overwhelming (Hubbard, Downs, & Tester, 2003; Nygård, 2006).

Additionally participant confidence can inhibit the ability of the researcher to elicit meaningful information from the person with dementia. This was mentioned by Lloyd, Gatherer and Kalsy (2006) who stressed the importance of the researcher's attitude: the person with dementia may be harmfully affected if they feel that the reaction to their impairment is negative. A researcher who demonstrates a respectful and sensitive approach will elicit a more open response from the person with dementia (King, Hopkinson, & Milton, 2016). Notwithstanding these difficulties it has been demonstrated that communication pathways and strategies for making sense of the stories can be developed (Goldsmith, 1996) and are particularly effective when coupled with the observation techniques often seen in ethnographic studies (Hubbard, Cook, Tester, & Downs, 2002).

Chapter summary

In summary, critical inquiry in the form of critical ethnography with the epistemology of constructionism was determined to be an appropriate framework in which to study the experience of people with dementia and the nurses who care for them in sub-acute facilities. In the following chapter the methods to be used in this study will be presented which align with the principles of critical ethnography, and the ethnographic methods of observation, fieldwork and interviews.

Chapter 4 Methods

Introduction

This chapter outlines the methods used to collect and interpret the data for this research. In the five wards a total of 30 patients and 29 nurses were interviewed using a conversational approach, and the interviews digitally recorded. A period of non-participation observation was conducted in which field notes were taken. Relevant ward documents were examined, including the progress notes of the patient participants. An outline of the data collection and analysis process follows.

Reflexivity

Reflexivity is the process of the researcher reflecting critically on the research process and the position that they occupy within the research (Guba & Lincoln, 2011). A self-aware researcher is able to bring a reflexive approach to the work and can explore and understand the dynamics between their position and the people they are studying through self-conscious reflection (Cruz & Higginbottom, 2013; Gobo, 2011). It is very important that the researcher is aware of his or her own assumptions and values and the effect that he or she can have on the subjective and structural elements of the research in order to minimise bias (Holloway & Wheeler, 2010). The researcher is not expected to portray themselves as a detached impartial observer but rather recognize that the ability to be completely separate from the research is a myth: instead the researcher should reflect on their own assumptions, values and biases and their inevitable influence on the research (Northway, 2000).

Nonetheless this is not an easy task as the researcher is required to operate on a number of levels at the same time, being aware of their own internal and external influences while simultaneously observing and noting the actions, motivations and responses of those being observed (Dowling, 2006). It must be acknowledged that the researcher has both an effect on the issue under scrutiny and is affected by it (Dowling, 2006).

There is an important connection between ethics and reflexivity. Reflexivity is focussed not only on the collection of data but on the research process as a whole including the performance of the researcher, the participants and the research context in a continuous process of critical scrutiny (Guillemin & Gillam, 2004). Reflexivity is an important factor in 'microethics' which has been defined as the "ethical dimensions of ordinary everyday research practice' for which the researcher needs skills to act and respond appropriately to whatever comes up in the research process" (Guillemin & Gillam, 2004, p. 265). Despite much talk of the importance of reflexivity, the way it should be applied in practice has not been made explicit in the literature, and there has been criticism that it is a device to produce the appearance of academic rigour and credibility rather than an improvement in practice (Dowling, 2006).

Reflexivity has been portrayed as a means of promoting transparency (Cruz & Higginbottom, 2013). To practice reflexivity in this study the researcher made copious notes of her own reactions and interpretations and the possible effect that her presence may have had on the data. Constant reflection on the effect that the researcher was having on the scene, recognition of previously held assumptions, background values and history, and an attitude of genuine curiosity contributed to the maintenance of reflexivity.

Rigour

Rigour for this research was demonstrated by the consistent use of the methodology and methods within the ethical framework. The procedures and practices used in research must be rigorous and ethical if the research is to be considered a reliable and useful contribution to the field (Liamputtong & Ezzy, 2005). 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). The criteria for rigour set by Lincoln and Guba (1985) are that the research has the following attributes: credibility or truthfulness of the data and its interpretation; transferability or the applicability of the results to different contexts; dependability or auditability; and conformability or neutrality which demonstrates that the researcher is neutral and does not demonstrate any bias (Prion & Adamson, 2014). The

aim is to demonstrate two forms of rigour, the first being of the application of method and the second in interpretation through the use of defensible reasoning (Guba & Lincoln, 2011). This has been explained as "... ascribing salience to one interpretation over another and for framing and bounding an interpretive study itself" (Guba & Lincoln, 2011, p. 205).

Moravcsik (2014) recommends that the rigour of qualitative research should be more openly demonstrated by the use of enhanced research transparency which involves the researcher revealing their data, theory and methodology on which their theories rest, suggesting that this could be done through the more widespread use of hyperlinks to the original data referred to in scholarly publications. However in this study the abundant documentation of the research methods and the data obtained was considered an appropriate format.

Rigour has been demonstrated by the liberal use of researcher reflexivity throughout the findings, and consistency between the research aims and the methodology. A number of techniques were used to ensure the credibility and trustworthiness of the findings including the collection of data from both patients with dementia and nurses, examining the ward documents and extensive observation and field notes. The thick, detailed description of the context and circumstances provided the necessary background so that the meaning of behaviour could be understood and the reader could be confident that as much detail as possible had been provided about all aspects of the research (Curtin & Fossey, 2007). Credibility has also been demonstrated by the validation of the findings and involving experienced researchers in the review of data coding and the meanings assigned to the findings. Providing the rationale for the choice of method, thoroughly outlining the research process including the details of data collection, and providing the specifics of the data analysis method further strengthen credibility (Higgs, 2001). Transferability is difficult to achieve in qualitative research because the studies including this one are relatively small scale and are specific to a situation, but the use of 'thick description' allows the reader to relate the findings to other applications (Clissett, 2008). Dependability is similarly problematic in that it relies on the premise that there are tangible facts which can be discovered, however it is clear that in this type of study it is impossible to replicate the findings exactly in other situations (Clissett, 2008). Transferability and

dependability as described by Prion and Adamson (2014) were established by a thorough description of the research methodology to assist readers' understanding of the decision-making and process and facilitate them to reach similar conclusions. Conformability or neutrality guarantees that the researcher's perspective and biases are made apparent and subjectivity is minimised (Prion & Adamson, 2014). This is achieved by documenting the links between the findings and the data to ensure that the constructions and assertions can be traced to the original source (Clissett, 2008). To demonstrate conformability in this study the researcher made copious reflective notes, supported the assertions by direct quotations and involved the expertise of experienced researchers in a review of the data analysis.

To further strengthen the rigour of this research, two researchers listened to the audiotapes and read through the transcripts to gain an understanding of the content. Common threads and associations between the themes were identified and grouped by the principle researcher referring back to the tapes for verification when required. At regular meetings the findings and any differences of interpretation were discussed until a final interpretation was agreed.

The research setting

The research was conducted in the geriatric subacute rehabilitation wards of two Melbourne, Australia, metropolitan health services. The researcher has previously worked in the area of geriatric rehabilitation in a senior nursing role, so the wards chosen were in different health networks to reduce the risk of power imbalance with the nurses. It was also important to be able to overcome any set views and regard the scene as an outsider which would have been difficult for the researcher if the study had been conducted in her previous place of work. In the nominated health services, a number of wards which regularly accommodate patients with dementia were identified by senior nursing staff as appropriate for inclusion in the study. A richer description of the setting will be provided in the findings chapter.

Researcher access

Approval for this research was obtained from the Human Research Ethics Committees (HREC) of each network (references 140494 and PAO1-2014), and Monash University (reference CF14/1210-2014000512) (Appendix 1). The researcher consulted with senior joint research champions of site 1 who endorsed the research and offered practical support for the researcher to gain access to the areas. A meeting was subsequently arranged between the researcher and the nurse managers followed by a tour of the three nominated wards. The researcher discussed the project at length with the nurse managers. Flyers informing the staff, patients and visitors of the research were distributed to the wards (Appendices 2 and 3).

Setting two included wards on different campuses, therefore an introductory meeting was arranged so that the project could be explained to the principal nurses who manage these sites. Meetings were subsequently organised between the researcher and the nurse managers of the nominated wards. The researcher then met with nurses on each ward to discuss the project and gain their support.

A gatekeeper is a person with the authority to allow or prevent access to an area (Neuman, 2006). Hammersley and Atkinson (1983) warn that it is common for 'gate-keepers' to be concerned about the picture that will be painted by the researcher to the outside world. They may put control and surveillance strategies in place to prevent access to certain areas or lines of inquiry to ensure that the organisation is presented in a favourable light (Hammersley & Atkinson, 1983). This was not the case in either setting. The researcher was given appropriate access and practical assistance to pursue the research by both the principal nurses and the nurse managers. It is possible that the medical officers who nominated specific patients to participate in the research may have screened out patients likely to give negative feedback.

Once the access is arranged, gaining the trust of the participants can take a great deal of time and energy on the behalf of the researcher: however failing to win and maintain that trust can lead to resistance and a decrease in the understanding gained of the phenomena under scrutiny (Hellström et al., 2007). The researcher spent time with the nurses to develop a rapport. It was

necessary to repeat details of the study many times to different nurses who were not present at the initial group introduction. The nurses were generally very welcoming and accommodating. For example a nurse identified that a potential patient participant was not in a receptive mood, and offered to alert the researcher when the patient had had a shower and lunch when he was likely to be more relaxed. At various times nurses commented on the suitability or readiness of patients to participate, and assisted with setting up the room for interview by taking the other patient in the room to the sitting room to make confidentiality possible.

Ethics

The researcher was very aware that the ethical issues when researching vulnerable groups can be significant because of the potential for exploitation. Ethics committees are understandably conservative when it comes to approving access to patients with dementia for the purposes of research. However it has been pointed out that this potential obstacle should not be a deterrent to researchers, as people with dementia have the right to be involved in research; failing to include them may result in valuable information being missed and can be seen as exclusionary (Dewing, 2007; Oliver, 2012).

In line with the Nuremberg Code (1947) and the Declaration of Helsinki (2013) the ethical principles which underpin the conduct of research involving humans including the protection of autonomy, veracity, justice, beneficence and non-maleficence were adhered to (National Health and Medical Research Council, 2014). The potential risks to individuals must be closely monitored and balanced with the benefits that may result in their involvement (H. Bartlett & Martin, 2002). Respecting dissent can be considered more important than obtaining assent as dissent has a protective factor that should not require justification (Black, Rabins, Sugarman, & Karlawish, 2010). Ethics committees tend to focus on what may happen in extreme cases and the worst case scenarios. In doing so they may neglect to give credence to the discretionary judgement and individual personal and professional ethic of the researcher when faced with real life situations with research participants (Madjar & Higgins, 1996). Many older people will agree to talk to a researcher but are daunted when asked to read written information about the

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research or sign a consent form as they have become either unused or unable to achieve such tasks (Madjar & Higgins, 1996). Despite lacking the capacity to formally consent, many people with dementia can retain the ability to make choices at some level and it is a mark of respect that they have their remaining abilities and opinions considered (Dewing, 2002).

The conservatism of ethics committees in regard to permitting research involving people with dementia has been a contentious issue for others including Dewing (2007) who believes that too much reliance has been placed on the traditional 'gold standard informed consent' which she suggests should be adapted for people in different circumstances. Research which seeks to include people with dementia, especially those in an advanced stage is easily stymied by ethics committees driven by a bioethics model who have the intention of protecting the vulnerable, but in the process, may disallow them to have a voice in research (Grout, 2004).

A process consent model was developed by Dewing (2007) for use with people who would normally have a very limited capacity to consent but remain able to indicate their wishes. This method includes forming a rapport with the person after establishing that they are in a state of well-being and therefore open to enquiry, then obtaining consent to participate and monitoring their on-going consent throughout the session (Dewing, 2007).

This method was followed in this research in addition to the formal processes required by the ethics committees. The method relies heavily on the researcher being skilled in assessing the intentions of the participants, and acting honourably if they choose to withdraw their participation. There are many ways that a person can indicate that they are willing to participate, including verbally, with body language or facial expressions, however it is less clear what part passivity (a common symptom of dementia) plays in this scenario (Black et al., 2010). Similarly dissent may be expressed verbally or by body language such as hitting out or trying to leave the scene and it is important that the researcher act ethically by respecting the person's wishes (Black et al., 2010).

The ethics committees of the institutions where this study took place required a strict adherence to the traditional model; however elements of the process consent method such as establishing a rapport with the participant, and on-going monitoring of consent were incorporated into the study.

Proxy or surrogate consent by someone representing the patient such as the next of kin, Power of Attorney or legally appointed guardian, has long been used to obtain access to people who do not have the standard capacity to consent on their own behalf; however this can be problematic for a number of reasons. The views of the participant may differ or not be known by the proxy, or the proxy may suffer undue burden in taking on the responsibility, and it is possible that they may have a conflict of interest which leads them to act in a way which is not in the person's best interest (Beck & Shue, 2003). An investigation of proxy burden showed that the degree of burden is a complex interaction of factors including the severity of the patient's dementia and their ability to contribute to the decision-making, and the invasiveness of the research (Sugarman, Cain, Wallace, & Welsh-Bohmer, 2001).

There is a danger in our society where cognition is highly regarded that a person's worthiness is judged dependent on this, and that those whose cognition is poor are considered to be inferior and therefore not worthy of inclusion in matters such as consent (Dewing, 2002). However people with dementia can often have fluctuating capacity to understand information, make decisions and communicate their ideas, dependent on the time of day, other health issues, medication and stress (Grout, 2004). Their ability may be situational and should not be regarded as an 'all or nothing' entity in which the person may have lost the capacity to make complex judgements but may retain other abilities particularly when they are in a context that is familiar to them (Nygård, 2006). It has also been pointed out that the experience of having dementia is an individual one which can be different for each person and must be considered and accommodated by the researcher with sensitivity (Hubbard et al., 2003).

Advance directives have been used in some situations to establish a person's willingness to participate in research, however this is not without problems, as it has been demonstrated that an advance directive does not consider the 'here and now' aspect of a person's viewpoint, and is based on a judgement about a situation which was impossible to really understand when the directive was made (Widdershoven & Berghmans, 2001). It can be argued that the person with dementia is actually a different person than they were when intact; accordingly the wishes of the person at the time however expressed should take precedence over advanced directives (Post, 1995).

This is not to say however that the use of proxy decision-makers and advance directives should necessarily be discarded. Consent in this instance should be seen as a collaboration with the person with dementia who is central to the decision-making but supported by others such as the clinical team, next of kin or Power of Attorney, and any advance directives (Widdershoven & Berghmans, 2001). Dewing terms this approach 'inclusionary consent' (Dewing, 2002). In this study, patient participants were encouraged to discuss their potential involvement in the study with their next of kin or power of attorney before making a decision. Advance directives were not consulted to determine consent to participate because patients were able to either consent themselves or provide assent with the formal consent of their nominated power of attorney or substitute decision-maker.

Participants

There were two groups of participants in this study who were directly involved in the observation and interviews.

1. Nurses, both registered (RN) and enrolled (EN), working in the nominated wards.
2. Current inpatients with dementia who were assessed by the senior medical officer as suitable according to the identified criteria.

In Australia there are two main nursing qualifications. A registered nurse is one who is either hospital trained or degree-educated whereas an enrolled nurse holds a certificate or diploma in

nursing. There are also differences in registration requirements, education, level of supervision and the expectation of the role (Jacob, Sellick, & McKenna, 2012).

Inclusion and exclusion criteria

Patients were included in the study if they satisfied the following criteria:

- had a diagnosis that included dementia;
- were assessed by the senior medical officer as suitable for inclusion in the study and did not have an acute illness (including delirium);
- could either consent to participate on their own behalf or had a suitable proxy available;
- were willing to be interviewed for the study;
- and able to have a conversation in English.

Patients were excluded from participating for any of the following reasons:

- the patient declined to be interviewed;
- the patient's proxy was unwilling or unavailable to sign the consent form (in the case of a patient participant who was deemed unable to consent on their own behalf);
- the senior medical officer determined that the patient was acutely unwell, or unsuitable for participation for other reasons;
- the patient was unable to have a conversation in English.

Nurses were included in the study if they satisfied the following criteria:

- they were a registered or enrolled nurse employed in a ward that was part of the study,
- were willing and able to participate,
- and formally consented to participate.

Nurses were excluded if:

- they declined to volunteer to be part of the study.

Recruitment

At a time nominated by the nurse managers as convenient, the researcher presented a short overview of the research to the nurses and an outline of their potential participation. Written information was made available in the form of flyers distributed to all nurses, and posters placed prominently in the ward. Nurses who preferred not to be involved in the observation phase of

the study were directed to alert the nurse manager who could advise the researcher, however none of them took up this option. The nurses were recruited in a convenience sample (Kam, Wilking, & Zechmeister, 2007). All RN and EN nurses who work on the wards involved in the study were invited to participate in the individual interviews through the flyers, and the first 15 from each setting who expressed interest in participating and formally consented were interviewed.

Purposive sampling was used to identify patients suitable for inclusion. Patients with dementia were identified by the senior medical officer at each site and considered for the study if they met the inclusion criteria: a diagnosis of dementia, no acute illness including delirium and able to have a conversation in English. If any of the clinical team, family or patient expressed any apprehension about the involvement of the patient they were not included. Once the potential participant was identified, the senior medical officer was asked to decide if the patient was competent to consent on their own behalf for the purposes of this research. If they were deemed competent the researcher approached the patient and explained the study and their potential involvement in it. They were encouraged to consult with a family member or friend before making a decision, and given a day to think about it. If they agreed to participate, a time for interview was scheduled and a consent form signed.

If the patient was identified as suitable for inclusion but deemed not competent to consent on their own behalf, the researcher contacted the next of kin or Power of Attorney (POA) either by phone or in person if they were visiting the ward. If the person responsible (next of kin or POA) agreed to the participation of the patient, the patient was approached by the researcher, the study explained and they were asked for their assent. The person responsible signed the consent form. There were six instances in which this was the case.

Data collection

Observation

Participant observation conducted in the natural environment (or field) is a commonly used data collection method in qualitative research and has been referred to as the mainstay or primary data collection method of ethnography (Douglas et al., 2010). The purpose is to acquire an insider's point of view while retaining the analytic perspective of an outsider which means that the researcher sees the setting from multiple perspectives at the same time (Neuman, 2006). It has been referred to as "one of the most impressive ways yet invented to make ourselves uncomfortable" (Van Maanen, 2011, p. 219). Gobo (2011) pointed out that we are part of the 'observation society' in which we are constantly observed through closed circuit television cameras, smart phones and web cameras. Having another person observing the activities on the ward would therefore not appear incongruous to the participants.

In this study the observation sessions took place in the ward environment over the life of the study and involved the researcher remaining in the background and observing from inconspicuous vantage points in order to facilitate immersion in the world of the patients and nurses and be as unobtrusive as possible. Occasionally the researcher would assist with bed-making or meal tray collection to appear to be part of the group (Douglas et al., 2010). The researcher endeavoured not to disturb the milieu and stay objective (Agrostino, 2005) although this was difficult at times. The traditional assumption was that the researcher could observe and document a situation as a neutral outsider, finding the truth by careful cross-checking with insider reports but more recently it has been acknowledged that the researcher will always bring their own gender, ethnicity, class and other factors to the research despite efforts to the contrary (Agrostino, 2005). Ethnographic observation is seen less as an endeavour involving a researcher and 'subjects' and more of a collaboration between them, and a context for interaction (Agrostino, 2005, p. 732). An important aspect of fieldwork is that the researcher had a continuous presence in the field unlike other techniques such as surveys and interviews which have been described as 'grab-it-and-run' methodologies (Gobo, 2011).

Gobo has described the characteristics of participant observation as follows:

1. The researcher establishes a direct relationship with the social actors;

2. Stays in their natural environment;

3. Purpose of observing and describing their social actions;

4. Interacts with them and participates in their everyday ceremonials and rituals; and

5. Learns their code (or at least parts of it) in order to understand the meaning of their actions. (Gobo, 2011, p. 316).

The researcher conducted the observation in each ward one at a time followed by the interviews with the patients and nurses, in line with the procedure recommended by Gobo (2008). The initial period of observation allowed the researcher to grasp the dynamics of the ward, the routine and the roles of the individuals. Following this, interviews were scheduled with patients and nurses when it was convenient to them, and the researcher continued observing the ward between these times. The relationship between the patients with dementia and the nurses, the attitude of the nurses towards the patients and the reaction of the patients to their treatment were the main focus. The observation sessions were carried out at different times of the days and the week including morning, afternoon and night shifts to maximize the variability of routines and tasks being performed, and ceased when no new information came to light.

The Hawthorne effect

The researcher was alert to the potential of the Hawthorne effect in which the participants change their behaviour because they know that they are being observed (McCambridge, Witton, & Elbourne, 2014). The phenomenon is named after an experiment which was conducted in the Hawthorne Illinois plant of Westinghouse Electric during the 1920s and 30s in which the productivity of the workers rose regardless of the modifications imposed, when they knew that they were being watched (McCambridge et al., 2014; Neuman, 2006). It has been argued that evidence of the Hawthorne Effect does not necessarily render the research invalid as despite some behaviour being modified, it is not usual for there to be alterations to the cultural milieu, although the change in behaviour must be acknowledged (Carspecken, 1996). Foucault (1980) referred to 'auto-surveillance' and suggested that the gaze of the overseer is internalised by

individuals to the extent that each individual is exercising surveillance over and against himself in the normal course of business. Being observed in the course of ordinary activities is accepted in the 'observation society' (Gobo, 2011) hence the presence of an additional observer would not generally result in a significant change in behaviour. It has been suggested that the Hawthorne effect is more evident in studies where the researcher remains solely as an observer rather than a participant as it can make people more aware that they are being watched and can lead to alterations in their behaviour (Clissett, 2008).

In order to strengthen the study findings, 120 hours of non-participant observation were undertaken across the five participating wards. The data was collected over a period of seven months in 2014 with a break of two months between the two health services. This was because the length of stay for patients in sub-acute care is approximately three weeks, and those with multiple co-morbidities often stay significantly longer. In order to observe a range of patients, it was necessary to spread the data collection over a longer timeframe. The gap between the data collection periods at the two sites was due to a delay in ethics approval from the second health service after another health service declined the request for research access.

During each period of data collection, the researcher arrived in the ward in time for the shift handover in order to form an understanding of the current issues and be introduced to the nurses working that shift. The nurses generally appeared to be comfortable with the presence of the researcher in the ward, occasionally asking questions about the research, but in most cases appearing unconcerned. In the two older wards on site one (wards A and B) handover occurred at the nurses' station which was in full view of the ward and within earshot of anyone coming to the desk. On the other wards, the nurses congregated either in the tea-room (wards D and E) or in a meeting room (ward C).

The observation periods lasted between one and three hours and were undertaken in various areas including the patient bays, patient lounge areas, patient gardens and the staff stations. In most cases the observation period ceased when the researcher felt that the presence of an external person was becoming intrusive. The older wards with five patients in a bay were easier to observe than those with a majority of single and double rooms, especially ward C which was

new and consisted of mostly single rooms and long corridors. Because the patients spent most of their time in their rooms, it was more difficult for the researcher to observe care and interactions unobtrusively.

Field notes

Field notes are the written recording of the experiences, observations, reflections and perceptions made by the researcher while in the field (Liamputtong & Ezzy, 2005). In this study, 110 pages of field notes were taken to record the researcher's observations on the interactions and other factors at play such as the level of activity in the ward, new patients or visitors arriving and other distractions. The researcher spent approximately two hours in the field per session, taking jotted notes of fragments of conversations or brief observations on the handover sheet in order not to draw attention to the researcher role. Nurses in the wards frequently use the handover sheet to make notes of their own so this activity did not look out of place. The jottings were incorporated in the field note journal once the researcher left the observation area.

Writing down in a regular and systematic way what is observed and learned in the field comprises the core of ethnographic research (Liamputtong & Ezzy, 2005). Field notes have been described as the ethnographer's *raison d'etre* - if there is no record of the experience the ethnographer might as well not have been there (Fielding, 1993, p. 161). The field notes were used to record not only what was observed, but also the researcher's thoughts and interpretations, thus beginning the process of sense-making and analysis (Liamputtong & Ezzy, 2005).

It is important that the field notes are written as soon as possible after the observation session while the impressions are still fresh however it is usually not appropriate to do this in view of the research participants (De Laine, 1997). Hammersley and Atkinson (1983) noted that the quality of the field notes diminishes rapidly with the elapse of time because the details are quickly lost or confused. In this study the researcher endeavoured to update the field notes at 1-2 hourly intervals.

The researcher used an A5 notebook to record field notes, with the right hand page used for recording direct observation of activities, and the left-hand page used for reflections on these observations. The reflective component was an important inclusion in order to demonstrate reflexivity and show awareness of the position of the researcher juxtaposed to that of the people being observed. In this section the researcher noted personal feelings and interpretation of the events as they occurred. The process of note-taking is a personal one which can be broadly divided into two categories: one in which the ethnographer subjectively chooses to describe the most interesting, noteworthy or salient points, and the other in which everything that happens during the observation period is comprehensively documented (Wolfinger, 2002). In this instance a combination of the two techniques was used, using the following framework as a prompt.

Spradley's Nine Dimensions of descriptive observation (Spradley, 1980) are:

1. Space: physical place or places
2. Actor: the people involved
3. Activity: a set of related acts people do
4. Object: the physical things that are present
5. Act: single actions that people do
6. Event: a set of related activities that people carry out
7. Time: the sequencing that takes place over time
8. Goal: the things people are trying to accomplish
9. Feeling: the emotions felt and expressed

The sights, sounds and smells of the situation were annotated in the notebook as they came to the attention of the researcher alongside the more formal observations prescribed by Spradley (1980).

Using this framework involved the researcher spending time in the wards observing the activities and the dynamics of the relationships with an attitude of ignorance (Spradley, 1980). This was difficult at times because of the researcher's long history of working as a nurse in a

similar area in another health service. Nevertheless because the physical layout of the wards was unfamiliar and none of the participants were known previously, to a large degree this was achieved. Endeavouring to see things as a complete outsider facilitated the researcher's understanding of events which occur routinely and allowed an etic perspective to be compiled through observation notes to achieve thick description (Allen, 2004). The 'monological' nature of the information reflected the third-person stance taken by the researcher in this stage. Reflective notes which are the beginning of data analysis were also taken during this phase.

Observation in wards A and B was made easier for the researcher by the glass-fronted 5-bed patient bays. The staff area in the centre of the ward was used by Associate Nurse Unit Managers (ANUMs) and often other nurses to observe the patients from a distance. All the bays had extra chairs at which the nurses often sat while writing notes or updating charts and where the researcher was sometimes based. Making beds and chatting to the patients and nurses was an easy way for the researcher to become part of the field, at the same time allowing a discreet exit for the purposes of note-taking. In wards C and D this was much more difficult because the patients were mainly housed in single or double rooms which led off long corridors. In most cases it was not possible to observe patients or their interactions except by being positioned in their room. None of the wards routinely used a central dining area for the patients and very few patients used the lounge areas for watching television, meaning that in some wards there were few occasions when the patients left their bedrooms except to go to therapy sessions or to the toilet. The researcher found opportunities for observation by accompanying the nurses into the patient rooms when they were administering medication, checking the charts or making beds, and at times the researcher sat with a patient in their room to observe the ward from the patient perspective.

Interviews

The interviews in this study took place after approximately four hours of observation had taken place to ensure that the researcher had a basic construction of the reality of the participants and identified relationships and the influencing factors on care. The researcher used

photoelicitation, a technique of using photographs to stimulate conversation (Clark-Ibáñez, 2004) when interviewing the patient participants. The questions were open-ended and semi-structured, starting with a general inquiry before probing deeper to illuminate the feelings and motivations of the informants (Douglas et al., 2010). An aide-memoire was used to prompt the participants when necessary (Appendix 4 and 5). Holstein and Gubrium (2011) compare interviewing to prospecting for truth in facts and feelings. They suggest that the researcher must overcome self-consciousness and suppress personal opinion in order to facilitate candid responses, avoiding 'by-the-book' interview questions and focus instead on what they call 'creative interviewing' in which the researcher also shares their thoughts in mutual disclosure. This is done to assure the respondents that they can in turn disclose intimate thoughts and feelings (Holstein & Gubrium, 2011). However this technique is not supported by all ethnographers as it can lead the participant to respond in a certain way. A more accepted technique involves 'reflexive interviewing' in which the researcher doesn't decide beforehand what questions will be asked (although they may bring a list of topics) but determines this during the interview process dependent on the way things are headed (Hammersley & Atkinson, 1983). Despite non-directive questioning being the most popular, there is also a place for directive and leading questions although caution is advised (Hammersley & Atkinson, 1983). In this study the researcher used reflexive questioning and commenced the interviews with broad questions, for example, "Can you tell me about your experiences of being a patient in this ward/ caring for people with dementia in this ward?" More specific questioning followed depending on the issues raised by the participant. The researcher brought a list of pre-determined topics to the interviews, but the conversation was largely driven by the issues which the participant appeared to find most pertinent to their experience.

 The process of obtaining and analysing information is complex and it has been suggested that no actual 'knowledge' about reality can be obtained because the interviewer and the respondent create and construct their own individual versions of reality dependent on their cultural understandings, race, age, class and gender (Miller & Glassner, 2011). This is exacerbated when interviewing people from a group with which the researcher does not share membership, and

some believe that a researcher should be a member of the group if they are to truly understand it (Miller & Glassner, 2011, p. 132). In this instance the researcher could be considered a member of the group from the perspective of being a nurse who has worked in sub-acute care for many years, however would be considered an outsider to the wards under observation due to not working in these areas previously. The researcher was known to the participants only as a PhD student.

Patient interviews took place after a rigorous consent process which is outlined below (Appendices 7 and 8). In most cases the interviews were conducted in a private space but there were some instances in which they occurred at the patient bedside despite being in a shared room because it was deemed by the researcher to be less disruptive to the patient who could have become agitated if moved to an unfamiliar place. It is often recommended that interviews should be conducted in quiet, private rooms away from distractions and background noise (Miller & Glassner, 2011). However rooms which fit this description in hospital wards are not only difficult or impossible to find, but they take the person out of the environment they are discussing: a factor which can influence their recall ability. Despite the inherent challenges of maintaining confidentiality and focus in a noisy environment, remaining in the participant's hospital room made it less threatening for the participant and shifted the balance of power away from the interviewer. This was an interview method recommended by MacDonald and Greggans (2008). The participants were mostly interviewed in their hospital bedrooms unless confidentiality was an issue. This meant that background noise and interruptions were frequent, however maintaining eye contact and a demonstration of interest in what the person was saying meant that in most cases the participant's attention was maintained.

Before being interviewed all patient participants were told that they were welcome to have a friend or relative with them, because some people with dementia like to be reassured that they have understood the situation and are making appropriate judgments (Digby et al., 2012). There were three occasions when a relative attended the interviews: one was the participant's wife, one a nephew and the third was the daughter of the participant. The researcher asked the

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accompanying person to let the patient speak for themselves and not add anything to the conversation unless specifically invited and they generally complied with this request. Photo-elicitation was used in an endeavour to enrich the patient interviews and stimulate conversation with the participants.

Interviews with nurses were conducted in a quiet, private space in the health setting at a mutually convenient time. It was sometimes difficult to find a time when the nurse could be spared from the clinical area, and there was also the problem in wards A and B of finding a space within the ward which was private and not being used for other purposes. Written consent was obtained prior to interview (Appendix 6). Interviews included open-ended questions and focused on the nurses' experience of caring for people with dementia, the enabling factors and problems, the motivation, rewards and disadvantages for their employment in this area of nursing, examples of care situations observed and how they included patients with dementia in care decisions.

All the interviews were digitally audio-recorded using a small Olympus digital voice recorder VN-712PC. The use of the recorder was discussed with the participants during the consent process, and there were no objections. In each case there was a table in the interview setting and the recorder was placed there and turned on from the start of the interview. Most of the participants did not give any indication that they constrained by the presence of a recording device, and did not pay any attention to it.

An article "Interviewing people with dementia in hospital" has been published in the Journal of Clinical Nursing (Digby, Lee, & Williams, 2016b). The article outlines the technique used in this study to engage with the participants with dementia in a way that facilitated their involvement to the research. Very little has been written about this topic in the past as until recently people with dementia were rarely asked for their opinion, with information mainly sought from health professionals and family carers.

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Interviewing people with dementia in hospital: recommendations for researchers

Robin Digby, Susan Lee and Allison Williams

Aims and objectives. This article aims to:

- Discuss the inclusion of the perspectives of people with dementia in research.
- Consider the major challenges involved in the process of interviewing people with dementia.
- Provide recommendations for those involved in interviewing people with dementia in hospital.

Background. People with dementia are frequent consumers of health care and often have a poor experience in hospital but have been largely excluded from direct participation in research until recently. Limited understanding of the specific communication needs of people with dementia restricts access to the person's viewpoint. Recommendations for interviewers which consider the specific requirements of people with dementia are presented.

Design/Method. This is a discursive article drawing on the experience of interviewing people with dementia in three separate studies. The conclusions that will be discussed are recommendations for researchers which were formulated following examination of the reflective journals written during the data collection phases of the studies and analysis of the data from the perspective of interviewer performance.

Results. Six main issues have been identified and discussed with reference to Habermas's theory of communicative action.

Conclusions. Interviewing people with dementia requires specific skills including an ability to be emotionally sensitive and respectful of the person. This engagement can be challenging and complex for the interviewer. It is vital that genuine engagement and mutual recognition are established before the interview is attempted. A more meaningful research outcome is likely to be the result.

Relevance to clinical practice. The suggestions outlined here are relevant to a variety of people who are in contact with people with dementia in clinical settings. Developing the skills of researchers in this area needs a commitment by organisations to promote the inclusion of the perceptions of people with dementia in research and in discussions about their own care.

Key words: dementia, hospital, interviewing techniques, patient, patient perspective, qualitative research

> **What does this article contribute to the wider global clinical community?**
>
> - The inclusion of people with dementia in research has increased in the last two decades; however, this needs to be expanded. Enhancing interviewer skill in including people with dementia in research is a positive step.
> - Researchers interview people with dementia for many reasons. The advice outlined here is also relevant to a variety of people who are in contact with people with dementia in clinical settings.
> - Improving the skill of researchers in interviewing people with dementia promotes the inclusion of this patient group in research and in discussions about their own care.

Authors: *Robin Digby*, RN, MN, PhD Candidate, Monash University, Sorrento, Vic.; *Susan Lee*, BAppSci, MBioeth, PhD, Senior Lecturer, School of Nursing and Midwifery, Monash University, Frankston, Vic.; *Allison Williams*, PhD, RN, MN, Associate Professor, Director, Monash Nursing Academy, Monash University, Clayton, Melbourne, Vic., Australia

Correspondence: Robin Digby, PhD Candidate, Monash University, Frankston, P.O. Box 190, 3943 Sorrento, Melbourne, Vic., Australia.

E-mail: rdig1@student.monash.edu

Aims

This article aims to

- Discuss the inclusion of the perspectives of people with dementia in research and in decisions about their care.
- Consider the major challenges which emerge when interviewing people with dementia.
- Provide recommendations for those involved in interviewing people with dementia in hospital.

Background

People with dementia are admitted as patients to most areas of health services due to a range of comorbid health problems and the life-shortening elements of the condition, but their experiences in hospitals have often been reported as poor (Cowdell 2010). Dewing and Dijk (2014) suggest that this could in part be related to the prioritisation of treatment for acute conditions and the limited understanding of dementia by hospital staff. Until the 1990s, most research concerning dementia focussed on the biophysical aspects of the condition, medical treatment, caregiver stress and management of behaviour (Bond 2001). Much of the existing evidence is derived from formal and informal caregiver opinion, as historically this was considered more valid (Nygård 2006). Until recently it was uncommon to directly investigate the experiences of the person with dementia from the perspective of the person with the condition (McKeown *et al.* 2010, van Baalen *et al.* 2011). Contributing to this was the belief that dementia meant an erosion of personhood or an 'unbecoming' which precluded the person from having a valid opinion (Fontana & Smith 1989, Moore & Hollett 2003). The double stigma of ageing and declining cognition added to this exclusion (Dewing 2002).

Fortunately, this trend is changing and it has been argued that supportive inclusive environments in which people with dementia are involved in research can change the way the person feels, enhancing self-esteem and validating their experiences (Hellström *et al.* 2007, McEvoy & Plant 2014). According to Parse (2007), the person who is living their life moment to moment is the only one truly qualified to comment on it. It is, therefore, important that people who have dementia, in the same way as people with other conditions, are included in research and given a voice and the opportunity to comment on issues which affect them (Beuscher & Grando 2009). Failing to consult the person with dementia can be seen as exclusionary (Dewing 2007) and denies the person's right and the positive satisfaction of engaging and contributing to research (Beuscher & Grando 2009).

Many clinicians do not have the necessary communication strategies to engage effectively with people with dementia (Einang Alnes *et al.* 2011, Eggenberger *et al.* 2013). Limited understanding of the specific communication needs that dementia creates unnecessarily restricts the interactions between patients with dementia and staff and leads to miscommunication and a failure of both parties to understand each other's perspective (Eggenberger *et al.* 2013). This article outlines recommendations for interviewing people with dementia which take into consideration their specific requirements. A current doctoral study and two previous interview-based studies conducted by the first author, as well as previous research by others, have been incorporated into this article.

Dementia can decrease a person's ability to order and articulate their thoughts which results in vague and empty speech with dwindling vocabulary (Hubbard *et al.* 2003). Hence, people with early to moderate dementia are more likely than those with more advanced dementia to be included in this type of research, leaving a gap in knowledge about the experiences of people with more advanced dementia. Most research with this group of patients has been done through observation rather than interview because of the deficit of verbal abilities; however, this approach assumes that the observer interprets the reactions of the person correctly (Smebye *et al.* 2012). More research needs to be done to elicit direct feedback from people with more advanced dementia.

Design

This is a discursive article which outlines the issues which became apparent during the data collection phase of the first author's PhD study exploring the experience of people with dementia in hospital and two other studies in which the same researcher interviewed people with dementia in hospital. The first author has had more than 20 years of experience working with people with dementia and considerable experience interviewing and exploring the views of this patient group. The information is considered in the light of Habermas's theory of communicative action (Habermas 1984).

Method

A total of 45 participants with dementia were interviewed by the first author (RD) about their experiences in hospital. The most recent study is research in which 30 people with dementia receiving inpatient rehabilitation in Melbourne, Australia, in 2014 were interviewed about their experiences

of hospital care. A similar interviewing technique was used to examine the experience of eight inpatients with dementia in moving facilities and how it affected them (Digby *et al.* 2012). In the third study, separate individual interviews were conducted with seven people with dementia to gain their perspective of the hospital design features that were most important to be incorporated into the construction of a new hospital facility dedicated to the rehabilitation of people with dementia (Digby & Bloomer 2014). The findings that will be discussed in this article are recommendations which stem from analysis of the interviews from the perspective of interviewer performance and examination of the reflective journals written during data collection. This was primarily done by the first author using thematic analysis. Further literature from previous research conducted by others has also been referenced for depth of understanding.

The interviewer kept detailed reflective journals during the data collection phases of the three studies which were used to enhance the information gained in the interviews and included the researcher's thoughts about the techniques used in the interviews. Human Research Ethics approval was gained from the university and each hospital where the studies were conducted. Informed consent was obtained from participants before the interviews were commenced. All the participants are referred to by pseudonyms to protect confidentiality.

Jurgen Habermas's theory of communicative action begins with the assumption that all people are in relationship and every process which leads to understanding another is filtered through the background of established customs and conventions (Habermas 1984). Communicative action is focussed on the understanding of others through communication and the use of language. According to Habermas, problems of domination and power stem from misrepresentation and distortion of language. 'Intersubjectivity' or 'recognition' is the shared understanding formed through reciprocal relationships between people (Habermas 1984). A complete absence of manipulation and domination would produce an idealised form of intersubjectivity in which each party could freely speak and be heard. This is unlikely to be completely possible, but striving to attain equality between communicators is a worthy aim (Schlosberg 1995). Habermas's theory is an appropriate framework for examining the process of interviewing individuals in this instance as it concerns the fundamental nature of the relationship of people with one another. Applying the theory of communicative action to analysis of interactions lead to an understanding of how communication in specific situations works to maintain or alter patterns of belief and worldview (Parkin 1996). In

this article, the attention will be focussed on understanding how forms of communication and interaction preserve and respect the essential relationship between people regardless of their cognitive ability. Six main recommendations have been identified which are specifically important when interviewing people with dementia. These are centred on the engagement of the participant with the interviewer.

Themes

Recognising readiness to talk

It is important to recognise that the readiness of a person with dementia to communicate can vary from time to time and the potential participant must be open to engagement before an interview can be attempted. Dewing (2002) called this ascertaining if the person is in a state of 'ill-being' or 'well-being' and saw it as a continuum between the two extremes. In the course of the fieldwork for the three studies, occasionally a potential participant was approached and was found to be withdrawn and uncommunicative, which might be referred to as 'ill-being'. However, in some cases, the same person was quite willing to talk later in the day or on a subsequent day. Attempting to interview a person who is not open to communicating will be futile, and the researcher may inadvertently contribute to the person's anxiety or distress. Respecting the right to decline to engage (dissent) is central to person-centred practice and shows respect for individuality. The relationship between the participant and the researcher must be built on mutual trust and understanding (McCormack 2003), and this cannot be established if the person indicates that they are not willing to talk. It is possible that in some instances a person with dementia may be more inclined to reject an approach by a researcher than a person with intact cognition because the rules of polite engagement may not always be evident to them (Sturm *et al.* 2015).

The body language of the participant can be an indication of the person's readiness to talk. A person who looks away, moves away or refuses to meet the gaze of the interviewer is showing that they are not willing to engage or recognise the other. Similarly this can be indicated by the person telling the interviewer to 'go away!' scowling or making other verbal or nonverbal indications. The refusal of the person must be respected regardless of the manner by which that refusal is made. Conversely, a person who meets the interviewer's gaze and responds readily to them is indicating that they are interested and willing to talk, a potential state of 'well-being' and recognition.

Facilitating and prompting conversation

To facilitate a conversation with a participant, the interviewer should commence with general topics such as the view from the window, the weather or what the person is doing (e.g. reading the newspaper or knitting) to facilitate a connection between the interviewer and the participant. This warm-up conversation helps to develop rapport and facilitate mutual recognition. It can be short or quite lengthy dependent on the participant. Frequently, this leads into discussions more relevant to the research question, but in most cases, it appears to 'break the ice' and make the interview process less intimidating for the participant. A flexible approach should be used to follow up any leads introduced with further prompts. The researcher demonstrated authentic engagement with the participant by listening and responding with warmth, understanding and genuine interest in the person and their views, an approach which has been described by Nunkoosing (2005) as embodied interviewing.

For someone with impaired cognition, direct questioning can seem threatening and can increase the likelihood of withdrawal from the conversation (Dewing 2007, Edvardsson & Nordvall 2008, Beuscher & Grando 2009). If a person is asked to provide specific details about something but cannot, it may make them feel inadequate or embarrassed (Hubbard *et al.* 2003). In this instance, it is better to steer the conversation to a more harmless topic rather than pursue this line of inquiry. Once a person feels their shortcomings are being revealed, they can retreat and become less engaged. An example of this was in an interview with a patient participant Esme who had been talking about her son:

Interviewer: Do you have any other children?

Esme: Isn't that a ridiculous question?! I'm not a spring chicken, now... Andy and Eli are my son's boys... when I'm put on the spot like this I'm totally confused!

The interviewer responded by making light of the memory problem and changing the subject:

Interviewer: No that's alright, it's hard to remember everything isn't it? Can you think of anything good about being in here?

The interviewer must be prepared to encounter a range of responses to the topics being discussed, including unanticipated emotion, sadness or anger (Tarzia *et al.* 2013). Esme after her initial irritation appeared to forget about her problem remembering details of her family. It is important that the participant does not feel that they have lost

face, or this can affect their confidence and willingness to disclose anything personal to the interviewer.

Gerry did not seem to be negatively affected by his inability to find the right words:

Gerry: I just want to go back to my place to see what it looks like and then um ... the neighbour there's got a fast machine there that er...

Interviewer: A fast machine to???

Gerry: A machine that er...

Interviewer: Like a scooter?

Gerry: No, no. About the size of the er... sits on the table. Gives you directions and tells you ...

Interviewer: Oh ok – like a computer?

Gerry: Exactly!

Interviewer: Oh so you want to have a look at that do you?

Gerry: Yeah, yeah I want to try that out see how it goes.

Gerry seemed pleased that the interviewer was able to help him find the word he was looking for and was not embarrassed by his inability to remember the name of the machine. In this instance, the mutual recognition was maintained.

Creating a feeling of safety for the person with dementia

Confidence, feeling safe and not judged are the key to successful engagement between the participant and the interviewer. Habermas considered that intersubjectivity demonstrated by interactive relationships was the path to the mutual understanding of subjects (Habermas 1984). To facilitate this intersubjectivity and convey a feeling of security to the participant, a calm, attentive and respectful interviewer uses interpersonal skills to show that they recognise the person's perspective and are open to what they have to say (Proctor 2001). Allowing people to talk about what is on their mind or reminisce can give them confidence despite the fact that the subject matter is not relevant to the study (Svanström & Sundler 2013). It is also a consideration of the right of the individuals to freely voice their opinions in an exchange that is mutual rather than dominated by the priorities of the researcher. Gentle redirection to the research topic can follow after first validating the meaningfulness of their relayed experiences. The following is an excerpt of the conversation with Arthur when he was asked what it was like for him being a patient in hospital:

Arthur: You tend to reflect on the past, worry about the future I suppose.

Interviewer: So you worry that you can't do the things you used to do – is that what you mean?

Arthur: Ah yeah I suppose I'll come into it now more so, seeing as I have to sell my car.

Interviewer: You've got to sell your car?

Arthur: Yeah I'm going to have to sell the car because I'm liable to have a … I feel I would be liable to have another blackout, and if I was behind the wheel of the car I'd kill someone most probably, so um

Interviewer: So how do you feel about that?

Arthur: Oh terrible. The body's er what they call a station wagon but er yeah so it's a very nice car.

The conversation about the car went on for some time, and then once he had discussed this issue, Arthur seemed happy to talk about his experiences in hospital.

Tangential stories may also be a way of diverting the interviewer's attention away from a sensitive topic or from recent events that the participant cannot remember (Edvardsson & Nordvall 2008). However, in demonstrating communicative action in practice, the interviewer endeavours to understand the subjective world of the participant by listening attentively. This shows genuine recognition of the other, as intersubjectivity only exists when there is symmetry of input without privilege on one side or another (Habermas 1984).

In the following case, it may be that Jenny, without consciously avoiding the question, associated the topic with a memory from her youth. When asked about her relationship with the doctors in the hospital, she responded with an anecdote about a family she knew when she was young:

Jenny: I don't worry about the doctors. When I was going through my degrees and things I had a family – the Steinberg family – I don't know if you've heard of them. They were pretty well off, but they were very, very nice. The boys had gone to XXX College. Anyway whenever we saw them they threw a party and they had a great big house on the main road towards the University and they'd really thrown a party but um, they were very nice generally speaking.

Interviewer: Oh that sounds fun. So what do you think of the doctors here?

Stories from the past can create a feeling of security for the participant in contrast to the present which is confusing and difficult for the person to comprehend (Edvardsson &

Nordvall 2008). Jenny did not appear to be consciously changing the subject, but the story about the family she knew came to mind when the topic of doctors was raised. While relating this story, she appeared quite animated and relaxed, and the story she was telling appeared to be well-rehearsed. This was not the case when asked to talk about recent events in hospital. In that instance, she was more hesitant, looked slightly uncomfortable and was very vague in her response. To steer her back to the topic, the interviewer listened attentively to the story about the family and then asked another question about Jenny's current experiences in hospital.

Tailoring the interview to individual physical and cognitive abilities

Habermas argued that the distortion of communication and the failure of one to understand another was a problem of domination and power (Schlosberg 1995). In an attempt to overcome this problem, it must be ensured that interviewing people with dementia, like any form of interviewing, must be tailored to the abilities of the individual and the researcher consciously minimises the power imbalance. However, dementia adds a further complexity to the range of ability which is likely to be even more complex. Every person with dementia is an individual with a unique background and specific communication style which is not solely attributable to the condition (Killick & Allan 2000). Pitching the tone of the interview as too academic or advanced may intimidate the person; pitching it at a level that is too basic will be interpreted as patronising. Establishing common ground can facilitate the connection. Responsibility for tailoring the conversation to fit the individual's needs rests with the interviewer who must adapt to the level of communication appropriate for the participant.

Loss of insight into the situation and lack of self-awareness about cognitive deficits can make factual information difficult to obtain from a person with dementia (van Baalen *et al.* 2011); however, most participants in this study had the capacity to comment meaningfully on how they felt about their here-and-now situation from their own perspective.

Keeping the questions short and simple facilitates a response in most people and is a nonthreatening approach. Extra time may be needed for the person with dementia to process the question, and it is important not to rush or prompt them too readily. Repetition and digression from the topic is inevitable. The person must be allowed to speak freely and not have this pointed out or their confidence may be undermined. Similarly, it is self-evident that the interviewer must not argue with the participant, despite

obvious discrepancies or confabulation in the story. For example, Bob was a patient who had previously absconded from the hospital and was describing how the ambulance came to his house to retrieve him. The following excerpt demonstrates obvious embellishment:

Bob: They bashed the door down! And they grabbed me like this – now this is a broken arm – one this way and one this way, and they dragged me out of the house. They were what you call 'transit police'. They couldn't fit the stretcher in so they dragged me out bodily. And everything … my room's there and the front door was there and they nearly broke my arm again! And they said 'If you don't come back peacefully, we'll break the other arm'.

Interviewer: Goodness me!

Bob: But fancy two big coppers saying I resisted. How could I resist? One of my neighbours came over and said 'Better go Bob because they're gunna bash your house. They'll kill you if you don't let them take you!'

Despite the discrepancies in Bob's stories, he nevertheless was able to convey reflections and insight into what it was like for him being in hospital. He felt lonely when his fellow patients had lots of visitors, whereas he had very few; he was bewildered about the reason he was being kept there, and he longed for his own home and the company of his cat.

In the interview with Benny, articulate moments were punctuated by gestures and nonverbal noises which he used to convey his thoughts when he was unable to find the words to express them.

Interviewer: Mmm. So you're in a room there with four other patients now aren't you?

Benny: Oh yeah! (Laughs)

Interviewer: Didn't realise?

Benny: Haha I didn't … haha.

Interviewer: Didn't realise? Oh OK. So how do you find that?

Benny: Oh just er the ones that come er (Benny rolls his eyes, gestures with his arms and makes grunting noises to convey the point that some of his roommates have displayed odd behaviour).

For some people with dementia, nonverbal communication is used as an attempt to cover a shortfall in language ability and must be taken into consideration along with verbal communication. In this setting, field notes written by the researcher immediately after the interview assisted in unravelling and clarifying the intended message that the participant was trying to convey.

Ensuring an optimal interview environment

Research generally recommends that the interview space should be quiet and free of distraction and background noise (Moore & Hollett 2003); however, in hospital wards, rooms which fit this description are difficult or sometimes impossible to find. If the interview topic is about the person's experience in that place, remaining in the environment being discussed makes it easier for the person to recall the details. It has also been suggested that conducting the interview in the participant's own space shifts the balance of power away from the interviewer, a factor that is important when interviewing vulnerable individuals (MacDonald & Greggans 2008). From a Habermasian perspective, maintaining the environment may also minimise the risk of distortion from external factors (Parkin 1996). The situated nature of the interviews puts the interviewer in a position to understand unfamiliar experiences and allows the interviewee to remain in-context. In the three studies which have directly contributed to this article, the participants were mostly interviewed in their hospital bedrooms unless confidentiality was an issue. This meant that background noise and interruptions were frequent; however, maintaining eye contact and a demonstration of interest in what the person was saying meant that in most cases the participant's attention was maintained. If an interruption caused a break in the dialogue, the interviewer made light of it and prompted the participant to resume.

Once a person is removed from the environment, they may have trouble with the recall of that environment. An example of this problem was demonstrated in the interview which was conducted with Fred in a small sitting room next to his bedroom. The other patient in his room was bedbound and awake so for confidentiality reasons the interview was relocated. Fred appeared unable to remember the details of his room once he was removed from environmental clues:

Interviewer: So, I notice that you're sharing a room with someone else.

Fred: No I'm not.

Interviewer: Your bedroom's got one other person in it – a lady, in another bed.

Fred: (Pause) Oh I see what you mean yeah. Yes.

Confusing hospital and home was common. Emma was interviewed in her room; however, she had trouble differentiating the two places. Commencing with a description of her day in the hospital, she concluded by mentioning that

she went shopping sometimes in the afternoon; something she only did when at home:

Interviewer: What happened today?

Emma: Oh well we went down and played some type of bingo.

Interviewer: Oh with the volunteers?

Emma: Yeah, that was good and then we had lunch and then physio so I thought it was a good old day here yeah.

Interviewer: Sounds like a busy day! So are most days busy with things like that or do you have quiet days as well?

Emma: 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.

Rather than point out the discrepancy, the interviewer steered Emma back to the topic:

Interviewer: OK but when you're in the hospital though?

Emma: Oh I'm just sitting down watching.

Presence of family

In the contributing studies, the participants could nominate to have a family member or friend with them during interview; however, very few did. Having a third person present changes the dynamic of the interview (Nygård 2006). The people involved can bring influences to the interview related to power dynamics and tensions unrelated to the situation being discussed and can potentially erode their autonomy. The person with dementia may deflect questions to their relative who they feel knows more about the situation than they do. It is also possible that they may feel constrained in their response because they do not want to hurt their relative's feelings or discuss a particular problem in front of them. It is possible that the relative might have their own interests at heart rather than those of the person with dementia. On occasion, the relative might interject and disagree with the participant. An example of this was encountered with Niko, an older Greek man whose daughter arrived unexpectedly during the interview and joined in:

Interviewer: What is it like for you here?

Niko: I am happy.

Daughter: I'm just going to ask him if he can stop and think about things for a moment and I'm going to suggest some things to him that he might remember.

A conversation in Greek initiated by the participant's daughter ensued:

Niko: People are not happy. Not a lot you can do.

Daughter: We're asking you...

Niko: I am happy! What you do people never happy. They find someone to blame, but I am happy what you (the hospital staff) do.

Despite the encouragement of his daughter to find fault with the care he was receiving, Niko declined to do so; however, it could be envisaged that other people in this situation may have deferred to their younger and more able relative in these matters.

Not all interviews which include a support person have this outcome however. In some instances, a participant may find the presence of a family member or friend reassuring. This was the case with Ned who had Lewy Body dementia and had been experiencing terrifying hallucinations:

Interviewer: What don't you like about being in here?

Ned: Well some of it's good. The things you don't know anything about, there's nothing you can do.

Interviewer: Things you don't know anything about? Like what?

Ned: Head disorders.

Wife: The dreams. He hallucinates.

Ned: The dreams I have to face, the hallucinations. I'm never quite sure when I go to sleep...When I go to sleep it's horrific.

Ned became emotional and his wife put her arm around his shoulders to comfort him. After a few minutes, the interviewer asked Ned if he would like to stop the interview. He decided to continue, but the interview was short as he had clearly not fully recovered and had difficulty re-engaging.

Discussion

Interviewing people with dementia requires specific skills to facilitate a meaningful and useful exchange. Acting reciprocally to grasp the experience of the 'other' in a collaborative dialogue leads to the two-way recognition of ideas and sets the stage for the analysis of the subtle ways that citizens this case patients with dementia are excluded from participation (Parkin 1996). Ensuring that the person leaves the encounter feeling that they have contributed and been received positively is important to prevent a feeling of harm and support this mutuality. Leaving the participant too

hastily after the information has been obtained is a 'hit-and-run' style which is unethical and should be avoided. To leave the participant with a feeling of positive contribution, the interviewer should continue to show interest in them for a time after the formal interview is completed (Hellström *et al.* 2007).

Using Habermas (1984) as a reference point, the researcher or interviewer must ensure that the essential element of mutual recognition with the participant is established or the encounter will be unproductive and a satisfactory interpretation of the situation will not be reached:

A situation definition by another party that prima facie diverges from one's own presents a problem of a peculiar sort; for in cooperative processes of interpretation, no participant has a monopoly on correct interpretation. For both parties, the interpretive task consists in incorporating the other's interpretation of the situation into one's own in such a way that ... the divergent situation definitions can be brought to coincide sufficiently. (Habermas 1984, p. 100)

Historically one of the reasons that people with dementia have been disqualified from participating in research of this kind has been doubt about the veracity of the data obtained (Nolan *et al.* 2002, Aggarwal *et al.* 2003). However, it is demonstrated in these studies that the information given by the participants, while not always straightforward to interpret or even factual, demonstrates genuine authenticity. When a participant is relating something which clearly feels true to them, then the story, however, it relates to face validity is a representation of the person's feelings at that time. Referring to intersubjectivity and mutual recognition, the approach outlined here ensures that the interviewer and the participant have the opportunity to consider each other as equals, both with a valid contribution to make to the conversation regardless of cognitive strength.

There are a number of key steps which support an approach which can facilitate a successful engagement between interviewer and participant. First and foremost is the establishing of a connection and evaluating the conversational pitch most appropriate to the participant. Research of this kind is a shared venture. The interviewer must display a calm, attentive manner and demonstrate that they are genuinely interested in the person's views. The body language of the interviewer, such as eye contact, smiling, leaning towards the person and validating their responses, is an example of positive reinforcement. It is particularly important to use strategies which provide the person with a safe space in which they feel that their cognitive strengths and weaknesses are accepted without judgement.

The nature of the condition means that digressions, repetitions and tangential conversations are inevitable. The interviewer must accept this good naturedly and tactfully steer the conversation back to the topic. Caution is advised when asking direct questions as the person can find it intimidating or embarrassing if they are unable to remember the facts. The person must not be compromised or they will feel they have lost face and the connection with the interviewer may be lost.

Semistructured conversational interviews give researchers the opportunity to probe areas of interest that arise rather than stay with predetermined questions. People with dementia can have unpredictable thought processes which mean that interviewers must be flexible and adaptable to respond to whatever arises. Despite being well-prepared for the interview, the interviewer may end up with a result which is far from that anticipated; however, it may be that this is a step closer to understanding the phenomenon being investigated.

Conclusion

Interviewing people with dementia requires specific skills including an ability to be emotionally sensitive and respectful of the person and their views. Engagement on this level can be emotionally challenging and complex for the interviewer.

In the studies referred to here, the experience of interviewing older people with dementia has led to an exploration of the practical issues facing researchers and may also be relevant to others interviewing or communicating with people with dementia. Capturing the essence of the views of the participants in this instance was more important than establishing the facts related to the experience of patients with particular events. The view of the participant is valid regardless of the facts, as this is information which can usually be gleaned from other sources. The approach recommended is intended to lead to better engagement and hence a better research outcome; however, the application must be tailored to the individual on the day.

The relationship aspects of interviewing are important with any patient group; however, with people with dementia, it is vital that the interviewer establishes a genuine engagement with the person before the interview is attempted. Failing to do this may result in psychological harm to the participant and a poor research outcome.

It is important that people with dementia are included in research and given the opportunity to contribute their views. Exclusion not only denies this section of the community their rights, but leads to a gap in our knowledge of their experiences. The last two decades have seen a welcome increase in the inclusion of people with dementia in research in both residential an acute care settings; however, the understanding of the perceptions of people with dementia needs to be further expanded. Enhancing interviewer skill in accessing this information is a positive step.

Relevance to clinical practice

Clinical staff and researchers interview people with dementia for many reasons. The techniques described here are relevant to a variety of people who are in contact with people with dementia in clinical settings. Developing skills in this area needs a commitment by organisations to promote the

inclusion of the perceptions of people with dementia in research and in discussions about their own care.

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Contributions

Study design: RD, AW, SL; data collection: RD; data analysis: RD, AW, SL and manuscript preparation RD, AW, SL.

Conflict of interest

The authors declare that they have no conflict of interest.

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Photoelicitation

Photoelicitation, also referred to as photo-interviewing, is a technique of using photographs to stimulate a response in research participants (Hansen-Ketchum & Myrick, 2008; Oliffe & Bottorff, 2007; Riley & Manias, 2003) and is thought to be particularly useful in involving people in research who may have communication problems such as children (O'Connell, 2012), the illiterate and people with stigmatized health conditions including dementia (Hulko, 2009). Using photographs as discussion stimulators circumvents the necessity to respond to questions and is less threatening to the participants (Wang & Burris, 1997). In photo-elicitation photographs taken by either the researcher or the participant are looked at and discussed during the interview (Weber, 2008). People with dementia, particularly those whose dementia is more advanced can find direct questions unsettling especially when it requires recall of specific information often leading to monosyllabic responses as a result (Dewing, 2007; Oliver, 2012).

In an effort to overcome this problem, patient participants were shown photographs taken by the researcher, of the ward environment such as the nurses' station, corridors, gym, patient bathroom and bedroom, the food trolley, and ward equipment such as lifting machines and wheelchairs. There were two photographs of nurses and patients but they were taken from behind or from a distance. None of the pictures included identifiable individuals. The subject matter of the photographs was chosen by the researcher to represent aspects of the ward environment which would be familiar to the patients and would potentially prompt conversation. Not all of the photographs were included in this thesis in order to protect service identity, however a number from each health service are shown in Appendix 9 as examples. The photos were expected to help overcome the barriers which may have prevented people from talking about issues which concerned them and gave them the opportunity to narrate and explain rather than answer questions.

Visual images have the potential to evoke emotional as well as intellectual responses and can trigger an outpouring of information (Guillemin, Gillam, Rosenthal, & Bolitho, 2010; Pink, 2007). They can potentially assist to build rapport and communication between the researcher and the participant and increase engagement with those who are hard to reach because of

communication, cultural or literacy issues or because of the sensitivity of the subject matter (Clark-Ibáñez, 2004; Oliffe & Bottorff, 2007; Pain, 2012). Using photographs in the interview process has the potential to produce not only more information, but a different type of information due to the reflexivity between the image and the dialogue which produces the data (Harper, 2002). Weber claims that the materiality of photographs provides a vehicle for the telling of personal stories, including those things that may be embarrassing or too painful to be tackled head-on (Weber, 2008). In this study, the engagement of the participants who have dementia was attempted by the use of visual images to start the conversation (Oliffe & Bottorff, 2007) and potentially give some structure to the interviews, with a view to lessening the awkwardness and providing a focus (Clark-Ibáñez, 2004).

The term photoelicitation was first used by photographer and researcher John Collier in the 1950s working at Cornell University on a project examining the experience of families adapting to living amongst ethnically diverse people (Harper, 2002). Collier noted that using this technique facilitated more comprehensive interviews and circumvented the boredom and repetition involved in traditional interviews. The photographs facilitated a connection between the researcher and the participant by establishing a common ground of understanding in a way that was described by Harper as 'mysterious' (2002). Pink (2007) agreed that the connection between the researcher and the participant could be enhanced by the introduction of visual images, however noted that the perception of the viewer is subjective and admits to being uncomfortable with the notion that the use of photographs allowed the researcher to *obtain* knowledge from the participant. She pointed out that individuals reference their own personal experience, knowledge and social discourse when viewing images which results in a personal interpretation and a demonstration of different understandings of reality (Pink, 2007).

The photographer/ researcher must be aware that they bring their own personal and social biases and references to the choice and framing of the photographs before they are even presented as part of the research and that this must be considered in the reflexivity process (Pink, 2007). There is an identified problem of treating photographs as neutral reflections of reality whereas they are in fact the representations of the photographer's view of reality

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(O'Connell, 2012) and there may be essential aspects of the world being examined which are omitted because the photographer is an outsider to that world, or the photographer may be tempted to use visually arresting images rather than those that are necessarily meaningful to the participants (Clark-Ibáñez, 2004). It can be argued that the photograph reveals as much about the photographer as it does about the subject matter (Riley & Manias, 2004). It would be naive to presume that the use of images in interviews necessarily automatically leads to a deeper understanding of the research question: the interpretation of images is subjective and the relevance of an image to an individual is complex. Furthermore despite the widespread success reported in the use of visual images in qualitative interviewing there is still the potential for an image to 'twist, distort and mislead' (Weber, 2008). Despite these limitations it was decided that this approach could potentially enhance the interviews with the patient participants.

Document analysis

Document analysis, or the examination of relevant textual documents, provides further insight into how language and discourses are characterized by the participants in the study, and can provide an insight into the way that they view themselves (Reeves et al., 2013). Furthermore document analysis has the potential not only to provide background and context but prompt the researcher to ask additional questions to clarify the issues raised (Bowen, 2009). Examining documents related to an issue can be useful to add perspective and frame a situation. Discrepancies between the expectations of an organisation, what people say they do and what they actually do can be identified.

The nursing entries in the progress notes of the patients included in the study were examined specifically to augment understanding of the attitude of nurses towards the patients with dementia. The nursing entries which had been written since the admission of the patient were read, and de-identified notes describing the language used were made using the three stages recommended by Bowen (2009): skimming (superficial examination), reading (thorough examination), and interpretation. The identity of the nurses and patients in these passages were not recorded because this information was not deemed to be relevant to the study. The posters

and charts on display on the wards were also examined. Notes and observations about these documents were recorded in the researcher's field notes.

Data analysis

There are many approaches which can be taken to analyse qualitative data which is generally agreed to be an on-going iterative process commencing at the beginning of data collection and continuing throughout the project (Bradley, Curry, & Devers, 2007). Thorne (2000, p. 69) described data analysis in qualitative research as "complex and mysterious and generally lacking in understanding", however there are a number of techniques which make this task clearer and more coherent. The interview data in this study were analysed using thematic analysis as described by Braun and Clarke (2006) and the documents examined as recommended by Bowen (2009). The Spradley (1980) method was used to analyse the field notes which described the observational data.

 Braun and Clarke (2006, p. 79) recommend thematic analysis as an appropriate method for identifying, analysing and reporting patterns or themes within data, despite lacking the kudos of other named methods such as grounded theory and discourse analysis. Their technique requires the researcher to ensure that the framework and method match the research question and is explicitly stated and consistently applied, leaving the reader in no doubt of the theoretical position being taken. The flexibility of thematic analysis mean that it can be used across the spectrum of clinical and health research including critical research (Braun, Clarke, & Terry, 2015).

Identifying what counts as a theme requires the judgment of the researcher, and is not strictly reliant on the prevalence of the issue identified in the data but it must also capture something relevant to the research question (Braun & Clarke, 2006). Using a numerical approach, counting the number of times a subject is mentioned, in the manner of quantitative research, has been described as trite and lacking in depth (Silverman, 2001), however consideration of the prevalence is a component in the complex process of identifying themes and is an adjunct to

researcher interpretation and flexibility (Braun & Clarke, 2006). In order to make the process of data analysis explicit, Braun and Clarke (2006, p. 87) have prescribed a six-stage process which is shown in Table 1.

Table 1: Phases of thematic analysis

Phase	Description of the process
1. Familiarizing yourself with your data.	Transcribing data, reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

In phase 1 of the analysis the researcher transcribed the 59 interviews, listening carefully to the audio files and reading and re-reading the data including the transcribed interviews, field notes and information identified from the documents. Frequently mentioned issues were highlighted and noted.

Formal data analysis commenced in phase 2. The descriptions of the physical environment, routines, social dynamics and power relations from the observation sessions as well as the rough codes identified in the interviews were reflected on to start the process of identifying

relevant features of the data. The aim was to generate the initial codes which focused mainly on relevance to the research question and prevalence (Braun & Clarke, 2006). This was done with the assistance of Nvivo 10 qualitative analysis software (QSR International Pty Ltd, 2012). The observational findings were compared with data from the interviews looking for congruence and conflicting findings. This highlighted the difference in the perception of the nurses and the patients, and any discrepancies between what people say and what they do, or in some cases how they are perceived. Information noted from the documents was compared to observations of nurse and patient behaviour and what they reported in the interviews.

In the third stage of the process the codes were collated into potential themes, a process which took a number of iterations to make sense of the data. It is always possible to group codes in different ways. In this instance the focus was on understanding the viewpoint of the individuals and the power and cultural influences at play. Mind-maps were used to clarify the relationship between codes and identify themes and sub-themes. Mind-mapping is a technique of representing a complex set of relationships in the form of a diagram in order to understand the relationships between the concepts (Davies, 2011). See figure 2.

Figure 2: Mind map to clarify themes

Following this the interpretative analysis of the data was commenced (Boyatzis, 1998). In phase 4 the researcher did a comprehensive review of the themes. A further re-reading of the interview transcripts was done while listening to the audio files to confirm meaning, and some of the codes were modified in order to form a more coherent pattern. It was evident that some of the codes were repetitive, and some of the initial themes were sub-themes of other themes. There were some codes which were ultimately deemed to have little relevance to the research question and were discarded. The interview extracts for each identified theme were re-read to ensure that they did present an accurate presentation of the data as a whole. Braun and Clarke (2006) suggest that coding data can go on forever, but that the researcher must stop when refinements are no longer adding anything significant. In this research coding was considered largely complete when the researchers considered that they reflected the substance of the interviews.

In phase 5 of the data analysis a review and further refinement of the themes established in the previous phases was undertaken. Braun and Clarke (2006) advise that the 'essence' of what each theme is about needs to be identified in this phase. In order to distil the information to understand how each fits with the broader story, the themes, their sub-themes and extracts were re-read to comprehend the established patterns and checked for coherence.

Chapter summary

In this chapter the methods and their practical application in this study have been discussed. The study was conducted in five wards at two hospitals in Melbourne, Australia in 2014. Semi-structured conversational interviews took place with 30 in-patients with dementia and 29 nurses. Additionally, 120 hours of non-participant observation was conducted in the wards, and relevant documents including the progress notes of the patient participants were examined.

Approval for the project was gained from the ethics committee of Monash University and the two hospitals. The nurses volunteered to be part of the study in response to flyers displayed in the wards. They formally consented to be part of the study before the interviews took place. The patient participants were purposively sampled with the assistance of the clinical team. Formal consent was obtained from the patients, and in the case of those who were not deemed

competent to formally consent on their own behalf, the next of kin signed the consent form. Assent to participate was obtained from all the patient participants.

The interviews were digitally recorded using a small Olympus digital voice recorder VN-712PC. and transcribed verbatim. The data were analysed using thematic analysis. In the following chapter the analysis of the data will be discussed in detail.

Chapter 5 Findings

Introduction

In this chapter, the findings of the study which included interviews with patients with dementia and the nurses caring for them, observation and document analysis are presented. The chapter commences with a description of the study participants using pseudonyms to maintain confidentiality. This is followed by information about the built environment and nurse workflow. The themes which were extracted from the data will then be presented.

The first theme relates to the experience of the patients and is entitled '*Patients with dementia are outsiders in the hospital system'.* The patient experience was characterised by bewilderment about many things including the hospital environment, the reason for being in hospital and the plans for the future. The patients reported feeling powerless, bored and fearful. There was evidence of stigmatisation and the prioritisation of the needs of patients with acute illnesses ahead of those with dementia.

The second theme '*Nurses' assumptions, expectations, principles and the reality of care'* relates to the viewpoint of the nurses who reported that they felt under-supported by the hospital system educationally, practically and psychologically. Being too busy to provide appropriate care created a stressful working environment, and the nurses consequently focused on completing tasks and avoiding risk.

The third theme*, 'The influence of hospital operational priorities on care practices'* highlights the organisational factors which are affecting patient care and the working environment of the nurses. The operational focus on minimising costs and maximising patient throughput has had a detrimental effect on the capacity of the nurses to form a therapeutic relationship with the patients and maintain a quality standard of care.

Patient participants

The patient interviews were conducted over a period of 5 months due to a range of factors including the complexity of identifying appropriate patient participants at the different sites. In the field notes it was recorded that during one episode of data collection there were seven patients with dementia in the 24-bed ward, however three of these were non-English speaking, one was dysphasic, one declined, one could not consent on their own behalf and did not have a suitable proxy available, and one had been interviewed by the researcher for the same study the previous week. Finally over a period of 5 months, 30 patients were interviewed. Thirteen men and 17 women participated. Their average age was 82.9 years. The total patient interview time was 567.94 minutes (9.46 hours). The shortest patient interview was 5.55 minutes, the longest 59.51 minutes, the median 13.34 minutes and the average 18.93 minutes. The questions were repeated and extra time allowed for response when necessary. Probing questions were asked at times to develop the narrative from the participants. All the patient participants had dementia, however in 50% of the patients the specific type of dementia was not mentioned in the progress notes which demonstrated the focus on the reason for acute presentation, and perhaps stereotyping of the patients. The patient participants' details are shown in Table 2.

The patient participants were a diverse group with very little in common apart from sharing a diagnosis which included dementia, and the reasons for admission to hospital varied. The opportunity to have a conversation with the researcher was generally welcomed as a form of focus and attention, particularly for those who lacked other visitors. None of the five wards routinely conducted formal cognitive testing which meant that the participants had a range of cognitive ability, however as long as they were able to have a conversation in English they were considered for inclusion in the study.

Table 2: Breakdown of patient participant demographics using pseudonyms

Name	Age	Ward	Diagnosis	Length of stay before interview
Alfie	83	C	Dementia (unspecified), falls, functional and cognitive decline	12 days
Anna	82	D	Dementia (unspecified), cellulitis left shin	5 days
Andrew	79	C	Dementia (unspecified), haematoma left knee	6 days
Angelique	86	B	Advanced dementia with behavioural symptoms	4 days
Arthur	78	E	Lewy body dementia, narcolepsy, fractured left ankle	19 days
Benny	68	B	Dementia (unspecified), neurodegenerative changes due to alcohol abuse	10 days
Bertha	77	E	Alzheimer's disease, neurodegenerative process with frontal lobe involvement	38 days
Bob	85	A	Alzheimer's disease, falls, fractured shaft of humerus	93 days
Cecilia	90	D	Vascular dementia, hypokalaemia	10 days
Emma	82	D	Dementia (unspecified), cognitive decline, urinary tract infection	3 days
Esme	87	D	Alzheimer's disease, fractured pelvis	5 days
Fred	91	C	Dementia (unspecified), respiratory infection, weight loss	12 days
Gina	87	B	Dementia (unspecified), functional decline	6 days
Greg	85	B	Dementia (unspecified), falls	28 days
Harriet	86	D	Dementia (unspecified), painful knee, social issues	29 days
Ines	77	B	Alzheimer's disease, temporal atrophy related to alcohol abuse	15 days
Jack	87	E	Dementia (unspecified), Parkinson's disease, arthritis	4 days
James	85	E	Alzheimer's disease, seizures, aspiration pneumonia	5 days
Jenny	75	D	Alzheimer's disease, abdominal pain	11 days
Kate	76	A	Dementia (unspecified), open fracture left ankle	8 days
Larry	82	C	Dementia (unspecified), urinary retention, chronic constipation	32 days
Lena	89	A	Alzheimer's disease, chest infection, breast cancer	36 days
Lettie	70	E	Dementia (unspecified), left knee weakness	13 days
Lex	84	E	Dementia (unspecified), urosepsis, falls	17 days
Martha	88	D	Alzheimer's disease, orthostatic hypotension, falls	26 days
Mark	99	C	Dementia (unspecified), pneumonia	12 days
Marion	85	D	Lewy body dementia, falls	13 days
Mary	86	E	Alzheimer's disease, subacute cerebellar infarct, haematemesis	7 days
Neville	74	E	Lewy body dementia with hallucinations, constipation	6 days
Pattie	86	A	Alzheimer's disease, functional decline	27 days

There was a range of patient length of stay with the shortest being 4 days, the longest 93 days and a median of 12 days. The most significant outlier was Bob (93 days) who was awaiting the

appointment of a guardian. Other participants with longer than expected lengths of stay (Lena, Larry and Bertha) were all waiting for placement in residential aged care.

Nurse participants

The nurses were recruited to the study through flyers distributed in the wards which were nominated as suitable by the senior nursing staff. All registered (RN) and enrolled (EN) nurses working on these wards were eligible for inclusion and all those who volunteered to take part were accepted for an interview. Twenty-nine nurses were interviewed. Two were male and 27 were female, which roughly correlates to the gender mix in Australian nurses (10.62% male) (AHPRA, 2016).

The time working as a nurse ranged from one year to 45 years with a median of 20 years and an average of 20.3 years. The youngest nurse was 25 and the oldest 68 with a median age of 45 years. Registration was evenly divided between registered and enrolled nurses although they were not recruited to participate on this basis. The total interview time was 475.4 minutes or 7.92 hours. The shortest interview time per nurse was 10.35 minutes, the longest 24.21 minutes with an average of 16.38 minutes and median of 16.17 minutes. The nurses agreed to participate at their workplace during the course of their paid employment as this was the most convenient. Moreover it was considered more relevant to interview the participants in the environment being discussed. The nurse participant details are shown in Table 3.

Table 3: Breakdown of nurse participant demographics using pseudonyms

Name	Designation	Age	Years working as a nurse
Ada	RN	55	25
Alyssa	RN	39	15
Angel	RN	25	4
Anne	RN	40	17
Audrey	EN	68	45
Bethany	EN	29	3
Carol	RN/ ANUM	58	40
Christine	EN	47	1
Edward	RN grad	36	1
Elsa	RN	45	20
Gary	EN	52	25
Jane	RN	40	20
Kara	EN	55	38
Karen	EN	32	14
Kimberley	EN	50	31
Kylie	EN	45	18
Lila	RN/ ANUM	42	24
Lil	RN/ ANUM	35	24
Mandy	RN/ANUM	54	35
Maree	RN	54	32
Margie	EN	51	31
Melissa	EN	30	1
Pam	EN	55	33
Poppy	EN	29	2
Rose	RN	67	10
Ruth	RN	53	9
Sinead	EN	28	1
Suzy	EN	52	30
Tina	RN	38	15

Observations

Observation sessions occurred on each ward before the interviews commenced in order for the researcher to form an understanding of the context in which the patients and nurses operated.

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The researcher attended at a range of times over all shifts in order to grasp the nuances of work practices over the course of the day. Handover was attended in most instances, and the researcher then spent time observing nurses and patients in their daily routines. Observation sessions lasted for a maximum of two hours, at which point the researcher would leave the ward to write field notes which included specific observations, thoughts about the ward dynamics and practices, and the relationship between the participants. Further observation sessions often occurred on the same day. The observation sessions and interviews for one ward were completed before moving to the next. In each of the five wards, 20-25 hours of observation were carried out, with a total of 120 hours.

The built environment

The wards nominated for inclusion included two identical older-style 24-bed wards (A and B) built in the 1940s and one 32-bed ward in a new building (two years old) on the same site. The two older style wards shared a common floor plan where the patients were accommodated in four 5-bed patient bays with glass fronts, and four single rooms. The 5-bed rooms were open to the corridor with no door, making it difficult to screen noise. The patients in these wards shared a total of four bathrooms with one toilet and shower in each. The patient rooms surrounded the staff station from where it was possible to see most of the patients except for those in the single rooms; a situation which appealed to the nurses because surveillance of the patients was facilitated. Shift handover and all administrative work occurred at the central staff station which was open to view by patients, visitors and other staff. Personal conversations with patients and relatives often took place in the patient's shared room with only a pulled curtain as a gesture towards confidentiality.

The researcher was initially struck by the lack of privacy for the patients in the shared bays, however during continued observation there were also some positive features evident. There was sometimes camaraderie observed between the patients and the nurse caring for them on the shift, and some of the patients appeared to be friendly with their roommates and their

roommates' visitors. This was also the case in another older style ward in the study (ward D) where the patient beds were only a metre apart. The single rooms on these wards in contrast appeared dark and had small windows facing another brick building. As a consequence the patients in these rooms were more isolated.

The 5-bed rooms had a long balcony on the other side of the windows, however the doors were permanently locked and the patients were forbidden access to them for safety reasons. The windows were all extremely dirty making it difficult to see outside. Both wards A and B were on an upper floor, and despite there being a patient garden in the grounds of the hospital, few could access it because they could only leave the ward in the company of a relative or staff member. In practice this was reported by the patients and the nurses to be rare. Some patients who were considered to be at risk of absconding were denied this privilege even if they had an agreeable relative.

In these older wards (A and B) there was very little storage, and the corridors were lined with equipment such as sphygmomanometers, lifting machines, intravenous pumps and so on. In all the wards, there was an area labelled 'patient dining room' or 'patient lounge' however it was rare to observe patients either dining or lounging in these rooms except in the case of the newest ward (C) which was more spacious than the other wards. However in the old-style wards the researcher rarely saw patients eating in the dining rooms. Most patients had their meals sitting on a chair next to their bed. As space was at a premium, the dining rooms were used for everything else, including equipment storage, as a meeting room for staff; nurses writing progress notes, nurse education sessions, allied health staff interviewing relatives, and in one ward a place for the volunteers to do activities with the patients.

Figure 2: Floor plan of the older style wards (A and B)

SECOND FLOOR

The new ward (Ward C) was a complete contrast with 24 single rooms and 4 double rooms all with en-suite bathrooms. The ward was very modern, (built in 2012), and there were a number of meeting rooms and extensive storage and office areas. The patient bedrooms were spacious and well-appointed, although unadorned. Ambulant patients could walk around the ward and choose to sit in a number of areas including a large outdoor deck. Meals could be taken in the dining room or the patient bedrooms. The long corridors in this ward and monochrome colour scheme made it confusing to navigate.

Figure 3: Ward C

Another ward in the study (ward D) had 38 beds including a six-bed secure unit usually used for people with behavioural problems, particularly wandering. The ward was originally built as a nursing home 30 years ago and had a confusing floor plan with multiple corridors, small bedrooms and no meeting rooms. Small nurse stations were contained within the wings. A multi-purpose patient lounge area was used for group activities with the volunteers, television viewing by the patients, and equipment storage. The corridors were crowded by linen skips and

trolleys, sphygmomanometers and lifting machines especially in the mornings. A small sitting room in the locked area was closed during the observation period for maintenance reasons.

Figure 4: Ward D

The remaining ward (Ward E) had 30 beds and was built eight years ago and was a combination of single and double rooms. The two-bed rooms were known as 'butterfly' rooms as they had two beds but were off-set for more privacy. There was a meeting room, a small patient sitting room and a larger patient area with a television. The patient-type was the same for each of the five wards.

The impact of the built environment was significant both on the way the nurses worked and the behaviour of the patients. In general there was a lack of privacy in the shared rooms both from the perspective of what others could see and hear but also in terms of being able to have time alone with relatives and friends without the intrusion of others. This was especially the case in the wards in which sitting rooms and outdoor spaces were not readily available. Shared bathrooms caused some conflict between the patients. The nurses however reported that they liked the shared rooms because they could watch all the patients at once and keep track of workflow more readily. There were instances of patients becoming very friendly with their room-mates and other instances where there was obvious conflict.

Nurse workflow

In each of the wards in the study the routine for the nurses was similar. Handover from the nurse in-charge of the previous shift occurred in a staff tearoom or in some cases around a white

board in the staff station. The process of allocating nurses to patients was variable. In some wards this was negotiated between the nurses themselves and in other wards the nurses were allotted to work in areas by the ANUM. During the handover, the researcher noted the new admission of any patients with dementia on the ward and their location. The language used by the nurses when discussing patients with dementia was observed. In most cases the general shift handover was confined to objective information delivered in a standard format with little personal opinion included. Following this, each nurse received a bedside handover from the nurse who had cared for that group of patients in the previous shift. The detail and format of this interaction varied enormously, with some nurses going from bed to bed checking the charts together, introducing the on-coming nurse to the patients and including the patients in the discussion. Topics included details about hygiene, tests, intravenous drugs, bowels, appointments and activity. Other nurses handed over from the corridor and didn't involve the patient. In general, there was more subjective comments made in the bedside handovers especially when out of earshot of the patient, and frequently included anecdotes about what had happened during the shift.

In the three wards of site 1, a morning hand-over also occurred between the Associate Nurse Manager (ANUM) on duty and the allied health staff which focused on new patients who had been admitted since the previous day, and the discharge-planning progress of the other patients. In the two older wards (Wards A and B) the allied health handover occurred standing in front of a white board containing patient details in full view and earshot of anyone walking by which may include patients, visitors or other staff. During one such handover, the ANUM made derogatory remarks about two patients with dementia, calling one "a real doozy" and commenting that another "needed fumigation" (Field notes, Ward B).

In some of the wards the nurses worked in teams of two so that instead of five patients each they had 10 patients between them. Often a registered nurse and an enrolled nurse were paired up to work together. This arrangement meant that patients who needed two people to assist could be more easily accommodated, and there were two nurses for patient surveillance. The nurses in

the team took meal breaks separately to ensure that one remained in that area to continue patient care and supervision.

During the analysis of the data in this study, the themes were derived from the interpretations of nurses and patients in response to questions about their experience of working or being cared for in a geriatric rehabilitation facility. The data from observation sessions were used to compare the observed behaviour of the participants with the data from the interviews in which they spoke about what they did. In this chapter the findings of the study will be presented in relation to these themes (refer to Table 4).

Table 4: Overview of the findings

Theme 1   **Patients with dementia are outsiders in the hospital system**

• I don't belong here
    - I don't know why they are keeping me here
    - I just want to go home
    - I am upstairs aren't I?
 	
• Patients are powerless
    - You go mad with boredom
    - I want to make my own decisions
    - The fear of nursing homes
 	
• Stigmatisation of patients with dementia in hospital
    - Some back off like you are cluttering up their hospital
    - Mentally there's not much that's done for them
    - Anyone who complains doesn't like being bossed around

Theme 2   **Nurses' assumptions, expectations, principles and the reality of care**

• Nurses are not supported to provide optimal care
    - We haven't had any cognition training on this ward
    - When I got hit by a patient I cried
    - The nurses are run off their feet
 	
• It can be hard to let them do what you need to do
    - Medicate the patients
    - Call a code grey
    - If it's too much I need to remove the patient
    - You don't have time to watch them all the time
 	
• Having the patients' best interest at heart
    - Once you start empathising you know what the patient wants

- I love working with older people
- Nurse leadership
- From the NUM onwards, it's a good feeling
- You can't be there all the time so we take turns

Theme 3

The influence of hospital operational priorities on care practices

- Time and resources
  - The focus is on turnover
  - IVs and MET calls
  - Specials allow you to still care for other patients

- The buildings
  - I like being able to see all my patients
  - The ward layout

- Our philosophy
  - Person-centred care
  - Just try to keep them safe

- The right staff
  - Cultural diversity of patients and nurses
  - The relationship between the discipline teams
  - Volunteers

The first theme 'The patients with dementia are outsiders in the hospital system' identified the overwhelming nature of the hospital experience for the patients. The patient interviews generated a large amount of data which pointed to the disaffection of people who did not fit the accepted acute care or subacute care mould, specifically those who had added mental health

problems or require additional resources in the healthcare system. Observation of the patients confirmed the findings from the interviews.

The second theme 'Nurses' assumptions, expectations and principles of care' highlighted the deficits in the hospital system from the nurses' point-of-view. There were clear discrepancies between the practical resources and support provided to nurses and that which they deemed necessary for the delivery of appropriate care for people with dementia. There was also a disparity for the nurses between what they were able to do and what they considered to be correct, resulting in some moral distress. Nurse caring, for the purpose of this study has been defined according to Greenhalgh, Vanhanen, and Kyngäs (1998, p. 928) who describe caring as "the acts, conduct and mannerisms of nurses which convey concern, safety and attention to the patients". In the case of nurses and patients with dementia examined here, the observable manifestations of caring were nurses listening, spending time and giving credence to the views of the patients.

The third theme ' The influence of hospital priorities on care practices' identified the effect that the focus on rapid patient flow, fiscal restraint and risk mitigation has had on patient care. Evidence highlighted the stigmatising effect on the patient with dementia who required additional resources, had a longer length of stay and a high risk of falling. The interviews demonstrated that the hospital focus on acute health and rapid discharge was not well suited to the needs of this patient group, and observation confirmed that patients with dementia were considered low priority.

Data collected and analysed

In chapter three a description of the data collection procedures was provided. In summary, this consisted of a period of observation and note-taking which was followed by semi-structured interviews with patients with dementia and nurses at two sites in five in-patient wards. Patient progress notes were examined using the method of document analysis prescribed by Bowen (2009) with a view to understanding the attitude of nurses towards patients with dementia demonstrated by the language used to describe their encounters.

The patient interviews were augmented by the use of photoelicitation which is a technique in which photographs were shown to the participants in order to stimulate the conversation to avoid undue reliance on direct questioning. In this instance the patient participants were shown photographs of the ward environment, meal trays, biomedical equipment, patient bedrooms and non-identifiable staff (Appendix 9). In this study the technique did not have the anticipated result. Many of the patients may have appeared to see the use of the photographs as another medical assessment, and focused on identifying the items in the photographs. Several of the patients declined to look at the photographs at all. In this study very little conversation could actually be attributed to the stimulation of the photographs.

Evidence pointed to the change that the ever-tightening hospital budgets have brought to bedside care, and the marginalisation and subjugation of patients with dementia. In this study, task-focussed nursing predominated when there was minimal time allowed for patient care. Although changes in nursing are occurring for complex reasons which will not be fully explored here, tight fiscal restraint and the focus on patient flow and risk management are contributors.

The findings are presented with a description of the themes illustrated by direct quotes from the participants, observations and information from the examined documents, and identified by randomly assigned pseudonyms and the letter signifying the ward. Observations and field notes are identified only by the ward.

Theme 1: The patients with dementia are outsiders in the hospital system

The first theme relates to the experience of hospital care from the perspective of the patient participants. Patients with cognitive problems are some of the most vulnerable and least powerful people within the hospital system. Difficulty adapting to the new environment, faces and routines augment disorientation for these patients. Although there were examples in this study of patients accepting that they were in hospital to regain their physical capabilities, few mentioned mental health or dementia, and many appeared to be unaware of the reason for their admission or the plans for their future. Feelings of being an outsider in the system were widespread.

I don't belong here

The concept of being an outsider was illustrated by the patient participants in a number of ways. Not understanding what was happening to them or happening around them or why they were being kept in hospital were frequent complaints and triggered anxiety and agitation. Many described feelings of homesickness and a longing for the familiar surroundings, people and routines of home. Not understanding the hospital environment and confusing the hospital with home was common, although this did not appear to bother the participants who mentioned it. The following examples illustrate the powerlessness and bafflement felt by some of the patients, describing their sense of not belonging in the ward space.

I don't know why they are keeping me here

Many of the patient participants described feeling completely ignorant about why they were there, and could not understand why they were being kept in hospital. This lead to conflicting expectations of care and to some of the patients feeling imprisoned. The salient concept of being an outsider was constructed in a number of ways. Firstly because of cognitive impairment the patients may have had difficulty remembering information which had been discussed with them, however it is equally possible that the patient had not been included in the discussions or that

the patient had been told but disregarded the information. The result of not knowing was widespread uneasiness and anxiety in the patients.

Lena was worried why she was in hospital and what was going to happen next.

> *I don't know why I am here. Why I can't 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.*
>
> (Lena, patient)

For one of the patients, anxiety about being imprisoned led her to grab the portable phone from the nurses' station and ring 000 (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)

Social problems, guardianship and Victorian Civil and Administrative Tribunal (VCAT) hearings were quite common in the patients in this study. VCAT is a body which provides dispute resolution, and may appoint a guardian or administrator to help manage the affairs of an adult with a disability (Victoria State Government, n.d.). A number of the patient participants had pending VCAT hearings.

Seven of the families were seeking permanent residential care and did not appear to have discussed this with the patient. Ines was in this situation 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)

Bob was concerned that he had been in the hospital for so long and was keen to get home to his cat and his 'lady friend'; however he was unaware that this ' lady friend' who was 40 years his junior was suspected of taking advantage of him financially and that VCAT were appointing a guardian to manage his affairs. The most likely scenario would be that he would go into residential care. The cat had already been removed by the Royal Society for the Prevention of Cruelty to Animals (RSPCA). Not knowing or understanding what was going on was a source of great anxiety for Bob:

> *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)

Some of the patients who didn't know what was going to happen to them didn't feel as anxious as Ines and Bob. This may have been due to the particular state of the relationship between the participants and their families. Fred had said previously that he had a very close relationship with his son:

> *Fred: I don't know what I'm going to do. I leave that to ... my son does most of the*
> *arranging for me. And er, what he's trying to do I'll put up with.*
> *Interviewer: You'll go along with whatever he decides?*
> *Fred: Yes.*
>
> (Fred, patient)

Similarly Andrew (patient) was indifferent to his situation and was confident that his daughter would sort everything out.

> *Andrew sits in his single room alone watching television or looking out the window all*
> *day. When he was asked what was going to happen next for him he responded "I*
> *dunno - ask my daughter" and looked unconcerned.*
>
> (Field notes, Ward C)

Bob didn't have any family involved in his affairs except for his 'lady friend', and Ines had a very strained relationship with her daughter because of previous behavioural incidents related to Ines's dementia. Issues of control between the patient and family, and lack of insight due to dementia could also be factors in this situation.

I just want to go home

Feelings of not belonging in the hospital environment lead to a yearning for the familiar. The patients almost universally expressed a desire to go home and homesickness was a common complaint. Mostly this was about missing family and friends, but some participants were also concerned about being separated from their pets which caused distress and anxiety. Jack expressed sadness that his cockatoo, which had been his companion for many years, would be missing him.

> *It's bit hard to be without my cockatoo. He call out Jack! Jack!*

(Jack, patient)

Disconnection was further fuelled by the unfamiliar food in hospital. Food is an important foundation for a sense of being 'at home', however for many the strangeness of the food increased their feelings of being an outsider. Lena was an 89-year-old patient with Alzheimer's disease and breast cancer who grew up in the Seychelles. Creole food is very spicy and colourful in comparison to the fare she was offered in hospital.

> *Well, it's not my food. My food is curry and all that sort of thing. Well, 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)

One of the patients was used to having his meals with his wife who he relied on to orientate him to what was happening.

> *Ned's wife comes in every day at lunchtime. She brings sandwiches and cake for them both and encourages him to eat. He seems to rely on her for reassurance and orientation. He told me it was the highlight of the day for him.*

(Field notes, Ward E)

Mostly the patients missed their family and friends who were the familiar companions and carers in their normal lives. As dementia progresses, the person may rely heavily on the recognisable faces and routines in their day to maintain stability. For some, being removed from this caused distress and disorientation.

I like my home and my family. I'm on my own now but my daughters are nearby. I see a lot of them and they do a lot for me. So do my grandchildren... the family's always in and out... I've got great neighbours, I've been in that house about 60 years, so I want to go home.

(Anna, patient)

Engagement with others and feeling valued in daily life was largely missing from the experience of the participants in this study. In contrast, many of the participants talked about activities at home which gave them great satisfaction and feelings of self-worth. Alfie spoke wistfully about his familiar routine:

I live in Mount Waverley and I know every shopkeeper. I've got me favourite coffee shop which I haven't been there since I've been in here... Every morning there'll be a little note on the kitchen table. There might be a list of things she [daughter] *wants me to get... First stop is the coffee shop - always! It might take me a couple of hours to get all the things she wants.*

(Alfie, patient)

Barriers to inclusion and belonging can be simply overcome in some instances. Ines spent much of her day pacing around the ward getting increasingly frustrated with the locked door, however on one occasion the researcher observed the Food Services Assistant occupying her for a short time helping him to collect the meal trays from the other patients on the ward. Ines appeared cheerful while doing this and chatted with the staff and other patients in a light-hearted way while she worked. On this particular ward there was no diversional therapy, only a fledgling volunteer program and no organised activities for most of the patients. Having a task to occupy her was a source of satisfaction for Ines.

Alfie was fortunate to be included in the gym program and it was something he enjoyed doing every day. He found satisfaction in the activity and the interaction with other people:

Interviewer: What do you like about the gym?
Alfie: There's other people there apart from you and you can see what they're having and the exercises are ... they're not strenuous but they're just nice and I've never done it myself - the only exercise I would get would be out in the garden. I like it.... Yes, yes, I like it very much. Plus I look forward to it, the gymnasium.

(Alfie, patient)

The exercise Alfie was getting in the gym was important for his physical rehabilitation, but the routine of attendance and the companionship of others appeared to be equally important to Alfie.

I am upstairs aren't I?

The hospital environment could be a confusing place for the patients, many of whom had trouble with spatial orientation and could not understand the environment they were in.   Not understanding where they were was a source of anxiety for some and contributed to feelings of being an outsider and not belonging.

A patient with advanced dementia who was not interviewed was being cared for in a single room. He called out continually unless there was someone in the room with him possibly because he felt too isolated or anxious when he was alone. The nurse complained to the researcher that she didn't know how to stop him calling out (Field notes, Ward E).

Martha could not easily understand where she was and often got lost when she went for a walk, however this didn't appear to trouble her:

> *Martha: Now that's down... I haven't... yes I've gone past there but I haven't gone in.*
> *Interviewer: The dining room? You don't go into the dining room?*
> *Martha: I don't think so. 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?*
> *Martha: I don't think so, I don't think so. No... see I could be saying all the wrong things.*
>
> (Martha, patient)

Patient participants often blurred the lines between the hospital environment and their normal residence, referring to them both as if they were part of the same place. Describing her experiences with the volunteers in hospital, Emma went on to say that she often went to Kmart (shopping centre) in the afternoons, confusing the two places:

Emma: 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.

Interviewer: Sounds like a busy day! So are most days busy with things like that or do you have quiet days as well?

Emma: I have quiet days because I um 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)

Spatial confusion did not appear to bother the participants in this study who mentioned it; in most cases they were unaware that they didn't understand the space. Several patients were surprised when it was pointed out to them that they were sharing a room with others. This was the case for Benny, who laughed when the interviewer mentioned his room-mates:

Interviewer: So you're in a room there with four other patients now aren't you?

Benny: Oh yeah! (Laughs)

Interviewer: Didn't realise?

Benny: Haha I didn't ... haha.

(Benny, patient)

Fred was similarly taken aback when it was mentioned that he was sharing a room with another patient:

Interviewer: So, I notice that you're sharing a room with someone else.

Fred: No I'm not.

Interviewer: Yes you are you've got another person in that room. Your bedroom's got one other person in it - a lady, in another bed.

Fred: (Pause)...Oh I see what you mean yeah. Yes.

(Fred, patient)

Pattie was not only spatially disorientated but also had poor vision. She was not able to remember where she was, but would get out of the chair periodically when she felt restless.

Observing a five-bed room from a distance I noticed one of the patients getting out of the chair suddenly and heading towards the door without her wheelie frame. I alerted a nearby nurse who ran into the room shouting "No Pattie!!!"

(Field notes, Ward B)

The patient participants in this study who were disorientated about space and place did not necessarily appear to be upset by this. Not knowing in this instance was something of which they were unaware or accepted.

Powerlessness

Rigid routines in which patients had no input could reinforce feelings of marginalisation while emphasising the boundaries between the staff and the patients. Individuality in the wards in this study was often disregarded.

> *It's er not very pleasant. You haven't got the freedom to do what you want to do, and that er you're at the beck and call, sort of beck and call of the nurses.*
>
> <div align="right">(Fred, patient)</div>

The patients demonstrated that they were powerless to change the routine of the ward which in many instances was described as being frustratingly boring.

The patients had very little power to influence their situation on any level as illustrated by a memo in the field notes. One of the doctors described the lack of power felt by one of the patients who had become resigned to the situation in hospital. The patient had been agitating to be discharged since she arrived. The doctor said that the patient was "much improved this week - she's more accepting and doesn't beg to go home every day on the ward round".

You go mad with boredom

Boredom was a common complaint from the patient participants. Those cared for on the wards which had a more developed volunteer program and access to outside areas were less likely to mention boredom. In two of the older wards which were on the upper floors of a building and in which the volunteer program was negligible boredom was frequently mentioned by the patients.

> *To me this is really boring. I just want out of here and back to work, and just do my jobs.*
>
> <div align="right">(Ines, patient)</div>

Martha told the researcher that although there were things to occupy her in hospital she felt she was in limbo and her life was on-hold while she was there waiting to recommence her normal life:

> *I just feel during the day there's nothing in it...No not nothing going on, but the things you are doing, they can't contribute to what your life's going to be like ...*
>
> (Martha, patient)

The patients could only go outside if taken by a staff member or relative. This rarely happened despite many of the patients expressing their desire to be taken out. In the wards which were on the ground floor and had direct access to a secure garden, the patients were more likely to go outside, especially if they were ambulant. This was not the case for Allan who required a wheelchair.

> *Allan: I asked a couple of days ago if I could go out and they said only if I get someone to push me out.*
> *Researcher: Hmmm. Did you get someone to push you out?*
> *Allan: No I didn't worry about it.*
>
> (Allan, patient)

The quote below illustrates how the compliant patients were favoured in this instance.

> *Pam (EN): On the weekends sometimes we do* [take a patient outside]. *We have to walk down the front office and get newspapers so we might say to someone you can trust will come back with us 'would you like to come for a walk and get the papers?' and yeah, yeah.*
> *Researcher: But generally a lot of them wouldn't go out?*
> *Pam: No, no.*
>
> (Pam, EN)

The ward being referred to here was upstairs, and despite there being a patient garden on the site, most of the patients were seated next to their bed for most of the day. In the case of the patients who did not attend therapy it was observed by the researcher that they 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 patients in this situation spent much of the day watching the nurses. The televisions at each bedside required payment in order to be operable, and consequently few of them were used. Ambulant patients could walk around the ward, but many were unable to do this unaided. Some patients did not appear to mind the inactivity, whereas others found it very frustrating:

> *Kate: I just watched one of them nurses making the bed this morning (laughs). I was just noticing how you can fold in the sheets and things.*
> *Interviewer: So you spend a bit of time watching what the nurses are doing?*
> *Kate: Yeah. I have no other, no other pastime, love.*
>
> (Kate, patient)

Several patients appeared to be very apathetic, a common symptom of dementia. For these patients, inactivity and an unstimulating schedule were quite acceptable:

> *Lettie: I get up in the morning, sit in my chair and wait for the nurse - she usually gives me an injection you know - and um I wait for a while, then they give me breakfast and all that.*
> *Interviewer: And then what happens?*
> *Lettie: Nothing.*
> *Interviewer: Nothing, OK. So how do you find it?*
> *Lettie: I find it alright.*
>
> (Lettie, patient)

The activities offered by the volunteers did not appeal to all the patients, however for some it was a welcome opportunity to be in a different space with other people, regardless of the focus.

> *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. A few of us went down and watched The Cup* [a Melbourne horse race which is televised] *and I thought well, at least, we might see the whole thing through...*
>
> (Harriet, patient)

The routine was monotonous for both the staff and the patients in hospital. The researcher spent many days observing the activity in the wards and wrote in the field notes that it was very repetitive. This excerpt describes one of the wards after lunch:

The ward remains unchanged from yesterday. Polly is sitting silently in the chair next to her bed, Bruce's wife is visiting, Ines is pacing, Gwen is lying on her bed with her head at the foot end. Nurses supervise from a distance unless the patients need medication, treatment or are seen to be doing something risky.

(Field notes, Ward A)

The regimentation of the wards and the sameness of one day to the next were noted by several of the patient participants:

Oh well, you're regimented. You know they er breakfast at eight o'clock, dinner at 12, and tea at six o'clock. In between somebody comes round to take your blood pressure... Then I just watch the telly and listen to the radio, and er that's about it I suppose.

(Lex, patient)

The sameness of the daily routine of the ward was not necessarily viewed negatively and in some instances, it served to ground a person with dementia who was feeling unsettled, however for those who were more cognitively intact it could be an irritation and trigger anxiety.

I want to make my own decisions

The power imbalance was further illustrated when there was opposition to the patients making decisions about their care or future plans. Patients with dementia can lack insight into their condition; however the participants often could not understand why decisions were being made by other people about their lives. Concern about risk was usually the reason cited by well-meaning others, but some patients would rather accept the risks and live the remainder of their lives in the way that made them happy. Marc pointed out that we will all die some time, and at the age of 100, despite opposition from health professionals, he wanted to go home to his house and friends. He knew that he had limited time left and was prepared to accept the risks:

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 year [old]. I pass away - you pass away... eh?! (shrugs)

(Marc, patient)

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Making decisions about discharge plans was just one of the ways the patients reported a lack of power. Patients described feeling that they were at the mercy of the health system and appeared to have very little control or independence, however during the interviews there were illustrations of the way that patients did exert some limited power:

> *I said watch me - I'm just going outside and I'm going to get a taxi and go back to the hospital...I said you come near me I'll kick every one of your heads in and I'll be taken and locked up, never mind. Come and get me. So I came and got a taxi and went back to the hospital* [following a pathology test conducted externally]
>
> (Larry, patient)

Bob recounted a story about being picked up by ambulance at his home after he had absconded from the hospital. The anecdote illustrates his unwillingness to be pushed around by the system. For his troubles, Bob was sent to a locked ward and at the time of the interview had not been outside the building for two months.

> *You won't believe this, 12 o'clock at night they came to my house, two policemen - they said "You can either come quietly or ...They broke the window, and they bashed the door down! And they grabbed me like this - now this is a broken arm, one this way and one this way - they were what you call "transit police". They couldn't fit the stretcher in so they dragged me out bodily... And they said, "If you don't come back peacefully, we'll break the other arm". One of me neighbours came over and said "Better go, Bob because they're gonna bash your house. They'll kill you if you don't let them take you."*
>
> (Bob, patient)

Bob did not succeed in this power struggle however there were several instances mentioned by the patient participants which demonstrated that this was sometimes the case. Angelique exerted her limited power when visited by the physiotherapist who recommended an exercise program to improve her strength and endurance; however she declined.

> *Forget the gym! I go before. I no need... now I am old 84 I no need. NOOO!!! Darling No!!! impa ompa impa ompa* [mimicking people repeating exercises] *no no no no! For me no good. Lot of work. My back no good.*
>
> (Angelique, patient)

Ines objected to the tablets she was being given and spat them in the bin when the nurse had gone. She smugly told the researcher how she had outsmarted the nurses:

> *Five, six vitamins! Now I have a lot of vitamins at home that I take, but not that many and not every day. Two or three times a day I've got to take all this stuff...sometimes I don't take them. Don't tell anyone...They just give them to me in a little thing and say "here's your vitamins" and off they go and then I spit them in the bin. I don't want to take them all the time – I don't need them.*

<div align="right">(Ines, patient)</div>

The patient progress notes told a similar story about one of the patients with dementia who refused to comply with the instructions of the staff:

> *Patient paranoid that OT was trying to get personal information (during OT assessment)... he became aggressive, raising his fists to staff... intimidating staff by stepping into their personal space. Refused rispiridone and barricaded himself in room, not allowing staff to open the door. Once settled patient agreed to take rispiridone...*

<div align="right">(Progress notes, Ward E)</div>

The patient comments and progress notes illustrated that the state of unknowing put them at a disadvantage in the health system that they had little power to influence because of their cognitive disadvantage. They chose to either accept powerlessness or fight against it.

Patient aggression could be a result of a battle for control between nurses and patients. Busy nurses trying to rush a person with dementia could potentially trigger an aggressive incident, however in some instances, the trigger was not easy to identify. Despite the reason for aggression, the response of the nurses was often to retreat from the patient in order to let them calm down. If the patient looked as if they might lash out or throw something a common strategy was to give the person some space and observe from a distance. The person may be more relaxed and responsive a short time later:

> *I would say I normally back off initially. If I see that there is a patient having an aggressive episode, rather than argue with them I sort of back off and give them a bit more time. By the time you come back, they've settled down. They forget after a few seconds what their problems are...*

<div align="right">(Jane, RN)</div>

Some nurses appeared to use this strategy as an excuse to avoid a patient they didn't like or who didn't like them:

> *Some patients they don't like you, you know, we have to check the patient. I don't want to always go into the patient's room disturbing them. I would look from the outside how is the patient.*

> (Elsa, RN)

Patient aggression could also spark fear in the nurses especially those who had been injured previously. Being hit or grabbed unexpectedly on one occasion could make a nurse more fearful or defensive in subsequent encounters with patients.

> *Yeah, I've been grabbed. They would have been fine but as soon as you touch them they ... you know you hold them and they don't like what you did. There's something... they maybe grabbed me a little bit. Like that...So definitely it's a bit um scary for me.* [It's made me] *bit like um defensive on what I do.*

> (Ada, RN)

Most of the nurses said in the interviews that they had not been hit by a patient because they were able to judge when a patient was getting aggressive, and stay well clear. However it was not always possible to know when this would occur and it lead to wariness.

The fear of nursing homes

The ultimate denial of freedom was considered by many of the participants as admission to a nursing home. The power and control exercised by others often took this decision out of the hands of the patients. The right of a person to make choices about their own life despite significant cognitive challenges is controversial. This comment conveys a belief that protection of the person against ill-health is not always appropriate:

> *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)

The relationship that the patients had to their families was key to this situation with some mistakenly trusting that their children would not let this happen. Power and secrecy kept the patients ignorant in many cases.

> *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)

Bertha was mistaken about this as noted in the progress notes:

> *...Neuropsych assessment has deemed patient unable to make complex life decisions and therefore has been assessed as unsafe to return home. Team and family agree she needs permanent care. VCAT have appointed daughter and son as joint guardians.*
>
> (Progress notes, Ward D)

One of the participants however had decided to make the decision to go to residential care based on her concern for her three daughters. She didn't want them to be worried about her or left with the responsibility of caring for her when her abilities deteriorated:

> *I've just had the startling news ... the doctor said I have dementia, which isn't what I thought to happen in later life I must admit. But I'm in the throes of moving out* [to an aged care facility] *mainly for the girls' sake, but I want to leave things so they don't have a terrible mess when I die.*
>
> (Mary, patient)

The demonstration of power relationships evident in this study between the patients and nurses, and the patients and their families influenced the experience of all the participants. At times there was noticeable stigmatisation of the patients with dementia which will be discussed in the following section.

Stigmatisation of people with dementia in hospital

 Stigmatisation of people with dementia was evident on a number of occasions when nurses made derogatory comments about patients or suggested that they should be cared for elsewhere. The following section will discuss the attitudes of the nurses towards patients with dementia, the

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use of space to enclose or exclude these patients, and stigmatisation demonstrated by preferential treatment given to patients with other diagnoses.

Some back off like you are cluttering up their hospital

Sometimes the nurses said that patients were acceptable if they were quiet and cooperative but those with behavioural symptoms were unsuitable. There were instances observed of nurses ignoring the patient with dementia or speaking to them in a patronising tone. Some of the nurses expressed distaste for the patients, suggesting that a 'dementia specific' care setting would be more appropriate. This was an example of nurses choosing the patients that they were willing to care for such as a patient with normal cognition or the 'good' dementia patient who didn't upset the routine.

> *I think it is very hard to look after the demented patient if they are ambulating… Lock the door otherwise they will go to other patients' room, maybe demented patients should be in … like the nursing home I think they got a dementia unit, so if the dementia patient is all together, one staff can look after the patients altogether.*
>
> (Elsa, RN)

Intolerance of difference and an unwillingness to shape care to respond to the particular needs of the patients was demonstrated by nurses who used labelling and identified specific patients they wanted to exclude. Nurses discussed the concept of the 'good patient' and the 'problem' patient in their responses. The following quote is another example of a nurse using the term 'demented' which is using the adjective to describe the person themselves thus reducing their identity to being defined by a disease:

> *There are also patients with dementia who are very, very good. Apart from being demented, they can function with prompting and a bit of assistance, and they don't have really, really bad behavioural issues.*
>
> (Tina RN)

The nurses were evidently transparent in their feedback to the patients, as several reported that they noticed that some nurses had a patronising or negative attitude towards them:

With some, you have some conversation, with others none, and still others they back off like you are cluttering up their hospital.

(Harriet, patient)

Similarly, there were nurse participants who commented on their colleagues' poor attitude to some of the patients. The demonstration of power through the use of bullying tactics and aggressive manner was counter-productive in that it was likely to produce an uncooperative or aggressive response in the patients.

Some nurses are assertive bordering on verbally aggressive with their manner and their body language, bossy, inflexible and they personalise the patient's behaviour... And get quite put out if the patient's, you know if they feel that they're deliberate or they get annoyed because it gives them more work, things like that.

(Suzy, EN)

During the handover to allied health staff one morning the researcher observed an ANUM speaking in a derogatory way about patients with dementia. Regarding a new patient, she said that he was "*a real doozy*" and "*needed fumigation*", and about another she said that the person would not need allied health interventions because the patient had dementia and *"would just get worse anyway"* (Field notes, Ward B). The researcher observed the allied health staff attending this handover, but they did not react as if this was an abnormal comment and remained silently standing around the desk taking notes.

Nurses also noticed that some of their colleagues did not relate to the patients equally and at times used demeaning language when speaking to people with dementia:

I have heard other nurses, the way they speak to people, and to be honest, it can horrify me at times; the way they speak to them...demeaning or really rude. I have heard that, and I would never speak to anyone like that, and I guess that just comes back to patience and being understanding.

(Christine, EN)

Demeaning language was also observed by the researcher during the observation phase of the study. A nurse was observed repeatedly speaking in a patronising pseudo-Italian accent to a

female Italian patient with dementia, calling her 'Mama'. The patient and the others in the room did not appear to notice.

The patient progress notes were in the main very factual with little subjective comment, although there were occasional examples in which the nurses used judgemental language.

> "...sometimes speaks very rude and uncooperative...argumentative and stroppy this morning".

(Progress notes, Ward C)

A further demonstration of stigmatisation of patients with dementia was observed when nurses used of the terms 'us' and 'them' when describing encounters with patients:

> Oh sometimes we just leave them as long as they are safe...if they become very aggressive we have to leave, then come back later when they settle down. Sometimes it doesn't worry us because we're looking after that patient for how many days. It doesn't worry us anyway.

(Ada, RN)

It was acknowledged by one of the nurse participants that some patients received less attention because of their personality or behaviour. This implied partiality and favouritism towards some patients:

> I mean if you've got a rapport you're probably more likely to spend more time with them...some people you just don't get on with - you know if they're not pleasant to you, you're more likely not to spend time, but you've got to do certain things so you've got to make the best of it and try and find some strategy that might help.

(Maree, RN)

Patronising language was also used by some nurses to describe the patients, and there was evidence that they used manipulative strategies on occasion:

> I suppose it's how you handle a patient with dementia. You have to more um a little bit like um tricking them. What they call that? Maybe... how do you say when you say that can be like a baby or something. Just the same for them.

(Tina, ANUM)

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The field notes illustrated further examples of patronising language including the following interaction which was observed when a patient with dementia fell in the corridor. A physiotherapist and a nurse came to help him up and had this discussion in front of the patient.

> *Physiotherapist: He's not at his best today is he?*
> *Nurse: Don't worry about that. He'll come to life at night!!*

(Field notes, Ward E)

The nurses used a variety of approaches with the patients with dementia based on their own personality and life experience rather than education or best practice.

Mentally there's not much that's done for them

The nurses reported that their chief priority was the physical care, especially hygiene, medication, wound dressings, observations and other tasks prescribed by the nursing care plan. Mental health care took a back seat to these priorities.

> *A dementia person would probably get left behind because you're busy doing other things. You haven't got time. You do what you can physically for them, but obviously, mentally there's not much that's done for them.*

(Christine, EN)

A further reflection of this attitude was demonstrated in the patient progress notes where was very little reference to cognition. Despite some of the patients having quite advanced dementia, most entries in the notes focussed on physical care. Below is an observation recorded in the researcher's field note journal:

> *Patient progress notes have revealed very little information...only the measureable facts are recorded not information about the patient's cognition. Lots of meaningless information such as " care delivered as per NCP* [nursing care plan], *no complaints voiced"*

(Field notes Ward B)

Despite having the opportunity on numerous occasions observed by the researcher, the nurses often didn't engage with the patients beyond small talk. Most encounters were the nurse directing the patient in their care, or asking them if they wanted to go to the toilet. In one ward the volunteers occupied patients with games, songs and craft activities. They also took patients to

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the garden for a walk, to admire the flowers and get some fresh air. The garden in that ward was an enclosed safe area leading directly from the patient lounge.

However, occupying the patients with dementia with activities was not deemed by the nurses to be part of their role. Physical care and rehabilitation of acute illnesses was the stated priority:

> *We're here to provide their care but ... we don't have time to be able to sit with them and talk to them and you know run groups and stuff... I mean this ward I guess is more about rehabbing patients to go back to their homes rather than anything else I guess. You know it's not a nursing home here...*
>
> (Lil, ANUM)

On one occasion the researcher witnessed a nurse sitting with a 100-year-old visually impaired patient with dementia holding her hand and engaging her in a conversation about football. After this they sang a song together 'After the war is over'. This encounter was very poignant but was the only one of this kind witnessed by the researcher.

> *The thing is we don't have like more to make them like busy... I think it's an OT thing... I think they need some activities to make them so busy. So like playing cards or whatever, you know.*
>
> (Ada, RN)

This comment conveys the belief that engaging the patients in activities beyond personal and biomedical care is not the role of the nurse and should be handled by other disciplines such as occupational therapists.

There was a lack of engagement demonstrated in the situation described by Larry (patient) who felt that he was being shunned by the physiotherapist who did not include him in the exercise group. This was because Larry was waiting to be discharged to residential care and it had been decided that physiotherapy was no longer necessary for him. Larry was not aware of the reason, although it is possible that it had been previously been explained to him, but nevertheless the experience left him feeling excluded.

> *When I came that physio he goes from room to room asking whether you want to do physio. Nobody asked me....Everybody do this or do that and I'm not asked.*
>
> (Larry, patient)

Practices such as this that reinforce division and the perception of not belonging, add to the construction of otherness and can lead to resentment, and in this case sadness. Patients waiting for discharge to residential care were at times mentioned in a derogative way.

In the field notes the researcher noted that some of the nurses spoke negatively or sarcastically when discussing patients with dementia during handover:

> *The ANUM skipped over several patients with dementia noting that they were just waiting for placement, so nothing going on with them. There is very little or no therapy for patients going to residential care. In the main they receive no input from allied health except for the social worker who mainly works with the families. The inference in the handover was that they were being 'babysat'.*
>
> (Field notes, Ward B)

It was evident in the words and actions of the staff that very little consideration was given to the mental state of the patients with dementia as long as they were quiet. Patients with a diagnosis of dementia and awaiting discharge to residential care were only assigned minimal resources.

Anyone who complains probably doesn't like being bossed around.

Nurses were at times observed to be paternalistic and patronising in their manner when dealing with older patients, especially those with dementia. The researcher observed a nurse using a loud, exaggeratedly jovial demeanor with her patients who were all in a 5-bed room together. Her approach created an additional barrier between her and the patients.

> *The nurse spoke in a loud 'cheerful nurse' voice. Very impersonal, doesn't know the patients. Efficient and gets it all done but is disengaged. The patients look intimidated and bewildered.*
>
> (Field notes, Ward B).

Some of the patient participants also commented on the bossiness of the nurses, with some objecting to this treatment and some appearing not to notice. Others such as Arthur objected to the manner of the nurses but not necessarily to the message being delivered:

> *Arthur: Anyone who complains they probably don't like being bossed around.*
> *Interviewer: OK. So do they boss you around a bit?*

Arthur: Ooooh yeah, Ooooh yes...Well, it's for your own good, but you don't realise at
the time. They say keep your weight off that leg which is the bad leg and you've
got to do it you know.

Interviewer: You're meant to be partial weight-bearing on that leg?

Arthur: Yeah, yeah, that's right.

Interviewer: So they get a bit cross about that do they?

Arthur: (Laughs) Oh that's for sure, yeah!!! Yeah, and if you give them a hard time
they'll give it to you back for sure.

(Arthur, patient)

Being forced into a strict routine was a source of aggravation for some patients who preferred to keep to their own schedule. Bob objected to a nurse trying to get him into bed in the evening when he was not yet ready. This example showed that some of the nurses could be domineering towards the patients, but that patients could refuse to be pushed around. The power struggle between nurse and patient is evident in the following quote:

One lady's a bit of crab-apple...She tries to bully ya. "Time for you to get into bed!!" No
good coming around at half-past 6 and asking me to get into bed! And she'll say "Get
into bed! Get into bed! Lights are out at 8 o'clock "...A real bully, you know. The others
are all very nice, but she's ugh! ...

(Bob, patient)

Further instances of power struggles were noted in the progress notes, including the example below.

"Patient argues about his medication time. He says he knows what he needs and wants
to take or do etc..."

(Progress notes, Ward D)

Some nurses commented that it was common for nurses to want all the patients to remain seated during the day and to stay in bed at night so that they caused the least bother to the nurses and their routines. The acceptable patient with dementia was one who did not demonstrate any behavioral symptoms and was preferably docile and compliant.

They want them to stay where they put them. They don't want to be disturbed. They
don't want to deal with someone who's not going to do what they want them to do. On
the nightshift some nurses - all patients have to be asleep, whereas some nurses, they

don't mind if the dementia patients get up and wait for the bus, or want a cup of tea, or want to go and play tennis.

<div align="right">(Kylie, EN)</div>

A couple of the nurses said that they would not force the patients to fit into a timetable despite this being the expectation of others in the team. Scheduling patients with dementia to attend physiotherapy or occupational therapy breakfast group early in the morning was considered to be particularly problematic. People with dementia often react badly to being rushed. Aggressive and uncooperative behavior can result.

I've got enough time, if I'm allowed to do my job, but everyone else wants to get involved. They've got to go to physio; they've got to go to make their breakfast. People with dementia need time... If I've got time to get them up and see them getting dressed and, "Go and have some breakfast now," no problem. But if they're pushed and rushed because they've got to be there at 8:15 or 8:30, well...

<div align="right">(Ruth, EN)</div>

The nurses' personality and manner were blamed for the aggression exhibited by the patients in the excerpt below. The nurse participant blamed the approach and behavior of the nurse as the trigger for aggressive behavior of a patient who may lash out in objection to being controlled.

Some nurses are combative...instead of having strategies - and I'm not saying - look, sometimes your best efforts don't work - you get the same handover from the same person who says the patient was aggressive each time. I just know that it's not the patient. I know that sounds awful, but it's true.

<div align="right">(Margie, EN)</div>

Esme (patient) showed insight into the behavior of the nurses who she considered to be domineering and concerned with their own interests ahead of those of the patient. The following excerpt demonstrated the issue of the nurse rushing the patient because the nurse wanted to get out of the room as quickly as possible:

You have some of them that charge in here. They literally swamp you as they take over ... they don't stop to think where you were at before they walked in the door... 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. They just want to go along.

<div align="right">(Esme, patient)</div>

Another patient participant, Jenny, despite having quite advanced dementia and not being able to remember the names of her children or where she lived, was quite perceptive when speaking about the nurses and their attitude to their work:

Some of them are friendlier and more understanding perhaps. If you've got a down
day they try to um, try to cheer you up and things like that. The others...they're OK.
They do their job but don't sympathise with you.

<div align="right">(Jenny, patient)</div>

Not all the feedback about nurses was negative, however. There were many examples of both nurses and patients commenting on the behavior and manner of nurses positively. Nurses who made the time to listen to the patients and accommodate their needs where they could were highly regarded:

Oh they're kind and friendly. And they go out of their way I think to help you. They're
not bossy.

<div align="right">(Kate, patient)</div>

Despite some of the patients reporting that the nurses were friendly, none said that they had had any lengthy conversations with the nurses, and most interactions were reported to be confined to small talk and practical matters. The patients did not appear to expect more depth than this. What they did expect was that the nurses would meet their needs and be pleasant and helpful.

Theme 1 described the experience of the patients with dementia as being determined largely by the power imbalance in the wards. The patients described not knowing why they were in hospital or what was going to happen to them, and felt bewildered by the built environment. Not being allowed to leave the locked ward, or decide their own schedule was a problem for some. Others were concerned that their rights had been violated by not being involved in decisions about their discharge destination.

Theme 2: Nurses' assumptions, expectations, principles and realities of care

The nurse participants in this study were asked to discuss what it was like for them caring for people with dementia in the ward where they were working. Many of the nurses demonstrated a strong attitude of caring and spoke about their frustration in being unable to care for patients in the way that they knew they should because of a lack of support and resources. Being at a loss to know what to do specifically for people with dementia who had behavioural symptoms was a problem raised a number of times by nurses who in the main had not received adequate education in this area.

Nurses are not supported to provide optimal care

Nurses described the changes that they had witnessed while working in sub-acute care over a long period. An increase in patient acuity and turnover, and an escalating amount of paperwork were cited as reasons for reduced time spent with the patients. Nurses also complained about their lack of specific preparedness and education for the role, and poor psychological and material support from the hospital administration.

> *The type of patients we're getting. They're getting older, they're getting frailer, and they're getting more and more dementia. We are getting more medical problems as well as the hips and the knees. When I first came to this ward, it was just an amputee ward and it was lovely, great ward. But over the last seven or eight years, it has changed. All the girls will tell you how, now, it's just got really busy.*

(Audrey, EN)

The morale of some of the nurses appeared to be affected by the pace of the ward. One of the patients could see that the nurses were not appreciated and supported by the hospital and made the following comment:

> *I said to one nurse how difficult it was for them and I said I'll write a letter to The Age* [newspaper] *and she said well you could write a letter to The Age and tell them we want more money to start off with! (Laughs) which is true isn't it? I think it* [being underpaid] *makes them feel worthless.*

(Mary, patient)

We haven't had any cognition training on this ward

When asked about the education they had received to prepare them for working with people with dementia, very few nurses said that they had received any relevant recent education, with several citing the mental health subject at university as their only formal education related to dementia. Nurses commonly responded that they learned on the job but generally felt under-prepared. Few mentioned that they had accessed education independently, demonstrating a hesitance to initiate their own professional development. In-service education was regularly offered in the wards, but the range of topics was very broad and generally focused on other more acute topics such as wound management, diabetes, education about complex equipment, and other topics focussed on biophysical care. The nurse education timetable for the previous six months was examined at both health services and neither listed cognition or dementia as a topic for this time period.

> *We do have education, but not dementia-specific. But we all know dementia and we all say oh they've got dementia what do you expect - that sort of thing - but we don't have the formal training on how to deal with them to get the calmest outcome. We haven't had any cognition training on this ward... I've been working on this ward since it opened - five or six years.*
>
> (Kimberley, EN)

One of the nurse participants cited personal qualities such as patience, empathy, calmness and maturity as key attributes for working in that area ahead of the amount of education they had received on cognition.

> *You can give them all the education, as much as you can, but it depends on the type of person. It takes a special type of person to be able to deal with dementia patients.*
>
> (Christine, EN)

Another nurse mentioned that being more relaxed and resilient were important qualities. She also considered that more experienced nurses were better at this role; however this was not borne out by observation in this study:

> (Nurses who are better at caring for patients with dementia) *are people that have been doing it for years, people who are ...more experienced and people who don't get so uptight, more relaxed yeah.*

<div align="right">(Kylie, EN)</div>

The oldest nurse participant in this study who had also been working as a nurse for the longest period of time agreed that experience was the most essential element in managing patient behaviour. She also declared that it is something which can't be taught:

> *Well, I mean, I suppose the in-services and things still have to continue, but I think a lot of it comes with experience. You watch the young - like, we've got students on the ward, and you watch the younger ones, and they're not taught the practical side of dealing with people. I think that comes with your years of being on the job. You have to be - you can't be taught patience. It's just something that comes.*

<div align="right">(Audrey, EN)</div>

Others thought that the lack of specific education was a major shortfall and contributed to the skill deficit of the nurses. In this quote the participant observed that the personality of the nurse was a defining factor and in some ways more important than education, although this was disputed by others in this study:

> *Training is very crucial, but most importantly it depends on the person who is being trained...complemented with practice and how you act with each patient is up to every individual. But firstly the training is very important. Just simple things with dementia like you don't argue with them. For example if someone says I'm going to the bus stop, or my mother's coming at 10 you just go along with all that. But it more depends with whether the person has been taught to put that into practice...*

<div align="right">(Edward, RN)</div>

Education that provided appropriate practical strategies that nurses could use in the workplace were more likely to be considered useful; conversely self-defence courses and education that focused on the biomedical side of the condition were not thought to be much help at the bedside. One of the nurse participants had done an external course to help her to work more effectively with patients with dementia, but found it disappointing.

Well, I did a course here through [external organisation], *which I thought was absolutely useless... A total waste of time... It didn't tell me anything I didn't know. The way it was worded, that they were going to teach me skills, and I got nothing out of it... I wanted to know, okay when somebody is* [agitated or aggressive] - *what was happening at the time? They're lashing out because their need wasn't being met. Well, what do we do when that's happening? Or when it's not so - then let's try this. Actually, what I got was from chatting at teatime from other people from other sections. "We do this," "We do that," but in the actual session itself, nothing.*

(Rose, RN)

A lack of useful education about dementia which focused on the practical issues was clearly identified, however not all of the nurses were interested in learning about dementia. In the following quote the nurse is dismissive of mental health nursing:

Look if I wanted to do mental health I would have trained, gone off on that route you know. It's not my interest so it's quite difficult you know... Also you know none of us are trained in that so... You know these people [in the psycho-geriatric ward] *are trained, they know how to you know divert them whereas we don't you know. We've got no idea so ...*

(Lil, ANUM)

The above quote illustrates that some nurses had little interest in caring for people with mental health issues.

When I got hit by a patient I cried

Participants identified that very little psychological or professional support was provided for the nurses. No clinical supervision was offered in either of the health services in this study and debriefing occurred only following major incidents at the discretion of the senior staff. In practice this was infrequent. The lack of psychological support was identified as a significant problem:

When I got hit by a patient I cried....... Awful! I was so shocked. I was tucking this man into bed and he's just got his fist and just gone whack! Straight into my face. And all I could do was walk away and cry. I couldn't do anything about it I was so shocked. I'm not trained to deal with that.

(Kimberley, EN)

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One of the nurses raised the issue of debriefing which she felt was very important but was rarely offered. She had been working as a nurse for only two years and would have liked to have been more closely mentored and supported in her role:

> I think we really need with those violent and abusive behaviours, debriefing... We don't actually have that here as much as we should from managers really - support from managers like they will back you up. We need that. Just to know that you can go to them with this issue... not just like you've just got to cope, this is how it is. I know that we have to do it regardless of the situation but still, it's knowing ...that they understand and just help, even like ANUMs or whoever is in-charge, hands-on and I really think we need more de-briefing.
>
> (Poppy, EN)

These comments illustrate the importance of psychological support for the nurses and identify a significant shortfall in the present system. In the absence of assistance from the organisation, informal support was considered by the participants to be important in relation to coping with violent and aggressive behaviours.

The patient progress notes showed further illustrations of nurses not coping and not having the mechanism or support to cope:

> "Pt very uncooperative with any nursing interventions, rather verbally abusive and aggressive. Pt raised his voice at nursing staff while being assisted with toileting. Pt used inappropriate and rude words to nursing staff... Pt told nursing staff your job is to do what I 'Fxxx...' told you to do. Nursing staff has to leave the room for pt to calm down"
>
> (Progress notes, Ward E)

In all five wards, the nurses relied on their colleagues and sometimes their nurse manager for practical and emotional assistance. Teamwork between the nurses was very strong and many described the team as being like family to them. One of the nurses had previously lived nearby but had relocated to the other side of the city because of her husband's employment. She continued to drive 1.5 hours each way to work two days per week despite having a job at a similar hospital close to her new home because she valued the staff and culture.

Maybe the staff and the helping hand, the way it works, the organization, the way it is. You do your work, there are things to be attended to, there is a sense of responsibility but it's like ... I think from the NUM onwards it's a good feeling... They're very supportive! ... The staff are retained more. It's more like a family, yes.

(Alyssa, RN)

Camaraderie between the members of the nursing team was robust and there were displays of support and practical help between the nurses witnessed during the observation period. On one occasion a patient with dementia became acutely unwell with an exacerbation of a medical condition and needed to be moved to a bed closer to the nurses' station. One nurse helped her colleague to move the bed and care for the unwell patient while another nurse attended to the remaining four patients left in the bay (field notes, Site 1, Ward B).

A number of the nurses reported in the interviews that they supported each other in a practical sense by sharing the work-load or coming to help when there was a problem. In this hands-on way the nurses helped their colleagues, but equally important was the strength of the bond that they had built within the nursing team on that ward which gave them great satisfaction.

It's always been a really cohesive - I mean, things go wrong and all the rest of it, but people actually pull together and...Even if they were busy you'd only have to just say something and someone will be there.

(Carol, ANUM)

Karen (EN) expressed frustration that people with behavioural problems were sent to them without the additional support that was provided for the nurses in the acute hospital. The frustration was not only from a practical perspective but she considered that this practice demonstrated a moral injustice:

What I find the most frustrating of all is they empty them out of [the acute hospital] *and they send them here because we've got the code on the door and they can't escape and we're expected to deal with it. But where they've come from, they've had CPOs* [Continuous Patient Observers] *assigned to them, they've been drugged - they're under control - and they've just been waiting to be shipped to us. So they come to us all agitated, quite a falls risk and we're expected to be able to deal with them and it's very difficult.*

The nurses in this study particularly appreciated the support of their colleagues and nurse managers in the face of little support being evident from other sources.

> *You always help each other in here, that's why, that's what I like, yeah. Whatever you need you don't have to ah... you don't have to ask. Sometimes they just know you need this and do it for you... Working together is (satisfying) ... it's hard to find anywhere else, and once you find it, it's hard to leave.*
>
> (Ange, EN)

The nurse in the following quote was specifically referring to the support she got from her nursing colleagues after being hit by an aggressive patient. She was able to deal with the situation because she felt backed-up by her team from a psychological and a practical perspective:

> *I get staff support and when I talk the conversation I feel like after I talking then I feel better. It's better than you hold inside, yeah. And then you get support and you also get help. If you can't deal with this patient, maybe they do better.*
>
> (Lila, RN)

The lack of psychological support from the organisation and the teamwork of the nurses as a group shaped the way that the nurses viewed their work. The support in the workplace influenced the ability of the nurses to deliver quality care to the patients both from a practical and psychological perspective.

The nurses are run off their feet

Many of the nurses attributed the deficiencies in care to the busy workload. The researcher observed some very busy times on the wards which tended to occur mainly in the morning when the patients were waking, needing toileting, medication, breakfast and assistance with hygiene. Patients might also need to be prepared for appointments, therapy or discharge. Dealing with the patient with dementia who might be wandering or agitated was an additional challenge.

> *0830 The ward seems busy this morning. Nurses giving out medications, patients eating breakfast, a man calling out, pathology nurse collecting blood, IV pump is beeping, call bells ringing. Several patients have to be ready for early appointments. A*

couple of nurses have started showering their patients and seem very focused on
getting all the work done.

<div align="right">(Field notes, Ward C)</div>

The afternoons when there were more visitors and double staff tended to be quieter. After dinner in the evenings when all the patients needed to be prepared for bed could also be a very busy time, and this was sometimes complicated by patients with dementia becoming more confused and unsettled at this time of day. When there was not enough time to attend to everything that was required, the nurses prioritised their duties and the physical tasks generally got precedence. The busyness of the nurses was evident to some of the patients, and there were times when this impacted on the care provided:

> *The nurses are run off their feet. They're too busy. This is the first hospital I've been in where there are so many patients and the buzzers never stop going. This morning the next door neighbour had done poo everywhere and er, he was sent for therapy without being cleaned.*

<div align="right">(Larry, patient)</div>

Dementia added another layer of complexity to the nurses' day. Often, a patient with behavioural symptoms would require immediate attention which frequently took the nurse away from other duties. There were reported delays in care for patients who were docile and compliant.

> *You tend to just focus on that patient with the behavioural issue because you have to do more for them, and just leave the other patients for later. That means you have a back-log of things happening later... wound dressings or notes, or any other things you know. Hygiene - some of the patients get done really, really later. And of course, you're rushing.*

<div align="right">(Tina, RN)</div>

The afternoon was generally a quieter time in the wards. Often there was a smattering of visitors, and patients might be watching television or dozing in their chairs. On one ward the volunteers would take a small group to the patient lounge to play bingo, a board game or a group singing activity. In all the wards observed in this study, nurses could often be seen talking at the desk or updating the charts and progress notes. It was observed that this was a time that could

be spent chatting to the patients or doing activities with them however nurses were rarely observed talking to the patients except about practical matters:

> *1430: The patients are nearly all sitting in the chairs next to the beds. No-one has gone in or out of Bay 1 (5 beds) for more than an hour. Nurses are at the desk chatting and writing notes.*
>
> (Field notes, Ward A)

Being too busy to deliver patient care in an appropriate way was cited as a source of frustration and regret for some of the nurses. Rushing patients who were required to go to therapy or fit into a timetable which didn't suit them was identified as a clear trigger for aggression or resistance.

> *I think when they're rushed, I think that's what flips them out a little bit because they get anxious and they get really worked up because they feel like someone's yelling at them.*
>
> *(*Bethany, EN)

Comments from nurse participants about being too busy and rushing the patients were common, however few mentioned any strategies for overcoming this problem. Only one of the nurse participants mentioned refusing to comply with the ward timetable:

> *I'm not a task-focused nurse; I'm a holistic nurse. I look at what the person needs and that's what they get from me that day. If they need to have a sleep-in and not get up today then that's what they'll get from me. I'll say, "No, they're not going to physio."*
>
> (Rose, RN)

The power play evident in this quote was unusual in that most of the nurses observed in this study accepted the timetable set by the allied health staff without questioning it. Like Rose, Suzy (EN) could see that pushing the patients to conform to a schedule was counter-productive however she could not see that there was an alternative:

> *... I wish we could um give their care in a much slower paced way... because it's a production line now and that just increases their agitation. .. and they're confused and frightened and resistive and everything just ... it all just gets worse. So I don't know how you could improve on that really.*
>
> (Suzy, EN)

A competent nurse is expected to complete their assigned tasks in a certain time-frame. The desire to get the work done according to the nursing care plan was very strong:

> *If we could have a CPO* [Continuous Patient Observer] *to just take care of this person so we could get on with the job, it would be great.*

<div align="right">(Kimberley, EN)</div>

However this comment could also be interpreted to mean that the care of the person with dementia was a hindrance to getting the more important work done, and should be handled by someone less skilled such as a CPO.

This comment conveys a belief that the nurses feel that they are powerless to change the system that they could see was not working for the patients and nurses. The patients demonstrated that they were powerless to change the routine of the ward which in many instances was reported as being frustratingly boring.

It can be very hard to get them to let you do what you need to do

When nurses were describing their encounters with patients with dementia it was common for them to use language which expressed their desire to control or manage the person or their behaviour. There was a struggle between nurses and patients to maintain power.

> *Trying to get them to understand that we need to be able to do certain things for them can be challenging. They don't always accept that they're in a hospital or that they need something done. That can be very hard to get them to let you do what you need to do.*

<div align="right">(Karen, EN)</div>

Patients with dementia could disrupt the flow of the nurses' work because of unpredictable behaviour, the inability to wait in turn for attention and an incomplete understanding of what was happening. In contrast the nurses were focused on getting their work done in the most efficient and timely way. This can lead to frustration on the part of the nurses:

> *It's sort of hard - like you're looking after five patients and if that patient's kind of 'off' you know they're resistive and you can't look after the rest of the patients. You have to*

be one on one to that particular patient. Especially if you're, everyone is busy,
especially in the mornings some patients they start in the mornings first thing and we
can't start our work with the team. First routine in the morning start the medications
because you have to look after that patient first.

<div align="right">(Ada, RN)</div>

The field notes illustrated a small section of the ward routine:

> *The rhythm of the ward is very similar and very repetitive from day to day. At 12.00*
> *the patients are starting to eat their lunch, nurses are administering the tablets and a*
> *couple are writing notes. Not many visitors have arrived yet - they tend to come later.*
> *Everything looks the same as yesterday.*

<div align="right">(Field notes, Ward E)</div>

The patient progress notes included very few subjective comments, however very occasionally a nurse would write something which showed evidence of underlying frustration or the failure of the nurse to understand the cognitive complexities related to the patient's condition:

> *Patient declined personal hygiene assistance from nursing staff but then complaining*
> *and arguing that "I am doing your job etc". Patient very uncooperative with any*
> *nursing interventions, rather abusive manner...Patient used inappropriate and rude*
> *words to nursing staff. Nursing staff had to leave the room for the patient to calm*
> *down....Requested nursing staff to put on his shoes on his foot while he is laying on the*
> *bed when nursing staff asked him to be sitting up and the shoes can be fit to his foot.*
> *Patient told nurse "your job is to do what I f**ing told you to do"...*

<div align="right">(Progress notes, Ward C)</div>

A poor understanding of dementia and lack of empathy for a patient who was clearly struggling was demonstrated in this quote. The nurse unwittingly illustrated the power that she had over the patient as she attempted to justify her right to control the situation.

Medicate the patients

Nurses reported using medication to control patient behaviour, often as a first-line response but more often after other strategies were tried such as investigating the cause of agitation or distracting the patient with an activity. In the extract below the nurse considered that sedating medication was necessary in order to mitigate against possible undesirable behaviour:

Some medication is started at seven o'clock because if they found that the patient start getting aggressive or resistive or whatever, it's hard to look after. Seven o'clock, we start by giving medication at seven. We had one patient who just left here last week. First thing in the morning she takes off her clothes, and then walking without clothes and very aggressive hitting staff, so we have to give medication first in the morning at seven o'clock oral and if oral didn't work with that patient we had to give the injection and call the security.

<div align="right">(Ada, RN)</div>

The following quote illustrates the belief that patients with dementia should be sedated while they are in sub-acute care as a first-line strategy in order to exert control.

[What do we need?] *Probably doctors um doing some medications, medication-wise, medicating the patients.*

<div align="right">(Tina, RN)</div>

In a patient's progress notes a nurse documented that she had tricked a patient into taking a tablet in order to control their behaviour:

Try to give risperidone 0.5mg but patient refuses to take it. At 1330pm kept the tablet in-between sandwich and gave it to her. From 1400 patient was calmed down."

<div align="right">(Progress notes, Ward A)</div>

Some nurses were successful in averting a crisis without the use of medication by talking with the patient and endeavouring to find out the cause of the agitation and doing something about it where possible.

Usually just approaching them in a really calm way, reminding them who I am: "Remember me? I'm Margie, I'm your nurse today, is there anything I can do for you right now? Is it the toilet you want? Has something upset you? Can we phone a family member so you can have a chat?" I usually check with family members, too, when I get to know them…. It can be a settling thing just to chat to a daughter, a husband or wife, or whatever works.

<div align="right">(Margie, EN)</div>

The approach of the nurses towards patient behaviour is complex and dependent on a number of factors including the education and personality of the nurse and the situation being faced. The

following section will look briefly at Code Grey which is an extreme example of nurses exerting control over patients.

Call a code grey

The nurse participants spoke about occasions when the usual strategies for controlling patient behaviour, including the administration of medication, were unsuccessful and it was necessary to call in extra help. A Code Grey is a response to patient aggression when there is a personal threat. A team which includes security staff is called in to help physically restrain the patient often to enable intramuscular sedation to be given. Most nurses saw this as an extreme measure but others considered it to be a necessary treatment for aggressive patients.

> *We called a code grey because we call code greys here if needed...so security and about six or seven other people held her down so I could give her the injection and she just went for me and got her head out of the way and just, first of all, pinched me and then bit me.*
>
> (Lil, ANUM)

More commonly nurses considered calling a code grey to be the last resort, instead using their skills to talk the patient around or use other strategies instead:

> *We try to avoid codes for a whole lot of reasons, depending on the patient, because they all come - once it's called, a Code Grey, they come and pin them down, it's awful, bloody awful.*
>
> (Carol, ANUM)

'Resistive' was a term commonly used by nurses to describe patients who did not respond readily to the nurse's instructions. The 'resistive' patient in this excerpt was considered by the nurse to be the person with the problem, rather than the nurse:

> *Once they don't want to shower they are resistive. Then you will come back to shower them they are more aggressive... Even some of them demented they don't have any problem they are very good but sometimes they are resistive.*
>
> (Elsa, RN)

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Most of the nurses who mentioned patients being resistant to care spoke about the factors which may have contributed to the patient responding in this way. The patient behaviour was generally attributed to dementia without consideration to the part played by the nurses or the environment.

If it's too much, remove that patient: the use of space

The patients could often be controlled by positioning either where they could be more easily supervised, or manoeuvring the environment to prevent absconding or other forms of harm. All the wards in the study had locked entrances. Some of the patients in the older wards which were on upper floors found the locked doors very upsetting, and trying to get out was a preoccupation for them. For ambulant patients this was occasionally achieved by following visitors closely, but for others being in a locked ward could be distressing. The nurses accepted that the patients were kept confined for safety reason and in the main did not question these practices.

Benny had some mild expressive dysphasia and used gestures and non-verbal noises to augment his verbal response. He was desperate to get out of the ward but was prevented by the locked door:

> *Benny: Er, for me I hate this here. A passage goes out there ...er...You can't get out.*
> *Interviewer: You can't get out, no. So you'd like to be able to go outside?*
> *Benny: Oh! Would I?! Would I?!!!*
> *Interviewer: Have you been outside since you've come in?*
> *Benny: Yeah, yeah but you have to have someone.*
> *Interviewer: You have to have someone with you?*
> *Benny: Yeah.*
> *Interviewer: So you hardly ever go outside. Is that what you're saying?*
> *Benny: Well, this is it. (Laughs)*
> *Interviewer: So you pretty much stay in the ward?*
> *Benny: You have to! You can't get down you know.*
> *Interviewer: You'd like to go out more would you?*
> *Benny: OH!!! OH!!! (gesturing and making choking noises to express affirmation)*
>
> (Benny, Patient)

At times the nurses moved the patients whose behaviour was disturbing others. This was mainly the case in the older wards where the majority of the patients were in 5-bed rooms. There was an additional room in the ward with a further 5 beds which was generally empty for funding reasons, however at times a patient with noisy or intrusive behaviour was put there to protect the other patients. The TV room (patient lounge) was also a place where the nurses put agitated patients.

> *I have to think about the others also, but if it's too much I need to remove that patient …I have to talk to the NUM about changing beds yeah. But sometimes at night we put them in another room like the TV room, just so that the other patients can have a rest… Even if they are not talking they're just fluffing around.*
>
> <div align="right">(Anne, RN)</div>

The cognitively intact patients were often disturbed by agitated patients who were noisy and sometimes intrusive.

> *I spoke to a patient without dementia in a 5-bed bay where the nurses were attempting to pacify a lady who was screaming. The patient said that between this lady, another with dementia who was wandering all night, and the two others in the room who were quite sick, she had hardly slept at all.*
>
> <div align="right">(Field notes, Ward A)</div>

Surveillance and supervision were major considerations for the nurses and this was often linked to the use of space. Wards which enabled easy visual access to the patients were viewed favourably by the nurses despite other architectural inadequacies.

You don't have time to watch them all the time

Surveillance of the patients with dementia was a key issue raised by many of the nurses. Patients who were unable to remember or follow instructions might take unnecessary risks such as walking without a gait aid or leaving the ward unaccompanied. In order to maximise the visual supervision of at-risk patients the nurses reported using a number of different strategies.

> *I prefer the five-bed rooms with everyone together because some other patients they have fall risk as well and sometimes they might do something to themselves without calling the buzzer. If they're in the same room you can visual them altogether and*

someone tries to stand up from the chair you can go there straight away. If they're all in a different room you know you can't watch them all the time.

(Angel, RN)

The other issue was that someone who was wandering could leave the ward either intentionally in a quest to escape, or unintentionally when a visitor opened the ward door and the person wandered through it. A person with poor judgment and lack of insight could then become lost or come to harm:

You know you don't have time to watch them all the time, sometimes you know you look after your other patients and maybe just in that minute they … just goes somewhere… You know sometimes you feel like safety is the biggest issue for them. Like wanderers and they are not really steady and they have a fall and they might hurt themself.

(Lila, RN).

In the absence of extra staff, the nurses resorted to some creative ways to ensure that the restless patient with dementia was supervised while they got through their other duties. The care of the patient was seen to be limited to personal care and supervision. Issues beyond this were not considered by the nurses to be in their scope. The nurses had various strategies for distracting the patients from undesirable behaviour. These included getting the patient a cup of tea or something to eat, changing their location so that they had something new to look at, or giving them an activity such as folding washing:

Normally I try and give them something to do - a magazine, puzzle, cards; something to get their mind busy. Sometimes I give them things to fold - the ladies - they particularly like to fold washing but they do it so quickly!

(Bethany, EN)

Nurses reported enlisting the help of cognitively intact patients to watch the patients with dementia:

Someone who hasn't got dementia will look after them, yeah. But I always ask them - I say "when I'm not here keep an eye out for him and press the buzzer for me". Like if I'm gone to morning tea or I'm in the bathroom, and they do. They do that all the time.

(Kylie, EN)

However there were instances such as that reported by a nurse participant below in which a patient would report a problem that they had observed without being prompted by the nurse:

> *If they were high falls risk or they're at risk of self-harm it's handy having them in a room with other people especially if there is an alert patient who can report something... I have had patients say "oh she's just grabbed a knife" or something... or you know she's taken her tablets but pretended to swallow them and spat them out.*
>
> (Gary, EN)

Patients with dementia were often observed seated at the nurses' station with something to distract them. There were usually several staff in that area and the surveillance of the patient could be shared for a time as observed in the field notes:

> [Patient] *has just been wheeled to the nurses' station to sit with the ward clerk while the nurse attends to some other duties.* [Patient] *has been given a cup of tea and the newspaper to read. She is wheeled firmly against the desk so that she can't get out of the chair. The ward clerk says to the nurse "I'm going to tea in half an hour". The nurse responds "I'll be back by then. I just have to shower room 5".*
>
> (Field notes, Ward D)

One nurse said that when she needed to get things done and had no other suitable options she would sometimes put a patient with dementia in a wheelchair and take them with her as she did her work:

> *It's hard because you want to spend as much time with them as you can, but you can't be everywhere. Sometimes, if they're really bad, in that they're not going to stay still, I pop them in a wheelchair and just wheel them around with me, to each place - whatever I'm doing... because they're happy to be with you and you're constantly keeping an eye on them.*
>
> (Bethany, EN)

A patient safety issue raised by the nurses was that the patients with dementia can have trouble remembering and following instructions which was a particular problem for those who were unsteady on their feet and likely to fall:

> *I try not to care that I've repeated myself 1,000 times. "I've already told you" I hear people saying... Well, they don't remember you've already told them... I think people*

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don't get the short-term memory part of dementia. I think that's the main issue they don't understand - that people (with dementia) don't understand..."I've told you not to get up." Yes, that might be, but they don't remember you've told them not to get up.

(Ruth, RN)

Surveillance of the patients to prevent harm such as falls or absconding was a preoccupation for the nurses in this study. Some of the nurses spoke about having the best interests of the patients at heart, and demonstrated that they could closely watch the patients at the same time as providing empathetic care.

Once you start empathising you know what the patient wants

During the interviews both nurses and patients mentioned that certain nurses were more suitable for the role of caring for people in that setting than others. In three of the wards about a third of the nurses were internationally-trained, mostly from India and China. Due to the location of the hospital there were also a significant number of patients from non-English speaking backgrounds although they were more likely to be from Mediterranean countries. The cultural disparity was less evident in the remaining wards which were located in an outer metropolitan area. The nurses who were able to see each patient as an individual appeared to be the nurses most suitable for this role, notwithstanding any cultural differences.

The key skills and attributes described by the nurse participants include the ability to care therapeutically for someone regardless of their diagnosis; to have a well-developed sense of humanity and genuinely endeavour to do the best for the patient. One nurse described this quality as empathy:

It's empathy. Like how you verbalize or your actions, how you act. Ultimately the patients are human beings the same like us. The way you interact with the other person must change a lot. Once you start empathising you know what the patient wants from the patient's perspective.

(Alyssa, RN)

Another nurse spoke expressively about the empathy that she felt when she could see that a patient with dementia was frightened and confused. The nurse in this quote showed a maturity and kindness that was not evident in every nurse in the study.

> *I always kind of look at them thinking "It must be frightening for you". It must be more frightening for you than it is for us. And that every room looks the same and so if they do wander into the wrong room and sit on the wrong bed how frightening it is for the other patient but for them as well... So I think it's probably more frightening for them than us so I always try to be aware of that.*
>
> (Pam, EN)

Jane (RN) related a technique for managing a patient to avoid agitation. In this extract she is describing a kinder and more empathetic approach which not only calms the patient but allows them to feel heard:

> *More relaxed, more calm. Some people are really rushed and you know really want to finish their work and go and do the other patients, and I think if you spend a little bit more time with them, listen to them, be patient, listen to them, I think it makes a lot of difference.*
>
> (Jane, RN)

Having a family member with dementia had an influence on the attitude and insight of some of the nurses. Audrey (EN) felt that her experience with both her parents gave her a deeper understanding and more empathy towards the patients with dementia:

> *(The work) is satisfying. Doing something worthwhile, I suppose... I mean, if we don't look after them, who is going to? Lots of these people don't have anybody. Those that are lucky enough to have families, they cope with them as long as they can, and then they're brought to us... they have the right to be cared for. They've done their bit for society over the years and brought up families just like we have done. Mainly because of my family background, I know quite a bit about the devastating effects that dementia can have on people who are close to them. When you look at a patient and say that could be my mother or my father...*
>
> (Audrey, EN)

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The trauma experienced by Ruth (RN) and her family having a parent with dementia had had a positive effect on her work with patients, but it also sparked a professional interest in the condition.

> *My mum's got dementia, so I'm quite interested in dementia… She's now in care, and being a nurse it was really hard… but it's the best thing I ever did. She gets to talk to somebody every day, and we're not the only ones hearing the same story every day. So I think that gave me more of an insight into dementia; experiencing it… I find it a very interesting field because everyone's got a story. It doesn't matter how much their short-term memory is affecting their life, there's a story in there. People love to tell a story.*
>
> (Ruth, RN)

The nurses in this study who appeared to have an affinity for this work, both on observation and during interview, displayed maturity, empathy and kindness, however these qualities were not dependent on age, years of experience, ethnicity, gender or education of the nurse. The attitude of the nurses and their self-perceptions influenced the way they approached their work and the patients in their care.

I love working with old people

All the nurse participants were asked to talk about why they were working in a sub-acute care ward. The motivation ranged across the spectrum from those who sincerely cared about this patient group to others who were working there as an interim measure. The difference in attitude between the nurses was considerable and was central to the way that they approached patient care. Constructing a positive view of their work and their patients was a determinant of a positive relationship between the nurse and the patient.

Some of the nurses such as Christine appeared to have a genuine affinity with older people and really enjoyed her work. She had a positive, calm manner and was quietly spoken.

> *I love working with old people. I do, very much so, which is something that I developed when I was a PCA, and then I was working as a nurse in aged care…I love it here, because you've got hands-on with the patients, as well as doing their medication. You do their shower and you look after them. That's what I like.*
>
> (Christine, EN)

One of the nurses admitted that she actually didn't like caring for people with dementia, and demonstrated in her attitude that she was not suited to this role:

> *I think it would be very hard to look for a nurse that's going to be good with dementia, unless there's - some nurses might actually like working in that situation.*[Do you?] *No, I don't.*
>
> (Rose, RN)

Another nurse when asked about her motivation for working in that ward said that she was looking for alternative employment because she felt that she was losing her acute skills and was not challenged by the work in GEM. This nurse had a very blunt manner and there were some problems evident in her relationships with other staff.

> *Ah no I'm looking at the moment to move on...It's sub-acute and I've done my master's in you know education so I want to get back into that...this place is not challenging for me at all with like my training and stuff....and I feel like I'm losing those skills which I don't like so yeah...It's certainly not a long-term situation for me.*
>
> (Lil, ANUM)

Bethany cited the patient length of stay as a contributor to her job satisfaction and a motivator for her to work in that area. The patients in sub-acute care stay longer than those in acute care and consequently there is a greater opportunity for nurses to form a therapeutic relationship with the patients.

> *I think it's rewarding because you get to see them come in at their worst and leave at their best, and it's really good to see some that you think are never going to get home and they end up going home, which is good...you get to know them so much better than acute, where you're with them for maybe a couple of days and then they're discharged, whereas here we have them for a couple of weeks.*
>
> (Bethany, EN)

The expectations of the nurses shaped their attitude to the work and to the patients. Karen enjoyed the process of working with the patients over a period of time to achieve their rehabilitation goals.

I've always wanted to work in rehab. I did a lot of aged care work before I started here... I suppose my idea of rehab is you get your patients, you help them, and then they get better and - you're not just managing them; you're actually treating them and improving them, which - that's true for any hospital, but - I don't know. I've just always liked the idea of rehab. [How do you feel about looking after people with dementia?] *I actually enjoy it.*

<div align="right">(Karen, EN)</div>

Geography was the main reason several of the nurses said that they worked where they did. In Jane's case she applied for the job because of the location, but stayed because she enjoyed it. There were a number of other nurse participants who cited the location of the hospital as the main incentive for employment there.

It's only one kilometre [from home]. *I used to work in* [another hospital]*, so it's like 12 kilometres or something, you know. So my husband said when they opened a facility here to try. So really there wasn't any passion for sub-acute nursing only I applied because it was close to my house and I thought oh yeah I will go and see if I would like because I had never done any rehabilitation...Oh yeah I liked it very well.*

<div align="right">(Jane, RN)</div>

Nurses who came to Australia as immigrants were additionally motivated by securing a permanent position which may be a visa requirement for those entering Australia as foreign citizens. For internationally trained nurses there is intense competition for jobs in Australia when applying from overseas. Regrettably an enthusiasm for coming to this country does not ensure that the nurse is suitable for the role for which they have applied, although some of the internationally trained nurses demonstrated both attributes.

This is my first job in Australia...And I am living close to here. I have worked five years I am here. This is my first job in this country. [And what motivates you to work here?]. *I am living close to here, and er otherwise there is no special motivation for the rehab.*

<div align="right">*(Elsa, RN)*</div>

Differing levels of interest in caring for older people appeared to influence the satisfaction of the nurses working in these wards and were indicative of their suitability for this work. These quotes highlight the importance of employing nurses who have an affinity and interest in older people.

There were differing levels of commitment to the profession and the patients demonstrated in the interviews and the practices observed.

A major influence in the nurses' job satisfaction stemmed from the ward leadership and the teamwork between the nurses and their colleagues. Positive role models and a supportive environment were drivers of good practice.

Nurse leadership

Nurse leadership was identified as an important motivator for nurses working in the wards in this study. The participants viewed the Nurse Unit Manager (NUM) as a source of knowledge, and on a practical level was a person who could influence the resources and support that were provided. The personality and leadership qualities of the NUM shaped the culture of the ward.

From the NUM onwards it's a good feeling

Nurse Unit Managers (NUMs) who were engaged with and available to the nurses were highly regarded by the participants and were a determinant of a positive ward culture. In two of the wards in this study, the participants reported that the NUM was a strong leader and a valuable supporter of the nurses; factors which shaped the satisfaction of the team in that ward.

> *...this is the best place.... I think from the NUM onwards it's a good feeling.*
>
> (Alyssa, RN)

Feeling supported by their manager was vital for the nurses from both a practical and emotional perspective. In one of the wards, several nurses talked about the positive example and support they received from the nurse manager. Knowing that their efforts were noticed, understood and appreciated was important for job satisfaction and helped the nurses to cope with challenging situations:

> *Very friendly staff and especially the unit manager she is excellent. She is very*
> *approachable. Like you know you can tell her what's your problems and I think not*

betray our trust, very patient, very friendly. Thank God this is the best manager I've ever come across.

<div align="right">(Jane, RN)</div>

In the face of very limited debriefing and formal psychological support, the nurses relied on their colleagues and the NUM to fill this gap. Certain attributes including the willingness to listen and takes steps to address the identified problems were highly regarded by the nurses. The following quote is an example of the material support that the NUM could provide when the nurses were stretched:

Getting the okay for specials or extra staff, I think it can be a bit challenging. I never personally have to deal with it, like to have a conversation, so I don't always know exactly how it all pans out. But I don't think they realise [the increase in acuity] - *So we've told our boss. She was going to see if she could get the OK. I'll let you know later.*

<div align="right">(Margie, EN)</div>

In one ward the NUM actually provided some hands-on care to the patients at times, although only one nurse participant mentioned this type of assistance:

If you need help he will come straight away. He doesn't stay in his office, he stay on the floor especially if we have demented patients he will help. Even first thing in the morning he come and shower a patient. The demented, especially the demented one that are hard to look after.

<div align="right">(Ada, RN)</div>

The Associate Nurse Unit Manager (ANUM) in-charge of a shift played an important role in the supervision of the patients when there was no funding to pay for extra staff. The teamwork on a shift included all the nurses and it was a shared venture to ensure that all the patients were cared-for and safe. The nurse in the quote below is describing how they managed a patient with dementia who needed constant supervision:

Usually it's the in-charge that will distract them for a little while, while we can do other things. But usually it's - like, we'll have ten patients between us and we'll just team them in and out. So we rarely get a special - I've been here six years and I reckon three times they've got somebody in to special.

<div align="right">(Kimberley, EN)</div>

The field notes also reflected the nurses' comments on teamwork:

> *The nurses appear quick to help each other out when there is a problem.* [Patient] *deteriorated suddenly this morning. Two nurses came to help. One assisted with moving him to another room and organise meds and equipment. One stayed with the other patients in the bay and kept an eye on them while their nurse was busy.*
>
> <div align="right">(Field notes, Ward A)</div>

The nurse leadership of the wards and the support of colleagues were important determinants of the nurses' job satisfaction and had a strong influence on the attitude of the staff to the patients.

You can't be there all the time, so we take turns

The wards in this study handled the allocation of patients to nurses and the workflow in similar but subtly different ways. Three of the wards used team nursing with two nurses in each team. In the newest ward that had a majority of single rooms off long corridors, the patients who required the most intensive surveillance or care were positioned in the rooms closest to the staff station, and one team cared for these patients. There were fewer patients in this group than in the areas where the patients were less dependent. In the older wards where the patients were in 5-bed rooms, a single nurse was allocated to each room. In the afternoons these nurses also cared for an additional patient in a single room.

In some cases, nurses rearranged the workflow so that a patient who required a high level of monitoring had more nurses working in the vicinity.

> *We configure our staff - it's not necessarily always possible, but sometimes we can reconfigure it so that three people will work one end where this person who needs constant observation is. So instead of having two people watching them there's three people watching them. It doesn't necessarily mean to say it's going to stop incidents anyway, but at least you might have more of a chance.*
>
> <div align="right">(Carol, ANUM)</div>

Another strategy the nurses used was to ask a colleague to watch the patients while they completed a task such as a medication round or showering a patient. This was also a

demonstration of the teamwork which was evident in times of stress and that was so highly valued by the nurse participants in this study.

> *You can't be there all the time, so we take turn. I look after this four for maybe 15 minutes and then you do your medication. When you finish your medication, you come take over I do something else. We work at that... you know because we understand how bad the situation is but sometimes we couldn't get enough help from the management from hospital.*
>
> (Lila, ANUM)

The allocation of the patients to the nurses was done at the beginning of the shift by the on-coming ANUM. There was often some negotiation with the nurses in regard to preferences, and discussion about the requirements of the ward with the out-going ANUM. The nurses at times came to the assistance of a nursing colleague who was struggling to cope with a specific patient and took over some of the duties:

> *And I always say to people if they've got a bay with a particularly difficult patient there, and they might have been in that bay for a few days, I might say to them "I'll pick up that patient, you do one of mine... Like if we just take it all in turns so you're not getting frustrated with it and you can sort of share the load like that.*
>
> (Pam, EN)

Teamwork was less evident in the newer ward with mainly single rooms, and the nurses complained about being isolated and not being able to access their colleagues for help when required.

> *For the staff, for the nurses* [the single rooms] *not good. Because the way they structured the building you can't see the other side. It's very long. You can't see - if you are looking after one patient in 44 or 45... some patients they need two staff, so they are engaged so you can't know what is going on there sometimes...* [the nurses are] *isolated.*
>
> (Elsa, RN)

The NUM in this ward was less available to the nurses for a number of reasons. This was partly due to an increase in duties with 38 beds in this ward in comparison to 24 beds in some of the other wards.

Teamwork and the support and camaraderie of colleagues was a strong motivator for the nurses working in these wards. For some the nature of the team was more important than the type of work or diagnosis of the patients.

> *I like nursing so I like working with people and that sort of thing, but the team is a very supportive team. It's the best I've - in 40 years, it's the best place I've worked.*
>
> (Carmel, ANUM)

Many if the nurses in this study had strong principles of care and appeared to genuinely strive to deliver quality care to their patients, however there were some differing levels of commitment to the sub-acute environment and to people with dementia. The picture that was created was of strong teams working in often difficult circumstance with less support than they required. The nurses did not recognize that they had any power in the organization, and in general they accepted the status quo without question.

In summary, the nurse participants in this study reported that they felt under-prepared educationally for caring for patients with dementia, and there was a lack of material and psychological support from the hospital administration. A positive contributor to job satisfaction was teamwork and the nurse leadership in the wards, although being unable to adequately address all their duties on a shift caused anxiety in some of the nurses. A number of the participants said that they enjoyed working in that environment and found satisfaction in caring for people with dementia despite the obstacles.

Theme 3: The influence of hospital priorities on care practices

The third theme identified the influences that the hospital priorities of budgetary restraint, risk mitigation, and maximising patient throughput has had on the care of patients. Despite the hospital documents and ward posters espousing person-centred care, this was not consistently reflected in the culture of the wards.

The focus is on turnover

Certain elements of the organisation restricted the ability of the nurses to provide the quality person-centred care that was expounded in the values statements of the organisations, and in posters displayed in the wards. Increasing the nurses' workload and decreasing the support provided to them defined the nursing environment and influenced the culture of care.

> *Time and resources and the general day to day running of the ward - what's expected of us... And the frustrating thing is the reporting system takes up the nurses time which could be well spent with the patients...reports, incident reports... when you could be making an extra cup of tea for somebody and spending extra time feeding somebody.*
>
> (Mandy, ANUM)

A major concern of the wards in this study was minimising the patient length of stay and maximising turnover in order to optimise the use of the beds and meet occupancy targets. This was greatly apparent in the handover between the morning Associate Nurse Unit Manager (ANUM) and the allied health staff. This meeting focused almost exclusively on the expected discharge date of each patient and the tasks which needed to be completed before this time. The nurses were also aware of this culture of prioritising discharge planning but some could see the effect it was having on the patients with dementia:

> *The focus is on turnover - get 'em in, get 'em out. But these patients need a lot of attention ...*
>
> (Mandy, ANUM)

The same nurse participant also noticed an over-emphasis by the allied health staff on discharge planning at the expense of other priorities. In this instance the nurse was pointing out that aside

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from working towards discharge, very little therapy occurred. For the person with dementia this could ideally include physiotherapy to improve strength and endurance, prevent deconditioning and alleviate boredom:

> *We have OT* [occupational therapy] *and we have physio* [physiotherapy] *and everyone does a good job but there could be a bit more not just concentrating on discharge planning but a better time while they're here in the ward.*
>
> (Mandy, ANUM)

Faster patient turnover has had an additional consequence noted by nurse participants: The drop in the length of stay in recent years had had an effect on the relationship between the nurses and the patients. One remarked that in some cases, the nurses and patients hardly got to know each other before discharge leaving very little time for a therapeutic relationship to develop.

> *Well, I used to like you know when you see the patients get better and they'd go home. And you used to be able to spend a bit more time with them and they used to be here longer so you had a bit more of a relationship with them... now they're really pushing for people to get out a lot quicker.*
>
> (Maree, RN)

The field notes reflected the attitude that the staff were focused on the outcomes rather than the individual patients:

> *It's all about 'getting through'. The nurses are focused on getting the work done, completing what is required on the NCP* [nursing care plan] *patients showered, medicated, beds made, paperwork done. For allied health and medical staff it's all about getting the patients treated and out.*
>
> (Field notes/ reflections, Ward C)

One nurse commented on what she saw as a lack of caring in the attitude of the organisation which dictated that they must discharge patients who have reached their rehabilitation goals but for whom there were obvious risks:

> *And now because of the budgetary constraints, I guess well it's just like that's just not our problem. If they're going home ... like with* [patient name]... *there's no-one to supervise her, an outside toilet, no heating, leaking roof, it's not our problem because*

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physically she's OK. Yeah, so that's hard to watch when you see some people going home that you think wow that's just a nightmare waiting to happen.

<div align="right">(Pam, EN)</div>

This remark conveyed the belief that the focus of the clinical team had narrowed to only include addressing the issues directly related to the admission diagnosis. Co-morbidities and social problems were often discounted as out of their direct scope of interest.

One of the patient participants understood that the doctors were not interested in her multiple problems, but were singularly intent on addressing only the acute condition that lead to her admission - her painful, swollen knee:

... and there's a routine they follow, and that disposes of the immediate responsibility. It's complex, but [the doctors], *they're only about the knee.*

<div align="right">(Harriet, patient)</div>

One of the patient participants commented that the role of the nurse had changed and that there was a greater emphasis on paperwork than there used to be. He noticed that the priorities of the nurses had shifted to a business-based model.

Well er, it's the first time I've been in hospital where it's work to a criteria of er quality control... Actually I liken it to the way they do things here are similar to er standards criteria, how to run a business. .. times have changed where nursing was nursing and now it's about er the percentage of the day is nursing and er putting procedures in place, adding data so one doctor will have a group of nurses all cross- referencing down on paper etc etc. And so the doctor can er read the notes after and then make a decision on whatever the patient's needs might be.

<div align="right">(Arthur, patient)</div>

Nurses stated that the recent increase in the paperwork and reports required in sub-acute care impinged on the time available for patient care and had changed the nature of their work:

The reporting system takes up the nurses' time which could be well spent with the patients...the reports, incident reports when you could be making an extra cup of tea for somebody and spending extra time feeding somebody...

<div align="right">(Mandy, ANUM)</div>

Documentation including audits, incident reports and risk assessments took up a considerable amount of time in the nurses' day. Ensuring that the paperwork was completed was a priority because it was evidence that the work had been done, as one of the nurses commented:

> [If you are caught up with a patient with dementia] *it's the paperwork that has to be left, and then it looks like you haven't done your job.*
>
> (Kara, EN)

One of the Nurse Unit Managers complained to the researcher that her day was overloaded by attending meetings, managing the budget and recording compliance, leaving very little time to do the parts of the role she considered more important such as clinical and staff management. In the field notes it was recorded that she rushed back to the ward and headed straight to do an audit:

> *The NUM returned to the ward in a rush. She was about to start an audit of a nurse's shift. This had to be done 3 monthly, 'shadowing' nurses and timing/ documenting all activities and tasks. The NUM looked tired and cynical.*
>
> (Field notes, Ward E).

The priorities of the health service were demonstrated by the emphasis on audits and compliance. Further to this, admitting acutely unwell patients to these facilities has had an effect on care practices.

IVs and MET calls interfere with basic care

The nurses in this study reported that the acuity of the patients in sub-acute care was rapidly escalating and had changed the focus of care over time. Several years previously the patients admitted to these wards would have been medically stable and ready for rehabilitation or geriatric evaluation and management, however now many are still acutely unwell and require a different type of care from the nurses. The biomedical focus has been more evident with the influx of sicker patients. The opposing force of these different priorities created a tension in the goals of care and was especially felt by the nurses.

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It's getting a lot busier. The type of patients we're getting. They're getting older, they're getting frailer, and they're getting more and more dementia...we are getting more medical problems...When I first came to this ward, it was just an amputee ward and it was lovely, great ward. But over the last seven or eight years, it has changed. All the girls will tell you how, now, it's just got really busy. At times, it can be really heavy.

(Audrey, EN)

The researcher observed that the needs of other patients were often prioritised ahead of those of patients with dementia. It was implied by some nurse participants that the people with dementia were taking up valuable space and time which could be devoted to others more deserving. Patients with dementia were commonly treated in the Geriatric Evaluation and Management (GEM) stream rather than rehabilitation stream because of the longer length of stay and generally slower progress:

We used to have more rehab patients and now we've got more GEM patients I think. We are at times taken away on other things. [The problem is] *mixing up the GEM patients with dementia with the rehab patients... I mean just our patients, they're more medically unstable, they're more ... you've got to spend more time doing IVs and all this that takes your time away from that...*

(Maree, RN)

The nursing entries in the progress notes reflected the nurses' focus on biomedical health issues, with the majority written in a style which used the body systems as minor headings under which patient condition was reported. In this way, the nurse commented on cardiovascular, gastrointestinal, renal, neurological, endocrine systems and patient activity following a medical model of cure rather than a nursing model of care. An example of this follows:

(Date) NURSING AM: Condition satisfactory. CVS: Obs P 84, R 20, BP 135/90, GIT: Input satisfactory, tolerating FWD and FF. Urinary output good, BNO. Endocrine: Blood sugar 6.2 mmol/l @11.30. Activity: Ambulating well with assistance, Skin: intact_____(signature of nurse).

(Progress notes, Ward C)

In most cases the nurses wrote very brief and factual entries, mainly describing the tasks that had been undertaken during that shift and any changes in the patient's physical condition, illustrating the prioritisation of physical care over psychosocial concerns. Stock phrases such as

'Care delivered as per NCP. No complaints voiced' (Progress notes, Ward B) were common. Patients were sometimes labelled as 'pleasantly confused', 'vague at times' or 'resistive to care'. Very little was written about psychosocial issues, and much of it lacked meaning.

Another style used in the nursing progress notes was a type of short-hand to describe the activities on the shift. Most nurses assumed a professional detached tone and reported only the things that were quantifiable further emphasising the medical model of care. An example of this is as follows:

> *(Date) NURSING AM: Pt* [patient] *A* [alert] *& confused, vital signs stable, pt afebrile, all medications given as charted, nil c/o pain, patient on behaviour chart, nil behavioural issues this shift, visual obs* [observations] */clothing chart, amb* [ambulating] *indep* [independently] *nil aids, FWD* [full ward diet] *and FF* [free fluids]*, good oral intake this shift, assist with shower minimal, continent, PUIT,* [patient urinated in toilet] *pad in situ, RIB* [resting in bed] *and SOOB* [sat out of bed] *this shift, skin intact, all care given as per NCP* [nursing care plan]*, nil further issues @ TOR* [at time of report]_____*(signature of nurse).*
>
> <div align="right">(Progress notes, Ward E)</div>

Documentation in the patient progress notes is important, but in general the nursing entries did not include important issues such as the decisions under consideration, progress on the discharge plan, or referrals for further support, instead focussing almost entirely on the patient's physical activities on the shift.

Specials allow you to still care for the other patients

The increasingly tight budget has had a detrimental effect on the staffing levels in the wards. Almost every nurse participant mentioned extra staff in the form of 'specials' or 'continuous patient observers' (CPOs) as part of the answer to the problem of managing a person with behavioural symptoms at the same time as getting the other work done, but this rarely happened:

Specials allow you to still care for the other patients. It's them who miss out if you've got the difficult patient. Otherwise, you're caught up for 80 percent of your shift, and the others get scant

<div align="right">(Kara, EN)</div>

Employing a special, a CPO, or a non-nurse staff member assigned to spend the shift observing the patient, allowed the nurses to continue working with the other patients, knowing that the person with dementia was safe. Approval for extra staff to help manage patients with behavioural symptoms was rarely granted for budgetary reasons and none were employed during the observation period of this study. In the face of unpredictable behaviour, the nurses reported feeling powerless to satisfy all the patient requirements, but used other strategies to optimise the supervision of patients.

Usually, it's the in-charge that will distract them for a little while, while we can do other things. But usually, it's - like, we'll have ten patients between us and we'll just team them in and out. So we rarely get a special - I've been here six years and I reckon three times they've got somebody in to special. It's just not on. It's just too hard. They won't spend the money.

<div align="right">(Ruth, RN)</div>

There were no specials or CPOs on this shifts observed by the researcher, however the nurses reported that on the rare occasion that one was provided to assist with a patient with behavioural problems, there were issues raised about the quality of the care provided. Nurses reported that the extra staff member in some instances had sat in the patient's room reading a magazine or watching television while the patient slept (rather than helping out with the bed-making as the nurse participant suggested) or shadowed the patient while they ambulated, invading their personal space and causing agitation where none previously existed. If the patient was aggressive the extra staff member did not have the skills to de-escalate the situation:

The problem I find with someone who they get in to special, often they are like a PCA [personal care attendant] *or an enrolled nurse who just sits on a chair and pretty much watches the patient. But when the behaviours start they don't know how to deal with them because they don't know them, so then you've got to do it anyway.*

<div align="right">(Margie, EN)</div>

Similarly other proposals including 'rounding' were rejected by the nurses as another example of the administration being out of touch with reality. Rounding was an initiative in which nurses were instructed to check each patient hourly to ensure that they were safe and had everything they needed, the rationale being that patients were less likely to get out of their chairs unaccompanied if they were settled.

> *We had this thing the other day that if we did rounding then people wouldn't fall over. Well, we do rounding and people fall over as soon as you walk out of the door. If someone can't remember something, they're not going to remember just because you were right there…*
>
> (Carol, ANUM)

The tone used by the nurse suggested that she was scornful of the suggestion that a rounding initiative could take the place of providing adequate staffing ratios.

The buildings

The behaviour of patients and nurses was controlled to an extent by their environment. During the observation period in the five wards, it was clear that nursing practices varied significantly in response to the ward architecture. As explained earlier the five wards were of varying size and style. The nurses almost universally preferred working in the shared rooms rather than the single rooms because having the patients all together made it easier for them to supervise.

I like being able to see all my patients

In the 5-bed glass-fronted rooms the nurses could monitor what the patients were doing and if anyone had stood up from their chair. There was also a certain sense of camaraderie in these rooms at times among the five patients and the nurse.

> *I'm old-fashioned! I like to eyeball my five patients and I can see them all. And they do look out for each other and they do talk to each other, yeah.*
>
> (Pam, EN)

By referring to herself as old-fashioned the nurse participant in this quote was alluding to the more recently built modern wards on the same site in which the patients are mainly accommodated in single rooms. Single rooms are an advantage from the perspective of infection

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control and privacy; however the opportunities for patient surveillance were greatly reduced. In the progress notes it was observed that the nurses in the new ward that had mostly single rooms and the most beds (38) found it a difficult place to work:

> *The ANUM in-charge of the shift complained to the researcher about the ward layout. She said it was very hard to keep an eye on all the patients, and the nurse working down the end feels that she is working alone.*
>
> (Field notes, Ward C)

In a 5-bed room a nurse was observed by the researcher to be having a joke with her five patients about the continental pastries in a nearby cake shop. It was a very light-hearted conversation and showed a sense of fun and connection between the nurse and the patients.

> *Sinead and her five female patients were having a laugh about eating cakes and pastries from the cake shop in* [nearby suburb]. *Sinead was trying to guess which ones each patient would like the best. They were all laughing, even one lady who did not speak English.*
>
> (Field notes, Ward B)

Sinead commented that she liked the shared room from a practical perspective because she could base herself in the room for the shift and be present for all her patients:

> *If you have everyone in a single room you could be stuck doing, helping someone for half an hour and you can't see all your other patients whereas everyone's together and you're constantly in there I think it's good personally. I understand from a patient's perspective maybe the privacy's a little restricted but nursing I quite like having a bay and being able to see all my patients all the time. You know I sit there and write my notes and have a chat with them and yeah.*
>
> (Sinead, EN)

There was a mixed response from patients about the shared and single rooms. Some appeared to be quite happy with what they had and didn't question the issue to any extent; others had stronger opinions. This was largely to do with the personalities involved:

> *I don't get along with her* [co-patient] *at all. I think something happened earlier in the piece, and I think I did something - I've no idea what - to put my foot in it... I'm not saying I want to know her business, but it would be nice to be compatible.*

None of the patients in mixed gender rooms commented on this. The majority of the patients interviewed didn't mind sharing as long as the other people were not noisy or intrusive. There were examples such as Cecily and her female room-mate who got on extremely well:

> [Room-mate] *treats me like I'm her mother. She brought me a coffee this morning. I don't mind sharing with* [room-mate] *no. Good mate.*
>
> (Cecilia, patient)

Like Esme, Lex was not so happy about the arrangements. He accepted the room allocation despite private objections, although he was relieved when the situation was changed.

> *I was in a room sharing it with this chap I came up with in the ambulance from* [acute hospital] *and he was a real funny sort of fellow. He was deaf as a post and yet he was complaining about the noise on the telly. He had a hearing aid! So he wouldn't take no for an answer on anything like that so...I didn't get on with him at all. So then I got shifted out which was a good thing for me.*
>
> (Lex, patient)

These quotes highlighted the powerlessness of the patients in the ward environment who were accommodated almost randomly in a room with other people with whom they may or may not be compatible. The following section looks further at the use of space and how this influences and intensifies power relationships.

The ward layout influences nursing work

The layout of the wards influenced the way that the nurses organised their work. The older-style wards on the first site had the problem of having very few doors, and the doors at the entrance to the pan room and the kitchen were always open and easily accessible to wandering patients. Entrenched practices meant that the doors were left open despite the obvious disadvantage. The central staff station was completely exposed to patients and visitors, making paperwork confidentiality an issue.

We've had quite a few patients who you know been able to grab things because there's no doors, doors that are unlocked...Having worked in a psych ward I know that the kitchen used to be locked and you couldn't get into the kitchen if you wanted to whereas here they can get into... and there are sharps and ...we've had quite a few patients that grab patient histories and you have to try and stop them especially if it's somebody else's patient history.

(Gary, EN).

The patient names were written on a mobile whiteboard in the main desk with other details such as admission date, expected discharge date, name of doctor and allied health staff assigned to their case, and some other procedural check boxes. The whiteboard was wheeled into the patient lounge for team meetings; otherwise it remained at the desk in view of anyone who cared to look.

The staff faced some obvious challenges with the floor plan of this ward; however there were practices which could have been changed to improve patient safety and the confidentiality of information. Entrenched habit meant that the nurses did not challenge these practices.

The third ward was recently built and completely different in style. All of the patient rooms were single or double rooms with their own en-suite bathrooms. The rooms were all mixed gender when necessary. The design was very spacious, and there were complaints from the nurses about the lack of visibility of both the patients and other nurses when help was needed. In this ward, it was more unusual to see nurses at the desk.

The nurses reported that despite the improved conditions for the patients in this ward layout, the nurses did not find it a good place to work:

The patients are happy with the single room because sometimes they are complaining "Oh I can't use the toilet because of the patient sharing", but for the nurses it's not good. Because the way they structured the building you can't see the other side. It's very long. If you are looking after one patient in 44 or 45...you can't know what is going on up there sometimes. The nurses feel isolated.

(Elsa, RN)

In one of the wards which had a keypad entrance, there was an additional locked area containing four beds and a small sitting room (which was not used during the data collection period for maintenance reasons). Patients who were likely to abscond or who had behavioural symptoms were housed in this area; however the small space and the locked door was an additional source of aggravation for the patients.

> *It's usually they are very much at risk of falling and getting lost so patients with dementia are usually in the 4-bedded room in the locked-up area. That's the basic thing that we do to prevent falls...Some of them don't cope well...mostly they're looking for a way to get out.*
>
> (Alyssa, RN)

As a strategy for behaviour management, the small locked section was questionable and served in some instances to augment the problems. The patient in the following quote was more agitated when confined in the small space. The nurse participant did not question the efficacy of this strategy despite its obvious shortcomings.

> *I had one gentleman - he was in our locked-up section, and it had to be locked because he was trying to get out all the time. I actually found that that agitated him more, because he was in such a small, confined space. At least when he was locked in the ward he could walk around a whole ward, but when he was in that tiny, little space - and you just couldn't reason with him. He tried to (hit me). He tried with the frame... He was going for it. With him, we'd back away, leave him to do his thing, because he couldn't get out, and then come back in a little while and hope that he'd settled down.*
>
> (Bethany, EN)

In the two remaining wards there was a mixture of single, double and a few four-bed bays with some of the bathrooms shared and mixed gender. The nurses did paperwork or chatted in small nurses' stations positioned in the corridors, mainly in the middle of the day when the morning work was done. These spread-out wards relied more heavily on chair alarms as patient surveillance.

A major problem in the older wards on both sites was lack of storage and meeting rooms. In practice this meant that the corridors and patient lounge were used to store equipment and there was very little privacy for patient interviews. This was noted in the field notes:

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> *The ward is very cramped and chaotic. There are obstacles everywhere in the corridors as there is not enough storage. The main lounge area is full of wheelchairs, IV pumps, WOWs (work stations on wheels). I have seen nurse education sessions, staff writing notes and volunteers and groups* [in the lounge area]*, but not really patients lounging.*
>
> (Field notes, Ward D)

The lack of meeting rooms meant that it was difficult to find a private space in which to conduct patient interviews for this study, especially when the weather was wet:

> *...the biggest problem was that I couldn't find a quiet space to talk to* [the patient]*. She shares a room with another patient; the dining room was busy, raining outside, OT area busy ... so we ended up in the corridor outside the ward. I faced the patient towards me and the window to minimise the distraction of people walking past...*
>
> (Field notes, Ward D)

More concerning was the lack of private space for the staff to have confidential conversations with the patients. This was even more problematic in the shared rooms in the older wards where the patient beds were close together and there was no alternative space for the interview to occur:

> *...The OT told me that he often had to conduct interviews with patients about private matters within earshot of others because there is no other space.*
>
> (Field notes, Ward D).

The layout of the wards had a significant effect on patient care and to a certain extent defined the culture of care in these wards. The proximity of the patients to the nurses and the provision of amenities such as bathrooms, private spaces and outdoor areas shaped the experience of both the patients and the nurses.

Our philosophy

Both health services displayed posters announcing the intention to deliver quality care to all patients. The objective of the health services was to encourage person-centred care; however this was not entirely successful as demonstrated by observed practices which did not align with the stated aims.

Person-centred care should govern care

In one ward, there was a framed declaration which read:

> *"Our philosophy is to provide high-quality care to individual patients. Our objectives are aimed at assisting patients to achieve their maximum level of independence whilst maintaining safety, dignity and the rights of the individual".*

(Observation, Ward B)

On another ward there was a poster displayed which outlined the 10 patient experiences of care principles:

1. *The patient's needs, wants, preferences and values are known and taken into account.*
2. *The patient is a partner in decision-making about their care.*
3. *The patient has access to safe, effective and high-quality health care delivered by skilled staff.*
4. *There is clear information that helps patients understand and manage their health as independently as possible.*
5. *Communication is open, honest and respectful, ensures confidentiality and is responsive to individual needs.*
6. *The physical environment promotes healing, is comfortable, clean, safe and allows privacy.*
7. *Staff listen, provide emotional support, and treat patients, their families and carers with dignity and compassion.*
8. *Family and friends are involved in care in accordance with the wishes of the patient.*
9. *Care is well co-ordinated to ensure that the patient experiences continuity and smooth transitions.*
10. *Meals are enjoyable and nutritious*

(Observation, Ward D)

Nurses demonstrated in some instances that they disregarded principles 1 and 2 above by using a domineering manner to push the patients to comply with their wishes. One of the nurse participants said that she found some of the patient behaviour annoying:

...when they're very, very confused and wandering as well you know even if they're not aggressive like that can get quite annoying at times because you know like they're just wandering around and you're busy with so many other things and you have to keep taking this patient back to their room.

(Lil, ANUM)

Similarly it was noted that a number of the principles were disregarded in an encounter recorded in the field notes. Two nurses in the nurses' station were discussing a patient's behaviour which was being described as difficult. One said forcefully *"tell her she'll get what she's given!"* (Field notes, Ward E).

There was an example in the progress notes which showed a nurse's failure to comply with principle 7 when a patient did not adhere to the desired behaviour. This comment conveyed a sense of the power imbalance between the nurse and the patient. The nurse was reporting an occasion where she had a disagreement with a patient, but she was insinuating that it was the fault of the patient and not her own performance which was to blame:

> *Language is not inappropriate if pt is 'managed' by staff but often the 'smallest thing' can set the pt off e.g. pt was set up in bathroom for a sponge but pt complained loudly that the nurse had not filled the water bowl...Patient has no understanding of medical condition she has or what caused her to be in hospital. If the staff ask the pt that question she becomes teary and cannot respond.*

(Progress notes, Ward D)

Notably most patients reported that they liked the nurses, but none said that there was any significant interaction with them except for that based on function. The nurses were pleasant but busy and did not engage on a deeper level with the patients.

> *The nurses beautiful for me...They ask "How are you?" Enough.* [Do they talk to you?] *Yes but no all the time. Sometime in the morning, sometime in the afternoon, depend on the time they have.*

(Angelique, patient)

Despite the emphasis on person-centred care principles displayed on the hospital documents; in practice they were not prioritised. This may be because person- centred care is difficult to

measure and does not relate directly to performance targets. Targets related to patient length of stay and the management of risks may be more important to hospital administrators.

Just try and keep them safe

The nurses were instructed by the hospital management to place a high priority on the prevention of falls and other risks, however the nurse participants felt that there was considerable disparity between the expectations and the practical implications. Despite agreeing that preventing falls was a worthy aim there was some cynicism expressed about the lack of funding available to increase staff to provide adequate surveillance of high-risk patients:

> *My first priority is just to try and keep them safe. Falls - that's the big worry for all the nurses - they fall. There's a big organisational push to minimise falls and if they deteriorate everything's due to poor practice. On most occasions you need the extra numbers to give these people the supervision they need.*
>
> (Mandy, ANUM)

The sense of prioritising risk mitigation ahead of other more caring practices was communicated to at least one of the patient participants who mentioned this during the interview. She felt that the nurses helped her in the shower, not because they were kind and caring, but because they feared the negative consequences for themselves if she fell:

> *Well, they have to help me in the shower because of my walking. I represent, a person like me - elderly and with a bad knee - a potentially very destructive experience...it's not just the risk to me but the risk to themselves, a risk to the organisation.*
>
> (Harriet, patient)

In the newest ward with mostly single rooms there was a preoccupation with falls prevention. The increased vigilance was because the falls statistics for that ward had been consistently higher than for the other wards. The focus was demonstrated by the posters displayed on the notice boards showing graphs of the number of falls, and falls with harm for the months and the year to date. The nurses working in teams took it in turns to do medication rounds to ensure that one nurse was available at all times to watch the patients.

One of the older wards had a fledgling volunteer program that was just beginning to be introduced specifically to monitor patients with a high risk of falls. The volunteers were doing activities to keep the patients occupied, not to maintain cognitive strength or alleviate boredom, but specifically to prevent falls:

> *We're trialling volunteers at the moment for falls prevention, trying to kind of get the high falls risk people all together. Keep them occupied so they don't get up and wander. And with the high falls risk obviously most of them are demented anyway I think. Because if you're a high falls risk and you don't have dementia you're not getting up and risking.*
>
> (Kimberley, EN)

Nurses were cynical about the motives of hospital administration focussing on the prevention of falls and their reluctance to spend money providing the staff needed for the level of patient surveillance expected:

> *Today, for instance, we've got people on bed/chair alarms and we've got a girl who's on bank who is only employed until 13:00 because they're cutting back. That leaves two staff for 15 patients, two who are on bed/chair alarms. They don't want anyone to fall over, they don't want anything to go wrong, but they leave us one short.*
>
> (Margie, EN)

There was widespread criticism from the nurses about the motivation of the health services in regard to the initiatives introduced and the way that funding was allocated.

The nurses considered that the expectations of administrators were unrealistic because they demanded more from the nurses all the time but for financial reasons didn't increase the resources available to cover these expectations.

> *It would be wonderful to have an extra pair of hands to help the situation. But they're very loathed to do it...it is definitely money. I think they always think, unfortunately, that nurses can always cope.*
>
> (Rose, RN)

There was a degree of bitterness that the same priority given to the prevention of falls was not given to other risks such as aggression against nurses. The disparity between the resources assigned to the acute hospitals and the sub-acute hospitals was noted resentfully:

> *Ten times out of ten the patient will come from* [acute hospital] *and they've had a CPO (continuous patient observer) the whole time and they hit our ward and there's nothing. And it's not until they hit a doctor or relative do they get shipped off to psych. So that's not right. If the nurses get hit nothing happens.*
>
> (Karen, EN)

This issue was mentioned by a number of nurses and there was clear resentment about what they saw as an injustice:

> *What I find the most frustrating of all is they empty them out of* [the acute hospital] *and they send them here because we've got the code on the door and they can't escape and we're expected to deal with it. But where they've come from, they've had CPOs assigned to them, they've been drugged - they're under control - and they've just been waiting to be shipped to us. So they come to us all agitated quite a falls risk and we're expected to be able to deal with them and it's very difficult.*
>
> (Kimberley, EN)

The result of the failure of the hospital administration to provide the resources the nurses believed were required in order to do their work was dissatisfaction and poor outcomes for the patients. The situation demonstrated the power imbalance perceived by nurses between the nurses and the hospital administrators. The nurses felt that they were forced to accept the status quo.

A further obstacle to achieving a quality therapeutic relationship between patients and nurses was language and cultural misunderstandings.

Cultural diversity of patients and nurses

The principle language in Australian hospitals is English, however, the range of cultural backgrounds of both nurses and patients can result in a diverse group within a ward environment. In this study, problems were revealed regarding cultural boundaries and

behaviours, and communication through accents and Australian colloquialisms. The issue of cultural diversity was raised by a number of patients and nurses in relation to the increasing number of internationally trained nurses being employed by the health services. While there were both positive and negative comments made about this situation, of note was the problem of cultural misunderstandings and strong accents causing difficulty with communication. In particular, Asian and Indian accents were prevalent, but there were also nurses with strong African and northern United Kingdom accents.

In one health service, the patient population included a significant number of patients from non-English speaking backgrounds, mostly from Mediterranean countries, and approximately half of the nurses from Asian and Indian backgrounds, many with strong accents. Racism on the part of the patients was also mentioned:

> *I think a lot of them here because we've got multi-cultural nurses, quite often they revert back to not liking - they become a little bit racist too, which seems to trigger off the dementia a bit worse at times.* [The nurse is] *Indian or - they're dark coloured, so they instantly are foreign to them.... I don't know if it's a communication issue, or if the patient is just aggravated from them. Everything is exacerbated.*
>
> (Kara, EN)

There was a specific incident which was discussed by one of the nurse participants which highlighted the problem of cultural misunderstanding between a patient and a nurse:

> *Well on our handover sheet we had a report that a patient who has got cognition impairment that he'd been sexually inappropriate with one of the nurses. But it actually wasn't, it was just a blow of a kiss, but that's his way of saying thank you. So this nurse who's from ... I'm not being racist, but not an Australian nurse. She took that as being sexually inappropriate...I think they* [the international nurses] *don't really understand the Australian nuances well. And it's a hard thing to teach someone or to say "You might have found that inappropriate but it's actually for us not inappropriate".*
>
> (Pam, EN)

Accents can be a problem for both staff and patients. This was acknowledged by a Korean nurse who had a strong accent and knew it was difficult for others to understand her:

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> *Like I am also Asian background I have accent. If the patient they no speak very good English and plus my accent so it doesn't work, so take somebody else to help.*

<div align="right">(Lila, ANUM)</div>

From a patient perspective there were mixed reactions, including some negative comments from several Anglo-Australians who disapproved of the international nurses and made patronising comments:

> *I feel sorry for them* [the international nurses]. *They don't know what the right words mean when they're reading out of whatever.... but given their er, I'll have to call it communication deficiency exists; it's er because they're the foreign ones and the standard is what it is.*

<div align="right">(Harriet, patient)</div>

Not all the feedback on this subject was negative however as one patient explained:

> *The Asian people are very nice. One thing I've found - it might be in their religion - they do have a special kindness to elderly people. Not that the Australian girls aren't good, but the Asian girls - I think it's in their religion - honour thy father and thy mother. But they are very attentive, you know.*

<div align="right">(Bob, patient)</div>

The researcher observed that some nurses regardless of their country of birth were more empathetic than others. The quality of care appeared to have more to do with the personality and maturity of the nurse and their understanding of patient needs rather than race or accent. An observation of an international nurse was recorded in the field notes

> *Watching an Asian nurse - she is shy and reserved with the patients, but gentle. They seem to respond well to her.*

<div align="right">(Field notes, Ward A)</div>

Relationship between discipline teams

Despite many interactions between nursing, allied health and medical staff being observed, the nurses only occasionally reported feeling that they were supported in their work by these teams. The roles of nurse/ doctor/ allied health staff in the wards included in this study were sharply delineated:

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Yes, but even if we've got Allied Health and all of that, their jobs are not that either [to assist with managing a patient with behavioural symptoms], *so they're not going to step up and jump in and help us out either, in that respect. That's seen as a nurse's job... Even with all the staff here, it makes no difference.*

(Melissa, EN)

The nurses often mentioned that the occupational therapy and physiotherapy staff had the potential to have a positive impact on patient behaviour, mainly through including patients with dementia in therapy and in the case of the occupational therapists, diversional activities. However due to the limited capacity of the allied health staff to take on such roles, and the focus on discharge planning, in the main this was not what happened.

Physio [Physiotherapy] *and OT* [occupational therapy] *do step in and do stuff but not a lot because they're so short-staffed so they don't do groups or anything. I think it's all individual. If they can't go home then OT are finished...We don't have time to do it ourselves so there's really no therapy for them as such the dementia patients. They just sit here waiting for a nursing home if they can't go home... Basically, they're just left there to meditate* [cynical tone] *or whatever.*

(Lil, ANUM)

The ANUM in the excerpt above was explaining that it was not part of the nurses' role to interact with the patients beyond personal care and medications, and the allied staff lacked capacity to do anything beyond limited therapy for patients returning to the community.

Beyond the ward teams, nurses considered that the hospital administrators were lacking knowledge and information about what was happening at the bedside and the difficulties the nurses were facing. Increasingly more acute patients, a rise in the number of people with dementia and greater administrative burden were adding to the demands of the job:

We're finding the work much more taxing, but it's not necessarily about people with dementia...We find that the workload is much heavier because the type of people we're getting is much heavier... They [the administrators] *all need to come and work on the ground floor and actually see what goes on, because they've forgotten...*

(Carol, ANUM).

In an effort to bridge the gap in resources volunteer programs had been introduced in some wards.

Volunteers help bridge the gap

In some health services, professional diversional therapists, often working under the supervision of the occupational therapy department, are employed to provide activities for older rehabilitation patients, especially for those with dementia; however in the two health services in this study this was not the case. On one site there was a new volunteer program which was still being developed in an endeavour to bridge this gap. Several nurses reported that they had seen volunteers chatting with patients, but there had not been any formal activities arranged at that point:

> *We're trialling volunteers at the moment for falls prevention, trying to kind of get the high falls risk people all together. Keep them occupied so they don't get up and wander...but it's not working... the volunteers, they come and they'll talk to people who actually want to sit there and have a conversation one on one. They're not actually engaging groups of people with dementia and high falls risk and keeping them occupied...*
>
> (Kimberley, EN)

The volunteers in this instance may not have had the skills to do this or the training and supervision required. Engaging groups of people with dementia in an activity is a specialist skill requiring education. It was acknowledged that the volunteers required close supervision and guidance in order to ensure that the program suited the needs of the patients and staff:

> [Some volunteers] *are making things more difficult because they'll listen to these people with dementia and then try and fix their problems, not understanding that these people are here for a reason and some of them have got some really serious social issues. And we've had volunteers sowing ideas into their heads that well maybe you can do this, that and the other when in reality they can't do any of that so they actually can make problems as well.*
>
> (Karen, EN)

The volunteers were not universally appreciated by the patients either. A patient with dementia who declined to be formally interviewed told the researcher that she didn't think much of a particular volunteer:

> *Researcher: Is that Mary's daughter over there?*
>
> *Patient: Oh her?! No! That's the bloody volunteer. That woman gives everyone the shits!*

<div align="right">(Field notes, Ward B)</div>

The volunteer program in the second health service was much more established, well organised and supervised. The volunteers wore white t-shirts with 'VOLUNTEER' printed in blue on the back. They seemed to take their role very seriously and were rostered to run small groups and also to spend time with specific patients nominated by the nurse-in-charge. The researcher observed the volunteers engaging with the patients with dementia on many occasions. The volunteers were not permitted to feed patients, but could sit with them and encourage eating, as observed in the field notes:

> *A volunteer is encouraging a patient to eat. She said "You are doing a good job! It's easier to eat when you are sitting up isn't it? Have another mouthful now, that's the way."*

<div align="right">(Field notes, Ward D)</div>

Each weekday in this ward after lunch the volunteers ran a small group around a table in the patient lounge. The attendees were nominated by the nurses, and there were usually 4-6 patients with dementia present. The activities were mostly games but on occasion, the researcher observed them doing craft projects or a reminiscence activity. The patients participating in these groups appeared to be enjoying themselves:

> *Some of the volunteers and that are very good...I like them because they take me out and we do little things... Oh just like they're doing now in the playroom...doing the bingo and all those things...Even just being down there and just everyone just talking I think is better than just all sitting...*

<div align="right">(Emma, patient)</div>

The volunteer groups did not appeal to all the patient participants and there were those such as Lex who were approached to participate but declined:

No, I've had a few (volunteers) call in here asking if they could do anything and I said no, not really. Nell came in today with her dog. I've met her a few times. Very nice lady and she had a big pet er what do they call those? A French dog, you know. It's a very intelligent animal.

(Lex, patient)

Volunteers in this ward also spent time with patients one-on-one when directed by the nurses. This was particularly useful when the nurses needed a patient to be watched or distracted so that the nurse could attend to other duties:

If I can find the right volunteer I'll say, "Have you got two minutes to sit with this lady while I do the drug round?" that will work beautifully because after two minutes they've had enough and I've finished what I had to do.

(Ruth, RN)

In some cases, the volunteer had the skills to be able to spend time with a patient with specific issues, such as a 52-year-old male patient with dementia related to Down's syndrome. The patient was ambulant but a serious falls risk and was not able to follow instructions; however he seemed to respond well to male staff and volunteers:

It has made a big difference, yes, and depending on who you get too - obviously, personalities - but this guy today, he was brilliant with [the patient], *and* [the patient] *related well to him, and it's all about that too. But it's also him having the time to do it.*

(Carol, ANUM)

Volunteers are a cost-effective alternative to professional diversional therapy however the quality of the therapy is not equivalent and the volunteers need to be trained and well-supervised in order to be effective. In the absence of professional diversional therapists in this ward, the volunteers were a useful adjunct.

Theme 3 highlighted the effect that the hospital priorities related to budgetary restraint and fast patient turnover was having on the patients and nurses. Nurse participants reported that the acuity of the patients had increased without a corresponding increase in resources, specifically specials to assist with patient supervision and care. The addition of volunteers was welcomed but was an under-developed resource in most cases. The culture of the wards hindered the delivery

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of the most appropriate person-centred care for the patients with dementia. Additional challenges included unsuitable physical space, and an attitude of exclusion by some staff to patients with mental health rather than physical health diagnoses.

Chapter summary

The findings discussed in this chapter obtained from interviews, observation and field notes contribute to an understanding of the complex issues which surround the care of people with dementia in hospitals. The patients reported feeling that they were outsiders in the hospital system and lacked control over their care and discharge planning. Nurses described feeing materially and psychologically unsupported by the hospital administration and educationally unprepared. However some continued to derive satisfaction from their work because of the supportive teamwork and the rewarding aspects of working with people with dementia. Hospital priorities were found to have a significant influence on care practices. In the following chapter, an in-depth discussion is provided to interpret these findings and draw together the elements which explain how and why the system plays a vital role in the provision of care in this setting and sustains a culture of marginalisation of people with dementia.

Chapter 6 Discussion

Introduction

In seeking to understand how people with dementia experience care during inpatient rehabilitation this study explored the perceptions of both patients and nurses in sub-acute geriatric rehabilitation facilities in Melbourne Australia. This chapter will focus on the culture of exclusion of people with dementia and its location in the broader issue of health service priorities. The purpose is to assimilate the themes that were identified into an overall argument which centres on the ways in which the budget and the biomedical care in the hospital system have shaped the attitude of the nurses and the experience of the patients.

This discussion centres on three areas of focus which emerged from the three main themes in the findings. *The patient experience: liminality and worthiness* discusses the marginalising experience felt by the patients. *Nursing in an evolving workplace* focuses on the viewpoint of the nurses and the power relationships between the nurses and the organisation, and the nurses and the patients. *Hospital culture at odds with caring and empathy* explores the impact of the organisational governance on nurse caring. The original contributions to research made in this thesis include the identification of the patient with dementia as experiencing a liminal state in hospital and being considered unworthy or less deserving of care by the nursing staff. Furthermore nurse recruitment has been identified as an area which deserves further scrutiny to ensure that the nurses who work in this area are suitable for the role.

The discussion will refer to the research of others, commencing with the issues identified for nurses and patients and those originating in the hospital system. Most significantly the findings of this study highlighted that the focus of health services on rapid patient flow, fiscal restraint and risk mitigation had a considerable effect on care practices, and produced an environment which does not fit with the nurses' expectations and principles of care. This is not reflected in the current literature. The biomedical influence in which a curing model is emphasised ahead of psychosocial factors and the tension between caring and economic dimensions had an alienating

and disempowering effect on patients with dementia in this study. The position put forward in this thesis is that these systemic attributes have shaped the physical, social and cultural dimensions of the patient care and produced an environment which privileges certain types of patients at the cost of those people with dementia.

Previously much of the literature has focused on the ward-based local and relational issues effecting the care of the patient with dementia. There has been a drive to improve person-centred care for older people in hospital (Clissett et al., 2013a; Edvardsson et al., 2013; Nay, Fetherstonhaugh, & Winbolt, 2014; Traynor, Brisco, & Coventry, 2005; Webster, 2011) however the organisational characteristics which influence implementation have not been adequately explored.

In his work *Knowledge and Human Interests,* Habermas put forward the idea that knowing and understanding are based on ordinary everyday communication and language rather than the philosophical idea of transcendental ego or the conscious self

The theoretical framework underpinning this study is constructionism which informed a critical ethnographic approach and led to an understanding of the way that patients with dementia and nurses experienced care in sub-acute rehabilitation facilities. Habermas (1972) suggested that the ordinary everyday communication and language was the key to understanding others. Thus in order to comprehend the power, dominance and subjugation problems experienced by both groups, many hours of observation and interviews were conducted. Underpinning the interpretation were biomedical, social and political factors which have engendered an entrenched stereotype of the patient who is appropriate for treatment in these hospitals. This reinforces systemic marginalisation of the person with dementia and resulted in practices and priorities which have produced negative experiences for one of the most vulnerable patient groups. An understanding of the lack of power of the nurses in the hospital hierarchy highlighted the tension between the traditional view of nurse caring and what is currently possible in these hospitals.

This chapter addresses the significance of the government funding priorities and how these have contributed to producing a ward culture intolerant of outliers who extend the average length of stay, require additional nurse input and disrupt the ward routine. In this study, such patients were not considered to be a priority or as worthy of resources in comparison to mainstream patients. The liminal experience has been described in a number of ways including being transitional between two states or an outsider in a situation (Lupton, 2013a). It has a strong association with 'otherness' and difference (Warner & Gabe, 2004).The liminalisation of patients with dementia is a result of the systemic attributes of the hospital system which work in such a way that those who failed to fit the mould were marginalised.

The worthy patient

In this study, despite hospital policies and formal nurse education which maintain that nurses should resist making value judgements about patients, the cultural process within wards support nurses to prioritise patients with acute health problems ahead of those with chronic health conditions, especially older people with mental health disorders. In discussing the hidden curriculum of medical education, Higashi, Tillack, Steinman, Johnston, and Harper (2013) suggested that healthcare is governed by a moral economy and implicit cultural beliefs and values which endorse the prioritisation of certain types of patient.

Older people are especially viewed as problematic because they can be slow, poor historians, and frequently have multiple chronic problems which are incurable and require significant community support beyond the hospital. The reason for admission is often relatively minor and uninteresting such as urinary tract infection or dehydration (Higashi et al., 2013). These factors add to the low significance attributed to such patients, and the perception that they are less worthy of care and resources than others. Higashi et al. (2013) referred to the judgment of a patient's worthiness as being the result of the cultural process through which students learn what is and what should be valued, and to characterise patients in ways that guide their interactions and influence care. Australian hospitals profess to support person-centred care in which judgements about patient worthiness do not play a part.

Person-centred care is a term frequently referred to in hospital documents however the ways in which it should translated into bedside nursing is not well defined (Goodrich, 2009). There are also various definitions of person-centred care, although the concept has frequently been associated with older people, especially older people with dementia (Edvardsson, Winblad, & Sandman, 2008; Kitwood, 1997a; McCormack, 2004). Nay et al. (2014, p. 138) have defined it as "the need for a recognition of, and a connection with, the person, a focus on the person's strengths and goals, an interdisciplinary approach, and recognition of the centrality of relationships" The definitions supported by the Victoria State Government (2015) and the Australian College of Nursing (2014b) both define person-centred care in ways which consider the protection of the person's dignity and rights as an absolute, and the therapeutic relationship between the nurse and the patient as central.

In hospitals today nurses and other health professionals must justify all expenditure to ensure the greatest benefit to the community is gained from the health dollar (Adams & Nelson, 2009). The culture of fast patient throughput which has been developed in response to this problem encourages nurses to consider patients with dementia as less worthy of care and resources than those with acute illnesses for several reasons. Patients with dementia can have a longer length of stay complicated by frailty, a tendency to develop complications, and often social problems which may lead to guardianship hearings through the Victoria Civil and Administrative Tribunal (VCAT), and disputes about the discharge destination (Australian Institute of Health and Welfare, 2012a). Those awaiting a decision from VCAT or a bed in a residential care facility have generally completed the treatment for which they were admitted and remain in hospital because there is no short-term alternative available. Patients in this situation rarely receive more than basic care and are sometimes referred to as 'bed-blockers' because of the difficulties encountered with discharge planning, and the longer length of stay often brought on by social rather than health issues (McMillan, 2015). Manzano-Santaella (2010) explains that the concept of 'bed-blocking', or the use of a bed by a patient who has over-stayed and thus caused a backlog of admissions, is an example of medical dominance which blames the patient for a systemic administrative problem. Examples of this attitude were demonstrated when nurses in

this study voiced their irritation about a patient with a delayed discharge who they felt they were 'baby-sitting'.

Patients with a chronic condition such as dementia can attract a label of unworthiness if they have unpleasant behavioural symptoms, they fall or can disrupt or be intrusive to others. A patient who has a high risk of falling requires constant assistance and surveillance, which adds to nurse workload and frustration. Falls not only cause inconvenience to the nurses and often injury to the patients, but they have the additional consequence of attracting scrutiny from health service administrators. Wards which have an unacceptable rate of falls may be required to demonstrate what is being done to address the problem.

Caring for someone who is slow, unco-operative and high in risk factors such as falls, absconding and aggression makes the job of the nurse more difficult. It has been reported previously that caring for people with dementia adds to the stress levels in staff and contributes to burnout (Edberg, Anderson, Orrung Wallin, & Bird, 2015; Sanchez, Mahmoudi, Moronne, Camonin, & Novella, 2015). In this study the nurses reported that caring for someone with dementia added significantly to their workload and often caused difficulties getting things done. Patients with these traits were consequently seen by some as unworthy and unattractive. However categorising the patients as either easy to care for or difficult is judgemental and hinders the ability of the nurse to respect the humanity of the patient and care empathetically (Borrell-Carrió et al., 2004). Dividing patients according to worthiness creates a perception that people with dementia do not belong. The outcome is that the needs of these patients are not met.

The technical side of nursing related to acute health issues such as intravenous drugs and medical equipment were often considered by the nurses in this study and elsewhere to be more important than softer skills such as listening to the patients (L. Carter et al., 2008). The aspects of patient care which are least related to medical knowledge and skills have the lowest status and are more likely to be delegated to less-educated staff or considered discretionary (Adams & Nelson, 2009).

In the wards observed in this study, the emphasis was on the biomedical side of care which refers to the medical model, rather than the caring model which belongs to nursing. Patients with acute health issues who were co-operative and uncomplicated (no mental health or social issues) were considered by the nurses to be more worthy or deserving of care and attention. It was observed that patients were more likely to receive positive attention from the nurses if they were pleasant and undemanding, grateful for the care and followed the nurses' instructions. People with dementia who were difficult, uncooperative, unresponsive or aggressive received basic practical attention, but the nurses were less inclined to engage with them or go beyond what was dictated by the nursing care plan. This finding is not new and has been discussed in the past by Stockwell (1972) and later by Johnson and Webb (1995) who documented the inequalities of nursing care administered to patients with different traits.

Nurses learn what is valued through a cultural process influenced by their colleagues and the habitus of the organisation. The worthiness of a patient is reflected in the priority given to their care in the ward situation, and the language and value judgments used by other staff when discussing the patient (Bail & Grealish, 2016). The senior nurse who spoke derogatively in nurse handover about a patient with dementia was communicating cultural beliefs about the patient's worthiness. Similarly a nurse who said that she didn't have time to sit and chat to a patient because 'it's not a nursing home here', was making a moral judgement about priorities. The nurses quickly learn that the cognitively intact patient with an appealing demeanour and an acute health problem takes priority over a patient with dementia, especially one who is awaiting placement in residential care. Nurses entering an environment where this attitude and language are common often quickly adopt the ways of the ward (Cowdell, 2010a) and person-centredness is overlooked.

 The strong influence of habitus and the ward milieu can influence nurses to consider patients with dementia negatively. Despite this there were nurses in this study who spoke about positive experiences with patients deemed to be unworthy by general consensus, and consciously or unconsciously declined to take on this attitude. A number of the nurses made reference to their relationship with individual patients with dementia and discussed the empathy they felt for

these patients. In fact some appeared to take the part of the person with dementia as the 'underdog' in an environment in which the nurse could see that they were treated unfairly. These nurses treated the patients with respect and engaged with them when attending to care tasks.

Dementia causes deficits of short-term memory meaning that a patient may not remember the attentions of a nurse a short time later. Consequently the rewards for the nurse in this interaction may be slim, unlike those with whom a more satisfying rapport can be established (Söderlund, Norberg, & Hansebo, 2014). Nurses consciously or unconsciously seek a connection with the people they work with and care for, but in the case of the patient with dementia the rewards from the nurses' perspective can be difficult to identify (Touhy, 2004). Sabat (2006) considered that to assume that there is no lasting effect of interactions with others on the person with dementia is erroneous. Despite having damaged explicit memory or conscious awareness the person can have implicit memory preserved in which the effect of an encounter is maintained despite the details being lost (Sabat, 2006). Feeling that what they say or do is not remembered adds to the nurses' feelings of futility, unfortunately it also gives the unscrupulous nurse licence to treat a patient punitively or ignore them as the nurse assumes that these actions will go unexamined. In this study nurse participants reported incidents where they had started their shift with an agitated or tearful patient with dementia who could not verbalise what had upset them however other patients reported that a nurse on the previous shift had been rough or chastised them inappropriately. None said that they had reported this to the nurse manager, addressed it with the nurse in question or written an incident report, demonstrating a habitus of acceptance and powerlessness to make changes.

The nurses' understanding of patient worthiness in this study was influenced by the focus of the health services which prioritise acutely ill patients ahead of those with chronic conditions such as dementia. Some of the nurses considered the patients with dementia to be a hindrance to achieving patient occupancy targets, a disturbance to the ward routine and less prestigious to care for because of the association with residential care. The ward habitus was a strong influence on behaviour and attitude, although some nurses maintained a positive manner towards the

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patients with dementia. As a result of a number of factors including the approach of the staff and their failure to consider the cognitive impairment of the patients adequately, some of the patients described feeling like outsiders in the hospital in what has been termed a 'liminal' experience'.

The liminal experience of patients with dementia

Liminality was defined by Lupton (2013a) as a state in which a person was transitional between one world and another and considered to be a stranger or an outsider. This difference renders the other as insignificant (Hall, Stevens, & Meleis, 1994). A liminal status means that there is the licence to treat the individual more harshly and allow them fewer rights (Lupton, 2013a). Furthermore treating a person as different or as an outsider is a form of stigmatisation or marginalisation and is widespread in the community (Meleis & Im, 1999). Stigmatisation is defined in this thesis as comprising three elements - stereotypes, prejudice and discrimination in the context of power differences (Rüsch, Angermeyer, & Corrigan, 2005). Many of the patient participants in this study described feeling excluded and outside the general realm of the ward, were unaware of why they were in hospital and felt removed from discussions about their own care and discharge-planning. Despite not using this terminology, some participants described liminal experiences when they discussed feeling alienated by the hospital environment and described feeling lost and having trouble adapting. Patients with dementia felt estranged when in hospital for a number of reasons, not least of which was the diminishing ability to understand new spaces and faces, however there were also factors which were imposed by the people and organisations entrusted with their care which added to feelings of estrangement. Nurses contributed to the liminal experience of the patients with dementia by failing to adapt practices to accommodate cognitive impairment, and by making assumptions about the patients based on their diagnosis or on the nurse's previous experience.

Most of the nurses said that they learnt techniques for interacting with people with dementia from working with others or from trial and error rather than formal education. A poor understanding of dementia and other forms of cognitive impairment resulted in the majority of

patients being treated in the same way that any older person would be treated, with no additional regard for cognitive disability. It has been observed in other studies that nurses often fail to identify agitation or aggression in a person with dementia as a sign of an unmet need such as pain or toileting (Dewing, 2009). Hence there can be significant gap between what is provided and what is required. People with dementia often need information repeated and reaffirmed in order to gain any understanding of the situation (Eggenberger, Heimerl, & Bennett, 2013). Reassurance and repetition may need to continue throughout the person's stay in hospital; however there was no allowance for the extra time this entails and minimal education for nurses to increase their understanding of this need. The embedded practices which direct nursing work create barriers to tailoring care to meet individual needs.

Despite most of the patients with dementia being admitted to the hospital with acute health diagnoses and similar rehabilitation needs to cognitively intact people, many of the nurse participants said that they thought the patients with dementia should be cared for somewhere else, in a dementia-specific facility. The attitude was that the patient with dementia was a nuisance or an inconvenience. This approach had the effect of reinforcing the liminality of patients many of whom already felt excluded and alienated. This negative attitude was fuelled by the traditional linear task work model entrenched in these facilities, which made the accommodation of patients with unpredictable complex needs additionally problematic for the nurses.

Language, voice and written communication are essential tools in conveying organisational and professional values to others (Batch & Windsor, 2015). Labelling patients as 'other' by using language that perpetuates stereotypes of the 'demented patient' reinforced the belief that patients with dementia did not belong in that environment and were a lower priority. The nurses who used patronising terms when addressing the patients (such as calling an older Italian woman with dementia 'mama') reinforced the lesser status of the patient in an environment where cognition and youth were valued. Some nurses in this study were also observed to adopt a demeanour of the 'loud and cheerful nurse' which had the effect of intimidating the patients and creating a barrier to more meaningful and personal communication.

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The loss of control was reinforced by the physical setting in which patient freedom was severely curtailed. Wards which had a locked area in which to confine patients who may wander or abscond accentuated exclusion by corralling the patients together away from others who were cognitively able and who were granted more rights. All the wards in this study were locked wards, with keypad entry for staff and visitors, however one of the wards also had a small area with four beds which was a locked area within this locked ward. In this way some of the patients with dementia were controlled in a very small space and excluded from walking around the ward or to the secure garden outside. Reinforcing difference by keeping the patients contained in a small area is understandable on one level from an operational perspective but unacceptable from the point of view of patient rights. Moreover it is known that people with dementia can respond negatively if they feel that their freedom has been impeded, making this strategy even more questionable (Torrington, 2006). Increasing surveillance to this degree reinforced the outsider status of these patients and augmented the power and control available to the nurses. Discriminating against certain patients because of their cognitive deficits is uncaring, not person-centred and in this situation led to further disruptive behaviour.

A number of the participants with dementia in this study remarked on the fact that they were excluded from participating in activities such as physiotherapy for reasons which were not known to them. The rationale behind this is contentious as it is known that people with dementia are at significant risk of physical and mental deconditioning in hospital (Draper, Karmel, Gibson, Peut, & Anderson, 2011), but cost containment has led to the prioritisation of resources for those who are returning to the community. Prioritising services for the cognitively intact is a form of stigmatisation, albeit one which is dictated by forces outside the direct control of the nurses and therapists themselves. In this instance exclusion led to the patient feeling lonely and rejected.

People with dementia are living with the gradual diminishing of their cognitive abilities, which puts them in an uncertain state outside of the mainstream cognitive world. Kelly (2008) describes this concept as "living loss", describing the grief response of a person and their significant others for the gradual diminishing of abilities and relationships. Coupled with this

personal grief is often the realisation that others in the community including hospitals, place the person in a position both metaphorically and often physically that emphasises liminality.

Nurses reinforce this liminality and stigmatise patients with dementia when they fail to make a personal connection when attending to the patient. In their publicly available policy documents, both health services purported to prioritise the patient experience and recognise them to be partners in care. However in this study, it was observed that conversations between nurse and patient beyond practical exchanges were rare: if more than one nurse was present, they frequently chatted to each other while they worked, to the exclusion of the patient. The person-centred approach, described was not immediately evident. Treating the patient as an accumulation of tasks rather than a person was surprisingly common and was a way of distancing the nurse from the person and their specific needs. This attitude of separation was reinforced by the hospital system which places very little actual priority on caring (despite theoretical support for person-centred care) and a pronounced emphasis on efficiency and swift discharge. The message (notwithstanding mission, vision and values statements), is that caring is not important and not valued. Predictably this had a detrimental effect on patients, including those with dementia.

As discussed in chapter 3, constructionism which shares epistemological foundations with ethnography, established that a person derives meaning and identity from their experiences built up over time through their interactions with others (Crotty, 1998). Importantly people rationalise their experiences through communicating and relating to others, thus creating their own version of reality in this process (Leeds-Hurwitz, 2009). In other words, reality is intersubjective, or based on the shared common-sense meanings created by people in their dealings with each other. Nurses who neglected to engage with the patient were denying them a fundamental right of personhood which is to engage in experiences and interactions with others (Dewing, 2008). Brannelly (2016) described this as a denial of citizenship, and a demonstration of the oppression of patients with dementia as a marginalised group.

Kitwood (1997a, p. 46) described a phenomenon which he termed 'malignant social psychology' to describe the effect that negative psychological treatment can have on the experience of

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dementia and the course of the condition. According to Kitwood (1993) the problem of dementia lies only in part with the neurological degeneration in the brain and is substantially influenced by the interpersonal interactions with others. The way the nurses respond to the patient is an integral determinant of the quality of the experience for the patient and should not be underestimated. The fractured connectedness which resulted from the perception that 'people with dementia did not belong in these facilities resulted in patients' needs going unmet, and cultivated otherness.

Ballenger (2006) suggested that the stigmatisation of people with dementia by people with normal cognition is triggered by deeply felt anxiety about the coherence and stability of the self rather than by ignorance or lack of education. Dementia impairs the person's ability to maintain a stable and coherent self to others and strikes at the core of what makes that person themselves. The loss of the ability to maintain control, awareness and personal responsibility triggers stigmatisation in those who see this as a failure of the person (Ballenger, 2006). Nurses in this study demonstrated their anxiety about people with dementia when they spoke about keeping patients confined, circumventing interactions with them or transferring to a dementia-specific facility where staff were expert in this field. Focussing on tasks rather than the individual is a form of avoidance which nurses use to shift the focus away from the source of their anxiety (Canales, 2010).

Denying the rights of people who have a mental health problem to the general care available to the general population is discriminatory and is an example of 'othering', a term used to describe the process that is undertaken to identify those who are classified as different in a negative way and considered of lesser significance (Doyle & Rubinstein, 2014). The term 'othering' has also been used to describe the refusal of the rights of those who are perceived as different from the self (Lupton, 2013a, p. 173). The unknown and 'dangerous' traits of the person with dementia can result in feelings of unease, anxiety and ambivalence in the nurses especially the potential for aggression and intrusion (MacKenzie, 2006).

Lupton (2013b, p. 176) referred to the concept of embodiment as being central to that of otherness, demonstrated in a culture which values the control and containment of a person's
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actions and bodily functions. In a person with dementia, physical control and social judgment can be compromised and unpredictable, resulting in feelings of unease and tension in the carer. The person can present a risk to the status quo and upset established norms of patient behaviour.

The dominant biophysical paradigm in the hospitals in this study reinforced the otherness of the patient with dementia because the focus of the facilities was on rehabilitation and treatment of physical illness. The patient who required additional input due to cognitive impairment was considered outside the core business of the ward, and care is to an extent, grudgingly and minimally administered.

The liminal status of the patient with dementia was emphasized during the staff dialogue, especially during handover, when derogatory terms were used to describe the patients and their behaviour. Labelling patients perpetuates stereotypes and reinforces the 'us and them' mentality commonly observed. Patients who were labelled were often assigned a set of attributes based on the nurses' past experiences not always applicable to that individual. The stigma was passed on from nurse to nurse without necessarily any direct reference to the patient. Nay et al. (2014) described effective person-centred care as a total experience starting from the language used to describe the patient's condition. The connection with the person, their strengths and goals and the centrality of relationships are paramount.

 Otherness can become explicit when a person diverges too much from what is considered acceptable and they become 'a problem' (Fortin & Maynard, 2015). In the case of patients with dementia this was observed when the person was disruptive, unco-operative or non-compliant. The language of otherness was communicated between staff members and had a bearing on the perception and relationships that the team had with this patient. An example of this was observed at a shift handover when a nurse said that a patient had not had any bad behaviour or aggressive outbursts this shift, implying that these things were expected of this patient.

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 widespread belief that the patients with dementia should be cared for 'somewhere else' despite having similar rehabilitation needs to other patients on the ward, fuels an attitude of otherness.

Stigmatisation and 'othering' can be a reflection of the treatment the perpetrator has themselves received (Canales, 2010). Evidence of exploitation of power within hospital hierarchies has been discussed previously (Hutchinson & Jackson, 2015; Li et al., 2013) and may also be a factor in the treatment of patients in this study.

Nursing in an evolving workplace

Support for the health system in Australia is facing rapid change driven by increasing competitiveness for government funding and the escalating costs associated with technology and an aging population (Australian Institute of Health and Welfare, 2012a). Nurses are absolutely central to meeting organisational goals. Nurses have a high level of practical and clinical skills but require support in their role in order to have the material and psychological preparedness to do the job well (Winstanley & White, 2002). In this study, and others reported in the literature, it was found that most nurses wanted to do the best job they could, however to be compassionate to others, they needed to feel that their work was appreciated and meaningful (Pavlish & Hunt, 2012). The focus on economics at the expense of good human resource management removed components which were vital to good care such as targeted education, extra staff when required, diversional therapy, clinical supervision and other forms of support.

The ageing society has resulted in more people with dementia, and chronic and complex health needs being admitted to hospital. Despite this the powerful groups which direct hospital governance have controlled nursing and managed it as an expendable and elastic workforce which will cope with increased patient dependency without additional assistance. The skills and critical role of nurses in the hospital organisation have rarely been acknowledged.

The medical model of care is curing based on science. The disease-based approach puts the pathology of the disease in the foreground and the patient's symptoms and experiences in the

background (Brink & Skott, 2013). Historically, a collection of symptoms were considered to be definitive of a person's illness, enabling the physician to identify the malfunction and prescribe a course of treatment (Edwards, 2008) in a disease-centred approach (Brink & Skott, 2013). In contrast, the person-centred care model considers each patient to be unique and therefore the approach to treatment is individualised according to their personal illness experiences (Clissett et al., 2013a). The dichotomy between the two approaches creates a tension between the traditional view of medical management and nurse caring, and has an effect on the patient experience. Nurses need to adapt to these evolving principles in order to continue to deliver quality nursing care which fits the current climate of healthcare. To be successful, the implementation of person-centred care in these hospitals requires an organisation-wide commitment that includes administrators and all clinical staff in order to have a united vision.

 The medically-dominated bureaucracy which governs Australian healthcare uses economic management models which are authorised from the top level and have major consequences for the way that hospital funds are allocated, consequently having a significant effect on resources for nurses (Crookes, Knight, & Brown, 2008). Having to do more with less was shown to have a significant impact on the quality of care in this study and others, and it is a demonstration of the reality that better nurse staffing and work environments result in better outcomes for the patients (Aiken et al., 2012; Cope, Jones, & Hendricks, 2016; Twigg, Myers, Duffield, Giles, & Evans, 2015). The value placed on caring is undermined by the failure to provide adequate nurse ratios to deliver the quality care that is expected. Nursing is differentiated from other industries in that nurses are assumed to be committed, compassionate individuals who will care for the patients to the best of their ability despite the obstacles (Austin, 2012). It could be argued that this disadvantages nurses in the medically dominated environment. Evidence in this study indicated that the power differential in the hospital system severely impacted on the nursing workforce who did not feel that they could advocate either for themselves or their patients. Common self-perceptions included that they had to work with the way things were and accept the status quo.

Material disempowerment was demonstrated by the constraints imposed by the institutions which failed to provide enough resources including the number of nurses necessary to do the job. In the absence of sufficient nurses, the completion of tasks dominated. The findings reported in the literature and also found in this study were that technical tasks were privileged at the expense of other aspects of caring such as talking to the patients and comforting them (Ball, Murrells, Rafferty, Morrow, & Griffiths, 2013; Duffield et al., 2011). The research findings of this study are consistent with Austin (2012) who reported that the moral distress experienced by the nurses when they failed to honour their professional principles, the expectations of their patients, the hospital and society to provide quality care could be intense. In this study there were many examples of this situation including patients observed to be left alone for long periods, and nurses who showed evidence of distress by their harried, brusque manner and focus on tasks. Many commented on their lack of time and were concerned that they were not able to meet patients' social and emotional needs. However despite reporting that they did not have the resources necessary to care for the patients appropriately none of the nurses said that they had any intention to take any steps to address this, demonstrating that they shared a sense of powerlessness.

Nursing is primarily a relationship-centred partnership between the nurse and the patient (Finfgeld-Connett, 2008), the key to which is intersubjectivity. It has even been said that this caring relationship is more than just a pleasant experience for the respondents, it is responsible for many positive patient health outcomes and makes the difference to patients between a technical job and one that results in satisfaction for both the nurse and the patient (Miner-Williams, 2007). The caring practices of nurses has also been linked to financial outcomes for health services (Buckley, 2014). When the nurse is engaged with the patient rather than just completing tasks, the outcome for the patient is much improved (Edvardsson, Sandman, & Rasmussen, 2012). The majority of the nurse participants in this study expressed a commitment to safe, high quality holistic care for patients and identified that empathy and caring were essential components. Despite this understanding however, in the busy ward the drive to complete tasks dominated and the specific needs of individual patients were often ignored. A therapeutic nurse-patient relationship is built on interpersonal sensitivity without

stigmatisation or power plays however in order for this to take place the nurses must have professional maturity and a conducive work environment (Finfgeld-Connett, 2008). In this study there were some instances of nurses using their power over patients observed. .

Nurses misuse their power over the patients when they use a domineering, officious manner to make the patient comply with their schedule and approved patterns of behaviour (Henderson, 2003). Sharing knowledge, giving the patient choice and the ability to contribute to their care and decision making is not only essential from a moral perspective, but a basic principle of person-centred care (Nay et al., 2014). Exploiting the power imbalance by withholding information from the patient, limiting communication and providing only minimal care is unjust, but nevertheless was observed at times in this study. The patients responded by withdrawing or becoming agitated.

The focus on cost containment and risk management favours the employer but comes at a significant cost to the patients and nurses. Although this may not be the primary intention, taking the focus away from relationship-based care is misguided. Looking principally at leadership, Cummings et al. (2010) described two opposing approaches: those that focus on people and relationships to achieve goals, and those that focus on the tasks. In this study it was the latter; there was an emphasis on getting the daily work done and discharging the patients as quickly as possible. The focus of patient care requires re-orientation away from the tasks and discharge-planning, and back to relationship-based nursing. 'Habitus' refers to the internalised and embodied social structures acquired and learned through operating in that world (Bourdieu, 1984, p. 468). "Nurses learn through a process of occupational socialisation which operates within certain habitus and lifeworld, as well as through their educative practices... certain habitus can dehumanise care" (Goodman, 2014, p. 1267). Therefore it is important that the milieu in which nurses learn and operate is supportive and nurturing in order to produce a habitus which facilitates empathetic caring. A number of factors impact on the way that the nursing workplace may evolve; nursing leadership and teamwork, the backgrounds of staff and patients, staff education and support.

Nurse leadership and teamwork

An inclusive culture which supports connection and values the contribution of the group members requires good leadership. Nurse leadership has previously been reported to have a significant effect on nurse job satisfaction, retention, and healthy work environments (Cummings et al., 2010). In this study Northouse's definition of leadership is used: "a process whereby an individual influences a group of individuals to achieve a common goal" (Northouse, 2004).

 Two of the wards in this study had nurse managers who were described by the nurse participants as exceptional, especially in regard to being sympathetic to their situation and being an advocate for them. Effective nurse leadership has been shown to positively impact patient outcomes through the influence of the leader on the performance of the staff (Wong & Giallonardo, 2013). The attitudes and practices of the leaders, nurses and other clinical staff in this study shaped patient care.

In all but one of the five wards nurse teamwork was very strong and a significant factor in staff retention. In this study the nurses who were under considerable time pressure relied on each other for support and there was observable cooperation and team coherence. This increase in teamwork in response to an increase in workload has been reported previously in the literature (Chan, Jones, & Wong, 2013).

Furthermore, resilience has been described as another essential factor for nurses in the hospital environment to cope with the significant stressors and adversity encountered in their everyday work (Jackson, Firtko, & Edenborough, 2007). Some of the nurses in this study demonstrated resilient personalities when discussing the confronting or difficult workplace situations. These nurses spoke calmly about the solutions and tactics they used in their everyday work. In contrast, others described their inability to deal with the stress or their intention to leave their employment or take leave, and did not appear to have developed significant resilience. In some instances they appeared burnt out as evidenced by their resigned attitude.

The question is whether the nurses who seek this employment can adopt an appropriate attitude that encompasses professionalism, technical skill and compassion if supported in an appropriate targeted way. In order to sustain a habitus of compassionate care Goodman (2014) suggested that the answer was in prioritising clinical rather than managerial leadership, remove layers of bureaucracy, and increase the support for the frontline care staff. An important aspect to address is the structure of the nursing teams which are evolving to include nursing assistants, volunteers and a variable skill mix of enrolled and registered nurses. Furthermore appropriate strategies are required to address under-performing staff and dysfunctional teams.

The multicultural hospital

An additional challenge facing the wards in this study is the increasingly multicultural nature of the workforce and the patients. Australia has one of the most diverse migrant populations in the world (Weston, Qu, & Soriano, 2003). A significant number of the nurses in this study had a non-English speaking background (NESB), mostly from Indian and Chinese cultural backgrounds. The patients, particularly in the wards on the first site, were a mixture of those who were locally born and migrants mainly from Mediterranean countries and some from Asia, principally Vietnam. The challenges of communication in English between patient and nurse, neither of whom were native speakers, was significant.

People with dementia particularly those with Alzheimer's disease and fronto-temporal dementia frequently experience a decline in language as the condition progresses (Veselinova, 2014). People commonly revert to the language of their birth and have difficulty understanding that of their adopted country (Hanssen, 2015). NESB nurses who in this study were mostly fluent in English could nonetheless have very strong accents, adding to the communication difficulties between nurse and patient. It is known that people with dementia can have trouble understanding high-pitched, rapid and complex speech (Hanssen, 2015). Some of the nurses in this study spoke very rapidly with strong accents. In order to be understood by people with dementia speech must be modified so that it is clear and simply worded. If both parties have language difficulties, adequate understanding is hard to achieve from both sides and can result in awkwardness and miscommunication.

Added to the issue of understanding speech is interpreting the communication from a cultural perspective. As reported in the findings of this study there are many ways to understand the actions, words and behaviour of others and it is easy to misinterpret the intention when the cultural background is not shared. For nurses and patients from diverse backgrounds who find themselves in an Australian hospital the potential for misunderstanding is significant.

Racism or an expression of 'otherness' was also identified in this study from the perspective of the patients, many of whom were raised in the era of the 'White Australia Policy' which banned the migration of people from Asian countries until it was revoked in the 1970s (Tavan, 2005). Asian or dark-skinned nurses could be viewed suspiciously and almost scornfully by some of the patients although this was not universal. The result of the deficit in communication and the attitude of some of the patients to nurses from other countries was a loss of connectedness and an escalation of attitudes of 'otherness' from both nurses and patients.

Education

Education for nurses must reflect the evolving workplace and the expectations of the organisations that nurses will care effectively for a range of patients from the acutely unwell to the person with dementia awaiting placement in residential care. The lack of targeted and on-going education was a barrier identified in this study to the effective care of patients with dementia, despite the known increase in incidence and prevalence of the condition globally (World Health Organisation, 2012)and specifically in Australia (Low et al., 2008). Disempowerment of the nurses in this way marginalised them as a group within the clinical team dominated by medicine. Many of the nurse participants had a limited understanding of dementia and the effect of hospital admission on people with this condition. Education about cognition was greatly lacking in both recently graduated and experienced nurses. Those who had received some education reported that it was inadequate, not recent, or commonly it was part of a short mental health subject at university which covered all mental health diagnoses. Considering the projected increase in the prevalence of dementia in the Australian community and globally due to the ageing population it is reasonable to expect that nurses receive adequate education on this subject. The key recommendations of the Clinical Practice Guidelines for

Dementia in Australia (Laver et al., 2016) propose that all staff working with people with dementia should receive comprehensive training in dementia-care which includes knowledge and skill development, recognising, preventing and managing behavioural and psychological symptoms, and communicating effectively with the person with dementia, their carers and family. The nurse participants in this study described their lack of knowledge as being a concerning shortfall in their ability to interact appropriately with people with dementia. Practical strategies focussing on managing patients who were agitated or aggressive were identified as needed. Most nurses said that they learnt on the job, but this can result in bad habits and an undesirable culture being formed and perpetuated (Jansson & Forsberg, 2016). Clearly there is a way to go before the recommendations of Laver et al. (2016) are fully realised. It must be noted however that there are many ways for nurses to update their knowledge, often at no financial cost, but it was evident in this study that most did not take personal responsibility for their own education.

A significant barrier to dementia education which has been identified in the United Kingdom is that most training programs, in order to be effective, require a considerable time commitment (Smythe, Bentham, Jenkins, & Oyebode, 2013) and consequently take low priority compared to other statutory and mandatory education and training (Bezzant, 2008; Horner, Watson, Hill, & Etherton-Beer, 2013). Privileging other topics of education over dementia and cognition is a demonstration of the low priority given to this patient group in the hospital system. Education programs about cognition vary considerably in content and duration however it has been demonstrated that there are benefits to tailored education with follow-up to ensure that learning is embedded into practice (Surr et al., 2016). A major government financial commitment will be required to enable effective dementia education to be implemented for staff in Australian hospitals, however free online courses are available and deserve to be more widely promoted. The recruitment criteria for nurses in sub-acute care also needs to be examined to ensure that nurses with appropriate skills are employed in this area and must include relevant education such as this.

Psychological support for nurses

The nurses working in hospitals undergoing rapid change require appropriate support mechanisms. Clinical supervision can play an important part in supporting nurses to care for patients in a stressful environment, however this is rarely provided in acute and sub-acute hospitals. Mental health nurses in Australia are required to attend continuing clinical supervision and reflective practice sessions which are considered an essential part of their core business (Victoria Health, 2012), however there is no such requirement or provision for general nurses caring for patients with dementia in subacute care. In the two health services included in this study there was no clinical supervision or mentoring offered to the nurses, and debriefing was only provided at the discretion of the senior staff after major critical incidents. Access to personal support was ad hoc and dependent on the individual style of the nurse manager. In some instances there was very little support available. Mentoring relationships can foster resilience, provide guidance and be very beneficial for nurses (Jackson et al., 2007) and are considered essential for maintaining good psychological health.

Nurse participants reported that one of the main difficulties for them was that they felt that the administrators had a poor understanding of their situation. The nurses assumed that if the administrators understood the difficulties they faced, they would then provide extra assistance and psychological support to enable the nurses to do the job they were employed to do. Additionally, some nurses showed insight into the political and budgetary reasons behind this shortfall.

The right nurses

More staff, targeted education and psychological support are important but unlikely to resolve all the issues identified in this study. The role and work practices of nurses need to be reviewed in order to adapt nurse caring to the evolving workplace. A subject which has received limited coverage in the literature about patients with dementia is nurse recruitment. It seems self-evident that the nurses who are working in this area of health must have an aptitude for the work and an affinity for older people, however some of the participants in this study demonstrated that they did not have these attributes. These particular nurses did not appear to

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have strong emotional intelligence, resilience, enthusiasm for the job or good communication skills. In contrast others showed genuine caring and compassion for the patients and described examples of situations that they found rewarding and professionally satisfying. It has been argued that nurses who view their role as important and their patients as contributors to care benefit both the patients who are the recipients of more positive communication, and the nurses themselves who find more satisfaction and value in their work (Norbergh, Helin, Dahl, Hellzen, & Asplumd, 2006). Nurses also reported finding satisfaction in their relationships with the patients' families, and from being an involved member of the clinical team. Nurses who work in this way can be good role models for less experienced staff.

There were nurses who were interviewed and observed in this study who showed an unsympathetic disregard for the patients with dementia and it was apparent that recruitment practices had failed to identify that they did not have the compassion or affinity for older people necessary for this work. A consequence of poor job satisfaction observed in this study was that nurses at times ignored or spoke harshly to patients with dementia, reflecting their own frustration by blaming the patient. Nurse dissatisfaction and lack of control in other areas at times resulted in displays of power over the patients who were the least powerful.

An initiative in the United Kingdom National Health Scheme (NHS) which has not yet been adopted in Australia requires training providers to adopt recruitment practices that are based on the values of the NHS constitution in an attempt to ensure that the individual values and behaviours of new employees is aligned with expectations (McPherson, Hiskey, & Alderson, 2016). The constitution values include "putting the patients first, valuing every person, a commitment to quality care, striving to improve lives, inclusion and compassion" (Health Education England, 2014). Research has suggested that the traditional recruitment methods for nurses including unstructured interviews, personal statements and references are inadequate, and it may be more effective to include situational judgment tests, structured interviews or multiple mini-interviews and personality tests as part of the values-based recruitment practices (Patterson et al., 2016).

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Nurses working in an evolving workplace in which there is an increase in patient acuity, an increase in the number of patients with dementia, an increase in the multicultural background of both patients and nurses, rapid patient flow and budget restraint, require significant support in order to be enabled to continue delivering appropriate quality patient care. In this study it was identified that there are significant shortfalls in the material, psychological and educational requirements currently being provided in these hospitals.

Hospital culture at odds with caring and empathy

The changes in hospital management in recent years have been introduced in response to a drastic tightening of budgets with which hospitals struggle to comply (Martin & Healy, 2009). It has been discussed previously that person-centred care is severely challenged in the face of these economic influences (Dewing & Dijk, 2014). In Australia the rapidly declining health care budget and the growing demand for hospital beds is having a detrimental effect on the caring practices of nurses and other staff working in public hospitals (Austin, 2011; Blay, Duffield, & Gallagher, 2012; Scott, 2010). Regrettably this is not a new issue. Turkel and Ray discussed the same problem in the year 2000 referring to hospitals in the United States, and observed that

> "...the cultures of nursing, medicine, and healthcare organisations (especially hospitals) are in a constant state of chaos because of radical approaches to cost containment with subsequent devaluation of nursing and nursing practice" (Turkel & Ray, 2000, p. 307).

In the United Kingdom there have been changes to the nursing skill mix in order to increase efficiency and contain costs, and a greater emphasis on patient throughput and measurement of specific performance targets (Doherty & Collier, 2009). Despite having some positive outcomes including reduced waiting list times and length of stay in emergency room beds, it was found that there was a loss of the caring aspects of nursing such as comforting and listening to patients, and a greater emphasis on technical tasks (Doherty & Collier, 2009; Duffield et al., 2011).

In Australia the financial situation for public hospitals looks unlikely to improve in the foreseeable future, with the Australian Medical Association predicting that the Commonwealth

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hospital funding from 2017 will be at inadequate levels based on current performance (AMA, 2015). Future funding will be based on the Consumer Price Index (CPI) and population changes only and will not increase capacity or allow public hospitals to meet the government mandated targets. Thus the number of beds available per capita is expected to continue to decrease (AMA, 2015)

Health expenditure is complex and the increase in costs over the last 25 years can be explained in part by the growing and ageing population, but it is also influenced by community expectations of the health system and access to technologies, treatments and services (Australian Institute of Health and Welfare, 2016). It is argued here that these systemic attributes which fail to adequately support patients with dementia and nurses are false economy and produces an environment in which there is dissatisfaction with care, alienation of the workforce and poor outcomes for the patients. Hospitals proclaim a commitment to person-centred care but the powerful bureaucracies which dictate work practices and allocation of resources deem this difficult to implement. Increased financial investment is required in the sub-acute geriatric rehabilitation facilities in order to provide the appropriate material resources, education and psychological support of nurses and improve the infrastructure of hospitals to accommodate the needs of older people and those with dementia. However hospitals are viewed as businesses, with priorities that may make the care of patients with dementia an unattractive option.

Hospitals are businesses

There is growing pressure on hospitals to increase their efficiency (Victorian Auditor-General, 2016), and many have adopted Lean Thinking strategies in order to contain costs and become more efficient, emulating the approach originally introduced by Toyota to improve the productivity and efficiency of automobile and other manufacturing sectors (Womack, Jones, Roos, & Yang, 1990). Lean Thinking is a system in which organisational practices are reconfigured in order to reduce waste and increase productivity (Radnor, Holweg, & Waring, 2012). Since the early 2000s, Victorian public hospitals have been encouraged to adopt Lean Thinking processes to improve efficiency, especially in regard to the widespread problem of

access block which occurs when emergency departments are overwhelmed by demand and there are insufficient inpatient beds to cope (Stanton et al., 2014).

Lean Thinking techniques clearly have some potential to positively contribute to the organisation of healthcare (Ben-Tovim et al., 2008), however there have also been some criticisms including that clinicians are redirecting their attention away from patient care in order to comply with administrative duties (Waring & Bishop, 2010). A consequence which relates to geriatric rehabilitation wards and which was observed in this study was that patients were discharged earlier, often with unresolved social issues, in order to create beds for others waiting to be admitted from acute hospitals. The arriving patients were sicker and required more acute-focused care than previously. This escalation in turnover and acuity both increases nursing workload and reduces the time that could previously have been used for caring practices and communication with patients (Quirke, Coombs, & McEldowney, 2011). Clissett, Porock, Harwood, and Gladman (2013b) go so far as to say that the focus on financial targets and turnover comes at the expense of person-centred care, and it is a view that is supported by the findings in this study.

In addition to the focus on budgetary restraint, Harrison (2002) identified that the increasing regulation of health practices in the United Kingdom which dictated that practice should be based on clinical guidelines and protocols, had caused delays in the system which was consequently caught up in bureaucracy. The term 'new managerialism' was used to describe the model of health care management based on the example of private sector business with continuous evaluation of performance against defined objectives, outputs and standards (Nettleton, 2013). Increasing the expectations that clinicians comply with the new model of management brought with it a plethora of quality monitoring activities to scrutinize and substantiate practice. On one level it was a positive move to improve standards of care and professionalism; however an additional consequence was that there was a decreased emphasis on individual clinical judgement and clinician-patient relationship (Green, Durand, Hutchings, & Black, 2011; Harrison, 2002). Additionally a greater emphasis on auditing and compliance was an arrangement that did not necessarily demonstrate improved practice (Nettleton,

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Burrows, & Watt, 2008). Nettleton et al. (2008) contend that formal regulation was a poor replacement for sensing, observing empathetically and using hands-on experience, or that audits categorically indicated quality.

In the Australian hospitals in this study, there were some parallels with the situation in the United Kingdom (Harrison, 2002). A number of the nurse participants claimed that the increased requirements for audits and documentation significantly detracted from the time available for patient care. This was also noticed by one of the patient participants who commented that the hospital was being run like a business using quality control and data, with only a percentage of the day spent in traditional nursing, unlike his previous experiences many years ago. Harrison (2002) asserts that in a society which is disproportionately concerned about health, there is a reliance on systems for what was formerly entrusted to individuals in order to gain a level of reassurance; however the off-shoot is that there is an increasing amount of auditing which takes nurses away from the bedside without necessarily an improvement in standards.

The new managerialism has had the unfortunate effect of constraining nursing decision-making and autonomy and subsequently decreasing trust in nursing staff (Goodman, 2014). There is also the danger that displays of compliance to the many rules and procedures will take priority over the desire to actually make the systems safer or of better quality (Dixon-Woods et al., 2014). A culture of self-protection can develop in which the requirements of the organisation for documentation and avoidance of litigation can take priority over the need to deliver compassionate care (Goodman, 2014). Rankin and Campbell (2006) suggest that the changes in practice accountability and surveillance, despite being efficient from a business perspective have had an unwanted effect on the quintessence of nursing, which as a result is becoming unrecognisable and unattractive to nurses and patients.

Controlling risk

In Australia, there is an emphasis in hospitals to comply with the required key performance indicators (KPIs) including prevention of falls, infection control and management of other risks.

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Reporting and reducing falls is a voluntary KPI agreed upon by the Victorian hospitals sub-acute peak body and a major focus of the sub-acute sites (Department of Health, 2012). Prevention of falls can consequently take operational priority over other issues which do not have KPI targets attached to them such as nurse workload and patient agitation. According to the nurse participants in this study, extra staff were seldom granted to cope with these additional demands, although on rare occasions a patient with an extreme falls risk might attract a 'special'. Focussing on a specific issue such as prevention of falls without considering the effect that this constraint has on the patients and the nurses leads to conflict between person-centred care and the need to control, record and risk assess everything (Goodman, 2014; Moyle et al., 2011).

Controlling risk is another example of the health service exerting power and is not only about preventing harm to the patients in an altruistic sense. Health services have a financial and reputational stake in ensuring safety for the people in their care. Litigation is becoming increasingly common (Ibrahim & Davis, 2014). The patient, particularly those with high risk factors such as people with dementia, can be seen as an obstruction to fulfilling the aims of the organisation, which can be made to seem more important than the actual delivery of compassionate care (Goodman, 2014). There are financial reasons why caring for patients with dementia is disadvantageous to the hospitals. The average cost for people with dementia is up to 2.7 times more per episode than for a person without dementia (Australian Institute of Health and Welfare, 2013a) and since improving operational efficiency and eliminating waste can optimise spending, certain patient diagnoses are more favourable than others (Sturgeon, 2010).

The nurses reported that they spent as much time documenting risk as delivering care. An excessive focus on risk added to the workload of nurses and unnecessarily confined the patients. From the patient perspective this was demonstrated in two of the older style wards which were on the fourth floor of a building and had no opening windows. Most of the patients were not permitted to go outside for safety reasons as they might fall, or abscond if taken to the ground floor. A number of the patient participants expressed their frustration and annoyance at this situation and felt that they were imprisoned.

Doing more with less

Healthcare institutions controlled by medically-dominated bureaucracies exert power over the patients, nurses and the organisation of caring and ways of working (Crookes et al., 2008). Unfortunately 'non-essential' staff, meaning those who are not governed by the Nurses Award (Australian Nurses Federation Victoria, 2012) such as diversional therapists, and non-nursing staff employed as specials or continuous patient observers (CPOs), are the first staff to be reduced when the budget is tight. Additionally specialist nurses in cognition and clinical nurse consultants in geriatrics are considered discretionary and non-essential from a budgetary and award perspective. As a result the wards in this study operated on the basic nurse ratios prescribed by the Nurses Award (Australian Nurses Federation Victoria, 2012) with some limited sessional assistance from volunteers. The reluctance of the hospital administrators to provide additional staff to assist with patients with behavioural symptoms caused considerable resentment in the nurses and added to the stress already felt.

One of the important findings in this study is that providing extra staff when needed has a positive effect on both the nurses and the patients. Although no extra staff were employed during the observation period of this study, nurses reported that on the rare occasion that this did occur, they felt appreciated and less stressed. The key positive was that rather than focussing almost exclusively on the patient who needed the extra attention, they were able to give all of their assigned patients the care that they deserved. It must be noted however that an increase in nurse numbers does not automatically result in an improvement in person-centred care (Cowdell, 2010b). Additional staff will not necessarily change attitudes and renew the focus on patient-centred priorities, in fact in this study staff reflected that employing specials does not necessarily improve patient care.

It is known that people with dementia have higher rates of hospital-acquired complications than those without dementia (Australian Institute of Health and Welfare, 2013a) and that many of the complications which extend length of stay such as urinary tract infections, pressure ulcers and pneumonia are sensitive to nursing care and therefore potentially preventable (Baillie, Merritt, Cox, & Crichton, 2015). The provision of adequate numbers of skilled nurses is

therefore not only necessary from a humanistic perspective but makes sense from a financial perspective (Bail et al., 2015).

The built environment and patients with dementia

The poverty of the ward environment in this study reflected the low priority assigned to these patients by the health services and was a further example of material disempowerment. There has been considerable research done previously on the effect of architecture on the care of people with dementia, although much of it has been focussed on residential care (Fleming & Purandare, 2010). Fleming and Bennett (2014) have identified some principles of design which enhance the care of people with dementia. They suggest that risks must be reduced unobtrusively to ensure that the person does not feel confined or overly restricted, that the buildings must be of modest scale so as not to overwhelm, and the people with dementia must be able to see and recognise where they are to minimise spatial confusion. They also recommend that unhelpful stimulation such as excessive noise be minimised and that helpful stimulation such as a specific colour for the patient's door, the smell of food at lunchtime, be provided. Clear direction, pictograph signage and pathways gives people opportunities to engage with their environment, and be alone or with others as they desire (Fleming & Bennett, 2014).

In the five wards in this study there was a range of architectural styles, none of them specifically designed to accommodate the needs of people with dementia. Two of the older wards had been used over their 40 year history for a variety of purposes including orthopaedic and renal units. Another ward on the same site was built in the last decade but not to accommodate the specific needs of people with cognitive deficits.

A conspicuous feature of the two older wards on site one was the circular floor plan in which the patient bays were arranged around the staff station in the middle. Agitated patients in both wards were frequently seen doing restless laps around the corridor, pausing only to check the exit door. The new ward with primarily single rooms had very long corridors with few distinguishing features or landmarks, was very confusing and difficult to navigate successfully.

Environmental design can affect the behaviour of people with dementia who may become agitated, aggressive or disorientated in response to confusing floor plans (Marquardt, 2011). Architectural features observed in this study, particularly in the two older wards definitely contributed to patient unrest and dissatisfaction, demonstrated by patient pacing and agitation. In these wards six patients shared a bathroom (five from one shared room and another from the adjoining single room) which limited privacy and access. The wards were all potentially mixed-gender, and although the staff did their best to segregate male and female patients this was often not possible as they were obliged to take whichever patients they were allocated, often at short notice. Male and female patients therefore shared the very limited bathroom facilities, severely compromising privacy and dignity. These older wards had balconies which were permanently locked for safety reasons, and the windows were extremely dirty, restricting the view to the outside. None of the windows was able to be opened. Dobrohotoff and Llewellyn-Jones (2011, p. 181) hypothesize that the 'atmospherics' or ambient environment which include temperature, humidity, air quality and smells, is crucial for the comfort of the inhabitants and can significantly affect their behaviour. In these wards, the air was stale and close and often overheated. Not having access to an outside space was a source of intense frustration for some of the patients. The ability to access or at least see a garden has been shown previously to have a positive effect on patients (Digby & Bloomer, 2014b).

The physical environment had a significant part to play in the experiences of the patients and the care delivered by the nurses. There were considerable limitations exposed in the architecture of the wards included in this study which contributed to the problems experienced by both patients and nurses. Hospitals need to use evidence-based design if they are to adapt their buildings to accommodate the needs of people with dementia with any degree of confidence. The fact that geriatric rehabilitation is often housed in extremely poor buildings, not designed for their current purpose is a demonstration of the low priority assigned to these patients.

The liminal experience of the patients in this study was the result of the hospital and the staff failing to cater to the needs of this patient group from a number of perspectives. The lack of appropriate accommodation for patients with dementia and the identified educational shortfall

of the nurses combined with an attitude of entrenched stigmatisation towards patients with dementia, created an atmosphere of exclusion.

Chapter summary

In summary this critical ethnographic study has revealed some significant new insights into the factors which influence the care of people with dementia and the experience of patients and nurses. The difficulties experienced by people with dementia were partly due to stigmatisation and a hospital culture focussed on acute care and efficient patient flow. A person-centred approach to care was not always evident in the wards in this study. This could be due to the effect that the macro organisational management, business and economic factors are having at the micro level.

Nurses were under supported both from an educational and psychological perspective and in terms of adequate staffing. A poor understanding of dementia resulted in care which was generalised and did not specifically take cognition into consideration. Patients with dementia were considered by many to be less worthy of care than others with intact cognition and this subsequently led to patients with dementia feeling excluded and alienated. Poor support for cognitive disability translated to a poor experience in hospital for these patients.

Hospital culture centred on biophysical care supported the dominance of the medical profession over nursing. The funding issues in health in Australia have shape the findings presented in this study.

Chapter 7 Conclusion and recommendations

Introduction

In this chapter the research findings will be summarised, drawing together the outcomes generated from this study. Additionally the strengths and limitations of the study will be addressed. Recommendations, specifically about nurse education and practice change will be proposed. Further research in this field will be suggested.

Overview of the findings

This thesis reported the findings of a study exploring the experiences of patients with dementia and the nurses caring for them in sub-acute hospitals. The purpose of the research was to critically analyse the factors which influenced care practices. The literature which examined the experience of people with dementia and the nurses caring for them from the perspective of the individuals was reviewed. This review has been published (Digby, Lee, et al., 2016b), and additional material which augmented the findings was added in chapter two of this thesis. Although accounts of hospital experience in which the patients themselves were directly consulted were rare, the identified literature reported that patients with dementia found admission to hospital stressful and difficult (Cowdell, 2010a; Norman, 2006; Porock, Clissett, Harwood, & Gladman, 2015) and argued that this was due to a number of factors including a lack of engagement with the nurses (Edvardsson et al., 2012). The view of the nurses reported in the literature centred mainly on the frustration they felt at not being adequately educated about dementia (Atkin, Holmes, & Martin, 2005) or having the resources they required to manage the patients with this condition (Byers & France, 2008; Clissett et al., 2013a). The recruitment processes used to employ the nurses who worked in these wards was not discussed at any length in the literature; however in this study it was found that the suitability of the nurses for the role had a considerable influence on care practices. Similarly the psychological support of nurses was only a minor consideration in the majority of the articles but it was found in this study that the

lack of support in this area was significant, especially in regard to job satisfaction and maintaining the ability of the nurses to care empathetically for others.

The experiences of people with dementia and nurses have not been previously explored using a critical ethnographic approach. Furthermore there has been a limited amount of research on this topic conducted in Australia, although there have been a number of studies in the United Kingdom and Scandinavia. In these latter studies the poor experience of people with dementia in hospital and the shortage of nurse empathy was found to be due to complex reasons mainly related to hospital culture and focus.

In order to address the research question, interviews were conducted with 30 patients with dementia who were current in-patients and 29 nurses who worked in the nominated wards. The interviews consisted of individual audio-recorded conversational interviews in which the participants were asked to discuss their experiences of being either a patient or a nurse in that ward. Additionally 120 hours of non-participant observation was conducted during which time copious field notes were taken. The relevant ward documents including the progress notes of the patients with dementia were examined.

The research findings of this study were consistent with those presented by Borbasi, Jones, Lockwood, and Emden (2006) and Clissett et al. (2013a). There were additional issues identified which supplemented the results of the studies reported in the literature. The present research demonstrated that there was a lack of specific requirements for the recruitment of nurses in this area, which must be addressed in order to ensure that the nurses working in this area have the necessary attributes. Additionally the effect of hospital governance on care practices in relation to people with dementia has not been comprehensively investigated.

The present research demonstrated that targeted education and psychological support for the nurses was needed, both in relation to the education provided by the hospitals and the professional development of the nurses themselves. Few nurses in this study reported that they had pursued education outside of the workplace despite there being a number of free resources

available to them. This finding was not influenced by the age, gender, years of experience or ethnicity of the nurses.

The patients with dementia were considered by many to be less worthy of care and attention than other patients because of the detrimental effect that these patients had on the ward routine, the budget and the length of stay statistics. The progressive nature of the condition lead some to believe that they were wasting time valuable on patients with dementia that could otherwise be spent on those for whom the immediate results were more obvious. The culture of exclusion of certain patient groups is inappropriate in a public health service.

The findings of this study will now be discussed in terms of the research aims and research question.

The aim of this study was to explore the experiences of people with dementia and nurses in sub-acute geriatric rehabilitation hospitals in order to offer a critical perspective of the widely reported poor care received by such patients. A further aim was to focus attention on the cultural and organisational factors which influenced care.

The central research question was: "What are the factors which impact on the care of people with dementia in sub-acute geriatric rehabilitation hospitals"?

Understanding the factors which impact on the care people with dementia and nurses in sub-acute geriatric rehabilitation facilities

The patient participants in this study reported that they felt like outsiders in the hospital with very little control over their care or discharge planning. To the patients, the hospital routine seemed very regimented and boring especially to those who spent the majority of the day seated next to their bed. There was very little occupation or activity offered to patients and restlessness was often the result. Patients with an acute illness or those returning to the community generally had regular physiotherapy, and potentially occupational therapy or speech therapy depending on need. However once the decision was made to discharge the person to residential care, it was

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rare for them to have any therapy at all, despite the risk this entails of deconditioning and further cognitive decline. A bed in residential care could in some instances take many weeks to organise, however there was no diversional therapy in any of the five wards in this study, and boredom and restlessness in some areas was acute. One health service had a volunteer group which had made a difference to some of the patients, particularly in one ward, however the attendance of the volunteers was minimal.

Many of the patient participants described feeling at a loss as to why they were in hospital and being kept there against their will. Some described feeling imprisoned and very frustrated. This was augmented by the lack of activity or occupation for many. A number of the patients complained about the bossy manner of some nurses and the failure of the team to include them in their care and discharge decisions. This resulted in a liminal experience for the patients who consequently felt like outsiders in the hospital system.

The nurses in this study reported feeling inadequately educated and unprepared for the role. Most said that they learnt on the job and had not received any significant education about dementia. In the face of the perceived lack of support from the hospital administration many of the nurses said that they relied on their nursing colleagues for practical and emotional assistance to get them through. Being too busy to deliver the care they knew that the patients deserved was a source of frustration for many. Some of the nurses focused on controlling the behaviour of the patients with dementia in a variety of ways including distraction, positioning and medication which enabled them to get the daily work done. Reports of the bossy paternalistic manner of some of the nurses came from both the patients and other nurses, and some of the nurse participants admitted that they did not like caring for people with dementia. Equally there were nurses who demonstrated genuine empathy and clearly enjoyed working in this area.

The nurses complained about the lack of support for their work however none felt that they had the power to change the situation or improve the status quo for themselves or their patients. There was an attitude of resigned helplessness among the nurses. They did not take the option

of pursuing education for themselves other than that provided by the hospital. This was the case for nurses of all age-groups and both registered and enrolled nurses.

Understanding the factors which affect nursing practice

The nurses work in a stressful environment in which the demands of the role are increasing with no corresponding increase in resources. Caring for patients with dementia in this environment caused additional stress because of the increased demands of caring for a person with cognitive deficits, at the same time as attending to other duties. The nurses did not receive any formal psychological support in the form of clinical supervision or mentoring, and there was very little debriefing initiated. To compensate, the nurses relied on each other, or in some instances, their nurse manager for support. A number of the nurses said that they were considering seeking alternative employment.

The nurses had received very little education about dementia and most said that they learned on the job from their colleagues and trial and error. The result of this is a culture of treating the patients in certain ways in the habitus of the ward, rather than according to best practice. Not knowing the most appropriate way of dealing with an agitated or aggressive patient led to some nurses avoiding certain patients, or administering medication as a first line of treatment for behavioural symptoms.

Nurse leadership was identified as an important influence on the job satisfaction and caring practices of the nurses. In the wards with strong nurse managers the nurses were more satisfied and better supported in the role. Good teamwork and working together was a feature of these wards and had an influence on the nurses' job satisfaction.

The nurses generally accepted their position of powerlessness in the hospital system and did not appear to have considered that they have an influence on the funding or resources allocated to them to carry out the role. In relation to decisions about the patients beyond minor, the nurses similarly accepted that they did not have a role and left this to allied health and medical staff.

Understanding the relationship between hospital culture and processes on the experiences of patients with dementia and nurses

The traditional medically-dominated bureaucracy governing hospitals use funding models which focus on maximising the output for the dollar and do not favour minority groups such as people with dementia which require extra resources. The patient with dementia is considered a hindrance to this aim because of the longer average length of stay and the propensity to develop complications or fall.

New managerialism which aligns health service management with private sector business practices requires that constant monitoring and evaluation of performance be conducted in order to compare performance against defined objectives and substantiate practice. This is very time-consuming and reduces the time available to nurses to care for the patients.

The push to achieve patient occupancy targets is strong due to the accountability of the clinical team for performance. Additionally the prevention of patient falls is a worthy goal but this requires auditing and managerial scrutiny. Nurses conform to this model and accept that they have little control over the administrative practices that have been imposed on them. The culture which is the result of the emphasis on these goals supports a belief that some patients are more worthy of time and resources than others.

Caring for people with dementia is complex because patients with this condition have a reduced capacity to interpret and understand the environment and manage stressors. Being in an unfamiliar place with unfamiliar faces and routines, such as when the person is admitted to hospital, can trigger serious behavioural disorders and disorientation. In this study, the inclusion of family in the care of a person with dementia was largely ad hoc and often left to the family to initiate, despite it being known that the presence of a familiar person can make a significant difference to the person with dementia and contribute information and practical help. Orientation of the patient with dementia did not go beyond that offered to any other patient admitted to the ward despite the additional needs, and there were no added resources provided to assist with the extra care required by these patients.

Methodological strengths

There are a number of factors which have impacted on this research. The study has some methodological strengths which have facilitated the gathering of extensive data. Critical ethnography was used in order to uncover the hidden agendas and power relationships that were relevant to the two groups of participants within the hospital environment. The rationale for the use of this methodology was to enable a focus on the patients with dementia and the nurses as marginalised groups and identify the practices which sustain this inequality.

The use of a number of different sources of data including interviews, extensive observation with field notes, and the examination of relevant documents is a further methodological strength which allowed the comparison of information gained from one source to be compared to others to verify the meaning and build up a complex picture.

Furthermore people with dementia have not been directly included in research until recently because of the perception that cognitive frailty would impact negatively on the reliability of the data. However this has proved to be unfounded in this research in which the participants with dementia demonstrated a unique perspective on their situation and had a valuable perspective. Interviewing the participants with dementia directly rather than seeking information through the interpretation of health professionals, carers or family allowed the authentic opinions of the individuals to be gathered. The information gained captured the essence of the person's experience as they saw it at that moment.

Method limitations

There are some method limitations to this study which are recognised. For reasons of time the viewpoint of family carers has not been extensively explored here despite many having relevant and interesting opinions on this issue. Other than incidental conversations during the observation period and some discussion during the patient consent process, the viewpoint of family carers was not actively sought. The opinions of medical staff and other health professional staff were not explored in this study because of time limitations. This thesis is

focussed on the nursing voice however in a critical paradigm medical dominance has an influence but in this case it was out of scope.

The patient participants were identified by the medical officers as being suitable for inclusion in the study, however on a number of occasions a patient was deemed by the clinical team to be too uncooperative or ill-tempered to take part. It is possible that such patients might have had a view of the hospital experience that would have added further information to the study, however the researcher was not granted access to their opinions. The inclusion criteria excluded people who were unable to have a conversation in English which meant that information about being in a foreign-language environment was not captured. Patients with advanced dementia were also excluded for practical reasons however eliciting the opinions of this patient group would be valuable should it be methodologically possible.

The second group within the scope of this study are the bedside nurses caring for these patients in sub-acute facilities. The nurses volunteered to participate in the interviews and it is possible that other nurses with different opinions of care declined to volunteer. The concept of interest in this study is the bedside care and the experiences of the patients and nurses involved, hence the opinions of more senior staff and administrators were not actively sought.

A further potential limitation in this study related to the time limitations on the interviews conducted with the nurse participants. Because all the interviews were conducted in the workplace during working hours there were competing priorities for the time-poor nurses who had to arrange cover for their patients in order to be interviewed. There were occasions when the interviews were curtailed for this reason.

There is the possibility of the Hawthorne effect in which the participants behave differently because of the presence of the researcher in order to present well (Neuman, 2006). This is difficult to ascertain definitively however in the fast paced hospital environment, it is considered to be improbable that the nurses would maintain this facade for any length of time (Chiesa & Hobbs, 2008; Leonard & Masatu, 2006). In this study it seems unlikely that the Hawthorne effect was present. A number of times during the observation period the nurses were witnessed

to be behaving in an unprofessional way despite being aware of the researcher's presence, and similarly a number of nurses were negative and judgemental about the patients during interview. They did not appear to be modifying their behaviour because of the presence of the researcher.

A further limitation is the location of the study in only two hospital facilities, both with a fairly similar patient and nurse demographic. The inclusion of other hospital sites in different locations could potentially uncover different patient and nurse experiences particularly if they included patients and nurses from different cultural groups. Within the same hospital system, different health networks choose to allocate funds to different priorities. For practical reasons, this research was conducted in five wards in only two networks and it is conceivable that the situation in other networks would be different. Further research undertaken across a range of hospital wards in different locations would be valuable.

Photoelicitation was attempted to lessen the reliance on direct questioning to prompt conversation with the patient participants. In practice this was largely unsuccessful. People with dementia endure cognitive testing repeatedly over the course of their condition and many of the participants saw it as another test, and concentrated on identifying the items in the photographs. Very little conversation could be attributed to the use of this technique, however it did not appear to have any negative effects.

The recommendations of the study

There are three main recommendations from this study related to hospital governance, nurse education and practice change, and future research.

Recommendations for hospital governance

- Hospitals must acknowledge the additional needs of patients with dementia and adapt services accordingly.

It must be recognised 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. Funding is needed to provide infrastructure which is suitable for older people including those with dementia. This is not currently the case and the patients are housed in unsuitable buildings not designed or necessarily appropriate for this purpose.

- Activity and engagement of patients with dementia should be supported by diversional therapy, targeted allied health sessions and appropriately trained volunteers.

Funding to allow the re-instatement of diversional therapists is important to prevent the de-conditioning of people with dementia while they are in-patients, and maintain cognitive strengths through occupation. Physiotherapy and occupational therapy is currently prioritised for patients returning to the community, however it is important for all the patients to maintain strength and fitness while in hospital. Removing this support for the patients is false economy and can result in more falls and complications brought on by inactivity. Appropriately trained volunteers are a useful adjunct to formal services and should be considered.

Recommendations for nursing

- In line with the clinical practice guidelines (Laver et al., 2016), nurses require additional role-appropriate dementia-specific education.

Very little hospital-based education appears to include cognition and dementia. The nurses in this study reported that this was a major shortfall and had a negative impact on their ability to make informed decisions about the care of people with dementia. The provision of education that included evidence-based strategies to inform nurses at the bedside is greatly needed. It is recommended that online options including Massive On-line Open Courses (MOOCs) be considered to fill this gap. Nurses in this study in the main did not take personal responsibility for managing their own professional development despite the requirements of their registration.

- Nursing resources should be adapted to ensure that appropriate staffing is available manage the additional needs of patients with dementia.

Minimum nurse ratios are governed by the Nurses' award (Australian Nurses Federation Victoria, 2012) however providing extra staff is done at the discretion of the health service and is related to need and priorities. The nurses in this study did not feel that they could advocate for appropriate staffing and adopted an attitude of powerlessness in the face of the medically-dominated bureaucracy governing the hospital. Nurses and nurse leaders must learn to use the power that they have to create change and innovate in the constantly evolving health system.

- Appropriate psychological support should be available to nurses

Nurses in this study were not well-supported psychologically. Clinical supervision which is compulsory for mental health nurses (Victoria Health, 2012) was not offered to the nurses in this study and there was very little debriefing or group reflection provided, and only on an ad hoc basis at the behest of the senior nursing staff. Hence the nurses supported each other where they could but for many this was not enough. Failing to support nurses in this way is a demonstration of lack of respect for the nursing profession and can result in poor job satisfaction and psychological exhaustion, ultimately reducing the quality care being delivered. It is recommended that the psychological support of nurses be further investigated, and appropriate strategies implemented.

- Recruitment processes must include appropriate screening for nurses applying for positions in this area of nursing.

Recruitment of nurses to work in the sub-acute wards requires review to ensure that those working in these roles have an affinity for older people, an understanding of dementia and experience in delivering person-centred care.

Recommendations for further research

There are a number of areas identified in this study which require further research. Importantly the model of care in geriatric evaluation and management facilities requires review to ensure that provision is made to adapt to the growing number of patients with dementia entering these

facilities. The organisation of nursing work is strongly influenced by habitus; however there are innovations in other countries which could be trialled in an Australian context.

Exploration of better ways of ensuring that nurse education equips nurses appropriately for the task at both an undergraduate level and in-service education is important and timely. Nurses are not currently well-equipped to deliver quality care for people with dementia in these facilities, and in this study identified that lack of knowledge and skill development was a key factor.

Chapter Summary

The experience of patients with dementia and nurses in sub-acute geriatric rehabilitation hospitals in this study were investigated through interview, observation and examination of documents using a critical ethnographic methodology. It was found that people with dementia can be marginalised and considered less worthy of care and resources than patients with acute illnesses. The patients reported a liminal experience as outsiders in the system which does not cater to the specific requirements related to cognitive impairment. The nurses are not well supported educationally, materially or psychologically to care for people with dementia in this environment, leading to reported frustration and poor satisfaction with work. The hospital culture which is heavily influenced by new managerialism promotes compliance to bed occupancy targets, budgets and risk minimisation at the expense of person-centred care.

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Appendices

APPENDIX 1: Monash University ethics approval

MONASH University

Monash University Human Research Ethics Committee (MUHREC)
Research Office

Human Ethics Certificate of Approval

This is to certify that the project below has been approved by the Monash University Human Research Ethics Committee under the Memorandum of Agreement with Monash Health

Project Number:	CF14/1210 - 2014000512
Project Title:	The care of people with dementia in sub-acute inpatient facilities: The nurse-patient relationship
Chief Investigator:	Assoc Prof Allison Williams
Approved:	From: 16 April 2014 to 16 April 2019

Terms of approval - *Failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.*

1. Approval is only valid whilst you hold a position at Monash University and approval at the primary HREC is current.
2. Future correspondence: Please quote the project number and project title above in any further correspondence.
3. Final report: A Final Report should be provided at the conclusion of the project. MUHREC should be notified if the project is discontinued before the expected date of completion.
4. Retention and storage of data: The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

Professor Nip Thomson
Chair, MUHREC

cc: Ms Robin Digby

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 3831
Email muhrec@monash.edu http://www.monash.edu.au/researchoffice/human/
ABN 12 377 614 012 CRICOS Provider #00008C

Research project

[Name of hospital]

A Monash University researcher will be spending some time with nurses and patients observing the everyday activities of the ward.

This is so that we can better understand how it is for people when they are in hospital.

If anyone would prefer not to be involved, please let a staff member know.

Some interviews will be conducted with patients. You don't have to be interviewed if you don't want to – it's optional. Anything you tell the interviewer will be confidential.

You or your relative will be asked to sign a consent form before any interviews are conducted.

If you would like further information, please contact:

Robin Digby

PhD candidate
rdig1@student.monash.edu 0400892518

This project has been reviewed and approved by ██████████ Human Research Ethics committee.

The care of people with dementia in a sub-acute inpatient facility:

GROUP OF EIGHT

The nurse-patient relationship

Attention all nurses

You are invited to participate in a study to explore nurses' experiences caring for people with dementia in sub-acute facilities.

This involves a confidential interview with me at a location convenient for you, lasting approximately 30-60 minutes.

If you are interested or would like further information, please contact

Robin Digby

PhD candidate
rdig1@student.monash.edu 0400892518

This study has been reviewed and approved by ██████████ Human Research Ethics Committee.

APPENDIX 4 : Aide-memoire (nurses)

- Can you tell me about your experiences of caring for people with dementia in this ward?
- What is it like for you when a patient with dementia has behavioural symptoms?
- What strategies would you use in this situation?
- How do you react if a patient is aggressive towards you?
- What support do nurses need to care effectively for patients with dementia?
- What more could the organization be doing to support nurses better?
- What motivates you to work here?
- What do you like/ don't like about this type of nursing?
- Have you had education about dementia/ cognition?
- How do manage your work when you are caring for patients with dementia, and have other patients as well?
- Is it better for the patients/ nurses if the patient with dementia is in a single room or in a shared room?

- Can you tell me what it's like for you being in the hospital?
- What are the good things about being in here?
- What don't you like about being in here?
- I notice you are sharing the room with x other patients. How is that for you? Do you like being in a room with other people?
- What do you do during the day?
- Do you ever go outside?
- How do you get on with the nurses/ doctors?
- What can you tell me about these photos?
- What could we be doing to make your stay in hospital better?
- What do you think will happen next for you?

MONASH
University

(Hospital Logo)

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

███████████████

Title	The care of people with dementia in sub-acute facilities: The nurse-patient relationship.
Coordinating Principal Investigator/ Principal Investigator	Robin Digby
Location	█████████████

Part 1   What does my participation involve?

1   Introduction

You are invited to take part in this research project, which is called 'The care of people with dementia in sub-acute facilities: The nurse-patient relationship'. You have been invited because you are a nurse at █████████████ who responded to the flyer and may be able to comment on this matter.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

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Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to take part in the research project

• Consent to be involved in the research described

• Consent to the use of your personal information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The aim of the project is to better understand the experience of people with dementia while they are in hospital and the experience of the nurses caring for them. We already know that people with dementia can have a difficult time in hospital because of their reduced ability to adapt to new situations. This can lead to unsettled behaviour. We also know that nurse can find caring for people with dementia stressful.

We have very little information about the experience of patients and nurses in this setting. The aim is to find out more information so that we can improve care for the patients and support for the nurses.

The results of this research will be used by the researcher Robin Digby to obtain a Doctor of Philosophy degree. There is no grant or sponsorship funding this project.

This research has been initiated by the researcher, Robin Digby, PhD candidate

3 What does participation in this research involve?

A consent form will be signed before any interviews are conducted.

All nurses working in this ward are eligible to participant in this research.

If you agree to participate, an interview will be conducted with you in a quiet place convenient to you which will last up to an hour. You will be asked to talk about your experiences of being a nurse caring for people with dementia in the ward. You do not have to discuss anything which you would prefer not to. The interview will be audio-recorded. You are welcome to have a relative or friend with you during the interview. The recording of the interview will be transcribed and all identifying information about you will be removed.

The project is being conducted at 2 Melbourne Hospitals and will be completed at the end of 2014.

This research project has been designed to make sure that researchers interpret the results in a fair and appropriate way and avoids researchers and participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid.

4   Other relevant information about the research project

On this site, about 15 patients will be interviewed individually by the researcher. This research will also be conducted at another Melbourne hospital.

5   Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with ██ ████████.

6   What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the opportunity to air your views with the researcher. The outcome of the research is expected to be an improvement in the support for nurses in your situation in the future.

There will be no clear benefits to you from your participation in this research.

7   What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or stressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8   What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. A member of the research team will inform you if there are any special requirements linked to withdrawing. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9   Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as illness of the researcher.

10   What happens when the research project ends?

When the research project is completed you will be provided with a summary of the results.

.

Part 2   How is the research project being conducted?

11   What will happen to information about me?

The information collected from you and other research participants will not be individually identifiable. The data will be stored electronically on a password-protected computer only accessible to the research team.

The data will be stored for 5 years as required in the NHMRC guidelines and then deleted.

The paper consent forms will be stored for 5 years in a locked filing cabinet in the principal researcher's locked office. After this period it will be shredded.

Your information will only be used for this project. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored.

12   Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

13   Who is organising and funding the research?

This research project is being conducted by Robin Digby, PhD candidate, Monash University, and no funding has been sourced.

No financial benefit is expected from this research project

You will not benefit financially from your involvement in this research project.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14   Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of ████ ████

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15   Further information and who to contact

 The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on 0400892518 or any of the following people: ████████████████████████████████████ ████

Research contact person

Name	Robin Digby
Position	PhD Candidate, Monash University
Telephone	0400892518
Email	Rdig1@student.monash.edu

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	[name of Operations Director]
Position	Operations Director
Telephone	████
Email	Insert email address

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Name: xxxx	
Position: Manager Research Services	
Telephone	xxxxxxxxx
Email	Insert email address

Consent Form - *Adult providing own consent*

Title   The care of people with dementia in sub-acute facilities: The
                           nurse-patient relationship

Short Title

Protocol Number

**Coordinating Principal
Investigator/**   Robin Digby, PhD candidate, Monash University

Location

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I
understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free
to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)
Signature   Date

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe
that the participant has understood that explanation.

Name of Researcher[†] (please print)

Signature   Date

_____   _____

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title   The care of people with dementia in sub-acute facilities

Protocol Number   *[Protocol Number]*

Coordinating Principal Investigator/   Robin Digby, PhD Candidate, Monash University

Principal Investigator
Location   [Name of hospital]

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or The [hospital].

Name of Participant (please print)
Signature   Date

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print)
Signature   Date

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature

(Hospital logo)

Participant Information Sheet/Consent Form

Health/Social Science Research - *Adult providing own consent*

[Name of hospital]

Title	The care of people with dementia in sub-acute facilities: The nurse-patient relationship
Project Sponsor	N/A
Coordinating Principal Investigator/ Principal Investigator	Robin Digby
Location	▮▮▮▮▮▮▮▮▮▮

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called 'The care of people with dementia in sub-acute facilities: The nurse-patient relationship'. You have been invited because you are a patient at ▮▮▮▮▮▮▮▮ and may be able to comment on this matter.   Your contact details were obtained from the team caring for you.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or staff member.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to take part in the research project

• Consent to be involved in the research described

• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2   What is the purpose of this research?

The aim of the project is to better understand the experience of people with dementia while they are in hospital and the experience of the nurses caring for them. We already know that people with dementia can have a difficult time in hospital because of their reduced ability to adapt to new situations. This can lead to unsettled behaviour. We also know that nurse can find caring for people with dementia stressful.

We have very little information about the experience of patients and nurses in this setting. The aim is to find out more information so that we can improve care for the patients and support for the nurses.

The results of this research will be used by the researcher Robin Digby to obtain a Doctor of Philosophy degree. There is no grant or sponsorship funding this project.

This research has been initiated by the researcher, Robin Digby, PhD candidate

3   What does participation in this research involve?

A consent form will be signed before any interviews are conducted.

Initially your doctor and other staff caring for you will be asked about your suitability to be included in the study.

If you agree to participate, an interview will be conducted with you in a quiet place convenient to you which will last up to an hour. You will be asked to talk about your experiences of being a patient in the ward. You do not have to discuss anything which you would prefer not to. The interview will be audio-recorded. You are welcome to have a relative or friend with you during the interview. The recording of the interview will be transcribed and all identifying information about you will be removed.

The project is being conducted at 2 Melbourne Hospitals and will be completed at the end of 2014.

This research project has been designed to make sure that researchers interpret the results in a fair and appropriate way and avoids researchers and participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid.

4   Other relevant information about the research project

On this site, about 15 patients will be interviewed individually by the researcher. This research is also being conducted at another Melbourne hospital.

5   Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship with

6   What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the opportunity to air your views with the researcher. The outcome of the research is expected to be an improvement in care for people in your situation in the future.

7   What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or stressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8   What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify a member of the research team before you withdraw. If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be retained. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project.

9   Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as illness of the researcher.

10   What happens when the research project ends?

 When the research project is completed you will be provided with a summary of the results.

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Part 2   How is the research project being conducted?

11   What will happen to information about me?

The information collected from you and other research participants will not be individually identifiable. The data will be stored electronically on a password-protected computer only accessible to the research team.

The data will be stored for 7 years as required in the NHMRC guidelines and then deleted.

The paper consent forms will be stored for 7 years in a locked filing cabinet in the principle researcher's locked office. After this period it will be shredded.

Your information will only be used for this project.

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

The personal information that the research team collect and use is information that you talked about during the interview.

Information about you may be obtained from your health records held at this health organisation, for the purpose of this research. By signing the consent form you agree to the research team accessing your health records if they are relevant to participation in this research project.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and/or Victorian state privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

12   Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

13   Who is organising and funding the research?

This research project is being conducted by Robin Digby, PhD candidate, Monash University, and no funding has been sourced.

No financial benefit is expected from this research project

You will not benefit financially from your involvement in this research project.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14   Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Eastern Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15   Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on 0400892518.

Research contact person

Name	Ms Robin Digby
Position	PhD Candidate
Telephone	
Email	Rdig1@student.monash.edu

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	
Position	
Telephone	
Email	

Consent Form - *Adult providing own consent*

Title   The care of people with dementia in sub-acute
facilities: The nurse-patient relationship

Coordinating Principal Investigator/   Robin Digby, PhD candidate, Monash University

Principal Investigator
Location   ▮▮▮▮▮▮▮▮▮

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I
understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free
to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____ Signature _____ Date _____

Declaration by Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe
that the participant has understood that explanation.

Name of Researcher† (please print) _____ Signature _____ Date _____

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title   The care of people with dementia in sub-acute facilities: The nurse-patient relationship

Principal   Robin Digby, PhD Candidate, Monash University

Location   ███████████

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or ██████ ██████

Name of Participant (please print) _____

Signature _____   Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature   Date

_____   _____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature

MONASH University

(Hospital logo)

Participant Information Sheet/Consent Form – Person Responsible

████████████

Title	The care of people with dementia in sub-acute facilities: the nurse-patient relationship
Coordinating Principal Investigator/ Principal Investigator	Robin Digby
Location	████████████

Part 1   What does participation involve?

1   Introduction

 The participant is being considered for inclusion in this research project, which is called 'The care of people with dementia in sub-acute facilities: The nurse-patient relationship'. This is because they are a patient at ████████████ and may be able to comment on this matter. Your contact details were obtained from the team caring for the participant.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want the participant to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to consent to the participant taking part, you might want to talk about it with a relative, friend or staff member.

Participation in this research is voluntary. If you don't wish the participant to take part, they don't have to.

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If you decide you want the participant to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

• Understand what you have read

• Consent to the participant taking part in the research project

• Consent for the participant to be involved in the research described

• Consent to the use of the participant's personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2   What is the purpose of this research?

The aim of the project is to better understand the experience of people with dementia while they are in hospital and the experience of the nurses caring for them. We already know that people with dementia can have a difficult time in hospital because of their reduced ability to adapt to new situations. This can lead to unsettled behaviour. We also know that nurses can find caring for people with dementia stressful.

We have very little information about the experience of patients and nurses in this setting. The aim is to find out more information so that we can improve care for the patients and support for the nurses.

The results of this research will be used by the researcher Robin Digby to obtain a Doctor of Philosophy degree. There is no grant or sponsorship funding this project.

This research has been initiated by the researcher, Robin Digby, PhD candidate

This research is not funded.

3   What does participation in this research involve?

A consent form will be signed before any interviews are conducted.

Initially the doctor and other staff caring for the participant will be asked about their suitability to be included in the study.

If you agree to consent to the participation, an interview will be conducted with the participant in a quiet place which will last up to an hour. The participant will be asked to talk about their experiences of being a patient in the ward. The participant does not have to discuss anything which they would prefer not to. The interview will be audio-recorded. The participant is welcome to have a relative or friend with them during the interview. The recording of the interview will be transcribed and all identifying information about the participant will be removed.

The project is being conducted at 2 Melbourne Hospitals and will be completed at the end of 2014.

This research project has been designed to make sure that researchers interpret the results in a fair and appropriate way and avoids researchers and participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will the participant be paid.

4   Other relevant information about the research project

On this site, about 15 patients will be interviewed individually by the researcher. This research will also be conducted at another Melbourne hospital

5   Does the participant have to take part in this research project?

Participation in any research project is voluntary. If you do not wish for the participant to take part, they do not have to. If you decide that they can take part and later change your mind, you are free to withdraw the participant from the project at any stage.

If you do decide that the participant can take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether the participant can or cannot take part, or that they can take part and then be withdrawn, will not affect their routine care, relationship with professional staff or relationship with ▮▮▮▮▮▮▮▮▮

6   What are the possible benefits of taking part?

We cannot guarantee or promise that the participant will receive any benefits from this research; however, possible benefits may include the opportunity for the participant to air their views with the researcher. The outcome of the research is expected to be an improvement in care for people in the participant's situation in the future.

7   What are the possible risks and disadvantages of the participant taking part?

The participant may feel that some of the questions we ask are stressful or upsetting. If the participant does not wish to answer a question, they may skip it and go to the next question, or stop immediately. If they become upset or stressed as a result of participation in the research project, the research team will be able to arrange for counselling or other appropriate support.

Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

8   What if I withdraw the participant from this research project?

If you do consent to the participant taking part, you may withdraw them at any time. If you decide to withdraw the participant from the project, please notify a member of the research team before withdrawal. If you do withdraw them, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

If you decide that the participant is to leave the research project, the researchers will not collect additional personal information from them, although personal information already collected will be retained. You should be aware that data collected up to the time of withdrawal will form part of the research project results. If you do not want the participant's data to be included, you must tell the researchers when withdrawing from the research project

9   Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as illness of the researcher.

10   What happens when the research project ends?

When the research project is completed you will be provided with a summary of the results.

Part 2   How is the research project being conducted?

11   What will happen to information about the participant?

The information collected from the research participants will not be individually identifiable. The data will be stored electronically on a password-protected computer only accessible to the research team.

The data will be stored for 7 years as required in the NHMRC guidelines and then deleted.

The paper consent forms will be stored for 7 years in a locked filing cabinet in the principal researcher's locked office. After this period it will be shredded.

The participant's information will only be used for this project. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about the participant that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify the participant will be treated as confidential and securely stored.

By signing the consent form you consent to the research team collecting and using personal information about the participant for the research project. Any information obtained in connection with this research project that can identify them will remain confidential. The participant's information will only be used for the purpose of this research project and it will not be disclosed to anyone.

The personal information that the research team collect and use is information that the participant talks about during the interview.

Information about the participant may be obtained from their health records held at this and other health organisations, for the purpose of this research. By signing the consent form you agree to the research team accessing the participant's health records if they are relevant to participation in this research project.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified.

12   Complaints and compensation

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If the participant suffers any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

13 Who is organising and funding the research?

This research project is being conducted by Robin Digby, PhD candidate, Monash University, and no funding has been sourced.

No financial benefit is expected from this research project

The participant will not benefit financially from their involvement in this research project.

No member of the research team will receive a personal financial benefit from their involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the HREC of Monash Health.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if the participant has any problems which may be related to involvement in the project, you can contact the researcher on 0400892518 or any of the following people:

Research contact person

Name	Ms Robin Digby
Position	PhD Candidate
Telephone	0400892518
Email	

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	
Position	
Telephone	
Email	

Consent Form – Person Responsible

Title   The care of people with dementia: The nurse-
                                             patient relationship.
                                             Robin Digby

Location   ████████████████

Declaration by Person Responsible

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to the participant taking part in this research project as described and understand that I am free to withdraw them at any time during the project without affecting their future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)

Signature of participant _____

Name of Person Responsible (please print) _____

Relationship of Person Responsible to Participant _____

Signature of Person Responsible _____ Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the person responsible for the participant has understood that explanation.

Name of Researcher[†] (please print)

Signature   Date

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation – Person Responsible

Title The care of people with dementia in sub-acute facilities: The nurse-patient relationship

Robin Digby

Principal Investigator
Location ████████████

Declaration by Person Responsible

I wish to withdraw the participant from taking part in the above research project and understand that such withdrawal will not affect their routine care, or relationships with the researchers or ████████████

Name of Participant (please print) _____

Signature of Participant _____

Name of Person Responsible (please print) _____

Relationship of Person Responsible to Participant _____

Signature of Person Responsible _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the person responsible for the participant has understood that explanation.

Name of Researcher (please print)

Signature _____   Date _____

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† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

APPENDIX 9: Photographs used in photo-elicitation