The Care of People With Dementia in Rural New South Wales

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Abstract

The aim of this study was to answer the research question "how do nurses in small rural hospitals care for people with dementia?" A qualitative methodology utilizing a case study research design was chosen to explore how a purposefully selected sample of 21 nurses, employed in three small rural hospitals in one region of New South Wales, Australia, cared for people with dementia. Data for this project were composed of transcripts of interviews with 19 nurse participants and field notes made by the researcher at the times of site visits and following periods of observation of six nurse participants caring for three purposively selected patient participants. The data reveals that the nurse participants are concerned about the safety of people with dementia at the study sites for the project. Nurses describe simple ways for caring for people with dementia such as maintaining a calm atmosphere, allowing people to wander when it is safe for them to do so, and the use of "specials" and restraint in order to keep people safe when no other alternatives are available. In addition, this study finds that the nurse respondents are keeping people with dementia in their own communities, where they can remain close to people who know them and can provide them with support. Nurse respondents value their positive relationships with other members of their communities, and utilize these relationships in order to enhance the care that they provide for people with dementia in their hospitals. The first conclusion of this study is that the physical environments of the study sites for the project influence the way that care is provided in these hospitals, resulting in some care that is person-centred and some care that is risk management or task focused. The second conclusion of this study is that the nurse respondents use their community connectedness to enable them to provide care for people with dementia, in partnership with families and other community members. The conclusions that have been drawn from this study have implications for practice, practitioner education and policy, with potential for this positive aspect of rural nursing practice to be applied in a wider context.
Acknowledgements

This project would not have been possible without the participants, both nurses and patients at the rural hospitals that became the study sites.

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## Abbreviations

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<tr>
<td>ACAT</td>
<td>Aged Care Assessment Team</td>
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<tr>
<td>ASGC</td>
<td>Australian Standard Geographical Classification</td>
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<tr>
<td>BPSD</td>
<td>Behavioural and Psychological Symptoms of Dementia</td>
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<tr>
<td>CEHR</td>
<td>Committee for Ethics in Human Research</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GWAHS</td>
<td>Greater Western Area Health Service</td>
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<tr>
<td>HREC</td>
<td>Human Research Ethics Committee</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>NSW</td>
<td>New South Wales</td>
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<td>UC</td>
<td>University of Canberra</td>
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Introduction

1.1 Introduction

This chapter will provide an introduction to the topic of the study. The rationale for the study will be provided. The aim of the study will be stated, and a brief explanation of important terms and concepts relevant to the study will be given. The chapter concludes with a brief overview of each of the chapters in the thesis.

1.2 Background to the Study

The term dementia refers to a collection of symptoms caused by neurological disease, and leading to deterioration in “cognition, behaviors and activities of daily living” (Black, Muralee & Tampi, 2005, p. 155). Alzheimer’s disease is the commonest type of dementia, with other causes being cerebro-vascular disease, Lewy body dementia, dementia of “Parkinson’s disease, alcohol abuse, normal pressure hydro-cephalus, Human Immunodeficiency Virus infection, hypothyroidism, and deficiencies of Vitamin B12 and folic acid” (Black et al., 2005, p. 155).

In 2005, 1% of the Australian population had been diagnosed with dementia and in 2050 this figure is predicted to be 2.7% of the population (Access Economics, 2009). While dementia is not exclusively a condition of older age, the likelihood of developing a dementia increases as a person ages, and “old age is the greatest dementia risk factor” (Access Economics, 2009, p. 4).

Behavioural and psychological symptoms of dementia (BPSD), which can include "psychosis, depression, agitation, aggression and disinhibition” (Brodaty, Draper & Low, 2003, p. 231), are distressing for the person with dementia and for those who are providing them with care. Most people with dementia will experience these symptoms at some stage during the course of the
disease, and their increasing severity is often the trigger for the person being unable to be cared for at home (International Psychogeriatric Association, 2002).

1.3 Significance of the Study

In 2009 approximately 245,000 Australians were living with dementia and by the middle of the century it is estimated that this figure will have increased to more than 1.13 million (Access Economics, 2009). As the prevalence of dementia increases with the ageing of the population, it remains imperative to investigate all aspects of care and services for people with dementia. Although it is known that there are significant gaps in services for rural people who have dementia (Alzheimer's Australia, 2007), there has been limited research about the impact of dementia on people who live in rural areas (Runge, Gilham & Peut, 2009).

Dementia is a condition that primarily affects older people worldwide. In Australia, rural areas are becoming increasingly populated by older people due to a combination of out-migration of younger people and in-migration of older people to these areas.

There are some challenges in the provision of services for people who have dementia and live in rural areas and with the provision of ongoing education for health professionals who practice in rural areas (Alzheimer's Australia, 2007).

Australians who live in rural areas experience disadvantage in access to health services in comparison with people who live in metropolitan areas (McGrail & Humphries, 2009). The reasons for this are complex and include political factors such as decentralization of services, small populations that make service provision unsustainable (Humphries, 2009), and difficulties
with recruitment of health professionals to rural areas (Hegney, Pearce, Rogers-Clark, Martin-McDonald & Buikstra, 2005).

When people with dementia are admitted to hospital it is most commonly for reasons not primarily related to their dementia (Natalwala, Potluri, Uppal & Heun, 2008). In 2003-2004, people who were hospitalized and had a diagnosis of dementia had the second longest hospital stays of any diagnosis recorded (Australian Institute of Health and Welfare, 2006).

Hospitalization can have adverse consequences for older people in general, and in particular for people with dementia (Hill, Vu & Walsh, 2007). The physical environment in hospitals can contribute to an increase in confusion for people who have dementia (Cheek & Gibson, 2003), as can the effects of physical illness (Poole & Mott, 2003). Nurses who work in acute care settings may not have the appropriate skills to care for people with dementia (Borbasi, Jones, Lockwood & Emden, 2006). Current care practices for people who have dementia and are hospitalized may be focused on risk management rather than on the person (Moyle, Borbasi, Wallis, Olorenshaw & Gracia, 2010). The local hospital is often the only option available to provide respite care for older people in rural areas, or to accommodate older people who are medically stable but cannot return home safely while waiting for a place in a residential aged care facility (Alzheimer’s Australia, 2007). Discharge planning may be particularly challenging in rural areas (Alzheimer's Australia, 2007).

Rural nursing practice is unique in that rural nurses are expected to be generalists (Hegney, 1996). Rural nurses care for patients with many different types of diagnoses, often on a single shift and this can have a negative impact on the quality of care that they are able to provide for people (Kenny, Endacott, Botti & Watts, 2007). Furthermore, rural nurses often have many
connections with people in the communities where they live and work (Mills, Birk & Hegney, 2010).

These factors are explored more fully in the review of the literature relevant to the study in the following chapter, demonstrating how important it is to understand how nurses in small rural hospitals care for people with dementia in order to ensure that appropriate person-centred care is provided for this vulnerable and increasing population. The findings from this study will contribute to our understanding of the requirements to deliver high quality care for rural people with dementia who are hospitalized.

1.4 Aim of the Study

The aim of this study is to explore how nurses in small rural hospitals care for people with dementia in one region of Australia. The research question for the study is "How do nurses in small rural hospitals care for people with dementia?"

1.5 Structure of the Thesis

The thesis consists of the following chapters: review of the literature, methodology, data analysis, and discussion and conclusions.

In Chapter Two the research-based literature relevant to the study is critically appraised and presented. The review of the literature examines the availability of health services in rural areas and nursing practice in rural areas. The shift towards person-centred nursing care, both worldwide and within Australia, and the incidence of dementia and the provision of services for people with dementia is described and discussed. Finally, the issues relevant to the hospitalisation of people with dementia and the current strategies nurses in acute care settings use to care for
people with dementia is presented and critically appraised. The chapter concludes with a description of the methodology and study design chosen for the study, which is further described in Chapter Three.

In Chapter Three the researcher provides an explanation and justification for the research design and methodological approach used in the study. The procedures for site selection, sampling strategies, data collection and data analysis are described. The ethical considerations relevant to the study are identified and discussed, the procedures for ensuring rigour and trustworthiness of the study are set out, and finally, the limitations of the study are presented.

In Chapter Four the procedure used for analysis of the data is described and justified and the two themes identified in the data are presented. The nurse participant demographic data is presented and used to describe the nurse participants. The patient participants are briefly described. The themes derived from the analysis of the data are illustrated using quotes from the participants and discussed in relation to the work of previous authors.

In Chapter Five the research findings are interpreted and discussed in relation to the research question. The implications of the results of the study for policy, practice, practitioner learning and the development of rural nursing practice are discussed and recommendations for further research are made at the end of the chapter.
Review of the Literature

2.1 Introduction

In this chapter, the literature relating to the care of people with dementia in rural settings is reviewed. First, the availability and accessibility of health services in rural areas is described and discussed. The aspects of rural nursing practice that differentiate it from urban nursing practice is discussed, along with recent initiatives in nursing, particularly in New South Wales (NSW) to facilitate the development of person-centred nursing practice. The incidence of dementia in the population, the availability of services for people with dementia in general and in rural areas in particular is discussed, along with service gaps and the aspects of those services that are helpful and not so helpful from the point of view of service users. The experience of being hospitalised with dementia is described and discussed, along with current strategies for caring for people with dementia in the acute setting.

The review of the literature will demonstrate that the problem of caring for people with dementia in small rural hospitals has been under researched. A qualitative study utilising a case study research design is proposed by the researcher as the most appropriate way of developing an understanding of how nurses in small rural hospitals care for people with dementia. As previously mentioned, the findings from this study will contribute to our understanding of the requirements to deliver appropriate and person-centred nursing care.

For this review, international peer-reviewed articles and grey literature in the English language were accessed using electronic databases and by back-referencing from the articles and documents that have been electronically retrieved.
2.2 Health Services in Rural Areas in Australia and Internationally

People living outside metropolitan areas often experience reduced access to the health services that they require compared with people living in urban areas (McGrail & Humphries, 2009). This is the case in Australia and internationally. The reasons for this inequality are complex and arise from the interaction of many factors including geographical isolation, transport difficulties and difficulties with recruitment and retention of health professionals. The relatively small populations in rural areas are not sufficient to support the infrastructure required to enable the local residents to have local access to a full range of health services. Finally, the distance that people need to travel to use health services has an impact on the access that residents of rural areas have to health services.

In some rural areas, the populations are not large enough to enable the provision of health services (Bushy, 2002; Humphries, 2009). In recent decades, increasing government attention to fiscal restraint has led to loss of health services in some rural areas, with them instead being centralized to larger population centres (Humphries, 2009). The health facilities that are available in rural areas are often too small to provide a wide range of services. This means that if people who live in rural areas have access to a health service it is unlikely to provide specialist services, such as dementia assessment and care, making it necessary for rural people to travel to larger population centres in order to have access to a full range of health services (Department of Health and Ageing, 2012). A North American study found that the economic disadvantage experienced by some rural older adults may contribute to their transport difficulties if they do not have the financial means to own and operate a private vehicle (Park et al., 2010). When people who live in rural areas do not have their own transport, they are dependent on others to take them to appointments. In some cases, such as when the appointment is with a service that carries a
stigma, such as a mental health service, concerns about confidentiality prevent people from asking someone to provide them with transport (Sanders, Fitzgerald & Bratelli, 2008). In Australia there are government subsidies available for rural people who need to travel for medical treatment, however these often do not fully cover the costs incurred by patients (Hegney et al., 2005). Many people who reside in rural areas do not live in rural towns, but may live long distances out of town. The cost of private travel to health services may be prohibitive and there is usually limited or no public transport in rural areas (Bushy, 2002).

In common with other parts of the world, including Canada and North America (Bushy & Leipert, 2005), it is difficult for health services in rural Australia to recruit nurses and other health professionals (Simpson & McDonald, 2011). Francis (2005) argues that the decline in the rural economy, out-migration of younger rural residents, and lack of educational and career opportunities in rural areas all contribute to this phenomenon.

Canadian and North American nursing students who were participants in a study conducted by Bushy and Liepert (2005) indicated that a number of factors led them to choose to practice in rural areas. These factors included having family connections or previous experience of living in rural areas, and a commitment to providing a service for their local communities. There is some evidence that having a positive experience while participating in a rural clinical placement in Australia (Webster et al., 2010), and that the duration of the placement, as well as the nursing or allied health student’s perception of it being a positive experience (Playford, Larson & Wheatland, 2006), may influence the intentions of students in the health professions to practice in rural areas in the future.
Increasing demands on rural health professionals to meet high consumer expectations of services, which are increasingly under-resourced, is one factor that Bushy (2002) claims is contributing to the problem of retaining health professionals in rural areas. In contrast, although the respondents in one study of rural health services were expected to care for the whole person rather than just attending to physical aspects of their care to ensure that patient care in their country hospitals met consumer expectations, they reported that they enjoyed the holistic and person-centred aspects of rural nursing care (Baernholdt, Jennings, Merwin & Thornlow, 2010).

Bourke, Humphreys, Wakeman and Taylor (2012) argue that the focus on the negative aspects of rural health, while useful for ensuring media and political attention and for attracting funding, has a detrimental effect on the public image of rural health and that this may deter health professionals from considering rural practice as an attractive career option. Furthermore, Simpson and McDonald (2011) propose that this focus on the negative aspects of rural practice may lead to recruitment strategies informed by the belief that any service or health professional is better than none, with subsequent outcomes that may be ineffective or unsustainable in the long term.

In conclusion, people who live in rural areas experience disadvantage in accessing the health services that they require, relative to people who live in metropolitan areas. The reasons for this disadvantage include lack of infrastructure due to small population numbers, transport difficulties related to the distance of their place of residence from services and the cost of travel, and difficulties that health services have with staff recruitment. As a consequence of all the factors discussed above, people who live in rural areas may not be able to access specialist health services when they require them, or they may not be able to travel to centres where specialist services are located, leading to their health conditions being managed locally by clinicians, including nurses, who are generalists rather than specialists.
2.3 Nursing in Rural Areas

There are a number of aspects of rural nursing practice that set it apart from nursing practice in metropolitan areas. Rural nursing practice is generalist in nature. Nurses are highly visible members of rural communities. In rural communities people generally have multiple intersecting connections and this can have positive and negative implications for nurses living and working in those communities. These implications include high community expectations about the care that they will receive at the local hospital, the challenge of maintaining confidentiality, the potential to utilise positive relationships to enhance care and the influence of social capital. Within NSW Health, in common with other health jurisdictions, there is a movement towards more person-centred ways of providing care.

Internationally, as well as in Australia, rural nursing practice demands a high level of expertise across a broad range of clinical areas (Baernholdt et al., 2010; Blue, 2002; Hegney, 1996). Furthermore, a nurse in a rural setting may care for people across the lifespan, with a multitude of differing conditions, and in different departments of the hospital, all in a single shift (Kenny et al., 2007). This workload can have an impact on the quality of the care that the nurses are able to provide. A study of nurses in small rural hospitals in Victoria, Australia found that the respondents reported that the range of different types of patients that they were required to care for in the same ward inhibited their ability to attend to the psychosocial aspects of care for people with cancer who were patients in their hospitals (Kenny et al., 2007). Rural nurses are expected to be generalists; this can be challenging for the practitioner and can have an impact on the quality of the care that they are able to provide for patients (Hegney, 1997).
An aspect of rural practice that practitioners may perceive negatively is that health professionals in rural areas have high visibility in the community, making it difficult or impossible to be anonymous (Blue, 2002). Allan, Ball and Alston (2008) found that for pharmacists and social workers, although they were highly visible in the community and felt that their practice was closely scrutinized, feeling as though they belonged in the community was a positive aspect of rural practice.

Rural communities are strongly interconnected, with many overlapping interactions between members of small communities in their personal and professional lives (Baernholdt et al., 2010; Caldwell, 2007; Evanson, 2006; Mills et al., 2010; Mills, Francis & Bonner, 2007; Penz, Stewart, D'Arcy & Morgan, 2008). Baernholdt et al. (2010) and Caldwell (2007) claim that this interconnectedness is a uniquely rural phenomenon. Mills et al. (2007, p. 583) have called this phenomenon “live my work”, while others call it “community embeddedness” (Lauder, Reel, Farmer & Griggs, 2006, pp. 75-76). There are some differences in this aspect of rural life between people who have family connections to the area spanning many generations and people who have recently migrated to rural areas (Baernholdt et al., 2010).

Rural people have a high level of trust in the nurses at their local hospital and the care that they provide, because they know them in contexts outside of the hospital, and rural nurses have a strong commitment to providing quality care for patients for the same reason (Baernholdt et al., 2010). Hansen, Robinson, Mudge and Crack (2005) found that health professionals in a rural area in Tasmania, Australia, used community connectedness to enhance their ability to work together as a team. Knowing people and their medical history when they are admitted to hospital can help nurses to plan their care without delay (Baernholdt et al., 2010). Caldwell (2007) found that interconnectedness between nurse practitioners, patients and their families in a rural area in the
United States led to mutual respect between the nurse, the patient and the patient's family. In contrast, Kenny et al. (2007) found that knowing people in other contexts than the hospital added to the emotional strain of caring for people with a diagnosis of cancer for the nurses in small hospitals in rural Victoria, Australia, who were participants in their study. Connections between people in the community are an important aspect of rural life, and these connections can have both positive and negative implications for rural nurses and their practice.

Maintaining the confidentiality of patient information can be challenging for rural nurses. Community members, who may be part of the patient’s extended family (Evanson, 2006), may enquire about people who are patients in the hospital when they encounter nurses in settings such as church or the local shopping centre or market (Baernholdt et al., 2010; Kenny et al., 2007). Home visit clients may ask nurses about other clients (Evanson, 2006). Rural nurses develop ways to maintain confidentiality by deflecting such enquiries without offending the enquirer (Baernholdt et al., 2010). Nurses may have personal information about community members that may be at odds with their public persona; for example, if respected members of the community are abusive to their partners in private. Cox, Cash, Hanna, D’Arcy-Tehan and Adams (2001, p. 283) have called this phenomenon “holding secrets.” The fact that patients know rural nurses in contexts outside the workplace may inhibit patients from disclosing intimate aspects of their personal and health histories to nurses (Evanson, 2006). Having access to personal information about other members of their rural community, and keeping that information confidential is an aspect of rural nursing practice that can be demanding for nurses.

Rural nurses utilise positive relationships with other service providers in the community, such as police (Cox et al., 2001; Evanson, 2006) and social services staff (Evanson, 2006) to enhance the care that they are able to provide to patients. Encountering community members in a multiplicity
of settings offers rural nurses an enhanced opportunity to build relationships with patients and their families (Caldwell, 2007; Evason, 2006). A differing perspective on this aspect of rural living was expressed by some rural residents, who were concerned that caregivers may gossip about their family member with dementia when they encountered them at community events (Morgan, Semchuk, Stewart, & D’Arcy, 2002). Community connections can enhance the feeling of team spirit among staff of small rural hospitals, and can enable them to work well together to provide the care that meets the needs of people in their community (Baernholdt et al., 2010). A program in a rural town in NSW utilizes community connectedness to involve community volunteers in providing people with dementia in hospital with emotional and other support (Bateman, 2010). Membership of an organised social support group has been shown to have positive effects on the emotional and physical health of older adults (McDonald & Brown, 2008).

The perception of the possession of, or the lack of, social capital is a means by which privilege and access to advantage is perpetuated (Lauder et al., 2006). In rural areas social capital is constituted of aspects such as descent from pioneering families, inherited land ownership, religious affiliation and volunteer community service activities. Nurses who have migrated into rural areas are perceived by patients as being outsiders and are sometimes not trusted by local people (Lauder et al., 2006). In contrast, community members place a great deal of trust in nurses who have community connections spanning many generations (Baernholdt et al., 2010). Social aspects of rural nursing such as horizontal violence perpetrated by senior nursing staff and lack of acceptance of them by longer-term staff who have connections outside of the workplace, as well as the patient load and level of responsibility associated with rural nursing practice, can contribute to the difficulties that new graduate Registered Nurses have in adjusting to rural nursing practice (Lea & Cruickshank, 2007). In rural areas, long-term residents usually possess
more social capital than newer residents. As a result of this, nurses who are new residents may have difficulty being accepted by patients and by their peers.

It is common for hospital staff and patients in rural communities to share multiple connections in the wider community, leading to a shared high expectation of the quality of the care that will be provided by the staff of the local hospital (Baernholdt et al., 2010; Mills et al., 2007). In rural communities, high quality care that meets the expectations of patients encompasses clinical excellence as well as caring for the whole person (Baernholdt et al., 2010; Caldwell, 2007). Rural nurses, invested in providing holistic care, pay attention to patients’ psychosocial needs as well as their physical needs (Baernholdt et al., 2010).

Community connectedness between hospital staff members leads to cohesiveness in the workplace and a valuing of the contributions of non-nursing members of the healthcare team, such as cleaning staff. Staff members in rural hospitals work as a team to ensure that all patients experience high quality care when they come to the local hospital (Baernholdt et al., 2010; Mills et al., 2007). Rural hospital staff members have pride in their hospitals (Kenny et al., 2007).

The person-centred approach and dedication of the care staff of services was appreciated by people with dementia and their carers, who participated in one study of rural services for people with dementia (Blackstock, Innes, Cox, Smith & Mason, 2006). Person-centred care is care that places the patient or client at the centre of care delivery (McCance, McCormack & Dewing, 2011) and is acknowledged to be the most appropriate care for people with dementia (Edvardsson, Fetherstonhaugh & Nay, 2010). Aspects of person-centred care valued by people with dementia, their families and the staff of their residential aged care facilities include knowing a person’s preferences, making their family members welcome, enabling them to have
meaningful activities, being flexible, and ensuring that the environment was personalized. All of these aspects were found to contribute to enabling the person with dementia to maintain their identity (Edvardsson et al., 2010). The recognition and valuing of the feelings and needs of staff, who are engaged in the emotionally demanding work of caring for people with dementia, are important aspects of person-centred care. A culture that places importance on the respect that nurses and other members of the health care team have for each other as well, as for the people they are caring for and their families, is necessary to enable person-centred practice to develop in an organization (McCance et al., 2011). Respectful relationships between nurses, patients and their significant others are central to the delivery of person-centred care (McCance, Slater & McCormack, 2008). In addition, the workplace culture in the setting where care is delivered has a significant impact on the ability of nurses to provide person-centred care (McCabe, 2004).

In recent years there has been a worldwide shift towards more person-centred ways of working in nursing and healthcare (McCormack, Manley & Walsh, 2008). The term “person-centred care” for people with dementia began with the work of Tom Kitwood, who proposed what he called a “new culture of dementia care” (Kitwood, 1995, p. 8). Central to Kitwood’s philosophy of care are the ideas that dementia is a disability that the personhood of the individual remains despite their dementia. Furthermore, the quality of the care that is delivered has an impact on how the person with dementia is affected by the disability, and that quality of care is informed by the interactions between people with dementia and staff, who respond to the person with dementia as an individual with unique characteristics, history and needs. Within this model of care, behavioural and psychological symptoms of dementia (BPSD) are seen as the person with dementia attempting to communicate their needs (Kitwood, 1995). Later authors have called this
“needs-driven dementia-compromised behaviour” (Kolanowski, Litaker, & Buettner, 2005, p. 220).

Practice development is a methodology that has as its purpose the enabling of practitioners to develop, through facilitated reflection on their practice, workplace cultures that are conducive to person-centred ways of working (McCormack et al., 2009). Emancipatory practice development uses skilled facilitation to enable practitioners to reflect on their practice in an environment of safety and challenge, with the ultimate goal of improving patient care through the recognition of the culture of an organization, reflection on aspects of practice that have not been critically examined and developing a more person-centred practice (Manley & McCormack, 2003). The process whereby culture change is achieved, with learning at its centre, is important (McCormack & McCance, 2006). Emancipatory practice development, which encourages the valuing of “the non-technical aspects of caring” (McCormack, Dewing & McCance, 2011, p. 11) is in contrast to technical practice development which has a focus on the technical aspects of practice (Manley & McCormack, 2003). Technical skills are important because clinical competence is an essential aspect of person-centred care (McCormack & McCance, 2006), however they are not the main focus of emancipatory practice development. Using emancipatory practice development, practitioners are enabled to work together to develop insights, causing change to come from within rather than from outside the group (Manley & McCormack, 2003).

Examples of practice development activities that have been applied in an older person’s care setting in the Republic of Ireland included observation of practice, with facilitated reflection on what was observed and observing the language that is used within the unit to speak to and about, and to write about older people, with facilitated reflection about the person-centredness of that language (McCormack et al, 2009). In NSW a program called "Essentials of Care" has been in
use since 2008 in urban and rural hospitals. The program uses practice development methodology in order to assist nurses to develop ways of practicing that are person-centred and relevant to their workplaces. This program incorporates active learning for practitioners (New South Wales Health, 2012).

The support of managers and nurse leaders is critically important for the development of sustainable person-centred practices (Manley & McCormack, 2008). Dewing (2008b) has identified the prevalence of short-term agendas in health care, and staff suspicion about the motivation of management, as being among the barriers to management acceptance of the relevance of practice development to their facilities.

As a consequence of the factors described above, which include the broad and general scope of practice expected of rural nurses and social issues such as community connectedness and social capital impacting on practice, rural nurses may find caring for people with dementia in their acute care settings particularly challenging. Recent shifts towards more person-centred ways of practising nursing may afford rural nurses the opportunity to develop ways of overcoming the effects of these challenges and of beginning to work towards the delivery of person-centred care that is appropriate to the settings in which they work. Because of the unique challenges faced by rural nurses, who are required to care for many different types of patients, including patients with dementia, it is important to gain an understanding of how nurses in small rural hospitals care for people with dementia in order to deliver person-centred care.

2.4 Incidence of Dementia and Services Available for People with Dementia

In 2003-2004 people with diagnoses of dementia accounted for the second highest number of bed days in Australian hospitals. This is predicted to increase as the incidence of dementia increases
with the ageing of the population. There are disproportionately large numbers of older people residing in rural areas compared with metropolitan areas. There is a range of services available in Australia aimed at preventing, treating and managing dementia. Not all of the services available for people with dementia are available or suitable for people with dementia who live in rural areas. Rural nurses are not always able to gain access to ongoing professional education. This is common to Australia and to other countries worldwide.

In 2005, 1% of the Australian population had been diagnosed with dementia, in 2050 this figure is predicted to be 2.7% of the population (Access Economics, 2009). Dementia is a condition that primarily, though not exclusively, affects older people (Access Economics, 2009).

In 2003-2004, Australians who had a diagnosis of dementia and were admitted to hospital had the second longest hospital stays of any recorded diagnosis that contributed to the cost of their hospitalisation. By the year 2031, due to the ageing of the population, there is predicted to be a four-fold increase in the numbers of people who have dementia and are hospitalised (Australian Institute of Health and Welfare, 2006).

Increasingly, rural areas have disproportionate numbers of older residents due to a number of factors. These factors include the migration of younger rural residents to urban or larger regional centres in order to pursue educational and employment opportunities, and the phenomenon of middle-aged and retired people moving to rural areas for lifestyle reasons. Because the most significant risk factor for developing dementia is old age, the ageing of the population is leading to an increased prevalence of dementia (Access Economics, 2009). The effect of the rural population ageing faster than the urban population will be an increased prevalence of dementia in rural areas in comparison with urban areas. By the year 2050, it is expected that dementia will be
more prevalent among Australians living outside of capital cities than among people living in capital cities (Access Economics, 2009). This is likely to lead to an increasing demand for services for people with dementia who live outside of metropolitan areas (Access Economics, 2009).

Dementia services in Australia range from public health initiatives aimed at preventing chronic health conditions that are risk factors for dementia, to specific treatment such as Commonwealth Government funding for pharmaceutical treatment for early dementia. In addition, the Commonwealth Government funds residential and community based aged care services targeted specifically for people with dementia. The consumer organization Alzheimer's Australia is funded by the Commonwealth government and provides education and support to consumers as well as education for health professionals. In NSW, the Behaviour Assessment and Intervention Services (BASIS) and Transitional BASIS (T-BASIS) services work with aged care facilities in caring for people with BPSD, and their carers. Dementia Behaviour Management Advisory Service (DBMAS) is an Australia-wide service with a similar function (Brodaty & Cumming, 2010).

In Australia, as in other parts of the world, General Practitioners (GPs) have an important role to play in the diagnosis and management of people with dementia. Within Australia, GPs report some difficulties with diagnosing dementia, mainly related to time constraints and lack of appropriate remuneration for the length of time required to make the diagnosis (Brodaty, Howarth, Mant & Kurrle, 1994). GPs practicing in rural NSW report lack of access to specialist geriatricians or psychogeriatricians and patients not wanting to be referred to specialists as barriers to appropriately treating their patients who have dementia (Alexander & Fraser, 2008).
Brodaty, Thomson, Thompson and Fine (2005) have identified a number of barriers to service use by carers of people who have dementia, both internationally and within Australia, including lack of knowledge of the existence of the service and their own perception that they do not require the service.

In common with people with dementia who live in metropolitan areas, people with dementia who live in rural areas may require access to health and support services. Some of the problems that people with dementia have in gaining access to services that they require are common to rural and metropolitan areas, and some are unique to the rural context (Alzheimer’s Australia, 2007).

Lack of access to specialist services in rural areas means that rural residents may have delays in obtaining a diagnosis of dementia. If an early diagnosis of dementia is made, it is possible that some people may benefit from pharmacological interventions aimed at delaying the progression of the disease. In addition, early diagnosis enables people to plan for the future, including thinking about and arranging future admission to an aged care facility for respite and/or permanent care, before a crisis point is reached (Szymczynska, Innes, Mason & Stark, 2011). When a diagnosis of dementia has been made, a lack of community services in rural areas limits the support and care options that are available to people (Teel, 2004). It is acknowledged that there is a lack of specialist services available in rural areas for people with BPSD (Brodaty et al., 2003).

Further to this, service providers in rural areas have noted lack of home care and home modification services and lack of respite services (Innes, Blackstock, Mason, Smith & Cox, 2005), shortage of local residential aged care beds and lack of daycare services (Mason, Blackstock, Cox, Innes & Smith, 2005) as service deficits in rural areas in Scotland. The lack of
appropriately trained staff, care that is not appropriate to their needs and inflexibility in the provision of services has been identified by some people with dementia and their family carers as being negative aspects of one rural service for older people (Blackstock et al., 2006). Family members of people with dementia who live in rural areas have identified waiting for a bed in a residential aged care facility as a stressful time (Morgan et al., 2002).

There may be a lack of alignment between the needs of services users and the priorities of service providers. A Scottish study found that the managerial imperative of fiscal efficiency in services for rural-dwelling older people was in conflict with the desire of service users for locally sourced services that enabled them to remain in their own homes or remain in their local area if they needed to live in residential aged care (Farmer, Phillip, King, Farrington & MacLeod, 2010).

Some rural service providers have identified a number of barriers that inhibit rural residents' access to mental health services in general and services for people with dementia in particular. These barriers include lack of financial resources, concerns about privacy, denial of the existence of a problem by the person with the health problem and their family members (Morgan et al., 2002) fear of stigmatization, lack of knowledge about available services (Hansen et al., 2005; Morgan et al., 2002), and the independence and stoicism of rural clients (Hansen et al., 2005).

Some services provided in rural areas may not meet the needs of service users, due to factors such as belief among family members that they should be providing care themselves and concern about the negative opinion of others if they use services (Arai, Sigiura, Miura, Washio & Kudo, 2000). Other factors include local services not being appropriate to the needs of the clients they serve, the distance to travel for services, cost, lack of skilled staff (Innes et al, 2005) and the person with dementia refusing services (Innes et al., 2005; Morgan et al., 2002). Service users
residing in rural areas have indicated that lack of knowledge about services, lack of availability of services or being too busy to use services as reasons for the non-use of services (Forbes, Morgan & Janzen, 2006). Travel time and costs in rural areas also have an impact on the number of clients that visiting services can accommodate within their budget and staff constraints (Dwyer & Hardill, 2011).

The interconnectedness of rural communities leads to some of the positive aspects of services for people with dementia in rural areas. Practitioners value the opportunities this interconnectedness provides for collaborative working (Allan et al., 2008; Hansen et al., 2005). Health service providers in rural East Anglia, United Kingdom, work together with other community members such as police, clergy and shop keepers to help them support people with dementia in their communities (McDonald & Heath, 2009). The fact that rural nurses and health service users encounter each other in settings outside the nurses' workplace provides opportunities for people to discuss their concerns with nurses in a setting where they feel comfortable (Cox et al., 2001).

Carers of people with dementia in small rural communities have indicated that knowing the people who are going to be providing care for their family member makes them feel more comfortable with that person (O'Reilly and Strong, 1997a). A small group of family members of people with dementia in an Australian country town identified respite services, as well as information and counselling as being particularly helpful to family carers of people with dementia (O’Reilly & Strong, 1997b).

In common with other rural health professionals, nurses who practice in rural areas in Australia experience difficulties with gaining access to ongoing professional training and education. Among the barriers faced by rural nurses wanting to pursue opportunities for further education are the distances that they need to travel to attend training (Blue, 1993, as cited in Blue, 2002;
Hegney, Tuckett, Parker & Eley, 2010) and the lack of financial affordability of courses (Hegney et al., 2010). Some initiatives have been put into place in order to address these problems, and these include scholarships for rural nurses and programs designed to encourage students from rural areas to study medicine and to practice in rural areas after graduation (Humphries, Hegney, Lipscombe, Gregory & Chater, 2002).

Along with reduced access to education and training opportunities in general, health professionals in rural areas also experience difficulty in accessing training and education about dementia. Family members of people with dementia who participated in a study in Western Australia indicated that doctors and nurses would benefit from further education about how to diagnose and treat people with dementia, speak with them and their family members appropriately about the condition and care for them while they were in hospital (Alzheimer's Australia, 2007). Recent initiatives are helping to address the need for further training about dementia for health professionals. Dementia Training Study Centres provide online dementia training and also scholarships for health professionals (Doyle, 2009). The DBMAS assists clinicians to manage behavioural problems and also has an educational role (Brodaty & Cumming, 2010). A local initiative in rural Victoria that aimed to provide dementia education for acute care staff was successful in increasing staff knowledge about dementia care, although evaluation of the program found that management and policy support was necessary to ensure sustained improvement in care (Foreman & Gardiner, 2005).

The prevalence of dementia is increasing due to ageing of the population. As previously mentioned, rural areas have a disproportionately high number of older residents and people with a diagnosis of dementia occupy a significant proportion of hospital beds in Australia which is predicated to increase. The demand for services for people with dementia is predicated to
increase faster in rural areas than in metropolitan areas. Currently people with dementia who live in rural areas experience reduced access to the health services that they require compared with people who live in metropolitan areas. The services that are available to people with dementia who live in rural areas are not always appropriate to their needs. Nurses in rural areas experience difficulties in gaining access to ongoing professional education, including education about dementia care, although some recent initiatives are helping to address this shortfall. Consequently, it is important to understand how nurses in small rural hospitals care for the population of people with dementia in order that this group of patients, who currently experience difficulty with access to services that are appropriate to their needs and whose numbers are predicated to increase, receive appropriate, quality person-centred nursing care.

2.5 Experience of Being Hospitalized with Dementia

When people with dementia are hospitalized they are at increased risk of developing complications associated with hospitalization. The physical environments of hospitals, along with the high level of activity in the acute care setting may result in increased confusion for people with dementia. Nurses working in acute settings report that they do not have the knowledge that is required to provide appropriate care for people with dementia and that they have many other competing demands on their time. These factors can contribute to the risks associated with hospitalization for people with dementia.

Dementia and other chronic cognitive disturbances are significant risk factors for falls in the acute hospital environment (Hill, Vu, & Walsh, 2007). Older people who are in hospital are at increased risk of the complications of decreased mobility such as deconditioning (Gill, Allore, Holford & Guo, 2004). The physical environment in acute care hospitals is often unsuitable for
people with dementia (Nolan, 2007). The way wards in acute hospitals are configured may exacerbate confusion for people who are already away from their familiar environments (Cheek & Gibson, 2003), and can contribute to people with dementia getting lost (Borbasi et al., 2006). Some people with dementia have difficulty expressing their needs, for example, letting nurses know if they are hungry, thirsty, in pain, or need to go to the toilet. Busy nurses may fail to anticipate the needs of the person with dementia, and this can lead to these needs not being met. Unmet needs can be expressed as agitated behaviour in a person with dementia (Kolanowski et al., 2005). When nurses fail to respond to and identify the causes of agitated behaviour, or respond inappropriately or in a rushed way, this can lead to an exacerbation of the patient’s agitation (Borbasi et al., 2006; Jones, Borbasi, Nankivell & Lockwood, 2006).

An older person who exhibits confused behaviour, perhaps with agitation and aggression, while in hospital, may have dementia and be chronically confused, or they may be acutely confused due to delirium related to an acute medical condition, or they may have a pre-existing chronic confusion with a superimposed delirium. Some nurses in acute care settings are unaware of how to differentiate between acute and chronic confusion (Moyle et al., 2010). This is important because acute confusion requires urgent attention in order to establish and treat the cause, which is related to a physical illness (Poole & Mott, 2003).

Agitated behaviour is a term used to describe the behavioural symptoms that can be present in people with dementia, due to a variety of conditions such as Alzheimer’s disease and vascular dementia (Volicer & Hurley, 2003). These behaviours may be verbal or physical. Verbal agitation, for example calling out, may be related to discomfort (Lemay & Landreville, 2010). Agitation is described as “a constellation of behaviours that are potentially harmful, both for caregivers, particularly nurses, and for patients themselves” (Poole & Mott, 2003, p. 307).
People with dementia who are in hospital are at risk of complications associated with hospitalization. Nurses who work in acute settings may be unable to respond to the needs of people with dementia, consequently leading to the exacerbation of the behavioural symptoms of dementia. Furthermore, nurses in acute settings may be unable to determine whether a patient is acutely or chronically confused, or a combination of both conditions. These factors indicate that it is important to understand how nurses in acute settings in rural areas provide care for people with dementia, in order to ensure that this vulnerable population receives appropriate and person-centred nursing care.

2.6 Current Solutions for Managing the Care of People with Dementia in Hospital

The acute care hospital environment can be an unsafe one for people with dementia and this, combined with the necessity to keep some older people in hospital when they are no longer physically unwell, can contribute to the perception held by some nurses that people with dementia do not belong in acute care settings. Some of the current strategies that nurses in acute care settings use to manage the care of people with dementia may not be appropriate or person-centred.

When people with dementia are admitted to hospital it is usually for a reason other than their dementia (Natalwala et al., 2008; Rudolf et al., 2010). Some people with dementia need to remain in hospital after their acute episode of illness has resolved because there is no safe way for them to return home (Borbasi et al., 2006; Travers et al., 2008). This is the case in both urban and rural areas, however, having dementia is a factor that contributes to an increased length of hospital stay (King, Jones & Brand, 2006) and that length of stay increases as the remoteness of the person’s place of residence increases (Zilkens, Spilsbury, Bruce & Semmens, 2009). The presence of
people with dementia in an acute hospital setting can cause concern for nursing staff, because they may not have the knowledge or skills that are required to provide appropriate care (Fessey, 2007). Aspects of the physical and ambient environments in acute hospitals can have a negative impact on the wellbeing of people with dementia. Furthermore, the clinical priorities in acute hospitals, with their focus on the biomedical model of treatment, are not conducive to providing the specialized care required by people with dementia (Borbasi et al., 2006; Moyle et al., 2010).

A study conducted in a large metropolitan hospital in Australia found that some nurse respondents expressed the view that older, confused people do not belong in acute care settings (Poole & Mott, 2003). Nurses who participated in a study conducted in a small rural hospital in Tasmania indicated that they would be able to provide more appropriate care for people with dementia if they had more education about dementia management (Hansen et al., 2005). This finding is similar the results of the study exploring the dementia care knowledge of acute care nurses, described by Fessey (2007).

Nursing care for people with dementia in an acute setting is optimal when it includes a focus on the acute condition and also the patient’s dementia (Tolson, Smith & Knight, 1999). Cheek and Gibson (2003) consider that the mix of an acute medical diagnosis and the person’s dementia causes their care needs to be complex and that this contributes to the difficulty nurses and other health care professionals experience in providing them with appropriate care.

A recent Australian study identified that a risk management approach to the care of people with dementia in an acute hospital ward can lead to the safety of the patient becoming the main concern of nurses rather than the person's dignity or their other care needs. The authors of this study have called this "paradoxical care" (Moyle et al., 2010, p. 420). This approach can lead to
the use of restraint and/or "specialling", a term that refers to the practice of having security staff or minimally trained nursing staff to sit with the patient to ensure that they are not injured by, for example, falling over or falling out of bed (Borbasi et al., 2006; Moyle et al., 2010). Previous authors have found that the need to attend to other patients and tasks and the perception by nurses that agitated patients were time-consuming led to the use of restraint even when it was acknowledged that physical restraint increased the person’s distress and agitation (Poole & Mott, 2003). Furthermore, previous researchers have found that higher education levels and greater length of nursing experience led to more positive attitudes to patients who were seen as being aggressive, and that this in turn led to reduced use of physical and chemical restraint by these nurses (Nakahira, Moyle, Creedy & Hitami, 2008).

Simple ways of orienting people with dementia while they are in hospital include the use of signs on doors and putting family photographs at the bedside (Borbasi et al., 2006). One way of mitigating the effect of the unfamiliar environment is to have the same staff care for the patient if possible, that way they become familiar to the person (Jones et al., 2006). When people with dementia who are in hospital wander, nurses are concerned that they may leave the ward and therefore be exposed to danger (Cheek & Gibson, 2003; Hansen et al., 2005; Nolan, 2007). People with dementia who are wandering may go into areas where they are exposed to hazardous chemicals or medications (Jones et al., 2006).

A study in rural Tasmania found that the nurses in a small local hospital had many demands on their time. People with dementia were nursed in an aged care wing of the hospital and the nurses frequently had to leave the wing to attend to patients in other parts of the hospital. The wing was not secure and the nurses were concerned that the people with dementia could wander away from the hospital when the nurses were absent from the wing (Hansen et al., 2005).
When antipsychotic medications are prescribed for people with dementia it is often with the intention of modifying BPSD (Banerjee, 2009). This practice is known as chemical restraint. While chemical restraint could be said to be less visually confronting than physical restraint, it often has a profound and long-lasting negative impact on the individual who is restrained (Banerjee, 2009). Chemical restraint is often prescribed on an as-required basis, meaning that nurses frequently make decisions about whether or not it should be used. Reasons nurses give for the use of chemical restraint are similar to those given for the use of physical restraint, including the safety of staff and other patients, the patient's perceived aggressiveness, their interfering with medical devices or the risk that the patient may wander or fall (Kwasny, Hagen & Armstrong-Esther, 2006). Clinicians have reported distress at having to restrain patients (Jones et al., 2006).

Nurses in a small study conducted in the United States by Byers and France (2008) reported frustration at not having enough time to enable them to provide proper care for people with dementia in their busy acute care setting. Similarly, Jones et al. (2006) found that nurses and doctors did not have time to read the notes of patients with dementia, or to conduct thorough patient assessments. While nurses may acknowledge the value of communicating with older people who are in hospital, this may not be evident in their practice (Armstrong-Esther, Browne & McAfee, 1994).

In Australia, if a person needs to be admitted to an aged care facility or to gain access to any Commonwealth Government funded services for older people, such as respite care or home-based care packages, an Aged Care Assessment Team (ACAT) must assess the person (Brodaty & Cumming, 2010). The ACAT is comprised of health professionals from a range of disciplines, commonly nursing, medicine and the allied health professions such as social work or occupational therapy. The team has a meeting with the older person who requires assessment and
their family members or other carers, either in the person's home or in the hospital if the person is in hospital in order to make an assessment of the person's ability to care for themselves. A recommendation is then made about the level of care that the person will be eligible to receive. In rural areas, where the ACAT may only visit infrequently, and the older person may not be known to them prior to the assessment, this important assessment is often made on the basis of one meeting with the older person and their family (Hansen et al., 2005).

There are circumstances where the demand for places in aged care facilities is greater than their supply. The acute care sector acts as a safety net, providing people with accommodation when they have high level care needs but they need to wait for a place to become available for them in an aged care facility (Travers et al., 2008). Due to the lack of availability of beds in residential aged care facilities in some rural areas, older people living in rural areas who require residential aged care are sometimes forced to accept accommodation away from their local area (Alzheimer's Australia, 2007; Bernoth, Dietsch & Davis, 2012; Hansen et al., 2005). This means that family members are required to travel long distances to visit their relatives after they have been placed in an aged care facility (Alzheimer’s Australia, 2007). This is disruptive to the person’s long-term connections to locality and family and has been likened to that person's going into exile (Bernoth et al., 2012). Hansen et al. (2005) found that carers of people with dementia in an area of rural Tasmania struggled to care for their family members at home for as long as possible, because they were reluctant to disrupt them by moving them out of the area in order to accept a bed in a dementia-specific facility.

Armstrong-Esther, Sandilands and Miller (1989), found that among nurses working in an acute setting, those who expressed a preference for working with older people had more positive attitudes to their presence in the ward than those who did not, and were less likely to perceive
older people as unnecessarily occupying a hospital bed when they are no longer physically unwell. When people with dementia are no longer acutely ill, but are unable to go home because they are waiting, either for home-based services to be arranged, or for a bed in an aged care facility to become available, this may further add to the perception of acute care nurses that they do not belong in the hospital (Borbasi et al., 2006).

In some rural areas the only option available for respite services for people with dementia and their carers is the local hospital. If respite services are available in rural areas, they may be inflexible and therefore not meet the needs of the people who require the service (Alzheimer’s Australia, 2007).

The lack of a safe environment for people with dementia can lead to nurses in the acute care setting regarding the person with dementia as a problematic patient to have on their ward and lead to the use of sub-optimal care practices such as "specialling" or restraint. These practices are likely to cause distress to the person and to exacerbate their confusion. Nurses in acute care settings have many demands on their time and may not have the knowledge or skills required to provide appropriate care for people with dementia. Shortages of places in residential aged care can mean that acute care settings provide accommodation for people with high-level care needs until a place becomes available for them in an aged care facility. Having a diagnosis of dementia is a factor that contributes to an increased length of hospital stay, and this length of stay increases with the remoteness of the residence of the person with dementia. Because of these factors it is important to gain an understanding of how nurses in small rural hospitals care for people with dementia.
2.7 Summary of Literature

This review has identified that there is a gap in the literature relating to the care of people with dementia who reside in rural areas. A combination of the factors that have been identified in the review of the literature make it important to understand how nurses in small rural hospitals care for people with dementia in order to address this gap.

People who live in rural areas experience difficulties with accessing health services. Rural nursing practice is generalist in nature and practitioners are highly visible members of their communities. Rural residents and practitioners have high expectations of the care that will be able to be provided in their local hospitals despite there being barriers to the provision of high quality person-centred care, such as high workload and reduced access to ongoing education for rural nurses. There has been a recent shift towards the development of person-centred nursing practice, both internationally and within Australia. People with dementia account for a significant proportion of extended hospital stays in Australia. The incidence of dementia is increasing as the population ages. There are a disproportionate number of older people residing in rural areas, and this is predicted to lead to an increase in the demand for services for people with dementia in rural areas. Currently people with dementia in rural areas, both in Australia and internationally do not always have access to services that are appropriate to their needs. Being hospitalised can be hazardous for people with dementia. Older people who are in hospital are at increased risk of developing complications of hospitalisation. Hospital environments and the effects of physical illness contribute to increasing confusion in people who are cognitively impaired. Nurses who work in acute care settings may not have the skills required to provide appropriate care for people with dementia. Current solutions for managing the care of people with dementia in acute settings are not always person-centred. Therefore, gaining an understanding of how nurses in poorly
resourced rural hospitals care for people with dementia, who are predicted to be a growing population, is critical in order to enable the delivery of good quality person-centred care.

2.8 Appropriate Methodology to Investigate the Problem

Unquestionably, the preceding review of the literature has shown that there is a gap in the research literature concerning the way nurses provide care for people with dementia in small rural hospitals, therefore the research question for this project is “How do nurses in small rural hospitals care for people with dementia?” Yin (2009) argues that case study research design is an appropriate choice when investigating research problems that are asking a “how” question about contemporary actions that are not being manipulated by the investigator. The exploratory nature of the study, that seeks to generate “a detailed and rich knowledge of a specific phenomenon” (Creswell & Maietta, 2002, p. 143), in this case how nurses care for people with dementia in rural hospitals, has led to the choice of a qualitative methodology, utilizing a case study research design. This design provides a rich description of the phenomenon of nurses caring for people with dementia in small rural hospitals (Marshall & Rossman, 2011) and this will be further discussed in the following chapter.

2.9 Conclusion

The review of the literature has revealed that there have been few studies examining how nurses in rural hospitals care for people with dementia. The proposed study, utilising a qualitative methodology and case study research design, is important in order to address this gap in the literature. This understanding is critical in order to ensure that nurses in rural hospitals, which are under-resourced, are able to provide appropriate and person centred care for people with dementia.
In the following chapter the methodology utilised by the researcher to investigate the research question, “How do nurses in small rural hospitals care for people with dementia?” is described.
Chapter 3

Methodology

3.1 Introduction

The research question "How do nurses in small rural hospitals care for people with dementia?" has been asked in order to explore how nursing care is provided for people with dementia who are patients in small rural hospitals. In this chapter the research design and methodological approach used in the study are described and justified. The procedures for site selection, sampling strategies, data collection and data analysis are also explained and justified. The ethical considerations relevant to the study are identified and discussed, the procedures for ensuring the rigour and trustworthiness of the study are set out and finally, the limitations of the study are presented.

3.2 Justification for a Qualitative Methodology and Case Study Research Design

The researcher’s initial interest lay in exploring the experiences of people who had a family member who was being cared for in a rural hospital while they were waiting for a place to become vacant in an aged care facility. This was directly related to her experience of working with people in this situation and hearing their stories over time. The researcher gained qualitative research experience while working on a large funded research project led by the University of Canberra, and reviewed the literature relevant to this topic. The review of the literature showed that little research has been conducted relating to the impact of dementia on people who live in rural areas, and the project evolved to become one about nurses caring for people with dementia in small rural hospitals. The review of the literature in Chapter Two has demonstrated that an
understanding of how nurses in small rural hospitals care for people with dementia is critical in order to ensure that this population, which is growing and already experiences reduced access to health services, receives appropriate person-centred care.

People with dementia may experience extended hospital stays if they are unable to be discharged home safely; this is particularly the case in rural areas (Alzheimer's Australia, 2007). Current practices utilized by nurses caring for people with dementia in acute care settings are not always person-centred and the reasons for this are complex. Acute hospital environments may lead to increased confusion for people with dementia (Cheek & Gibson, 2003). Nurses who work in acute care environments often do not feel that they are able to provide appropriate care for people with dementia due to lack of specialized knowledge (Fessey, 2007). Competing demands on the time of acute care nurse has been found by previous researchers to lead to the nurses feeling dissatisfied with the standard of care that they have been able to provide for people with dementia (Byers & France, 2008). The perception that people with dementia are at risk of harm while they are in hospital may lead to the use of practices such as "specalling" and restraint (Moyle et al., 2010). Despite this, some person-centred practices have been described in the literature (Jones et al., 2006).

Mills et al. (2010) claim that rural nurses often work without easy access to multidisciplinary specialist teams. In addition, nurses in small rural communities must possess a broad range of skills in order to provide care for their local populations (Hegney, 1997). It is not uncommon, in the researcher’s experience, to hear rural nurses describing themselves as a “Jack of all trades, master of none” or as Hegney, (1995, as cited in Hegney 1996, p. 1) calls it “Jack of all trades, master of many”). While rural nurses are required to be skilled in many areas of practice, they
encounter barriers to accessing education, such as the distances they have to travel to attend courses (Blue, 1993, as cited in Blue 2002, p. 199, Commonwealth of Australia, 2002).

Previous researchers have identified the social aspects of rural nursing practice that distinguish it from nursing practice in metropolitan areas. For example, nurses in rural communities are likely to have connections with people for whom they provide care, in contexts outside the workplace (Bushy and Liepert, 2005; Evanson, 2006; Lauder et al., 2006; Penz et al., 2008). Some rural nurses perceive this interconnectedness positively, with these connections being one of the factors that attract them to practising in a rural area (Hegney, McCarthy, Rogers-Clark & Gorman, 2002). In contrast, connections that span multiple contexts between established staff members in rural hospitals can make it difficult for new staff members to feel accepted by their colleagues (Lea & Cruickshank, 2007). Baernholdt et al. (2010) argue that, while there can be positive and negative aspects of community connectedness for rural nurses, nurses in rural hospitals are able to utilize their connections within the community to help them to provide appropriate care for community members. Practice development methodology aims to enable nurses to develop the person-centred aspects of their practice (Manley & McCormack, 2003). A recent initiative in NSW uses practice development methodology in both rural and metropolitan hospitals to facilitate the development of local initiatives to enhance person-centred care in participating hospitals (New South Wales Health, 2012).

A qualitative methodology was chosen as an appropriate one for the current study because an exploratory approach was required in order to answer the research question (Creswell, 2003). The specific research design chosen is an exploratory case study. This mode of inquiry is appropriate to the study because the purpose of the research was to develop “an in-depth analysis of a single case” (Creswell & Maietta, 2002, p. 147). Miles and Huberman describe a case as “a
phenomenon of some sort occurring in a bounded context” (1994, p. 25). The data collected from the three study sites have been aggregated, and the nurse participants who provided nursing care for the patient participants who had dementia, are the “case” or “culture sharing group” (Creswell & Maietta, 2002, p. 162).

3.3 Selection of the Study Sites

A purposive sample of study sites was selected, consisting of three small rural hospitals of less than 50 beds each located in rural New South Wales. The choice of hospitals with fewer than 50 beds was an appropriate one because it is in hospitals of this size that nurses are required to have generalist skills in order to manage the many different types of patients for whom they are required to care (New South Wales Health, 2009). While hospitals of fewer than 50 beds have a variety of different types of patients presenting to them for care, they are not of a sufficient size to have on-site specialist services (New South Wales Health, 2009). Three was an appropriate number of study sites in order to provide sufficient data for comparison of three typical cases (Miles & Huberman, 1994, as cited in Marshall & Rossman, 2011) because the original design of the project, as described below, sought to compare the three sites as separate cases. In addition, three sites represented a project that was achievable within the constraints of the researcher’s time and financial resources (Marshall & Rossman, 2011). The number of beds in the hospitals in the sample represents the most common hospital size in rural New South Wales (NSW) (New South Wales Health, 2009). Rural hospitals of this size typically have a mix of acute services, as well as, in some cases, dedicated long-term aged care beds (New South Wales Health, 2009).

There are a number of accepted ways of classifying rural areas that are similar but have subtle differences (Australian Institute of Health and Welfare, 2004). Small hospitals were considered
for this study if they were located in Inner Regional Australia, Outer Regional Australia, Remote Australia or Very Remote Australia as defined by the Remoteness Area Structure of the Australian Standard Geographical Classification (Australian Bureau of Statistics, 2006). These classifications, in recognition of the distances rural and regional Australians often need to travel to obtain access to services, are based on the distance by road to service centres (Australian Institute of Health and Welfare, 2004). The three hospitals eventually selected for the study, are all situated in Inner Regional or Outer Regional areas as defined by this classification system (Australian Institute of Health and Welfare, 2008).

Early in the project the intention was to compare the three cases, in order to strengthen the claims made by the findings of the study (Yin, 2003). After data collection was complete the decision was made to analyze and present the data as a single case. This decision was made due to the researcher’s concerns about the risk of the participants or the study sites being able to be identified if the data were analyzed and presented as three cases. The researcher has an ethical responsibility to maintain confidentiality of the research participants and to de-identify the study sites. When informed consent for their participation in the project was obtained prior to data collection, all participants were given an undertaking that they would not be identifiable in the final results of the study.

The first step in negotiating access to potential study sites was to compile a list of geographically accessible hospitals that met the criteria for inclusion in the study. This was done using a publication that describes, among other attributes, the service characteristics and bed numbers of public hospitals in NSW (New South Wales Health, 2009). This list was compared with tables listing the remoteness classifications of towns in Australia (Australian Institute of Health and Welfare, 2008) to ensure that potential sites met the geographic criteria for inclusion in the study.
Following compilation of the list of potential study sites, nine sites were identified as suitable for inclusion in the study. The Senior Nurse Manager of each agency was approached to be included in the research study and three of these agreed. Following the telephone contact, a letter (Appendix 1), explaining the purpose and significance of the study, providing a brief professional biography and statement of the researcher’s academic affiliation and brief background to the research was sent to the managers.

At meetings between the managers and the researcher, the three managers indicated that they were willing to support the project and the three hospitals could become study sites. They provided letters of support for the project and these were submitted with the applications for approval of the ethical aspects of the project by the University of Canberra (UC) Committee for Ethics in Human Research (CEHR) and the Greater Western Area Health Service (GWAHS) Human Research Ethics Committee (HREC). In addition, the Nurse Managers were asked to nominate people at the hospital that they would recommend as key informants for the project.

3.4 Sampling Procedure for the Nurse Participants

In order to explore how nurses in small rural hospitals care for people with dementia, it was appropriate to select a purposive sample of nurses employed at the hospitals that were study sites for the project (Marshall & Rossman, 2011). Two weeks prior to commencement of data collection, the researcher visited the sites and distributed a flyer (Appendix 2) to advertise an information session about the project, scheduled for the following week. The flyer invited nursing staff and family members of people with dementia who were patients in the hospital, to the information session. The managers notified staff members whom they felt might be key informants, and at one site, family members of potential patient participants, about the sessions.
The information session, conducted by the researcher, included an introduction to the researcher and a brief biography, details of her academic affiliation and reasons for conducting this research. Data collection methods were described, and an invitation to participate in the study was extended to those people who were present. The final sample included 21 nurse participants, 13 of whom were interviewed only, two of whom were observed providing nursing care for patient participants only and six of whom were both interviewed and observed providing nursing care for patient participants.

3.5 Sampling Procedure for the Patient Participants

The managers of the three sites identified possible patient participants and contacted their family members to explain the project. At one site, family members of inpatients with dementia attended the information session that was also attended by potential nurse participants and informed consent (Appendix 3) for the participation of their family members in the project was obtained from them at this time. At another site, the person responsible for the decision making for the potential participant was a family friend who lived 80 kilometres from the hospital at the time of the study. The researcher visited the friend and his wife in their home to explain the project to them and to invite their friend to participate in the project. Informed consent for their friend’s participation was obtained at this visit.

The three patient participants were people with dementia who were being cared for by the nurse participants at the time of data collection. Two of the patient participants were patients in a long-term care area of one of the study sites. The other patient participant, who was being treated for an acute infection in a general ward at one of the study sites, was not expected to return home due to concerns about her self-care prior to her admission to hospital.
At the time informed consent was obtained, the persons responsible for the decision-making of the patient participants were given an information sheet about the project to retain (Appendix 4), and, consistent with the requirements of the UC CEHR, a document describing the procedure for them to follow if they had any complaints or concerns about the research project (Appendix 5) was also given to them to retain. There were three patient participants in the final sample.

3.6.1 Data Collection Methods

Data collection commenced in June 2011 and ceased in August 2011. Individual interviews with nurse participants, observation of nurse participants caring for patient participants and field-notes written after periods of observation and at the times of visits to the study sites were the methods of data collection for the study.
Table 1 Data Collected For The Project

<table>
<thead>
<tr>
<th>Data</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse participant demographic data.</td>
<td>Obtained during participant interviews.</td>
</tr>
<tr>
<td>Nurse participants' experiences of caring for people with dementia in a small rural hospital.</td>
<td>Obtained during participant interviews.</td>
</tr>
<tr>
<td>Observations of how nurses provide care for people with dementia at the study sites.</td>
<td>Obtained during observation. Recorded in the researcher’s field notes.</td>
</tr>
</tbody>
</table>
3.6.2 Nurse Participant Interviews

Individual private interviews were conducted with the majority of the nurse participants, and recorded electronically with the permission of the participants. Three participants were interviewed individually but in each other’s presence (as described below). The interviews were conducted in meeting rooms, empty patient rooms or, in some cases, in the nurse participant’s office in the hospital. One of the participants preferred not to have the interview recorded and the record of her interview is based on notes taken by the researcher during and after the interview. Three participants were present during each other’s individual interviews, which were conducted in the staff office of the hospital ward on an afternoon shift. The researcher asked each of these participants if they would like to go to a private room, however they were reluctant to leave the ward due to their concerns about patient safety. The researcher was concerned with the impact that the lack of privacy could potentially have on the quality of the data collected, however she was reluctant to insist and risk losing the rapport that she had built with the participants, which could have resulted in a loss of richness in the interview data (Marshall & Rossman, 2011). One of these participants was only present for part of the other participants’ interviews, because she had to leave the office to attend to a patient in the Emergency Department. The interviews with the nurse participants were all conducted at the participant's place of work and during work time, with the exception of one interview, which was done by telephone because the participant was absent from work at the time of the site visit.

The interviews with the nurse participants commenced with a re-iteration of the identity and academic affiliation of the researcher, confirmation of consent, indication that the appropriate ethical approvals had been granted and a reminder that the participant was free to stop the interview at any time.
Basic demographic information about the age, gender, highest nursing qualification and number of years nursing experience of the participants was collected, as per Table 2, below.

**Table 2 Demographic Questions For The Nurse Participants**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender was recorded in the researcher’s notes at the time of the interview.</td>
<td></td>
</tr>
<tr>
<td>Is your age between 20 and 30, 30 and 40, 40 and 50, 50 and 60 or 60 and 70?</td>
<td></td>
</tr>
<tr>
<td>What is the highest nursing qualification you hold?</td>
<td></td>
</tr>
<tr>
<td>How many years’ experience do you have in nursing?</td>
<td></td>
</tr>
<tr>
<td>What position do you hold at this hospital?</td>
<td></td>
</tr>
</tbody>
</table>
A list of questions was developed prior to the data being collected.

**Table 3 Questions For The Nurse Participant Interviews**

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is important to you when you are caring for people with dementia?</td>
</tr>
<tr>
<td>What would be your ideal in terms of caring for people with dementia?</td>
</tr>
<tr>
<td>How does this differ from your daily reality at work?</td>
</tr>
<tr>
<td>What works well when caring for people with dementia at this hospital?</td>
</tr>
<tr>
<td>What doesn’t work well?</td>
</tr>
<tr>
<td>Are there any aspects of working in a rural area that affect the way you care for people at this hospital?</td>
</tr>
<tr>
<td>Is there anything else you would like to talk about?</td>
</tr>
</tbody>
</table>
3.6.3 Observation of Nurse Participants Caring for Patient Participants

At the third site, there were no patients with dementia in the hospital at the time of data collection. The Nurse Manager at this site invited the researcher to telephone regularly to inquire whether any people with dementia had been admitted to the hospital. Unfortunately, any admissions of potential patient participants did not coincide with the researcher’s availability to visit the site, so no observational data were able to be collected from that site.

Eight nurse participants, out of a total of 21 nurse participants, at two of the study sites, were observed providing nursing care for people with dementia, for a total of twelve hours over four days. At the third study site (as described above) there were no patient participants. Intimate personal care such as showering or washing, toileting and continence care was not observed. The care that was observed was assistance with nutrition and hydration, administration of oral medications, wound care, assistance with mobility and interpersonal communication between the nurse participants and the patient participants. At the end of each of eight blocks of observation, each lasting between one hour and two hours, the researcher recorded what she had observed in the field notes. These recordings of observational data were done immediately after the periods of observation in order to ensure that the researcher recollected the events accurately (Grbich, 1999). Specific notes were made about the physical environment, interactions between staff and patients, about what was said, how it was said, what was done and how it was done. The same observations were recorded for each period of observation, this procedure is consistent with that described by Flick (2006). Observation was discontinued when nothing new was being observed (Agar, 1996).

At the end of each day's field-work a thorough, rich description of the day's events which included the researcher's impressions about what had taken place was recorded in the field notes.
At one of the sites, with the participant’s permission (as described below) the researcher was able to sit in a vacant room opposite the room occupied by the patient participant, where she could see the patient participant but not be seen by her, and observe all the interactions between the patient participant and the nurse participants. At this site, the researcher was able to make notes about interactions between the patient participant and the nurse participants as they occurred, because she was able to do this without being observed. All interactions between the patient participant and the nurse participants were recorded in the notes. The periods of observation occurred at times when the researcher was not conducting interviews with nurse participants. At the other site where participant observation was able to take place, the researcher sat in the day room of the long-term care area with the patients. This did mean that she had some interactions with the patients, who treated her as if she were a visitor. To sit with them and not interact would have been unnatural, however the researcher did not provide the patient participants with any care. At this site the researcher made notes at the end of the periods of observation and all interactions between the patient participants and the nurse participants were entered into the field notes. The periods of observation occurred at times when the researcher was not conducting interviews with nurse participants.

3.7 Data Analysis Procedure

In this study, data, consisting of interview transcripts and field notes, were subject to thematic analysis, an approach that aims to capture the most important themes in the data (Franzosi, 2004). Consistent with the principles of case study research design, data analysis was guided by the purpose of the study, which was to explore how nurses in small rural hospitals care for people
with dementia (Yin, 2009). Data analysis was an iterative process, which involved multiple close readings of the data, along with consultation with colleagues and the project supervisors, and looking at the data in different ways. This iterative process led to the development of the two themes, which are “watchful wandering” and “keeping people close to home”.

A comprehensive discussion of the procedures used in the analysis of the data is provided in the following chapter.

3.8 Reflexive Researcher

The researcher has been a Registered Nurse for more than two decades, so is thoroughly enculturated in the world of hospitals and nursing. In Bourdieu’s terminology, she has acquired the habitus of the nurse, the mantle we assume as we internalize the culture of the field (Mahar et al., 1990). It legitimizes us as actors in the field. Examples of this specific to rural nursing would include being familiar with people and their relationships within the community.

“…the world encompasses me (me comprend) but I comprehend it (je le comprends) precisely because it comprises me. It is because this world has produced me, because it has produced the categories of thought that I apply to it, that it appears to me as self-evident.” (Bourdieu & Wacquant, 1992, p. 128).

The researcher practiced as a nurse in rural areas for 20 years. This has been both an advantage and a disadvantage in this project. No doubt the researcher’s background in rural health has provided her with easier access to and acceptance in the study site than if she were a “city person”. The other side of this is the risk that, due to internalization of the values of rural nursing practice, the site, its practices and culture are overly familiar and that some aspects of culture and
patient care may have been overlooked. In addition, as someone who has always felt slightly out of place in the profession of nursing and as someone who was brought up in the city, but moved to the country, she is in effect an outsider as well as an insider in both of these worlds.

“It’s possible that a history of the individual is never anything other than a certain specification of the collective history of his group or class, each individual system of dispositions may be seen as a structural variant of all the other group or class habitus, expressing the difference between trajectories and positions inside or outside the class” (Bourdieu, 1977, p. 86).

During the course of the project, contemporaneous reflexive field notes were kept, starting when the researcher first began to negotiate access to the study sites. During this project the researcher has been careful to maintain an awareness that the influences of her own experiences in rural nursing and her strong views about the person-centred care of people with dementia may colour the lens through which she views the data that she has collected.

The journal that was commenced at the beginning of selection and recruitment of the study sites contained the notes the researcher made after periods of participant observation, notes made about other points that she observed during site visits, impressions and reflections.

In order to aid reflexivity, described as “a constant reflective and self-critical process” by Grbich, (2004, p. 133) the researcher used memoing (Gibbs, 2007) to record ideas during data analysis. Vignette writing (Miles & Huberman, 1994) was helpful for allowing the researcher to process her feelings about the data and to get past her initial response to it, which was to see it in the context of her own strongly held views about nursing practice and her experience of practice in a small rural hospital. The researcher is a product of the hospital-based system of training nurses.
In order to complete her training and remain practising as a nurse in the public health system and in rural health, she has certainly unconsciously assumed the habitus of an actor in that field, albeit one who at times feels like an outsider. Indeed her background and experience to date have led her to identify the importance of this project and pursue it to completion (Bourdieu, 2003; Mabry, 2008).

Initially, the researcher did not attach a great deal of significance to the data describing how nurses use rural interconnectedness to enhance their nursing care of people with dementia. She thought that it was self-evident because it was very familiar to her as rural nurse. It was only when she began to explore the construct further during the process of developing themes and reflecting on peer feedback and the work of other researchers that she realized that this is a minimally documented finding in the nursing literature. Baernholdt et al. (2010) claim to have newly discovered that “the sense of community in rural settings contributes to quality care, because people know each other outside the hospital, commitments exist to assure all patient experiences are optimal” (Baernholdt et al., 2010, p. 1346).

3.9 Ethical Considerations for the Study

Before the research was carried out approval for the ethical aspects of the project was sought and obtained from the UC CEHR (Appendix 6) and the GWAHS HREC. In addition, Site Specific Approval was sought and obtained from the GWAHS HREC for two of the three sites and from the Southern and Murrumbidgee NSW Local Health Networks HREC for the third study site. These approvals have not been included in the appendices because they contain the names of the hospitals that were the study sites for the project.

The issues that were considered in the applications for approval of the ethical aspects of the
project are discussed below. These relate to cultural awareness of issues relevant to potential participants who may be of Aboriginal and/or Torres Strait Islander descent, substitute consent for potential participants who may be cognitively impaired and potential risks to participants.

The National Health and Medical Research Council (NHMRC) Guidelines that relate to research that may involve participants who are of Aboriginal and/or Torres Strait Islander origin are derived from values that are important to Aboriginal and Torres Strait Islander peoples (National Health and Medical Research Council, 2007). A condition of ethical approval for the project being granted by both the UC CEHR and the GWAHS HREC was that the researcher undertake cultural competence training prior to working with any participants of Aboriginal and/or Torres Strait Islander descent. No participants in the study identified themselves to the researcher as being of Aboriginal and/or Torres Strait Islander descent.

One of the features of dementia is progressive impairment of cognition. Consent to participate in research by a person who is cognitively impaired is addressed in paragraph 4.5.5 of the NHMRC National Statement on Ethical Conduct in Human Research (2007).

If a person who is cognitively impaired is deemed to be unable to make decisions independently, substitute consent for participation in a research project must be obtained, from a person who is responsible for their decision-making (New South Wales Government, 1987). Substitute consent was sought on behalf of the three patient participants due to their cognitive impairment.

In order to manage the risk of damage to work relationships, at the time informed consent (Appendix 7) to participate in the study was obtained, the nurse participants were given an undertaking that their confidentiality would be maintained in any dissemination of the results of the study. Rural communities are small and lack of privacy can be a negative aspect of living in a
rural area. In recognition of this, the researcher has withheld two demographic items in the description of the nurse participants. First, the data that was collected to describe the position participants held at the study site has not been displayed. Second, the data about the participant’s years of experience in nursing has been simplified. During data analysis the researcher began to reflect on the possibility that, if these aspects of the demographic data were displayed as part of the data, this may make participants identifiable to other participants and to other readers who may know them. The data identifying the participant’s job titles have not been displayed, in order to make them less able to be identified.

In order to maintain the confidentiality of the participants and the study sites, nurse participants and patient participants were given pseudonyms by the researcher, and the data from the three study sites were aggregated into a single case in recognition of the fact that people in small communities may be easily identified (National Health and Medical Research Council, 2007).

All of the nurse participants were informed, at the time informed consent was obtained, that participation in the study was voluntary and that they could withdraw their consent at any time without prejudice or penalty. Furthermore, they were provided with an information sheet (Appendix 8) and the purpose of the study was explained to them.

In order to manage the risk of unauthorized people gaining access to the data, and to comply with the UC policy as stated by the UC CEHR, data for the study, with identifiers removed, are stored securely. Computer files are password-protected and hard copies are stored in locked filing cabinets at UC. When five years have elapsed after the completion of the study the data will be securely destroyed.

There was a risk that patient participants could become agitated during periods of observation...
due to the presence of the researcher. In order to manage this risk the researcher gave an undertaking that she would cease observation if she observed any patient participant beginning to become agitated or becoming increasingly agitated during any period of observation. No patient participants became agitated during any period of observation.

3.10 Rigour and Trustworthiness of the Study

There is ongoing debate about how to ascertain the quality of qualitative studies (Lincoln, 2002). The quality of the current study can be determined by the degree to which it can be found to be trustworthy. The credibility, dependability and confirmability of the study have been addressed in order to ensure the trustworthiness of the study (Lincoln & Guba, 1985). The procedures used for addressing these concepts are discussed below.

In common with other qualitative studies, the results of the study are not transferable (Lincoln & Guba, 1985). The data provided in this study are rich, enabling readers to make a judgement about their applicability in other situations, based on relevance of the setting of the current study to the setting under consideration (Marshall & Rossman, 2011).

The researcher has addressed the credibility of this study by triangulating the data and by peer debriefing and member checking. The dependability of this study has been addressed by the researcher creating a case study database and a chain of evidence, in order to ensure that the study is auditable. In order to establish confirmability, the researcher has established an audit trail as stated above and kept a reflexive journal throughout the study (Lincoln & Guba, 1985).

The procedures the researcher has used to ensure the credibility of the study are as follows. The data were triangulated. This was accomplished by using three sources of evidence, that is,
participant interviews, participant observation, and field notes which were “aimed at corroborating the same fact or phenomenon” (Yin, 2009, p. 116). In order to ensure the quality of the evidence gathered for the project, the researcher gained experience in conducting interviews and observations (Yin, 2009) by participating as a student researcher alongside experienced qualitative researchers on a large funded research project led by UC. The researcher also undertook training in qualitative data collection and analysis with the Australian Consortium for Social and Political Research Incorporated. At the time of the interviews, the nurse participants were asked if they would like to be sent a copy of the transcript of their interview for member checking (Kvale, 2007). Only two participants requested a copy of their transcript, which was subsequently sent to them. Neither of these two participants requested that any changes be made. All participants were given a card with the researcher’s contact details, and advised that they should make contact if they would like to retract any statements made in the interview or add anything to what they had said. No participants requested that the researcher do either of these things.

During the course of the project, peer debriefing was utilized in order to enhance the study’s credibility. In order to further enhance the credibility of the study, the data have been represented to participants at one site for verification. This member checking (Lincoln & Guba, 1985) ensures that the author's creative license, used to de-identify individuals and agencies, has resulted in an analysis that remains grounded in the participant's experience of practice. Ten nurses at one of the study sites attended a meeting during which the researcher described the background to the study, the data collection and analysis methods and gave a summary of the results of the project. While none of the staff members present at the meeting had been participants in the project, they were all nurses employed at the study site, and they agreed that
the results of the study resonated with their experience of caring for people with dementia at that hospital. Also present at this meeting was one of the project supervisors, who is able to validate the accuracy of this statement.

In order to enhance the dependability of the study, the researcher created a case study database that consisted of the de-identified transcripts of the interviews with the nurse participants, the field notes and the researcher’s reflexive journal (Yin, 2009). This database is, in principle, available for other investigators to enable them to review the evidence. The dependability of the study is further enhanced by the maintenance of a chain or evidence linking the research question to the research report via the research protocol and the case study database (Yin, 2009). A step-by-step plan has been used for the project. All steps of the project were repeated for each study site in order to minimize errors (Yin, 2003).

The confirmability of the study was addressed by the researcher keeping a reflexive journal throughout the project (Lincoln & Guba, 1985), beginning at the time that access to the study sites was first being negotiated, thus reflexively situating the researcher’s point of view alongside the data. In addition, an audit trail was established, as described above.

During data analysis, the researcher examined all of the data as part of ensuring the quality of the study (Yin, 2009).

Marshall and Rossman (2011) argue that in good quality qualitative research the trustworthiness of a study is inextricably bound to the researcher’s ethical responsibility to respect the rights and contributions of the research participants. The ethical considerations for this study, and the changes made to ensure the confidentiality of the participants, have been discussed earlier in this chapter.
3.11 Limitations of the Study

There are potential limitations to the study and these are described below. Some of the limitations relate to decisions made by the researcher in order to ensure that the participants and the study sites were not able to be identified in the final results of the study, and to ensure that the three nurse participants would be able to be interviewed by acceding to their request to be present during each other's interviews.

While the multiple case study design is acknowledged as a stronger design than the single case study design (Yin, 2003), the data from the three study sites were analyzed and reported as a single case, due to concerns about participants and study sites being recognizable in the results of the study.

At one of the study sites, as described previously, three of the participants were interviewed in the same room, within hearing of each other, by their own choice. There is the potential for this situation to have influenced their responses to the interview questions.

One participant did not consent to her interview being recorded, therefore her transcript was not a verbatim account, although the researcher made notes during and after the interview. In addition, there is potential for the notes to be influenced by the researcher’s particular point of view about the research topic.

A further potential limitation of the study is the limited time spent in the field. There is the possibility that, had the site visits been of longer duration, further significant events may have been observed, but it is equally possible that nothing further may have been observed (Flick,
2006). However, on each occasion of observation, observation was discontinued when no new events were being observed.

The results of the study cannot be generalized to the wider population due to the study being conducted with a small sample size and in only one rural region in NSW. While the researcher acknowledges that this is a limitation of the study, the study nevertheless has provided rich valuable data that will add to the existing body of literature and provide further insight into the topic.

3.12 Conclusion

The aim of the study was to explore, through interviews with the nurse participants and observation of the nurse participants caring for the patient participants, how nurses in small rural hospitals care for people with dementia, to answer the research question "How do nurses in small rural hospitals care for people with dementia?" This chapter has provided a justification of the choice of qualitative methodology and case study design. Site selection, sampling of nurse and patient participants and data collection have been described. The ethical issues relevant to the study, procedures for ensuring rigour and trustworthiness of the study, and the limitations of the study have been presented.

In the following chapter the procedures used for analysis of the data that was collected in order to answer the research question will be described and discussed in detail, illustrated with quotes from the participants.
Chapter Four

Data Analysis

4.1 Introduction

Chapter Four describes the analysis of the data collected for the research project conducted to explore how nurses in small rural hospitals care for people with dementia, and presents the findings of the study.

In this study, and as previously mentioned, a case study approach was chosen to explore how nurses in three small hospitals in rural Australia care for people with dementia, in order to gain a "deep understanding" of this occurrence (Mabry, 2008, p. 214). Miles and Huberman describe a case as “a phenomenon of some sort occurring in a bounded context” (1994, p. 25). In this instance the case, which relates to the research question (Yin, 2009), is the nurse respondents employed at the three study sites, who provide care for people with dementia in their hospitals.

In recognition of the fact that people in small communities may be easily identifiable to other people in that community, the data from the three study sites have been aggregated as a single case for analysis. As previously mentioned, the researcher believed that de-identification of the sites and the respondents was necessary in order to manage the risk of harm to participants due to “damage to social networks or relationships with others” (National Health and Medical Research Council, 2007, p. 16) that may potentially have occurred if the participants were able to be identified by others.
The aim of the study was to explore how nurses care for people with dementia in small rural hospitals in one region of Australia. In order to do this it was necessary to ask the following questions:

- What do nurses in small hospitals say they do when caring for patients with dementia?
- What do nurses in small hospitals say about the impact of living in a rural area on the care that they provide for people with dementia?
- What do nurses in small rural hospitals do (observed to do) when caring for patients with dementia?

The chapter first presents the justification for the analysis technique, followed by the demographic data that provide a snapshot of the 19 nurse respondents who were interviewed for this study. At the beginning of their interviews, respondents were asked to identify their gender, age range, highest qualification in nursing, position at the hospital of employment and years of experience in nursing. These data are used to describe the study sample and to help illuminate the results.

The qualitative data collected for this project include the transcriptions of interviews with the nurse respondents, the researcher’s field notes made during and after the site visits and following periods of observation of nursing care of people with dementia at the study sites.

Following presentation of the nurse respondent demographic data, the procedures used in the analysis of the data are described and justified. The two themes identified in the data are then presented, illustrated using quotes from the nurse respondents and discussed in relation to the work of previous authors. When quoting the respondents the researcher has been mindful to
eliminate any catch-phrases or quirky colloquialisms that may make it possible for respondents to be identified by readers who may know them (Boyatzis, 1998).

The two major themes that emerged from the data are as follows:

- **Theme One “Watchful Wandering”**.

  In this theme, nurses claim wandering is best for managing stress, restraint leads to adverse outcomes in people with dementia, and “going along” with people calmly decreases distress. This is balanced with a professional responsibility to protect vulnerable people who are being provided with care.

- **Theme Two “Keeping People Close to Home”**.

  In this theme, despite barriers such as unsuitable physical environments, nurses are keeping people with dementia in their own communities, where they are close to people who know them and can provide them with emotional and social support.

4. 2 Justification of the Data Analysis Technique

Thematic analysis (Miles & Huberman, 1994) was used to analyze the data. The analysis of the data was an iterative process, which began with listening to the recordings of the interviews, and reading and further writing of field notes at the end of each day of field work. Initial use of contact summary sheets (Miles & Huberman, 1994) at the end of each day’s field work was valuable for capturing important points raised during interviews and enabling the researcher to reflect on issues raised by participants.
The next stage of interacting with the raw data was for the researcher to transcribe the taped interviews verbatim and to type the field-notes. These activities began the process of repeated close reading of the data. The data were read multiple times as they were reduced to categories and after several iterations, two major themes emerged from the data. At this stage of analysis feedback from the project supervisors and a “critical friend” (Miles & Huberman, 2002, p. 397) was important because it helped the researcher to progress past the stage of being “stuck” in seeing the data from her own viewpoint. Eventually, a way was found to look at the data in different ways and to subsequently develop themes that reflected the research question and the reality of the field (Miles & Huberman, 1994), with its inherent contrasts and tensions.

During analysis, the data were displayed as text; “a focused, partially ordered display” (Miles & Huberman, 1994, p. 110). The reason this was done was to preserve the contextual integrity of the data (Grbich, 2004).

After several iterations, two themes were identified in the data as “watchful wandering” and “keeping people close to home”.

4.3 Nurse Respondents

There were 21 nurse respondents, 13 of whom were interviewed only, two of whom were observed providing nursing care for patient participants only and six of whom were both interviewed and observed providing nursing care for patient participants.

The demographic data are used to describe each of the 19 nurse respondents who were interviewed. All respondents have been given pseudonyms by the researcher in order to de-identify them.
Table 3 Demographic Profile of Nurse Respondents

<table>
<thead>
<tr>
<th>Name</th>
<th>Qualification</th>
<th>Age Range</th>
<th>Years of Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann</td>
<td>RN (Registered Nurse)</td>
<td>50 - 60</td>
<td>33</td>
</tr>
<tr>
<td>Carol</td>
<td>RN</td>
<td>50 - 60</td>
<td>More than 30 years</td>
</tr>
<tr>
<td>Christine</td>
<td>RN + post basic education</td>
<td>60 - 70</td>
<td>30</td>
</tr>
<tr>
<td>Denise</td>
<td>RN + post basic education</td>
<td>50 - 60</td>
<td>35</td>
</tr>
<tr>
<td>Ellen</td>
<td>RN</td>
<td>50 - 60</td>
<td>32</td>
</tr>
<tr>
<td>Emma</td>
<td>EEN (Endorsed Enrolled Nurse)</td>
<td>20 - 30</td>
<td>7</td>
</tr>
<tr>
<td>Lucy</td>
<td>RN</td>
<td>30 - 40</td>
<td>18</td>
</tr>
<tr>
<td>Karen</td>
<td>RN</td>
<td>40 - 50</td>
<td>10</td>
</tr>
<tr>
<td>Kim</td>
<td>EEN</td>
<td>30 - 40</td>
<td>8</td>
</tr>
<tr>
<td>Liz</td>
<td>RN</td>
<td>20 - 30</td>
<td>5</td>
</tr>
<tr>
<td>Lorna</td>
<td>AIN (Assistant in Nursing)</td>
<td>50 - 60</td>
<td>2</td>
</tr>
<tr>
<td>Margaret</td>
<td>EN (Enrolled Nurse)</td>
<td>50 - 60</td>
<td>38</td>
</tr>
<tr>
<td>Maria</td>
<td>RN</td>
<td>50 - 60</td>
<td>30</td>
</tr>
<tr>
<td>Mary</td>
<td>RN</td>
<td>30 - 40</td>
<td>17</td>
</tr>
<tr>
<td>Penny</td>
<td>RN</td>
<td>40 - 50</td>
<td>20</td>
</tr>
<tr>
<td>Rachel</td>
<td>EEN</td>
<td>30 - 40</td>
<td>19</td>
</tr>
<tr>
<td>Rosalie</td>
<td>RN + post basic education</td>
<td>50 - 60</td>
<td>34</td>
</tr>
<tr>
<td>Sonia</td>
<td>EN</td>
<td>60 - 70</td>
<td>18</td>
</tr>
<tr>
<td>Val</td>
<td>RN + post basic education</td>
<td>50 - 60</td>
<td>28</td>
</tr>
</tbody>
</table>
4.4 Patient Participants

The patient participants in the study were people with dementia who were patients in two of the three participating hospitals and therefore receiving care from some of the nurse respondents. The three female patient participants have been given the pseudonyms “Lily”, “Coral” and “Beatrice” by the researcher in order to ensure that they are not able to be identified in the final results of the study.

4.5.1 Theme One "Watchful Wandering"

In this study the majority of respondents believed that wandering is best for managing stress, restraint leads to adverse outcomes in people with dementia, and that “going along” with people calmly decreases distress, this is balanced with a professional responsibility to protect vulnerable people who are being provided with care.

The respondents spoke about matters relating to this theme most frequently when answering the following interview questions:

- “What is important to you when caring for people with dementia?"
- “What is your ideal when caring for people with dementia?"
- “How does this differ from your daily reality at work?"
- “What works well when caring for people with dementia in this environment?"
- "What doesn’t work well?"

The researcher asked these questions in order to explore the perceptions of the participants about the aspects of caring for people with dementia that mattered most to them and how they would care for people with dementia if they could do so in an ideal way. Ways of caring that were
successful and not so successful at the sites were also explored using these questions. The questions were deliberately open-ended in order to elicit the widest range of responses possible and allow participants freedom to talk about what was important to them as nurses (Briggs, 1986).

Within the theme of "watchful wandering" respondents discussed a number of issues. For example, keeping people safe, minimizing distress, and caring for people in ways that were respectful of their dignity and their personhood were all described as being important to participants.

“I think that we still treat them as human beings and not depersonalise them.”

Christine

“...that they’re acknowledged, not just left. I know that there might be other things that need your attention quicker but you can always get a relative or somebody in to sit with them to calm them.” Ellen.

The unsuitability of their physical environments, as well as staff shortages, were seen by the respondents as being barriers to the provision of optimal care for people with dementia. The “busyness” of the ward, and not “going along with” the person were seen as not conducive to minimizing distress for people with dementia when they were in hospital. Using the existing resources that were available to them led to participants finding simple ways of caring for people safely in their existing environments. These "ways” included taking people with them when possible while they were working, admitting people with dementia into beds which were close to the nurses’ station, having staff or family members sit with a person who was distressed and
trying to maintain a calm atmosphere in the ward. These formed the sub-themes from the major theme "watchful wandering" and are explored in the following section.

4.5.2 The Importance of Keeping People Safe

Respondents in this study were overwhelmingly concerned with maintaining patient safety in the often physically unsuitable acute care setting. This risk management focus was particularly noted when nurse respondents were concerned that patients would wander and disturb other patients, fall and injure themselves or go outside the building.

“The layout of the hospital is difficult with dementia people because of the stairs and you don’t have the staffing to supervise them like you’d like to, so it only seems to take a second sometimes and they’re gone...” Liz.

“Even at night they can still walk out the door from this side, they’re not locked in, you’re locked out but you’re not locked in, so that’s a problem.” Kim.

This finding supports those of earlier researchers, who found that, when caring for people with dementia, nurses’ concerns about the safety of the patient, as well as that of “other patients and staff” (Moyle et al., 2010, p. 423), often led to them prioritizing safety over other needs of patients, including the need for respect of their dignity. In addition to being concerned about safety, many of the respondents in the current study stated that treating people with respect and being mindful of their dignity were important to them when they were caring for people with dementia. Jacelon (2003) researched the concept of dignity in older people who were hospitalized and found that the respect given to older people by staff was an important aspect of maintaining dignity as perceived by the older people in her study. In the current study, nurse participants
recognized that their hospital environments were not safe environments for people with dementia who wander.

Borbasi et al. (2006, p. 306) describe people with dementia who are in hospital as “requiring familiarity, order, peace and serenity.” Participants in the current study supported this contention. Many participants spoke of the importance of maintaining a calm atmosphere for patients with dementia and of the difficulty of achieving this in the acute care environment. There is tension between the ideal ambient environment of calm routine for a person who is confused and the ambience in an acute hospital ward, with its organization-centred routines, task focus, busyness and noise.

“Well, it’s just nearly impossible, and it’s dangerous, and that’s what we find, you know. We have the falls, the incidents and things like that, when you’re busy.” Val.

When people with dementia are being cared for in a busy and stimulating environment, such as an acute care ward in a hospital, their confusion is often exacerbated (Borbasi et al., 2006) and this can lead to an increase in behaviours such as wandering.

4.5.3 The Simple Ways of Caring for People with Dementia

Respondents spoke of simple, inexpensive ways of monitoring patients, of finding ways to keep patients busy and of wandering with patients if they had time to do so, although the use of these interventions varied across the sites. Many participants acknowledged that they did not have specialist knowledge about caring for people with dementia.
“… if they’re a wandering dementia we try to put them in with someone else you know that might notify or ring the bell, if they’re young so they can say “that patient’s gone out the door or something.”’’ Ellen.

“Sometimes putting a black strip (like a piece of tape on the floor) across the doorway of a person’s room will stop them going out of the room. We have a bell on the back door that we can set so we know when someone is going out it. Having the patient’s name and the date on the door is good for orientating them.”’’ Margaret.

“Bea’s got one, Bea’s got a fiddle box.” Lorna. (A fiddle box is a box containing items that are of interest to the person that can keep restless people with dementia occupied. In this case the box contains craft items such as balls of yarn because Bea enjoys doing craft activities).

"I don’t think there’s enough true education on how dementia works.”’’ Lucy.

If the person with dementia is being cared for in their local hospital, family members are more likely to be available to provide care and support to the person than if they were in a hospital that was not in their local area. Having a familiar person with them while they are in hospital ensures that the person with dementia is not in a completely unfamiliar environment, surrounded by unfamiliar people, which will exacerbate confusion. Working collaboratively with family members and the wider community enabled the nurses at the study sites to use these resources to assist them to care for the people with dementia. Family members who are able to be with the person while they are in hospital are seen as an important asset by nurses (Jones et al., 2006). Many participants spoke of calling on family members to come to the hospital and sit with their loved one when they were concerned about the person’s agitated behaviour.
"It’s probably more the small, I guess a small community, because (mostly) we will know their family, or someone’s very close with their family or you’ll know the person themselves or their husband or their wife, and you tend to work in well with them and we, well we like to, if they do get agitated at the end of the day, or different times of the day, we like to sort of have that relationship with the family where we can ring them and they’ll come and sit with them and things like that, that tends to work quite well with us here, we do have a good rapport with the majority of the families that we nurse with.” Mary.

"Volunteers in general come in, I think that’s important and it needs to be encouraged a lot more, the volunteer system, even if it’s just to read them a book and things like that." Penny.

The respondents in the current study acknowledged the usefulness of simple and often person-centred interventions, such as the fiddle box spoken about by Lorna (above), to keep people with dementia safe and to keep them occupied. In addition to being able to call on family members and having community volunteers visit patients informally, two of the study sites have day care available for inpatients. Where they are available, services such as day care and community volunteers, as described by the respondent Penny above, are helpful for maintaining social connectedness for people with dementia who are in hospital. Previous researchers have found that nurses have utilized simple means of orienting patients with dementia, such as placing a clock or familiar photographs in the patient’s room (Borbasi et al., 2006). These simple interventions align with the perception of some participants in the current study that, while people with dementia may need to wander, nurses need to intervene at times in order to maintain their safety. The
perception of some nurse participants in this study, that they did not have enough knowledge about dementia, supports the findings of a previous study (Fessey, 2007).

4.5.4 The Use of "Specials" and Restraints to Manage Patients who Exhibit Behavioural and Psychological Symptoms of Dementia

Respondents in this study also identified other ways of managing patients who exhibited BPSD, for example, the use of security staff to “special” patients and using physical and/or chemical restraints. There was a difference in the attitudes to the use of restraint expressed by participants with greater acceptance of the practice by an inexperienced AIN than by experienced RNs.

"I don’t see anything wrong with it." Lorna.

“... we’ve had to special a few, and that’s for their own safety, in the unit, and then hence you get the security, so you’re bringing another frightening thing at them.”
Karen.

“We do use restraints a lot, but that is because we do not have any other safety mechanisms in place, you know we don’t have the chairs that will alar(m), that will alert us if someone tries to get up, stuff like that, restraints are probably a very interesting topic to get into because you know, whereas you say that people have the right to chose and all of that sort of stuff, but busted bones are frowned upon.” Val.

“I hate to do the physical, but the chemicals just as bad. A restraints a restraint but sometimes you need to for the safety of them, safety of other patients and the safety of the nursing staff...” Lucy.
Participants in the current study indicated that they used "specials", as well as physical and chemical restraints in order to keep people with dementia and in some instances staff, safe in their hospitals. The research literature also indicates that these are solutions that are commonly used to manage “disruptive behaviour” (Borbasi et al., 2006) in the acute hospital sector (Jones et al., 2006).

4.5.5 Theme Summary

This theme has illustrated that the nurse respondents recognized that their acute hospital environments were not suitable places for caring for people with dementia. The physical environments do not have any secure areas where people can wander safely, although some facilities have alarms on some doors, and one facility has closed circuit monitoring in some rooms. Many participants felt that they did not have enough knowledge about dementia to care appropriately for people with the condition. In common with nurses in other settings, these nurses used the limited resources that they had at their disposal to enable them to provide care for people with dementia in their environments, including endeavouring to maintain a calm demeanour and atmosphere, trying to have a routine for people with dementia while they are in hospital, having someone familiar such as a family member sit with them, trying to keep patients who have dementia occupied, and physical and chemical restraint.

The findings that have been discussed above all describe how the nurse respondents at the small participating rural hospitals provided care for people with dementia. These findings of recognition of the inherent dignity of the individual, concern for safety, acknowledgement of the importance of a calm atmosphere, simple ways of caring for people and the use of "specials" and restraint have been used by the researcher to develop the theme of "watchful wandering."
4.6.1 Theme Two "Keeping People Close to Home"

This study showed that despite barriers such as unsuitable environments, nurses are keeping people with dementia in their own communities, where they are close to people who know them and can provide them with emotional and social support.

Participants spoke about matters relating to this theme most often when answering the following interview question:

- “Are there any aspects of working in a rural area that affect the way you care for people at this hospital?”

This question was asked in order to explore whether or not the participants perceived that working in a rural area had any impact on the care they provided for people with dementia.

An important element of this theme is rural interconnectedness. Rural interconnectedness has positive and negative aspects for nurses, who are also community members. The point of view of the individual is the key to their perception of this phenomenon. One respondent, Denise, told the researcher that she felt privileged that people felt able to approach her in the supermarket to discuss the care of their relatives. In contrast to Denise’s view, another respondent, Carol, felt that it was an advantage not to know people, because the problem that the person came to hospital with was then the focus, rather than perceptions of the person being influenced by knowledge of their personal history. Knowing about older people in the community because they have been in hospital previously, or because they are users of services connected to the hospital such as Community Health Services, or through personal networks, led to some of the respondents in this study more readily accepting the need for people to come to hospital because
they could not manage to care for themselves at home or they needed respite care or to wait for a bed in an aged care facility. The respondents in this study expressed some differing points of view about the phenomenon of rural interconnectedness. There was general agreement among the respondents about the benefits of rural interconnectedness in positively affecting the knowledge nurses, patients and family members had of each other and how informal networks were helpful in caring for people. This finding supports the findings of previous researchers (Baernholdt et al., 2010; O’Reilly & Strong, 1997b).

“Well I guess a lot of the people are, a lot of the staff who work here, they’ve grown up in this town and they know people, so it’s like a big extended family...” Christine.

The positive perception of rural interconnectedness expressed by most respondents is in contrast with perceived negative aspects of rural small town life that have been identified by previous researchers, which include a lack of privacy (O’Reilly & Strong, 1997a). There was some acknowledgement of the potential disadvantages of rural life by the respondents. One respondent indicated that she felt that not being a long-term resident in the community was an advantage because she did not know people in the area. At one site respondents who were not long-term residents expressed the perception that they did not have as much social capital as those who were long term residents.

“It is, you don’t know people, as in their background. They’re a person that’s come in that needs care.” Carol.

“I’ve been here just on three months, shy a week and hazing for some people still hasn’t finished as in they don’t trust you. Sometimes something I do will be overridden or ignored.” Lucy.
“I guess people don't realize that when they move here, they're not accepted, yeah, it's a bit unfortunate.” Maria.

The respondents in the current study described both positive and negative aspects of rural community connectedness, with many respondents agreeing that informal connections were an important aspect of the rural health-care setting. In contrast, some respondents felt that there was inequality between long-term residents and newer residents in rural areas.

An additional part of this theme is the fact that respondents in this study acknowledged that when older people in their rural communities need to be in hospital, the people and their families expect that they will remain in their own community and that this is preferable to care being provided elsewhere because if they are in their own community family members can visit to provide them with social and emotional support. Being a part of their community is an important part of personal identity for lifelong residents of rural areas (Bernoth et al., 2012). Linked with this finding is the difficulty rural people experience because of the distances that they need to travel to access health and aged care services.

The data that were obtained from asking the above research question led to the development of the second major theme, "keeping people close to home", plus the sub-themes that are presented in the following section.

4.6.2 The Problems Rural People Experience due to the Distance from Services

As previously mentioned, the difficulties of travel and access to health services in rural communities are documented in the literature (Alzheimer’s Australia, 2007; Forbes et al., 2006; O’Reilly and Strong, 1997b). The respondents in this study also identified distance from services
as problematic for older people in their areas. One participant spoke about a patient participant, Lily, who was in hospital because she was not able to care for herself at home any more, but who lived too far out of town to enable services such as home care to provide support which might have enabled her to continue living in her own home.

“If she actually lived in (town) where there was more services available and you could get a bit of extra help going in, that’s if she lets them in the door, there might have been a possibility, because physically she’s quite well, we perhaps could have kept her at home a bit longer but you see (her town) is so isolated, there’s very little services out there.” Ann.

“Um, I guess being in a rural area there’s not the resources available that are available in the city centres, I mean it takes a long time if we need to get like a geriatrician review or something like that. There seems to be a lot of processes and a lot of time waiting for someone to come and review them." Emma.

“We don’t have a lot here of carer respite, to help the carers.” Rosalie.

Furthermore, people who are patients in small rural hospitals can experience delays in specialist assessment and review related to their distance from larger centres. In addition, there is a lack of domiciliary services in more remote areas (Alzheimer's Australia, 2007).

The literature shows that remaining close to home may have a significant impact on the lives of rural older people living in areas with limited transport options, particularly when their partner no longer drives (O’Reilly & Strong, 1997b). The lack of public transport in rural areas means that if a person is admitted to a hospital or an aged care facility in another town and their partner no
longer drives, their partner is dependent on others for transport to enable them to visit (Alzheimer’s Australia, 2007). This is one of the reasons that rural residents want to stay in their own town if they are admitted to an aged care facility. The community where a person may have lived all of their lives is part of their identity, and for a person to have to accept an aged care place in another community has been likened to being in exile (Bernoth et al., 2012). The desire to be admitted to the local aged care facility to the exclusion of other facilities can cause tension between families and staff, who have competing needs. The hospital staff have a need to free up a bed in their acute hospital, while the family has a need to keep their family member close to home so that they can continue to remain in regular contact with them and provide them with ongoing support and companionship, and this was discussed by the respondents.

“... we’ve had times over the years where we’ve been full and we’ve had, say a local resident, and they’ve had to be shipped to outer lying areas so therefore they’re uprooted from this environment and then they’ve got no family and they can’t travel as well and you don’t know how long that’s going to be for, and you’ve got always that worry that that environment might need to ship them out further, that happens, probably once every 6 months or twice every 6 months, something like that, the same happens with the base hospitals, they’ll ship them to us and it catapults if need be, that is very disturbing for them.” Rachel.

“... sometimes the family put on a bit of pressure that they only want them to come into the aged care facility which is our closest one, but the deal being is if there’s a bed there’s a bed and they should be taking the bed and then when one comes available in the aged care facility they can transfer across from another institute and
I don’t think the family understand that because of course it might be another town or somewhere like that and it’s difficult for family too.” Denise.

Participants acknowledged that it was not desirable to move people away from their communities, while expressing the view that people should accept a place in an aged care facility when it was offered to them even if it was not in a local facility. These complexities that surround admission to aged care facilities in rural areas can contribute to extended hospital stays for older rural residents.

4.6.3 The Length of Time Older People Can Spend in Hospital in Rural Areas

Rural people can spend lengthy periods of time in hospital while waiting for a bed in an aged care facility (Alzheimer’s Australia, 2007) if there is no other available suitable accommodation. The length of hospital stay for people with dementia increases as the remoteness of their place of residence increases (Zilkens et al., 2009). Participants in the current study spoke about the need to provide somewhere for people to be cared for while they wait for a bed in an aged care facility.

“There are not a lot of nursing home places, people can be in hospital waiting for placement for a long time.” Margaret.

“If they’ve been ACATed and they need to go into a nursing home and we can’t put services in place, we would not send that person home because that’s inappropriate, so if they can’t be cared for at home, then they will have to stay here”. Denise.

The respondents in the current study noted that people could be in hospital for a long time while waiting for a place in an aged care facility and that sometimes it was not safe to send people home to wait for a place if there were no local domiciliary care services.
The respondents at one facility spoke of older people living in the community who were no longer able to manage to live at home, and of being aware, through formal or informal networks of these people, and being willing to accommodate them at the hospital when they reached a crisis point.

“... we’ve been having issues, or this lady’s been aware, we’ve been aware of her for the last couple of weeks, the husband’s just got to the crisis point where he needs emergency respite.” Mary.

While the local hospital may not be the most suitable environment for people with dementia, participants indicated that families often have the expectation that this is where care will be provided for their family member. Rural communities have a strong sense of ownership of their local hospitals (O’Reilly & Strong, 1997b).

“... people who have donated money, significant money to the hospital, so in some ways they do own it. So, the family would expect that they would go from here to wherever else that they chose to send them to.” Denise.

Some respondents in the current study indicated that they were willing to provide emergency respite care for people who had reached the point where they were not able to be cared for at home and that this willingness was consistent with expectations within the local community.

4.6.4 Theme Summary

This major theme has identified that a lack of services to enable people to remain in their own homes with support, and sometimes, lengthy waits for admission to aged care facilities may mean that older people with dementia in rural areas may spend extended periods of time in hospital.
Furthermore, there is often an expectation among family members that this time will be spent in the local hospital. People in rural communities often feel a strong sense of ownership of their local hospital for a number of reasons, which have not been fully explored in this study but include the history of the establishment of the hospital and a history of community fund-raising efforts to support the hospital. Because rural hospitals are often significant employers in country towns, large numbers of community members are employed at the hospital or related to someone who is, further enhancing the links between the hospital and staff in the wider community. Keeping older people, and specifically those who have dementia, in their local area enables nurses to use their local knowledge and their community interconnectedness to call on family members to help with caring for the person with dementia while they are in hospital. The elements of this theme, as described above, have been used by the researcher to develop the theme of "keeping people close to home"

4.7 Conclusion

This chapter has provided a justification for the data analysis technique utilized in this study and has presented the demographic data of the nurse respondents, and described the nurse and patient participants. The two major themes and sub-themes, which emerged from the data, were described and illustrated using the voices of the participants and the findings of the study have been compared with the work of previous authors.
In the following chapter the major conclusions of the study will be identified and discussed. The potential impact of the findings of the study on practice, policy and practitioner learning will be discussed. Finally, the researcher will make recommendations for research to further investigate the major finding of the study; that the rural nurses who were respondents in this study were using their community connections to enable them to provide person-centred care for people with dementia.
Chapter Five

Conclusions and Discussion

5.1 Introduction

In this chapter, the conclusions that have been drawn from the findings of the study are presented and discussed in relation to the work of previous researchers. The implications of the conclusions of the study in terms of their potential influence on policy, practice and staff education are discussed. Finally, recommendations for further research that builds on the findings of the study are made.

5.2 Conclusions That Have Been Drawn From the Findings of the Study

The first conclusion of this study is that the physical environment of the care setting had an influence on the way that care was provided for people with dementia at the participating hospitals in the study, with nurses using a number of different ways to keep people with dementia safe and cared for in their hospitals. The second, and important conclusion of this study is that many nurse respondents in the study were working in ways that utilized their community interconnectedness to enable them to collaborate with other service providers, community volunteers and family members of patients with dementia in order to provide care for people with dementia in their hospitals.

5.2.1 Conclusion One: Influence of the Environment of the Care Setting on Care Provision

As mentioned above, the first conclusion of this study is that at the participating hospitals, the physical environments where the care for people with dementia was provided had an impact on
the way that care was provided. This impact encompassed nurse respondent concerns about patient and staff safety, patient physical and psychological well-being and the impact of the presence of people with dementia on usual ward routines. This conclusion is discussed below.

The three participating hospitals in this study were housed in older buildings, two of the three have the patient care areas in upstairs wards, none has any secure areas for people to wander in and one is close to a busy highway. The lack of any secure areas where people with dementia can wander in relative safety, as well as the presence of environmental hazards such as stairs and second storey verandahs combine to make these environments potentially unsafe for people who are cognitively impaired. The majority of the respondents in the study indicated that patient safety was one of their most important concerns when caring for people with dementia in their hospitals, due to the unsuitability of the physical environments of their hospitals. Previous researchers have also found that the physical environment in acute care settings is often not suitable for people who are cognitively impaired (Cheek & Gibson, 2003). Consistent with the results of the current study, Nolan (2007) found that the small number of nurse participants in her study expressed the view that they were most worried about safety when caring for people with dementia in their acute care environment.

Consistent with the results of the current study, Moyle et al. (2010) found the unsuitability of the physical environment of the hospital for people with dementia resulted in nursing staff believing that safety was the most important aspect of their care. These authors used the term “paradoxical care” (Moyle et al., 2010, p. 420) to describe the type of care that privileges safety over other aspects of care for people with dementia, including the dignity of the person. The physical environments of the three hospitals in the current study were also unsuitable for people with dementia. This may contribute to the perception of some respondents in this study, that restraint,
either physical or chemical, is needed in order to keep people with dementia safe in their hospitals. This finding supports the finding of Moyle et al. (2010) that due to the unsuitability of the acute care physical environment for people with dementia, nurses participating in their study placed a higher priority on safety than on any other aspect of care. This prioritizing of safety was found by the researchers to lead to care practices such as the use of "specials", usually by junior staff members, who monitor the patient to make sure that they do not come to any harm, for example, by falling, or removing medical devices such as intravenous cannulae. In addition, participants used physical and chemical restraint, often with the involvement of security staff, when people with dementia became aggressive.

The respondents in the current study shared common concerns about the safety of individuals in their physically unsuitable environments, about balancing the needs for some people to wander with the risk of them falling or leaving the building. There were some differences in the way these concerns were operationalized between the three study sites, with sites using different ways of keeping people safe, that were similar to the ways nurses who participated in the study conducted by Moyle et al. (2010) kept people safe, including having family, or nursing or security staff sit with the person, or physically or chemically restraining them.

There is a tension between the desirability of encouraging people to be ambulant and to maintain as much of their independence as possible and the risk to the person (and the organization) of harm from accidents such as falls. At two of the hospitals that were study sites for the current project, this tension commonly results in the use of physical and/or chemical restraint for people with dementia because the nursing staff have many competing demands on their time. At one particular site, the building is configured in such a way that the patients are not visible to the nurses when they are required to help in other areas of the hospital.
There were some differences in the attitudes that the respondents in the current study expressed to the use of restraint and these relate to the experience and qualifications of the respondents. For example, one respondent, an Assistant in Nursing, accepted physical restraint as normal practice, while another respondent who was a Registered Nurse, acknowledged that physical restraint could increase agitation in people with dementia. This finding is consistent with the finding of Nakahira et al. (2008) that the attitudes, educational preparedness and experience of nurses can have an influence on their attitude to perceived patient aggression, and this can affect their willingness to use physical restraint.

The respondents in the current study reported that they were most able to care for people with dementia in ways such as wandering with them or taking the extra time that is required, for example to answer repetitive questions, when the overall workload was lower. Respondents additionally reported that they found it difficult to provide appropriate care for people with dementia when they were busy. Previous researchers (Borbasi et al., 2006; Byers & France, 2008) have found similarly, that the multiple demands on the time of nurses in acute settings make it difficult for them to take the time required to properly care for people with dementia. The nurses who participated in the small study conducted by Byers and France (2008) reported that this led to their dissatisfaction with the level of care that they were able to provide for people with dementia in their acute environment. The authors described this in terms of the participants reporting feelings of “frustration and remorse” (Byers & France, 2008, p. 47).

The respondents in the current study spoke of endeavoring to maintain a calm atmosphere in order to avoid exacerbating confusion for people with dementia. This finding supports the findings of Nolan (2007). In her study, participants related that when there was a lot of activity
on the ward, people with dementia were likely to experience an increase in their usual levels of agitation.

At one hospital, which was a study site for the current study and where the most consistently person-centred practices were observed and spoken about among the three study sites, one staff member was acknowledged by other staff and by management as having a particular interest in the care of older people. This echoes the example provided by Moss and Chittenden (2008) of one nurse influencing the practice of the team.

The way nursing is practiced at another site seems to be decided by a group of very long-term staff members who organize patient care according to what Binnie calls the “‘worker’ ethos” (2000, p. 41) in which nursing is practiced as a series of tasks.

Some respondents who had migrated into rural areas spoke of their perception that they did not have as much social capital as people who had grown up in the area, that long-term local staff were reluctant to accept change and that the suggestions of newer staff were disregarded by long-term staff. This finding is similar to that of Lea and Cruickshank (2007) who found that new graduate nurses experienced difficulty being accepted by long-serving staff members in the rural hospitals where respondents in their study had been employed.

As reflected in the nursing literature, the rural nurses at the study sites involved in this project use a number of ways of caring for people with dementia, within the limiting context of the physical environment. The subsequent emphasis on safety sometimes led to care that may not be considered to be person-centred. Connections with the local community appeared to increase person-centred care in these sites.
5.2.2 Conclusion Two: Use of Relationships, Collaboration and Networking to Enhance Nursing Care

As mentioned above, the second conclusion of this study is that the nurse respondents used collaboration with other service providers, and community networking, including, importantly, networking with family members of patients with dementia, in a positive way. This helped them to provide care that was person-centred for people with dementia who were patients in their hospitals. One site in this study had volunteers who informally visited patients. A number of the respondents spoke about the value of volunteers in providing social support for people with dementia who were in hospital. Family members and the relationships between them and staff members were an important aspect of rural nursing care that many respondents in this study spoke about. This conclusion is discussed below.

The interconnectedness of rural communities means that staff at the study sites may have connections with patients and their families outside of the hospital setting; this finding is similar to that of Mills et al. (2007). Lauder et al. (2006, pp. 75-76) use the term “community embeddedness” to describe the interconnectedness of rural communities. The respondents in the current study claimed that these already existing relationships made it easy for them to call on family members to assist with that care when needed, for example to sit with a person with dementia when they were distressed and confused in the unfamiliar environment of the hospital. Moyle et al. (2010) describe participants in their study, which took place in a large metropolitan hospital, as requesting that family members be more involved in the care of their relative with dementia, but only making such requests infrequently. Participants in the current study, who mentioned that family members spoke with them about their relative’s care, outside of the hospital and while they were off duty, did so in a positive way; this finding supports the findings
of Baernholdt et al. (2010). One participant stated that when people felt that they could approach staff at any time, relationships were enhanced and this often led to improved patient care. This finding is similar to the findings of previous researchers (Cox et al., 2001; Evanson, 2006). One site in the current study seemed to have a culture of accepting that older people would need to stay longer in hospital than younger people, that there was nowhere else more suitable for them to go when they needed respite services, and that they were part of the “core business” of the hospital. This need relates to the lack of any other respite services available locally and the lack of domiciliary services for people who live in isolated areas.

Boredom can lead to an increase in agitated behaviour for people with dementia (Kolanowski et al., 2005). The acute hospital environment and the staff who work there are not equipped for keeping people occupied or socially engaged (Armstrong-Esther et al., 1994). While boredom and social isolation are difficulties encountered when people are in hospital for extended periods of time, respondents in the current study reported that they have some simple ways of helping to keep people occupied, when time permits, and of enabling them to continue to have social contact with others in their community. Respondents in this study spoke about local strategies for keeping patients socially engaged and occupied, including giving them small tasks to do, taking them with them while working, or wandering with them. The nursing staff at two of the three sites work collaboratively with local day-care services in order to keep people with dementia occupied and for them to experience some social interaction. At one study site, community volunteers visit patients informally. The use of appropriately trained community volunteers to visit people with dementia in one hospital in rural New South Wales has been shown to have positive effects on the emotional wellbeing of the people with dementia who were involved in that study (Bateman, 2010).
When people with dementia become bored, they can become increasingly agitated. This can complicate their care in acute hospital settings, where there is little to occupy them. This study has found that the nurse respondents used simple person-centred strategies to keep people with dementia occupied and socially engaged while they were in hospital.

Consistent with other research into the work of rural nursing, the nurses in this study were using their connections with families and volunteer networks to develop person-centred strategies to care for people with dementia.

5.3 **Summary of the Results of the Study**

This study has found that the physical environments in the study sites had an influence on the way that care was provided to people with dementia in those hospitals. While there were person-centred nursing practices evident at all study sites, there were also some practices that were related to managing risk and some that were task focused.

In addition, and importantly, this study found that the nurses at the study sites are using their community connectedness to help them to provide person-centred care for people with dementia in their hospitals. In rural areas, the hospital is part of the town, and the town is part of the hospital (Baernholdt et al., 2010). Because of the geographical isolation of country towns, staff and patients are largely drawn from the local population, contributing to a shared sense of community connectedness (O‘Reilly & Strong, 1997a). Baernholdt et al. (2010) identify this sense of community connectedness as unique to rural communities. Nurses at all three sites used collaboration and networking with other service providers, with community members and with family members of people with dementia to assist them to provide person-centered care for people with dementia.
5.4 Implications of the Results of the Study for Practice, Practitioner Learning and Policy

The implications of the results of this study for practice, practitioner learning and policy are related to the two conclusions that have been drawn from the results of the study. There are two implications from the results of the study for practice. The first of these implications is the potential to utilize practice development methodology to develop the person-centred aspects of rural nursing practice as it relates to the care of people with dementia. The second of these implications is the recognition of a strength of rural nursing practice, that is the utilization of community connectedness to enhance nursing care. The implications of the results of the study for practitioner learning and for policy are that practitioner learning occurs as an integral part of practice development activities, and the results of these activities are able to inform policy. These implications are discussed below.

5.4.1 Implications of the Results of the Study for Practice

The results of this study have the potential to influence nursing practice and this relates to the conclusions of the study that have been described above.

The first conclusion of the study is that the physical environment of the participating hospitals in the study had an influence on the provision of care for people with dementia at those hospitals. The nurse respondents in the study cared for people with dementia in a number of different ways. Some of these ways were person-centred and some were risk management or task focused. This conclusion relates to the implication of the study that, potentially, skilled facilitation will enable nurses in acute care settings to reframe the way they conceptualize the care of people with dementia, leading to the development of practices that are more person-centred.
The second, and important conclusion of this study is that the rural nurses at the study sites for the project recognize the value of the relationships that they have with the family members of people with dementia for whom they are providing nursing care, and with other service providers, and utilize these relationships to enable them to provide better care for people with dementia. The interconnectedness found in this study is noteworthy and it is hoped that this will continue. The use of these interconnected relationships represents a unique and powerful resource, with the potential to be developed, through skilled facilitation that enables reflection on practice. This would assist in translating personal strengths into collective actions, making it possible for rural nurses to provide more truly person-centred care in an environment where all persons are respected. This implication illuminates a strength of rural nursing practice that is to be commended, while acknowledging that this aspect of nursing practice is not unusual in rural communities.

One way of facilitating the development of person-centred nursing care is by the use of practice development methodology. In NSW, a program called “Essentials of Care” (NSW Health, 2012) has been running since 2008. Essentials of Care uses trained local facilitators to engage nursing staff in a program that is designed to enhance their ability to provide care that is more person-centred. The program is informed by the principles of practice development and has "been developed by nurses to bring the focus back to the fundamental aspects of patient care; the things necessary for a person to feel well cared for, valued as an individual and to have a positive health-care experience" (NSW Health, 2012, n.p.).

Practice development, as described in Chapter Two, enables practitioners, with facilitation, to examine their practice in order to strengthen the ways they have of working that are person-
centred, and to identify areas of practice where change would lead to improvement in the care that is able to be delivered to people.

One of the features of the Essentials of Care Program is the role of local facilitators or champions, who are part of the nursing staff in the care setting where the program is being implemented. Local facilitators work alongside external facilitators. In order to be effective in their role, it is necessary for the facilitators to undergo training. The challenge for managers in rural areas, where there are shortages of health professionals, and particularly in small hospitals, with small budgets, is to find the resources, both human and fiscal that are required to enable staff to be replaced so that they can undertake the training required for them to be able to facilitate the program in their hospitals. As with any practice development activity, the support of frontline management is crucial to ensure the success of this program. The support of managers and nurse leaders is critically important for the development of sustainable person-centred practices (Manley & McCormack, 2008). Nurse leaders must be appropriately resourced in order to be able to support staff to develop their practice.

One participant in this study spoke about being asked by management to be the first to adopt a new practice, the wearing of safety goggles while working in the hospital's Emergency Department. She related that long-term staff members regarded this behavior as evidence that she was “weird”. This incident seems to indicate that the manager of that particular site was interested in changing practice, but unsure of how to proceed. The development of more person-centred practices in settings where practices are entrenched, and people who are not long -term residents do not have as much social capital as those who are, is likely to be challenging. The engagement of all staff members must be genuinely sought for any activities that are aimed at changing practice at the site.
In her anecdotal article about the experience of facilitating practice development, one author describes people who could not cope with the challenges of practice development in their workplace, as moving on to “pastures new” (Hunnisett, 2011, p. 2). It is not always feasible for people in rural areas to change jobs due to the geographical isolation of their workplaces. For this reason, it is crucial to support all staff members, including those who may be rigid in their practice and wedded to less person-centred and more task focused ways of working, to reflect on their practice and to develop the positive aspects of that practice. This is challenging because it involves examining workplace cultures and these are a part of the practitioner’s identity.

In recognition of the interconnectedness of rural communities, the author acknowledges the danger that if work that is aimed at achieving culture change is not done sensitively and with a genuine effort to include all staff, negative emotions may be generated and these may have consequences in the wider community. All persons are valued (McCance et al., 2008), therefore any attempt to change the culture and practice of the workplace where care is provided must be consistent with that ideal and recognize the needs of all persons who are involved, including those who are challenged by the idea of change. Furthermore, Moss and Chittenden (2008) argue that if you invalidate a person’s culture, then you are invalidating that person and that working in culturally sensitive ways encompasses openness to the potential of people to evolve. Skilled facilitation enables staff to be supported through challenging situations (Clarke & Wilson, 2008). To be genuine and self-sustaining the impetus for change must come from the practitioners themselves. This concept is challenging in workplaces where people are comfortably set in their ways, with familiar, taken-for-granted routines and believe the care they are providing is good care.
With skilled facilitation to enable reflection on practice, and support from management and the wider organization, rural nurses who use their local knowledge and connectedness to enhance the care that they provide for people with dementia in their communities could develop this knowledge into “local theories” (Moss & Chittenden, 2008, p. 171). Disseminating insights from such projects in rural areas has the potential to enable the unique skills possessed by rural nurses to inform care in the wider population by adding to the modest body of knowledge on this topic.

5.4.2 Implications of the Results of the Study for Practitioner Learning

The results of this study have implications for practitioner learning and these relate to the conclusions of the study as previously described. The implications of the results of this study for practitioner learning relate to both the first and second conclusions of this study and flow from the recommendation, as described above, that practice development methodology be utilized in order to develop the person-centred aspects of rural nursing practice as it relates to the care of people with dementia. The process of practice development incorporates learning; as practitioners are facilitated to reflect on their practice, learning follows naturally (Clarke & Wilson, 2008). Dewing (2008a) provides an example of the incorporation of active learning into practice development work. The example is an activity where participants observe the care environment, utilizing their senses. The facilitator then encourage the participants to reflect on how they think and feel about what they have observed. This is a beginning activity and has a low level of threat to participants, because it does not involve the observation of practices or practitioners. After beginning the process of developing practice with an activity such as the one described, participants would then move on to activities that encourages them to reflect on and learn from their practice. A hypothetical example of such an activity that relates to the conclusions of this study would be an activity that facilitates practitioners to reflect on the aspects of their nursing
practice that is focused on the safety of people with dementia in their hospital environments. Skilled facilitation would enable practitioners to recognize that, while the safety of patients is an important responsibility for nurses, it is also important to develop ways of caring for people that prioritize their individual needs and preferences, while also keeping them safe in the hospital environment.

5.4.3 Implications of the Results of the Study for Policy

The results of this study have implications for policy and these relate to the conclusions of the study as previously described. The implications of both the first and the second conclusions of this study have led to the recommendations for practice and practitioner learning as described in the preceding section. The implications of the results of the study for policy flow from the implications of the results of the study for practice.

There are some important areas where the goals of health policy makers and the goals of practice development are aligned. These relate to the development of workplace cultures that aim to enhance the experience of the health care system from the point of view of the users of that system. Policy makers within hospitals and at government level, and practice developers may appear to have different philosophies and do use different language, and these factors can contribute to the perception of policy makers that practice development is an agenda that is peripheral to their real concerns. It can be argued that without attention to the processes by which policy makers derive the outcomes that they desire, then these outcomes will not be real and sustainable (Manley, McCormack, Wilson & Thoms, 2008). In order for policy makers to be able to understand the contribution that practice development activities can make to the achievement of the goals that are important to them and to the organization, it is important for practice
developers to make practice development “user friendly” by speaking in terms that policy makers understand (Manley et al., 2008). The Essentials of Care Program that is described above is an example of how this has been achieved. The development of new knowledge and local theory is an integral part of practice development activities (McCormack, et al., 2006, as cited in Hoogwerf, Frost & McCance, 2008). Dissemination of this knowledge and theory, as well as dissemination of the results of more formal research projects such as the one proposed in the following section, have the potential to influence policy makers in health care, encouraging the inclusion of person-centred ways of working with older people in policy documents related to the care of older people.

5.5 Recommendations for Further Research

The recommendations for further research relate to the second conclusion of this study, that nurses in the rural hospitals that were the study sites for this project are using their community interconnectedness in order to enhance their ability to provide person-centred care for people with dementia.

When the researcher visited one of the study sites for the purpose of member checking, the staff members present at the meeting where the results were presented to them agreed that this finding was consistent with their experience. It was agreed at the meeting that this was not considered to be remarkable, but was in fact taken for granted. Baernholdt et al. (2010) have identified the need for further inquiry into the positive effect that rural interconnectedness has on the quality of nursing care in rural hospitals. In order to address this research gap, the researcher has two recommendations for further research to investigate the phenomenon with relation to the care of people with dementia within rural hospitals.
The first recommendation is that the findings from the study be further explored by duplicating the study in all rural hospitals in NSW. The findings of a study that includes all rural hospital sites in NSW has the potential to make a valuable contribution to the scant body of evidence that relates to the care of people with dementia in rural NSW.

In addition, there is potential to explore this little-documented and unique aspect of rural nursing practice using an action research framework. Action research is a style of research, commonly utilizing qualitative methods, in which researchers and participants work in partnership in order to examine problems of a practical nature. Action research is suitable for exploring areas of practice that clinicians would like to improve, and uses “practitioners' intuition and experience” to “generate findings that are meaningful and useful to them” (Myer, 2000, p. 179). Important elements of this style of research are its democratic and participatory nature, and “its simultaneous contribution to social science and social change.” (Myer, 2000, p. 178). Action research aims not only to achieve a specified change but also to generate new knowledge by studying the process and outcomes of change” (Myer, Bridges & Spilsbury, 1999, p. 329). The proposed project would enable the participants to reflect on and develop this aspect of their practice.

It is hoped that participants at rural hospitals will be willing to explore the aspect of their practice that involves working in partnership with families and community members. A project that has the intention of making this aspect of rural nursing practice more explicit has the potential to enhance the practice of participants, and the healthcare experience of patients and also to contribute to the body of knowledge about rural nursing. The researcher intends to explore this topic further as part of her Doctor of Philosophy candidature.
Much of the rural nursing literature is focused on the challenges facing nurses who choose to practice in rural areas (Bourke et al., 2012). The implications of the positive use of interconnectedness in rural communities in order to enhance the care of people with dementia are positive ones that will reinforce community cohesiveness and contribute to patient and family satisfaction with care. The researcher hopes that further research conducted with the aim of further exploration and development of a positive area of rural practice that is potentially applicable in other practice areas, will result in findings that reflect a positive aspect of rural health.

5.6 Chapter Conclusion

This study has answered the research question "How do nurses in small rural hospitals care for people with dementia?" in the following ways:

The data that were collected for the study were subjected to thematic analysis and two major themes were developed. The first theme is 'watchful wandering', in which nurses claim that wandering is best for managing stress, that restraint increases distress, that going along with people calmly decreases distress, and that this is balanced with the nurse's responsibility to protect vulnerable people in their care. The second theme is 'keeping people close to home', in which despite unsuitable physical environments, nurses are keeping people with dementia in their own communities, where they are close to people who know them and can provide them with emotional and social support.

An important aspect of both these themes and a significant finding of this study, is that nurses in the small rural hospitals that were the study sites for this project were using their community interconnectedness in order to enhance the care that they were able to provide for people with
dementia. This encompassed connectedness with the family members of people with dementia, and with the wider community such as volunteer visitors and day care services. This is a finding that is previously not well documented in the literature.

There is potential for the use of an existing program in New South Wales Health, Essentials of Care, to be used more effectively to enable nurses in small rural hospitals to reflect on their practice, and develop the more person-centred aspects of their practice. One of the most person-centred aspects of the practice of the nurse respondents in this study is their use of community connectedness to enhance the delivery of person-centred care for people with dementia, and this could be further enhanced using the Essentials of Care framework. Learning from reflection on practice is an integral part of such an activity.

There is potential for the results of this study to influence policy using the results of the evaluations of practice development activities such as those that form part of the Essentials of Care program. In addition, policy may be informed by the results of the two proposed research projects, enlarging the study to encompass all rural hospitals in NSW and exploring the way rural nurses use community connectedness to enhance person-centred care delivery for people with dementia.

Finally, the author proposes that the finding that the nurses at the study sites are using community interconnectedness, which encompasses their relationships with the family members of people with dementia who are patients in their hospitals, and with people in the wider community, be further investigated. The results of the proposed studies will add to the body of knowledge about the care of people with dementia in rural hospitals, and about the way rural nurses work with families and with other community members to enhance person-centred nursing practice.
References


Appendices

Appendix 1. Information Sheet, Health Service Managers
The Care of People With Dementia in Rural New South Wales.

Information Sheet

Health Service Managers

My name is Kay Shannon and I am a Registered Nurse and a student at the University of Canberra. I have worked in rural health for 19 years, both in the acute sector and in aged care. As a Master of Nursing candidate at the School of Nursing and Midwifery, University of Canberra, I am undertaking a research project about the nursing care of people with dementia in small rural hospitals. The results of the study will contribute to nursing knowledge in the area of dementia care, particularly in the rural setting.

The purpose of the study is to identify how nurses care for people with dementia in small rural hospitals. The ultimate aim of the research is to share knowledge and enhance our nursing practice.

If your hospital chooses to participate in the research I will be spend approximately 2 days at the hospital. Prior to this I will visit the hospital to give a short presentation to staff explaining the study and inviting them to participate. I would like to interview nurses about caring for people with dementia. I would also like to observe nurses caring for patients with dementia. Intimate personal care such as showering or washing, toileting, continence care and pressure area care would not be directly observed.

An information sheet explaining the purpose of the study will be given to family members of patients who will have their care observed. Written consent will be obtained from the next-of-kin of patients having their care observed. If the patients are deemed capable of providing consent, their consent will be sought. Lastly I would like to interview members of the nursing staff about their experiences caring for people with dementia.

The data collected will be securely stored throughout the project in a locked filing cabinet. Electronic records will be kept in a password-protected computer. At the completion of the study, all data will be securely stored at the University of Canberra. Access to the data will be limited to the researcher and the supervisors of this project.
Following completion of the research project, the results of the project will be presented at a seminar at your hospital. All staff will be invited to attend. In addition, the results of the project will be submitted for publication in refereed nursing journals.

Approval to undertake this research project will be obtained from the University of Canberra Committee for Ethics in Human Research and the Greater Western Area Health Service Human Research Ethics Committee.

If at any time, you have queries about this project, please do not hesitate to contact the supervisors of this project, Professor Diane Gibson, on 6201 2314, or Dr Laurie Grealish, on 6201 2229 at the Faculty of Health.

Thank you for your consideration,

Kay Shannon,
22 October 2010
Kay.Shannon@uni.canberra.edu.au
0409815311
Appendix 2. Flyer inviting nurses, patients and family members of patients to an information session about the project
Nurses, patients and family members are invited to an information session about the Dementia Care in Small Rural Hospitals research project, which will be conducted at this hospital in July and August.

Presented by Kay Shannon - Master of Nursing (Research) candidate, University of Canberra.

Date:

Time:

Location:
Appendix 3. Informed consent. Patient participants and their families or persons responsible for them
The Care of People With Dementia in Rural New South Wales

INFORMED CONSENT

Patient participants and their families or persons responsible for them

I have read the information sheet for the project titled ‘the care of people with dementia in rural New South Wales’ and I am aware that:

- The aim of this project is to describe what works well for nurses when caring for people with dementia in small rural hospitals and to share that information with other nurses.

- Participation in this study will involve allowing the researcher to observe nurses caring for me/my relative/the person for whom I am responsible. It will not involve the researcher observing any intimate care such as showering, pressure area care or continence care. Participation in this study is voluntary and I may withdraw from this study at any stage;

- I will be guaranteed confidentiality and anonymity, except if the researcher identifies issues that require mandatory reporting under legislative requirements;

- The data will be securely stored throughout and upon completion of the project;

- The results of this study may or may not be of benefit to me;

- The results of this study will be presented in a seminar at the study site and all participants will be invited to attend;

- The researcher intends that the results of this study will be presented at health conferences and published in refereed journals. In any publication, information will be provided in such a way that I cannot be identified.

- Approval to undertake this research project has been obtained from the University of Canberra Committee for Ethics in Human Research.

- The ethical aspects of the project have been approved by the Greater Western Area Health Service Human Research Ethics Committee.
• This research project is being undertaken by Ms Kay Shannon, a Registered Nurse and a Master of Nursing (Research) Candidate at the School of Nursing and Midwifery, University of Canberra; and

By signing this consent form, I agree to participate in this research project. I have read and understood the information provided and I have had the opportunity to ask any questions.

____________________________________
Signature

Name (Print)

_______________________________
Relationship to Participant

Name of Participant (Print)

___________________________
Date

If at any time, I have queries, complaints or concerns about this project, I may contact the supervisors of this project, Professor Diane Gibson, on (02) 6201 2314 or Associate Professor Laurie Grealish, on (02) 6210 2229 at the Faculty of Health, University of Canberra. If I am not comfortable contacting the supervisors of the project I may contact the University of Canberra Human Research Ethics Committee on (02) 6201 5870.

Alternatively, to contact NSW Health (Greater Western Area Health Service Human Research Ethics Committee), please contact: The Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339 5601.

Attachment:

University of Canberra Contacts For Information On The Project And Independent Complaints Procedure (to be held by the research participant).

Appendix 4. Participant information form, Patient participants and family members/persons responsible
The Care of People With Dementia in Rural New South Wales.

Participant information form.

Patient participants and family members/persons responsible.

My name is Kay Shannon and I am a Registered Nurse and a student at the University of Canberra. I have worked in rural health for 19 years, both in the acute sector and in aged care. As a Master of Nursing (Research) Candidate at the School of Nursing and Midwifery, University of Canberra, I am undertaking a research project on nursing care of people with dementia in small rural hospitals. The results of this study will contribute to nursing knowledge in the area of dementia care, particularly in the rural setting. The purpose of the research is to investigate how nurses in three small rural hospitals care for people with dementia, what works for nurses, and for people with dementia. The ultimate aim of the study is to share knowledge and enhance nursing practice.

The research design will involve the collection of two types of data. I will observe nurses caring for people with dementia, and interview nurses about caring for people with dementia. The data obtained will be analysed for themes and add to the body of knowledge about how nurses care for people with dementia in small rural hospitals.

If you agree to take part in the project, I will observe staff caring for you/your family member/the person for whom you are responsible. Intimate personal care such as showering or washing, toileting, continence care and pressure area care would not be directly observed. Participants will be free to terminate the observation at any time if they feel uncomfortable.

I will be at your hospital for approximately two days. Observation of nursing care will take place in blocks of one hour or less. Following periods of observation I will make notes, either on paper or using a voice recorder. If participants do not want their data to be part of the study their wishes will be respected.
The data collected will be securely stored throughout the project in a locked filing cabinet. Electronic records will be kept in a password-protected computer. At the completion of the study, all data will be securely stored at the University of Canberra. Access to the data will be limited to the researcher and the supervisor of this project.

Following completion of the research project, the results of the project will be presented at a seminar at this hospital. All participants will be invited to attend. In addition, the results of the project will be presented at conferences and submitted for publication in refereed nursing journals. Participation in this study is voluntary and you may withdraw consent at any time without any effect on your health care.

Approval to undertake this research project has been obtained from the University of Canberra Committee for Ethics in Human Research. The ethical aspects of the project have been approved by the Greater Western Area Health Service Human Research Ethics Committee.

If at any time, you have queries, concerns or complaints about this project, please do not hesitate to contact the supervisors of this project, Professor Diane Gibson, on (02) 6201 2314 or Associate Professor Laurie Grealish, on (02) 6201 2229 at the Faculty of Health, or the Greater Western Area Health Service Human Research Ethics Committee: The Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339 5601.

Thank you for your consideration,

Kay Shannon,

(02) 48 321 438

University of Canberra. Master copy version 3. 21 April 2011
Appendix 5. University of Canberra Committee for Ethics in Human Research.

Independent complaints procedure
COMMITTEE FOR ETHICS IN HUMAN RESEARCH

PROJECT INFORMATION

The following study has been reviewed and approved by the University of Canberra’s Committee for Ethics in Human Research.

Project title: The care of people with dementia in rural New South Wales.

Project number: 10-156

Principal researcher: Ms Kay Shannon

INDEPENDENT COMPLAINTS PROCEDURE

1. As a participant or potential participant in research, you will have received written information about the research project. If you have questions or problems which are not answered in the information you have been given, you should consult the researcher, or (if the researcher is a student) the research supervisor. For this project, the appropriate person is

   Name: Professor Diane Gibson
   Contact details: Faculty of Health
   University of Canberra
   ACT 2601
   Phone: (02) 6201 2498

2. If you wish to discuss with an independent person a complaint relating to:

   - conduct of the project, or
   - your rights as a participant, or
   - University policy on research involving human participants

Please contact:

   Ethics and compliance officer
   Telephone (02) 6201 5870
   Room 1 D 116
   University of Canberra ACT 2601.
Providing research participants with this information is a requirement of the National Health and Medical Research Council *National Statement on Ethical Conduct in Research Involving Humans*, which applies to all research with human participants conducted in Australia.

Further information on University of Canberra research policy is available in *University of Canberra Guidelines for Responsible Practice in Research and Dealing with Problems of Research Misconduct and the Committee for Ethics in Human Research Human Ethics Manual*.

These documents are available from the Research Services Office at the above address or on the University’s website at


Approval- Project number 10-156
COMMITTEE FOR ETHICS IN HUMAN RESEARCH

11th March 2011
APPROVED - Project number 10-156

Ms Kay Shannon
Faculty of Health
University of
Canberra BRUCE
ACT 2617

Dear Kay,

The Committee for Ethics in Human Research has considered your application to conduct research with human subjects for the project entitled The care of people with dementia in rural New South Wales.

Approval is granted until 15/12/11 the anticipated completion date stated in the application.

The following general conditions apply to your approval.

These requirements are determined by University policy and the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 2007).

| Monitoring: | You, in conjunction with your supervisor, must assist the Committee to monitor the conduct of approved research by completing and promptly returning project review forms, which will be sent to you at the end of |


Discontinuation of research: You, in conjunction with your supervisor, must inform the Committee, giving reasons, if the research is not conducted or is discontinued before the expected date of completion.

Extension of approval: If your project will not be complete by the expiry date stated above, you must apply in writing for extension of approval. Application should be made before current approval expires; should specify a new completion date; should include reasons for your request.

Retention and storage of data: University policy states that all research data must be stored securely, on University premises, for a minimum of five years. You and your supervisor must ensure that all records are transferred to the University when the project is complete.

Changes in contact details: You should advise the Committee of any change of address during or soon after the approval period including, if appropriate, email address(es).

Please add the Contact Complaints form (attached) for distribution with your project.

Yours sincerely
Committee for Ethics in Human Research

Michaela Dalgleish
Ethics & Compliance Officer
Research Services Office
T (02) 6201 5870 F (02) 6201 5466
E Michaela.Dalgleish@canberra.edu.au
Appendix 7. Informed consent. Nurse participants – observation and interview
The Care of people With Dementia in Rural New South Wales

Informed Consent

Nurse participants – observation and interview

I have read the information sheet for the project titled ‘the care of people with dementia in rural New South Wales’. I am aware that:

- The aim of this project is to describe what works well for nurses when caring for people with dementia in small rural hospitals and to make that information available for other nurses.

- Participation in this study will involve allowing the researcher to observe me caring for people with dementia and, if applicable, I will be interviewed about caring for people with dementia.

- Participation in this study will involve the researcher collecting, retaining and using information relating to the nursing care of people with dementia.

- Participation in this study is voluntary and I may withdraw from this study at any stage;

- I do not have to answer questions I do not wish to answer;

- I will be guaranteed confidentiality and anonymity except if the researcher identifies issues that require mandatory reporting under legislative reporting requirements.

- The data will be securely stored throughout and upon completion of the project;

- The results of this study may or may not be of benefit to me;

- The results of this study will be presented in a seminar at my workplace and all participants will be invited to attend;

- The researcher intends that the results of this study will be presented at health conferences and published in refereed journals. In any publication, information will be provided in such a way that I cannot be identified.
• Approval to undertake this research project has been obtained from the University of Canberra Committee for Ethics in Human Research. The ethical aspects of the project have been approved by the Greater Western Area Health Service Human Research Ethics Committee.

• This research project is being undertaken by Ms Kay Shannon, a Registered Nurse and a Master of Nursing (Research) Candidate at the School of Nursing and Midwifery, University of Canberra, and

By signing this consent form, I agree to participate in this research project. I have read and understood the information provided and I have had the opportunity to ask any questions.

__________________________  ____________________________
Signature                  Name of participant (Print)

__________________________
Date

To contact NSW Health (Greater Western Area Health Service Human Research Ethics Committee), please contact: The Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339 5601.

Attachment:

University of Canberra Contacts For Information On The Project And Independent Complaints Procedure (to be held by the research participant).

Appendix 8. Participant information form. Nurse participants
The Care of People With Dementia in Rural New South Wales.

Participant information form. Nurse participants.

My name is Kay Shannon and I am a Registered Nurse and a student at the University of Canberra. I have worked in rural health for 19 years, both in the acute sector and in aged care. As a Master of Nursing candidate at the School of Nursing and Midwifery, University of Canberra, I am undertaking a research project about the nursing care of people with dementia in small rural hospitals. The results of this study will contribute to nursing knowledge in the area of dementia care, particularly in the rural setting.

The purpose of the research is to investigate how nurses in three small rural hospitals care for people with dementia, what works for nurses, and for people with dementia. The ultimate aim of the study is to share knowledge and enhance nursing practice. The research will involve the collection of two types of data. I will observe nurses caring for people with dementia and interview nurses about caring for people with dementia. The data obtained will be analysed for themes and will ultimately add to the body of knowledge about how nurses care for people with dementia in small rural hospitals.

If you agree to take part in the project, participation in this study will involve allowing the researcher to observe you caring for people with dementia, and/or interview you about caring for people with dementia. Intimate personal care such as showering or washing, toileting, continence care and pressure area care would not be directly observed.

Any information about you that is obtained in connection with this study will remain confidential and will be disclosed only with your written permission, except if issues are identified that require mandatory reporting under legislative reporting requirements.

I will be at your hospital for approximately two days. Observation of nursing care will take place in blocks of one hour or less. Following periods of observation I will make notes, either on paper or using a voice recorder. Interviews will be in private, in work time, and will take approximately twenty to thirty minutes. Interviews will be recorded, and then the recordings will be transcribed. If you participate, a transcript of your interview will be made available to you for you to check before final analysis of the data.

If participants do not want their data to be part of the study their wishes will be respected. Participants will be free to terminate the observation or interview at any time if they feel uncomfortable.
The data collected will be securely stored throughout the project in a locked filing cabinet. Electronic records will be kept in a password-protected computer. At the completion of the study, all data will be securely stored at the University of Canberra. Access to the data will be limited to the researcher and the supervisor of this project.

Following completion of the research project, the results of the project will be presented at a seminar at this hospital. All participants will be invited to attend. In addition, the results of the project will be presented at conferences and submitted for publication in refereed nursing journals.

Participation in this research is voluntary and you may withdraw at any time without any effect on your relationship with the University of Canberra or Greater Western Area Health Service or the University of Canberra. Approval to undertake this research project has been obtained from the University of Canberra Committee for Ethics in Human Research.

The ethical aspects of the project have been approved by the Greater Western Area Health Service Human Research Ethics Committee.

If at any time, you have queries, concerns or complaints about this project, please do not hesitate to contact the supervisors of this project, Professor Diane Gibson, on (02) 6201 2314 or Associate Professor Laurie Grealish, on (02) 6201 2229 at the Faculty of Health, or the Greater Western Area Health Service Human Research Ethics Committee: The Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 6339 5601.

Thank you for your consideration,

Kay Shannon,
(02) 48 321 438
University of Canberra.