

**The nursing experience of caring for patients living with dementia and
co-morbidities on surgical wards in the acute healthcare setting**

Virginia L. Armour

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Australian Institute of Health Innovation
Faculty of Medicine and Health Sciences
Macquarie University



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DECLARATION

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at Macquarie University or any other educational institution, except where due acknowledgement is made in this thesis. Any contribution made to the research by others, with whom I have worked with at Macquarie University or elsewhere, is explicitly acknowledged in the thesis.

I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that the assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

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ABSTRACT

Background: The complex needs of patients living with dementia and co-morbidities and the consequent growing burden on the healthcare system necessitates consideration of new ways of delivering care in the acute setting. Patients living with dementia are high users of acute care, but have poorer clinical outcomes and higher rates of mortality and adverse events in hospitals when compared to the general population. Care of this vulnerable group is complex and time consuming, as well as physically and emotionally demanding on nursing staff. This presents challenges to nursing staff in the acute setting.

Aims: This study had four aims to: (i) explore the attitudes of nursing staff providing care to patients living with dementia and co-morbidities on surgical wards in the acute setting; (ii) measure the extent to which care was perceived by nursing staff to be patient-centred; (iii) measure the satisfaction of nursing staff with providing patient-centred care; and (iv) identify barriers and facilitators to the provision of patient-centred care to patients living with dementia and co-morbidities on surgical wards in an acute setting.

Method: A mixed-method study design was used to explore the experience of nursing staff caring for patients living with dementia and co-morbidities on surgical wards in an acute healthcare setting. Participants were purposively chosen from three acute surgical wards in a tertiary metropolitan teaching hospital. Each participant completed three questionnaires and a semi-structured interview. A total of 13 registered nurses were recruited.

Results: The nurses were found to have a positive attitude towards patients with dementia. They recognised the importance of establishing communication and a bond with these patients to address their unique needs and to provide patient-centred care. However, many nurses expressed frustration and stress at not being able to provide this care on the acute surgical ward. Nurses' satisfaction with providing patient-centred care was dependent on the amount of support received from the organisation in terms of resources, such as adequate staffing, and the ward environment. Barriers identified included a lack of time and resources to provide patient-centred care and a lack of training to acquire the skills needed to care for this vulnerable group. Facilitators to patient-centred care included strategies or 'work-arounds' to provide safe care and extra nursing staff, called patient specials, who provided constant patient supervision.

Conclusion: Despite the significant relationship between the nursing staff-patient experiences, there is a lack of research focusing on the staff experience of providing patient-centred care to patients living with dementia and co-morbidities on surgical wards in the acute setting. Understanding the nursing staff experience of providing patient-centred care in this setting and using this knowledge to develop and improve systems to support excellence in care is needed.

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LIST OF ABBREVIATIONS

ADQ	Approaches to Dementia Questionnaire
AIN	Assistant in Nursing
CNC	Clinical Nurse Consultant
EEN	Endorsed Enrolled Nurse
EN	Enrolled Nurse
HREC	Human Research Ethics Committee
IPS	Individual Patient Special
NSW	New South Wales
NUM	Nurse Unit Manager
PCC	Patient-centred care
P-CAT	Patient-centred Care Assessment Tool
RACF	Residential Aged Care Facility
RN	Registered Nurse
SEWDRS	Staff Experience Working with Dementia Residents Scale
SD	Standard Deviation
SIBR	Structured Interdisciplinary Bedside Rounds
SVH	St. Vincent's Hospital
SVHA	St. Vincent's Healthcare Association

CHAPTER 1 - INTRODUCTION

Dementia is the broad term used to describe the symptoms of illnesses which cause a progressive decline in a person's cognitive abilities and functioning. This includes a loss of memory, intellect, rationality, social skills and physical functioning. The three most common causes of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy Bodies (1). Alzheimer's disease is the most common form and affects up to 70% of patients living with dementia (1).

All forms of dementia are progressive neurodegenerative diseases for which there is no known cure. The impact of the disease on patients living with dementia and their families and caregivers is significant. This includes a progressive decline in the ability to perform activities of daily living, a reduction in social interactions and depression (2-4). Many patients living with dementia are initially cared for in the community by family and loved ones. However, as the disease progresses many patients living with dementia are cared for in long-term care institutions.

The rise in prevalence of dementia in Australia is well documented. An estimated 342,800 Australians are currently living with dementia and this figure is expected to grow to 900,000 by 2050 (5). In a report commissioned by Alzheimer's Australia, Access Economics estimate that by 2060 spending on dementia will outstrip that of any other health condition (5). Complex patients with multiple health conditions are becoming the

main patient profile for acute inpatient admissions across Australia. It is estimated that 39% of Australians have three or more chronic conditions and that this percentage increases with age (6). People with multiple chronic conditions have complex needs and are frequent users of health services. An estimated 40% of people with chronic conditions are likely to be hospitalised within a 12 month period (6).

Dementia primarily affects people over the age of 65 years and is often associated with other co-morbid conditions linked with ageing (2, 3). These co-morbid conditions do not differ significantly from those seen in the general population and include diabetes, hypertension, cardiovascular disease, malnutrition, anxiety, depression, injury and frailty (4-8). Patients living with dementia may also suffer from acute illness or injury. Injury is the most common reason for hospital admission for patients living with dementia (7, 8). Ninety percent of injury-related hospital admissions for patients living with dementia are as a result of a fall (8). Less than 10% of hospitalisations of persons with dementia in New South Wales (NSW) are specifically for dementia or conditions which are often characterised by dementia (such as Alzheimer's or Parkinson's disease). The remaining 90% of hospitalisations for patients living with dementia are for other unrelated conditions with dementia identified as a comorbidity (9). In 2013-14, 29,401 (3%) people admitted to hospital in NSW had dementia as a principal diagnosis or comorbidity (9). This places a tremendous burden on the health care system, particularly the acute hospital system, where unavoidable complex admissions are predicted to grow (6).

Patients living with dementia are high users of acute care but have poorer clinical outcomes and higher rates of mortality when compared to the general population (10-13).

Care of these patients is complex and presents particular challenges to staff in the acute care setting (14-16). This is evident on surgical wards where nursing staff are trained in post-operative management, such as wound care, but lack training in the care of the older person with dementia (17) (18). These challenges include the physical environment of the acute ward, patient factors (such as challenging behaviours and impaired communication skills), and a heavy workload that allows little time for the emotional and social aspects of caring.

There is a clash between the traditional medical/disease management approach and the need to incorporate the medical, behavioural and psychological complexity of treating dementia and associated chronic conditions (19-21). The focus of acute care on disease management limits opportunities for providing integrated care and communication between different teams and specialities (22). The patient with dementia may interact with many specialists and services in the acute setting, making these patients vulnerable to fragmented and less than satisfactory care during an acute care episode (20, 23). Patient factors, such as a limited ability to participate in self-management beyond the early stage of dementia (24, 25), increased anxiety in unfamiliar surroundings resulting in difficult behaviour (26), and an often limited ability to communicate and interact with clinicians, can have a negative impact on care and safety (27-29). Patients with dementia are also more likely to suffer an adverse event during their inpatient admission and have an increased risk of falls and functional decline (28).

The influence of direct care providers, specifically nurses, on the patient experience cannot be underestimated. Nurses' attitudes towards patients living with dementia are fundamental

to the patient experience (30, 31). Nurses are consistently present providing treatment and care around the clock. The relationship a nurse develops with their patient is a key factor influencing the type of experience the patient will have. A positive staff experience has been associated with high patient experience ratings and improved clinical outcomes (32-34). A sustained focus on staff satisfaction and building staff capacity have been identified as key components of high performing patient-centred care facilities (35) and the provision of high quality care (32, 34, 36). Despite the importance of the relationship between nurse-patient experiences, there is a lack of research focusing on the experience of nursing staff of providing patient-centred care to patients living with dementia and co-morbidities, particularly on surgical wards in the acute care setting.

There are two prominent conceptual models of care for the delivery of healthcare to patients living with dementia in the acute setting. These are the patient-centred care model and the medical disease model. The Australian Commission on Safety and Quality in Healthcare offers the following definition of patient-centred care, “*Patient-centred care is health care that is respectful of and responsive to the preferences, needs and values of patients, their families and consumers*” (page 4) (37). Models of patient-centred care focus on the need to build collaborative relationships between the patient and the care providers and to include patients as part of the health care team to improve the patient experience and clinical outcomes (37). There is now strong evidence that adopting this model of care results in improvements in the patient experience, clinical outcomes, quality care and the efficient use of resources (38-41). In a systematic review of 55 studies, Doyle et al (39) concluded that the patient experience was a central component in the provision of quality health care and impacted positively on clinical outcomes, treatment compliance and resource use.

In contrast the medical/disease model focuses on the diagnosis and treatment of a disease using a problem solving approach (42). The medical model is focused on the physical and biological aspects of specific diseases and conditions. Advances in technologic development and medical science coupled with an increase in community expectations of access to the best medical care have strengthened the use of the medical/disease approach to health care. The result is an undervaluation of the sociocultural and humanistic aspects of patient care (43).

Kitwood (44) suggests that the medical/ disease focused models of dementia care have resulted in a technical approach to the treatment of dementia that ignores the ‘human issues’ of care. Kitwood (45) offers this definition of personhood to guide a new approach to dementia care: *“It is a standing or status that is bestowed upon human beings, by others, in the context of relationship and social being. It implies recognition, respect and trust.”* (page 8). Crucial to Kitwood’s theory are the interactions between patients living with dementia and those who care for them. Understanding the person with dementia and their capabilities, in addition to providing the technical care, results in improved patient outcomes and experience (45, 46). Unfortunately, busy surgical wards are often unable to provide the culture or the environment where the focus on understanding the person with dementia is a priority over the focus on the disease itself.

Being admitted to hospital is a stressful time for patients living with dementia and their families. Anxiety levels can be high for patients with dementia who are removed from their usual place of residence (15, 26). They may also be experiencing pain or discomfort and

will be cared for by staff who are unfamiliar with their usual individual needs and preferences (47). All of these factors will increase the distress of the dementia patient, worsen cognitive function and increase behavioural and psychological symptoms of dementia. Clinicians may find it difficult to communicate effectively with the person with dementia and miss subtle changes demonstrating escalating levels of anxiety.

The care of patients living with dementia in acute hospitals has become a priority of healthcare policy in Australia in recent years. In 2015, the Australian Commission on Safety and Quality in Healthcare launched, *A better way to care: Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital* (48). These resources provide guidance to managers and clinicians to develop patient-centred models of care for patients living with dementia in the acute setting. Despite the increased burden on the acute healthcare system and the importance of managing dementia care, little is known about the experience of nursing staff caring for this patient group on surgical wards in the acute healthcare setting.

A literature review was conducted to identify and explore current research relating to the experiences of nursing staff caring for patients living with dementia and co-morbidities in the acute healthcare setting. The scope of the review included attitudes of nursing staff towards patients living with dementia, the barriers and facilitators to providing person-centred care in an acute setting. Gaps in current knowledge and the opportunities for further research were also explored.

Chapter 2 - LITERATURE REVIEW

This chapter introduces the search strategy that was followed to identify previous studies that examined the nursing experience of caring for patients living with dementia and co-morbidities in an acute healthcare setting. For the purpose of this literature review, nursing experience was defined as: the attitudes of nursing staff providing care to patients living with dementia and co-morbidities in the acute care setting; the extent to which care was perceived by nursing staff to be patient-centred; and the barriers and facilitators associated with the provision of patient-centred care in the acute setting.

2.1 SEARCH STRATEGY

In this section the search strategy that was undertaken to identify studies relevant to the literature review criteria is described. In addition, this section reports on the databases and the search terms that were used.

A multi-phased search strategy was used to ensure a thorough representation of the literature. The first phase involved a search of the following databases: PubMed, Medical Literature Analysis and Retrieval System (MEDLINE) and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search terms used were: [Dementia OR Alzheimer OR cognitive impair OR confus] AND [hospital OR acute OR ward] AND [Staff OR nurse OR clinician OR practitioner] AND [co-morbidity OR chronic illness OR comorbid OR “other medical conditions”]. The search range was restricted to publications from the year 2000 to May 2016. The titles and abstracts were initially reviewed by the researcher for relevance based on the selection criteria, detailed below.

Following the identification of relevant abstracts and titles, the second phase of review focused on literature sources taken from the reference list of relevant articles identified in the first search phase, and other relevant systematic and literature reviews identified. The researcher reviewed all titles and abstracts for relevance based on the selection criteria. All duplicates were removed from the results.

Finally, the third search phase focused on the quality of the articles selected. The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (Appendix 1) was used to evaluate the robustness of the qualitative methodologies and results.

2.2 INCLUSION CRITERIA

Only primary, peer-reviewed studies published in English using qualitative, quantitative or mixed-methods designs were included. All studies had to directly report on the experience of nurses caring for patients living with dementia in an acute setting. ‘Experience’ included attitudes toward patients living with dementia, strategies used that were specific to the needs of patients living with dementia that provided insight into providing care in an acute setting. ‘Acute setting’ included medical and surgical hospital wards and day-only surgical units. ‘Nursing staff’ included all professional designations of nurses providing direct care to patients.

2.3 EXCLUSION CRITERIA

Articles were excluded if they investigated long-term care facilities, dementia-specific nursing homes and dementia-specific wards, Residential Aged Care Facilities (RACF), outpatient clinics or dementia day centres. ‘Nursing staff’ did not include strictly administrative nursing positions. Studies primarily reporting on the nursing experience of

implementing a dementia specific intervention or program, including medications, education programs, policies and models of care, were excluded.

2.4 SEARCH RESULTS

The search strategy resulted in a total of 1253 abstracts identified from all databases. PubMed (n=528), CINAHL (n=398), MEDLINE (n=312) and from secondary sources (n=15). The results from the three databases were saved in EndNote® version 7 and cross-referenced, following which 505 duplicates were identified and removed. The remaining 748 abstracts were reviewed by the researcher against the selection criteria. This was conducted in three stages. The first stage removed all abstracts that did not directly address the nursing staff experience of caring for patients living with dementia or included reviews, opinions, editorials or were not primary, peer-reviewed studies. This resulted in the removal of 583 abstracts. The second stage excluded all abstracts of the remaining 165 that were not exclusively conducted in an acute setting. This resulted in 109 abstracts being removed from the database. The third stage reviewed the remaining 56 abstracts. Following a review of the remaining 56 abstracts a total of 51 were excluded because they did not meet the selection criteria for quality research methodology as assessed by the CASP Qualitative Checklist. In addition, articles were excluded if the population was described as 'health care professionals' or 'staff' and did not specifically include nurses, or the patients that were being caring for were from a mental health setting and not specifically patients living with dementia, or the exact diagnosis could not be identified.

Figure 1. Multi-phased process of searching and identifying relevant papers for review

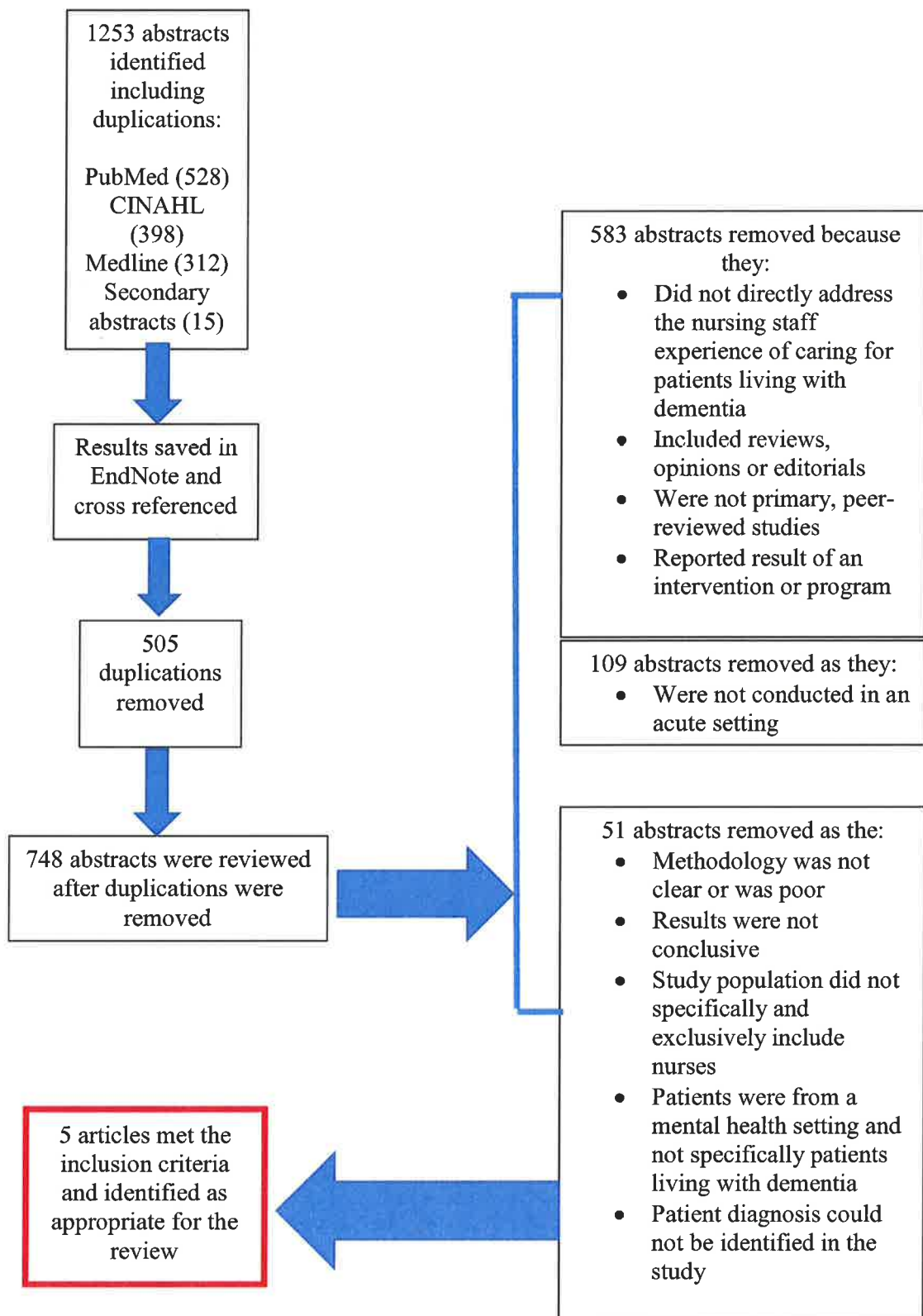


Table 1 - Research Studies of the Experience of Nurses Caring for Patients living with Dementia in an Acute Setting

Researcher/year	Aim	Country	Setting	Design-method	Participants	Findings
Nolan, L 2007 (14)	The aim of this study was to explore nurses' experiences of caring for older patients living with dementia in an acute hospital setting.	Ireland	Specialist unit caring for older people in large acute hospital.	In-depth, non-directive conversational interviews.	7 nurses	Structural inadequacies of the acute environment for dementia care. Difficulties encountered by patients with dementia when admitted to acute setting. Patient unique needs identified. Concerns need addressing to enhance care and patient experience. Lack of evidence studies in this area.
Kang, Y, Moyle, W, Venturato, L. 2010 (49)	To identify and describe Korean nurses' attitudes towards older patients living with dementia in acute care settings and to examine the effect of selected socio-demographics and nursing work characteristics on attitudes.	Korea	Two large hospitals.	Descriptive survey design using standardised questionnaires.	100 nurses	Moderately positive attitudes to patients living with dementia. More positive attitudes on medical than surgical wards. Demographics did not significantly correlate with attitudes. The environment, work routine and technology may influence the likelihood of negative attitude towards patients living with dementia.
Fukuda, R, Shimizu, Y, Seto, N 2015 (50)	This study aimed to explore the challenges nurses face in providing care to patients with dementia in acute care hospitals in Japan.	Japan	Six acute hospitals (av. Beds 471) – med/surgical wards.	Focus groups.	50 nurses	Seven groups of issues identified. Three of these resulted in a negative interactive cycle. Nurses adapt to situation, feel conflicted. Nurses do their best to adapt to these conditions despite feeling conflicted.
Eriksson, C Saveman, B 2002 (51)	The aim of the study was to describe nurses' experiences of difficulties of caring for patients with dementia in the acute setting.	Sweden	5 acute care wards (25 beds each) and 1 Accident and Emergency ward.	Interviews using an interview guide and semi-structured questions.	12 nurses	Nurses experience various difficulties and frustrations. Not enough time to care for patients living with dementia. Patient conduct, ethical problems and organisation deficiencies sometimes led to abuse and neglect of these patients
Cowdell, F 2010 (15)	To investigate the experiences of patients and nursing staff in relation to the care delivered to, and received by older patients living with dementia in an acute setting.	Northern Ireland	3 specialist older people wards.	Ethnographic approach- interviews and observations.	58 nurses	Nursing care delivered was influenced by philosophy of care, value attached to their work, perceived ability to provide care. Nurses strive to provide optimal care but not always achievable.

2.5 FINDINGS

A total of five research studies met the selection criteria and directly addressed the topic of the nursing staff experience caring for patients living with dementia in an acute healthcare setting. General information about each study was extracted and included the study aim, the setting, participants' characteristics, methodology, key findings and the country where the study took place. The study characteristics are summarised in Table 1. Qualitative methods to collect and analyse the data were used in four studies (14, 15, 50). One study used standardised questionnaires to collect the data and statistical analysis to analyse results (49).

A modified content analysis based on Churchill's seven steps framework (52) was chosen to analyse the results of the five papers. Content analysis is used in social research to reduce large sets of qualitative data into a manageable form for analysis. The advantages of using content analysis include its applicability across a wide range of research and subject matter, the analysis of text units of data to provide a deeper understanding of patterns and contextual meaning, and to summarise text into more meaningful categories for comparison (52). Although content analysis is used primarily to understand social science research data, it is also a relevant framework for the analysis of the findings of the five papers because most of the studies used a qualitative methodology and presented their results descriptively.

The data were extracted from the results section of each of the five papers. For comparison, related results were highlighted in each paper with different colours, according to the similarity of words and meaning. The following codebook was developed.

Table 2 - Codebook developed for content analysis of study results

Coding category	Code	Related theme	Results
Did the study findings address:			
a) Nursing attitudes toward patients living with dementia	Yes = 1 No = 2	The importance of establishing a meaningful connection or relationship with patients living with dementia.	Yes (4) No (1)
b) The provision of patient-centred care	Yes = 1 No = 2	The importance of establishing a meaningful connection or relationship with patients living with dementia.	Yes (2) no (3)
c) The organisation or environment in which the care was given	Yes = 1 No = 2	Acute ward environment is inappropriate and dangerous for patients living with dementia.	Yes (4) No (1)
d) The education and knowledge of nurses	Yes = 1 No = 2	A general lack of education and knowledge regarding the care of patients living with dementia impacted on the care provided.	Yes (4) No (1)
e) Barriers to providing patient-centred care	Yes = 1 No = 2	Providing patient-centred care to patients living with	Yes (4) No (1)

Coding category	Code	Related theme	Results
f) Facilitators to providing patient-centred care	Yes = 1 No = 2	dementia in an acute setting is challenging. Providing patient-centred care to patients living with dementia in an acute setting is challenging.	Yes (1) No (4)

Four key themes defining the experience of nurses caring for patients living with dementia in an acute setting emerged following analysis of the coded data and grouping of related results from each study. In the following section, each theme is discussed with reference to the findings of the five papers.

Theme one: Providing patient-centred care to patients living with dementia in an acute setting is challenging

All studies identified challenges to providing best practice care to patients living with dementia on an acute ward. Identified challenges included the ability to connect with the patient as a person rather than a diagnosis, providing care in ethically challenging situations, lack of time and resources to provide good care, the busy ward environment and patient behaviours.

Connecting with the patient as a person rather than a diagnosis was a key challenge identified by Nolan (14). In-depth, conversational interviews with seven nurses working on a specialist ward caring for older patients living with dementia within a large acute

hospital were used to best explore nurses' lived experience of providing care. Integral to the issue of connection was the need to identify with the person as an autonomous individual and nurses saw their role as facilitating as much patient independence as possible. However, participants found this difficult to accomplish in the acute environment due to limited time available to establish a relationship with the person and the various, sometimes conflicting, demands of providing care on an acute ward. The nurses reported feeling frustration and guilt when not able to provide personalised care (14).

Feelings of frustration and guilt were also identified by Eriksson et. al.(51) following interviews with twelve nurses working on five acute wards in a large hospital. The nurses in Eriksson's study described ethically difficult situations where they had to provide care against a persons' wishes leading to feelings of guilt (51). The challenges expressed in this study reflected those of the Nolan study. Not having the time or resources to treat patients satisfactorily was a prominent message and resulted in frustration for the nurses. This included not having the time to attend to their patient's needs or to establish a relationship with them (14, 51). Feelings of frustration were compounded by the nurses' need to care for other, sometimes sicker, patients on the ward (51).

Theme two: The importance of establishing a meaningful connection or relationship with patients living with dementia

Evidence suggests that the quality of care received by older patients is closely linked to the attitudes of the nurses providing that care (53). The bonding process with patients was described by nurses as very important for promoting trust and enhancing care (15,

50). However, it was noted that this bond could be difficult if the person's behaviour became aggressive (15, (14). Nurses identified a lack of available personal information as a barrier to establishing a good bond and emphasised the importance of working closely with family/carers to overcome this (15). Nurses noted that establishing a relationship with family/carers was difficult due to the limited time available on a busy ward (15).

Kang et. al. (49) surveyed 100 nurses to identify and describe their attitudes towards working with patients living with dementia in the acute setting (49). They found moderately positive attitudes across all acute settings. However, nurses working on medical wards had significantly more positive attitudes than those working on surgical wards. The researchers speculated that this may be due to patients with dementia on a surgical ward being viewed as overly demanding, and the patient needs may conflict with the highly technical nursing interventions required (49). This was supported by Eriksson et. al.(51) who observed that nurses reduced time spent with patients with dementia to care for sicker patients . Kang et. al.(49) also found a significant relationship between positive attitudes and training and reduced stress, improved job satisfaction and overall satisfaction with the outcomes of care. Nurses described the difficulties of establishing a connection with the person with dementia in an acute setting. They were frustrated because they did not have personal information about the patient and they did not have the time to learn this information with the demands of acute care (15).

Coldwell observed that cultural norms resulted in a tendency for nurses to label patients, which influenced how they interacted with them (15). Less demanding patients

living with dementia were labelled as “sweet” and were generally “*left in their own world*”. Other more aggressive patients with dementia were labelled as “difficult” and were avoided by nurses (15).

Kang et.al. (49) discovered that nurses had a positive attitude towards involving family members in the care of patients with dementia. This was supported by Fuduka et. al. (50) who found that nurses reported “*turning to the patient’s families for help*” when they could not manage alone.

Theme three: Acute ward environment is inappropriate and dangerous for patients living with dementia

The acute hospital ward was described by nurses in all studies as not the appropriate environment for patients living with dementia, irrespective of their reason for admission. However, many nurses commented that the frequency of patients living with dementia being admitted to a variety of acute wards was increasing and at some point all nursing staff, regardless of specialty, would have to care for these patients (51, 54). Nurses felt that the acute ward was a strange, unfamiliar and even dangerous place for patients with dementia and that admission should be avoided where possible (51).

Fukuda suggested that the strategies used by nurses to ensure the environment was safe, such as alarm mats, may even add to the person’s confusion therefore increasing their risk of harm (50). Kang et. al. (48) speculated that the more positive attitudes of nurses toward patients living with dementia on a medical ward when compared to nursing staff on a surgical ward might be due to the medical ward environment being more conducive to establishing a relationship with patients with dementia.

The physical layout of the acute ward was an additional challenge. Examples of bathrooms being too far from beds, rooms not allowing constant surveillance and challenging behaviours impacting on nurses' time were cited factors that impact on patient safety(51) . Care in the acute setting was described as largely focusing on the physical needs of the patient. Staff had a desire to meet certain standards that were task focused (15) and were frustrated by the conflicting need to reduce 'care time' to establish a relationship with the person with dementia with the requirement to accomplish set tasks (14, 51) .

Theme four: A lack of education and knowledge regarding the care of patients living with dementia impacted on the care provided

Nursing staff working in the acute setting are not always prepared to care for patients living with dementia. Their care focus is on the specialty of their training, such as surgical nursing. Cowdell (15) found that although nurses working on a variety of acute wards had a positive philosophy of caring for patients living with dementia they expressed concerns about not being able to meet their needs due to a lack of education in this area. Nurses described their inability to address common behaviours of the person with dementia, such as, aggression and wandering, as having a significant impact on how they cared for them. Nurses described patients with dementia as difficult, disruptive, time-consuming and frightening (14, 51). The nurses felt stressed as the demands on them increased due to an increasing number of patients living with dementia on acute wards, coupled with a lack of knowledge and suitable professional education to gain the skills and understanding to provide good care to this patient group.

The growing burden of an ageing population on the healthcare system and the complex needs of patients living with dementia and co-morbidities necessitates further investigation and consideration of new ways of delivering care in the acute setting. This literature review revealed little empirical research directly addressing the experience of nurses providing care to patients living with dementia and co-morbidities in the acute healthcare setting.

Providing care for patients living with dementia in an acute setting is complex and challenging. The hospital ward is a busy and dynamic environment that presents challenges to both nursing staff and patients living with dementia (39). Evidence suggests that the quality of care provided to patients living with dementia in the acute setting is not of the same standard as that provided to patient without dementia (55)(38). Admission to an inpatient unit is often a stressful and unpleasant experience for patients living with dementia. Yet hospital admission is becoming increasingly unavoidable for this patient group as the prevalence of both co-morbidity and dementia increase with an aging population. Despite the significant relationship between the nursing and patient experience, only five primary research papers were found that directly addressed this relationship in the context of caring for patients living with dementia in an acute setting.

Many gaps in knowledge remain. In a scoping review of the literature, Bunn et.al.(10) identified few studies that focused on the experiences of health care providers who manage the care of patients living with dementia across all service delivery models and identified the need for more research on this topic. Of the few studies available, most were conducted in primary care, community living or residential/long-term care

facilities. None of the five papers found in this literature review were conducted in Australia. Only one study clearly described the acute environment in which the research was conducted (50). Vague terms such as 'large hospital' and 'aged care specific units' were inadequate and made it difficult to compare results across facilities. Research that is conducted on busy acute wards such as surgical wards is needed to better understand the impact of the acute healthcare setting on the care of patients living with dementia. Almost half of the studies were conducted on wards that specialised in aged care. It could be argued that this represents a biased study sample of nurses. Nurses working on aged care wards are more likely to have received prior training and relevant experience to equip them with the skills needed to care for patients living with dementia. In addition, nurses who have chosen to work on an aged care ward are more likely to be agreeable towards caring for patients living with dementia than nurses who have trained in other clinical specialities (49). Understanding the nursing experience of nurses working on a non-aged care/dementia specific ward such as a surgical ward, will provide greater insight into the nursing staff experience and the challenges of providing patient-centred care in this environment. Only two studies addressed the nursing experience of providing patient-centred care to patients living with dementia on an acute ward. Patient-centred models of care focus on establishing relationships with patients, collaboration with patients and families/carers and understanding the patient as an individual so that the care that is received is mindful of the needs and preferences of the person. Patient-centred models of care are complimentary to the care of patients living with dementia and are widely used in aged care and long-term residential facilities. However, delivering this model of care in the acute setting presents challenges. More research into the capacity and experience of nursing staff to provide

patient-centred care to patients living with dementia and co-morbidities on the acute hospital ward is needed.

Despite the significant relationship between nursing staff and patient experiences, there is a lack of research focusing on the nursing staff experience of providing care to patients living with dementia and co-morbidities in the acute setting. Given the strong influence that nursing staff have on the patient experience, further research in this area is required to provide insight into improving the quality of care provided. The five studies included in this literature review were conducted in four countries: Sweden, Korea, Japan and Ireland. Research to understanding the impact of cultural differences on the care of patients living with dementia and comorbid conditions may provide better patient focused care by delivering appropriate care for patients who come from different cultures.

CHAPTER 3 - METHOD

This chapter describes the methodology used to investigate the experience of nursing staff caring for patients living with dementia and co-morbidities on surgical wards in an acute hospital. The methods of recruitment, data collection and data analysis also are identified and justified. As identified in the literature review, there are few research studies that explored the experience of nurses caring for patients living with dementia and co-morbidities on acute hospital wards in Australia. This is particularly evident in acute hospital wards that are not designated as an aged care or dementia-specific ward, such as a surgical ward.

3.1 RESEARCH AIMS

The aims of the study were:

1. To explore the attitudes of nursing staff providing care to patients living with dementia and co-morbidities on surgical wards in the acute setting;
2. To measure the extent to which care was perceived by nursing staff to be patient-centred;
3. To measure the satisfaction of nursing staff with providing patient-centred care; and
4. To identify barriers and facilitators to the provision of patient-centred care to patients living with dementia and co-morbidities on surgical wards in an acute setting.

3.2 MIXED METHOD DESIGN

This study used a concurrent mixed-method design to explore the experience of nursing staff caring for patients living with dementia and co-morbidities on surgical wards in an acute healthcare setting. Mixed method research design combines qualitative and quantitative methods to provide a better understanding of a research question than either method can achieve alone (56). Diverse types of data are collected using a variety of techniques. The purpose of using a mixed method research design in this study is to support the assertion that variation in data collection will provide a better understanding of the research question and will lead to greater validity of results (56). Rather than focusing on the relationship between cause and outcome, mixed method research design focuses on the relationships between data and the collective themes that result (57). Jick points out *“It is not enough to simply collect and analyse qualitative or quantitative data, they need to be mixed in some way so that together they form a complete picture of the problem than they do when standing alone (page 109)”* (57) . When conducting a mixed method study the potential for tension between the two approaches must be addressed. In this study the quantitative and qualitative tools were selected to be supportive rather than divisive. For example, the questionnaires addressed the topics explored by the semi-structured interviews questions; attitudes towards patients living with dementia, perceptions of patient-centred care and satisfaction of caring for patients living with dementia on their ward. Once the themes of the qualitative analysis have been completed they will be compared with the results of the quantitative data to identify similarities or discrepancies. In this way the quantitative and qualitative results complement each other and strengthen the reliability of the results through the direct comparison of results.

This study used three standardised and validated questionnaires and a demographic information questionnaire to collect quantitative data (Appendix 2). Qualitative data was collected from all participants using semi-structured interviews. Semi-structured interviews gave participants time to provide more in-depth responses to the topic of their experiences of providing patient-centred care to patients living with dementia and co-morbidities (58). Semi-structured interviews gave the opportunity for complex questions and issues to be discussed and clarified (58). Within the interviews, participants had flexibility regarding how much to say and how to express their opinions, providing rich data on the participants' experiences (58).

3.4 ETHICS APPROVAL

Ethics approval for the study granted by St. Vincent's Healthcare Association (SVHA) Human Research Ethics Committee LNR/16/SVH/143 and site approval SVH/16/093, Appendix 3). An Honorary Appointment was also granted by the intended hospital to proceed with the data collection process. All external ethics approval documentation was ratified by the Macquarie University Human Research Ethics Committee.

3.5 STUDY SETTING

This study was conducted in a 380-bed tertiary teaching hospital in Sydney, Australia from 12/09/2016 to 25/09/2016. Nursing staff working on three acute surgical wards participated in the study. The three wards were chosen in consultation with the Aged Care Clinical Nurse Consultant. The Aged Care Clinical Nurse Consultant provides an evidence-based consultancy service for patients with cognitive impairment, dementia and delirium. This includes, policy development, education and the implementation of

evidence based person-centred care. The Aged Care Clinical Nurse Consultant was the site lead for the research study.

All three wards provide specialist services that are not primarily focused on patients living with dementia or aged care. This makes it more likely that patients were admitted to these wards for the management of a co-morbidity unrelated to their dementia.

Table 3 - Description of acute wards

WARD	SUMMARY OF WARD	NUMBER OF BEDS
Ward A	Specialising in orthopaedics, urology, gynaecology and plastics surgery. The Geriatric Department provides an ortho-geriatric service. The ward has a very high turn-over of patients.	34
Ward B	Specialising in general surgery, colorectal and head and neck surgery. The ward also cares for very complex surgical patients, including those who have had tracheostomies performed.	34
Ward C	Specialising in cardio-thoracic care which incorporates a 4 bedded Non-invasive Ventilation Unit. The ward also specialises in cardio-thoracic surgery including heart and lung transplant surgery.	34

3.6 PARTICIPANT SELECTION

Nurses who had recent experience caring for patients living with dementia on one of the three study wards were the population of interest for this study. Participants were purposively selected from a fixed sample of permanent nursing staff employed at St. Vincent's Hospital (SVH), Sydney, Australia on three surgical wards.

Purposive sampling, also known as judgmental, selective, or subjective sampling, was used to select the study sample. A purposive sample is a non-probability sample that is selected based on characteristics of a population and the phenomena being studied. Purposive sampling involves the researcher selecting participants who are likely to provide information rich data on the phenomenon being studied (58, 59). In this study, the phenomenon being studied was the experience of nurses who have cared for patients living with dementia and co-morbidities on surgical wards in an acute hospital.

All nurses recruited to the study met the following inclusion and none of the exclusion criteria:

3.6.1 Inclusion criteria.

- Employed as permanent nursing staff (including RN, EN, EEN, AIN) at St. Vincent's Hospital, Sydney.
- Over the age of 18 years.
- Nursing staff working on an acute ward (including surgical, medical, rehabilitation and acute geriatric wards but excluding Emergency Department, Operating theatres, outpatient clinics and Intensive Care Units).
- Have cared for a person with dementia and co-morbidities in the previous 12 months.
- Participants must be willing and able to complete the 3 questionnaires (approx. 10 minutes each) and the face-to-face semi structured interview (approx. 30 minutes).
- Able to answer the questionnaires and semi-structured interviews in English.
- Willingness to give written informed consent and willingness to participate in and comply with the study protocol.

3.6.2 Exclusion criteria

- Nursing staff that are unable to meet the inclusion criteria.
- Causally employed or agency nurses.
- Nurses who are temporarily working on the selected wards.

3.7 RECRUITMENT

Once the participating wards were identified and willingness to participate was confirmed with the Nurse Unit Mangers (NUMs), the study team, consisting of the principle researcher and the site lead, met with the NUMs to provide information about the study and to answer any questions that they might have. The NUMs were asked to invite up to five nurses from each ward to participate in the study. Information flyers and posters were given to the NUMs for display on their wards. In addition, the *Participation Information and Consent Sheet* (Appendix 4) and the *Questionnaire Booklet* (Appendix 2) were provided to the NUMs to distribute to nurses who confirmed they would participate in the study. Nurses completed the Questionnaire Booklet prior to the scheduled interview. Dates and times for the interviews were confirmed with the NUMs to best suit the routine of the wards. This time was identified as following the afternoon handover on all three surgical wards. Thirty minutes was allocated for each interview. The interview room on each ward was used for recruitment, informed consent and to conduct the interviews.

Recruitment was finalised during the scheduled interview time via written informed consent. The consenting process was completed at the beginning of each interview,

when it was confirmed that the participants met all inclusion criteria and none of the exclusion criteria. All participants had completed the Questionnaire Booklet prior to the interview time, and this was collected by the researcher at the beginning of the interview. Participants were assigned a study code, used to identify the demographic, questionnaire and semi-structured interview data bundle for each participant. All data was non-identifiable and the study code was not traceable to any identifying information about the participant. During the recruitment process participants were given an opportunity to ask questions about the study. All study participants joined voluntarily.

3.7 STUDY INSTRUMENTS

Three standardised questionnaires were completed prior to the semi-structured interviews. Each questionnaire took approximately ten minutes to complete. Questions were adapted where relevant to reflect the acute hospital environment. Specifically, where questions referred to 'residents' the word 'patient' was substituted. The three questionnaires included in the questionnaire booklet are described below.

1. Approaches to Dementia Questionnaire (ADQ) (60)

The ADQ was used because it captures a respondent's attitudes towards patients living with dementia specifically. The ADQ includes 19 attitudinal items, each scored on a Likert scale with 1 (strongly disagree), 2 (agree), 3 (neither agree nor disagree), 4 (agree) and to 5 (strongly agree). The scores are added to achieve a total score ranging from 19-95. Higher scores indicate more positive attitudes. There are two subscale scores: the Hopefulness sub-score (8 items) and the patient-centred sub-score (11

items). The Hopefulness sub-score questions were reversed scored. The Hopefulness sub-score reflects a sense of optimism/pessimism towards the abilities and the future of patients living with dementia while the person-centred sub-score refers to the way in which patients living with dementia are recognised and responded to as unique individuals. Lintern et. al. (60) reported test-retest reliability for the ADQ as good with the ADQ total of 0.76, ADQ Hopefulness sub-score was 0.70 and ADQ Patient-centred sub-score was 0.68 ($P > 0.001$).

2. The Patient-centred Care Assessment Tool (P-CAT) (61, 62)

The P-CAT measures the extent to which the care provided by a health service is experienced by staff as being person-centred. It consists of 13 statements about patient-centred care. Each item is rated on a Likert scale; 1 (disagree completely), 2 (disagree), 3 (neither agree nor disagree), 4 (agree) and to 5 (agree completely) according to how closely it reflects staff experience of providing patient-centred care. The P-CAT has three sub-scales: Extent of Personalising Care, Organisation Support and Environmental Accessibility. The Organisation Support sub-scale was reserve scored. The scores are added to achieve a total score range of 13-65. Reliability and homogeneity were reported in the literature to be satisfactory for the whole P-CAT questionnaire as demonstrated by a Cronbach's α of 0.75. Test-retest reliability showed temporal stability of the scale (61).

3. Staff Experience Working with Demented Residents Scale (SEWDRS) (63)

The SEWDRS measures staff satisfaction of people caring for patients living with dementia. The 21-item scale measures staff satisfaction in both their work environment

and in their experience of working with patients living with dementia. Each item is scored on a 5 point Likert scale 0 (not at all), 1 (somewhat), 2 (a moderate amount), 3 (very much) and 4 (extremely). Possible total scores range from 4 to 84. A higher score indicates greater satisfaction. The SEWDRS includes six sub-scales: Experience of feedback at work, caring organisation, satisfaction with meeting own expectations, satisfactory contact with patients, satisfaction with meeting expectations of others and satisfaction with the environment. Astrom et. al. reported good reliability and good validity of the overall SEWDRS and the six sub-scales (63).

The mean scale score was calculated for all scores using the Likert scale parameters. The ADQ and the P-CAT mean scale scores were calculated on a Likert scale of 1 – 5 and the SEWDRS mean scale score was calculated on a Likert scale of 0 – 4.

Semi-structured interviews using open-ended questions were undertaken to elicit the experience of nursing staff attitudes toward patients living with dementia, perceptions of current care provision, barriers and facilitators to providing patient-centred dementia care. The four broad questions were developed by the researcher based on the results of the literature review presented in the Chapter 2 and their relevance to the study questions. Due to time limitations, the interview questions were not piloted prior to undertaking this study. Interviews were audio recorded with responses transcribed verbatim by the researcher. Each interview took approximately 30 minutes. The interview questions and prompting questions used are described in Table 4.

Table 4 – Semi-structured Interview questions and prompting questions

Question	Prompting questions
1. Describe a typical shift looking after a person with dementia and co-morbidities on your ward.	<p>What impact does a patient with dementia have on your workload?</p> <p>What strategies do you use to manage the increased workload?</p> <p>How does not meeting the patient's expectations impact on you?</p>
2. Do you feel you are able to provide a level of patient-centred care (PCC) to patients living with dementia and co-morbidities on an acute ward that is of a high standard?	<p>What does patient-centred care mean to you?</p> <p>Do you involve the family members or carers?</p> <p>Do you feel confident in providing patient-centred care to patients living with dementia on your ward?</p> <p>Should patient-centred care be a priority on a busy acute ward?</p> <p>Do you worry about the other patients that you are looking after also?</p>
3. What do you perceive are facilitators to providing PCC to patients living with dementia and co-morbidities on an acute ward?	<p>How do these strategies help you to provide patient-centred care?</p> <p>Can you think of a situation recently where you have looked after a patient with dementia and what things helped you to provide the best care possible for that patient?</p> <p>In an ideal world what strategies or programs would you like to see implemented on your ward?</p>
4. What do you perceive are the barriers to providing PCC to patients living with dementia and co-morbidities on an acute ward?	<p>Do you feel the organisation as a whole supports you in providing patient-centred care to patients living with dementia?</p> <p>Why? Why not?</p> <p>What are some of the characteristics of these patients that makes it more difficult to look after them?</p> <p>What are some of the things that make it really hard to provide patient-centred care?</p>

3.8 QUALITATIVE ANALYSIS

Qualitative research is conducted to understand phenomena in the natural world, as opposed to the experimental world (58). Qualitative data analysis focuses on exploring meanings, experiences and the views of participants which allows the researcher to gain a deeper understanding of the research question that quantitative research alone can provide (58). The context within which qualitative data is collected is dynamic and unpredictable, mirroring the real world and results in the researcher developing concepts and themes that describe the experience of participants in their reality.

Analysis of the transcripts of the semi-structured interviews was conducted by the researcher using the framework analysis method described by Gale and colleagues (64). The interview data were analysed individually and then jointly across all interview transcripts. This inductive method was chosen because the developed framework is used to group data and then from these groupings identify relationships among the groupings or categories. The framework method examines the relationships and differences between qualitative data to develop descriptive themes. This analytic methodology is best suited to exploring the study aims described in the previous section because it organises large amounts of descriptive data resulting in the identification of emergent themes. From these themes the researcher gains insight into the nursing experience of caring for patients living with dementia in an acute healthcare setting. (66-68). The credibility of the qualitative data was upheld through the use of the framework analysis method, providing structure and standardisation to the analysis, and also by linking the qualitative data to the quantitative results achieved from the standardised questionnaires. The latter is explored in the discussion.

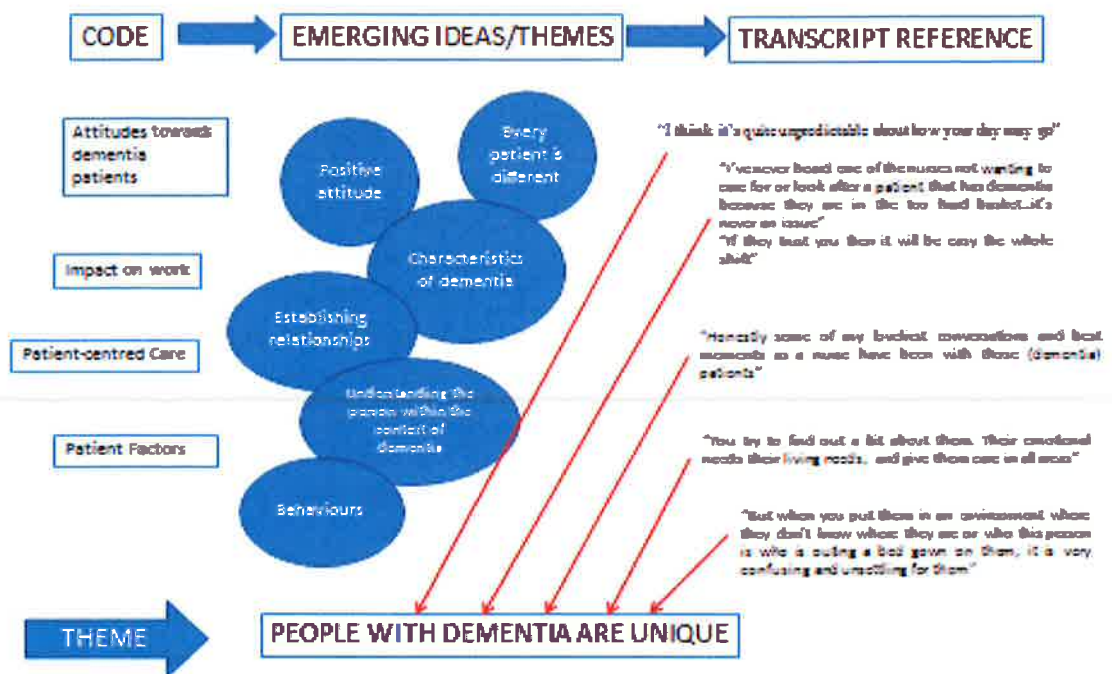
Two other methods of qualitative analysis considered for this research study included content analysis and narrative analysis. Content analysis is the procedure used for the categorisation of verbal and behavioural data. It is both descriptive and intuitive (58). Narrative analysis focuses on the reformulation of transcribed experiences presented by people in different contexts (58). Both methods allow for the categorisation and summarisation of qualitative data. However, both methods lack the in-depth mapping and interpretation of data required to fully meet the research aims of this study.

Table 5 – Summary of method of the framework analysis of qualitative data

Stage	Task	Description
Step 1	Transcription	Interviews were audio recorded and transcribed verbatim by the researcher
Step 2	Familiarisation with the interview	Familiarisation with the interview accomplished by the researcher transcribing interviews from the audio recording them re- listening to the audio recording and cross referencing the transcript to ensure all information had been captured. The transcripts were read again without the audio recording.
Step 3	Coding	Transcripts were read line by line by the researcher and a code or a label was applied to all sentences, phrases or words that were important to the research questions and provided further insight into the overall nursing experience of caring for patients living with dementia and co-morbidities on surgical wards. Three of the transcripts were also coded by an independent clinician at this stage. This was done to strengthen the validity of the coding framework by ensuring it was consistent and appropriate.
Step 4	Developing a working analytical framework	The researcher and the independent clinician then met to discuss the coding of the first three transcripts to agree on a set of

Stage	Task	Description
		codes to apply to all transcripts. Once agreement was reached the codes were grouped into categories to form the working analytical framework. For example, initially three codes (work arounds, teamwork and alternatives to PCC) were used to categorise how nursing staff managed the care of patients living with dementia. These were grouped under the one code 'Strategies of care' following discussion with the second reviewer. The codes 'impact on nurse' and 'impact of workload' overlapped. However, it was decided to separate them to improve the clarity of the results.
Step 5	Applying the analytical framework	The analytical framework developed at stage 3 was then applied to the remaining transcripts by the researcher. The analytical framework identified twelve codes that were defined and applied consistently to the remaining transcripts thereby improving the reliability of the results. (See Table 10 for examples)
Step 6	Charting the data into the framework matrix	A spread sheet was used to generate a matrix consisting of the category, code and data from the interviews. Data included quotations to provide added richness to the data alone. (Table 10)
Step 7	Interpreting the data	During stages 1 to 6 the researcher maintained a log of relevant and emerging ideas and concepts. This was used to interpret the data from the framework matrix. In addition, mapping connections between categories and codes was used to identify themes and enhance understanding the meaning of the data.(Figure 2)

Figure 2: Example of mapping the matrix to identify themes



3.9 QUANTITATIVE ANALYSIS

The demographic data and the data from the questionnaires (ADQ, P-CAT and SEWDRS) were analysed using simple descriptive statistics. This included mean and standard deviation. Questionnaire scores were totalled for an overall score and for each sub-scale score. The mean scores and standard deviation of the Likert scale responses were also calculated. Pearson's correlation coefficient statistic was used to identify any significant relationships between variables.

CHAPTER 4 - RESULTS

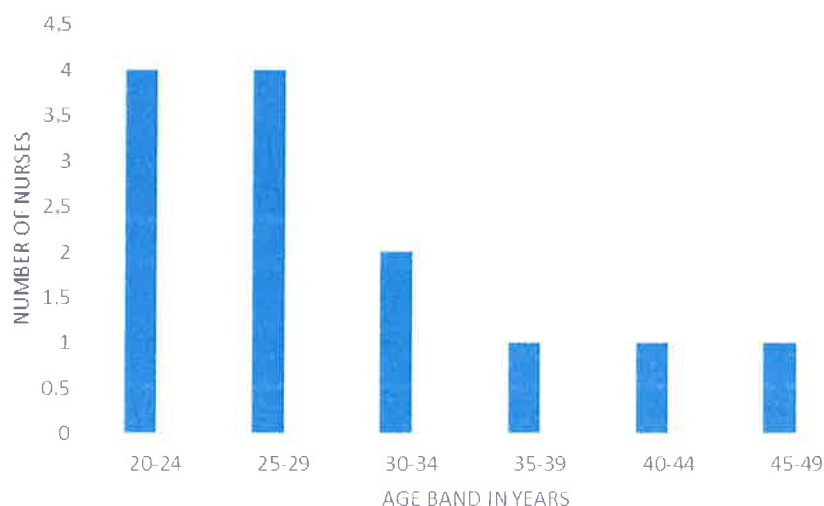
In this chapter the results of the quantitative data, including the demographic data and the results of the three questionnaires, and qualitative data, from the semi-structured interviews, are presented. First, the demographic characteristics of the study participants are presented. Second the results of the three questionnaires, ADQ, P-CAT and the SEWDRS are described, and statistically significant relationships between variables are identified. Third, the results of the framework analysis of the transcripts of the semi-structured interviews are presented. Finally, the results are reported in relation to the research questions.

4.1 QUANTITATIVE ANALYSIS

4.1.1 Demographic data

Participants were purposively chosen to participate in the study. A total of 13 nursing staff on three surgical wards were recruited. The participating nursing staff were all female and 92% (n=12) were Registered Nurses, the other participant was a Nurse Unit Manager with direct patient care responsibilities. The nursing staff participants were representative of the younger age bands, with 76.9% (≤ 34 years old).

Figure 3. Distribution of age group of participants



The number of years of nursing experience was broad and ranged from 0.5 – 17 years (mean 6.3; SD 4.9). The number of years of experience working with patients with dementia reflected the number of years of nursing experience and ranged from 0.5 – 17 years (n=11, mean 4.7 SD 5.1). Nurses with ≤ 8 years of experience were representative of 76.9% of the group and 81.08% had ≤ 8 years of experience caring for patients with dementia.

4.1.2 Approaches to Dementia Questionnaire (ADQ)

Nursing staff attitudes towards patients living with dementia were positive. Total overall mean scores and the mean scale scores both for the ADQ and two sub-scales, Hopefulness and Person-Centred Care, clustered at the mid to high end of the score indicating positive attitudes. This result indicates the nursing staff have a general sense of optimism regarding the abilities and future of patients living with dementia. The patient-centred care scores indicated nursing staff had a positive attitude regarding and responding to the person with dementia as a unique individual with the same value as other persons.

Table 6 - ADQ and sub-scales: Mean overall and mean scale scores

Scale	N*	Min.	Max.	Mean	SD	N*8*	Mean Scale Score	SD
hopescore	13	21	33	29.2	4.1	8	3.7	0.6
pccscore	13	36	50	41.7	4.0	11	3.8	0.7
adqscore	13	59	79	70.9	5.96	19	3.7	0.7

N* number of questionnaires completed

N** Number of questions included in the score

4.1.3 Patient-centred Care Assessment Tool (P-CAT)

The nursing staff's perception of the extent to which the care provided by the health service was experienced as being person-centred was somewhat neutral. The overall

P-CAT mean score and the three sub-scores: personalised care, organisation support and environmental accessibility, were clustered around the middle range of the score. The most positive response was for the sub-scale personalised care (mean score 24.9; SD 5.5).

The total mean P-CAT score of 44.3 (SD 8.2) indicates a less than positive response to the extent to which person-centred care is provided to patients on the study wards. The P-CAT Personalised Care sub-score measures the extent to which the nurse feels they can provide individualised care to the patient. Scores are clustered around the middle range with means scale scores reflecting the nurses' neutral response to this set of questions. The P-CAT Organisational score measures the extent to which the nurses feel they are supported by the organisation to provide patient-centred care to patients. Score distribution was clustered around the mid score region. The mean score of 12.9 (SD 3.0) indicates a moderate response to this set of questions. The P-CAT Degree of Environmental Accessibility sub-scale measures the extent to which the nurses feel that the physical environment is supportive of patient-centred care. The scores are clustered around the lower end of the range indicating the nurses felt that the environment did not support the provision of patient-centred care to patients living with dementia.

Table 7 - PCAT and sub-scales: Mean overall and means scale scores

Scale	N*	Min.	Max.	Mean	SD	N**	Mean Scale Score	SD
Personalised care score	13	9	31	25.0	5.5	7	3.6	0.4
Organisation support score	13	8	19	13.0	3.0	4	3.2	0.4
Environmental accessibility score	13	4	12	6.3	2.3	2	3.0	0.3
Overall P-CAT score	13	25	57	44.1	8.2	13	3.4	0.4

N* number of questionnaires completed

N** Number of questions included in the score

4.1.4 Staff Experience Working with Demented Residents Scale (SEWDRS)

Nursing staff satisfaction with caring for patients living with dementia was measured using the SEWDRS overall score and six sub-scale scores. Nursing staff satisfaction was moderate with total SEWDRS and mean scale scores clustering around the low to mid-range. The SEWDRS overall mean score of 49.5 (SD 9.0) and a mean scale score of 2.4 (SD 0.5) indicates a low level of nursing staff satisfaction when caring for patients living with dementia.

Nurses' satisfaction with the experience of feedback at work (sub-scale 1) was low to moderate with the mean score at the low to mid-range of the measure. The mean scale score of 2.1 (SD 0.5) also reflected a low amount of satisfaction with the nurses' experience of feedback at work. The mean scores of nurses' satisfaction with the care organisation (sub-scale 2) were clustered around the mid-range of the measure. The mean score 7.5 (SD 1.7) and the mean scale score of 2.5 (SD 0.1) suggested a moderate amount of satisfaction reported by nurses for this measure. The nurses' satisfaction with meeting their own expectations (sub-scale 3) was solid with scores clustered around the high end of the measure. A mean score of 7.4 (SD 1.7) and a mean scale score of 2.5 (SD 0.4) indicated satisfaction with this measure. The Patient Contact sub-score (sub-scale 4) measures the extent to which the nurse is satisfied with the amount of patient contact that they have when caring for patients with dementia. Scores were clustered around the high end of the scale with a mean score of 8.2 (SD 1.6) indicating strong satisfaction with this measure. The meeting others expectation score (sub-scale 5) measures the nurses' satisfaction with meeting the expectations of others. A high mean score for this measure of 8.2 (SD 1.3) and a high mean scale score of 2.8 (SD 0.2) reflected a high level of satisfaction with this measure. The work environment (sub-

scale 6) means score measures nurses' satisfaction with the work environment. Scores were clustered around the mid-range with a mean score of 4.9 (SD 1.3) and a means scale score of 1.8 (SD 0.5). This suggested a moderate amount of nursing satisfaction with the work environment.

Table 8 - SEWRDS mean scores and sub-scale scores (overall and sub-scales)

Scale	N*	Min.	Max.	Mean	SD	N**	Mean Scale Score	SD
Experience of feedback (F1)	13	6	21	13.2	3.9	6	2.2	0.5
Care organisation (F2)	13	4	10	7.5	1.7	3	2.5	0.1
Own expectations (F3)	13	3	9	7.4	1.7	3	2.5	0.4
Patient contact (F4)	13	5	10	8.2	1.6	3	2.7	0.3
Others' expectations (F5)	13	5	10	8.2	1.3	3	2.8	0.2
Work environment (F6)	13	3	7	5.0	1.3	3	1.8	0.9
SEWDRS overall score	13	28	61	49.6	9.0	21	2.4	0.5

N* number of questionnaires completed

N** Number of questions included in the score

Ratings for each score and sub-scale scores were developed based on the highest possible score and the mean scores for the overall scores and the sub-scale scores of the three questionnaires (ADQ, P-CAT and SEWDRS). The ratings were defined as a percentage of the highest score possible for the measure (mean score/high score X 100%). The ratings are defined as; Low (0-60%), Moderate (61-80%) and High (81%+).

Table 9 - Summary of ratings of the three questionnaires (ADQ, P-CAT and SEWDRS) and their sub-scales

Questionnaire	Scale/Sub-scale	Percentage	Rating
ADQ	Hope sub-scale	72.8%	Moderate
	PCC sub-scale	75.8%	Moderate
	ADQ overall	74.6%	Moderate
P-CAT	Personalised care score	81.7%	High
	Organisation support score	52.0%	Low
	Environmental accessibility score	63.0%	Moderate
	P CAT overall	67.8%	Moderate
SEWDRS	Experience of feedback	55%	Low
	Care organisation	62.5%	Moderate
	Own expectations	61.7%	Moderate
	Patient contact	68.3%	Moderate
	Others' expectations	68.3%	Moderate
	Work environment	40.8%	Low
	SEWDRS overall	58.9%	Low

A series of Pearson's r correlational tests were conducted and identified two statistically significant relationships between the ADQ, P-CAT and SEWDRS (overall scores and sub-scale scores). The overall ADQ score was positively correlated with overall satisfaction with the care organisation (SEWDRS) ($r = 0.572$; $p < 0.05$). A positive attitude toward patients living with dementia is strongly associated with nurses' positive satisfaction with support received from the organisation. Satisfaction with the work environment was positively correlated with the extent to which the nurses felt the environment supported the provision patient-centred care (P-CAT) ($r = 0.631$; $p < 0.05$). Nurses were more likely to feel satisfied with the work environment if it supported the provision of patient-centred care.

4.2 QUALITATIVE ANALYSIS

The framework method of analysis of qualitative data was used to categorise and code the data to identify themes to address the research aims. This process is described in the discussion of the research methodology chapter and is summarised in Table 5. Three categories were identified from the coded data: Nursing Practices/Care, Organisational Support, and Quality of Care. The data was organised into a framework matrix consisting of the category, code and data from the interviews (Table 10).

4.2.1 Data Themes

Following the organisation of the qualitative data into the framework matrix five themes emerged that offered insight into the nurses' experience of caring for patients living with dementia and co-morbidities in an acute setting (Framework Analysis Step 7):

1. Attitudes towards patients living with dementia and their family/carers formed the basis of care

Nurses' attitudes toward patients living with dementia were encouraging. Nurses reflected positively on the uniqueness of patients with dementia and their willingness to communicate and build a relationship with these patients. Despite having a positive attitude towards patients living with dementia, nurses identified numerous ways in which the person with dementia impacted on their ability to provide patient-centred care, such as difficulties communicating with patients, increases in workload and the constant need to re-orient and reassure these patients which was viewed as very time consuming. Nurses identified the severity of the dementia as a key factor impacting on the provision of patient-centred care suggesting the more cognitive impairment suffered by the patient the more difficult it was to provide patient-centred care. Patients with

dementia were viewed as unpredictable and care was described as more time consuming than for other patients. Patients living with dementia were described as having a negative impact on nursing workload and stress. Nurses recognised the value of using family members or carers as a strategy to supervise and care for patients. Many nurses described instances where family members were called in to help to settle very distressed patients living with dementia. However, a few nurses also commented that family could “*get in the way*” (B09I) of providing patient care and that they sometimes had unreasonable expectations which resulted in feeling of frustration and guilt for the nurses.

2. Support from the organisation impacts on providing patient-centred care

Nurses reported a lack of support from the organisation to care for patients with dementia and provide them with patient-centred care. The use of standard formulas such as the ‘Nursing hours per patient day’ to calculate staffing was reported to be a major barrier to providing patient-centred care. The nurses identified the use of ‘patient specials’ to provide one-to-one care for patients with dementia as a facilitator of patient-centred care and patient safety. However, nurses all felt unsupported by the organisation when it came to their use. Requests for the extra staff were often rejected and had to be accomplished within the allotted staffing ratios. This then added to the workload for the nurses as they were “one staff down” for the shift. A lack of support for training to acquire the necessary skills to care for patients with dementia was non-existent for most nurses. However, the nurses stated that training would be useful to assist them to provide better care to patients with dementia.

3. Patients living with dementia are unique.

Nurses recognised the uniqueness of the dementia patient. Nurses found it difficult to generalise their approach to caring for the patient with dementia because each person was seen as an individual with unique needs and experiences. Also, nurses reflected that the behaviours and needs of the patient could change from shift to shift. When discussing the provision and definition of patient-centred care the nurses expressed the importance of establishing a relationship with the patient with dementia in order to understand their goals, history and needs. This relationship was perceived as necessary for providing good care. The importance of equity of care was expressed by nurses as important for ensuring that patients with dementia received the same level of care as patients without dementia.

4. The acute ward is not suitable for providing patient-centred care to patients living with dementia

The acute ward was described as an unsafe and unsuitable environment for the person with dementia. Nurses reflected on their inability to provide 'good' patient-centred care due to the constraints of the surgical ward environment. Nurses described post-operative care of the patient with dementia as very challenging due to the patients' poor memory and inability to follow instructions and the anxiety and fear associated with being in an unknown environment. The busy ward was not conducive to meeting the nurses' expectations of person-centred care. These expectations focused on establishing a relationship with the patient and family to fully understand the person with dementia. Many nurses reported positive attitudes to the philosophy of patient-centred care but

grappled with how to accomplish this in the surgical ward environment. Comments such as “*there is no time*” (B08I) and “*there is a focus on task completion not how much time you spend talking to patients*” (A06I) demonstrated this theme. Being able to spend more time with patients living with dementia was desired by most nurses who reflected that building a relationship with the patient to understand their individual needs was necessary for providing patient-centred care. However, nurses felt that the focus on task completion and the heavy patient load of the surgical ward did not permit this. Patient-centred care was described by the nurses as something that was done once the nursing tasks, such as medication administration or wound dressings, were completed. Nurses reflected on the busy surgical ward as a major hindrance to patient safety. Nurses expressed concern that patients would harm themselves if they were not continually supervised in this busy environment. Examples of patients climbing out of bed with multiple intravenous lines and surgical drains attached to them and being unable to constantly supervise them reflected their dissatisfaction with the environment for providing care to patients with dementia. Participant comments during the semi-structured interviews such as “*we just need an extra set of hands*” (B12I) and “*eyes in the back of my head would help*” (C14I) are examples of this. Nurses reported conscripting other ‘well’ patients to help to supervise the patient with dementia to reduce the risk of patient harm. For example, patients sharing a room with the dementia patient were asked to press the call bell if they noticed the dementia patient trying to climb out of bed or wandering off.

5. *Clinical experience is important to providing patient-centred dementia care*

When discussing feelings of confidence in caring for patients with dementia, nurses felt experience was more important than formal education or training in dementia. Nurses

reported receiving little in the way of formal dementia training or education. Instead they reported that learning from experience had helped them to manage patients with dementia more effectively. *“I started off as a Registered Nurse up in a geriatric ward and I learned quite a lot about how to adjust my care to meet the needs of the patient as opposed to making the patient adjust to me”* (B08I). Nurses with less experience described their work as being task driven and that the completion of these tasks was a priority for them. They felt that nurses who had more experience would find these tasks routine and would therefore have more time available to interact with and supervise the patients with dementia. This viewpoint was reflected in the staffing strategy described by nurses of allocating patients with dementia to more experienced nurses.

Table 10 - The Analytical Framework (Steps 3-6)

CODE	DESCRIPTION	SUPPORTING DATA (with participant code)
Nursing practices and care		
Strategies of care	Strategies used to manage the care of patients living with dementia	<p>“They need a lot of reorientation and reassurance” (B09I)</p> <p>“I try to keep a close eye on them” (B09I)</p> <p>“I ask the other patients in the room to keep an eye on them if I have to leave” (C013I)</p> <p>“We get a picture or something familiar with their memory as well” (C13I)</p> <p>“We get a special nurse* just to come for 1 to 1 nursing as well” (C13I)</p> <p>“I have to prioritise my care” (C013I)</p> <p>“It’s more organising your time plan really” (A05I)</p> <p>“You plan your shift around them (patients with dementia) and their care needs” (B011I)</p> <p>“Knowing how we need to adjust for her because her memory is poor” ((A08I)</p> <p>“Trying to explain and thinking of different ways of doing things or giving them a few minutes” (A05I)</p>
Impact on the nurse	Descriptions/ insight into the impact of patients living with dementia on the nurse e.g. emotions	<p>“It does make it a bit difficult” (A05I)</p> <p>“If it’s advanced, you can’t maintain a plan...so I find that quite difficult” (A06I)</p> <p>“It becomes very hard for us because these people are very unwell and in pain but they are very, very time consuming” (A08I)</p> <p>“Dementia can be quite challenging” (B08I)</p> <p>“Emotionally it’s very tiring as well. But we understand...as I said because of the character, the nature of this ward, it’s very hard” (C15I)</p> <p>“When you’re going in to do your cares it can be quite frightening for them. To witness that as a nurse can be quite confronting” (B08I)</p>

CODE	DESCRIPTION	SUPPORTING DATA (with participant code)
Impact on work	Descriptions/ insight into the impact of patients living with dementia on the shift e.g. workload, stress	<p>“Just making sure that person is safe, it can be very stressful” (B011I)</p> <p>“So I try...if I spend time with my dementia patient I’m not going to complete all of my tasks” (B011I)</p> <p>“You know this nurse will need a hand because this patient (cognitively impaired) and it’s very time consuming” (A08I)</p> <p>“Sometimes our other patients without dementia who are in here for other reasons sometimes don’t get the attention they need” (A08I)</p> <p>“It can take just one patient to make the ward very busy” (B010I)</p> <p>“I think it’s quite unpredictable about how your day may go” (A06I)</p> <p>“We can’t be spending more time because you know there are the other patients as well”(C15I)</p> <p>“Dementia care is exhausting. I mean having to repeat yourself 20 times is exhausting” (A06I)</p>
Attitudes towards patients living with dementia	Descriptions of relationships, communication with patients living with dementia e.g. stereotypes	<p>“It’s just not letting the whole dementia override the situation which it can at times” (A08I)</p> <p>“The new staff they don’t recognise that her memory is so short term. She comes across very well but her memory is very poor” (B08I)</p> <p>“I’ve never heard one of the nurses not wanting to care for or look after a patient that has dementia because they are in the too hard basket...it’s never an issue” (B12I)</p> <p>“If they trust you then it will be easy the whole shift” (C013I)</p> <p>“If it’s a really busy shift you can end up getting quite frustrated with the dementia patient” (B011I)</p> <p>“I don’t mind having these patients but in a surgical ward...it can be quite stressful” (B011I)</p> <p>“They just don’t listen to you. They can be educated but they are like a little kid” (C013I)</p> <p>“Honestly some of my loveliest conversations and best moments as a nurse have</p>

CODE	DESCRIPTION	SUPPORTING DATA (with participant code)
		been with those (dementia) patients” (A08I)
Organisational support		
Ward environment	Including the ward setting e.g. appropriateness	<p>“We are not a locked ward, we don’t really have the ability to keep them on the ward all the time” (C14I)</p> <p>“having someone who has dementia in an acute setting is extremely difficult...especially if they’re in the post-operative phase of care” (C14I)</p> <p>“This is a surgical ward. Everything is clean cut and in its place. But we would make sure they’re in a room that is close to the nurses’ station or in a thoroughfare so there is always someone to keep an eye on them” (B011I)</p> <p>“Sometimes it doesn’t feel like the right environment to be talking for ages about their grandchild when I have someone who needs a blood transfusion” (A08I)</p> <p>“I just think we are a very busy ward” (A05I)</p>
Staffing	Issues of workload, support for resources	<p>“In terms of the patients with dementia, we need more hands” (C15I)</p> <p>“It’s hard very hard to get (special nurse) but we try. Because otherwise myself the patient everyone can be at risk” (C15I)</p> <p>“We are so busy. And sometimes we are very understaffed. We have a very diverse range of patients” (A06I)</p> <p>“When these patients are specialised that helps for obvious reasons” (A08I)</p> <p>“the nurse with the dementia patient is allocated a lighter patient load” (B08I)</p> <p>“We work on nursing hours per patient day, but then we have patients living with dementia who need to be more closely monitored” (B08I)</p> <p>“When we say we need an extra nurse there shouldn’t be any questions asked. They should just give it to us” (B12I)</p>
Safety	Concerns for patient safety – both the dementia patient and the non-patients living with dementia	<p>“You’re also putting your other patients at risk because you’re not giving them great care either” (C14I)</p> <p>“We are not a locked ward. We can’t provide that sort of safety” (C14I)</p> <p>“Patients living with dementia, they have a high falls risk” (B011I)</p>

CODE	DESCRIPTION	SUPPORTING DATA (with participant code)
		<p>“You just need to keep reorienting them because they’re at risk of getting up and having a fall at some time” (B12I)</p> <p>“Patients that need specialising, I think that helps them and keeps them safe” (A14I)</p>
Education/training	Use of knowledge, impact of nursing experience, availability of education Training in care of patients living with dementia. Skills needed	<p>“That’s (confidence) purely from experience. Seeing it, not form trial and error, but seeing it first-hand”</p> <p>“I think from experience I feel more confident that I can care for them (patients living with dementia) but not so much from formal training”</p> <p>“Sometimes junior staff not having education about how to manage these types (dementia) of people”</p> <p>“You just learn from being with these people and watching how other people settle them but not really anything formal”</p> <p>“A lot of the senior staff they have their experience down pat so they can afford patients with dementia a bit more time”</p> <p>“I knew a little about it but I didn’t get any formal training. When I was an AIN I just fumbled about”</p> <p>“I don’t have any formal training. It would be great to have a little bit more knowledge about it (dementia care)”</p>
Quality of Care		
Patient-centred care	Meanings of PCC, ability to provide PCC, facilitators of PCC, barriers of PCC	<p>“The patient is the main focus. It can make it easier by adjusting the way we do something” (A06I)</p> <p>“You try to find out a bit about them. Their emotional needs their living needs, and give them care in all areas” (B011I)</p> <p>“You have to fulfil their needs. It is essential care of the patient” ((C013I)</p> <p>“Involving and having the patient in every decision that you make” (B12I)</p> <p>“Knowing the care they are receiving is right for them” ((B08I)</p> <p>“It’s getting to know the patient first and foremost” (A08I)</p>

CODE	DESCRIPTION	SUPPORTING DATA (with participant code)
		<p>Barriers: “Literally just how time consuming the tasks are, how busy it is, how heavy the patients are” (A08I)</p> <p>“We are so busy. It’s not that we don’t want to do it” (A06I)</p> <p>“We are very busy and sometimes we are very understaffed” (A06I)</p> <p>“Because of the character, the nature of the ward it’s very hard” (C15I)</p> <p>“The budget” (C13I)</p> <p>Facilitators: “Having a patient specialised in the night” (A05I)</p> <p>“Having a good understanding of who they are as an individual and what are their healthcare goals” (A06I)</p> <p>“We have a lot of allied health staff and we do SIBR rounds” (B09I)</p> <p>“We do the round and make sure everyone’s on the same page, make sure we are providing the care that the patient needs” (B09I)</p> <p>“Getting help and working as a team and having specials when we need them” (A14I)</p>
Patient factors	Characteristics of patients living with dementia e.g. forgetfulness, behaviours, anxiety	<p>“Once they get to know the environment then they aren’t too bad” (A14I)</p> <p>“It very much depends on the degree of their illness, or how advanced their illness is” (A06I)</p> <p>“You can see that they are becoming more unsettled and that may be a sign because they are in pain for example” (A06I)</p> <p>“It’s very hard to get their co-operation because they’re forgetful” (B09I)</p> <p>“But when you put them in an environment where they don’t know where they are or who this person is who is outing a bed gown on them, it is very confusing and unsettling for them” (A08I)</p> <p>“Even though they are confused they still feel pain and get worried and anxious” (A08I)</p> <p>“It depends on the level of dementia...if it’s just forgetfulness then you can discuss their care with them” (B08I)</p> <p>“I definitely think that the patient themselves is a big barrier” (B08I)</p>

CODE	DESCRIPTION	SUPPORTING DATA (with participant code)
		“It becomes more difficult if they have symptoms of agitation” (C14I)
Family	How family are included in the healthcare team, positive and negative feelings toward family,	<p>“Sometimes they actually get in the way a little bit” (B12I)</p> <p>“I find usually people want to help with their family” (B11I)</p> <p>“Most of the time families will come in and they will help” (A05I)</p> <p>“They’re a familiar face and the family can help to settle them so I can go and do that wound dressing” (A05I)</p>
Professional responsibility	Ethical conflicts/considerations of care, responsibility to the patients, accountable for actions	<p>You feel like even though you have handed over this patient because you have to escort another patient to x-ray, you feel like I just want to be quick and come back because if something goes wrong it comes back to you”(C013I)</p> <p>“In nursing there is no bible. It’s all up to you. Your clinical judgement. Your clinical decision” (C013I)</p>

*Special nurse is referred to as an Individual Patient Special (IPS) in hospital policy. This nurse is requested by the NUM to provide 1 to 1 nursing for a patient. The IPS nurse is used in addition to the staff allocation for the ward.

CHAPTER 5 – DISCUSSION

The care of patients with dementia and co-morbidities on surgical wards in the acute setting is challenging. As the population ages, there will be an increase in unavoidable admissions of complex patients to the acute hospital system, including those with dementia. The nurse-patient relationship is the key to providing excellent patient-centred care to this patient group and improving the patient experience. Due to the lack of research in this area, this study sought to explore the experience of nursing staff caring for patients with dementia and co-morbidities on surgical wards in an acute healthcare setting using a mixed method design.

The results of this study suggested that nursing staff attitudes towards patients with dementia were positive overall despite the limitations and constraints of the surgical ward. Nurses stressed the need to understand the patient and expressed empathy towards them. The importance of building a trusting relationship with the patient was viewed as paramount to providing patient-centred care. Similar findings were revealed by Nolan (14) in a study of seven nurses working on an acute aged care ward. In Nolan's study the centrality of relationships with the patient and the importance of communication and respecting personhood were demonstrated to be central to providing care to patients living with dementia. This is contrary to the findings of Cowdell's (15) study which demonstrated nurses' lack of valuing patients living with dementia with nursing staff appearing to perceive the person-as-other rather than as an individual. Seeing the patient as an individual and focusing of their needs and preferences is the foundation of the model of patient-centred care. Kitwood (45) transformed the philosophy of the care of patients living with dementia with the introduction of the concept of 'personhood' and the need to develop and hold

relationships resulting in an understanding of the person's interests, needs and desires (45, 65). This is in contrast to the medical/disease model of dementia care which focuses on the technical and curative approach to care and ignores the social psychological aspects of the person with dementia. Kitwood (45) refers to this as the 'standard paradigm' and asserts that it supports an extremely negative and deterministic view of patients living with dementia. The conflict between the two models of care is no more apparent than on a surgical ward.

The current study found that the nurses were more positive about the general abilities and the future of patients living with dementia than the actual provision of patient-centred care on the surgical wards. This result is not surprising. The surgical ward does not provide an accommodating environment for the provision of patient-centred care for patients living with dementia. Borbasi et. al. (54) identified the layout of acute wards as not conducive to the effective care of confused patients. Acute wards are busy and noisy settings where care can be very task focused. For example, on the surgical wards where this study was conducted the nurses described administering medications, mobilising patients and completing wound dressings as priorities over 'chatting' with patients or taking time to understand their individual needs. Their focus and training were on the highly technical nursing interventions required of post-operative care. Although they recognised the unique needs of patients with dementia and they had positive attitudes towards them, spending extra time with patients with dementia was not always possible or prioritised.

This is supported by previous research. Kang et. al. (49) discovered that nurses working on medical wards had more positive attitudes toward patients with dementia than nurses

working on surgical wards. It was speculated that this was because nurses on the medical wards were more likely to have received training in the management of patients with dementia and were less distracted by high-tech nursing interventions (49). Further research is needed to explore the factors that impact on the provision of patient-centred care on highly technical wards, such as surgical wards or intensive care units, in order to develop more suitable models of caring for patients with dementia in the acute setting.

The patient-centred care model focuses on developing relationships with patients and family/carers to understand their unique needs. It requires that the patient and family/carer are involved in all aspects of care and decision making about their care. This takes time and a commitment by the nurse to provide care that goes beyond the completion of essential tasks. It also requires a commitment by the organisation to value patient-centred care as a goal across all areas of the organisation. Luxford et.al. (35) interviewed leaders of healthcare organisations with high patient experience metrics to explore facilitators and barriers to providing patient-centred care. The study identified nine organisational facilitators to patient-centred care including a strong commitment by senior leaders and adequate resourcing of care delivery. Organisations must embrace the principles of patient-centred care from the top down in order to support staff to provide this care. Otherwise they are at risk of trivialising its importance and setting their staff up to fail (55). The results of this study demonstrated a statistically significant relationship between the overall ADQ score and overall satisfaction with the care organisation and satisfaction with the extent to which the nurses felt the environment supported the provision patient-centred care. The qualitative analysis of the semi-structured interview responses explored this further. Nurses reported that

support from the organisation, such as adequate staffing, impacted on their ability to provide patient-centred care. Nurses described patients living with dementia as having a negative impact on nursing workload and stress. They reflected that the busy ward and a focus on completing set tasks did not support patient-centred care. "So I try...if I spend time with my dementia patient I'm not going to complete all of my tasks".

Clearly the role of the organisation and its culture in conjunction with a safe and appropriate ward environment have a great influence on the nurses' experience of providing patient-centred care to patients living with dementia on surgical wards. Nurses' satisfaction with caring for patients with dementia was found to be lower in this study than previous studies (69, 70). In particular, the sub-scale 'experience of feedback at work' and the sub-scale 'satisfaction with the work environment' were both scored and rated low. The validity of these results was strengthened when the qualitative findings were taken into consideration. During the semi-structured interviews the nurses' described not being supported by the organisation to provide patient-centred care to patients with dementia and that the surgical ward is not suited to caring for patients living with dementia patients living with dementia. One nurse stated, "When we say we need an extra nurse there shouldn't be any questions asked. They should just give it ot us", and another suggested "I don't mind having these patients but in a surgical ward...it can be quite stressful".

Barriers and facilitators to the provision of patient-centred care to patients living with dementia on surgical wards were identified by nurses in this study. The most prominent barriers identified in this study were a lack of time and resources. Nurses expressed frustration and stress at not being able to provide patient-centred care on the surgical

ward due to understaffing. Few nurses in this study had received training in dementia care or had the skills to manage these patients. These results have been reported in previous studies and reviews (49-51, 66, 67). Facilitators identified by nurses in this study included the development of care strategies to assist with maintaining patient safety and years of nursing experience. Strategies included enlisting other patients to supervise patients with dementia to ensure they were not at risk of harm. In addition, the assignment of extra nursing staff, called individual patient specials (IPS), to provide constant supervision of patients with dementia was identified as a facilitator to providing patient-centred care.

The results of this study highlight a number of recommendations to improve the care of patients living with dementia on surgical wards in this acute care facility. They are summarised:

- Ensure the organisation's commitment to providing patient-centred care is clear and communicated to all staff through the review of strategic/organisational plans and core values.
- Explore the experiences of patients living with dementia and their family/carers receiving care on surgical wards
- Establishing a working party to identify gaps in care delivery for people living with dementia receiving care on surgical wards and undertake quality improvement projects to address these gaps through innovative models of care
- Ensure 100% of nursing staff on surgical wards receive education on dementia and caring for patients living with dementia on surgical wards.

- Review the process/policy for the use of and permission to use Individual Patient Specials on surgical wards for patients living with dementia to ensure it is equitable and safe.

5.1 STUDY LIMITATIONS

The limitations of this study are related to the sample size, the setting, and the assumed definitions of key terms. The study obtained data from only one hospital therefore the study findings are limited to information from this one site. Other settings may have produced different results. The study collected data over a two-week period from three wards in one hospital from 13 nurses who were purposively selected to participate. This does not mean it is representative of other nurses' experiences working in other wards across the hospital or in other hospitals.

The sample of participants who provided the data for the study was small but not unusual when qualitative methodologies are used to collect data. The sample size was relatively small ($n=13$), and drawn from surgical nurses. Different nurses from different work areas may have resulted in similar or different findings. Caring for patients with dementia on acute medical wards or aged care acute wards may be different to caring for patients with dementia and co-morbidities on a surgical ward.

Key terms such as dementia and patient-centred care were not clearly defined for the study participants. This allowed participants to rely on the assumptions of their individual understanding of these terms when answering the questionnaires and responding during the semi-structured interviews. This may have contributed to a reduction in the reliability of the results.

CHAPTER 6 - CONCLUSION

This study was the first study in Australia to explore exclusively the experience of nurses caring for patients living with dementia on surgical wards in the acute healthcare setting, specifically on three surgical wards in a large teaching hospital. In addition, it is the first study to use a mixed method design to explore this topic. This provided valuable insight into the nurses' experience and identified the key role that organisation support can play in providing patient-centred care to patients living with dementia. Nurses' efforts to provide patient-centred care to patients living with dementia in the acute healthcare setting were restricted by unique environmental and healthcare system issues. A lack of time and resources, conflicting priorities between caring for the medical condition and the needs of the patient with dementia, and an absence of education about how to recognise and care for the patient with dementia all impacted on the nurse's experience of caring for this vulnerable patient group.

Despite the significant relationship between the nursing staff-patient experiences, there is a lack of research focusing on the staff experience of providing patient-centred care to patients living with dementia and co-morbidities on surgical wards in the acute setting. Understanding the nursing staff experience of providing patient-centred care in this setting and using this knowledge to develop and improve systems to support excellence in care is needed.

Further research is needed that explores the provision of patient-centred care to patients living with dementia in surgical wards in the acute setting in order to add to the small

amount of empirical evidence currently available. Research investigating all aspects of the experience of patients living with dementia who are admitted to surgical wards, including but not limited to, the types of surgery, length of stay, details of re-admissions and the integration of care between discharge and the community would assist in the future development of appropriate and patient-centred models of care resulting in improving the patient experience for this vulnerable patient group.

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10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting

There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?



Detailed questions

3. Was the research design appropriate to address the aims of the research?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

☐

Yes

☐

Can't tell

☐

No

HINT: Consider

- If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data

6. Has the relationship between researcher and participants been adequately considered?

☐

Yes

☐

Can't tell

☐

No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used



MACQUARIE
University



Thank you for agreeing to participate in the research study,

The Nursing staff experience of caring for people with dementia and co-morbidities in an acute healthcare setting.

Please provide the requested demographic information below and complete all three questionnaires.

Each questionnaire will take approximately 10 minute to complete.

Following this you will be asked to participate in an interview and to respond to four general questions. All responses will be audio recorded and transcribed verbatim.

All responses are recorded and stored as non-identifiable data.

DO NOT WRITE YOUR NAME ON THIS QUESTIONNAIRE

Thank you for completing the three questionnaires and the interview.

If you have questions or require further information please contact Virginia Armour at virginia.armour@students.mq.edu.au

Or 0407061834



Demographic Information

Please place a cross X in the box to indicate your answer

Male ☐ Female ☐

Name of ward where you currently work _____

Your Professional nursing group

Registered Nurse (RN)

☐

Enriched Enrolled Nurse
(EEN)

☐

Assistant in Nursing (AIN)

☐

Nurse Practitioner (NP)

☐

Nurse Unit Manager
(NUM)

☐

Your age group

20-24 years

☐

45-49 years

☐

25-29 years

☐

50-54 years

☐

30-34 years

☐

55-60 years

☐

35-39 years

☐

60 + years

☐

40-44 years

☐

Estimate the number of people with dementia and co-morbidities that you have cared for in the past 12 months (circle) 1-4 5-9 10-14 15 + not sure

How many years of nursing experience do you have? _____

How many of these years have been working specifically with people with dementia? _____

Was this in a Hospital Residential Aged Care Facility Primary Care Other _____

Do you have formal training in caring for people with dementia? (Circle) Yes No

University TAFE Private course Ward in-services Other _____

Approaches to Dementia Questionnaire (ADQ)¹ © Tracey Lintern 1996

Instructions for use:

This questionnaire is designed to capture staff attitudes towards people with dementia.

The ADQ as two sections:

1. Hope sub-score which reflects a sense of optimism/pessimism towards the abilities and the future of people with dementia
2. Person-centred sub-score which refers to the way in which people with dementia are recognised and responded to as unique individuals with the same value as any other person.

There are 19 questions to answer. Please complete all questions.

DO NOT WRITE YOUR NAME ON THIS QUESTIONNAIRE

¹ Lintern T, Woods B. (1996) Approaches to Dementia Questionnaire. Bangor: University of Wales; 2001.5.

Approaches to Dementia Questionnaire (ADQ) © Tracey Lintern 1996

Put a cross X in the box that best reflects your experience and opinion

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1. It is important to have a very strict routine when working with people with dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. People with dementia are very much like children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. There is no hope for people with dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. People with dementia are unable to make decisions for themselves.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. It is important for people with dementia to have stimulating and enjoyable activities to occupy them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. People with dementia are sick and need to be looked after.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. It is important for people with dementia to be given as much choice as possible in their daily lives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. It is important not to become too attached to patients with dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Nothing can be done for people with dementia, except for keeping them clean and comfortable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. People with dementia are more likely to be contented when treated with understanding and reassurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Once dementia develops in a person it is inevitable they will go downhill.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. People with dementia need to feel respected just like everyone else.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Good dementia care involves caring for a persons' psychological needs as well as their physical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. It doesn't matter what you say to people with dementia because they forget it anyway.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. People with dementia often have good reasons for behaving the way they do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Spending time with people with dementia can be very enjoyable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. It is important to respond to people with dementia with empathy and understanding.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. There are a lot of things that people with dementia can do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. People with dementia are just ordinary people who need special understanding to fulfil their needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The Person-Centred Care Assessment Tool (P-CAT)

© La Trobe University

Instructions for use:

This questionnaire aims to measure the extent to which the care within a facility is experienced by staff as being person-centred.

The questionnaire consists of 13 statements about the care you provide to people living with dementia and co-morbidities. You are asked to decide to what extent you think the statements correspond to your own experiences working on your current ward.

Please put a cross X in the box that best describes your experience.

It is important that you answer all of the statements.

If you feel uncertain, choose the answer closest to your experience.

DO NOT WRITE YOUR NAME ON THIS QUESTIONNAIRE

¹ Edvardsson, E., Winblad, B., Sandman, P. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet*; 7:4, pp362-367

The Person-Centred Care Assessment Tool (P-CAT) © La Trobe University

The term "Patient" refers to people living with dementia and co-morbidities that you have cared for on your ward.

	Disagree completely	Disagree	Neither agree or disagree	Agree	Agree Completely
	1	2	3	4	5
1. We often discuss how to give person-centred care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. We have formal multidisciplinary team meetings to discuss patients' care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The life history of the patient is formally used in the care plans we develop.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. The quality of the interaction between staff and patients is important.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. We are free to alter work routines based on patients' preferences.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Patients are offered the opportunity to be involved in individualised activities based on their interests and needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I simply do not have the time to provide person-centred care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The ward feels chaotic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. We have to get work done before we can worry about a homelike environment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. This organisation prevents me from providing person-centred care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Assessment of patients' needs is undertaken on a daily basis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. It is hard for patients on this ward to find their way around.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Patients have access to an outside space or a safe room.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ID code:

Staff Experience Working with Demented Residents Scale¹ (SEWDRS)

This questionnaire aims to measure staff satisfaction in their work environment and in their experience of caring for people with dementia.

There are 21 questions. Please answer all questions based on your experience caring for people with dementia and co-morbidities on your ward.

DO NOT WRITE YOUR NAME ON THIS QUESTIONNAIRE

-
1. ¹ Astrom, S., Nilsson, M., Norberg, A., Sandman, P., & Winblad, B. (1991). Staff burnout in dementia care—Relations to empathy and attitudes. *International Journal of Nursing Studies*, 28, 65–75

Staff Experience Working with Demented Residents scale (SEWDRS)

The term "Patient" refers to patients living with dementia and co-morbidities that you have cared for on your current ward.

Please rate each statement by placing a circle around the response most appropriate to you

To what extent:	Not at all	Somewhat	A moderate amount	Very much	Extremely
1. Do you experience stimulation in your work?	Not at all	Somewhat	A moderate amount	Very much	Extremely
2. Do you experience satisfaction in your work?	Not at all	Somewhat	A moderate amount	Very much	Extremely
3. Can you respond to expectations from the patient's relatives?	Not at all	Somewhat	A moderate amount	Very much	Extremely
4. Do you feel satisfied in your contact with dementia patients?	Not at all	Somewhat	A moderate amount	Very much	Extremely
5. Do you experience the contact with a confused patient as stimulating?	Not at all	Somewhat	A moderate amount	Very much	Extremely
6. Do you experience the contact with a patient in his/her terminal state as stimulating?	Not at all	Somewhat	A moderate amount	Very much	Extremely
7. Does communication function well between day staff and night staff?	Not at all	Somewhat	A moderate amount	Very much	Extremely
8. Is your manager a good one?	Not at all	Somewhat	A moderate amount	Very much	Extremely
9. Are your expectations from work satisfied?	Not at all	Somewhat	A moderate amount	Very much	Extremely

ID code:

To what extent:	Not at all	Somewhat	A moderate amount	Very much	Extremely
10. Are the supervisory staff good as work-organisers?	Not at all	Somewhat	A moderate amount	Very much	Extremely
11. Do you experience satisfaction in your social life?	Not at all	Somewhat	A moderate amount	Very much	Extremely
12. Do relatives of patients with dementia respond to your expectations of them?	Not at all	Somewhat	A moderate amount	Very much	Extremely
13. Can you be helpful and see to the needs of a patient with dementia?	Not at all	Somewhat	A moderate amount	Very much	Extremely
14. Do you find your work rewarding?	Not at all	Somewhat	A moderate amount	Very much	Extremely
15. Can you respond to the expectations of your co-workers?	Not at all	Somewhat	A moderate amount	Very much	Extremely
16. Do you respond to the expectations of your co-workers?	Not at all	Somewhat	A moderate amount	Very much	Extremely
17. Are you satisfied with your work goals?	Not at all	Somewhat	A moderate amount	Very much	Extremely
18. Do your co-workers respond to your expectations?	Not at all	Somewhat	A moderate amount	Very much	Extremely
19. Is your workplace (ward) ideal for the care of patients with dementia?	Not at all	Somewhat	A moderate amount	Very much	Extremely
20. When you feel satisfied in your contact with patients with dementia how satisfied do you feel?	Not at all	Somewhat	A moderate amount	Very much	Extremely
21. How often do you feel strained in your contact with patients with dementia?	Not at all	Somewhat	A moderate amount	Very much	Extremely

ID code:



Thank you for completing the three questionnaires. Please return the completed booklet to the researcher or place it in the designated box on your ward.

The researcher will now conduct the face-to-face interview with you. The interview will take approximately 30 minutes or less to complete. Interviews will be audio recorded and transcribed verbatim by the researcher. All information collected will be stored and managed as non-identifiable data to ensure your privacy and confidentiality.

If you are not able to participate in the interview at this time, please let the researcher know and another more convenient time can be arranged with you.

The questions below will be used to guide the interview.

1. Describe a typical shift looking after a person with dementia and co-morbidities on your ward.
2. Do you feel you are able to provide a level of PCC* to people with dementia and co-morbidities on an acute ward that is of a high standard?
3. What do you perceive are facilitators to providing PCC* to people with dementia and co-morbidities on an acute ward?
4. What do you perceive are the barriers to providing PCC* to people with dementia and co-morbidities on an acute ward?

PCC* Person-centred Care

Thank you for your time and expertise

If you have questions or require further information please contact Virginia Armour at virginia.armour@students.mq.edu.au



St Vincent's Hospital

A facility of St Vincent's
& Mater Health Sydney

St Vincent's Hospital Sydney Ltd
ABN 77 054 038 872
390 Victoria Street
Darlinghurst NSW 2010
Australia

T + 61 2 8382 1111
F + 61 2 9332 4142
www.stvincents.com.au

7 July 2016

Ms Elizabeth Endean
Aged Care Services
St Vincent's Hospital
Darlinghurst NSW 2010

Dear Elizabeth,

SVH File Number: 16/093

Project Title: The nursing staff experience of caring for people with dementia and co-morbidities in an acute healthcare setting

Short Title: Nursing staff experience and dementia care

HREC Reference Number: LNR/16/SVH/143

Thank you for submitting the above project for ethical and scientific review.

Based on the information you have provided and in accordance with the NHMRC National Statement 2007 and NSW Health Policy Directive PD2010_055 'Ethical and Scientific Review of Human Research in NSW Public Health Organisations', this project has been assessed as low/negligible risk and is therefore exempt from full HREC review.

St Vincent's Hospital HREC (EC00140) has been accredited by NSW Ministry of Health as a Lead HREC under the model for single ethical and scientific review and Certified by the NHMRC under the National Certification Scheme. This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. No HREC members with a conflict of interest were present for review of this project.

This project meets the requirements of the National Statement on Ethical Conduct in Human Research. I am pleased to advise that the Committee at an Executive meeting on **5 July 2016** has granted ethical and scientific approval of the above **single centre** project.

You are reminded that this letter constitutes *ETHICAL* and *SCIENTIFIC* approval only. You must not commence this research project at a site until a completed Site Specific Assessment Form and associated documentation have been submitted to the site Research Governance Officer and Authorised. A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Please note that it is not considered best practice to store research data on personal hardware. No identifiable participant data can leave a site. There always needs to be data security measures in place and a clear plan for permanent destruction of data needs to be adhered to at completion of the project.

The project is approved to be conducted at **St Vincent's Hospital, Sydney**

If a new site(s) is to be added please inform the HREC in writing and submit a Site Specific Assessment Form (SSA) to the Research Governance Officer at the new site.

The following documents have been approved:

- Protocol, Version 6.0, dated 6 June 2016
- Participant Information Sheet and Consent Form, Version 3.1, dated 6 June 2016
- Flyer, Version 4.0 dated 31 May 2016
- Information poster, Version 7.0, dated 6 June 2016
- Questionnaire Booklet, Version 1.0, dated 31 May 2016

The Low and Negligible Risk Research Form (LNR) reviewed by the HREC was LNR **AU/6/55D5212**

Please note the following conditions of approval:

- HREC approval is valid for **5 years** from the date of the HREC Executive Committee meeting and expires on **5 July 2021**. The Co-ordinating Investigator is required to notify the HREC 6 months prior to this date if the project is expected to extend beyond the original approval date at which time the HREC will advise of the requirements for ongoing approval of the study.
- The Co-ordinating Investigator will provide an Annual Progress Report beginning in **July 2017**, to the HREC as well as a Final Study Report at the completion of the project in the specified format.
- The Co-ordinating Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including unforeseen events that might affect continued ethical acceptability of the project and any complaints made by participants regarding the conduct of the project.
- Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the HREC Executive for review, in the specified format.
- The HREC Executive will be notified, giving reasons, if the project is discontinued before the expected date of completion.
- Investigators holding an academic appointment (including conjoint appointments) and students undertaking a project as part of a University course may also be required to notify the relevant University HREC of the project. Investigators and students are advised to contact the relevant HREC to seek advice regarding their requirements.

Please note that only an electronic copy of this letter will be provided, if you require the original signed letter please contact the Research Office and we will be happy to provide this.

Should you have any queries regarding this project please contact the Research Office, Ph: (02) 8382-4960 or by E-mail: SVHS.Research@svha.org.au. The HREC Terms of Reference, Standard Operating Procedures, *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice* and standard forms are available on the Research Office web-site to be found at: <https://svhs.org.au/home/research-education/research-office>

Please quote **SVH File Number: 16/093** in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely,



Sarah Charlton
HREC Executive Officer
St Vincent's Hospital Research Office
Translational Research Centre, 97-105 Boundary Street
TRIM REF: D/2016/48721



MACQUARIE
University



ST VINCENT'S
HEALTH AUSTRALIA

Participant Information Sheet/Consent Form

Non-Interventional Study - Adult providing own consent

St Vincent's Hospital, Sydney

Title	The Nursing staff experience of providing care to people with dementia and co-morbidities in an acute healthcare setting.
Short Title	Nursing staff experience and dementia care
Protocol Number	[Protocol Number]
Project Sponsor	St Vincent's Health Network and Macquarie University
Coordinating Principal Investigator/ Principal Investigator	Ms Elizabeth Endean and Ms Virginia Armour
Location	St. Vincent's Hospital

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research study, *The Nursing staff experience of providing care to people with dementia and co-morbidities in an acute healthcare setting*. This is because you have cared for patients with dementia and co-morbidities on your ward and you have unique insight into how their care is delivered. The aim of the research project is threefold. First, to explore the attitudes of nursing staff providing care to people with dementia and co-morbidities in the acute setting; second, to measure the extent to which care is perceived by nursing staff to be patient-centred and their satisfaction with providing care; and third, to identify barriers and enablers to the provision of care.

This Participant Information Sheet/Consent Form tells you about the research study. It explains the research involved. 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 friend or colleague.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. It will not affect your employment at this hospital or hospitals within the St. Vincent's Hospital Network.

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 study
- Consent to be interviewed

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The study is a part of a Masters of Research (MRes) degree project and is being undertaken in collaboration with St Vincent's Hospital. Findings will be presented at conferences, workshops and will be written up for publication. The Principal Investigator is Ms Elizabeth Endean, Aged Care CNC, St. Vincent's hospital. The associate investigator/researcher is the MRes candidate at Macquarie University, Ms Virginia Armour.

3 What does participation in this research involve?

If you decide to participate, you will complete three standard questionnaires each taking approximately 10 minutes to complete. Questionnaires will be made available to nursing staff as a paper Questionnaire Booklet. In addition you will be asked to provide general, non-identifiable, demographic information. The three questionnaires you will complete are:

- Approached to Dementia Questionnaire (ADQ)
- Patient-centred Care Assessment Tool (P-CAT)
- Staff Experience Working with Demented Residents Scale (SEWDRS)

After you complete the Questionnaire Booklet you will be interviewed by the researcher. It is anticipated the interview will take approximately 30 minutes to complete. The interviews will be audio recorded and then transcribed verbatim for analysis purposes. Only the research team members will examine the interview results for the purposes of assessing responses generally, not any one specific person's responses. Interview appointments can be made for another time if you cannot participate in the interview immediately after completing the Questionnaire Booklet. Participants must complete both the Questionnaire Booklet and the interview.

There are no costs associated with participating in this research project, nor will you payment for participating.

4 What do I have to do?

You will complete three standard questionnaires each taking approximately 10 minutes to complete and a short (approximately 5 minutes to complete) demographic survey. You will also be interviewed by the researcher. It is anticipated the interview will take approximately 30 minutes to complete.

5 Other relevant information about the research project

You may complete the Questionnaire Booklet and the interview in one sitting or complete the Questionnaire Booklet first then return at an agreed date and time to complete the interview. Both the Questionnaire Booklet and the interview must be completed.

6 Do I have to take part in this research project?

Participation in this research study 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 may withdraw your participation at any time by notifying the principal investigator or researcher.

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.

7 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 of the research may include:

Understanding the challenges of caring for people with dementia and co-morbidities on an acute ward will provide valuable insight into nursing staff attitudes and knowledge of PCC, facilitators and barriers to providing excellent care and how this affects care practices and the overall quality of care provided. This insight will inform the provision of appropriate support, resources, education and systems resulting in improved staff experiences and better care for people with dementia and co-morbidities.

8 What are the possible risks and disadvantages of taking part?

The risks and disadvantages of taking part in this research are considered to be negligible. Although every effort will be taken to ensure all data and participants are non-identifiable, there is a small risk that you may be recognised as taking part in the study when you are completing the Questionnaire Booklet or taking part in the interview as these will be undertaken on or close to your ward. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your employment at St. Vincent's Hospital or within St. Vincent's Hospital Network.

In addition, the names of patients discussed by nursing staff during the interview will not be recorded in the transcribing of the interviews. The database and recorded interviews will be stored electronically on a password protected secure server located at the Australian Institute of Health Innovation (AIHI), Macquarie University. Only the named researchers will have access to the secure computer folder where the data is stored. Paper copies of demographic data, transcribed interviews, questionnaires and informed consent forms will be stored in a locked filing cabinet located in the AIHI. All data stored and analysed will be non-identifiable.

Part 2 How is the research project being conducted?

9 What will happen to information about me?

By signing the consent form you consent to the researcher collecting and using personal information about you for the research project. This information will be non-identifiable and will only include the demographic information provided in the Questionnaire Booklet. Your name will not be recorded, instead your information will be assigned a code and all information will be stored and analysed as non-identifiable data. Any information obtained in connection with this research project that can identify you will remain confidential. If you give the researcher your contact information to arrange an alternative time for the interview, this will be deleted once the interview is completed and will not be included in the data collected for analysis. Materials collected during the study will be stored at the Australian Institute of Health Innovation at Macquarie University. Computers will be password protected and filing cabinets will be locked. 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.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums including reports, seminars, conference papers and peer reviewed journals. In

any publication and/or presentation, information will be provided as non-identifiable data. Newsletters about the research process and findings may also be sent to facilities within the St Vincent's Hospital Network at the completion of the study. Any information that is obtained in connection with this study will remain confidential and non-identifiable and will be disclosed only with your permission, except as required by law.

10 Complaints and compensation

If you have any complaints as a result of this research project, you should contact the study team as soon as possible and all efforts will be taken to resolve your concerns.

11 Who is organising and funding the research?

This research study is being conducted by Ms Elizabeth Endean and Ms Virginia Armour.

Macquarie University may benefit financially from this research project if, for example, the project leads to the Macquarie University obtaining research grants and further research opportunities.

The research student will not receive a personal financial benefit from your involvement in this research project. The Principal Investigator/researcher will receive no financial incentive or benefit in relation to this research.

12 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 St. Vincent's Hospital and Macquarie University (HREC/16/SVH/143).

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.

13 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 you can contact the researcher, Ms Virginia Armour on 0407061834 or Virginia.armour@students.mq.edu.au or any of the following people.

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

Position	Manager, Patient Safety & Quality
Telephone	02 8382 2495

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:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	St Vincent's Hospital Network
Telephone	02 8382 2075
Email	SVHS.Research@svha.org.au

Local HREC Office contact (Single Site -Research Governance Officer)

Position	Research Ethics Officer
Telephone	02 8382 2075
Email	SVHS.Research@svha.org.au



Consent Form - *Adult providing own consent*

Title	The Nursing staff experience of caring for people with dementia and co-morbidities in an acute healthcare setting
Short Title	Nursing staff experience and dementia care
Protocol Number	<i>[Protocol Number]</i>
Project Sponsor	St Vincent's Hospital and Macquarie University
Coordinating Principal Investigator/ Principal Investigator	Ms Elizabeth Endean and Ms Virginia Armour
Location	St Vincent's Hospital and Macquarie University

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 health care.

I understand that I will be given a signed copy of this document to keep.

I understand that my employment at St. Vincent's Health Network will not be affected by my participation in this study.

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 Study Senior
Researcher[†] (please print)

Signature

Date

[†] A senior 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 - *Adult providing own consent*

Title	The Nursing staff experience of caring for people with dementia and co-morbidities in an acute healthcare setting
Short Title	Nursing staff experience and dementia care
Protocol Number	<i>[Protocol Number]</i>
Project Sponsor	St Vincent's Hospital and Macquarie University
Coordinating Principal Investigator/ Principal Investigator	Ms Elizabeth Endean and Ms Virginia Armour
Location	St Vincent's Hospital and Macquarie University

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my employment or my relationships with the researchers or St, Vincent's Health Network.

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.

