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Too close to home: The lived experiences of rural Queensland nurses who have cared for people with cancer who have died

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Acknowledgements

My PhD focused on the experience of others and now it is time to reflect on my own. Some people reflect on their doctoral experience as a journey, and it is true to say that if that was the case in the time that it has taken me to complete my thesis, I could have travelled around the world several times on the proverbial slow boat to China. I experienced several foreign encounters along the way including challenges to my physical and psychological health. These challenges resulted in time spent in the academic doldrums. However, with the patient support and encouragement of my supervisors, my family and my friends I have managed to finish my journey and give voice to the valuable messages of my study participants.

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Statement of Contribution of Others

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Abstract

Rural nurses are not specialist oncology nurses; rather they are specialist–generalists. Specialist oncology nurses working in specialist units accept that the loss of a patient from cancer is something that will happen as a regular part of their working experience. Specialist nurses also enjoy a large degree of anonymity away from their workplace that allows them to leave their work and patients behind them at the end of their working day. Anecdotal evidence suggests that many rural nurses would not choose to care for patients with cancer as a long-term career choice, but because of the nature of their work they accept the task of meeting the often advanced needs of these patients and their families. In many instances rural and remote nurses caring for patients with cancer may be caring for friends and in some cases, family.

For the past 25 years I have worked alongside nurses caring for patients with cancer in both metropolitan and rural and remote settings. More recently I have observed rural nursing colleagues caring for their friends and supporting them with compassion and skilled care to a good death. Many staff experience this several times in a year, and many times over during their time in that rural setting. Anecdotally, there is little opportunity to recover from the stress of providing that care or from the loss of a friend, before nurses are called on to support another.

This study used the phenomenological methodology of van Manen to examine and understand the lived experience of rural nurses who have cared for people with cancer who have died. In-depth interviews were conducted with nurses from across Queensland, providing them with the opportunity to share their feelings and experiences of caring for people with cancer, and of the effect of the death of their patient. Common themes have been highlighted and explored, with the three main phenomenological themes being:

1. Accepting the need to adopt progressive ways of delivering nursing care.
2. Learning different ways of relating to patients and families.
3. Seeking to achieve a work–life balance.

There are several sub-themes in each main theme.

The results of this research will lead to recommendations relating to staff support in rural settings for nurses caring for patients with cancer. This will provide team leaders and members alike in rural settings with information that may be used to identify and manage situations that may lead to staff distress. Among other aspects, recommendations relate to grief management, ways to separate home and work situations to ensure that staff members receive time apart from the care of the patient, and ways to manage the expectations of the patient, their family and the community in general in the rural setting. The identification of themes relating to this subject may also provide reassurance for nursing staff in similar situations who may have in the past struggled with their own feelings and reactions to the loss of a patient with cancer. The themes raised in this research might also be applied to areas outside of the care of patients with cancer, to include the support of nursing staff in rural settings who care for patients with chronic and complex illness who also have extended or frequent stays in hospital.

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Chapter 1: Introduction and Literature Review

This chapter will provide the background information to the research and will support this introduction with reference to the literature throughout. A separate literature review will not be provided in the thesis instead the literature will be integrated within the introductory information.

As the title of this thesis suggests, the focus of my research has been the lived experiences of rural Queensland nurses who have cared for people with cancer who have died. When I initially described my research project, people presumed that it was like any other study that examined issues relating to grief and oncology nurses. In developing my research proposal it became clear that there were several issues that differentiated this study from others, and as the research has progressed, these issues have been added to in areas that I had not expected.

The research project arose from my own nursing practice. The first decade of my nursing career was spent in the area of oncology. Like other specialist oncology nurses, I chose to be there. I studied and developed my skills and knowledge in the specialty area. I worked in major specialist centres in Brisbane. Many of my patients came from rural areas of Queensland and some came for multiple treatments. Others came from Brisbane. One deterrent for nurses choosing the speciality of oncology is that around one-third of all patients diagnosed with the disease will die from it. As specialist oncology nurses we developed effective and therapeutic relationships with our patients and we were sad when they deteriorated or died. I rarely saw my patients outside of the hospital setting.

The past two decades of my career have been spent in rural practice. I am proud of being the ‘jack of all trades and master of none’ described by one of my supervisors Professor Hegney in the late 1990s (Hegney 1997, p. 24). At times I have been lucky enough to again ‘dabble’ in my beloved oncology, but generally I have worked across a broad cross-section of medical specialties: I am a specialist–generalist nurse.

Rural nurses may care for people with cancer across the full cycle of the disease: from diagnosis and active treatment to palliative and terminal care. Unlike their metropolitan counterparts who may work in sub-specialist units of the oncology service, rural nurses will have more frequent contact with patients, and will require different skills to care for the individual and their family throughout the progression of the disease. In many instances rural and remote nurses caring for patients with cancer may be caring for friends and in some cases, family.

For years since moving to rural Queensland, my path has crossed with those of my patients at the shops, at school, and at events in the community. For years I have observed my colleagues provide wonderful nursing care to people they know who are diagnosed with a terminal illness, supporting them with compassion and skilled care to a ‘good death’. A good death is as unique and individual as the person who passes away. For the palliative care nurse, the features of a good death are highly subjective but include the person dying on their own terms: for example being at home or in hospital, with their pain and other symptoms well controlled, and supported and surrounded by the people who are important to them. During their working week, many nurses will provide palliative care to several patients, and several patients may died during that time, with this experience compounded for the nurse over and over again in any given week, month or year at our busy rural hospital. Many staff do this several times in a year, and many times over during their time in that rural setting. There is little opportunity to recover from the stress of providing that type of care or from the loss of a friend, before they are called on to support another.

Systemic challenges affect the experience of the rural nurse. Nurses may be professionally and personally isolated from others—a situation that reduces opportunities to formally de-brief. In small communities the plight of the patient with cancer will be well known. Family and friends of a patient may look to the health professional for information and support to help them through the sadness resulting from the diagnosis. Who does the nurse look to for support?

In 2006 one of our nursing colleagues died at our hospital, after a short battle with a recurrence of cancer. She was 42. I saw the effect of caring for Nicky and of her death on our team at the hospital, and as a result I knew I needed to formalise my research question. It was this experience that sowed the seed for this research proposal. Although this specific event concerned a close colleague of the nurses, I had observed many nurses with similar experiences when they had cared for other patients with cancer who had died. How do staff continue to present for duty knowing that they may be supporting another close friend or acquaintance through a diagnosis of a life-threatening disease such as cancer, and that this may progress to the need for palliative and terminal care? My PhD journey had begun.

1.1 Research question

My research question has had several iterations over the years, and has changed over time to better reflect what it was that I was trying to achieve. It was initially difficult to articulate the scope of the research with the risk that if it was not properly defined the range would be too large, or alternatively it would not be specific enough. Working with my advisors I was able to define the relevant components of the research. My final research question is: ‘What is the lived experience of rural Queensland nurses who have cared for people with cancer who have died?’

1.2 Study objectives

The objectives of the study are to:

- understand the experience of the rural nurse who has cared for people who have died from cancer
- provide participants with the opportunity to share their feelings and experiences of caring for patients with cancer, and of the effects of the death of their patient
- develop recommendations for the development of strategies to support rural nurses who are caring for people who may have died from cancer.

1.3 Significance of the study

As Director of Nursing at a rural hospital my key priorities are the provision of safe quality nursing care and the support of the nursing staff to ensure that they can undertake their roles to the best of their ability. The area of staff support is multifaceted and includes workforce management, education and the provision of a supportive work environment. Emotional support has been recognised in the literature as a major factor in improving rural and remote nurse retention rates. The most recent Australian government report (Commonwealth of Australia, 2014) regarding nurse workforce sustainability includes a series of recommendations that also argue for the importance of workplace support beyond education in retaining early career registered nurses (RNs), particularly in rural and remote areas.

Having personal experience of the effects of caring for patients with cancer who had died, and then observing the effect of this on other nurses I believed that my capacity to provide optimal support to staff who were caring for patients with cancer would be enhanced by fully understanding the experience of other rural nurses who had cared for patients with cancer who had died. By understanding the challenges faced by the staff on a regular basis, I would be better equipped to understand the strategies that are required to support them proactively to best fulfil their role when caring for patients with cancer.

The results from my study have led to recommendations relating to staff support in the rural setting for nurses caring for patients with cancer. I also anticipate that the findings of the research will be transferred to areas outside of the care of patients with cancer, to include the support of nursing staff in rural settings who care for patients with chronic and complex illness who also spend extended or frequent periods in hospital, and who die from their disease.

1.4 Background

Prior to embarking on the research interview phase of the study, and to gain a better understanding of some of the key areas of the topic, a broad review of the literature was undertaken. No research was found that pertained specifically to the experience of rural nurses caring for patients with cancer. The reviewed literature confirmed that my research question is multifaceted and suggested that consideration be given to the individual components of the study and the relationships between them.

1.5 Search strategy

A literature review was conducted using the databases of CINAHL, Pre-CINAHL, Health Source, MEDLINE, Social Science Index and Psych Info. The search of the literature was limited to the years 1994–2014, and to resources written in English. This 20-year span was chosen as it covers the period from the completion of Professor Desley Hegney’s seminal research into rural nursing in Australia to the present day. Searches were guided initially by the use of the key words ‘nursing’, ‘oncology nursing’ and ‘rural nursing’ in combination with others including ‘bereavement’, ‘burnout’, ‘grief’, ‘nurse–patient relationships’, ‘emotional support’ and ‘resilience’. Searches were also conducted using the key term ‘rural health nursing’ in combination with ‘Australia’, ‘Canada’, ‘USA’ and ‘palliative’.

1.6 Palliative care nursing

How people die remains in the memory of those who live on.

—Dame Cecily Saunders

You matter because you are you.
You matter to the last moment of your life.
We do all that we can, not only to help you die peacefully,
but also to live until you die.

—Dame Cicely Saunders

Palliative care is the active total care of patients and their families by a multi-professional team from the point at which the patient’s disease is no longer responsive to curative treatment (Keeley, 2011; Keeley & Noble, 2008). Palliative care is a philosophy based not on physical facilities but on attitudes and skills (Saunders, 2001). Palliative care is synonymous with care that meets the physical, social, psychological and spiritual support of patients with life-limiting illness (Clark, 2007). The World Health Organization (2002, p.17) defines palliative care in the following way; that it:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement

- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Despite the fact that everyone is going to die, and that most would benefit from palliative care in the later stages of their life, palliative care is a relatively new area of medical specialty. Palliative care was recognised by the Royal College of Physicians as a medical specialty in 1987, and a formal training program was established (Keeley, 2011). Many people, including health professionals, automatically consider palliative care as only being relevant to people with cancer. Despite these strong links between palliative care and cancer care, in the 1950s, professional and public interest in cancer was mainly focused on the potential for curative treatment. At this time dying patients were overlooked and at times abandoned by physicians who told them to go home as there was nothing more that could be done (Clark, 2007). Palliative care developed as a specialty that was strongly tied to the specialty of oncology, and over the past 40 years it has progressed from the periphery of this specialty to being a key component of modern cancer care (Clark, 2007).

Despite the concept of the hospice being evident in Roman times, the modern hospice unit did not evolve until the mid-1960s, with the first modern hospice being St Christopher’s Hospice, founded in 1967 (Keeley, 2011). The modern hospice movement developed from the work of Cicely Saunders (Clark, 2007). Hospice care strives to provide holistic care to patients and their families. Caring for the spiritual needs of patients and families was acknowledged by Saunders (2001) as one of the greatest challenges to be faced, with fear and grief often unable to be articulated (Saunders, 2001); with this in mind it was important that hospices were not seen as ‘death houses’.

Saunders initially trained as a nurse before studying medicine in the 1960s. She focused her attention on the terminal stages of cancer care. Her work relied heavily on individual patient experiences, and in particular explored the relationship between physical and mental suffering, which she described as ‘total pain’. The concept of total pain includes physical symptoms, mental distress, social problem, and emotional difficulties, and was described by one of Saunders’ patients as ‘all of me is wrong’ (Clark, 2007). Efforts to change attitudes to end-of-life care were based on rigorous philosophical, political and spiritual discussions; from the beginning the emphasis was on ‘living until you die’ (Saunders, 2001).

One patient described the symptoms of her terminal disease as a ‘many-headed dragon’ and Saunders acknowledged that all of these ‘heads’ should be analysed and addressed to the fullest extent possible (Saunders, 2000). Saunders was adamant that ‘constant pain needs constant control’ and argued that analgesics should be given regularly to ensure that pain was prevented in advance rather than attempting to alleviate it once it had become established—an approach that is much less successful and always more distressing and frustrating for patients and staff alike (Clark, 2007). Saunders was a strong proponent of the ‘Brompton Cocktail’, which was first described in the 1950s. The cocktail contained a mixture of morphine hydrochloride, cocaine hydrochloride, alcohol, syrup and chloroform water (Clark, 2007). It lost favour in the 1970s and was replaced with simpler approaches to the administration of morphine for pain control. Prior to the 1970s, pain caused by cancer had received little international attention as either a clinical or public health problem, and was often regarded as an inevitable but not fully controlled consequence of the disease. The convergence of pain specialists with palliative medicine specialists and relevant oncologists led to the development of improved methods for pain and symptom management (Clark, 2007).

Difficult symptoms do not suddenly appear in the last 48 hours of a patient's life; they are often present throughout the patient's journey and for this reason palliative care services will frequently be involved in the care of the patient from early on to alleviate complex symptoms as they arise (Keeley, 2011; Keeley, Waterhouse, & Noble, 2007). Although pain and symptom control has improved in the hospital setting over time, psychosocial needs and continuity of care are more effectively managed in the hospice (Clark, 2007). With ongoing developments in palliative care, the specialty is no longer based solely in a hospice, with community and hospital teams now being an integral part of most primary and secondary health care services (Keeley, 2011; Keeley et al., 2007).

The philosophy of the hospice movement began to infiltrate the hospital setting in the mid-1970s with the establishment of formal support teams for terminal care (as they were called) in hospitals such as St Thomas's in London (Clark, 2007). The palliative care team quickly expanded to include members from diverse backgrounds and professions, and this multidisciplinary approach to care is acknowledged as the best approach to manage the complex and at times overwhelming needs of the palliative patient. The multidisciplinary team may be formally or informally integrated and may work out of a hospice, hospital, day centre or at home (Saunders, 2000).

Also in the mid-1970s in England, the MacMillan Organisation experienced unprecedented growth and became involved with palliative care and supporting training programs. In the early 2000s the organisation became known as MacMillan Cancer Support (Clark, 2007) and at that time there were over one thousand specialist MacMillan nurses working in palliative care in the United Kingdom, along with approximately 400 home-based teams, 200 day-care facilities and 200 hospital-based services (Clark, 2007).

A systematic review of the literature by Hearn and Higginson (1998) concluded that patients who were cared for by a multidisciplinary team had improved outcomes in their palliative care based on the amount of time they were able to spend at home, patient and carer satisfaction, symptom control, a reduction in the overall cost of care and the likelihood of the patient dying where they wished to (Hearn & Higginson, 1998). This was revisited by another systematic literature review by Higginson et al. (2003) who considered the evidence that palliative care teams positively altered the end-of-life experiences of patients and their care givers, and concluded that there was a positive benefit to patients from the team approach; however, it was acknowledged that the difference was small, and that the study did not compare different team models. Higginson and Evans (2010) again revisited the question using the same methodology in 2010 and at that time concluded that specialist palliative care delivered at home, in hospital or in the inpatient specialist setting significantly improved patient outcomes in the areas of pain and symptom control, anxiety and reduced hospital admissions. On this basis they suggested that specialist palliative care should be part of the care for cancer patients, although at that time they still failed to review the preferred model of specialist service delivery (Higginson, 2010).

Palliative care in Australia is delivered in different ways depending on the geographic location and available resources. ‘Place’ and geographical location are important determinants of general health, and should also be considered as important determinants in the effectiveness of palliative care services for those living in rural and remote areas (Castleden, Crooks, Schuurman, & Hanlon, 2010; Robinson et al., 2009). Different levels of palliative care services are categorised according to their resourcing and include specialist units in hospitals, standalone palliative care services providing community-based care, care provided by general practitioners (GPs) and primary health care (Palliative Care Australia, 2005).

Research conducted in 1998 established that patients and carers in rural Australia first wanted palliative care that addressed their needs for symptom management and pain control, with that care provided by experienced clinicians in the home or home-like environments that are located close to families, and proposed that even the smallest hospitals can incorporate a palliative care unit (Sach, 1997). Sach concluded that palliative care teams should be developed to reflect the context of the service provision, and that emphasis should be given to providing palliative care nursing expertise in a given region (Sach, 1997). Providing this care in rural areas is not as easy as it sounds, and in 2001, Wilkes and Beale reported that rural nurses experienced role conflict and stress from the effects of family relationships, and from the need to provide a 24-hour service over vast distances with a lack of financial resources (Wilkes & Beale, 2001).

Australian patients receive palliative care on the basis of need, and not on the basis of prognosis. To achieve this, patients will move between available services depending on the complexity of their needs. This integration of care is achieved when smaller services develop links with larger services that provide advice and at all times palliative care should be linked to the patient’s GP or primary care provider to ensure that care can be shared (Mitchell, 2011). This is described as rural palliative care that emphasises partnership and capacity building from the ‘ground up’ with obvious benefits for individual patients, their families and the health care professionals involved (Kelley, 2007). This concept is further supported by White, Wall & Kristjanson (2004) and Kelley (2007) who believe that rural and remote communities are able to develop and use palliative care services based on the principle of community capacity building with consideration of local and human resources to provide a contextually relevant palliative care service for individuals with a life-threatening illness in remote locations (White et al., 2004; Kelley, 2007).

As already alluded to, access to integrated palliative care services is limited for those living in rural and remote settings (Robinson, 2009); however, there is limited research to support service development in rural settings. A comparative study by Peters and Sellick in 2006 focused on the experiences of terminally ill cancer patients cared for at home and in the inpatient setting. Terminally ill cancer patients receiving home-based care have better health status and quality of life than those cared for in an inpatient setting; terminally ill cancer patients cared for at home have greater control over the effects of their illness and report better quality of life based on indicators of physical health, perceived control and depression scores (Peters & Sellick, 2006). The ongoing challenges for the provision of quality palliative care in Australia are the need to meet the requirements of people with non-malignant life-limiting illnesses; growing the specialist workforce; maintaining the skills of the primary care workforce; and providing palliative care to special populations such as the aged, Indigenous Australians, non-English-speaking Australians and children (Mitchell, 2011).

Masso and Owen (2009) reviewed the findings of an evaluation of three community-based palliative care programs in rural Australia and concluded that the integration of service providers in palliative care in rural settings was supported by interventions such as formal governance structures; provision of education programs;

case conferencing; dissemination of information; development of formal arrangements; development of protocols and the use of common clinical assessment tools (Masso & Owen, 2009). An integrated approach to care is vital if patients and their families are to experience support, and identifying district nurses as key workers in palliative care supports integration (Dunne, Sullivan, & Kernohan, 2005).

The needs of patients with advanced non-malignant disease are very similar to those of cancer patients (Keeley & Noble, 2011), and although it is generally agreed that cancer patients are now likely to have access to appropriate palliative care at the end of life, the modern challenge is to deliver expert palliative care to those with non-malignant disease also.

A global review of palliative care services revealed that only around half of the world’s countries had established one or more hospice palliative care services by 2006, and that only 15% of these countries had achieved a measure of integration with other mainstream service providers (Clark, 2007). The review confirmed that at that time only a tiny proportion of patients who would benefit from palliative care received it and that the solution to this overwhelming problem would only be achieved through the better integration of palliative care into mainstream services (Clark, 2007). In the developing world tens of millions of people are affected by life-threatening illnesses such as HIV/AIDS and cancer, and in this setting expensive curative treatment is not available. In light of this it is even more important that effective low-cost palliative care is developed to meet the needs of the sick and improve their quality of care (Sepulveda, Marlin, Yoshida, & Ullrich, 2002). The global challenge for palliative care in the 21st century is the development of models and coverage appropriate to those in need, whatever their diagnosis, income or setting (Clark & Graham, 2011).

1.7 Rural health

In Australia there is an active debate about the definition of rurality and remoteness (Commonwealth of Australia, 2013). There are a number of approaches currently being taken to define and compare rural communities in Australia. The Australian Standard Geographic Classification-Remoteness Areas (ASGC-RA) is the foundation for a number of overlay classifications that have been suggested (AIHW, 2004). These include the Humphreys/Monash Model, the Modified Monash Model and the Australian Bureau of Statistics Socioeconomic Indexes for Areas (AIHW, 2004). This study utilised the ASGC-RA in its original form to classify participants as rural nurses. Figure 1 shows the ARIA+ Accessibility Remoteness Index Australia 2006 that informs the ASGC-RA Classification. According to ARIA+, 89% of Australians live in major urban cities and inner regional areas; these are the red and yellow areas on the map. The remaining 11% of the population is distributed across the vast majority of the country in outer regional, remote and very remote areas (AIHW, 2014a).

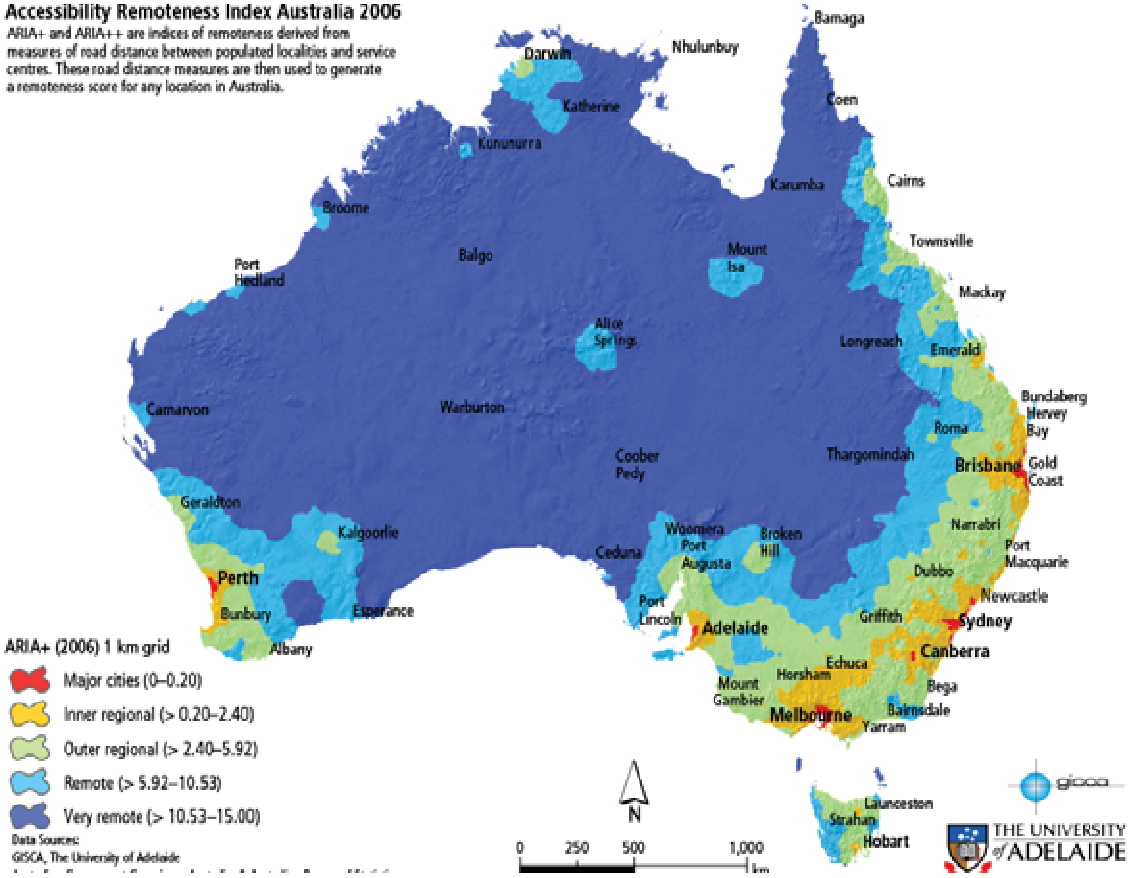

Figure 1.1. ARIA+ Map of Australia (2006) (Australian Institute of Health and Welfare, 2014).

The ASGC system was used in the current research as it classifies the Australian population by use of a remoteness category based on the distance of the community from different-sized urban centres; the population size of the urban centre differentiates the range and type of services available (AIHW, 2008b). The ASGC has five major ‘rural’ classifications: Major City, Inner Regional, Outer Regional, Remote and Very Remote (AIHW, 2008). The term ‘regional’ is used by the ASGC to imply ‘rural’ (Australian Institute of Health and Welfare, 2008b). In Australia, approximately 32% of people live outside major cities; 29% in rural area (AIHW, 2008b). The proportion of people living in rural areas of Canada and the USA is similar to that in Australia (Bushy, 2002).

The lack of consideration of qualitative descriptors such as social characteristics, community relationships and attitudes has been criticised when reviewing indexes of rurality (Kulig, Edge, & Joyce, 2008). Despite the overarching description of ‘rurality’, there are marked social, economic and cultural differences within and among rural communities both in Australia (AIHW, 2008b) and internationally (Bushy, 2002). That is, no rural community is the same—they are unique. Despite this uniqueness, some features are shared by all rural communities including the challenges of distance between people and services, reliance on agriculture and tourism, the seasonal nature of work, and the level of familiarity between community members as outlined in greater detail in Chapter One (Bushy, 2005).

Although each rural community is unique, there are features that characterise the experience of living outside a metropolitan centre:

- greater spatial separation of people and services
- an economic orientation related to the land and nature, for example agriculture and mining
- work and recreational activities that are cyclic and seasonal in nature
- social interactions that facilitate informal, fact-to-face negotiations; most, if not all, residents are related or acquainted (AIHW, 2014).

Research has demonstrated that rural populations have different and higher morbidity and mortality rates than their counterparts living in major cities (AIHW 2014) with contributing illness including coronary heart disease, other circulatory diseases, poor dental health, motor vehicle accidents and chronic obstructive pulmonary disease (AIHW, 2014a). Several factors contribute to the poor state of health in rural areas. The lower socioeconomic status in these areas results in difficulty accessing health services, which in turn leads to poorer health outcomes (AIHW, 2014a). Rates of smoking and obesity are also greater in rural areas of Australia, and both of these contribute to heart, stroke and vascular disease, and to cancer (AIHW, 2014a).

Life expectancy in regional areas is one to two years less—and in remote areas can be up to seven years less—than in major cities (AIHW, 2008b). The lower life expectancy in remote areas reflects the reduced life expectancy of Indigenous Australian, which is 17 years less than that of Australians overall (AIHW, 2008a).

The poorer health status in rural communities results from the complex issues of socioeconomic and environmental factors that influence health. People living in rural communities are disadvantaged in relation to education, employment, and access to goods and services including health services (AIHW, 2008a). People living in rural areas also experience lifestyle factors that negatively influence their health status compared to people living in major cities. These include higher rates of cigarette smoking and consumption of alcohol, sedentary lifestyle, greater unprotected exposure to sunlight, increased driving risks as a result of poorer roads and increased travelling times, and employment in occupations with a higher risk of occupational illness and injury, such as primary industry and mining (AIHW, 2008a).

For many rural people, their definition of health correlates directly with their ability to work (Lauder, Reel, Farmer, & Griggs, 2006). This definition may be extrapolated to mean that rural clients will not seek medical assistance unless they are unable to work at their normal capacity. Some authors refer to this as ‘stoicism’, but the stoic behaviour is misguided as it may result in clients taking risks with their health, such as not seeking treatment early (Pashen, Grant, Veitch, Sheehan, & Chalmers, 2002). There are several factors that rural people consider before seeking help in relation to their health:

- the distance to be travelled and its effect on their work routines, including their ability to take time off work to attend an appointment (Pashen et al., 2002)
- the fact that many rural GPS do not bulk bill, meaning that many patients may opt to wait until they can get an appointment at the local hospital—a factor that likely delays diagnosis (Margo, 2001)
- the loss of income, up-front costs, and out-of-pocket costs after reimbursement experienced by many people using health services in rural areas, with the result that some will delay or decide to not access health service treatment at all (Australian Institute of Health and Welfare, 2008a)
- coinciding a visit to a health professional with another need or to wait until seasonal work, such as a crop harvest, has been completed (Hegney & McCarthy, 1999)

1.8 Cancer in rural areas

In Australia, cancer accounted for 30% of all deaths in 2005 (AIHW, 2008a). In 2006, cancer was the most common cause of death for females aged 25–44 years, and for males and females aged 45-84 (AIHW, 2008a; AACR, 2007). The incidence of melanoma, cervical cancer and smoking-related cancers is higher in rural areas of Australia (AIHW, 2008a; AACR, 2007).

The best approach to cancer control is the prevention of the disease in the first place, a concept that forms the basis of many health promotion projects (AIHW, 2008a; AACR, 2007). However, if prevention fails it is important to diagnose the presence of cancer and commence treatment at the earliest possible stage to improve the likelihood of positive treatment outcomes (Taktak & Fisher, 2007).

Once a diagnosis of cancer has been made, the stoicism of rural people is once again evident. Authors report that a high quality of emotional and social support exists through informal networks in rural communities (Hegney & Mc Carthy, 1999; Margo, 2001) however, these can be stretched to breaking point as individuals try to get through stressful times relying on their own resources (Hegney et al., 2007). Rural people also have a reputation for being intensely private in relation to their personal affairs, and will often not seek help, thus ensuring that the general community does not know about their plight (Bushy, 2005).

Research suggests that patients with cancer should be cared for by specialist health professionals in specialist oncology centres; however, data from the USA indicate that this is not what happens in 80% of cases and that a significant proportion of these are from rural settings (Kenny, Endacott, Botti, & Watts, 2007). Information from the Australian context is limited but it is suggested that a similar situation occurs in this setting (AIHW, 2008a), with rural nurses in Australia providing care for patients with cancer without necessarily having specialist knowledge and skills in this area (Kenny et al., 2007). Rural nurses may care for their patients with cancer across the full cycle of the disease—from diagnosis and active treatment to palliative and terminal care. Unlike their metropolitan counterparts who may work in sub-specialist units of the oncology service, the rural nurse will have more frequent contact with the patient, and will require different skills to care for the individual and their family throughout the progression of the disease.

Cancer accounts for approximately 30% of male and female deaths in Australia (AIHW, 2014b). Cancer mortality increases in line with distance from major cities, which is due in part to limited access to mainstream cancer treatment services (AIHW, 2014a,b) The best approach to cancer control is the prevention of the disease in the first place, a concept that forms the basis of many health promotion projects. However, if prevention fails it is important to diagnose the presence of cancer and commence treatment at the earliest possible stage to improve the likelihood of positive treatment outcomes. Evidence suggests that the attitude of some rural people is at direct odds with these principles (Hegney, Pearce, Rogers-Clark & Martin-McDonald, 2005).

Many rural people's definition of health relates directly to their ability to work (Lauder, Reel, Farmer & Griggs, 2006). This definition may be extrapolated to mean that rural people will not seek medical assistance unless they are unable to work at their normal capacity. Some authors refer to this as stoicism (Pashen, Grant, Veitch, Sheehan & Chalmers, 2002), but such stoic behaviour is misguided as it may result in people taking risks with their health such as not seeking treatment early. Once a diagnosis has been made, the stoicism of rural people is once again evident. Authors report that a high quality of emotional and social support exists through informal networks in rural communities; however, these can be stretched to breaking point as individuals try to get through stressful times relying on their own resources (Hegney, McCarthy & Pearson, 1999). Rural people also have a reputation for being intensely private in relation to their personal affairs, and will often not seek help to ensure that the general community does not know about their plight (Bushy, 2005).

This behaviour has implications for the care provided by rural nurses. The majority of nurses working in rural areas are women and in rural communities there is an expectation that they will volunteer their time to help others (Hegney, 1999; Bushy, 2005). This may result in female rural nurses, particularly those who have lived in rural areas for a long time, providing ongoing voluntary assistance to the local patient who looks to friends and family for support rather than using the local health or other support agencies for this reason. As a result the female rural nurse may find herself providing physical and emotional support in her work role, and then repeating the process in her unpaid time and in the role of friend or family carer.

1.9 Rural nursing

In 2005, more than 30% of all registered and enrolled nurses in Australia were employed in rural and remote areas (AIHW, 2008a). The rural and remote nursing workforce is predominately female and is more likely to be employed on a part-time basis in rural areas, and a full-time basis in remote areas (AIHW, 2008a).

As already stated, rural and remote nurses are expert–generalists (Bushy, 2005) who have been described as ‘Jack of all trades, master of none’ (Hegney, 1997). The rural nurse will care for people of all ages and with a variety of health conditions. The challenge for the rural nurse is to possess a wide range of diverse skills, both professional and otherwise, and once these have been obtained to maintain them in an environment in which such skills may not be used frequently (Hanna, 2001). The day-to-day activities of the rural nurse will be linked directly to the features of the community where the nurse is employed (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002), and in this role the nurse must be able to assess the health needs of the local community including causes of morbidity and mortality (Bushy, 2005).

It has been suggested that the rural nurse faces specific challenges within the rural setting. The lack of anonymity that is associated with the role results in the nurse being highly visible in the community and of having a sense of never being off duty. Rural nurses inevitably care for people who are friends or acquaintances and this familiarity can have implications for the nurse who may make incorrect assessments based on assumptions from prior knowledge, and who may be challenged by issues of confidentiality within their small community (Barber, 2007; Bushy, 2005; Hanna, 2001).

Role conflict has also been described in rural nursing in relation to the notion of ‘women’s work’. Rural communities are generally more traditional in their view of gender-defined role behaviours. Traditional values suggest that ‘women’s work’ is less important than that of men, and as such it may be provided on a voluntary basis. These beliefs may have additional implications for rural nurses. As already established, the majority of nurses working in rural areas are women (AIHW, 2008a) and in some rural communities there is an expectation that rural women will volunteer their time to help others (Bushy, 2005; Hegney, 1999). This may result in female rural nurses, particularly those who have lived in rural areas for a long time, providing ongoing voluntary assistance to patients who look to friends and family for support rather than using the local health or other support agencies for this reason. As a result the female rural nurse may find herself providing physical and emotional support in her work role, and then repeating the process in her unpaid time and in the role of friend or family carer.

Geographic and professional isolation also pose challenges to the rural nurse. Geographic isolation may refer to the distance between the nurse and patients, between the nurse and other health professionals, or between the nurse and family or friends based in other rural or metropolitan communities (Bushy, 2005). Professional isolation may be in direct proportion to geographic isolation, but more specifically it relates to the distance that the nurse may experience from other health care professionals for advice, consultation and debriefing, and for professional education and networking (Barber, 2007; Bushy, 2005; Hanna, 2001; Kulig et al., 2008). Improvements in technology have helped to reduce the sense of isolation to some degree with rural nurses able to contact other health professionals for advice, education and networking via video conferencing, the internet and improved telecommunications (Bushy, 2005).

The issue of scarce resources is also raised in relation to rural nursing. The absent or restricted resources may encompass equipment; staffing including other health professionals such as allied health professionals and support staff; and other service providers (A. Bushy, 2005; Hegney, 1999). Resource shortages cause frustration and resentment for nursing staff, who may find they take on additional tasks to meet the shortfall in resourcing, and which in the longer term may reduce the retention of staff in rural areas (Hegney, 1999).

The increasing scope of practice for nurses in rural practice has resulted in changes to legislation and models of nursing care in Australia and internationally. In Australia, Canada and the USA nurses are undertaking specific education programs for advanced practice roles (Bushy, 2002). In 2001, supported by changes to its *Health (Drugs and Poisons) Regulation 1996*, Queensland Health introduced the *Rural and Isolated Practice Endorsed Registered Nurse* (RIPRN) program, which expanded the scope of practice of endorsed RNs (Timmings, 2006). Nurses who are endorsed as RIPRN's work in an advanced practice role but are not nurse practitioners.

The first authorised nurse practitioner in Australia was appointed to a community in remote New South Wales in 2001 (Turner, Keyzer, & Rudge, 2007). Since this time there has been inconsistency among the states and territories in Australia in relation to the role development, guidelines and preparation for authorisation for practice for nurse practitioners (Turner et al., 2007). There have been varied levels of acceptance of this advanced role for nurses in Australia, and there is a sense that the nurse practitioner role legitimises the existing role of rural and remote nurses where professional boundaries were blurred out of necessity (Turner et al., 2007). There is consensus that there is the need for ongoing international and national collaboration and development to support the informed expansion of advanced nursing practice roles (Bushy, 2002; Turner et al., 2007).

Regardless of whether the nurse is working in an advanced role, or whether they are registered or enrolled, much of the available literature in relation to rural nursing issues has originated in Canada, the USA and Australia. Bushy (2002) believes that it is possible to compare across these three similar countries because they have:

- equivalent geographical areas defined as ‘rural’
- similar demographic changes in rural areas with regional variations
- similarities in the rural lifestyle regardless of community location
- global economic factors resulting in policy initiatives designed to reduce costs, and improve access and consumer satisfaction are placing additional demands on health professionals
- decentralisation of financial control of health services
- similarities in rural nursing practice, including expanded roles such as nurse practitioners (Bushy, 2002).

However, it should be noted that the health system in the USA is very different to that in Australia. In contrast, there are many similarities between the public health system in Canada and Australia based on similarities in their health expenditure as a percentage of GDP and per capita health expenditure (Heijink, Noethen, Renaud, Koopmanschap, & Polder, 2008), and with similarities in the social determinants of health including disadvantage for Indigenous communities in the areas of education and income (Mitrou et al., 2014).

In 2004, the National Rural Health Alliance (NRHA) developed a list of issues affecting Australian rural nurses. The list was compiled through a stakeholder forum titled *Action on nursing in rural and remote areas* and resulted from a recommendation made at the 6th National Rural Health Conference held in 2001. The issues identified by forum participants were:

- an increased shortage and rapid turnover of appropriately skilled rural nurses
- a rural nursing workforce that appears to be older on average than the nursing workforce overall
- a growing general shortage of nurses in Australia that means greater competition for the dwindling supply
- a paucity of leadership and management skills
- limited attention to workforce planning; limited incentives to attract and retain new rural nurses
- a poor image of rural nursing
- isolated practice
- increasing demand for advanced practice skills
- limited opportunities to up skill and maintain practice skills (NRHA, 2004).

Many of these issues are mentioned in other literature, including internationally (Bushy, 2002).

1.10 Nurses: Grief and loss

Grief has been defined as the normal process of reacting to the loss of something loved, whether an object or a person, with those reactions being experienced in the psychological, emotional, physical and social contexts (National Cancer Institute, 2008). Although debate continues about the process of grief, theorists agree that individual responses to grief vary enormously, and depend on many factors including the strength of the relationship between the deceased and the individual, the timing of the death, the cause of the death, and the age of the deceased (Costello, 1995). As stated, these features apply to each individual, and are important considerations when examining the question of grief and the nurse.

Issues of grief and loss are attributed to oncology nurses based on the physical and emotional energy that they invest in their patients (Brown & Wood, 2009). This considerable investment of energy results from, among other things, the complexity of the treatments that cancer patients receive, combined with their loss of bodily function, and fear of death and dying (Ko & Kiser-Larson, 2016).

Numerous international studies have been conducted over the past two decades to examine the issue of nurse–patient relationships, and grief and loss in the oncology setting (Desbiens & Fillion, 2007; Feldstein & Buschmann, 1995; Jacob, 1993; Medland, Howard-Ruben, & Whitaker, 2004; Mok, 2004; Saunders & Valente, 1994). Words such as ‘suffering’, ‘powerlessness’, ‘burnout’, ‘distress’, ‘occupational hazard’, and ‘stress’ are used throughout these studies to describe the reaction of nurses and patients to the diagnosis and progression of cancer. With such negative connotations associated with these words it is surprising that nurses are attracted to the area of oncology.

In general, the aim of the studies listed above was to understand the issue of grief for oncology nurses, and to investigate strategies that would assist oncology nurses to cope. Researchers have employed methods such as systematic reviews of the literature, focus group discussions, and interviews with individual nurses and patients in an effort to understand their topics of interest.

A range of strategies have been developed as a means to support nurses experiencing grief and loss. These strategies include:

- development of education programs about care of the dying patient, grief and bereavement to support staff working in specialist units (Feldstein & Buschmann, 1995; Saunders & Valente, 1994)

- development of communication skills education programs (Brown & Wood, 2009; Ergun, Oran, & Bender, 2005)
- development of staff support groups to provide staff with the opportunities to deal with their grief experiences (Escot, Artero, Gandubert, Boulenger, & Ritchie, 2001; Feldstein & Buschmann, 1995)
- the promotion of formal support for staff through the development of clinical supervision programs (Caton & Klemm, 2006)
- enhancement of the communication skills of nurse managers to help nurses avoid personalisation and suffering through a better understanding of the consequences of their personal involvement with patients and families (de Carvalho & Muller, 2005)
- enhancement of the personal skills and qualities of specialist hospice nurses to strengthen their relationships with patients (Boyle, 2000; Isikhan, Comez, & Danis, 2004); these in turn constitute excellence in nursing care (Mok, 2004)
- normalising of the experiences of work-related grief and bereavement for oncology nurses through education and open communication (Medland et al., 2004).

Although these recommendations have evolved from research conducted in international specialist oncology settings, it is possible that these strategies would be applicable to rural nurses who have experienced the death of a patient. A greater understanding of the issues of death, grief and bereavement will lead to improved support for nurses in any clinical area where the death of a patient is experienced. Challenges in the rural setting may be in relation to the development and delivery of such a program. Enhanced communication skills for staff and nurse managers would also be relevant in any nursing setting. The development of staff support groups and clinical supervision arrangements in rural settings may not be feasible due to limited resources and the issues of geographic and professional isolation.

A 2007 Australian study examined the issue of psychosocial care for patients with cancer in rural settings (Kenny et al., 2007). The main focus of the study was on the psychosocial needs of cancer patients in rural areas. However, as a spinoff of this research, the needs of the nurses caring for the patients were also highlighted in relation to the issues that were generated when providing the recommended care for the patients. Although cancer patients should ideally be cared for in a specialist oncology setting, a large proportion of them are cared for in non-specialist and/or rural settings. Kenny et al.'s (Kenny et al., 2007) research suggests that rural people with cancer are at greater risk of psychological dysfunction than those from other regions due to:

- their lack of access to services
- their greater need for information
- the fact that their cancer is more likely to be at an advanced stage when diagnosed (which is more common for rural people) (Kenny et al., 2007)

Conclusions drawn from Kenny et al.'s study (Kenny et al., 2007), are supported by the research done by Shepherd et al in 2008 (Shepherd, Goldstein, Olver, & Parle, 2008) and suggest that rural nurses may experience emotional turmoil through the process of providing support to patients, and that in part this is due to their dual relationship of nurse and community member (Kenny et al., 2007). Recommendations have been made in relation to supportive management practices and clinical supervision for staff (Kenny et al., 2007). Despite the different contexts of their studies, these Australian-based findings concur with those for the American setting by Jezuit (Jezuit, 2003) and the Irish setting by Dowling (Dowling, 2008). Similarities between these previous studies and the current research include the rural setting and the theme of patients with cancer. Kenny et al. (Kenny et al., 2007) note that it is not appropriate to generalise from their Victorian-based project, although there is consideration for transferability of the results to other settings.

1.11 Criticisms of the literature

The review of the literature revealed that there are some issues in common between the work that has already been done and the current research. There are several similarities in relation to the issues of rural nursing in Australia and internationally in Canada and the USA (Bushy, 2002). However, it should be noted that while Canada has a similar public health system to Australia (but without a substantial private system), the health system in the USA is very different to that of Australia (Schoen et al., 2004). Nonetheless, I believe that the similarities and features described in the literature about rural nursing practice will help to set the context of the research and will provide valuable background information to support the research. The issue of transferability between the findings of the Canadian, USA and Australian studies will also be considered given the similarities between the rural health delivery systems in these countries.

Much previous research addressing the areas of grief and loss has been conducted in international specialist oncology units. The research undertaken in these specialist care settings involves nursing staff who choose to work in that area of practice. This is not the case in rural settings.

It is possible that some of the concepts from the reviewed literature can be applied to nurses caring for patients with cancer in rural areas; however, such application would need to be made in the rural context where there is an absence of specialist support for staff or patients. Further, there are few formal palliative care or grief/loss specialists in practice outside major cities. Thus the journey may be quite different without these support services for both the nurse and the patient/family carer.

Recent limited research has considered the pre-existing relationships between rural nurses and patients (Kenny et al., 2007) but the small participant sample in that study of only 19 nurses from three practice settings limits the generalisations that can be drawn from the study. Without pre-empting the findings of the current study, it is possible that the proposed research thus has the potential to add to the preliminary knowledge gathered by Kenny et al. (Kenny et al., 2007).

1.12 Methodology

I have used phenomenology as the methodology of choice for this research. The goal of a phenomenological study is to fully describe a lived experience, and to do this participants are asked to describe ‘what it is like’ so that the researcher may understand and make sense of experiences. Known as the father of phenomenology, in 1936 Husserl described the methodology as the ‘basic science of philosophy’ (Holt & Sandberg, 2011). Husserl’s descriptive phenomenology uses the concept of the ‘lifeworld’ or ‘lived experience’ (Holt & Sandberg, 2011) to describe and clarify an experience as it is lived, with the goal being to describe it from the perspective of those who have experienced it. The ‘lifeworld’, or ‘*lebenswelt*’ (Reeder, 2010), is what individuals experience without interpretation. Using a Husserlian approach requires the researcher to maintain an open-minded attitude, where preconceptions are set aside to allow descriptions to reveal the meaning. This process of the researcher suspending their own beliefs is known as bracketing (Reeder, 2010).

In contrast, Heidegger, who was a student of Husserl, claimed that the use of phenomenology challenged the researcher to look beyond what is known and taken for granted, and to see things with fresh eyes (Burch, 2011). Heidegger asked the question ‘what is it to be’ and used the term ‘*dasein*’ or ‘being in the world’ to emphasise the notion that human existence was always in the world, and that it was not possible to set aside or bracket the researcher’s pre-understandings of a phenomenon (Thoibisana, 2009). This concept finally made sense to me as I listened to the stories and reflections shared by the research participants. It was impossible to ignore the way my own memories and feelings of caring for people with cancer were rekindled. I recalled similar conversations with patients, a similar stirring of emotions; at times my senses refreshed smells, scenes and sounds from my clinical past. I have used my own experience and knowledge to become immersed in the information provided by the study participants, and in turn the interpretation of the data is enhanced to allow the true themes and meanings of the phenomena to be revealed.

Acknowledging my being in the world of the participants links to van Manen’s existential concept of relationality (Dowling, 2007) and is underpinned by how I related to the participants, and how their stories influenced the perspective of my interpretation. Like that of Heidegger, van Manen’s approach uses a combination of descriptive and interpretive methods. A strong emphasis is placed on the role of the hermeneutic circle, a circular process that enhances the understanding of the researcher by allowing them to move between parts and the whole of the text. van Manen described ‘mining for meaning’ in his approach of reading and writing, and re-reading and re-writing to reveal the parts and then the whole of a phenomenon (Heinonen, 2015; van Manen, 2002).

Phenomenology has been used for some decades in nursing research. Adopted cautiously in the 1970s, it formed the basis for Benner’s seminal work *From novice to expert* in 1984 (Benner, 1984). Dowling (2007) described phenomenology as an appropriate philosophical grounding to represent the reality of the complex and situational reality of nursing practice (Dowling, 2007). Several authors have also noted that there have been inconsistencies in the application and philosophical underpinnings of phenomenology in some contemporary nursing research.

This research is set in rural Queensland. I have lived and worked in this region for more than 20 years; however, I believed it was important that the research was not just based on the experiences of rural nurses from the communities in my own area. I used my connections with other Directors of Nursing at rural communities in Queensland to gauge the interest of their local nursing staff to participate in the research interviews. I asked the Directors to distribute my project information to their nursing staff and based on interest at each community I planned the itinerary for a road trip through rural Queensland to interview research participants. I took my husband and young daughters on the research trip. They spent their days enjoying the local sights in each community and I visited the local hospital to meet research candidates and complete the interviews.

Our two-week trip began in rural north Queensland and covered several thousand kilometres and six communities before finishing in the south-west of the state. Understanding rural communities is important; however, in many ways the literature does not do them credit. My family still talks about the fun we had on our trip to talk to the rural nurses. Each community looked a little different depending on the local geography and the rural industries that supported the community; however, the warm welcome that we received at each location was consistent regardless of the postcode. My husband and children shared their stories of the people they met and the interesting things they did while I was ‘working’. My experiences were very similar with the local staff very happy to show me through their facility and to discuss the work they do and the challenges in their local towns. Several years later I have fond recollections of the warmth and openness of each research participant as they spent time with me sharing their stories.

1.13 Thesis outline

This thesis is presented in six chapters. Chapter 1 presents an overall introduction to the thesis. The methodology and methods used for the research study are examined in Chapter 2. Chapter 3 introduces the research participants, providing general but non-identifying information about each. The research findings are presented in Chapter 4, including identification of the three key phenomenological themes and their sub-themes. Chapter 5 provides a discussion of the key themes identified from the research including reference to past research and scholarly literature here available. The thesis concludes in Chapter 6 with recommendations and their implications being discussed.

1.14 Chapter summary

This chapter provided an overview of my motivation for conducting the research study and provided the relevant background in relation to setting the scene for rural nurses in Queensland who care for people with cancer. The purpose of the study and the approach undertaken was also described.

This chapter has also outlined pertinent research and literature related to the areas of palliative care, rural health and in particular, cancer in rural areas, rural nursing, and the experience of grief and loss for nurses. Palliative care is a relatively new area of medical specialty and—despite the fact that most people would benefit from palliative care as they approach the final stage of their life—large proportions of the global population, including those in rural areas of developed countries like Australia, do not have ready access to palliative care services. Access to health services in rural areas varies depending on geographical distance from specialist and general health services. Poor access to health services is further exacerbated by the global shortage of health workers, something that is particularly pertinent to nurses, as they comprise the largest proportion of the health workforce. Health workforce shortages in rural areas are made more difficult where recruitment and retention of staff is difficult for a variety of reasons. The problem of an ageing workforce, which is a national concern in Australia, is more evident in rural areas.

Nurses in rural areas are described as being multi-skilled generalists, ‘jacks of all trades and masters of none’, who work across many areas of clinical practice. As a result of this demand, nurses may experience role stress due to the generalist nature of their roles, and having to do their best to provide care for anyone who presents to their facility. Other nurses find that this broad diversity of skill requirements and lack of specialisation keeps them in the rural areas.

The following chapter discusses phenomenology—the methodology chosen to conduct the study. The chapter sets out the historical development of the methodology and important components of the approach. It also provides information about the methods employed to undertake the research including participant selection, the interview process and data analysis.

Chapter 2: Methodology

The goals of this research project were achieved through application of the phenomenological research process. Phenomenology provides an approach that considers the complex features of human experience such as values, beliefs and feelings (Mok, 2004). Several authors describe confusion when referring to the use of phenomenology in nursing research (Crotty, 1996; Dowling, 2007; Paley, 2014). Dowling (Dowling, 2007) believes that the confusion is created by the dual role of phenomenology as both a philosophy and a qualitative research method, and because there are many different styles of phenomenology.

The founding father of phenomenology was the German philosopher Edmund Husserl (1859–1938) (Mackey, 2005). Husserl developed the phrase '*zu den sachen*' which means 'to the things themselves' and defined his interest in the human experience 'as it is lived' (Dowling, 2007). Husserl based his eidetic or descriptive phenomenology (Dowling & Cooney, 2012) on the work of Franz Brentano, and took the latter's phrases of 'descriptive psychology' and 'intentionality' to create the fundamental concept for phenomenological understanding (Moustakas, 1994). Intentionality is the belief that any mental act such as thinking, imagining or remembering is always consciously thinking about something (Moustakas, 1994). It was Husserl's belief that to truly understand something (a phenomenon) it must be considered without the preconceived ideas and interpretations that the observer brings to the situation being considered. The term 'epoch' is used to describe this process of considering something without prior judgement (Moustakas, 1994).

The Husserlian approach to phenomenology requires the researcher to first consider and define their preconceptions on the issue, and to then 'bracket' or put these views to one side, thus removing them from consideration of the phenomenon in question (LeVasseur, 2003). This process of ‘bracketing’ is defined as phenomenological reduction (Dowling, 2007). The idea that researchers are able to completely disregard prior beliefs, values and knowledge remains contentious (LeVasseur, 2003). Numerous authors, including Dowling (2007), Paley (1997) and Crotty (1996) (Crotty, 1996; Dowling, 2007; Paley, 2014) contend that it is impossible for researchers to completely disengage from their consciousness of the topic under examination and that because of this their limited attempts at bracketing do not satisfy the concept of the Husserlian ‘epoch’ (Lowes & Prowse, 2001). Commentators also believe that the process of bracketing is even more difficult for the research participants to achieve due to their lack of knowledge of this difficult concept.

The second form of phenomenology was developed by Martin Heidegger (1889–1976) and is known as hermeneutic phenomenology. It is also known as hermeneutics or interpretive phenomenology (Mackey, 2005). Although he was a colleague of Husserl, Heidegger’s priority was the understanding of the concept being examined, rather than the emphasis that was placed on description by Husserl (Dowling, 2007). Heidegger’s key concept was that of ‘being in the world’ or ‘*dasein*’ (Mackey, 2005). In contrast to Husserl’s approach of putting the researcher’s beliefs to the side by bracketing, Heidegger believed that interpretation could only take place when the researcher was truly focused on their own awareness and knowledge of a phenomenon, and that this was further enhanced when the researcher used these experiences and knowledge to become immersed in the information provided by research participants, and in turn to allow the themes and meanings of the phenomenon to be revealed (Mackey, 2005).

In Heideggerian phenomenology, the interpretation of a phenomenon is a circular process, which the philosopher described as a hermeneutic circle (Gadamer, 1989). This process initially involves interpretation of the fore-structures or prior knowledge that the researcher may have of the phenomenon, and then the partial understanding of the phenomenon as components of it are explored in more depth; finally, the phenomenon is considered as a whole with the components considered together (Gadamer, 1989).

In addition, time and space are also key concepts in interpretive phenomenology. Simply put, this means understanding the human experience, or ‘being in the world’, is grounded in time and location. Time for Heidegger was referred to as temporality; rather than clock time, this term describes subjective time, which is the past, present and future that each person experiences (Mackey, 2005; van Manen, 1990). Lived space or spatiality refers to the places where experiences happen. Heidegger referred to the location or space as ‘the there’, and concluded that everything in the world ‘belongs somewhere’ (Moustakas, 1994). The concept of spatiality acknowledges the effect that a location may have on an individual’s experiences, such as the comfort of home or in contrast, the loneliness that one may experience in a busy city (van Manen, 1990).

I have chosen the methodology described by Max van Manen to guide this research. As outlined in the background section of this paper, personal experiences of caring for patients with cancer who have died, and the experiences of working alongside other nurses who have shared these encounters, were the catalyst to this research. A Husserlian approach to phenomenology would result in the isolation of and disregard for these past experiences and beliefs, with a focus solely on the experiences of the research participants. A Husserlian approach to phenomenology also disregards the moods, thoughts, memories and emotions that are associated with a phenomenon, thus leaving the researcher to focus on its fundamental and conscious awareness instead

(LeVasseur, 2003). In contrast, the moods, thoughts, memories and emotions of the nurses in this study will be paramount to the understanding of the experience of the phenomena, and so again, this approach is not appropriate.

van Manen is a member of the Dutch school of phenomenology, and uses a combination of descriptive and interpretive phenomenological methods (Dowling, 2007). The use of bracketing is not supported as van Manen believes that it is not possible for researchers to ignore preconceived ideas and knowledge, as they persistently affect and influence reflections on phenomena (van Manen, 1990). A strong emphasis is placed on the role of the hermeneutic circle, and van Manen believes that through reading and writing, and re-reading and re-writing, meaning is revealed through parts and then as the whole of the phenomenon (van Manen, 2007). van Manen also places a strong emphasis on the art of writing to reveal the true meaning of a phenomenon (Heinonen, 2015; van Manen, 2007), and as a result this approach has supported the revelation of the rich tapestry of experiences and meanings for the research participants.

In research, the use of the terms method and methodology, and technique or procedure often causes confusion. Methodology is used to describe the philosophical framework being used by the researcher, which van Manen calls the theory behind the method or way of undertaking the research; he considers that this method is made possible by the application of certain techniques or procedures by the researcher (van Manen, 1990). The method used by van Manen employs three approaches to achieve the hermeneutic circle and in turn to isolate thematic statements. The first approach is the holistic or sententious approach, which as the name suggests involves reading data such as the transcribed interview records as a whole in an attempt to express the overall meaning of the text in a pithy statement (van Manen, 1990). The philosopher acknowledges that different readers may find different meanings through this approach.

The second step in this process is described as the selective or highlighting approach. Again as the name suggests this step involves the process of discovering themes by re-examining sentences or part-sentences for phrases that stand out (van Manen, 1990). The final step described by the philosopher is the detailed or line-by-line approach, which involves even closer examination of the text with each sentence or cluster of sentences carefully examined for further thematic evidence (Heinonen, 2015; van Manen, 1990). This systematic approach supports the revelation of essential and incidental themes (van Manen, 1990). van Manen suggests that without the essential theme(s) the phenomenon would not exist, and he proposes that the researcher uses free imaginative variation to examine a phenomenon hypothetically in the absence of the theme to determine if the phenomenon still exists (van Manen, 1990). The importance of sensitive writing is also stressed by van Manen with particular attention to language when describing themes and phenomena. He believes that responsive-reflective writing, through a process that he describes as ‘poetizing’ is the essence of undertaking phenomenology (van Manen, 1990).

Examples of where van Manen’s approach has been used by nurse researchers in the past include the examination of the complex issue of nurse–patient relationships in palliative care (Mok, 2004), and of the concepts of caring from the perspective of surgical nurses (Enns & Gregory, 2007). van Manen’s approach was selected in the first instance because of the emphasis on interpretation, innovation and dialogue through self-reflection (Mok, 2004). Similar to the current research, this approach was used to investigate and understand the experiences of patients with incurable cancer, and of the nurses who cared for them. In the second study, phenomenology is described as the study of ‘essences’ (Enns & Gregory, 2007) and was applied by the researchers in this instance to support the examination of caring, which they considered to be the essence of nursing.

2.1 Methods

This research project was granted ethics approval in September 2008 by the Behavioural & Social Sciences Ethical Review Committee at the University of Queensland, prior to my transfer to James Cook University. Due to ethical considerations the decision was made to exclude Indigenous nurses from the project based on the complexity of the issues associated with death and dying in the Indigenous culture. Indigenous RNs account for approximately 0.05% of the RN population in Australia. Many Indigenous nurses return to rural and remote communities, and therefore it was possible that Indigenous nurses may have been working in communities from which research participants were sought.

Project participants were sought through the network of Directors of Nursing at rural Queensland Health facilities. The total of 20 participants came from eight rural facilities located from the south-west to the far north of the state. All participants were offered the opportunity to use a pseudonym to protect their identity—all participants declined this opportunity. On reflection and in discussion with my academic advisers it was felt that the participants could be easily identified from the information provided in the thesis, and therefore to support the anonymity of participants, their locations were not identified and their names were changed. Participants were nurses who were both registered and enrolled.

I used in-depth, face-to-face interviews to gather information from individual participants to better understand their lived experience of caring for patients with cancer until their death. It was important that the interviews were not rigidly structured to provide the flexibility to allow the questioning go where the issues raised directed it. However, to ensure that the researcher stayed on track and sought relevant information, questions were developed to guide the discussion with participants. With the permission of the participants, the interviews were recorded in audio and transcribed to assist with the process of data analysis.

Walker (Walker, 2011) acknowledged that the process of interviewing in phenomenological research can be emotive for both the researcher and the participant. With this in mind, I ensured that a private room was available to conduct the interviews, and provided comfortable chairs, water and tissues to ensure participant comfort. Some participants experienced some sadness when they revisited their experiences of caring for patients with cancer who had died. During reflections on their past experiences some participants shed tears, some laughed, and there were frequent pauses in the conversation while participants collected their thoughts prior to continuing. Several participants stated that the interview was the first opportunity they had had to discuss their experience of caring for the patients and what it meant to them, and most indicated that it had been a positive experience to share their thoughts and experiences.

van Manen (van Manen, 1990) outlined six methodological steps to assist the researcher undertaking phenomenological research. The steps were not designed as a rigid structure to guide the research; in contrast they provide points to prompt the researcher to keep on track with the research methodology. I found the list useful and it was reassuring to tick off each point as the research progressed. As previously described, my research evolved from my own nursing practice and issues about which I am passionate. During the research I used a personal journal to document my personal views on the topics and my experiences during the interview period. I investigated the lived experience of research participants through the in-depth interviews. To identify the themes and sub-themes from the research I repeatedly examined the transcripts line by line, highlighting the statements that seemed particularly relevant to the phenomenon. In the same way that I was reading and re-reading the transcripts I was also writing and re-writing my thoughts and analysis of the data. At times I was overwhelmed by the information in front of me, and at these times I found it useful to refocus on the research question. I did this by laminating the question and placing it around my office where I could see it easily, and I also found that revisiting my journal and the project objectives was useful. In line with van Manen’s suggestion, it was also useful to consider individual elements of the research and to then consider the whole issue again by stepping back and considering the big picture (van Manen, 1990).

As outlined above, methodology is the term used to present the philosophical framework being used by the researcher, or the theory behind the method or way of undertaking the research. The method is made possible by the application of certain techniques or procedures by the researcher (van Manen, 1990). This chapter outlines the steps or methods employed to complete this research. It presents the principles of ethical research and the steps taken in this project to ensure that these principles have been adhered to. The chapter addresses issues relating to participant selection, including how the participants were recruited to the project. Methods used in data collection and analysis are outlined in detail, and in this way the approaches prescribed by van Manen’s to successfully achieve the hermeneutic circle—which underpins this framework of phenomenological research—are summarised (van Manen, 1990).

2.2 Research ethics

This research project was awarded ethics approval by the Behavioural and Social Sciences Ethical Review Committee at the University of Queensland in September 2008. The project clearance number is 2008001495, with ethics approval current until 30 September 2013 (Appendix A). The researcher was initially enrolled at the University of Queensland and transferred to James Cook University in September 2009. The research interviews had been conducted prior to the transfer date, and on that basis advice was received that indicated that additional ethics approval would not be required from James Cook University.

The *National Statement on Ethical Conduct in Human Research* was published by the National Health and Medical Research Council (NHMRC) in 2007 (updated in 2015) and sets out the ethical guidelines that are applicable to all human research (NHMRC, 2007 updated 2015). These guidelines are designed to ensure that both the individual researcher(s) and organisations such as universities that auspice research are equally responsible for ensuring that research involving humans is conducted in a quality, safe and ethically acceptable manner. The document does not provide a simple checklist of items to be considered when undertaking research on humans; rather, it reinforces the need for thorough analysis of any proposed research to ensure that potential and actual risks to participants are identified and action is taken to eradicate or minimise them. The risks from the research are summarised as potential harm, discomfort and/or inconvenience that may be experienced by the participants, the likelihood of it happening and the degree to which it may be experienced The four principles that ensure that the rights of human participants in research are protected are beneficence and non-maleficence, respect for human dignity, justice and integrity (NHMRC, 2007 updated 2015).

2.2.1 Protecting research participants—beneficence and non-maleficence

Beneficence is defined as ‘doing good’ and in research this principle is achieved by producing outcomes that will have positive benefits for individuals or society as a whole (Danchev & Ross, 2014). It was anticipated that the positive benefits that would be provided by the outcomes of this research would include recommendations relating to staff support in rural health care settings for nurses caring for people with cancer. It was anticipated that this information could be used by team leaders and members alike to identify situations that may potentially lead to staff distress. Areas for action could include grief management' ways to separate home and work situations to ensure that staff receive time apart from the care of patients; and strategies to manage the expectations of patients, their family and the community in general in the rural setting. It was further anticipated that the identification of the themes from the research may provide reassurance for some nursing staff in similar situations who may have struggled in the past with their own feelings and reactions following the death of a patient with cancer. It was also predicted that the themes identified from this research could be applied to areas outside of the care of patients with cancer, to include the support of nursing staff in rural settings who care for patients with chronic and complex illness who also spend extended or frequent periods in hospital.

As an extension to 'doing good', non-maleficence is the principle of 'doing no harm' as a result of the research (Danchev & Ross, 2014). In planning the research considerable thought was given to its potential to cause harm to, or to exploit participants, and whether the risks of this harm or discomfort may outweigh the benefits of the study. It is acknowledged that phenomenological research often explores sensitive issues, that the interviewing process may be emotive for both participants and the researcher (O'Brien, 2003), and that this can in turn cause emotional harm to participants (O'Brien, 2003). Danchev et al (2014) (Danchev & Ross, 2014) state that emotional harm may result from the discomfort experienced by participants due to a perceived invasion of privacy when they share information that on reflection they preferred that they had not. They add that it can be distressing for participants when they recollect memories that they had previously and consciously avoided.

The *National Statement on Ethical Conduct in Human Research* (2007) reinforces the importance of protecting research participants based on the fact that such participants interact with researchers whom they do not know but need to trust, and because they contribute their time and information ‘altruistically, for the common good, without thought of recompense for their time and effort’ (NHMRC, 2007 updated 2015). After consideration it was decided that participants in this study could be at risk of psychological and/or mental stress and/or distress or discomfort. This potential was identified as a result of the depth and length of the conversation that formed the basis of the interview between the researcher and individual participants. Such a conversation is designed to let the interaction go where the discussion takes it, thus exploring themes and reactions as they arise. It was identified as being possible that some participants would experience some sadness and distress when revisiting their experiences of caring for patients with cancer who have died, and when the participant was reacquainted with their grief. Based on anecdotal evidence it was also possible that the research interview would provide the first opportunity for the participants to discuss their experience of caring for the patient and what it meant to them, and that this experience would be therapeutic for those involved (O’Brien, 2003). Although potentially distressing, this interaction was considered potentially helpful to participants by allowing them to share their concerns and experiences with another health professional.

As an experienced oncology nurse and nursing administrator the researcher was skilled and comfortable in the area of communication with patients, their families and nursing staff. The risk of possible sadness was raised with participants through preliminary discussions, and was addressed in a comprehensive Participant Information Sheet (see Appendix B).

Each potential participant in this research study was provided with the Participant Information Sheet. This three-page document was written in plain language and included information about the researcher, the title and purpose of the study, the participant's role in the study detailing the type of interaction required with the researcher through the interview process, the voluntary nature of participation in the study, the ability to withdraw participation at any time without penalty and with assurance that information received prior to withdrawal will not be used in the project, the benefits of the project, the potential risks to the participant, assurance of confidentiality for the participant, information about storage of data and information from the study, ethical clearance details and information about feedback of the findings from the study. Contact details for the researcher were also included in this document, along with contact details at the university. Information sheets were distributed to facilities and organisations by the researcher – I did not initially approach potential participants. Potential participants self-selected and contacted me if they were interested in taking part in the study. After further discussion about the study I provided the consent form to the potential participant.

A Participant Information Sheet and Participant Consent Form (see Appendix C) were forwarded to potential participants at the time of them indicating an interest in participating in the study. The consent form was returned to me prior to arranging to interview the participant. The consent form was signed by the participant and witnessed at the time of signing. The consent form identified the participant by name, and confirmed on signing that the participant had received the Patient Information Sheet. The consent form also included some basic information provided by the participant including their designation as registered nurse or enrolled nurse, the length of time they had worked as a nurse and how long they had worked in a rural setting, their age and gender, their cultural background, address, and preferred method of contact from the researcher. The form also provided the opportunity for the participant to nominate a pseudonym they would like to use for the purposes of the study. The information in the information sheet and consent form was revisited at the beginning of each interview, particularly reinforcing that the participant could withdraw at any time without penalty after the interview had commenced. The option to nominate a pseudonym was also reinforced as all participants had initially declined the use of a pseudonym. At this time participants were given the opportunity to ask any additional questions about the study.

Participants were provided with the contact details of professional counsellors at the Bush Crisis Line (1800 805 391) and at Interlock (1800 172 069) who were available to support participants through debriefing if this was required. The Bush Crisis Line provides free counselling services to nurses who work in rural and remote settings, and Interlock was contracted to provide similar services to Queensland Health employees. Both services are free to charge to those who access them. I contacted key staff at each agency prior to the commencement of the interviews to alert them that the research was taking place and that participants may contact them for more information.

I took a proactive approach to participant distress and stopped or delayed the discussion if individual participants were distressed. This happened on only two occasions during the 20 interviews. Participants were also reminded that they could withdraw from the study at any time without penalty or prejudice. I followed up with participants by telephone after the interviews to ensure that they were not experiencing ongoing distress, and that they were seeking appropriate help if necessary.

A strong motivation of this study was my extensive experience in oncology nursing, and in preparation for the interview it was also acknowledged by my advisory team that I could experience the re-awakening of previous feelings of sadness and grief as a result of the in-depth conversations with study participants. My professional practice has been underpinned by self-reflection, and it was agreed that this approach would continue throughout the study. It was agreed that this professional self-awareness would ensure that assistance would be sought in a timely manner if emotional distress was experienced. It was also agreed that I would seek the advice and guidance from my advisors in relation to experiences of personal distress, and that the services of a professional counsellor would be sought if necessary.

In line with the principle of non-maleficence, and to assist in the identification of potential or actual risks of harm from research, the *National Statement on Ethical Conduct in Human Research* (2007) (NHMRC, 2007 updated 2015) has identified certain groups as vulnerable or with specific ethical considerations. These groups include:

- pregnant women and the foetus
- children and young people
- people in dependent or unequal relationships
- people highly dependent on medical care (section 4.4)
- people with cognitive impairment, intellectual disability, or mental illness
- people involved in illegal activities
- Aboriginal and Torres Strait Islander peoples
- people in other countries (National Statement on Ethical Conduct in Human Research, 2007).

In this study, participants were registered and enrolled nurses who have worked in rural areas of Queensland. Due to the demands of the nursing profession, required competency standards and the requirement for nurses to be deemed fit for practice by the regulatory authority, the Australian Health Practitioner Regulation Authority, participants were deemed unlikely to have an intellectual impairment or rely heavily on medical care. All participants were over 18 years of age.

A decision was made to exclude participants from Aboriginal and Torres Strait Islander nurses based on the complexity of the issues associated with death and dying in the Indigenous culture. In 20005 Indigenous RNs accounted for approximately 0.5% of the RN population in Australia (Usher, Miller, Turale, & Goold, 2005). Many Indigenous nurses return to rural and remote communities, and therefore it is possible that Indigenous nurses may have been working in the communities from which research participants were sought. Weeramanthri (1998) (Weeramanthri, 1998) states that activities associated with the communication of information after death are culturally sensitive in the Aboriginal culture, and the author supports this claim through the nomination of the widespread taboo of the naming of deceased people (McGrath & Phillips, 2008); the phenomenon of blame (McGregor, 2014) and payback (Frost, 2014); the widespread belief in sorcery (McKnight, 2005); the existence of ritual inquests and complicated mortuary rituals (Peile, 1997). A separate study would be more suitable and required to explore similar issues in Indigenous nurses.

2.2.2 Protecting research participants—respect for human dignity

The principle of respect for human dignity in research relates to the right of humans to determine their own actions. In research this principle relates to the right of participants to choose to participate after comprehensive information has been provided about the project, and reinforces that they have the right to refuse to participate or to withdraw from the project at any time and without penalty (De Koninck, 2009). Informed consent, which is composed of the two parts of information and consent, is the process by which a potential participant is informed about a research project and in turn agrees to participate (De Koninck, 2009). Informed consent is a legal principle defined as:

> The knowing consent of an individual or his/her legally authorised representative, under circumstances that provide the prospective subject or representative sufficient opportunity to consider whether or not to participate without undue inducement of an element of force, fraud, deceit, duress or other forms of constraint or coercion.

2.2.3 Protecting research participants—the principle of justice

The principle of justice supports the protection of research participants by ensuring that they are treated with respect and courtesy throughout the research process. The principle of justice is applied when participants are selected on the basis of relevance to the research topic rather than simply based on their availability, and is further reinforced by the assurance of participant anonymity, privacy and confidentiality (Taylor et al., 2006).

As the aim of the research was to understand the experiences of rural Queensland nurses as a result of caring for people with cancer who have died, the participants were selected from a variety of rural locations in Queensland, from a variety of professional experiences and educational backgrounds and from both genders. The criteria for participant selection were that they:

- were a registered or enrolled nurse with a current unrestricted licence to practice in Queensland
- had lived and/or worked as a nurse in rural areas of Queensland

- had cared for patients with cancer in that rural setting who have died
- had agreed to participate in in-depth interviews about their experience of caring for a patient or patients who have died following a diagnosis and treatment for cancer.

Potential participants who did not fit these criteria were not chosen to participate in the study. Partial anonymity of participants was assured throughout this study. The researcher knew the identity of participants but this information was concealed from all others. Given the small nursing teams in the communities and organisations in which many of the participants had worked, concern was raised after data collection that participants could be potentially identified through the combination of their name, location and the information provided in their interview. It is possible that the participants did not understand the implications of their commentary being identifiable by members of their local community or others who may be able to identify them fairly easily. Thus, I allocated a pseudonym at random for each participant. This allocation of pseudonyms was summarised in a table stored securely with the data collected from the interviews.

All participants in research have the right to privacy and to decide what information they wish to disclose to the researcher. Such information can relate to attitudes, beliefs, behaviours, opinions and personal records (Taylor et al., 2006). The principle of justice is maintained when the researcher respects this right to privacy and does not coerce the participant to disclose more information than they are comfortable with, and that information that is sought by the researcher is relevant to the study at all times. In this study the researcher used in-depth face-to-face interviews with individual participants to elucidate the lived experience for the nurse as they cared for a patient(s) with cancer until their death. It was important that the interview would not be rigidly structured to allow the flexibility to let the questioning go where the issues raised may have taken it. However, to ensure that the researcher stayed on track and sought relevant information, questions were developed to guide the discussion with participants, and thus ensure that only relevant information was sought – these are outlined in more detail in the section *3.4 Data Collection*.

The right of participants to privacy is further supported by the safe storage of participant records, data collected and other documents relating to the implementation of the study (Taylor et al., 2006). This is closely linked to the participant right to confidentiality. In this study, all information, whether identifiable or not, was stored securely within a locked filing cabinet in the researcher’s home office. There is limited access to this office. Electronic data were password protected with only the researcher having access to that password. Names, addresses and other contact details were only available to the researcher, and a master file that linked the participants’ details to the interview transcripts was kept in a password-protected electronic file, and only available to the research. Only personal data directly relevant to the study were collected by the researcher. Names and addresses collected on the Participant Consent Form were used for follow-up purposes only, and this was outlined on the information sheet. Participant contact details were not used to create mailing lists. No identifiable information about participants or where they live will be used in any reports, presentations or publications of the research findings. On completion of the study, all electronic data were transferred to a CD-ROM and removed from the computer hard drive. The CD-ROM will be stored, along with all other study material and hard data, in a secure area of the university and will only be accessible to the researcher and advisors for a period of seven years. After this time the information will be treated as confidential waste and destroyed accordingly.

2.2.4 Protecting research participants—the principle of research merit and integrity

The principles of research merit and integrity relate to the researcher, the way the research is planned and conducted, and the way the researcher is supervised throughout the study. These factors are expanded by the NHMRC (2007) in the following way. Research that has merit is:

- justifiable by its potential benefit, which may include its contribution to knowledge and understanding, to improved social welfare and individual wellbeing, and to the skill and expertise of researchers. What constitutes potential benefit and whether it justifies research may sometimes require consultation with the relevant communities;
- designed or developed using methods appropriate for achieving the aims of the proposal;
- based on a thorough study of the current literature, as well as previous studies. This does not exclude the possibility of novel research for which there is little or no literature available, or research requiring a quick response to an unforseen situation;
- designed to ensure that respect for participants is not compromised by the aims of the research, by the way it is carried out, or by the results;
- conducted or supervised by persons or teams with experience, qualifications and competence that are appropriate for the research; and
- conducted using facilities and resources appropriate for the research. (NHMRC, 2007, p.10)

The NHMRC (2007) also outlines the features of research that is conducted with integrity. Research integrity is support by researchers who demonstrate a commitment to:

a) searching for knowledge and understanding;
b) following recognised principles of research conduct;
c) conducting research honestly; and
d) disseminating and communicating results, whether favourable or unfavourable, in ways that permit scrutiny and contribute to public knowledge and understanding. (NHMRC, 2007)

This study was underpinned by both merit and integrity. The research question developed as a result of observation and experience in clinical nursing practice, and was refined over several years of self-reflection and questioning by the researcher. The findings from the study will contribute in a positive way to nursing practice. A thorough literature review was conducted prior to seeking ethics approval and to support the formulation of the research question, identification of the appropriate study methodology and method. The researcher has maintained respect for the research participants at all times, and as outlined above, steps have been taken throughout the research to ensure that study participants are protected at all times. The researcher has been supported throughout the study by advisors with advanced skills and knowledge in the research methodology, subject areas and study methods. This support was provided in face-to-face meetings, remotely using technologies such as Skype, e-mail communication and telephone, and was enhanced by regular attendance at formal workshop activities to increase the researcher’s investigative skills and knowledge. The researcher had ready access to research facilities and resources at both the University of Queensland and James Cook University.

The researcher’s integrity is demonstrated by an obvious commitment to understanding the experiences of rural nurses as a result of the death of a patient from cancer, and in doing so, seeking to understand the humanity of this practice. This commitment has been maintained for a decade while the research question was formulated and refined, and while the study was conducted. The research has been conducted using the recommended processes to successfully complete a phenomenological study, with these being identified through the literature review and in discussion with the research advisors. The research has been conducted honestly and may be readily audited through the review of electronic and hard copy transcripts of interviews, the researcher’s diary, and other hard copy information associated with the study. The results of the study have been formulated into this thesis, submitted for review, and will be prepared for publication. The research advisors oversaw these processes throughout the study, providing timely feedback and advice as required.

2.3 Participant recruitment

I made contact with potential study participants through the informal network of rural Directors of Nursing in Queensland. Information packages were initially sent to the Directors at rural hospitals across the state. The information packages included the Participant Information Sheet, Participant Consent Form and a covering letter requesting that the information be distributed to staff at their facility. This mail out was followed up by a telephone call, and an offer to address staff groups via video or teleconference to answer any specific questions about the study. I was invited to introduce the study at several professional meetings in the local areas, and this proved to be a valuable approach to recruiting participants.

An itinerary was developed to support visits to rural facilities. To support the recruitment of sufficient numbers of participants, a snowballing technique was used to recruit further from initial contacts. This technique involved the researcher making contact with those who have already been interviewed, encouraging them to ask a colleague who might also be interested in participating.

Potential participants contacted me and at that time a more in-depth conversation was held to explain the information sheet and consent form in more detail. If I had not heard from the potential participant after a reasonable period (up to two weeks), further contact was made with the person to seek clarification of any initial questions or concerns, and this was followed up again after another two weeks if there was still no response. Upon return of the completed consent form, participants were contacted to discuss a suitable time and venue to conduct the interview on a face-to-face basis. At the beginning of the face-to-face interview the project was again outlined and the participant given the opportunity or not to proceed.

It was initially envisaged that 30 interviews would be conducted; however, members my Confirmation Committee suggested that 15 interviews would be a more realistic number of interviews to achieve. At that time, and prior to seeking expressions of interest, it was not possible to predict levels of interest and willingness to be involved by potential participants. It was also not possible to predict at that time when data saturation would be reached. Developed in consultation with my Advisors, the suggested make-up of the pool of interviewees is outlined in Table 3.1.

Twenty participants were recruited to the study. In contrast to the suggested make-up of the pool of interviewees, all participants were female, with five being enrolled nurses and the other 15, registered nurses. During recruitment I only had interest from one male nurse who decided not to participate, as he would be away at the time of my visit. The median age of participants was 47 years with a range of 31–59. The median number of years of nursing experience for the participant pool was 23.5, with a range of 7–40 years. The median number of years of rural nursing experience was 19 years, with a range of 2–38 years.

Table 2.1 Summary of Characteristics of the intended Sample Pool of Interviewees

Gender and years of experience		**Options**			
male	<5 years' experience as a registered nurse (RN)	A + C 1	B + C 1		Numbers are an indication only—study aimed for data saturation
male	>5 years' experience as an RN	A + C 1	B + C 1		
male	>5 years' experience as an RN	A + D 1	B + D 1		
female	<5 years' experience as an RN	A + C 5	B + C 5		
female	>5 years' experience as an RN	A + C 5	B + C 5		
female	>5 years' experience as an RN	A + D 5	B + D 5		
Legend		A = RN based in a rural area	B = enrolled nurse based in a rural area	C = <5 years' experience living in rural & remote areas	D = >5 years' experience living in rural & remote area

2.3.1 Participant recruitment—defining 'rural' for participants

The characteristics of rural settings for nursing practice, and rural experience as a nurse are important features of this research, and as such require specific consideration in relation to participant recruitment. The broader issues of rural and remote areas of Australia, rural health and rural nursing were explored in greater depth in the literature review of this study. As already suggested, rurality is a difficult concept to define with classification based on various characteristics including community population, distance from major cities, distance from emergency care, numbers of medical practitioners, consideration of community infrastructure and amenities (Bushy, 2002; J. C. Kulig et al., 2008).

Nurses are often integral members of rural health services and the rural communities where they live and work (Lauder et al., 2006). Rural nursing was originally defined as the provision of health care by professional nurses to people living in sparsely populated areas, and included reference to the presence or absence of medical officers (Hegney, 1999; Lauder et al., 2006; Mills, 2007; Mills, Birks, & Hegney, 2010). Francis et al. (Francis, 2005) observe that this definition has been expanded in recent years to include nurses who provide health care to patients with reduced access to health services outside of major metropolitan areas. There is general agreement that the test for ‘rural’ for participants such as those recruited for this study is that of self-definition (Francis & Chapman, 2014; Mills, Birks, & Hegney, 2010).

In this study, I nominated specific rural towns in Queensland, and made contact with the Directors of Nursing at the hospitals and health care services in each community. Based on the location of these facilities and potential participant interest I developed an itinerary to support visits to the individual communities to conduct face-to-face interviews with participants. Interviews were conducted over a period of several months from late 2008 to mid-2009. Participants worked at health care facilities in Atherton, Mareeba, Charleville, Charters Towers, Longreach, Roma and Winton. I undertook a two-week long road trip in mid-2009 during which I completed fourteen interviews. All participants identified themselves as rural nurses, and this was further supported by their actual experience working in rural settings, with that experience ranging from 2 to 38 years in total.

2.4 Data collection

Face-to-face interviews were used to gather information from the study participants. The aim of the interviews was to elucidate the lived experience of nurses as they cared for their patients with cancer until their death. It was anticipated that the initial interviews would take approximately 90 minutes, and these may have been followed up with further contact at a later date to clarify issues identified or specific questions raised after the initial data analysis. This secondary contact was not required. The interviews were not rigidly structured as it was believed that this flexibility would allow the questioning to go where the issues raised took it.

van Manen (van Manen, 1990) provides suggestions for producing a lived experience description, which reinforces the depth of the conversation between the interviewer and participant:

1. Describe the experience as you live(d) through it;
2. Describe the experience from the inside, as it were; almost like a state of mind: the feelings, the mood, the emotions etc.;
3. Focus on a particular example or incident of the object of experience: describe specific events, an adventure, a happening, a particular experience;
4. Try to focus on an example of the experience which stands out for its vividness, or as it was the first time;
5. Attend to how the body feels, how things smell(ed), how they sound(ed), etc.; and
6. Avoid trying to beautify your account with fancy phrases or flowery terminology (van Manen, 1990, p. 64-5).

Based on van Manen's suggestions, the following prompts were devised as a framework for the interviews with participants:

- Recall when you cared for a patient who died from cancer. Tell me about your patient, how long you cared for them, and what you remember about them during that time.
- Describe what it was like to care for the patient as you lived through it.
- Describe your emotions associated with that experience—what were your feelings, your mood and your emotions?
- Tell me about particular events that stand out in your memory during your journey of caring for that patient. Why does this/these stand out for you?
- Tell me how you felt and reacted after the death of your patient.
- Tell me what was most helpful to support you to continue your work during your care of this patient and then after their death.
- What was least helpful in allowing you to work, and to cope in this stressful situation?
- Do you have any further comments to make?

The questions provided a starting point to allow the conversation between researcher and participant to begin, and they also provided a guide for the conversation to be brought back to the study themes if the conversation stalled or wandered completely off track.

As already acknowledged, in Section 2.1, the process of interviewing in phenomenological research can be emotive for both the researcher and the participant (Walker, 2011). With this in mind, the researcher ensured that a private room was available to conduct the interviews, and provided comfortable chairs, water and tissues to promote participant comfort. Some participants experienced some sadness when they revisited their experiences of caring for patients with cancer who had died. During reflections on their past experiences, some participants shed tears and some laughed;

there were frequently pauses in the conversation while participants collected their thoughts prior to continuing. Several participants stated that the interview was the first opportunity they had had to discuss their experience of caring for the patients and what it meant to them, and most indicated that it had been a positive experience to share their thoughts and experiences.

Interviews were scheduled to allow sufficient time for each to be completed, and to ensure that I also had sufficient time between interviews so as not to be rushed, to ensure that reflections on each experience could be noted, and to ensure that if participants were upset that time would be available to support them. As already outlined, participants were provided with the contact details of professional counsellors at the Bush Crisis Line (1800 805 391) and at Interlock (1800 172 069), who were available to support participants through debriefing if this was required. A proactive approach was taken to participant distress and the discussion was stopped or delayed if the participant was distressed. Participants were reminded that they could withdraw from the study at any time without penalty or prejudice. Following the initial interviews, I contacted participants in person or by telephone to ensure that they were not experiencing ongoing distress, and that they were seeking appropriate help if necessary.

On days when multiple interviews were conducted I felt emotionally drained due in part to the depth of the conversations, the number of interviews and through the sharing of raw emotions at times. I had also experienced many of the participant experiences in the past. On some days interviews flowed more freely than others, and on reflection less effective interviews took place when I was tired, and when the initial connection between the participant and me was less strong.

Five study participants were staff members who worked with me, and in particular three were managed by me. The study Advisors raised the issues of power hierarchy and familiarity as potentially influencing the success of the interviews with these participants, including its potential impact on the validity of the data arising from them. I was mindful of these concerns, and consciously attempted to put affected participants at ease by reinforcing the aims of the study, the issues of confidentiality and that during the study interview the researcher was not acting in the role of manager or supervisor. On reflection the interviews with those participants who were personally known to me were positive experiences for all, and were frequently enhanced by the knowledge that participant and researcher had shared experiences, caring for the same patients in some instances.

Interviews were recorded on an electronic voice recorder. Permission to do this was sought in the informed consent process. Steps were taken by me to make the presence of the voice recorder as unobtrusive as possible to help enhance the comfort of the participant during the interview. Twenty interviews were conducted in total. Interviews were saved electronically, identified by the name of the participant and with the interview date. The interviews were transcribed verbatim by a typist. A confidentiality agreement was developed by me and signed by the typist prior to completing the transcripts of the interviews. All data from the interviews were returned in full to the researcher, with none retained by the typist.

2.5 Data analysis

Lowes and Prowse (Lowes & Prowse, 2001) acknowledge that the analysis of phenomenological research data is dependent on the quality of the information collected, which in turn depends on the way in which the interviews are approached and conducted. The authors (Lowes & Prowse, 2001) further reinforce that in contrast to

Husserlian phenomenology, which relies on the researcher distancing themself from the interview process by bracketing preconceived ideas and beliefs, the application of the Heideggerian philosophy of phenomenology can only be used to interpret the data according to the researcher’s own beliefs, experiences and preconceptions, and that these are an integral part of the research process and should not be excluded. In line with the guidelines in the literature, the researcher acknowledged and documented any preconceptions in relation to the interview framework and participant responses, and supported this through the use of a reflective journal and field notes to help highlight biases and preconceptions in relation to the data being collected (Lowes & Prowse, 2001).

The transcribed interviews were prepared in table format using a landscape orientation. Segments of the interview pertaining to each speaker were identified and organised into separate rows, and each line of text was numbered chronologically on each page. This allowed each segment of text to be clearly identified and located for reference and audit purposes. All hard copy transcripts of the interviews were organised by participant into two ring-binder folders for ease of access and transport. Interviews were labelled by the participant’s name, and separated from other transcripts by a labelled divider in the folder. An easy reference summary of participant details including their first name, the date and length of the interview document (in kilobytes), location, their designation as registered or enrolled nurse, years of nursing experience and of rural experience, and age was provided at the front of each folder.

van Manen (M. van Manen, 1990) describes a circular process of writing and re-writing passages of the transcripts with a view to clarifying content and themes, promoting reflection and allowing for deeper themes to be highlighted. Van Manen (Adams & van Manen, 2008) describes this methodological technique as hermeneutical phenomenological writing. van Manen (van Manen, 1990) describes phenomenological themes as the ‘structures of experience’ and states that the process of finding such themes is like mining for meaning. This process ensures that themes are grouped into clusters of similar experiences and themes, ensuring that contradictory themes are not discounted.

The content of the transcribed interviews was reviewed several times, and significant statements made by participants were highlighted. The researcher chose not to report the data from one of the interviews as the participant did not discuss her experiences of caring for patients with cancer, but in contrast described her experiences caring for people in an aged care setting. The significant statements from the transcripts were written in longhand onto sticky notes with a re-adherable strip of adhesive on the back, designed to temporarily attach notes to documents. These notes were organised by emerging themes and placed in an A3 sketch pad for ease of access and review. Pages of the sketchpad were labelled with the emerging themes and the note papers were placed onto the sketchpad page of the relevant theme. This approach allowed the significant statements to be moved from theme to theme and sub-theme as the data analysis was further refined. A summary of the selected statements was also organised in table format within themes. The electronic table supported the easy reallocation of statements to themes and sub-themes as data analysis progressed.

I found that the initial identification and labelling of themes and sub-themes from the data required further and ongoing revision. A poor fit between the initial themes and the significant statements resulted in the inability to highlight deeper themes and to progress with data analysis. Revisiting the content of the interview transcripts and the identification of new themes and sub-themes resulted in a greater congruence between the study themes and participant statements. This process of reading and re-reading, and revisiting and redefining of themes mirrored the ‘mining for meaning’ described by van Manen (M. van Manen, 1990). The study Advisors provided valuable support and guidance throughout this component of the study, ensuring that emerging themes could be identified, defined to ensure that they reflect the language of phenomenology and then examined in further detail. An exhaustive description of the phenomena or themes from the experiences of the research participants was developed at the conclusion of the data analysis.

McConnell-Henry et al. (McConnell-Henry, Chapman, & Francis, 2011) stated that participants may be contacted during the analysis of the data for purposes of member checking. The authors suggested that this contact could be made via telephone or in person. This process can be used to validate the data collected by inviting participants to check various parts of the data to ensure that their contributions are being interpreted in the way that it was intended. It may also be used to clarify with the project participants any questions or points of clarification that the researcher may have after conducting the initial data analysis. In this study the researcher made the decision not to contact participants during or following data analysis. The in-depth interviews provided extensive information, and questions were asked during the interview process if necessary.

2.5.1 Ensuring rigour

Sandelowski (Sandelowski, 1993) stated that criticism of qualitative research such as phenomenology relates to its lack of scientific adequacy. Sandelowski (Kenny, Carter, Martin, & Williams, 2004) and others (Koch, 1995; Mill & Ogilvie, 2003; Rose & Webb, 1998; Tuckett, 2005) agree that the criteria for confirming rigour in qualitative research are credibility, fittingness, auditability and confirmability.

Credibility is defined as the degree to which participants and readers of the research recognise the lived experiences described by the researcher as being similar to their own (Sandelowski, 1993). Koch (Koch, 1995) investigated the application of Heideggerian phenomenology in relation to the four criteria of rigour. The author (Koch, 1995) stated that credibility in phenomenological research is enhanced when the researcher demonstrates self-awareness and that this self-awareness is demonstrated by their ability to express their own beliefs and preconceptions. In line with the recommendations made by Koch (Koch, 1995) and the guidelines expressed by van Manen (van Manen, 1990) I supported the credibility of this research by disclosing preconceptions and experiences of the phenomenon (see Chapter 1.5). A field journal was also maintained throughout the study and was used by me to describe experiences during the interviews with participants, and thoughts as the research study progressed. The information generated by me was integrated into the data analysis as themes were identified, and in turn examined in more depth.

Fittingness is described by Sandelowski (Sandelowski, 1993) as the process by which the findings of the research are able to ‘fit’ into a different context and also relates to the extent that the readers of the research believe that the findings are meaningful and applicable to their own situation. As outlined in the discussion section of this thesis, the researcher believes that the themes raised by this research can also be applied to areas outside of the care of patients with cancer, to include the support of nursing staff in rural settings who care for patients with chronic and complex illness who also spend extended or frequent periods in hospital. The researcher assessed the fittingness of the outcomes of the research through personal reflection, and discussion with colleagues and study advisors.

Auditability in qualitative research is the process by which a study's methods, decision trail and processes are documented by the researcher, with a view to them being easily adopted by another researcher to arrive at similar or comparable findings (Sandelowski, 1986; Taylor et al., 2007). Sandelowski (1986, p. 92) also refers to this process as 'dependability'. The researcher has ensured that the decisions and methods employed throughout the stages of this study are clearly described and presented in a logical format to enhance the ability of others to review or audit the approach taken and subsequent findings.

Finally, confirmability is determined by the achievement of the previous criteria of credibility, fittingness and auditability (Tuckett, 2005). O'Brien (2005) states that the achievement of rigour in phenomenological research is challenged in the same way as in other methods of qualitative research; however, the author lists particular features of the research that will support the rigour of the research. These are:

- the acceptance of the validity of the participants' descriptions of the experience and the understanding that the stories emerge out of the unique context of their conversations;
- the use of the researcher's perspective of the experience of the phenomenon;
- the use of other sources of understanding and contextualising the phenomenon;
- the bringing together of participant, researcher and other sources in the interpretation;
- the provision of a narrative illustrated by concrete examples in anecdotal form; and
- a recognition that the experience being described resonates with the reader's understanding of what it is, or what it might be, to experience a life in that context. (O'Brien 2005, p. 199)

The method employed by van Manen uses three approaches to achieve the hermeneutic circle and in turn to isolate thematic statements. The first approach is the holistic or sententious approach, which as the name suggests involves reading data such as the transcribed interview records as a whole in an attempt to express the overall meaning of the text in a pithy statement (van Manen, 1990). Van Manen acknowledges that different readers may find different meanings through this approach. This was reinforced during this research by the input of the study Advisors in supporting me to elucidate themes and sub-themes, particularly when the process seemed to stall at times.

The second step in this process is described as the selective or highlighting approach. Again as the name suggests, this step involves the process of discovering themes by re-examining sentences or part-sentences for phrases that stand out (van Manen, 1990). This was completed in this study by the collection of statements from the participant interviews, which were prepared on sticky notes allowing their allocation from one preliminary theme to another.

The final step described by van Manen is the detailed or line-by-line approach, which involves even closer examination of the text with each sentence or cluster of sentences carefully examined for further thematic evidence (van Manen, 1990). The author believes that this systematic approach supports the revelation of essential and incidental themes (van Manen, 1990). van Manen suggests that without the essential theme(s) the phenomenon would not exist, and he proposes that the researcher uses free imaginative variation to examine a phenomenon hypothetically in the absence of a theme to see if the phenomenon still exists (van Manen, 1990). The importance of sensitive writing is also stressed by van Manen with particular attention to language when describing themes and phenomena. He believes that responsive-reflective writing through a process that he describes as ‘poetizing’ is the essence of undertaking phenomenology (van Manen, 1990).

Examples of the previous use of van Manen’s approach by nurse researchers include the examination of the complex issue of nurse–patient relationships in palliative care (Mok, 2004), and when examining the concepts of caring from the perspective of surgical nurses (Enns & Gregory, 2007). van Manen’s approach was selected in the first instance because of its emphasis on interpretation, innovation and dialogue through self-reflection (van Manen, 1990). Similar to this research, the principal investigators used this approach to investigate and understand the experiences of patients with incurable cancer, and of the nurses who cared for them (Mok, 2004). Enns et al. (Enns & Gregory, 2007) described phenomenology as the study of ‘essences’ and applied it in this instance to support the examination of caring, which they considered to be the essence of nursing.

2.6 Chapter summary

This chapter discussed the use of phenomenology as an appropriate methodology to describe and interpret the lived experience of Queensland nurses who have cared for people who have died from cancer. The current research is underpinned by the phenomenology developed by van Manen, and this approach was also outlined including description of the six methodological steps proposed by van Manen (van Manen, 1990) as a means to guide phenomenological analysis. These steps were elaborated on in the description of the methods used in this research, along with an overview of the data collection and analysis techniques employed in the study. Issues of rigour and ethics were also addressed.

The following chapter introduces the study participants and provides some background for each as a context for locating them in the research study.

Chapter 3: Introducing the Study Participants

This chapter will introduce the participants in the study. General information is provided about each participant. Information is also provided about the steps taken to ensure the anonymity of each study participant as outlined in Chapter 3.1.

Although offered the opportunity to use a pseudonym as part of their participation in this study, each participant elected to be identified by their real name. Given the relatively small populations in each of the communities where interviews were conducted, and the small number of nurses in each community, it was possible that participants could be identified through the combination of their first name, their location, and their professional role. Thus, pseudonyms have been allocated to each participant by the researcher; other identifying information has been kept to a minimum to ensure that participants are not readily identified by readers.

3.1 Participant summary

Twenty Queensland nurses based in diverse rural areas of the state agreed to participate in this study. The nurses were based in seven communities located in the far north, the south-west and the central west of the state.

The average age of the 20 participants in the study is 47 years, with a range of 31–59 years. On average, participants had been nursing for just over 24 years, with their average total rural experience being just less than 19 years.

Following is a brief profile of each study participant. This information is provided to understand the background and context of each participant when considering the experiences that each shares through their interviews.

3.1.1 Introducing Participant 1: Barbara

Barbara is a 48-year-old RN. She had worked as an Assistant in Nursing in nursing homes prior to completing her Bachelor of Nursing three years before the current study commenced. Although she is a relative newcomer to the hospital in which she is working at present, all of Barbara's nursing experience has been in rural areas. She lives 10 minutes out of town on a small property and enjoys the relative peace and quiet afforded by living in the country.

3.1.2 Introducing Participant 2: Teresa

Teresa is an RN and the youngest participant in the study at 31 years of age. Like Barbara, Teresa has been working as a nurse for seven years, but in contrast has only two years' experience in a rural setting. Teresa has worked at the hospital where she was interviewed for a relatively short period of time, but has additional rural experience from New South Wales and the Northern Territory.

3.1.3 Introducing Participant 3: Angela

Angela is a 57-year-old RN with 38 years' experience. She has worked in rural areas of Queensland, New South Wales and Tasmania. Angela's husband is an Anglican priest and her movement from town to town has been as a result of his transfers from parish to parish. Angela spoke freely of her strong Christian faith and she believed that this helped her to cope with the pressures of her role in the hospital, and that it enhanced her ability to support patients, their relatives and staff alike.

3.1.4 Introducing Participant 4: Nancy

Nancy is a 51-year-old enrolled nurse who has worked in rural areas of Queensland for the 38 years of her nursing career. Nancy has strong ties to the community where she lives and works, having married and lived there for several decades. When she was interviewed her role had a community focus; however, prior to that she had worked in the local hospital for many years. Nancy is passionate about her work and describes it as energising.

3.1.5 Introducing Participant 5: Cheryl

At 42 years of age Cheryl has spent half of her life working as an RN, with all of that time spent in rural areas of Queensland. Cheryl has recently made the change to a career path in nursing management, but admits that she still has plenty of hands-on nursing experience, particularly when her hospital is short staffed. Cheryl is pleased to maintain this close contact with patients and their families, and stated that she would hate to be locked away in an office all day.

3.1.6 Introducing Participant 6: Tina

Tina is an RN who like Cheryl is in a managerial position but still describes daily contact with patients and their families. Tina is 36 years of age and has been working in rural settings for 15 years, which is only one year less than the total time she has been registered. Tina is a midwife and also has completed her Rural and Isolated Practice endorsement for RNs. Tina stated that the secret of working successfully in rural areas is to be confident in what you are doing, and on this basis she believed that rural areas are not the best places for new graduates to be employed.

3.1.7 Introducing Participant 7: Robyn

Robyn is a 43-year-old enrolled nurse who has been working in rural areas of Queensland for all 12 years of her nursing career. Robyn works in a community-based service and commonly works alone in consultation with a, RN. Robyn described the limitations of the enrolled nurse role in the community but added that the team of RN, enrolled nurse and personal carer can successfully support patients to stay in their own homes much longer. Robyn is passionate about her work and about the communities in which she works.

3.1.8 Introducing Participant 8: Carol

An RN for 29 years, Carol is aged 47 years. Carol has spent all of her nursing career working in rural areas; mostly in the one community. Carol's role is based in the community and although she is a manager, she relishes the hands-on opportunities brought by her diverse role brings. Carol describes herself as being passionate about respecting the rights and wishes of patients when providing their ongoing care at home.

3.1.9 Introducing Participant 9: Rhonda

As a rural RN for 10 years, 40-year-old Rhonda worked as an enrolled nurse prior to completing her course at university. Rhonda is based in a busy rural hospital and lives in the community in which she grew up. Rhonda is passionate about rural nursing and believes that an experienced rural nurse has the skills and knowledge to work just about anywhere.

3.1.10 Introducing Participant 10: Lisa

Lisa is an RN with 30 years' experience, and all but five of those years spent in rural centres. Lisa is 47 years old. Lisa works in a community setting, and like others in this study, although she has a managerial role much of her working day is spent providing hands-on care and support to patients and their families. Lisa has returned to the rural community in which she grew up, and states that she is pleased that her children are able to have some of the same happy experiences that she had growing up in a rural area.

3.1.11 Introducing Participant 11: Patricia

Patricia is a 48-year-old enrolled nurse with 32 years' experience. Patricia has worked in rural settings for the past five years. Although her role is primarily based in the hospital, Patricia has developed a diverse set of skills that has allowed her to extend her work into the community. Patricia describes herself as passionate about self-education and admits that this is difficult to pursue in rural areas.

3.1.12 Introducing Participant 12: Linda

At 44 years of age, Linda has been an RN working in rural areas for 23 years. Linda is also a midwife who works across all ward areas in the busy rural hospital at which she is employed. Linda is passionate about helping patients to stay in the local area for their ongoing care, and acknowledges that the travel to and from larger metropolitan centres can often be more unsettling than the treatment that the patients receive when they get there.

3.1.13 Introducing Participant 13: Donna

Donna is a 57-year-old RN. She has 27 years' experience as an RN, with most years more recently spent in rural settings. Donna is an agency nurse who has been on a long-term contract at the hospital where she was interviewed, having spent the past 12 months in that facility. Donna embarked on agency work in rural settings as part of a 'tree change' after the death of her husband.

3.1.14 Introducing Participant 14: Michelle

Aged 39 years, Michelle is an RN who has enjoyed the eight years she has spent in rural settings. Michelle has 20 years' experience as an RN. Her role is based in the community and she describes it as being 'very hands-on'. Michelle has strong ties to her community, having returned to her home town and married a local man.

3.1.15 Introducing Participant 15: Cynthia

Cynthia was an enrolled nurse for a number of years prior to completing her studies to become an RN. Cynthia is 43 years old and has been nursing for 24 years with all but two of those in rural practice. Cynthia has returned to the community where she went to school, and is very pleased that her children are able to have the same experiences she enjoyed as a child.

3.1.16 Introducing Participant 16: Sandra

Aged 59 years, Sandra is the most experienced nurse in the participant group with 40 years spent as an enrolled nurse. Sandra has spent half of her career in rural settings. Sandra reported that although she struggled to complete primary school by correspondence while her parents worked on their farm, she always knew that she wanted to be a nurse. Sandra stated that when she put her first uniform on at 17 years of age she knew she would never take it off again.

3.1.17 Introducing Participant 17: Tammy

Tammy has been an RN working in rural centres for the past 38 years. Although she is 58, Tammy reports that she has no intention of retiring in the near future. More recently Tammy has worked in a managerial role and stated that this was not her passion in nursing. She enjoys hands-on care and looks for every opportunity to interact with her patients and their families.

3.1.18 Introducing Participant 18: Pamela

Pamela has spent half of her 40 years of age as an RN and has spent all but five of those years in rural settings. Pamela is also a paramedic and has more recently dedicated most of her professional time to this role. Pamela works part time as an RN and states that she does this to maintain her skills. Pamela has worked in rural and remote settings across Queensland and states that she has no intention of returning to larger communities.

3.1.19 Introducing Participant 19: Julie

Julie is an enrolled nurse with 18 years of experience in that role. Julie is aged 50 years and is based in her home town. She is working at the facility in which she completed her initial training. Julie works in all clinical units at the hospital and states that this variety is one of the best things about being a rural nurse.

3.1.20 Introducing Participant 20: Brenda

Brenda is an RN who has spent all 31 years of her career working in rural areas. She trained in the hospital in her home town and worked in the facility for a number of years after the completion of her initial training. Brenda has spent many of the recent years working in the nursing home that is part of the town’s hospital, and has also enjoyed time spent as a community nurse. She likes the variety that rural practice affords her, and stated that one of the best things about caring for people from the local community is that relationships are developed that span across the hospital and the town as a whole.

3.2 Chapter summary

This chapter has introduced the 20 participants in this research study. Most were very experienced rural nurses who were passionate about their work and supporting their local communities. The following chapter discusses the phenomenological themes identified through the interpretative analysis of the interview transcripts. This process is reinforced by excerpts from participant’s narratives, which have been interpreted and grouped together to support the existence of the themes. The chapter will outline the three main themes and 12 sub-themes that have been identified in total.

Chapter 4: Identifying the Phenomenological Themes

4.1 Introduction

This chapter discusses the phenomenological themes identified through the interpretative analysis of the interview transcripts. A total of 12 sub-themes were identified and these were grouped together under three main themes. Table 5.1 identifies each theme and the associated sub-themes based on the experiences described by the participants in the study.

Table 4.1

Phenomenological Themes

Theme	**Sub-theme**
Accepting the need to adopt progressive ways of delivering nursing care	Identifying the importance of effective communication
	Accepting the patient has the lead in care
	Recognising the importance of confidentiality
	Learning a new role or new way of being
Learning different ways of relating to patients and families	Struggling with the close relationships in small rural towns
	Learning to live with blurred relationship boundaries
	Learning how to involve relatives in the nurse–patient relationship
	Knowing death in a relationship
Seeking to achieve work–life balance	Finding ways to care for the self
	Accepting the benefits of close relationships
	Learning personal boundaries (while working through team issues)
	Sharing and learning from experiences in the rural context

4.2 Phenomenological Theme 1—Accepting the need to adopt progressive ways of delivering nursing care

4.2.1 Identifying the importance of effective communication

Several participants expressed their frustration with the poor communication that they had experienced with the new medical and nursing staff in the area, which they believed had resulted in less than optimal treatment outcomes for patients. A combination of poor communication, some team members' poor understanding of treatment options and perceived poor understanding of the patient's needs results in a clash between the established ways and those of the newcomer to the team. Many participants described effective communication as the key to an effective care team and good outcomes for the patient and their family.

Patricia described her frustration at ineffective communication between existing and new members of the treatment team, resulting in an inability to reach consensus in treatment planning for the patient. For Patricia the key to success is effective communication:

> Definitely communication between doctors and nurses. [Also] between the agency nurses and the regular nurses that are on because it, they bring in a totally different model of care to what we're used to. And try and incorporate and we're used to … there is tension there sometimes …Yes but communication out here is a big factor. (Patricia (18) 19–20; 22–24; (19) 1–5; 12–13)

For Cheryl, ineffective communication within her team resulted in poor outcomes for the patient and the exclusion of family members in the care of a dying patient:

> I don't think his pain was well managed. I don't think … there was enough communication amongst staff, [about] the management of him and his death, his daughter felt like she was locked out. And felt there was a lot of things that could have been done better. (Cheryl (8) 17–24)

Robin specifically targeted the medical staff for criticism in relation to their poor communication with the family, and the negative effect that this has on the involvement of family members in the care of their loved one:

> Yeah, with the doctors I suppose—most of them are great but there have been a few that, you know, left the family and naturally when there's no information or little information they make it up themselves. (Robin (55) 5–10)

4.2.2 Accepting the patient has the lead in care

Several of the nurses in this study acknowledged that in their experience it was important to accept that patients will take the lead in their own care. Although the role of being a patient—and for this study, a dying patient—had not been experienced before by each of the patients the nurses described, it was clear that for many of the nurses the patient was definitely in charge of what was happening to them. 'Being in charge' related to many aspects of their care including how they received their care, what treatment they had and where they died.

Sandra recalled an interaction with a patient who made the difficult decision to stop treatment, and to leave hospital:

> I've had enough of it, I don't want it anymore but I want to die at home. (Sandra (2) 25–27)

Donna recalled the clash between the instructions of the care team and the patient's wishes, and the point of resignation where it was acknowledged that the patient should be able to do whatever they wanted to do:

> So a lot of staff don't realise that when you're palliative, you're palliative, you shouldn't make people do what they don't want to do. If they're palliative and they're on analgaesia and all that stuff, if they want to stay in bed all day, let them stay in bed all day. It's the last days of their life, they're tired. (Donna (15) 9–17)

Several nurses used the term 'bushie' to describe a type of patient. Apart from illustrating the context from which these patients came, most participants used the term as an explanation for behaviour demonstrated towards them; on one occasion as an excuse for the sometimes tactless nature of those interactions. As an example Sandra used the term ‘bushie’ to excuse the abrupt approach of her patient:

> [He] told them what he thought or whether they were doing a good job or what they weren’t doing or you know; he didn’t beat about the bush. He just said what he had to say, he felt he had to say it, he was a bushie. (Sandra (5) 23–28; (6) 1—2)

In contrast for Carol the term ‘bushie’ described a patient who was most comfortable in his own environment:

> Like the little old man saying to me I was born in the bush, I’ll die in the bush. (Carol (85) 11–13)

Supporting patients to take the lead in their care is not new and is not something that relates specifically to rural settings. Nurses work with other members of the health care team to provide patients with the information they need to make choices about their care. This reinforces the concept of a partnership between the nurse and their patient, and most participants agreed that the effectiveness of this partnership is underpinned by effective communication. Lisa outlined the need for effective communication in several sections of her interview:

> You know, it’s not up to us to make these calls, that’s the most unhelpful thing because you are not actually listening to the person, you’re just making an assumption or it’s your view what they should be told they’re dying or whatever instead of working through it with them. (Lisa (27) 22–28; (28) 1–4)
>
> All those sort of really good communication skills though is all that you really need because it is not about you it’s about that person. (Lisa (36) 13–18)

4.2.3 Recognising the importance of confidentiality

Several nurses acknowledged that the blurred relationship boundary lines extended past the direct relationship with patients, to frequently include the patient’s relatives and other friends who would target the nurse to gain additional information or to have tasks completed, often when the nurse was not even at work. Experiencing these incidents left many participants feeling as though they were not off duty even when they were away from work, forcing many of them to stay on their guard when away from the hospital. Staying alert ensured that the nurse did not breach patient confidentiality, or get caught in the external relationship dynamics between the patient and others. Cheryl explained:

> They [community members] wouldn’t come up to see him but they would try and feed information from staff members, staff down and stuff like that. And because of his very strong personality and his close relationship with his carer we had to be very mindful in that. His umm, his confidentiality was something that we had to respect, people fished definitely. (Cheryl (7) 3–11)

Pamela described being asked to do something for a patient when she was off duty. She stated:

> With palliative care in the smaller community … on your days off if you ran into their partner or them you know they might tell you something that they want done, and you ring up and get it done or whatever. (Pamela (43) 6–12)

4.2.4 Working within team boundaries to ensure the best approach to the care of the rural patient

In the same way that there are professional boundaries between the nursing staff and their patients and families, boundaries also exist between the members of the health care team in rural areas. Participants stressed the need for an effective partnership approach between the members of the care team, and to achieve this for many of the participants the boundaries between professions were blurred. This may be due in part to the multi-skilled ‘jack of all trades’ (Hegney, 1996) approach that is required in rural nursing practice, which may encompass some areas of responsibility of other professions such as those from allied health in the absence of specialist staff.

All of the nurses interviewed had worked in rural areas and in most instances in the same rural area for many years. They described teams of core staff where members were very comfortable with each other and able to pre-empt each other’s actions. Some participants acknowledged that such familiarity could lead to contempt in some settings, and that this was frequently exacerbated when combined with perceived familiarity with and presumption of patient needs.

As outlined above, the criticism relating to team effectiveness was not only directed towards those situations where new team members affected the team dynamic. Participants noted that team effectiveness was also reduced by other factors including members taking their knowledge of the patient for granted and therefore not checking the current situation prior to making a decision about care; poor teamwork between existing team members; the need for ongoing education for rural staff to ensure treatment options are current and effective; and a lack of consistency in treatment approaches.

Patricia described the frustration she experienced when staff took their knowledge of a patient for granted and did not consider the current situation when planning patient care:

> They [the nurses] know them so well and when people get stuck with something when they know they are going to die, it could go totally out the window and that can be hard for everybody especially nursing because you think you’re doing the right thing and then you’re told you’re not, so you have to change your ways. (Patricia (6) 10–18)

The need for effective teamwork is taken for granted in all treatment settings and it is clear from participant comments that this is also the case in the rural setting. Carol acknowledged that nursing staff could not achieve good care on their own and that it was important for the care team to be effective. She explained:

> It’s a team effort. You can’t do it on your own and that’s something that we all need to remember. (Carol (59) 2–4)

Sandra and Pamela targeted the medical staff in relation to their contribution to the effectiveness of the care team. It is clear from their comments that optimal patient outcomes require effective communication between the medical and nursing staff, and when this is lacking it is the patient who suffers. Sandra explains:

> [referring to GPs] it’s not beyond us to ask for help but some of it seems to be beyond them because they don’t know what to do. (Sandra (41) 24–27)

Pamela outlined her irritation with a lack of consistency in care planning when medical staff were unsure of appropriate treatment options.

> It’s mainly to do with pain relief, (16–18) … because we have no permanent doctor, everyone has their own [idea]. (Pamela (19) 16–18; 23–26)

The need for ongoing and relevant professional education was also raised by a number of participants. The nurses experienced frustration when patients were offered sub-therapeutic treatment options because doctors would not listen to the nurses or because the skills of the doctors were perceived to be inadequate. Patricia summarised the need for effective communication and ongoing education in her comments:

> Communication but the thing is that doctors are unwilling to take that step forward and communicate with the nursing staff ‘cause they know what is best’. (Patricia (8) 21–25)

> Not having to suffer and there’s a bit of frustration there ahh with the way the medications are handled, you know, and umm, just the way some of the doctors handle things too. I think they need updating. (Patricia (7) 21–26)

4.2.5 Learning a new role or new way of being

The ‘way of being’ for nurses encompasses the way they feel about their work, their mood, the way they interact with others, and the things that they say and do. This sub-theme examines the effect on rural nurses’ way of being of caring for patients who have died. Many of the nurses in the study discussed having to put on a brave face, the effect of the death of their patients and compassion fatigue, all of which affected their way of being.

For nurses and others, putting on a brave face is the act of suppressing emotions such as fear, anxiety and sadness, and ensuring that the people that the nurses are interacting with are not aware of the way that the nurse is really feeling. In this instance the nurse will smile, may make jokes to make light of a situation and will do everything possible to carry on like normal in their usual role. For some of the nurses this involved physically preparing themselves for the day ahead, where they would literally take a deep breath and hope for the best as they walked through the doors of their ward.

Linda describes the effect of working with patients and families who had a negative outlook as ‘emotionally draining’ particularly when she was trying to be positive:

> It’s the emotional drain. Like, they seem to just, you’ve got to put on the brave face for them. And you’ve got to … try to remain positive for them … particularly people who have got a negative outlook on life [which] I find particularly draining. (Linda (5) 10–18)

Carol acknowledges the unpredictable nature of caring for dying patients and the need to ‘brace yourself’ for what might come:

> It was an up and down … Each day you walked in there and thought okay … you would question is this going to be ongoing, one day would be great, one day would be really sad. Ahh you went with the ups and downs. Yeah, you walk in there … trying to brace yourself for the worst and then you’d have a good day and you’d go phew that was great. You know, celebrate that day, you know and hang on to the good times … The bad days you’d just go okay we just need to … be focused on what needs to be done at that time. (Carol (17) 8–14; 18–26; (18) 1–3)

Carol extended her idea to describe the ‘emotional rollercoaster’ that the unpredictability of caring for someone who is dying could bring:

> You never knew what the day’s gunna bring. And the highs and the lows of the emotional rollercoaster that you are on is just, it’s phenomenal, you just cannot describe it in some way or form. (Carol (37) 1–6)

For Pamela, putting on a brave face was the ‘professional’ thing to do, despite how she was feeling about the deterioration in the condition of her patient, particularly when she considered them a friend. Pamela explained:

> You know how you go through the emotions of grief, you go through the emotions of caring for someone as well (7) 23–26. The patient might be at a different stage too and you’d have to keep that professional … and it’s hard when, especially when you know the people, like they’re your friends some of them (8) 9–15. (Pamela (7) 23–26; (8) 9–15
>
> And it is harder in areas where you do know them. … In the bigger centres, you do have that bit of they’re the patient, you’re the nurse (31) 15–19. And you know them, you know what they were like before and you can see it’s hard like

> to see someone go downhill, which they do. And it’s harder also to see other people seeing someone go downhill and wanting to do something—but not knowing what to do (31) 23–18. (Pamela (31) 15–19; 23–28)

Rhonda also referred to the professional need to put on a brave face:

> The whole time that umm even when I talk about it now I get a lump in my throat. … I guess the professional takes over and you sort of think well you know even though I know the family and ya know, I know all that sort of stuff you have to draw a line, you know I am a professional—this is my work. (Rhonda (15) 14–25)

Despite their best intentions, some participants described their inability to put on a brave face. Nancy shared her story:

> Sometimes they [a relative] will want to share an experience with me and you know you’d always end up in tears. And I give them permission, I said look it’s okay to cry, I said sometimes I think that my anatomy’s wrong, they built my bladder too close to my eyes … you know, make them feel that yes you can cry, it’s okay I cry. (Nancy (25) 9–17)

Cynthia echoed Nancy’s experience:

> When they’re dying and you’ve got these close bonds with people, yeah, I cry with them but I think that’s okay too. I think most of the time most people appreciate that you actually are genuinely feeling for them and that’s not just a professional persona that you’ve got happening. (Cynthia (12) 24–25; (13) 1–7)

Several participants described the profound effect that caring for patients who died in the rural setting had on their practice as a nurse. For many it challenged and changed the way that they worked as a nurse and how they interacted with patients and their families. Participants described the need to be flexible and to approach their work in different ways. Angela explained:

> We … really do the social work, we do the OT [occupational therapy], we do the family support. Some of us do the spiritual part for them … I think they soon realise who can and can’t. (Angela (10) 11–15)

Carol echoed Angela’s need for flexibility, and added that it was very important that this was impressed on new staff:

> And I think as nurses yeah, we, we are learning to do that [be flexible] and we’re in the community, it’s really important that we learn to do that. One of my first orientation situations I do with the new staff is you learn to accept, you try

> to learn to accept and learn to be flexible with what you are dealing with. (Carol (83) 22–6)

Traditionally nurses care for patients and their relatives. They are the care givers rather than the ones being cared for. During the interviews, several participants described their experience of the reverse of this usual situation where the community cared for them. This experience of being cared for resulted in a profound change of mindset for some. Angela summed it up in the following way:

> And allowing our community to care for us. Yeah, as nurses we're not good allowing others to care for us. And our community will often want to care, support. (Angela (20) 9–10; 12–13)

4.3 Phenomenological Theme 2—Learning different ways of relating to patients and families

The second phenomenological theme, 'Learning different ways of relating to patients and families' encompasses the issues of differences in the perceptions of care requirements held by the nurse, the patient and their family. The substance of this theme is provided by strategies to resolve these differences resulting in an effective partnership between the nurse and those for whom they provide care. Considerations of caring for a dying patient and the effect of this on the nurse and the broader health care team are also addressed. The second phenomenological theme will be examined with reference to each of the sub-themes.

The nurse–patient relationship is defined as the essence of professional nursing practice, defining who nurses are and what they are supposed to do (Milton, 2008). As an extension to this concept, professional nursing boundaries have been described as 'the spaces between the nurse's power and the client's vulnerability' (Milton, 2008), and have been presented as a continuum of the nurse being under-involved, helpfully involved and over-involved with their patient. The extremes of the professional nursing barrier continuum describe over-involvement such as sexual misconduct, and under-involvement characterised by disinterest and neglect (with both extremes likely to be detrimental to the nurse and their patient).

Many of the nurses in this study referred to ‘professional barriers’, ‘boundaries’, ‘distance’ and ‘relationships’ when they described their experiences of caring for patients in rural settings. Many referred to what they ‘should’ and ‘should not’ be doing, with many of these conjectures based on the professional norms ingrained in them during their training and/or their work as a nurse. The nurses did not elaborate on what ‘professional boundaries’ or ‘professional relationships’ meant to them, but within the conversation it was as if these terms stood for the same thing for both interviewer and participant. Without defining what the boundaries were, Barbara stated that she stepped over them all the time, and that she had been ‘pulled up for it’ (Barbara (20) 25–27). Lisa also referred to a respectful friendship with her patient, that fell ‘within the boundaries of being the community visiting nurse’ (Lisa (7) 22–26). Again in this instance she did not define what these boundaries were, but rather presumed that as a fellow nurse I knew where they were placed. At the time, and in my role as interviewer, I did not explore this concept in the context of the stories told as I intuitively understood what each participant was describing.

Despite their lack of detail regarding professional boundaries, it was clear that many of the nurses believed that the boundaries of the relationships with their patients blurred between the professional and the personal, and that many of them struggled with the blurred boundaries of the relationships as they progressed along the continuum of care with their patients. These issues form the basis for the first sub-theme of Theme 2, which is defined as struggling with the close relationships in small rural towns.

4.3.1 Struggling with the close relationships in small rural towns

The average number of years that study participants had lived in rural areas was just short of 19 years, with a range of 2–38 years. Despite the considerable experience of most participants as members of rural communities, many of them mentioned the challenges that faced them as a result of their close relationships within communities. Many participants acknowledged that they would frequently meet patients and their families in places such as the local supermarket, at the Post Office, on the street and at social gatherings. Their lack of anonymity caused concern for several participants and was exemplified by Cynthia who said:

> Umm, yeah, it bothers me sometimes that they [patients and families] know where I live … they say, 'oh I saw you out in the garden the other day', and you think oh (Cynthia (9) 15–21)

Despite her obvious concern about her lack of anonymity, Cynthia admitted that she did not try to keep her life away from the hospital a secret, adding:

> Yeah, I don't block people out … especially when you know them from chemo. Chemo's a whole different ball game where there are no barriers and they know about your kids. It is, it took my breath away at different times [that] a couple of them … seem to know a lot more than what they should do (Cynthia (8) 19–24; (9) 3–6).

Several nurses in the study intimated that the close relationships they shared with their patients were based on friendship rather than the professional nurse–patient relationship. It was acknowledged that this influenced how the participants cared for, and felt about the care they provided for their patients. Barbara described this in the following way:

> Everybody knows everybody and … when they come through the hospital doors, it makes it more personal. When people walk through the door they're not seen as [a] UR number [Unit Record Number]… they're known either by their first name, or last name, or family, or yeah, they're friends from friends from friends. (Barbara (2) 15–25).

Lisa described the initial effect for her when she was caring for someone she knew:

> probably in the beginning you're a bit anxious because you're dealing with someone that you know. (Lisa (6) 3–6)

Tina acknowledged that patients are often friends and added that the relationships can often be closer than that:

> [n]ot only are you probably related to the client … you definitely know the client or the client's family or are friends with the client's family or you're friends with a friend of the family and they're asking questions. (Tina (11) 20–26).

Cheryl expanded on the concept of close relationships with patients and described the effect that this would have on the care provided by the local staff:

> When it's one of your own [a friend or colleague] you become very defensive and very protective of them and in that sense I think that's one of the areas that isn't well looked at. You know, when it comes to one of our own, 'cause we do close ranks'. (Cheryl (27) 7–13)

4.3.2 Learning to live with blurred relationship boundaries

Several nurses described the emotional effect that blurred relationship boundaries had on them at times. Barbara detailed an emotional interaction with her patient in the hospital where she worked:

> He was crying, he was grateful, he gave me a hug and I hugged him. You know, like, we're not supposed to be doing that as nurses but hey, stuff that. Let me be a nurse and I hug. You know, like I hug, it gives people comfort and you're together and I mean, and I said to Graham, I've got to go now before I bloody start bawling my eyes out here. It gets emotional for me too. (Barbara (14) 6–16)

For Patricia, the emotional interaction took place out of the hospital environment and in the community:

> You've got to have that empathy there and even share it if you do see them in the street, you know, like one day I saw this person and she just looked at me, collapsed into tears and gave me a cuddle you know. What are you supposed to do? You can't say 'oh, no, don't cuddle me' (laughter) 'cause that's just not done but there's a real fine line there, a real fine line, … without crossing that barrier. (Patricia (12) 2–22)

Several participants agreed that the blurring of boundaries was even more noticeable when acquaintances or friends became relatives, and when they were ill and needed to be cared for. Carol described her experience when her patient was related to a family member by marriage:

> it became a little bit personally touching … because I had family member through … marriage … that was actually related to this person. So that [connection] brought another dimension personally to me because I'd go to family gathering and … this person would actually come up … and they knew my name and things like that. Being in a small rural area that's what actually happened. (Carol (4) 15–21).

Carol also reflected on how the relationships she had with her patients and their families in the community affected her own family and in particular her children. The children were either irritated by having to wait for their mother to talk to the people she met in the community, or were angry that they could not have uninterrupted time out with their mother. The blurred boundaries affected more than just the nurse:

> My kids say to me, 'Oh God Mum, I'm not coming shoppin' with you ever again because all you do is get caught up' (laughter). Instead of taking an hour to do the shopping, it takes three hours because you pull up to have a chat and my girls actually are old enough now to understand a little bit but they still get angry because Mum can't be Mum. (Carol (53) 12–23)

In contrast to the sometimes frustrating effect described by Carol, Lisa outlined the special relationship that she had with her patient. She acknowledged that it overstepped the accepted boundaries of the professional relationship; however, she could only see positive outcomes for both her and her patient:

> I guess I could maintain a detachment to some degree as I think most nurses are taught to do … but I expressed my emotions with her much more and was sad when she was sad … and felt what she was feeling. Umm, as in a relationship. And I think vice a versa too. She was able to express herself. (Lisa (8) 24–27; (9) 1–7)

4.3.3 Learning how to involve relatives in the nurse–patient relationship

Caring is a fundamental component of the relationship between nurses and their patients. There is general agreement that nurses and their patients have unique and at times differing perspectives on what constitutes optimal levels of care, with nurses focusing on the importance of psychosocial aspects of care, and patients assigning higher value to the technical skills and professional competence of the nurse (Patistea & Siamanta, 1999). There are clearly differences between nurses’ and patients’ perspectives on care, the effects of which will be explored further in this study.

Most participants acknowledged that their experience of caring for their patients was affected by the relationships that the patient and the members of the care team had with the patient’s relatives. For many of the participants this involved learning how to involve the relatives in the patient’s care, and for some they were conscious that this meant prioritising the needs of the patient over the needs of the family and the team.

Participants agreed that a positive relationship between staff and relatives made the care of the patient much easier in the long run. For several participants the relationships between the care team and relatives could be soured by relatives’ unmet expectations in the care of their loved one. The participants described facets of their relationships with patient’s relatives.

Lisa coined the term ‘difficult family’ to describe relatives who were not happy with the care being provided to the patient, a concept echoed by Donna who stressed the need to understand how to communicate effectively with family members:

> I find it [taxing] when we’ve got difficult family (laughter). Not so much with family that need, and really want help and whatever. I find it when they aren’t happy with what you’re providing when they, that their expectations might be way out of … what you can provide. (Lisa (19) 4–23)

> Just show you how to communicate with the rellies and that. I mean, that’s difficult too, depending on the rellies because as you know, some of them can be a bit difficult no matter what you do. (Donna (18) 19–23)

For Carol, a family’s issue of unmet expectations provided a source of tension between them and the care team:

> being where we live and [given] what we do and what resources we have got [it] can be difficult because the family want everything and we’ve only got this much—that’s very hard … sometimes. (Carol (81) 19–2)

Cynthia found interactions with unhappy family members in the community setting very confronting:

> In the community, in their home, their dynamics and their personalities can be full on in your face and I felt really defenceless. The hospital’s really umm, four walls, very secure, very safe. (Cynthia (21) 12–17)

For Cynthia, the effect of a negative relationship with the relatives of her patient also extended to her life outside of the hospital. She explained:

> So I walked in there and started the spiel and went through a palliative [explanation] and next thing the daughter’s irate and hates my guts and all I could find out was she works at Woollies so every time you go through Woollies you think oh [16–21] … bloody hell, you know, you’re waiting for someone to bear down and really rip it into you. (Cynthia (10) 7–14)

While acknowledging that a strained relationship with relatives can make the care of the patient difficult, more participants explained that they had experienced a very positive relationship with the relatives of their patient, and for many their focus shifted from the patient to the relatives as the patient came closer to death. Donna acknowledged the suffering of the relatives along with the patient:

> ‘Cause, as I said it’s not them [patients], they might be suffering but it’s the rellies that are suffering, too. (Donna (17) 13–15)

Rhonda acknowledged that there was a point in care where her focus moved from the patient to the family:

> I don’t know why this happens but this happens for me that umm the patient is your total focus for a long time and in the last few days you seem to divide your focus to the family as well. (Rhonda (22) 22–26)

Rhonda revealed that although she had done this for some time, it was something that she had not been conscious of. She explained further:

> You seem to be concentrating on what, how they’re going to cope afterwards. So … you know even though she’s becoming, her liver disease is progressing, she’s becoming more unresponsive she’s going into a semi-comatose all that sort of stuff so it’s just general nursing care then you’ve, you’re really

> concentrating on what, what those kids and the Mum and sister are going through. So I guess that that, I, I didn't realise I did it for a long time but that's, that's what I do. And I don't know why I do it but umm I, I guess I recognise a need in them. (Rhonda (23) 2–18)

Lisa explained that if the family was well supported they were often better able to support the patient:

> Yeah, … sometimes we're more involved with the families than we are with the patient. Our job is to support the family to support the patient. I might know the family more in the [community], being more my age than an elderly patient, so yeah, families, are really big criteria for what I do. (Lisa (18) 11–20)

Cynthia acknowledged that the issue of boundaries also applied to the relationship between the nurse and the relatives:

> I try really hard to make sure I don't impose anything on them or push my own ideas or become heavily involved. You sort of stand back when it's the family group and that but you're there if that, if you're needed. You know, you just know that where you stand in the, in the circle of things and you try really hard not to push those boundaries. (Cynthia (13) 15–21; 27–28; (14) 1–3)

Barbara also described the effect of her close relationship with the relatives of a patient and how this triggered concerns for her about professional boundaries. She described her experience:

> His family made a really big impression on me … it was a huge family and they would come and ask for me to look after Dad and they were forever hugging and oh, it was like, oh, God here we go again. And, you know, it was okay and then they'd cry and they'd get me all emotional. And it's like, oh, stop it, you know. Because I'd fall to pieces too … as a nurse you're supposed to be the strong one because you're supposed to not get involved, you're supposed to not get involved with your patients, you're supposed to have that distance because otherwise you're going to overstep your professional boundary. And this is what they say you are not supposed to do. (Barbara (19) 23–25; (20) 1–19)

4.3.4 Knowing death in a relationship

The end of a relationship caused by the death of a person may be difficult and even painful. Closure in any relationship means finality, and letting go of what once was (Jevon, 2010). Finding closure in the relationship that the nurse has with a patient implies a complete acceptance of what has happened and the ability to move on to a life without the person who has passed away. The participants in this study experienced the death of patients over and over again, and many of them referred to the need to find closure, or to let go of the person who had died. In highlighting the need for closure nurses discussed their need to be comfortable that they had done all they could for the patient; their need to grieve the loss of the patient; the strategies they have developed to move on and the rituals that they performed to honour the person who had died.

Several study participants described the process of saying goodbye to their patient before they died. Sandra described the very frank and heartfelt conversation that she had with a patient who she knew well and who was close to death:

> Leading up to that I had, umm, I had seen the deterioration in him and I thought, ohh, I said, I'll say goodbye [name deleted], but you might be still here when I get back but don't, you let go when you're ready, you can go whenever you're ready. I was waiting for that call [that the patient had died] but it didn't come. (Sandra (10) 16–22; (11) 1–2)

Pamela described the inner battle she experienced when wanting to ensure that patients are pain free but not feel as though she was hastening their death. She explained her experience:

> It was hard but sometimes it was a relief. Umm, yeah, because they'd gotten so, they were so sick and you knew that no matter how much pain relief you give them, is it really, you'd go through that, you're a nurse; you go through, you don't want to knock 'em off but you want them to be pain free and you know that they're not lasting that long anyway. (Pamela (9) 20–26; (10) 1–3)

Donna described the death of a patient as 'relief', and for her this relief was closure for the patient and herself. She reflected:

> [on death] I think probably relief more than anything. 'Cause there's nothing worse than watching them for days and days or weeks sometimes you know. (Donna (3) 23–26)

Lisa described how her state of mind reflected that of a patient as she approached her death. She recalled:

> I don't think I became any more emotional just a bit sad that she was going to die but happy that she was happy. (Lisa (12) 9–12)

Several participants recalled their responses to the death of a patient. These varied from an emotional response to almost an indifference to the fact that patients die. Donna's response implied indifference. She explained:

> I think as nurses you just get used to people dying and if it's not of cancer, it's something else. I know, that's terrible to say but you just get used to it. And, I suppose, we're not hardened but it's just a fact of life, I think. (Donna (11) 18–23)

In contrast Lisa and Michelle described their emotional responses to the death of patients. For Lisa, tears could mean closure.

> If you're quite emotional about it you'll have a cry and you're usually okay then. And that you've closed—you must have closure on some of these things otherwise you wouldn't be able to keep going, I don't think. (Lisa (24) 5–8; 10–14)

Michelle supported the need for an emotional response to the death of a patient:

> It's hard because me personally, I'm a sook (laughter). I really, I am. I'm a sook but I mean it's death. Death is going to come to us all so it's just, you're just emotionally attached I suppose. (Michelle (8) 1–5)

Most of the participants described the rituals that they performed following the death of a patient. Some described their experiences of attending funerals, and their decisions not to attend funerals, and others described other practices that they did to find closure with the death of a patient. Linda explained that initially she was attending a lot of funerals:

> So when I first started out I was going to quite a few funerals and that was a form of closure for me. (Linda (10) 13–15)

Angela also saw value in attending funerals, and explained that if necessary she would do what she could to help her work colleagues attend funerals of patients that were special to them. She said:

> For me, … if I possibly can it's important to go to the funerals, 'specially if I've got a good relationship going with them. … I would obviously, if someone's [another colleague's] got a real special relationship with someone, and I see it's more of a, not so much saying more special, but it's different from my relationship and my relationship isn't that special I will make sure that they have an offer, the ability to go by offering to work for them. (Angela (11) 12–23)

For Lisa, the risk of committing to the ritual of attending funerals meant that she could be attending funerals all the time in her small community. She explained:

> Sometimes living in small rural areas, I know a lot of the people and … often I am going to their funerals as well. … and it could be a relative, ‘cause I’m related to every man and his dog. So sometimes I’ve had three people die and two of them might be relatives and I’ve had to say no I can’t go to that funeral. (Lisa (16) 20–29; (17) 1)

Robin also attended funerals of the patients she considered to be ‘special’. In many instances she had known these patients for many years and had her own ritual to ensure she could say goodbye without imposing on the family. She reflected through tears:

> I go to other funerals with some regular special clients, I shouldn’t say special, they’re all special, but some of the long-term ones that do come in under the radar a bit I do make a point for my own sense of closure, that I do go to the funerals and it’s important for me I just sort of slip in the back and have a wee goodbye and then slip out again. (Robin (14) 4–14)

Sandra used a different approach to the ritual of remembering a special patient who had died. This nurse regularly attended the Queensland Cancer Council *Relay for Life* and used the candle-lighting ceremony to remember him. She explained:

> I thought he was a great man, he was a wonderful person and every time I go to *Relay for Life* I always light him up (Sandra (11) 10-11.

Other participants reflected on the added challenges of finding closure in a rural community where you would often meet or see the relatives of the patient who had died. For many, this made the task of closure more difficult but for others it was a positive experience. Cynthia described the inner turmoil that she experienced when asked by relatives to continue the friendship developed in the hospital while caring for their loved one. She was conscious of the issue of professional boundaries that have been described earlier. She explained:

> the instances in the community when you become really good friends with people as well and … the invitation would come to their house whenever is open and I haven’t taken it up yet like [name deleted] has died now and feel

> guilty that I haven't been to their house because of the, the thing in the back of your head … it's hard on us too because ethically you're not supposed to be friends with people but we live in a small community. (Cynthia (14) 23–25; (15) 7–11; (15) 15–18)

In contrast, Robin saw the opportunity of meeting relatives in the community as a pleasant experience. She reflected:

> [when you see someone in the community] yeah, it brings it all back. Yeah, it's like a little story book every time you see someone. You'll see them in the community and then you'll, yeah, you understand the history that they've shared. (Robin (19) 1–7)

Cynthia also reflected on seeing family members after the death of a patient, but for her there was some guilt and no closure as she experienced sadness for the surviving children each time. She explained:

> and that's where you, like with [name deleted], I didn't mean to but like [name deleted]'s children, you see them out at school with our kids and yeah, it's a reminder every single day that you're there, yeah, you know, these kids have lost their Mum. (Cynthia (6) 4–11)

4.4 Phenomenological Theme 3—Seeking to achieve a work–life balance

The third phenomenological theme, 'Seeking to achieve a work–life balance' encompasses the lessons that the nurses in this study reported as a result of caring for patients and their families. Although study participants repeatedly described the sadness and challenges they had experienced during this process, all had also found positive experiences and lessons to be learnt.

The first three sub-themes detail the privilege of caring for someone who is dying, the benefits of the close relationships experienced by the nurses, and learning personal boundaries while working through team issues. Through their words and observations the participants share their experiences and reflect on changes they have made to their practice as a result of those experiences.

The final sub-theme is more tangible than the others. It details the experiences of the nurses in relation to formal and informal debriefing. The last sub-theme details the outcomes for nurses who do not learn from their experiences of caring for the dying patient, and the results of this for themself and the broader team.

4.4.1 Finding ways to care for the self (identifying the privilege of caring for someone who is dying)

Compassion fatigue occurs when nurses are placed under continuous stress from meeting the often overwhelming needs of patients and their families (Stamm, 2002). This syndrome may affect the nurse’s job satisfaction and emotional and physical health, and also has an effect on the broader workplace environment by decreasing productivity and increasing turnover (Lombardo & Eyre, 2011). Compassion fatigue, which incorporates the two concepts of secondary traumatic stress and burnout, may affect nurses who personally experience the pain of their patients and their families through the process of providing empathetic support (Lombardo & Eyre, 2011). As outlined in earlier sections of this chapter, participants in the study described their own emotional pain resulting from caring for dying patients and their families. Although participants did not label their experience ‘compassion fatigue’, their descriptions of experiences read like a symptom list of the condition. For example, Carol’s story has a raw and sensory effect:

> I think I had four deaths within a short period of time and one of ‘em I actually found dead in the home and she was sadly on her own and things like that. And the recognition [that] something wasn’t quite right was the fact that I woke up in the middle of the night absolutely gasping for breath, and I could smell the death … that was definitely a sign of yeah you just need to have a bit of a chat. (Carol (73) 7–20)

Rhonda acknowledged that she got to a point where she could not take any more loss, a realisation gained when she experienced her emotional response unexpectedly getting the better of her:

> At the time I had a little old man that I didn't even like die one day and my grandfather had died the week before and for some reason I cried and cried and cried about this little old man who I didn't even like (laughter). And I thought you know that was because I didn't cope with Grandad and you know I think that umm, you, you have to know that you know. That was a couple of years into nursing so I think I learnt from that [experience] that you know you need to deal with what's going on now before you move onto the next thing and if you don't it will rear its ugly head again, you know. (Rhonda (48) 9–24)

Like Rhonda, Barbara also reached the point when she was aware that she was unable to do her job because of the emotional turmoil she experienced:

> I saw her lying there and I just bawled. I just cried, I just walked out and I said I can't, please, I cannot look after this patient. Not today, I just can't do, I just went into one of the other rooms and just bawled my eyes out and I said look, I don't know whether this is like an after effect from my sister's passing. (26–28) … was totally unrelated but all of a sudden it just, I don't know, it just hit me. Like bang and it was like out of control, I just couldn't control it, I just walked out. 'Cause I was in here, and I saw the whole family was there and I started to cry and I'm in uniform and like whoa, this is not good. (Barbara (25) 13–22; 26-28; (26) 1–7)

Despite understanding the theory of how to cope, Angela found that she was unable to do it in practice:

> But I do remember being taught that you must stand aside and I just found I couldn't. Yes, I do cry, I do get emotionally involved, that is the cost. (Angela (7) 17–20)

Several of the participants described their tactics to avoid secondary traumatic stress and the burnout that they recognised could easily affect them as a result of their work. Sandra acknowledged the benefits of self-awareness:

> you've got to keep coming back every single day to work as well and you have to know when your burnout level is and what your family at home is—all of the things that happen. (Sandra (36) 4–9)

Cynthia described a process of using emotional barriers to prevent burnout:

> Personally, you try really hard to put up barriers so that it doesn't affect you and erode away your emotions too much otherwise you'll just burn out. (Cynthia (7) 3–7)

Lisa agreed with Cynthia's approach but acknowledged that such barriers could at times be detrimental:

> You can do so much and you will be supporting them and you do like them but I'm not too sure but I think it comes over years being that way with our patients, clients. That you build up, sometimes detrimentally, you build up a barrier but I think if you're dealing within the community you change your whole perspective 'cause they're community members. … [the barrier] actually protects you from, because, your patients die. So it protects you that little bit. (Lisa (9) 23–27; (10) 1–10; 13–16)

In contrast to Cynthia and Lisa, Patricia recommends a more practical approach to release work-related stress:

> And I try to kind of go and do something after the shift that's actually going to be a kind of a stress release like I have a massage, go have your hair done, just something to take the edge off. (Patricia (13) 21–27)

Most of the nurses in this study referred to the privilege of caring for a dying patient, and supporting their family through the process. Several of the nurses referred to the experience as making them 'feel special' and that it was 'an honour' to be involved. During interviews there was a noticeable shift in the tone and atmosphere of the discussion when participants began to describe these experiences. In most cases they went from being animated, to being thoughtful and quiet as they described their experience. For some participants there were tears, but a noticeable calmness, not distress as there had been when discussing the emotional pain that they experienced at times.

Several study participants explained that the relationship that they had developed with a patient helped them to support the patient to the end of their life. Sandra explained this in the following way:

> I felt a privilege. I felt an honour and a privilege to be there with them for the time of their last. I felt probably in a position of I think I can make this a little bit easier for them asking them questions that other people maybe not being able to ask. Asking them what they wanted as in a normal conversation instead of [the patient] thinking it's a stranger asking me this. (Sandra (18) 2–11)

Sandra added the following reflection:

> And I felt, I felt yeah, it was good to be there and to know that they looked forward to me coming back on my shift. (Sandra (18) 16–19)

Rhonda and Robin both felt that their special experience was related to being with a patient to the end of their life's journey. Robin explained:

> I think it's always a privilege to help them through to that end of their journey. (Robin (16) 2–4)

Rhonda described the end-of-life period as the 'worst part of their life'; despite this she was able to find a positive in the experience for herself:

> It feels a bit special and it feels … you're treating someone … when they're at the worst part of their life. So that's a real privilege too. (Rhonda (8) 18–21; (9) 1)

For Carol and Lisa, another dimension was added to the experience for them as they cared for patients in their own homes. Again, each nurse felt it was a privilege to be with the patient in the end stage of their life; however, they had added satisfaction that they were able to support the patient to die where they wished, rather than being forced to go to hospital. The nurses explained:

> I keep saying to people it's a privilege to go into people's homes and it's not what we do, it's just being there for them, it's just the support, don't expect to make miracles just be there, just be yourself and accept 'em, realise this is a normal household and you have a privilege of being in these people's home. (Carol (36) 8–17)

> You went along feeling ahh, that you were actually helping her stay at home or become a different person before she died. You know, like to actually address her, given her health needs or you were able to actually get her eating better or whatever and yes, it's a fulfilling thing. (Lisa (11) 1–12)

A sense of satisfaction is clear in the descriptions provided by each of these study participants. What they say and how they say it shows that each was confident that they had done as much as they could to ensure that the patient experienced a good death. There is a sense that the nurses provided confident and calm reassurance as they supported their patient and family to the end of the patient's life.

4.4.2 Accepting the benefits of close relationships

As with the previous sub-theme, many of the study participants reached a point in their interview where they became quiet and reflective, and spoke warmly about the positive experience of the close relationships they had had with their patients and their families. In most instances these were the same patients and families who the nurses had previously described as ‘difficult’, ‘draining’ and ‘demanding’.

Several of the nurses described the blurred relationship boundaries with their patients as being positive features of their work, and their broader relationships with community members. Pamela describes the advantages that she saw in closer relationships:

> You are part of the community and that can make it easier hey, ‘cause people will say to you, ‘how’s ....?’ And we would have to say you know, you can go see them today. (Pamela (4) 21–25)

She added:

> And with some of the patients, they’d say, ‘if you see so-and-so, you can tell them not to see me today or come and see me today’. Which is an advantage. (Pamela (5) 4–8)

It is evident from the information provided by the participants that some are more comfortable than others with the ways that they find themselves relating with their patients and their families in small rural communities. Several nurses described anxiety and the tangible emotional effect of caring for patients whom they considered friends and who were in some instances family. Participants stated that they had clearly lost their privacy and anonymity when caring for some members of the community, and that although on reflection this made them feel a little uncomfortable; they did not consciously try to distance themselves from their patients in light of this. All participants agreed that their relationship with patients extended to include a wider circle of the patient’s relatives and friends. Despite the emotional effects described by the nurses, most considered the close relationships with their patients to be positive, for both the nurse and the patient. Several participants stated that their relationships with their patients overstepped the accepted boundaries of professional relationships, implying that this was in some way not the right thing to do, but in practice they continued to do it.

Nurses reflected on both the relationships they had enjoyed with their patients prior to their deaths and on the ongoing contact that they had with family members through living and working in the same community. For some participants the relationships they enjoyed with families made them feel more a part of the community that they lived in, and reassured them that they were doing their job well. Robin explained this concept:

> Well in this small community it [caring for someone who has died] makes you feel more part of the community, well it does for me … [I] go for walks in the morning and I'll pass someone's house … [where] I'd been to deal with the palliatives and, yeah, generally I feel that I can effectively do my job. (Robin (17) 8–20)

For some participants their experience of the ongoing relationship with relatives after the death of the patient varied along the spectrum from warmth to avoidance. Robin experienced both extremes, which she described in detail:

> I remember one lady in particular, she always seemed to look away a little like she's, you know, she remembers the difficult time they had at that end stage with the husband. I remember one in particular—and there are some that come up and give you a hug and you know, they always make you feel that special, that you'd shared that time with them. (Robin (17) 8–20)

Lisa acknowledged that everyone is different in the way that they recover from the loss of a loved one and that this is reflected in their interactions with nurses when they see them in the community or at the hospital for other reasons. She explained:

> Yeah, it can be an ongoing thing. There is no particular time for grieving; some people are back on their feet quickly and well seem to be. And you know, seem to move on. Other people just don't ever. So, you know, I think, that's … in just being open. They usually come back for other services, to this particular area. But if you know, you actually, you're going to bump into them somewhere around. You can usually tell when you just, 'how you going?' and they cry. (Lisa (21) 9–26; (22) 1)

Lisa also reflected on the effect of multiple losses for some people and how the close relationship that the nurse enjoys with others may help to support them through such difficult times. In particular Lisa talked about the staff working at the hospital who were also members of the local community:

> They're all locals, most of the people that work here … and a lot of people die. I mean, I had one of my team had lost three major people in her life and her husband very unwell all in a matter of two months. And it was like, how do we deal with this? And just the support, she didn't stop coming to work; she wanted to come to work for that support. (Lisa (25) 17–19; 25–26; (26) 1–8)

Angela's husband was a religious minister in the community where she lived. She described the positive effects from the relationships that she developed in the hospital when caring for dying patients and their families, and how this extended and enhanced her role as a minister's wife in the local community. She explained:

> My husband's the [name deleted] clergyman so we actually have the ongoing pastoral care of the families afterwards so it's an, yeah, from that point of view, it's probably a conglomerate but it really works for us, for us two it works really well, that hospital/community role. As a clergy wife as well, as well as the role as a nurse. (Angela (4) 11–19)

Cynthia and Michelle both saw positive benefits from the close relationships they enjoyed with their patients and their families. For Michelle, the satisfaction that she was able to keep the patient at home was a benefit that arose from developing strong relationships of trust with patients and families:

> I feel probably with my people that are on palliative, you do become a lot closer to them because you're there you know. The family ring you and whenever they want to ring you to talk, you're there with them the whole time. Umm, it's crazy to say it but it's like a, I suppose, a satisfaction, you keep them at home. (Michelle (7) 5–13)

Like Michelle, Cynthia got involved with her patients and their families, despite her best efforts not too, but on reflection she was able to see the great benefits that this had brought to her both professionally and personally. Cynthia explained:

> You try really hard not to get too involved but you do, and they … but I find that each and every one of them have taught me something that makes me I hope a better person and a better nurse for the next person. (Cynthia (8) 7–13)

4.4.3 Learning personal boundaries while working through team issues

In the same way that there are professional boundaries between nursing staff and their patients and their families, boundaries also exist between the members of the health care team in rural areas. Participants stressed the need for an effective partnership approach between the members of the care team, and to achieve this for many of the participants the boundaries between professions were blurred. This may be due in part to the multi-skilled ‘jack of all trades’ (Hegney, 1996) approach that is required in rural nursing practice, which may encompass some areas of responsibility of other professions such as those from allied health in the absence of specialist staff.

All of the nurses interviewed had worked in rural areas and in most instances in the same rural area for many years. They described teams of core staff where members were very comfortable with each other and able to pre-empt each other’s actions. Some participants acknowledged that such familiarity could lead to contempt in some settings, and that this was frequently exacerbated when combined with perceived familiarity with and presumption of patient needs.

As outlined above, the criticism relating to team effectiveness was not only directed towards those situations where new team members affected the team dynamic. Participants noted that team effectiveness was also reduced by other factors including members taking their knowledge of the patient for granted and therefore not checking the current situation prior to making a decision about care, poor teamwork between existing team members, the need for ongoing education for rural staff to ensure treatment options are current and effective, and a lack of consistency in treatment approaches.

Patricia described the frustration she experienced when staff took their knowledge of a patient for granted and did not consider the current situation when planning patient care:

> They [the nurses] know them so well and when people get stuck with something when they know they are going to die, it could go totally out the window and that can be hard for everybody especially nursing because you think you're doing the right thing and then you're told you're not, so you have to change your ways. (Patricia (6) 10–18)

The need for effective teamwork is taken for granted in all treatment settings and it is clear from participant comments that this is also the case in the rural setting. Carol acknowledged that nursing staff could not achieve good care on their own and that it was important for the care team to be effective. She explained:

> It's a team effort. You can't do it on your own and that's something that we all need to remember. (Carol (59) 2–4)

Sandra and Pamela targeted the medical staff in relation to their contribution to the effectiveness of the care team. It is clear from their comments that optimal patient outcomes require effective communication between the medical and nursing staff, and when this is lacking it is the patient who suffers. Sandra explains:

> [referring to GPs] it's not beyond us to ask for help but some of it seems to be beyond them because they don't know what to do. (Sandra (41) 24–27)

Pamela outlined her irritation with a lack of consistency in care planning when the medical staff were unsure of appropriate treatment options:

> It's mainly to do with pain relief, (16–18) … because we have no permanent doctor, everyone has their own [idea]. (Pamela (19) 16–18; 23–26)

The need for ongoing and relevant professional education was also raised by a number of participants. The nurses experienced frustration when patients were offered sub-therapeutic treatment options because doctors would not listen to the nurses or because the skills of the doctors were perceived to be inadequate. Patricia summarised the need for effective communication and ongoing education in her comments:

> Communication but the thing is that doctors are unwilling to take that step forward and communicate with the nursing staff ‘cause they know what is best. (Patricia (8) 21–25)

> Not having to suffer and there’s a bit of frustration there ahh with the way the medications are handled, you know, and umm, just the way some of the doctors handle things too. I think they need updating. (Patricia (7) 21–26)

Some of the study participants discussed their experiences with other staff not coping in the rural setting and choosing to leave. Some discussed what they had seen in colleagues and others related their own experiences and the effects of these experiences.

The coping mechanisms of nurses or the lack of such mechanisms were seen by some participants as a cause for their departure from the rural setting. Cheryl explained:

> Yeah, their own coping mechanisms aren’t there and they rely on being propped up and so I think myself lucky that I grew up and was brought up in the age where you know, deal with it or leave. (Cheryl (19) 8–13)

In contrast, Carol and Lisa saw the need for greater support for the nurses from the staff team, rather than expecting them to find the strength to cope within themselves. Carol stated:

> The desperation of, you know, I want to take them home, I want to wrap them up, I want to help, yeah, 24/7 and unfortunately that’s where we lose our nurses. (Carol (30) 12–16)

Lisa believed that there was a clear need for nurses to work together to ensure that they felt supported. She explained:

> We should be working together and you know but … it’s all this … frustrating you know and I think if only we could say let’s just work together. (Lisa (33) 20–28)

Sandra mirrored Lisa and Carol’s thoughts be describing her own experience of working in a supportive environment. She reflected:

> I’ve always felt safe in any situation in that ward. And if you haven’t got it covered, they’ll cover it before you think about how am I going to get that. You know, and that’s what I love about it, it’s just there all the time. It’s great support. (Sandra (39) 2–3; 7–12)

For Cynthia the key stressor in her decision to leave the rural setting was the number of deaths she experienced in a short period of time. Cynthia recalled:

> In the seven months with Blue Care, I think I had 27 deaths and by the end of it, I'd just had enough (laughter). I was over it. (Cynthia (20) 19–23)

For Linda and Carol a key stressor in their consideration of leaving the rural setting was that of limited resourcing. Linda explained:

> It's the sense of isolation and that everything has to be in, like a Brisbane location and it's only offered once. You know Queensland's a huge state and, … I'm sure up as far as Townsville, also Townsville would be able to offer independent to Brisbane … things need to be offered more than once. Rural nurses are intelligent nurses as well…Online education is good, but you don't always get the time to do it. (Linda (18) 5–14; (19) 14–15)

Carol agreed that the limited resourcing in rural areas was a key source of frustration for staff. She said:

> The hardest thing is I found, is we're a rural community, our resources are very limited and that's quite frustrating—physical and people resources. (Carol (27) 3–6; 9)

4.4.4 Sharing and learning from the experiences in a rural context

Debriefing is the process of telling a story about an experience. The story is told by the people who were involved in it, and is told complete with the facts, experiences and feelings (Wickers, 2010). The process of debriefing invites feedback from the others involved and from those who are prepared to listen, and it is important that this feedback is given without judgement or criticism.

Debriefing may happen in a formal or informal way. Formal debriefing may involve the use of an external team or facilitator who will manage and direct the conversation between participants. An informal debriefing may simply involve a conversation between nurses during patient handover or during a work break such as morning tea.

Many participants in this study referred to the process of debriefing when caring for a dying patient or following their death. Although some did not use the term ‘debriefing’, it was this process that they were describing as a way to learn and move on from the difficult experiences they had had. At times the nurses described the support they received from insightful colleagues who seemed to know just what to say or do when they were having a difficult time. Participants described the benefits of the ‘tearoom debrief’, an informal process that has been a feature of nursing for many generations. Others were critical of a more formal debriefing process, while some colleagues spoke of the benefits that they perceived would be gained from a formal arrangement.

Several participants reflected on their positive experiences of working with colleagues and managers who were in tune with the emotional needs of others. Lisa explained:

> It’s very open team and everyone can pick up if someone’s upset and have a lot of informal discussions and … about lots of things and work related, have jokes, humour … I’m pretty open about emotions and so if I’m upset they’ll know and they’ll say something so … I think they’re very in tune. (Lisa (24) 25–27; (25) 1–4; (26) 18–22)

Cynthia described a similar situation of supportive colleagues, and the benefits of talking through issues with them:

> We all support each other pretty well. So if you’re having a really crap day on the day, you can say ohh, I’m having a really crap day, you know. And you can blah, once you do that, for me it’s over, you know, so then the next, I always look forward to coming to work regardless whether it’s been an absolute bummer day, the next day’s a new day. (Cynthia (33) 20–29; (34) 1–2)

Julie agreed with Cynthia. She explained:

> Oh, because a lot of the girls that work here for so long together, we all know each other so I suppose whether we realise it or not we’re probably debriefing. (Julie (14) 16–19)

Sandra also stressed the need for support from the work team. She said:

> It's definitely the team, definitely the team … They all have compassion; they all know where you are at with what you're dealing with day after day after day. (Sandra (26) 20–21; (27) 13–16)

Carol felt that this form of debriefing was developed by previous generations of nurses:

> Debriefing is something that the old nurses, you know, I think it was the beauty of the nurses' quarters to lie on somebody's bed and just have a chat. You did it and even nurses would hang around in the lounge rooms and dining rooms you know and you would do it. (Carol (68) 4–11)

Tammy echoed the thoughts of Carol. She reflected:

> [debriefing is] probably more of an informal thing. I think that's the way we were brought up, weren't we? Back in our training days, yeah, we'd go to morning tea or afternoon tea or lunch and have a big bitch … (laughter). (Tammy (10) 19; (11) 12–16)

Robin believed that discussions such as these would help with closure for the staff. She said:

> Just to have a couple of the staff members that were involved with the particular client, to have a debrief and an offload wobbly would be beneficial to do umm, you know, close that chapter and move one. (Robin (47) 11–17)

Linda reflected on the qualities that she saw in her manager that was supportive to the staff and said:

> I think approachability and that open door is always helpful. (Linda (20) 8–10)

Sandra also highlighted the need for supportive managers. She explained:

> I think our nurse unit manager and her superiors know the situation before we step in to it. I think they're aware, they mightn't know the closeness or the bonding or the outside things, they know who's sick, they know who is involved and they are there for them … [our manager] is one of those very, very special people who just takes it all on board, fixes it when she can, listens when she can't. (Sandra (38) 17–24; (40) 6–9)

Other participants discussed the value of finding someone, not necessarily a work colleague, with whom to talk through issues. Rhonda gave this example:

> When I have other nurses that aren't coping on the ward I quite often will say to them, find someone in your life that loves you unconditionally that you can talk

> to about stuff and it doesn’t have to be naming names but if you can have an outlet that will make you sleep better at night. (Rhonda (19) 13–24)

Lisa agreed that someone to share your feelings with at home was helpful:

> I think your home structure. Like, if I’m really upset over someone, I’ll go home and talk about it. You know, that’s whether he likes it or not. But he’s fine, that’s our coping thing. (Lisa (23) 23–27)

Several participants raised the value of the informal group debrief, something that many of them described as the ‘tearoom debrief’. Linda explained:

> It’s usually a tearoom debrief and if people want to debrief than they seek out relevant people. But generally it’s just that they might have a cup of tea or something, talk it over with whoever they’ve been working with. (Linda (13) 14–20)

Donna added in her interview:

> Yeah, it’s not like a formal debrief. It’s just you know, like a chat as you say in the tearoom or at the desk or whatever. Yeah, but I think you know, most nurses cope with it pretty well. ‘Cause we talk about the patients when we’re at morning or afternoon tea (laughter). (Donna (10) 22–24; (12) 11–14)

Questions about the process of formal debriefing for the nurses brought mixed and at times passionate responses. Barbara was adamant that something more could be done where she worked. She stated:

> No, I find debriefing in this hospital is piss-poor. That’s the only word I can say for it. It’s piss-poor. (Barbara (31) 9–10)

Lisa also believed that a more formal approach could be taken to the debriefing process where she worked. She revealed:

> No, it’s an informal [discussion]. And we’ve actually developed quite a good rapport. It could be more formal, we probably could develop that a bit further but … I think what happens is that we just don’t debrief enough … I think we skirt around it at debriefing and feel that we’ve debriefed but I don’t think we do. Ahh, we don’t, nurses do not do good peer support. (Lisa (23) 8–12; (34) 12–13; (35) 5–10)

Patricia stated that she had requested formal debriefing previously and explained the reasons why:

> I have, aah, suggested that, I actually asked last time whether there was a counsellor available for that debriefing because I’m quite sure that sometimes

> we just need a little bit more than what our other team members can give us … So we can all have input and you hear each other’s inputs. We understand where everyone is coming from. (Patricia (10) 3–9; (11) 3–6)

Although initially reluctant, Teresa also supported the place of formal debriefing to support nurses following the death of a patient. She stated:

> Even if you think at the beginning of a debriefing session, oh, I don’t need this but once you’re in there and you’re hearing what other people are talking about, it always brings out with myself I know, always brings out, you know, an idea or something that I can pass it to them or gives me an idea and just sharing it even if you don’t think it’s affecting you. (Teresa (12) 25–28; (13) 1–7)

In contrast, Angela was opposed to the idea of formal debriefing. She explained:

> I think the singular unhelpful thing is sending in a debriefing team. The time’s not right. Everybody’s emotions are different. They can’t always get to everybody that’s on the team into the debriefing situation. It’s a stranger; often the debriefing doesn’t need to be done so soon after. If it’s all up to me, it’s often done too soon. (Angela (18) 10–11; 13–16; 18–20)

Cheryl was also not supportive of formal debriefing but her view was based on her belief that too much support was not a good thing for the team as they are then less able to cope. She outlined her view:

> Up until about ohh, six years ago, there wasn’t anything formal or informal basically. Oh, there was informal. You always, if you had a yucky shift you’d always sit down with everyone and go, ‘Oh, crap, I feel terrible’ sort of thing. But there was never anything, it’s only since the high tech and stuff come on … and I suppose, I don’t know, it sounds like you know, it’s probably the wrong thing to say but it makes it less emotionally prepared to deal with things like that when there’s too much support. (Cheryl (18) 21–24; (19) 1–5)

4.5 Key findings

Two of the main reasons for undertaking research such as this study are to better understand the issue being investigated and to apply those findings to practice. The research is based in the context of practice and it is important that key learnings can be translated back into practice to bring improvements for those in similar situations to the study participants. As outlined already in this thesis, I am regularly reminded of the challenges facing rural nurses who care for people who die, and it has been these observations that formed the impetus for this study. The key findings from the study will be used to form the basis of the recommendations from the research.

The key findings from the research are:

7. Effective communication between the care team members, the nurse and the patient, and the nurse and the patient's family is very important.
8. Although frequently challenged, confidentiality is very important in rural communities.
9. Familiarity with patients over a long period can mean rural nurses make assumptions about their care requirements.
10. Repeatedly caring for someone you know who dies has a high personal cost.
11. Some rural nurses struggle with the close relationships of rural towns and the blurred relationship boundaries that these can create.
12. Some rural nurses find the extended role of caring for patients with cancer very satisfying.
13. Some rural nurses struggle with the high demands of palliative care nursing in their generalist nursing role.
14. High levels of compassion fatigue exist in rural nursing.
15. Support strategies and structures for rural nurses are inconsistent across rural health facilities.
16. The 'tearoom debrief' is an important but unrecognised strategy to support rural nurses.

4.6 Chapter summary

This chapter has identified the three phenomenological themes and 12 sub-themes that have been established by reviewing the experiences of the nurses who participated in this study. Excerpts from participant's narratives have been interpreted and grouped together to support the existence of the themes. The main themes of ‘accepting the need to adopt progressive ways of delivering nursing care’, ‘learning different ways of relating to patients and families’, and ‘seeking to achieve a work–life balance’ can be linked in turn to the concepts of patient-centred care, issues of living and working in the same rural town, and resilience. These concepts will be explored in more depth in the following chapter, which will allow the findings from this study to be explored further in light of the existing literature.

Chapter 5: Discussion

5.1 Introduction

The objectives of this study were to understand the experience of the rural nurse who has cared for people who have died from cancer; to provide participants with the opportunity to share their feelings and experiences of caring for patients with cancer and the effects of the death of their patient; and to develop recommendations for the development of strategies to support rural nurses who are caring for people who may or have died from cancer. The research question, ‘What is the lived experiences of Queensland rural nurses who have cared for people who have died from cancer?’ was explored using a hermeneutic phenomenological approach guided by van Manen’s (1990) methods of analysis and interpretation. To achieve this, the responses from the interview participants were read and re-read, to reveal and understand the common themes in the information they provided.

As indicated in the previous chapter three main phenomenological themes emerged, and these themes are supported by sub-themes. The first theme encompasses the need for the nurses to adopt progressive ways of delivering nursing care and this is underpinned by the importance of effective communication, accepting that the patient has the lead in care, recognising the importance of confidentiality and learning a new way of being. The second theme relates to the nurses’ need to learn different ways to relate to the patient and their family, and is affected by the sub-themes of struggling with the close relationships in small rural towns, learning to live with blurred relationship boundaries, learning how to involve relatives in the nurse–patient relationship, and knowing death in a relationship. The third theme identifies the need for the nurse to seek and achieve a work–life balance, and incorporates the sub-themes of finding ways to care for the self, accepting the benefits of close relationships, learning personal boundaries and working through team issues. This chapter will discuss the key findings that have emerged in relation to past research and scholarly literature where available.

On the first page of this thesis I revealed that the driving force for this research was my extensive experience caring for people with cancer in both metropolitan, and rural and remote settings. As I listened to the stories and reflections shared by the research participants it was impossible to ignore the way my own memories and feelings of caring for people with cancer were rekindled. I recalled similar conversations with patients and a similar stirring of emotions; at times my senses refreshed smells, scenes and sounds from my clinical past. In conducting this phenomenological study underpinned by the principles of Heideggerian phenomenology it is not necessary to put aside my own beliefs or experiences. In contrast, my history supports Heidegger's key concept of 'being in the world' or '*dasein*' (Mackey, 2005). I have used my own experience and knowledge to become immersed in the information provided by the study participants, and in turn the interpretation of the data is enhanced to allow the true themes and meanings of the phenomenon to be revealed (Mackey, 2005). Acknowledging my being in the world of the participants links to van Manen's existential concept of relationality, and is underpinned by how I related to the participants, and how their stories influenced the perspective of my interpretation (van Manen, 1990).

5.2 Overview of themes identified

This study has identified three main phenomenological themes, each comprising a number of sub-themes. Although the themes are different they cannot be considered individually or in isolation of one another as each is intertwined with the others, and in totality they provide an overall interpretation of what it is like for rural nurses to care for patients who have died from cancer. The three major themes are ‘Accepting the need to adopt progressive ways of delivering nursing care’, ‘Learning different ways of relating to patients and families’, and ‘Seeking and achieving a work–life balance’. The key findings of this study will be examined in more detail with consideration to past research and scholarly literature.

5.2.1 Communication and the importance of confidentiality

The first theme from the findings focuses on the elements of effective nursing care for patients in the rural setting and the model of care that is evident during the patient’s transition to end-of-life care. A key sub-theme in this finding relates to the need for effective communication between members of the health care team and the patient and their relatives—‘identifying the importance of effective communication’. Several participants expressed their frustration at what they perceived to be less optimal outcomes for patients resulting from clashes between team members; a poor understanding of the patient’s needs and treatment options; and resistance to the inclusion of new members to the treatment team and their suggestions for patient care. Study participants linked each of these features to poor communication among key stakeholders in the care of the patient by study participants.

While there is no specific literature relating to issues of communication in the Australian rural health care team, communication is regarded as a fundamental nursing skill that is used in assessment, patient education and therapeutic education (Sully & Dallas, 2010). There is a commonly held view that most patients and their caregivers assume that members of their health care team communicate effectively with one another (Sully & Dallas, 2010). There is general consensus that this is not the case in practice, and that this situation is exacerbated by an unrealistic expectation that patients and their caregivers will provide critical information at the appropriate time during their care. Starr (Starr, 2015) believes that poor communication between health care providers leads to dangerous and at times life-threatening situations for patients, particularly when they are transitioning from one phase of care to another. The lack of timely and effective communication can lead to clinical errors, patient safety issues, miscommunication between the members of the health care team and the patient and their care givers, patient safety issues and sub-optimal care (Starr, 2015; Sully & Dallas, 2010). A study conducted in Ontario in 2000 also identified the need for improved communication between health care providers and family care givers (Stiell, Forster, Stiell, & van Walraven, 2005), and in another study examining the nature and timing of family and care provider communication in late stage cancer it was acknowledged that communication was less effective again when care givers were exhausted and yet still expected to seek considerable information for their loved one (Waldrop et al., 2012).

Blue and Fitzgerald (Blue, 2002a) examined the inter-professional relationships between doctors and nurses working in rural health care settings in Australia. The authors reported that much of the research relating to the doctor–nurse relationship had been conducted in large hospitals, a context that differs greatly from rural facilities. Previous studies showed a history of conflict and domination by medicine over nursing. In large hospitals the traditional power base is found with medicine, in a setting where doctors prescribe the care to be delivered by nurses (Brehaut, 1971). Blue et al. (Blue, 2002a) contend that the professional relationship in rural practice is different as the doctor is frequently not resident in the hospital in the same way as in metropolitan settings, where a greater level of solitary practice demands additional skills. The authors believed that where there was a climate of equality, mutual respect and appreciation of each other's skills in the rural setting, professional skills would exist and flourish. However, the reverse of this situation and the absence of these desired features in the inter-personal professional relationship between the doctor and the nurse would result in poor-quality practice, a higher risk of clinical incidents resulting in poorer outcomes for the patient, and greater tensions among the members of the health care team (Birks, Al-Motlaq, & Mills, 2010). Trust, respect and dependence were deemed critical to successful professional working relationships between rural RNs and GPs. This took time and was developed when GPs understood the individual capabilities of nurses and vice versa (Blue, 2002b). In this study many of the participants had worked in their rural community for many years, and had been able to develop professional working relationships with the permanent medical staff in the town over that time. For some participants in this study, familiarity seemed to breed contempt in the relationship between the doctor and the nurse. Treatment decisions were based on habit with team members able to pre-empt each other's actions, and this led to sub-optimal outcomes for patients when there was a presumption of their needs, without checking the actual situation.

Blue et al. (Blue, 2002b) suggest that the professional relationships that develop between the doctors and nurses in rural settings are built on trust and dependence on each other due to the small size of the local community, higher social interaction and professional isolation. The authors conclude that these professional relationships are co-dependent ones in which neither rural nurse nor doctor can operate successfully without the other. In some cases the only factor preventing the rural doctor from burnout and leaving was the ability of the nurses to protect and support the way in which the doctor worked. Several of the concerns raised by participants in this study related to the apparent inability of locum doctors and nurses to relate to local staff and to understand how care was generally provided at the particular facility. While the research does not suggest that relationships between doctors and nurses in rural settings are problematic, it has highlighted that the importance of the relationship between medical and nursing staff should not be underestimated in relation to its effect on quality service provision and workforce stability (Blue et al., 2002).

Participants in this study also raised their concerns in relation to the regular challenges they experience to maintain confidentiality of patients. This concept forms another sub-theme within the first theme, ‘recognising the importance of confidentiality’. Participants related stories about how community members would target nurses outside of the hospital to gain additional information about a patient. This constant probing for information added to the experience of the nurses that they were never off duty, even when they were away from work, forcing many of them to stay on their guard when away from the hospital. Staying alert ensured that the nurse did not breach patient confidentiality, or get caught in the external relationship dynamics between the patient and others. In a study examining the psychosocial care of patients with cancer in rural Victoria, Kenny (Kenny et al., 2007) compared the difficulties that study participants expressed, the difficulties that rural nurses faced, and the emotional challenges that they encountered as a result of the dual relationship: that of nurse but also member of a small community. For each group, there was a suggestion that they were under considerable pressure to maintain confidentiality in a community where most people knew each other.

5.2.2 Living where I work

Workplace satisfaction is important for rural nurses and is influenced by several factors including workplace support and communication, potential for career progression, management and peer recognition, and support from more experienced nurses (Hegney, 2002). Experienced nurses engaged in clinical practice have the potential to cultivate and grow new or novice nurses. Recognising this role and providing opportunities for development will help grow a positive, supportive work environment that nurtures the experienced nurses of tomorrow (Francis & Mills, 2011).

Mentoring is a concept referred to when supporting and developing nurses with a view to improving staff retention (Kilgallon & Thompson, 2012; Nelsey & Brownie, 2012), and is often seen as a ‘one size fits all’ solution (Mills, Francis, & Bonner, 2007). Mentoring is a form of professional support used by nurses and is the most common term that rural nurses used to describe their experiences of developing new and novice nurses (Mills, Birks, Francis, Coyle, & Al-Motlaq, 2008). The authors referred to this process of development as ‘cultivation and growing’ the new nurses within the context of the cultural, political and clinical aspects where they exist (Mills, 2007). The authors emphasised that by living and working in the same community, rural nurses live their work, and stressed that surviving this phenomenon is a complex process that comes from experience, which they can pass onto new and novice nurses (Mills, 2007).

Mentoring and preceptoring are terms that are used interchangeably by some to describe supportive relationships in the nursing workplace. The terms have different meanings, with preceptoring focusing on orientation and the achievement of specific skills to achieve work readiness (Usher, Nolan, Reser, Owens, & Tollefson, 1999) and mentoring being conducted both within and outside of the workplace and focusing on broad aspects of the mentee’s life with a view to personal and professional development (Mills, 2005).

5.2.3 Compassion satisfaction, compassion fatigue and burnout in rural nursing

Several findings in this research relate to the sense of satisfaction experienced by the nurses in their role of caring for people with cancer. Several nurses described the satisfaction they experienced from their work; however, in contrast, others articulated the stresses and challenges that they experienced. For this second group of nurses there is a risk that they will disengage from their role due to the repeated discomfort they experience resulting from a number of issues highlighted by the study, including repeatedly caring for someone who dies, the extended skills and knowledge required to provide palliative care, and the stress created by the blurred boundaries of living and working in a rural community. The ultimate risk to the nurse and the community in which they work is that the nurse will permanently leave nursing, taking their valuable skills and knowledge away from those who need them. Given the existing nursing shortages in rural areas, and the likelihood that the working environment for rural nurses in Australia will not change in the short term, this section of the discussion chapter will focus on the issues of compassion fatigue, burnout, compassion satisfaction and resilience in nursing. It will explain each of the issues including the causes, experience for the individual, implications for patient safety and quality health care, recommended interventions for each and why further research into the topic should be undertaken.

A review of the literature reveals that there is no reference to compassion fatigue and compassion satisfaction in Australian generalist rural nursing. Recent research by Drury et al. (2014) focused on the issue of compassion fatigue in a sample of 10 nurses from a large tertiary hospital in Western Australia. Pinikahana and colleagues (2004) researched levels of stress and burnout in 136 rural psychiatric nurses in Victoria. This research did not refer to compassion fatigue and the researchers were surprised to find that overall the rural nurses experienced lower levels of stress and burnout in the workplace; a result that contradicted the expectation that rural psychiatric nursing is difficult (Pinikahana, 2004).

Compassion fatigue and compassion satisfaction are directly related to the interaction between health care professional and patient. Compassion fatigue was first referred to in a nursing journal in 1992 and described the reaction of nurses who had apparently turned off their own feelings or experienced helplessness and anger in response to observing patients go through distressing illness or trauma (Joinson, 1992). Compassion fatigue, which is also referred to as vicarious or secondary trauma has been described as the ‘cost of caring’ (Figley, 1995). There is a saying that you cannot wipe the tears from someone’s face without getting your hands wet. Professionals who listen to clients’ stories of fear, pain and suffering may feel similar fear, pain and suffering because they care (Figley, 1995).

The ability to understand another person’s feelings is known as empathy. Empathy is one of the most frequently cited personality traits of the nurse (Miller et al., 1988; Sand, 2003) and is essential for caring for patients with cancer (Kruijver et al., 2000). A study examining the personality profiles of nurses working in cancer or palliative care highlighted that nurses were empathic (Gambles, 2003). The more skilled a nurse is at being able to empathise, the more at risk they are of experiencing vicarious traumatisation (Adams et al., 2006; Figley, 2002; Sabo, 2008; Sinclair & Hamill, 2007). Nurses who are empathic and demonstrate the personality characteristics of being overly conscientious, perfectionistic and self-giving are more susceptible to stress and compassion fatigue (Keidel, 2002).

Compassion fatigue is not a mental illness. In contrast it is considered a behavioural response that results from helping another person from suffering pain or trauma. It occurs through giving high levels of energy and compassion over a long period of time to patients who are suffering, often without experiencing positive outcomes of seeing patients get better (McHolm, 2006). For example, and as illustrated by this study, if a patient has been traumatised as a result of a cancer diagnosis and shares this trauma with the nurse, who in turn feels unable to rescue the patient and a resultant sense of personal and professional failure, there could be a risk of compassion fatigue in the nurse (Sinclair & Hamill, 2007; Valent, 2002). Copp et al. (1993) reported that patients coming to terms with dying were the main death-related concern of nurses working in acute care, hospice and community settings (Copp & Dunn, 1993). Nurses who are repeatedly exposed to the trauma of their patients may lose their ability to feel and care for others over time because it becomes eroded through exhaustion of their ability to be compassionate (Bush, 2009). The literature suggests that although the effect is cumulative, compassion fatigue appears suddenly and subsides quickly, in contrast to burnout, which develops and declines more slowly (Figley, 1995).

At the individual level, the symptoms demonstrated by those suffering compassion fatigue include emotional exhaustion, depersonalisation and an inability to work effectively (Stamm, 2010). Symptoms may be insidious, and include sadness, depression, anxiety, intrusive images, flashbacks, numbness, avoidance behaviours, cynicism and poor self-esteem (Stamm, 2010). Many of those who experience the symptoms of compassion fatigue will attempt to ignore their distress until an intolerable level of discomfort is reached. This may mean that the nurse is unable to work as effectively as they once did or as well as they would like to due to the symptoms they are experiencing. For others the cause may be the progressive debilitation associated with somatic symptoms or embarrassment and pain associated with secretive self-destructive comfort-seeking behaviours such as the compulsive behaviours of overeating, overspending or alcohol/drug abuse to soothe the anxiety they feel. Other sufferers of compassion fatigue simply try to work harder, something that becomes increasingly difficult and destructive as their symptoms progress (Gentry, 2008).

Regardless of the individual presentation, compassion fatigue cannot be addressed until carers acknowledge and address rather than avoid their symptoms and their causes (Gentry, 2008). Health care professionals experiencing compassion fatigue respond to intervention (Drury et al., 2014).

At an organisational level compassion fatigue reduces productivity and job satisfaction, increases staff turnover and sick days, and leads to patient dissatisfaction and risks to patient safety (Drury et al., 2014; Hooper et al., 2010; Mealer et al., 2012). Drury et al. (2014) confirm that the incidence of compassion fatigue in Australian nurses is poorly understood but American studies indicate that it is a real phenomenon that disrupts lives, destroys careers and adversely affects organisations (Ainsworth & Sgorbini, 2010; Aycock & Boyle, 2008; Beck, 2011; Boyle, 2011; Bush, 2009; Coetzee & Klopper, 2010; Henry & Henry, 2004; Hooper et al., 2010; Maytum et al., 2004; Potter et al., 2010; Sabo, 2006). Drury et al. (2014) contend that psychological wellbeing of nurses is important, particularly when the work of nurses is becoming increasingly challenging with exposure to both chronic and acute stressors including high workloads, inflexible working hours and conditions, family issues, agency staff and dealing with difficult clients and colleagues, which in turn can lead to the development of compassion fatigue. Nurses who are psychologically unwell are more likely to resign from the nursing workforce, or may reduce their hours, which has financial costs for the organisation relating to recruitment and retraining (Mealer et al., 2012). Given the projected shortages of nurses in both rural and metropolitan areas of Australia strategies need to be developed to retain nurses in the workforce.

Compassion fatigue focuses on the negative effects of dealing with individuals who have been traumatised and does not acknowledge the many positive aspects of working with such individuals including developing new skills and knowledge through professional development and the privilege of being involved in patient care (Cropley & Millward Purvis, 2004; McGrath et al., 2003; Tyson & Pongruengphant, 2004). In contrast and as a counterbalance to compassion fatigue (Stamm, 2002), compassion satisfaction is the emotional reward of caring for others in a health care setting. It is characterised by ‘the sense of return, efficacy and competence that is experienced as a helping professional’ (Figley, 2002) and may demonstrate the ‘resiliency of the human spirit’ (Stamm, 2002).

Although burnout is the result of organisational features rather than a reaction to patient and nurse interactions, it may also be characterised by emotional exhaustion and depersonalisation (Killian, 2008). Authors exploring the topic of burnout agree that it is related to high workloads, unsupportive work settings and poor management decisions (Figley, 2002; Jenkins & Baird, 2002; Stamm, 2005) and failure to achieve personal goals (Valent, 2002). In other words, burnout is a stress reaction to role expectations exceeding what is being achieved (Chang et al., 2005). Of relevance to this research study Keidel (2002) highlighted the risk of blurring the boundary between being a professional and being a friend as another source of burnout (Keidel, 2002), as several participants in the current research reported.

In the same way that compassion fatigue affects several aspects of a nurse’s life, researchers suggest that the treatment for compassion fatigue should be multifaceted. Early research by Trippany et al. (2004), who worked with counsellors rather than nurses, outlined six key areas for consideration to prevent compassion fatigue. These included simple changes such as limiting the number of trauma clients seen per week; gaining education and training in treating clients who have experienced trauma; having access to professional development resources such as supervision and adequate staffing; provision of peer supervision; developing personal coping mechanisms and developing a sense of spirituality. Gentry (2008) suggested that primary traumatic stress should be addressed first before addressing secondary traumatic stress and/or burnout. More recently Drury et al. (2014) linked remedial support designed to build psychological wellness in nurses to the targeted areas of individual social networks and support, organisational infrastructure and support, environment and lifestyle, professional development, leadership and stress management.

In part, the literature focuses on the need for effective self-care for individuals who are suffering from compassion fatigue. Promoting self-care enhances compassion satisfaction and decreases burnout and compassion fatigue (Alkema, Linton & Davies, 2008). Living a well-rounded life is a useful coping strategy that relates to physical, emotional and spiritual aspects of life (Yoder, 2010). Gentry (2008) described self-care as ‘refill and refuel oneself in a healthy way’ encompassing a commitment to exercise, meditation, good nutrition and spirituality. Gentry added that some individuals will need to be vigilant in their self-care strategies, while others will be able to experience the benefits of such a program with minimal effort. Other authors suggest that meditation can be enhanced by the addition of other emotion-regulating skills such as mindfulness, refocusing and relaxing (Masten & Reed, 2002; Haglund et al., 2007). There was general consensus in the literature that education on coping, stress management and dealing with conflict including mindfulness and meditation was helpful in future management of stress in the workplace.

The personality characteristic of hardiness (Kobassa, 1979; Kobassa et al., 1982) has been found to be associated with decreased burnout in oncology nurses. Hardiness consists of the three characteristics of commitment, control and challenge. Hegney et al. (2014) suggested that a nurse’s capacity to cope in a stressful workplace is enhanced through ‘strong social and collegial support, infrastructure that supports the provision of quality nursing care and positive affirmation'. Buykx et al. (2010) agreed that building strong personal and work-based relationships were important in developing resilience, and others proposed that this was further enhanced through the development of behaviours that support problem solving, self-regulation and emotional awareness (Revich et al., 2011; Seligman et al., 2005, 2006, 2009). Concepts such as these are strongly linked to personal resilience. Resilience supports psychological wellness but it is poorly understood how nurses can become and remain resilient (Gillespie et al., 2007; Mealer et al., 2012). In their 1994 study, Papadatou and colleagues agreed that nurses were protected from emotional exhaustion, depersonalisation and a lack of personal commitment through a sense of control over what happens in life and in the workplace.

Hegney et al. (2014) proposed that resilience is more effective than compassion satisfaction for nurses as it enables them to work in the increasingly challenging nursing environment. The authors explained that resilient nurses will remain in the workforce and provide higher quality patient care; as such, nursing management need to develop appropriate interventions to build resilience in nurses. For rural nurses working in a close-knit setting the support of colleagues and managers is even more crucial (Kenny et al., 2007). Role modelling by senior staff was found to be invaluable and to lead to support, mentorship and improving the practice environment. This approach also supports effective teamwork and team building, which in turn provides a supportive environment for team members (Vachon, 1987).

Hegney et al. (2014) stressed that apart from the philosophical commitment to providing a psychologically supportive workplace for nurses, there needs to be a commitment from organisations to address infrastructure issues such as fatigue caused by shift rostering, difficulties in accessing suitable and affordable car parking, and obtaining leave, including study leave. The authors contested that debriefing opportunities need to be supported by the provision of a quiet room and paid time to get away; work-initiated programs to develop coping techniques among staff; formal and informal mentoring programs; teaching spaces available around the clock; and a positive family-friendly workplace that values staff.

The literature provides strong support for the value of informal debriefing and incidental mentoring by peers as key factors to support nurses (Hays et al., 1994; Hegney et al., 2014; Vachon, 1994, 1995, 1998). Nurses in the current research reported they used informal debriefing to assist them in coping with stressful situations. Most often, this occurred with other nursing colleagues on their unit, but at times they used managers and physicians (Yoder, 2010). Nurses indicated they were able to identify when peers were having a bad day and that they provided support. Other researchers have suggested that a formal peer support group facilitated by ward managers to promote information sharing and emotional catharsis is a way to prevent or manage vicarious traumatisation (Clemans, 2004; Illiffe & Steed, 2000; Trippany et al., 2004). A reactive support strategy is demonstrated by debrief following a challenging or difficult incident on the ward, facilitated by a counsellor or psychologist (Illiffe & Steed, 2000). For rural nurses working in a close-knit setting the support of colleagues and managers is even more crucial (Kenny et al., 2007).

The benefit of support from professional colleagues over personal support systems is that professional colleagues understand the professional’s role and are able to provide technical support as well as technical challenges (Pines et al., 1981). However, the problem with an informal arrangement is that nurses do not always have time to access valuable support informally from colleagues, or to build relationships with other members of the multidisciplinary team. As a result of these limitations, nurses may go home carrying the negative effects that working with patients may have had on them. Nurses are not permitted to discuss patients outside of work due to confidentiality, and this may result in them not receiving adequate support to psychologically sustain them (Sinclair & Hamill, 2007).

Mentoring promotes role and skill acquisition for nurses as well as providing psychosocial support (Mills et al., 2006). Mills and colleagues contest that investing in programs that prepare clinical leaders including mentors, preceptors and clinical supervisors can only benefit the workforce. Numerous studies have identified the value of clinical supervision for nurses (Bowles & Young, 1999; Burnard et al., 2003; Bush, 2005; Carney, 2005; Edwards et al., 2005; Gilbert, 2001; Hancox et al., 2004; Jones, 2003; Robinson, 2005; Walsh et al., 2003) The literature provides clear support for the benefits of clinical supervision with protected time for nurses working in clinical practice, with authors suggesting that this could be facilitated by a suitably trained counsellor or psychologist on an individual or group basis (Kenny et al., 2007; Sinclair & Hamill, 2007).

5.3 Chapter summary

The chapter has discussed the key areas of communication including the importance of confidentiality in rural nursing practice, the complicated issue of ‘living where I work’, and the inter-related experiences of compassion satisfaction, compassion fatigue and burnout in rural nursing. It has examined each topic in more detail and supported this discussion with reference to the literature. The final chapter of this thesis will reflect on the rigour of the research, provide an overview of the finding, and summarise the new knowledge revealed through the research. The limitations of the research will be discussed along with the recommendations from the study. The recommendations from the study will be presented in the areas of implications for nursing practice, policy, education and research.

Chapter 6: Conclusion

This concluding thesis chapter will reflect on the rigour of the research, provide an overview of the findings and summarise the new knowledge revealed through the research. The limitations of the research will be presented along with the recommendations from the study, which will be presented in the areas of implications and insights for nursing practice, policy, education and research. This final chapter will also allow me to reflect on my experience as the researcher.

6.1 Ensuring rigour in the research

As previously outlined in section 2.5.1, the criteria for confirming rigour in qualitative research are credibility, fittingness, auditability and confirmability (Sandelowski, 1986). Credibility is defined as the degree to which participants and readers of the research recognise the lived experiences described by the researcher as being similar to their own (Taylor et al., 2007). During my candidature I presented my research at various stages at six local, state and national conferences. I received positive feedback from rural nurses in the audience at each conference who concurred with the information that I was presenting. In line with the recommendations made by Koch (1994) and the guidelines expressed by van Manen (1990) I supported the credibility of this research by disclosing my preconceptions and experiences of the phenomenon in Chapter 1. The information generated by the researcher through notes made in a field journal when reflecting on the experiences of interviewing the participants was integrated into the data analysis as themes were identified, and in turn examined in more depth.

Sandelowski (1986) described fittingness as the process by which the findings of the research are able to ‘fit’ into a different context; it also relates to the extent that the readers of the research believe that the findings are meaningful and applicable to their own situation. As outlined in Chapter 5, it is proposed that the themes raised through this research can also be applied to areas outside of the care of patients with cancer, to include the support of nursing staff in rural settings who care for patients with chronic and complex illness who also spend extended or frequent periods in hospital. The researcher established the fittingness of the outcomes of the research through personal reflection, and discussion with colleagues and study advisors.

Auditability in qualitative research is the process by which the study's methods, decision trail and processes are documented by the researcher, with a view to them being easily adopted by another researcher to arrive at similar or comparable findings (Sandelowski, 1986; Taylor et al., 2007). I have ensured that the decisions and methods employed throughout each stage of this study are clearly described and presented in a logical format to enhance the ability of others to review or audit the approach taken and to question the subsequent findings.

Finally, through the achievement of the previous criteria of credibility, fittingness and auditability, the fourth criterion of rigour—known as confirmability—is in turn achieved (Taylor et al., 2007). In line with the features outlined by O'Brien (2005) to support the rigour of phenomenological research, I have accepted the validity of the participants' descriptions of the experience and the understanding that the stories emerge out of the unique context of their conversations; and I have used my perspective of the experience of the phenomenon and other sources including the literature to better understand and contextualise the phenomenon. In other words I have brought together the participants, myself as the researcher, and other sources to support the interpretation of the phenomenon. I have used the research to develop a narrative that is supported by the concrete examples presented in anecdotal form from the interview extracts. Finally, I recognise that the experiences being described resonate with the reader's understanding of what it is, or what it might be, to experience the phenomenon in that context.

6.2 Overview of the findings

The interpretative analysis of the transcripts has resulted in the identification of three main phenomenological themes and 12 sub-themes.

The first phenomenological theme is ‘Accepting the need to adopt progressive ways of delivering nursing care’; in essence this theme relates to the participants’ experience of the model of nursing care, and the factors that influence it. Through the research, the participants acknowledged that factors such as effective communication and adherence to confidentiality affected the nursing care that they provided. The need for effective communication was highlighted between members of the care team, with several participants reflecting on the challenges that can come from the presence of an outsider to the team, such as a locum nurse or doctor, when the norms or assumptions of care are tested and challenged.

Flowing from effective communication is the importance of maintaining confidentiality. Most participants acknowledged that they experienced frustration and some stress as a result of the repeated challenges to maintaining the confidentiality of their patients. Challenges came from the sometimes mutual family and friends of patients who used their relationship with the nurse to seek information about the patient in care. Although this probing was with the best of intentions in many cases, it clearly resulted in the nurse needing to be on guard against such breaches of confidentiality. Several nurses acknowledged that the need to debrief and share their day with others posed a continual risk of such a breach and that this had implications in relation to how they coped with the pressure of their work, and were able to work successfully in their rural community.

Throughout their interviews, several participants implied that the sub-theme of ‘Accepting the patient has the lead in care’ was a cause of tension in their effective delivery of nursing care. For decades nurses have considered that patients should take the lead in their care, with it being paramount for nurses to help equip patients with the skills and knowledge required to do this successfully. However, in this study several participants saw the patient taking the lead in their care as a challenge to their role in providing that care, and something that did not sit comfortably with them. Several participants described the challenges of difficult personalities, and patients who would not be moved once they had made a decision about their care. Several participants indicated that they did not know how to get past this point, and that it caused tension within the care team and the relationship with their patient and their family. It was clear that inflexibility on the part of the nurse, matched with the same determination from the patient and their family, made for a sub-therapeutic care relationship. Unfortunately several participants saw this as an issue relating only to the patient rather than themselves.

Following on from this conflict is the fourth sub-theme, ‘Learning a new role or new way of being’. Several participants acknowledged that their usual way of doing things did not always work when caring for people who were dying. They acknowledged that they were forced to adopt a new role of following the lead of the patient rather than setting the direction and pace of interactions between care team and patient and/or family members. Participants described the difficulty of making these adjustments initially but several acknowledged the benefits of such changes in specific cases.

The second identified phenomenological theme is ‘Learning different ways of relating to patients and families’. As the name suggests, this theme is based on the relationships experienced by the participants with their patients and families. Participants described their experiences of the close relationships within their small rural town, with many acknowledging that such closeness led to a blurring of the relationship boundaries with their patients. This is not new, and has been described by several authors in the literature. Although these phenomena can be seen as positive features of the relationship between the nurse and their patient, this is not without its risks, which include blurring between the lines of friendship and professional interaction, clouding of the decision making process relating to care planning and increased sadness with the deterioration of the patient’s condition.

All of the features already described in the literature were highlighted in the current study as affecting the nurse’s ability to effectively include relatives in the nurse–patient relationship. Blurred relationship boundaries make it difficult in some instances for the nurse to effectively include the relatives, a situation that may result in challenges for all in the therapeutic relationship. The blurred relationship boundaries were also noted by some nurses as reducing the effectiveness of patient treatments as a result of presumptions that were based on history rather than accurate and current assessment.

The majority of study participants mentioned rituals or practices they undertook following the death of their patient. Some attended the funeral; some chose not to. Those who did attend the funeral felt that this was an effective way of moving on following the death of their patient. Some participants stated that they were challenged by the reminders of surviving relatives and in many cases did not know how to react during subsequent encounters with family members in the community.

The third phenomenological theme relates to the needs of individual nurses, and was entitled ‘Seeking a work–life balance’. Throughout the interviews participants referred to the need to have a balance between work and life in their rural community. In line with the existing literature, many acknowledged that it was difficult to get away from work when you frequently saw your patient and/or their family away from the hospital, either directly or indirectly. Several participants saw this as a positive feature of living in their rural community, acknowledging that the community supported them through such relationships if the nurses allowed this. However, it was clear that this closeness needed to be managed through the nurse being able to define her personal boundaries and find ways to exist within them. Several participants described their ways of defining their personal boundaries and looking after themselves through the means of regular pampering and distracting strategies.

Several of the participants suggested that their ability to cope was enhanced by strong social and collegial support. The literature suggests that these features are strongly linked to personal resilience. In contrast other participants referred to compassion fatigue. Stamm (2010) described compassion fatigue as a precursor to burnout associated with emotional exhaustion, depersonalisation and an inability to work effectively. The symptoms of compassion fatigue develop over time, and are exacerbated by repeated exposure to difficult situations. Stamm’s summary of the symptoms of compassion fatigue includes sadness, depression, anxiety, intrusive images, flashbacks, numbness, avoidance behaviours, cynicism and poor self-esteem. According to Hooper and colleagues (2010), compassion fatigue reduces productivity, increases staff turnover and sick days, and leads to patient dissatisfaction and risks to patient safety.

Study participants highlighted several team issues. These included ineffective communication, tense relationships among team members, varying levels of support from service managers during difficult times, and the effect of an outsider such as a locum on the effectiveness of the team. Participants referred to the sometimes mixed benefits of participating in debriefing following the deterioration or death of a patient. Most participants favoured the benefits of the ‘tearoom debrief’ over a formal debriefing process.

6.3 What does the research add to nursing knowledge?

The findings from this research can be summarised as a mix of findings that support existing knowledge and those that provide new knowledge to nursing. The research has reinforced previous findings relating to the effect of caring on nurses. This research has highlighted that repeatedly caring for someone you know who dies has a high personal cost and that high levels of compassion fatigue exist in rural nursing. Each of these features is supported by the findings that some rural nurses struggle with the close relationships of rural towns and the blurred relationship boundaries that these can create.

The research has reinforced the generalist nature of rural nursing and supports previous findings that some rural nurses struggle when forced to work in specialist roles such as the demanding areas of palliative and cancer care. Despite this struggle, the research has revealed that some rural nurses find the extended role of caring for patients with cancer very satisfying. The research has reinforced that support strategies and infrastructure for rural nurses are inconsistent across rural health facilities.

The research supports the importance of the concepts of effective communication in the relationship between nurses, their patients and their families. It also supports the importance of confidentiality, and in particular reveals that although it is frequently challenged, confidentiality is very important in rural communities.

Although of concern in relation to patient safety and quality of care, the research has offered new knowledge in relation to the familiarity that some rural nurses may have with their patients. The research raised the issue that familiarity with patients over a long period can mean rural nurses make assumptions about their care requirements.

The research has also identified the ‘tearoom debrief’ as an important but unrecognised strategy to support rural nurses.

6.4 Recommendations – insights and implications

Table 6.1 maps the key findings from this research to the recommendations that have been developed under the areas of nursing practice, nursing policy, education and research.

Table 6.1

Mapping the Key Research Findings to the Recommendations

Finding	**Area**	**Recommendation**
1. Effective communication between the care team members, the nurse and the patient, and the nurse and the patient’s family is very important.	Nursing practice	1
2. Although frequently challenging, confidentiality is very important in rural communities.	Nursing practice	6
3. Familiarity with patients over a long period can mean rural nurses make assumptions about their care requirements.	Nursing practice	7
4. Repeatedly caring for someone you know who dies has a high personal cost.	Nursing practice	3
5. Some rural nurses struggle with the close relationships of rural towns and the blurred relationship boundaries that these can create.	Nursing practice	
6. Some rural nurses find the extended role of caring for patients with cancer very satisfying.	Nursing practice	2
7. Some rural nurses struggle with the high demands of palliative care nursing in their generalist nursing role.	Nursing education	8
8. High levels of compassion fatigue exist in rural nursing.	Nursing practice	3, 4
9. Support strategies and structures for rural nurses are inconsistent across rural health facilities.	Nursing practice	3, 4
10. The ‘tearoom debrief’ is an important but	Nursing practice	2

unrecognised strategy to support rural nurses.

6.4.1 Implications for nursing practice

6.4.1.1 Recommendation 1

In the area of nursing practice I contend that programs designed to strengthen multidisciplinary teamwork in rural settings will enhance communication and improve patient outcomes. Several of the participants in this study described their frustrations at the apparent disconnection between some members of the multidisciplinary team, and in particular between the medical and nursing staff in the area of planning patient care. Initiatives to strengthen the effectiveness of multidisciplinary teamwork could include joint care planning through case conference and patient reviews, where each member of the team is able to contribute equally to the discussion relating to client needs and care planning. This may also be enhanced by the opportunity for team members to understand and appreciate the scope and limitations for practice within their individual roles.

6.4.1.2 Recommendation 2

The current results suggest that the effectiveness of the rural team will be enhanced by effective team briefings following the death of a patient. Participants in the study described considerable emotional and physical investment in the care of their clients, and their ability to share their experiences and feelings following the death of their client will allow them to move on from each case. It is important for each team to decide on the type of team briefing that they require: a formal session with a facilitator or a less formal approach such as the ‘tearoom debrief’ where participants are supported by each other in a more relaxed and familiar setting to share their thoughts and feelings.

6.4.1.3 Recommendation 3

Equipping staff with the skills and confidence to indicate when they need time out from an emotionally draining situation or situations will enhance individual capacity. Participants indicated that such admissions can be seen as a sign of weakness, a factor that influences individuals to struggle on when in reality they need to step away from the situation. This process would also be supported by equipping managers and mentors with the skills and knowledge required to recognise features such as burnout and compassion fatigue in the members of their team, and be able to support them to recovery.

6.4.1.4 Recommendation 4

The risk of rural nursing staff experiencing burnout and compassion fatigue will be exacerbated when staff are caring for people who die from chronic disease such as chronic obstructive airways disease, heart disease or cancer. The symptoms and treatment of such diseases necessitate frequent admissions to hospital, providing the opportunities for staff and those they are caring for to develop therapeutic relationships. Managers and mentors should be supported to recognise the flags from such interactions, and in turn to pre-empt the support that their staff may need.

6.4.1.5 Recommendation 5

Rural clinical practice will be enhanced by commitment to effective orientation for locum staff. Study participants described their frustration at locum staff who were not aware of the policies, procedures and norms relating to clinical care at their facilities. Effective orientation of locum staff from all streams will enhance their effectiveness in the workplace and support the overall teamwork in the rural setting. This orientation should also extend to the expectations within the rural community.

6.4.2 Implications for policy

6.4.2.1 Recommendation 6

This study has highlighted the need to strengthen and reinforce policies relating to patient confidentiality in rural areas. Many study participants described the challenges posed to them by community members seeking access to information relating to client condition or treatment. Strengthening local policies relating to this area and supporting these changes with education programs for staff and community members would enhance the understanding of the right of all individuals to expect the confidentiality of their information.

6.4.2.2 Recommendation 7

There is a need for effective patient assessment for all clinical presentations in rural settings. Several participants in this study described a lack of effective patient assessment; in contrast care was planned around prior knowledge of patient needs and previous presentations. There is a risk that such apparent familiarity with community members by the care team will lead to potential clinical incidents where assumptions, rather than current and detailed assessments, are used as the basis for care planning. An effective education program will support this reinforcement of policy for locum and existing staff in the rural setting.

6.4.3 Implications for education

6.4.3.1 Recommendation 8

Several participants in this study indicated that access to appropriate educational programs is limited and frustrating. I recommend that attention is given to developing user-friendly education programs for rural settings using technologies such as online learning programs for ease of access, and that such programs include palliative care up-skilling, professional development to enhance teamwork including support for team leaders and staff mentoring, work–life balance, dealing with difficult people and an effective induction program for locum staff.

6.4.4 Implications for research

6.4.4.1 Recommendation 9

Finally, this study highlights directions for further research that widens the scope of the project to include rural nurses from other states of Australia or overseas, to evaluate the effectiveness of the implemented recommendations from above, and finally to apply the research to a specific metropolitan setting to assess similarities and differences between there and the rural setting.

6.5 Limitations

The goal of a phenomenological study is to fully describe a lived experience; to do this participants are asked to describe ‘what it is like’ so that the researcher may understand and make sense of the experiences. Interpretative phenomenology was used to support this study; in this approach the interpretation of phenomena is a circular process, which Heidegger described as a hermeneutic circle (Mackey, 2005). This process initially involves interpretation of the prior knowledge that the researcher may have of a phenomenon, and then of the partial understanding of the phenomenon as components of it are explored in more depth. Finally, the phenomenon is considered as a whole with the components considered together (Mackey, 2005). The emphasis in this process is on gaining an understanding of the phenomenon; however, studies employing this approach are not designed to develop a theory or to produce results that can be generalised across large populations (Spencer, 2008).

In this study participants volunteered and were selected on their stated experience of caring for people with cancer who had died. Twenty in-depth interviews were conducted, and the transcripts of these interviews were analysed in depth to gain an understanding of the phenomenon. This number of participants in a phenomenological study is greater than that recommended as a reasonable sample size (Ray, 1994); however, when participants were being recruited it was unclear when data saturation would occur; and as such the decision was made to interview all volunteers. Participants were recruited from six rural centres from across Queensland, and it is possible that a limitation of this study is that only nurses from Queensland were interviewed.

All participants were female and most worked for Queensland Health; again these features may be seen as limiting factors in the study. Further limitations may exist as a result of some of the interview participants being service managers, and that no Indigenous nurses were interviewed as outlined in the ethics section of this thesis. Each further delineation in the group of interview participants places additional limitations on the research findings. However, as already supported by Spencer (2008) the results of phenomenological studies such as this are not designed to be generalisable, and as such it is likely that different participants and/or a different researcher may result in other findings and interpretations.

As already implied it is important that my influence as the researcher is considered when reviewing the limitations of the research. I am a rural nurse who has cared for many people with cancer who have died. This was acknowledged at the beginning of this research study and was part of the impetus for the study. This acknowledgement is in line with the expectations of Heidegger when undertaking hermeneutic enquiry, and enhances the development of the interview questions through a deep understanding of the study context (McConnell-Henry, Chapman et al., 2009). As I listened to the stories and reflections shared by the research participants, it was impossible to ignore the way my own memories and feelings of caring for people with cancer were rekindled. I recalled similar conversations with patients, and a similar stirring of emotions; at times my senses refreshed smells, scenes and sounds from my clinical past. I have used my own experience and knowledge to become immersed in the information provided by the study participants, and in turn the interpretation of the data is enhanced to allow the true themes and meanings of the phenomenon to be revealed. The similarities between my own experiences and those of the study participants, despite the uniqueness of each experience, gives additional weight to the trustworthiness of my interpretation of the data (McConnell-Henry, Chapman et al., 2009).

I acknowledge that my interpretation of the data is strongly influenced by my own experiences, and that this interpretation will be different from another researcher without these experiences. It is possible that my experience is both a limitation and a strength in this research; it is possible that there could be bias in my interpretation based on my own experience (a limitation). However, my experience is also a strength in enhancing my ability to understand the information provided to me through the interviews with the participants (Carolan, 2003). Acknowledging my being in the world of the participants links to van Manen’s (1990) existential concept of relationality and is underpinned by how I related to the participants, and how their stories influenced the perspective of my interpretation.

6.6 Reflecting on the PhD experience

As I have already stated, my research question had been shaped almost 10 years before my enrolment in the research and higher degrees program, while completing my master degree. Following the death of a work colleague in 2006; the reaction of colleagues to the death of their friend; a timely conversation with one of my former professors; and some predictability in my personal and professional circumstances I was excited to enrol in my PhD. On reflection, that was the easy bit.

During my enrolment in my PhD there have been several challenges outside of my control that have affected the progress of my research. I changed universities and supervision team; my paid work became more demanding; my children became teenagers with the unpredictability that this brings; my husband became ill and changed jobs; and I have experienced a health event that continues to provide challenges to my health and wellbeing. Given the time that is allocated to the completion of a PhD I understand that there is time for circumstances to change for all candidates in such a way that their progress may be stalled. Despite the challenges I experienced, and when it may have been much easier to withdraw from my program, my observations of my nursing colleagues at work, and the random conversations that we shared about their experiences reinforced the value of my research and my need to see it to the end.

There have been several highlights since I commenced my PhD. Very skilled and knowledgeable supervisors have supported me throughout my program. Each has contributed their own expertise, and I feel very privileged to have completed my research under their supervision.

I was humbled by the open and honest responses I received from all of my participants during the interview phase of the research. Most were strangers but their willingness to share their experiences with me both reinforced the value of my research and made the task at hand so much easier. Our conversations also reinvigorated my love of the art of nursing: I felt comfortable in the participants’ company; I spoke their language, including the unspoken messages; and shared the emotion of their experiences through their descriptions and the way that my own experiences were awakened.

Although tedious at times due to the large volume of information that I had to review and analyse, it was exciting to find the common themes in the experiences of the participants. It was also exciting to revisit the transcripts after a break away from them and to once again hear the words of the participants and to feel their emotions. The process of refining the raw themes into the final themes with their sub-themes was illuminating. Although the themes have been untangled and described on their own in this thesis, in reality they are interwoven for the participants who experienced them.

I have presented several papers at various conferences during the years that I have been undertaking this research. Papers were presented over subsequent years at the annual Queensland Cancer Council Oncology Nurses' Group conferences. Attendees at subsequent conferences were supportive and encouraging as my progress was presented through my presentations.

A particular highlight of my PhD experience was the opportunity to present a paper in May 2011 at the Seventh International Congress of Qualitative Inquiry held in Urbana-Champaign at the University of Illinois. I was sponsored by James Cook University to travel to the USA for the congress and was supported by one of my supervisors, Associate Professor Jane Mills. With almost two thousand delegates at the conference from more than 67 countries the program was very diverse. The theme of the 2011 congress was 'Qualitative inquiry and the politics of advocacy' and among other things the congress provided participants with the opportunity to 'engage in debate on how qualitative research [could] be used to advance the causes of social justice, while addressing racial, ethnic, gender and environmental disparities in education, welfare and healthcare'. My paper, which summarised the preliminary findings from my research, was presented as part of the concurrent program in a session titled 'Mourning and loss'. Other papers presented in this session covered the subject areas of men’s experiences with miscarriage; collaborative reflections between and artist and researcher in relation to mourning; and retreat participants who had experienced the homicidal death of a loved one. As a novice researcher this was an amazing experience and I am very grateful to James Cook University and Associate Professor Mills for their support and encouragement to participate.

As an external student I have enjoyed the opportunity to attend the annual Research Schools at both the University of Queensland and at James Cook University. It is very helpful to be able to interact with other students who are at various stages of their research projects. I have made friendships with other research students that will last far beyond the completion of my research. Presentations by members of faculty and students are both inspiring and reassuring. It is also useful to be able to brainstorm solutions to shared problems in the research process. The ‘writer’s retreats’ incorporated with the James Cook University Research School were very productive, with quality feedback provided by fellow students and faculty members.

Key milestones in the research process were my confirmation presentation and pre-completion seminar. My confirmation presentation was delivered during Research School at the University of Queensland. Although the process was daunting, the feedback from the panel was very supportive and helped to shape my research as I prepared to undertake the interviews. My pre-completion seminar was presented to my supervisors and faculty at James Cook University, members of my family and work colleagues. It was also daunting to prepare and present the paper; however, the process helped to clarify in my own mind what had been achieved to date, and what was required to complete the thesis.

Now, at the completion of my thesis, I have a good understanding of the research process and of my subject matter. I consider that I have achieved the aims and objectives of my research project, and that the recommendations from my research will be transferrable to other areas of rural nursing practice where there is a long-term relationship between the nurse and the patient through frequent contact such as in the management of individuals with chronic disease.

In summary there have been challenges to progress throughout the PhD process. These have been overcome by reacquainting myself with the aims of my research, and by listening to and observing my nursing colleagues. The guidance and advice from my supervisors has always helped to provide the direction that I have needed to progress.

6.7 Conclusion

The focus of my research has been on the lived experiences of rural Queensland nurses who have cared for people with cancer who have died. The beginnings of my research project were based in my own nursing practice. For the past 25 years I have worked alongside nurses caring for patients with cancer in both metropolitan and rural and remote settings. More recently I have observed rural nursing colleagues caring for their friends and supporting them with compassion and skilled care to a good death. Many staff do this several times in a year, and many times over during their time in that rural setting. There is little opportunity to recover from the stress of providing that care or from the loss of a friend, before they are called on to support another.

This study has used the phenomenological methodology of van Manen to examine and understand the lived experience of rural nurses caring for people with cancer who have died. This is an appropriate methodology to gain an understanding of a phenomenon about which little is known. In-depth interviews were conducted with nurses from across Queensland, providing them with the opportunity to share their feelings and experiences of caring for people with cancer, and of the effects of the death of their patient.

I have developed nine recommendations from the findings of this research. Several recommendations relate to ways to improve team effectiveness in the rural setting with a focus on better communication, the capacity to welcome and support locum staff through effective orientation, and strengthening the function of the multidisciplinary team as a whole. Recommendations also focus on the welfare of staff through the need for effective and appropriate debriefing following the death of a patient, supporting staff to identify when they needed time away from a stressful situation and equipping managers and mentors to anticipate this need and to support their colleague to have an effective break. The research concluded that such a need could be associated with staff who are caring for people with chronic disease such as heart disease or cancer where there is the need for frequent contact with the staff. Additional recommendations related to the need for staff to maintain client confidentiality in the rural setting and the need for appropriate client assessment that did not rely on previous assumptions of client needs. It was also recommended that consideration be given to widening the scope of the research to include nurses from other states of Australia, from overseas, or from metropolitan settings to assess the similarities in the results from each of the settings.

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