Finding balance as an invited guest: Registered nurses' lived experience of providing home-based palliative care in rural communities.

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DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signature
Mrs Lyn Rabbetts
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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACN	Australian College of Nursing
AIHW	Australian Institute of Health & Welfare
ANMAC	Australian Nursing & Midwifery Accreditation Council
AHPRA	Australian Health Practitioner Regulation Agency
ARIA+	Accessibility Remoteness Index of Australia Plus
CASP	Critical Appraisal Skills Program
CN	Clinical nurse
CNS	Community nursing service
COAG	Council of Australian Governments
DDA	Dangerous Drug Administration
DoH	Department of Health
EN	Enrolled nurse
GP	General practitioner
HCP	Home care packages
ICM	International Confederation of Midwives
ICN	International Council of Nurses
MBS	Medicare Benefits Schedule
NMBA	Nursing and Midwifery Board of Australia
NMC UK	Nursing and Midwifery Council of the United Kingdom
NP	Nurse Practitioner
NSW Health	New South Wales Department of Health
PCA	Palliative Care Australia

PRISMA	Preferred reporting items for systematic reviews and meta-analyses
RAI	Regional Australia Institute
RN	Registered nurse
SA Health	South Australian Department of Health
SPCS	Specialist Palliative Care Service
WHO	World Health Organization

GLOSSARY

Accessibility Remoteness Index of Australia (ARIA) – a geographic accessibility index that aims to reflect the ease or difficulty people face in accessing services in non–metropolitan Australia. ARIA measures remoteness in terms of access along the road network from over 11,000 localities to five categories of service centres (Australian Government Department of Health [DoH] 2011).

Australian Health Practitioner Regulation Agency – regulates training, qualifications and safe practice of all health practitioners in conjunction with national boards (AHPRA 2023)

Burden of disease – the gap between optimal health and actual health in decline because of disease (Australian Institute of Health & Welfare [AIHW] 2021).

Clinical nurse (CN) – a Registered Nurse (RN) who has completed postgraduate training, assessed complex needs, and provided clinical care to patients in a specialist field of nursing such as palliative care (Australian College of Nursing [ACN] 2015).

Community nurse – a Registered Nurse who provides home-based nursing care in metropolitan areas and rural communities throughout Australia and other countries. Their role focusses on optimising the health of vulnerable groups of patients including people requiring palliative care (ACN 2015; Government of Canada 2016; National Health Service, United Kingdom 2023).

Enrolled nurse (EN) – a person who has completed a Diploma course in nursing from an accredited training organisation. An Enrolled Nurse cares for patients under the supervision of an RN and must practice with current registration (Nursing and Midwifery Board of Australia [NMBA] 2018.

General practitioner (GP) - a doctor who is also qualified in general medical practice. GPs are often the first point of contact for someone, of any age, who feels sick or has a health concern. They treat a wide range of medical conditions and health issues.

Health care professionals – a wide range of professional people working within the health care industry such as doctors, nurses, physiotherapists, pharmacists, nutritionists, and others (Palliative Care Australia [PCA] 2021).

Home care packages (HCP) – one of the ways that older Australians can access affordable care services to secure some help at home (Australian Government 2023).

Inner Regional Australia – in the ARIA remoteness structure, areas where geographic distance imposes some restriction upon accessibility of the widest range of goods, services and opportunities for social interaction (Queensland Government 2019; ABS 2023)

Level One Palliative Care Service – offered to people living with a life-limiting illness whose needs are straightforward and predictable, including families and carers of these people. Ongoing clinical management and care coordination including assessment, triage and referral for the person with uncomplicated needs. Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary. Health professionals involved in providing Level 1 palliative care do not work full-time in palliative care or in established multidisciplinary teams (PCA 2018).

Level Two Palliative Care Service – offered to people living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating; includes families and carers of these people. Provides palliative care for the person, carer and family whose needs exceed the capability of the person’s normal treating physician. Provides assessment and care of more complex pain and distressing symptoms. Provides counselling about disease progression, and assessment and management of psychosocial care needs for the person living with a life-limiting illness, their family and carers. Active implementation of advance care planning. Provision of education, training, and consultancy support to Level 1 service (PCA 2018).

Level Three Palliative Care Service – offered to people living with a life-limiting illness whose needs are straightforward and predictable, intermediate and fluctuating or complex and persistent; includes families and carers of these people. Management of complex and persistent symptoms that are not effectively controlled by standard therapies. Provision of after-hours access including telephone advice, nursing and medical support. Education, counselling and support for resolving complex issues. Assessment and management of complex psychosocial care needs for the person living with a life-limiting illness, their family and carers. Education, training and consultancy support to Level 1 & 2 services (PCA 2018).

Medicare – Australia's universal public health insurance scheme (Australian Government Department of Health and Aged Care 2023.

Medicare Benefits Schedule (MBS) funding – is the wide range of consultations, procedures and tests and the Scheduled fee system set by the government under Australia's universal public health insurance scheme (DOH 2022)

National Palliative Care Standards – a set of nine standards to be used by specialist palliative care services to support the delivery of high-quality palliative care for the person receiving care, their family, and carers (PCA 2018).

Nurse Practitioner – an RN who holds an endorsement of registration. This endorsement recognises that an RN has an extended scope of practice in a particular field of nursing because they have an additional qualification that is approved by the National Board—that is, the Nursing and Midwifery Board of Australia (Nursing and Midwifery Board of Australia 2021).

Outer Regional Australia – in the ARIA remoteness structure, areas where geographic distance imposes a moderate restriction upon accessibility of the widest range of goods, services and opportunities for social interaction (Queensland Government 2019; ABS 2023).

Palliative care – an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual (World Health Organization 2020).

Palliative Care Australia – the national peak body for palliative care. Palliative Care Australia represents all those who work towards high-quality palliative care for all Australians (PCA 2023).

Registered midwife – a nurse who has successfully completed a midwifery education programme that is based on the International Confederation of Midwives (ICM). Essential Competencies for Midwifery Practice and the framework of the ICM Global Standards for Midwifery Education and is recognised in the country where it is located; who has acquired the requisite qualifications to be registered and/or legally licensed to practice midwifery and use the title 'midwife'; and who demonstrates competency in the practice of midwifery (International Confederation of Midwives 2018).

Registered nurse (RN) – a nurse who has completed a Bachelor of Nursing degree full-time over three years at a tertiary training Institution. The training facility must be accredited by the country's Nursing and Midwifery Accreditation Body (Australian Nursing and Midwifery Accreditation Council 2019; Royal College of Nursing United Kingdom 2023; Canadian Council of Registered Nurses Registration (CCRNR)). Registration must remain current with the Regulatory Body (NMBA 2016; Canadian Council of Registered Nurses Registration 2023; Nursing and Midwifery Council of the United Kingdom 2023).

Specialist palliative care service (SPCS) – multidisciplinary teams that can include clinical nurses, nurse practitioners and allied health workers with training and experience in palliative care. These services receive support from general and specialist palliative care medical practitioners (PCA 2018).

Subcutaneous syringe driver (skip pump) – a portable infusion pump delivering a continuous infusion of medication over 24 hours for the management of distressing symptoms experienced within the trajectory of a life-limiting illness such as pain, nausea, dysphagia or restlessness (NSW Government 2023).

ABSTRACT

Registered nurses (RNs) play a pivotal role in rural communities, in the care of patients dying at home. However, the lived experiences of these RNs are poorly reported in research studies to date. In this study, a phenomenological study guided by a Gadamerian approach was adopted to explore the experiences of 16 RNs, including two Nurse Practitioners. All were employed by government funded community-based health care services in one state of Australia. The analysis of data followed an extended version of Diekelmann, Allen & Tanner's (1989) seven-stage process.

Data revealed the lived experience of these RNs to be more than the work they undertook; it was an ongoing process of finding balance between their professional and personal selves. Complex, intertwined relationships between the community, patients' families and themselves determined how the RNs went about their professional work and personal lives.

These lived experiences occurred within three environments (or settings): the community, the health care service and the home. The home emerged as the dominant environment. In this environment, the RNs found they were invited guests within their professional roles as they worked in the private space of another family. Furthermore, the work in patients' homes in rural communities evoked unique experiences; experiences that would not have occurred in other care settings.

Suggested strategies include the implementation and strengthening of innovative models of service provision to support RNs in rural communities in Australia, to improve the standard of home-based palliative care.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

This thesis presents a study of the lived experiences of Registered Nurses (RNs) who provide home-based palliative care in regional areas in one state of Australia. A study that uses a phenomenological approach which highlights nurses' experiences of what it is like to live and work in rural communities while providing palliative care in patients' homes. It is underpinned by Hans-Georg Gadamer's (1900–2002) philosophical hermeneutics (Gadamer 1975/2013). Gadamer's hermeneutic process is the analysis of language within the text which illuminates lived experience. The evidence gathered from participating Registered Nurses provides new understandings to inform future clinical practice and policy making.

Palliative care in the home via community-based nursing services is currently available in most inner and outer regional areas of Australia. This specialist nursing service is provided in the home, rather than in a hospital-based acute care setting or a Residential Aged Care facility (Australian Primary Health Care Nursing Association 2021). In 2015 the Australian College of Nursing (ACN) identified an escalating need for community-based palliative care nursing services in response to the following: the increasing population; people choosing to live in regional areas; and the flow of migrant workers being attracted to working in industries located outside metropolitan areas of Australia (ACN 2015). Additionally, as the nation's population continues to age, there are more people who live with chronic illnesses, including cancer, in regional Australia (ACN 2015; Borbasi 2017; Australian Institute of Health and Welfare [AIHW] 2021; Palliative Care Australia [PCA] 2022d).

In Australia, the level of any service provided in a regional area including all health care is determined by a nationally set classification system, the Accessibility Remoteness Index of Australia

Plus (ARIA+) (Queensland Government 2019; ABS 2023). This geographical categorisation influences the allocation of funding of health care services and includes home-based palliative care.

When palliative care is provided in a patient's home in a rural setting there is an added dimension to the therapeutic relationship between the nurse, patient, and family because nurses are community members as well as professional practitioners. Pesut, Robinson, and Bottorff (2014) described this occurrence as nurses working within the context and culture of their communities. However, little is known about the experiences of RNs providing home-based palliative care in Australian rural communities.

The aim of this study was to explore the lived experiences of RNs who provide palliative care for patients who wish to die at home in their own rural communities. It became clear after extensive searching of literature that little was published about RNs' experiences. Rather, the literature has reported the experience of families, patients, and other health care providers (see Chapter 2), but there was a gap in the reporting of what it is like for RNs to care for these patients. A qualitative paradigm was used to capture these views and facilitate an inquiry into this phenomenon (Gelling 2015). This first chapter will introduce the setting, background, context, and an overview of the study.

1.2 Background to the study

Qualitative research values 'past experiences of the researcher that provide familiarity with the topic' (Creswell 1994, p.147). I brought my own experience of being a palliative care nurse who worked for 17 years in this specialty area into this study. At the conclusion of my work in this area, questions emerged about the experiences I had in the provision of home-based palliative care in my own rural community. In this predominately farming area there were stories of dying and death that were worthy of being told. These stories awakened my interest in researching this phenomenon.

Further questions relating to what it was like for others to live and work in a similar rural community needed to be asked. Did the community itself affect the way RNs went about their work? How did working in patients' homes differ from nursing in a hospital setting? Questions that related to the emotional impact of caring for dying patients in the home environment also needed to be explored. My passion to gain new understandings of the work these RNs undertook in the provision of home-based palliative care in their own rural communities was ignited. My goal was to understand the deeper meaning that emerged from being involved in this specialist field of nursing.

I turned to phenomenology from a German perspective. The philosophy of Hans-George Gadamer (1975/2013) provided a philosophical hermeneutic paradigm to engage with and interpret other nurses' accounts of providing patients with home-based palliative care in rural settings. Phenomenology facilitated a deep exploration that moved past a descriptive collection of reflections about past experiences (Crotty 1996).

The work done by RNs providing palliative care in patients' homes in rural communities, outside of a hospital or hospice setting, is affected by unique circumstances. The goal was to honour this work through the collection of data from either face-to-face or telephone interviews with RNs employed in rural communities. Once interviews were conducted, data analysis followed and findings reported—as Austgard (2012, p.832) states, with 'accuracy and structure'. The outcome was to present new knowledge of this unique and specialist field and, furthermore, to provide government departments involved in policy making at a state, national and international level with evidence to improve service provision. The next section of this introductory chapter will outline the context for this study.

1.3 Context of this study

This study was conducted in several regional areas in one state of Australia. These regional areas consist of different sized communities: some towns are large regional centres, while others are medium to small communities. As mentioned above, the level of health care services that include palliative care in these settings is based on a zoning classification followed by the Australian Government Department of Health (DoH).

1.3.1 Zoning classifications of communities in Australia

According to the ARIA+ classification system, Australia is divided into five geographical zones. These five zones include major cities, inner regional, outer regional, remote, and very remote areas (Queensland Government 2019; ABS 2023). This scoring system considers the road distance from main centres and the ease or level of difficulty in accessing services required (ABS 2023). The Australia Bureau of Statistics (2022) and Australian Institute of Health and Welfare (AIHW) (2022) reported the population of Australia as 26,124,814 people, with an estimated 28% of this population living in regional areas.

Geographically, regions can vary in size depending on the overall area of each state or territory. For example, Western Australia, the largest state geographically, accounts for one-third of the entire area of Australia; therefore, many health care services are provided remotely via outreach services and clinics from health care services based in larger regional centres (Healthdirect 2021). Other states including South Australia, Victoria and New South Wales also provide health care services from larger, medium, and small regional communities (Department of Health Victoria 2015; NSW Health 2020; SA Health 2022a).

The next subsection of this chapter will provide a profile of people who live in inner and outer regional areas of Australia. This profile is pertinent to where participants in this study lived and worked, as well as families who were recipients of a home-based palliative care service.

1.3.2 Profile of people living in inner and outer regional areas of Australia

People who live in inner or outer regional areas of Australia reside in towns or on farming properties. Within these larger regional centres, medium and small sized communities provide agricultural products for regional and metropolitan populations. These products include dairy goods, meat, cereal cropping, orchard products, wineries, varieties of nuts and vegetables (Australian Government Department of Agriculture, Water & Environment [DAWE] 2021), and most are in fact exported overseas. Other industries in regional areas of Australia include fisheries, forestry, and the supply of farming equipment such as machinery and replacement of parts (DAWE 2019). A percentage of this produce is exported. Local and regionally based community businesses support these industries with commercial supplies, construction, tourism, banking, advisory and insurance agencies (ABS 2021). In support of these farms, regional industries and businesses, the Australian Federal and State governments provide facilities such as public schools and hospitals (Australian Government Department of Education, Skills, and Employment 2021; National Health Funding Body [NHFB] 2021).

According to the ABS (2020), 39% of people who live in regional Australia are over 50 years of age compared with 32% in the same age bracket living in metropolitan areas. In recent years, however, several factors have seen a change in the demographic profile of people who live in regional Australia. Firstly, there has been an increase in the number of migrant families moving to regional communities, which has changed the profile of people living in some towns (Regional Australia Institute [RAI] 2017b). Secondly, an increase in the nation's ageing population has affected these communities. That is, an estimated 31% of people born between 1945 and 1961 are still actively contributing to the workforce in regional areas. This portion of the population are seen as valuable contributors to the economic status of regional communities (RAI 2017b). It is therefore important to acknowledge that a significant percentage of families seeking palliative care support in regional areas of Australia are actively contributing to the economic viability of their communities, as were participants in this study.

Thirdly, younger people between the ages of late twenties and 40 years have moved to some regional areas from cities, seeking a more relaxed lifestyle, lower housing costs and less commuting time between work and home (RAI 2017b). The choice to live in a regional area of Australia applied to some of the RNs who were participants in this study. Interestingly, the level of education acquired by people living in rural areas of Australia compared with metropolitan zones was also represented within the profile of study participants (see below). The AIHW (2020a) estimated in 2019 that just over half, 53%, of people living in inner regional areas had completed a year 12 level of secondary education. Similar numbers—that is, 52% of people—living in outer regional areas were reported to have completed their secondary education, compared with 75% of people living in major cities.

According to the AIHW (2020a), relatively low numbers of people who live in inner and outer regional areas of Australia access tertiary education. Approximately 21% and 18% respectively have completed tertiary education, because most universities or training facilities are based in cities. The availability of work after completion of tertiary studies also affected the numbers of people returning to live and work in regional parts of Australia from metropolitan centres (AIHW 2020a). For example, the Regional Australia Institute (2017) reported that only 30% of graduates returned to live in regional areas after completing their tertiary education. These figures support the impression that students from regional areas staying in metropolitan areas to commence their careers.

However, as pointed out, recently the age bracket of late 20 to 40-year-olds families have been choosing to move to regional areas to live and work (RAI 2017a). One participant in this study, as will be reported in the fourth chapter, stated that she chose to undertake postgraduate training in a regional area. Another participant also shared that she had moved back to her own rural community after she had completed the Bachelor of Nursing degree in the city. This relocation was because of her desire to be close to immediate and extended family. Furthermore, the inner regional community offered her the opportunity to pursue her professional goal of employment with a community-based palliative care service.

Another aspect in the profile of people living in regional areas of Australia is the differing level of income earnt compared with those living in metropolitan areas. Overall, the income earnt by people living in rural and regional areas is reportedly lower than in city areas. This deficit is compounded by higher prices for commodities, goods and services, equating to earning 19% less than their city counterparts (AIHW 2020a). In contrast, housing prices in regional areas were found to be lower than in cities, making living in rural communities economically attractive to young families (AIHW 2020a).

Nevertheless, living in regional Australia also presents challenges in accessing some services, including health care. According to the Australian Institute of Family Studies (AIFS 2021), 36% of families experience difficulties in accessing appropriate services in outer regional areas of Australia. This level is compared with 16% of people living in metropolitan areas and 23% in inner regional areas who reported that accessing health care was problematic (AIFS 2021). Of interest, only slightly more people from inner and outer regional areas of Australia were recorded as living with morbidities associated with chronic illness than was the case for people from metropolitan areas: 21% of people in regional areas compared with 18% in cities (AIHW 2020a). However, poorer access to health care in regional areas of Australia impeded the long-term management of chronic illness. For example, 34% of people living in regional Australia wait longer than they consider reasonable to see a local general practitioner (GP; see Glossary). Twenty-one percent of people who live in cities stated that they found securing an appointment with a doctor took too long. Thirty-seven percent of people in regional areas reported that their waiting times to see a doctor were longer than they liked (AIHW 2020b). As will be reported in the Results section (Chapters 4, 5 and 6) of this thesis, some families who received home-based palliative care in rural communities experienced challenges in maintaining access to specialist medical care in the city.

Participants in this study provided home-based palliative care for patients diagnosed with a wide range of terminal illnesses. The AIHW (2021) estimated that 51,000 people in Australia would be diagnosed with cancer in that year. Forty-nine thousand people would die from various types of cancers such as breast, prostate, lung, bowel, and skin (AIHW 2021a). Other prominent contributors to the burden of disease in Australia include cardiovascular disease, cerebra-vascular accidents, obstructive airway disease and arthritis (AIHW 2020b). These statistics attest to the need for home-based palliative care in rural communities in Australia. In the next section of this chapter a brief overview of funding sources for palliative care services across Australia will be provided.

1.3.3 Funding for palliative care services

Across all Australian states and territories, health care is delivered through a complex system of federal, state, and private providers. The Federal Government provides funding for specific health services such as aged care, support for indigenous groups, funding for ex-military personnel through veterans' support programs, and palliative care. Funding for palliative care services throughout Australia is provided by a matrix of sources from two levels of government. State and Territory Governments both provide funding for public hospital and health care services under the jurisdiction of the Council of Australian Governments (COAG) (DoH 2021b). COAG also has the oversight of people who live in individual states and territories through the regulation of private hospitals and related health care services. At a regional level, people who live in these areas of Australia receive services such as palliative care as either public or private patients (DoH 2021b).

In each state and territory, Departments of Health are funded by individual State or Territory Governments (DoH 2021a). Country divisions are positioned within each state and territory's Department of Health to administer healthcare services outside of the metropolitan areas (DoH 2021a*)*. These services are divided into health networks or districts based on geographical areas in each state or territory. For example, in the state of South Australia there are six regional health networks (Government of South Australia 2021). Titles given to various departments responsible for health care outside of the major cities differ from state to state or territories. For example, in New South Wales (NSW), governance is provided from a department known as a Health District, namely HealthShare NSW (NSW Government Health 2021); in South Australia, the government departments responsible for administration and oversight of health-related services in regional areas are referred to as health networks. Therefore, palliative care support in regional areas of New South Wales and South Australia is accessed from HealthShare NSW and Country Health Connect respectively (NSW Health 2020; Government of South Australia 2021).

To complete the setting of the context of this study, a brief overview of how to locate different levels of palliative care services in metropolitan and regional areas of Australia will be provided next.

1.4 Location and levels of palliative care services available in Australia

Information on the location of palliative care services in Australia is accessed from several sources. The Australian Government DoH's website provides a comprehensive list of services available in each state and territory (DoH 2021*b*). Alternatively, the website of the national peak advocacy body, Palliative Care Australia (PCA), provides information by directing patients and families to local service providers, including specialist palliative care teams and community nursing (PCA 2022a; PCA 2022b).

PCA provides guidelines for the standard of care to be received by all patients seeking support in end-of-life care (PCA 2018). Within these guidelines, nine nationally set standards for service provision are stipulated. This framework also defines the level of care for palliative care patients and their families. According to PCA there are three main levels of palliative care support available (PCA 2018).

A *Level One service* provides baseline local support for patients with a life-limiting illness that has an expected trajectory. As the primary caregivers, families receive support from local GPs, other medical specialists, RNs working as general community nurses, personal care attendants and allied health workers. In rural areas community groups such as Rotary clubs, Country Women's Associations, Men's Sheds, and churches are valuable contributors of support (PCA 2018).

Level Two services are provided for patients whose life-limiting illness is presenting some challenges in the management of distressing symptoms. In these circumstances a higher level of care is needed and therefore a referral to a specialist palliative care team is initiated. Level Two specialist teams are located in most inner and outer regional areas of Australia. These teams consist of multidisciplinary health care professionals including RNs, nurse practitioners (NPs), social workers and pastoral care workers who have specialist training and experience in palliative care (PCA 2018). Some support is also provided from visiting Level Three service practitioners (information to follow) or via remote connections to metropolitan services on a needs basis. Additionally, Level Two services provide consultative support to Level One services in metropolitan and country areas throughout each state and territory in Australia (PCA 2018).

All *Level Three* services are based in metropolitan areas and consist of large multidisciplinary teams that have extensive training and experience in palliative care (PCA 2018). All other general services—including community nursing and personal care workers—are also involved in caring for patients and their families and friends as primary care providers. Each state's DoH may choose to tier their palliative care services with different classifications for the level of service. However similar levels of support apply as set by PCA to ensure equality of service provision throughout Australia (PCA 2018; Government of South Australia 2021; NSW Health 2020; Queensland Health 2021).

In rural areas of Australia, *Level Two Services* are based in the larger regional centres—that is, communities with a population of less than 50,000 (RAI 2017a). Depending on the size of the local population, these teams may consist of one or two RNs employed on a full-time equivalent, a social worker on a part-time or full-time basis and a pastoral or bereavement care worker on a part-time tenure. In some regional cities, an NP may also be employed. As introduced above, these teams are also responsible for the consultative support of Level One services within their geographical region (PCA 2018).

In many regional areas, community health services and therefore palliative care services are co-located with local hospitals and other health-related services. These services are multidisciplinary in composition and provide outreach services to smaller communities in surrounding areas. Sub- acute and non-acute services including palliative care are provided according to a nationally set Activity Base Funding system (NHFB 2021). Each episode of inpatient care is allocated an appropriate amount of funding according to a patient's diagnosis and expected length of stay (NHFB 2021). However, funding for community health care services is calculated from staffing ratios according to the population-based model as outlined in the Level One, Two and Three palliative care services mentioned above.

The final section of this chapter provides an outline of the thesis that follows. In line with the hermeneutic circle in a Gadamerian approach to understanding (Gadamer 1975/2013), one needs to understand the parts in order to understand the whole with the use of language within the text and vice versa (Gadamer 1975/2013). Thus, understanding of each part of the thesis is needed to understand the overall contribution to the existing body of research.

1.5 Overview of thesis

This thesis is presented in eight chapters, all underpinned by the philosophical thinking of Hans-Georg Gadamer (1975/2013). The second chapter provides an exploration of a wide range of literature using key words and terms related to the research question, which is ‘what are the lived experiences of RNs providing home-based palliative care in rural communities?’ Searches via databases, peer reviewed journals, reference lists and grey literature produced few results specifically exploring the lived experience of nurses in the context of providing home-based palliative care in rural communities in any country worldwide. The few articles that were identified were appraised and reported using a qualitative appraisal tool. Braun and Clarke’s (2006) qualitative analytical process was adopted to clarify emerging themes.

The third chapter presents the methodology and research methods adopted for this research study. As mentioned, the study follows the philosophical thinking of phenomenologist Hans-Georg Gadamer (1975/2013). Phenomenology sits within the qualitative research paradigm and careful consideration was given to the selection of a suitable phenomenological philosopher whose work would accommodate an in-depth exploration of the research question.

The first part of Chapter 3 provides an overview of the process followed in deciding to adopt Gadamer’s work as a guide to gain new understandings of this specialist nursing work. In the second part of the chapter, a concise overview of the framework chosen to bring structure to the analytical processes of this study is presented. That is, Diekelmann, Allen and Tanner’s (1989) extended seven-stage hermeneutic data analysis is explained. In the final section of the third chapter, demographic information relating to nurses who participated in this study is presented. The next three chapters in this thesis are then dedicated to reporting the findings of this study.

The chapters that present the results (4, 5 and 6) are guided by a pictorial representation to aid the reporting of the findings of this study. A table at the beginning of each chapter details categories, relational themes and sub-relational themes related to the common emergent overarching pattern identified utilising Diekelmann, Allen and Tanner’s (1989) analytical process. Excerpts from interviews with participants are reported under relational and sub-relational themes in each results chapter. These findings report RNs’ experiences of providing home-based palliative care in their own rural communities—experiences that would not have occurred in other settings such as metropolitan areas and hospital-based admissions.

A discussion of all the main findings from the previous three results chapters is presented in the seventh chapter. Literature is cited to support this discussion. A combination of natural cultural occurrences unique to living and working in rural communities are discussed. External organisational influences that affect home-based palliative care services are highlighted. The home itself as the setting of care is discussed because it has a prominent impact on the provision of palliative care. Gadamer’s hermeneutic philosophical thinking is woven throughout the discussion chapter, providing further insight and new understanding of the phenomenon.

The final chapter (8) provides a concise conclusion to this thesis. Final points are presented in a methodical way, leading to a series of suggested strategies being made in relation to improving support for nurses working in the unique care setting of patients’ homes in rural communities while providing palliative care. Strategies that will guide healthcare services in planning future home-based services and influencing government policy making at state, national and international levels are made. Finally, the limitations and strengths of this study are acknowledged and suggested areas for future research directions are outlined.

1.6 Summary

This introductory chapter has presented the aim, background, and context of this study. The rural communities represented in this research were from inner and outer regional areas of one state in Australia. These communities provide a range of industries, farming and produce to meet the needs of people who live in the local area, larger regional centres, cities, and export markets. Accessing health care services is one of the challenges faced by many rural communities in Australia, with funding for health care services being determined by the ARIA classification.

Palliative care services are funded by a complex mix of State and Federal governments, with specialist palliative care teams being located in the larger and medium sized regional communities. These teams provide consultative support to general community nursing teams located in smaller communities throughout the state. Both levels of services are supported by the city-based multidisciplinary specialist palliative care team on a needs basis.

This study was inspired by the author’s own professional experience of providing home-based palliative care in rural communities in the past. A phenomenological approach as guided by Gadamer was chosen because Gadamer recognised the researcher’s contribution to the outcome of their research. Matching this research approach, Diekelmann, Allen and Tanner’s (1989) extended method of data analysis was adopted. The next chapter in this thesis reports on the thorough search of published literature relating to nurses’ experiences of providing home-based palliative care in rural communities.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The purpose of this chapter is to report the literature that relates to the lived experience of RNs who provide palliative care for patients in rural communities, in the patients' own homes. In embarking on this research, it was firstly necessary to explore, review and evaluate existing published literature. This exploration was required to establish what was already known about this particular type of nursing and to identify any gaps in the research to date—a necessary step to validate the execution of a new study (Burns, Grove & Gray 2011). Thus, an integrated literature review was conducted. This process employed a structured systematic approach in identifying explicit and implicit themes from published literature (Murlow 1994; Fink 2010). The literature searched included peer reviewed articles, reflective or scholarly papers, dissertations, and grey literature in the form of government reports. Furthermore, reference lists of all articles retained were searched to ensure publications that related to the research question were covered.

2.2 Inclusion criterion

Extensive discussion with supervisors and a librarian after an initial broad search of sources determined an appropriate inclusion criterion for in-depth literature searches. This inclusion criterion guided searches of publications available in the English language, reporting primary research studies published between 1990–2022 with full text available. The commencement date was chosen because of its relevance to when funding for SPCSs was instigated in regional areas of Australia. Full text accommodated citing direct quotes from retained articles. Included in the criterion were key words relating to end-of-life care or palliative care in rural communities by nurses, with a focus on their lived experience. The most applicable databases for searches were then identified.

2.3 Searches

As illustrated in the preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow chart (Figure 2.1), searches included databases, journals pertaining to palliative care, reference lists. As detailed in section 2.3.3 key websites were searched in conjunction with a librarian to identify grey literature that may have included reference to primary research studies, or that provided background information to the research question.

2.3.1 Search by database

Databases searched included Google, Google Scholar, Scopus and ScienceDirect (via Elsevier), Medline and PsycINFO (via OVID), Pubmed, Proquest and CINAHL. An initial broad search using only the search terms was conducted before limitations were applied to the inclusion criteria. A combination of the following key search terms were used: ‘end of life care’, ‘palliative care’, ‘dying’, ‘nurse’, ‘experience’, ‘rural’, ‘regional’, ‘community’, ‘nurses’ lived experience’. These initial searches yielded 1,179 results. The search was refined, focusing on the following terms: ‘experience’, ‘end-of-life care’ and ‘community’.

The truncation ‘nurs*’ was then used as a method of widening the search term of ‘nurse’ so all nurse qualifications across countries of origin were included. The search term ‘end of life care’ yielded articles relating to palliative care and the term ‘nurs*’ included articles relating to ‘community nurse’ or ‘district nurse’. A total of 197 articles of interest were identified and further assessed for relevance from the search results as reported above. One hundred and forty-three articles were discarded as not relevant or being duplicates, with 54 being assessed further from an initial reading of titles. Of this number, four were excluded following re-reading of abstracts from 50 articles, with 41 being discarded. From these articles, further scrutiny of the full text reduced the number of articles to 9. Full text articles were retrieved to allow for the ability to offer direct quotes from retained articles.

No articles were excluded due to full text not being available. That is, all articles requiring a detailed read were available in full text.

2.3.2 Search by journal

The *International Journal of Palliative Care Nursing* and *Journal of Hospice & Palliative Nursing* were identified as publications reporting primary research studies that related to nursing in the specialty field of palliative care. These two journals were searched in accordance with the inclusion criterion, with 140 articles of interest being identified. Further reading of titles and abstracts excluded 133 articles that did not meet the inclusion criterion or were duplicates. Seven full articles were assessed for relevance, with one article being retained.

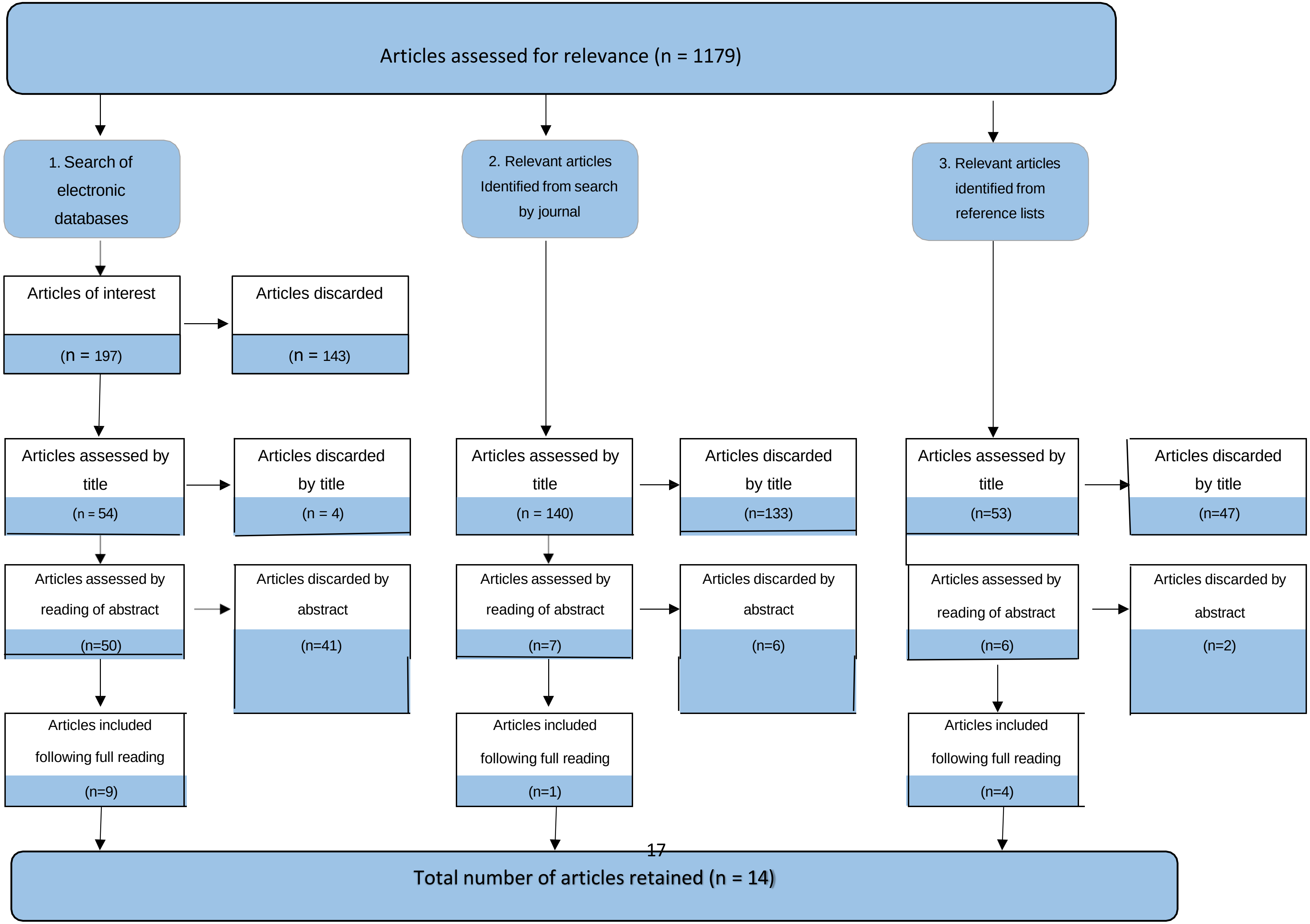
2.3.3 Search by grey literature

A search of governments reports was conducted from the following sources: World Health Organization (WHO), AIHW, DoH and PCA websites. Additionally, a dissertation search via the ProQuest database yielded one possible document of interest in the initial search of 49 titles; however, this thesis was later excluded in the second reading of titles.

2.3.4 Search by reference list

The reference lists of 10 articles from the first two search methods were hand-searched and a further 53 articles were assessed for relevance. A total of 47 articles were then discarded after reading of the titles as guided by the inclusion criterion. Finally, the abstracts then the full text of the six retained articles were read, which resulted in two articles being excluded and four articles being included. Figure 2.1 provides a PRISMA chart of all searches conducted from literature. A total of 14 articles were included from the search methods as reported above.

Figure 2.1: PRISMA flow chart of literature searches



2.4 Quality appraisal

A systematic appraisal of all included articles was necessary to establish rigour and trustworthiness. Koch and Harrington (1998) reported that once the use of qualitative methodology had expanded in the field of nursing research, angst relating to achieving rigour and trustworthiness increased. These authors and others have suggested that adhering to a systematic approach with well-recorded steps in the researcher's processes of analysis allows readers to determine the validity and trustworthiness of the results (May & Pope 1995; Koch & Harrington 1998). A later publication by Nowell and others (2017) confirmed that meeting the criteria for rigor and trustworthiness in qualitative research methodology relates to clearly defined thematic analytical processes.

Of the 14 articles retained from the search strategies as reported above, 11 articles employed a qualitative methodology, including three studies that used a mixed method design. The criterion for conducting the literature search (Section 2.2) was to identify articles that reported the lived experiences of nurses, rather than gathering numerical data. Therefore, a tool for appraising qualitative research design was required. The Critical Appraisal Skills Programme ([CASP] 2013; see Appendix 1) provided a clear 10 question checklist to guide the critique of articles and report research studies with a qualitative design.

2.5 Data analysis and abstraction

Each retained article was critiqued according to the CASP (2013) checklist and a detailed record of responses to each question was compiled (Appendix 2a). A table was then developed to present a concise summary (Appendix 2b). Nowell and others (2017, p.3) also advised that to strengthen credibility, the use of 'peer debriefing' is an integral tool. Aligning with this advice, multiple readings of all articles retained were conducted by the primary researcher over an extended period. Then, rigorous discussions took place at regular supervision meetings with the principal and associate supervisors to identify emergent themes.

Assisted by the completed CASP (2013) appraisal of each article, a thematic analysis was employed to identify emerging themes and subthemes. Braun and Clarke's (2006, p.87) method of analysis was chosen for its simplicity and thoroughness. This method provided a six-step process to follow in the analysis of data, including:

1. Researchers becoming acquainted with the data
2. Collating initial points of interest from the data
3. Identifying themes
4. Reassessing themes
5. Giving themes a title
6. Writing a detailed account of the findings

One common main theme, multiple themes and subthemes were identified. Discrepancies were resolved by returning to the research question as posed, re-reading articles and regularly reviewing the CASP (2013) checklist notes, as well as referring to the summary table. Furthermore, an ongoing process of reviewing all identified themes was employed throughout the writing of this chapter. The outcome of this analysis was to establish the contribution literature made in the assessment of the research question of this current study—that is, 'what are nurses lived experience of providing home-based palliative care in rural communities?' The next section of this chapter reports on findings from a thorough analysis of the 14 articles retained from the integrated review of literature as guided by the CASP appraisal tool and Braun and Clarke's (2006) six step process as outlined above.

2.6 Results

The 14 articles retained from all searches were primary research studies conducted in Canada (5), Australia (6) and the United Kingdom (3). Eleven articles reported on studies exploring experiences of nurses providing home-based palliative care specifically. Three articles presented experiences from the perspectives of family caregivers and nurses. Methodologies used in these studies included phenomenological designs, qualitative descriptive analysis, qualitative constructive or grounded theory, mixed method studies and cross sectional qualitative studies.

Table 2.1 presents a summary of the research question, themes, and subthemes to emerge from extensive analysis of the 14 retained articles. Two themes were discovered along with four corresponding subthemes. Each subtheme was placed under the research question of nurses' lived experience of providing home-based palliative care in rural communities. These themes assist in the presentation of the findings of the analysis in the results section of this chapter.

Table 2.1: The research question with themes and corresponding subthemes from the retained articles

Nurses' lived experiences of providing home-based palliative care in rural communities	
2.6.1 Nursing in rural communities	2.6.2 Nurses' emotional responses
2.6.1.1 Community connections (7)	2.6.2.1 Feeling rewarded (11)
2.6.1.2 Geographical distances (8)	2.6.2.2 Feeling frustration (9)
2.6.1.3 Organisational deficits (10)	2.6.2.3 Feeling hopeful or hopeless (5)
2.6.1.4 A lack of education (6)	2.6.2.4 Feeling fearful (5)

Note. The number of articles found are represented in each subtheme and detailed numerically alongside each subtheme.

The table above presents a synopsis of two dominant themes under the research question of nurses' lived experiences of providing home-based palliative care in rural communities. The first dominant theme was *nursing in rural communities* and the second, *nurses' emotional responses*. The theme of nursing in rural communities consisted of four subthemes: 'community connections', 'geographical distances', 'organisational deficits' and 'a lack of education'. The subtheme of community connections was present in 7 articles and geographical distances, 8 articles, while the subtheme of organisational deficits was present in 10 out of 14 articles. Six articles featured the subtheme of 'a lack of education'.

The second theme also consisted of four subthemes reporting on nurses' emotional responses:

‘feeling rewarded’, ‘frustration’, ‘hopeful or hopelessness’ and ‘fear’. The subtheme of feeling rewarded was present in 11 articles and frustration, 9 articles, while 5 articles reported feelings of hope or hopelessness. Similarly, 5 articles presented evidence of nurses experiencing feelings of fear. Each of these themes will be reported succinctly in the following sections of this chapter.

Nursing in rural communities

The literature revealed that some nurses had pre-existing connections with the families they were supporting. These pre-existing relationships presented personal and professional challenges for some RNs. Several studies reported specific examples of how community connections affected the role of the nurse and their private lives.

Community connections

Half of the studies (7) reported in the retained articles referred to the existence of complex social, business and family linkages between the nurses, patients’ families and other community members. For example, some RNs had connections through various business, sporting and school organisations where both parties attended (Wilkes & Beale 2001; Wilkes & White, 2005; Arnaert, Seller & Wainwright 2009; Cumming, Boreland & Perkins 2012; Reid 2013; Kaasalainen et al. 2014; Reed, Fitzgerald & Bish 2017). One study by Arnaert, Seller & Wainwright (2009, p. 202) exploring the attitudes of home care nurses involved in the provision of palliative care in Canada described nurses’ encounters with people their knew as ‘experiencing community embeddedness’. It was noted that community embeddedness occurred more for those RNs who had worked and lived in a community or rural region for many years. However, Arnaert, Seller & Wainwright’s (2009) study recruited only five participants from just one community raising questions about its generalisability. Reid (2013) presented results from a qualitative phenomenological study that explored the preparedness of six community nurses and four palliative care clinical nurse (CN) specialists working in rural regions of Scotland. They also found that pre-existing relationships between recipient families and themselves was a common occurrence in country areas. Therefore, when a child was terminally ill the whole community was affected, from the children at school to the wider village and including the nurses involved in providing home-based palliative care. However, Reid (2013) reported scantily about the specific nature of these multi-layered community contacts. For example, There was little or no explanation of the four excerpts relating to the theme of community connections included in the discussion section of the article.

From a different perspective, a study by Reed, Fitzgerald and Bish (2017) conducted in one state of Australia reported that knowledge about local resources and networks of support in their community contributed to RNs being able to successfully meet their patients' care needs. Furthermore, Reed, Fitzgerald and Bish (2017) found that district nurses' prior knowledge of families assisted in guiding patients to achieve their end-of-life goals. While the Reed, Fitzgerald and Bish (2017) study highlighted some understanding of community connections, it did not explore the broader experience of what it was like to work in patients' homes in rural communities.

Another study conducted in Australia by Cumming, Boreland and Perkins (2012) did expand a little on the phenomenon of community connections. They reported a mixed methods study that was conducted in the state of NSW. In the first phase of the study, 34 district nurses returned completed surveys mailed to 14 primary health care services in rural and remote areas. In the returned surveys 65% of the participating nurses had cared for their own friends or family members. Being involved in caring for these close associates or family members was accepted by these nurses as an expected part of both working and living in the same rural area. However, some nurses reported that in doing so the 'emotional burden was high' (Cumming, Boreland & Perkins 2012, p.279).

Arnaert, Seller and Wainwright (2009) agreed that close social and family connections in a rural community could result in taxing emotional responses. Caring for one's own community members came with a sense of community responsibility. For example, Cumming, Boreland and Perkins (2012) reported that the community's expectations may cause RNs to feel obliged to attend the funerals of all their patients. At times, this obligation caused additional stress as the RNs endeavoured to support patients in their care as well as being a supportive community member in times of grief (Cumming, Boreland & Perkins 2012).

An article by Wilkes and Beale (2001) explored the origin of community-initiated stressors. Their study reported details of the origins of stress for nurses who were involved in providing palliative care in either urban or rural settings. This comparative study was conducted to establish whether there were any differences in the stressors between the two groups of nurses. The participant group consisted of seven nurses from a metropolitan suburb and five nurses from a rural region. The lived experiences of both groups of nurses were recorded collectively; therefore, it was unclear whether the stressors experienced were directly related to both the work and residing in a rural community (Wilkes & Beale 2001). Within this study, role conflict within the community was reported a major stressor for some RNs. Navigating the care of patients while dealing with tumultuous family dynamics was also stressful. Additionally, working in small communities presented the challenge of maintaining patients' confidentiality and RNs' privacy.

Kaasalainen and others (2014) provided some insight in a descriptive qualitative methodological study that explored the experiences of 21 RNs involved with the provision of home-based palliative care in a large province of Canada. It was expected that the community members knew a family was receiving palliative care support. The RNs involved in visiting the home were also known by the wider community. Thus, the privacy of both parties was at stake. Interestingly, Kaasalainen and colleagues (2014) reported the RNs were more concerned with upholding the confidentiality of their patients than preserving their own privacy. While Kaasalainen and others (2014) mentioned RNs had some difficulty in protecting their own anonymity, they did not provide information that explored this occurrence further (Kaasalainen et al. 2014).

A study conducted by Wilkes and White (2005) in Australia found that RNs who worked in rural communities readily formed close professional relationships with families whose loved ones required palliative care. These partnerships were established with ease when previous community connections existed. Furthermore, because they all lived in the same area, they had insight into what it was like living in that particular community or district. For example, when families lived on farming properties in some arid areas, RNs knew they needed to take into consideration environmental factors that may affect the care they needed to give. These factors included low seasonal rainfall, which meant they were not to assume there was enough water to provide patients with daily personal hygiene (Wilkes & White 2005). However, this article reported both the lived experiences from the perspective of family members and nurses together. Therefore, details that related to the 10 participating RNs was limited (Wilkes & White 2005). In contrast, the research by Wilkes and Beale (2001) found that close family links to patients contributed to RNs stress. These researchers reported and highlighted that close relationships in rural communities could be contrary to nurses' professional roles. In other words, Wilkes and Beale (2001) identified a quandary for RNs in seeking to uphold professional boundaries. These boundaries were tested in some circumstances; one nurse shared 'on a bad day you could run into six bereavements on the way around shops' (Wilkes & Beale 2001, pp.309–310). This excerpt illustrated that community connections between the family and nurses did not cease upon the death of the patient.

A study by Reid (2013) agreed that ongoing relationships with families is a unique phenomenon in rural communities. While these studies reported some lived experiences of nurses living and working in the same rural community they did not delve deeply into the professional and personal impacts of these community connections. More exploration is needed utilising an in-depth phenomenological approach rather than descriptive qualitative or mix method designed studies.

The next subtheme to emerge from the literature was nurses' experiences of working across large geographical distances.

Geographical distances

Several studies reported challenges nurses experienced working in large geographical areas. Most families living in country areas were familiar with the need to travel long distances to access services such as health care. Likewise, health care professionals including community nurses accepted that driving varying distances to reach patients homes was an expected part of their role. The long-distance drive to visit patients at home was featured in eight of the 14 retained articles (Wilkes & Beale 2001; Rosenberg & Canning 2004; Wilkes & White 2005; Arnaert, Seller & Wainwright 2009; Cruickshank, et al*.,* 2010; Reid 2013; Kaasalainen et al. 2014; Spelten et al. 2019). An early article by Wilkes and Beale (2001) found that long-distance driving in a large geographical region like Australia was a challenge for some community-based RNs. Their explanation was that distances travelled not only reduced the amount of time nurses spent with each patient but also affected the number of home visits possible on any given day (Wilkes & Beale 2001). For example, patients' face-to-face support could be reduced from a daily visit to once a week or less.

Another study also conducted in Australia (Spelten et al. 2019) reported that the need to travel long distances to patients' homes added to the complexities of the work involved, particularly at the beginning of a care episode. Forming a therapeutic relationship to conduct an in-depth assessment of patients' care needs took time, which was extended when factoring in travel to and from the home. Participating nurses found the use of technology in the set-up of an iPad did assist the family to feel supported in subsequent contacts. Furthermore, the iPads mitigated the nurses' need to drive out to the home in order to stay up-to-date with changes in a patient's status and care needs. However, this study only gathered data from interviews with four nurses; therefore, the depth of understanding the lived experience was minimal.

Extensive travel in another large country (that is, Canada) affected the RNs' workload. Two different studies conducted in Canada highlighted that careful workload planning was needed to deliver patient-centred care in a timely manner (Arnaert, Seller & Wainwright 2009; Kaasalainen et al. 2014). This scenario was specifically illustrated by Cruickshank and others (2010), who found that the set-up of equipment such as a portable syringe driver (see 'subcutaneous syringe driver' in Glossary) for symptom management could be impeded by having to travel long distances. Any delays caused by long distances could also impede the provision of quality care in the management of symptoms. Furthermore, adverse weather conditions could prevent, or delay nurses' return to patients' homes to monitor the function of a syringe driver and review the effectiveness of medications being administered by this device.

When care coordination was affected by long distances or inclement weather, both the family and nurses reported negative experiences (Cruickshank et al. 2010). However, the article by Cruickshank and others (2010) included just one short paragraph in the results section about the impact of geographical distances on nurses' work. Further, it only reported the experience of just one or two nurses. It was unclear whether the two quotations included were from the same community nurse, as no number of participants was recorded. As previously noted, this article presented a study from the perspectives of family carers, patients, and nursing staff; therefore, inclusion of nurses' lived experiences was limited.

Further challenges relating to geographical distances were also reported in other studies. Kaasalainen and others (2014) explained that the role of the RN in rural and remote areas involved not only travelling long distances but also driving on poorly maintained roads in inclement weather. In addition to these concerns, many nurses worked alone. One nurse shared that working in her rural area involved driving between five different towns (Kaasalainen et al. 2014).

Arnaert, Seller and Wainwright (2009) presented similar geographical profiles and found RNs experienced feelings of physical isolation because of large geographical distances. This isolation was compounded by infrequent contact with other health care professionals, such as pharmacists, doctors, and allied health care workers (Arnaert, Seller & Wainwright 2009). Reid (2013) agreed and suggested that some RNs working in rural and remote areas felt they had no one to support them professionally. Reid’s (2013) article as reported in the previous subtheme related to lived experiences of nurses supporting families caring for terminally ill children. These nurses felt particularly isolated when specialist palliative care teams were involved in supporting their local families. These teams were based in centres located large distances away, so contact was infrequent, resulting in haphazard interdisciplinary communication and support. However, Wilkes and Beale (2001) found small cohesive teams of nurses in remote communities in Australia seemed to benefit more from their local ad hoc professional networks of support than did their city counterparts. This situation continued even when larger metropolitan teams of nurses had structured systems of debriefing readily available.

From a different stance, Wilkes, and Beale (2001) found that nurses’ physical isolation was compounded when the patient’s family was not coping in the primary caregiver role. On occasions the RN noted that it was a struggle for the family to care for their loved one. However, despite their difficulties, most families wished to continue to care in order to honour a loved one’s wish to die at home. In these situations, having limited opportunities to visit to provide additional support (because of large geographical distances) affected the nurses’ professional role and their personal emotional wellbeing (Wilkes & Beale 2001).

Feelings of professional isolation manifested in other ways, too. Rosenberg and Canning’s (2004) research presented results from a descriptive evaluation of a two-day face-to-face educational program. This program was for RNs and enrolled nurses (ENs; see Glossary) working in regional areas in the state of Queensland in Australia. Topics covered pertained to providing palliative care (Rosenberg & Canning 2004). All participants who returned a survey (17 RNs & Enrolled nurses (ENs): the article did not itemise results according to nurse qualification status) indicated that it was difficult for them to attend educational updates (Rosenberg & Canning 2004), citing ‘geographical isolation increased the time required’ to travel to and from these programs (Rosenberg & Canning 2004, p.169). The results section of the article only briefly recorded this challenge, with a generalisation in discussion of the article stating that despite several challenges in accessing education, the nurses were still eager to pursue opportunities to attend face-to-face forums (Rosenberg & Canning 2004).

Further exploration is required to gain insight into the effects of geographical distances on the lived experiences of nurses accessing professional development programs. It was evident from these seven articles that geographical distances affected nurses’ work of providing palliative care in rural communities. However, little in-depth attention has been given to this subtheme. Another subtheme to emerge from the retained articles related to deficits in service provision at an organisational level.

Organisational deficits

In rural communities where RNs are placed, both community nurses and specialist palliative care teams (see Glossary) contribute to the care of patients requiring palliative support at home. Ten out of the 14 retained articles contained evidence of challenges in dealing with organisational gaps in the delivery of home-based palliative care (Arnaert, Seller & Wainwright 2009; Cruickshank et al. 2010; Penz and Duggleby 2011; Cumming, Boreland and Perkins 2012; Marchessault, Legault & Martinez 2012; Penz & Duggleby 2012; Tunnah, Jones & Johnson 2012; Kaasalainen et al. 2014; Reed, Fitzgerald & Bish 2017; Spelten et al. 2019). The main concern for community nursing teams was a lack of funding for educational support. In smaller country towns community nurses may care for just a few palliative care patients over several years (Cruickshank et al. 2010). Given the infrequent nature of this type of care, it could be difficult for these RNs to retain up-to-date clinical knowledge such as how to set up and maintain a subcutaneous syringe driver. RNs who work in this field also needed to provide families with information about how to manage a syringe driver, including reloading medications. This aspect applies particularly if home visits are to be provided every day (Cruickshank, et al. 2010). This lack of knowledge was reported by Cruickshank and colleagues (2010) as reflecting on the nurses' ability to provide appropriate care. It could also reflect an organisation's failure to support clinical staff need for regular education. Furthermore, owing to their infrequent use, syringe drivers could be poorly maintained and may reflect on poor management by the organisation. In addition, delays in accessing a replacement syringe driver may affect the setting up of this device in a timely manner. Such gaps in service affected the management of a patient's distressing symptoms.

In another article by Tunnah, Jones and Johnson (2012), community nurses experienced other organisation-related stressors as they went about their work in the provision of home-base palliative care. Tunnah, Jones and Johnson's (2012) study, conducted in Northwest Wales in the United Kingdom, showed job satisfaction as a major theme to emerge. While most nurses found they made a difference in the home by their quality patient care together with the support of family caregivers and this was rewarding, organisational stressors such as poor team communication, heavy workloads and a lack of debriefing affected their experience negatively (Tunnah, Jones & Johnson 2012). These RNs found that they needed to seek support from their own work colleagues and families to help mitigate a lack of debriefing support from the organisation.

The rigour of Tunnah, Jones & Johnson's (2012) study may have been partially compromised because the interviewer was also the manager of the research project and had previous professional connections with interviewees. This limitation was acknowledged as the authors noted that because of these factors, the depth of deficits within the organisation may not have been revealed. However, Creswell (1994) suggested a researcher's familiarity with the setting of a study could aid insight and understanding as data analysis proceeds.

Spelten and others (2019, in an Australian study) highlighted the RNs' need for the opportunity to debrief, further reporting that this type of support was in reality ad hoc. RNs knew that to receive a debrief when they needed it, other informal avenues from within the organisation, such as a text message from another RN in the team, were timelier. These participants readily recognised that they were sole practitioners and working in rural communities meant that at times official support was not available when they needed it. The findings reported that the camaraderie between colleagues did help to support some RNs. They appreciated informal support from other colleagues, who would give them a call to check on their wellbeing (Spelten et al. 2019). Retaining a sense of hope was cited as an important aspect of working alone in a rural setting and overcoming organisational deficits.

The aim of a study by Penz and Duggleby (2011) was to explore sources of hope for RNs providing home-based palliative care in a western province of Canada. These RNs worked in a large geographical area covering urban, rural, and remote community locations. The study followed a grounded theory methodology to establish a practice model (Creswell 1994). Purposeful sampling was used in recruiting RNs who worked in either urban or rural areas. The article provided a comprehensive record of the study design, recruitment, data collection and analytical processes. A total of 14 RNs participated in semi-structured interviews. These participating nurses were interviewed via a telephone call and kept a daily journal over a two-week period to record their thoughts about feelings of hope as they conducted their role (Penz & Duggleby 2011). All participants except one were interviewed twice to accommodate any clarification needed from the first round of data collection. Creswell (1994) considered multiple methods of data collection in qualitative research design to be useful. For example, journaling may suit participants who were not at ease in the interview setting. Penz & Duggleby (2011) recorded most participants said they endeavoured to have a positive attitude about their work despite negative organisational influences such as inadequate time allocation for patient visits. One strategy used to retain some feelings of hope was to negotiate positive outcomes for their patients and themselves. The RNs proactively pursued the need for purpose and meaning in their work—an attitude that assisted in deflecting negative thoughts about gaps in service caused by organisational constraints.

As previously noted, Penz and Duggleby published a second article the following year that identified more of the challenges and rewards RNs experienced as they cared for patients requiring palliative care at home. Penz and Duggleby's (2012) thematic analysis clarified the contextual characteristics of the RNs' work by the use of constant comparative methodology. Multiple subthemes that related to RNs' lived experiences as employees of a health care organisation were identified. Participants described feeling resigned to a system in which they experienced a lack of support, lack of resources and gaps in service provision. To counteract these occupational stresses, participants found that autonomy within their roles did contribute to feelings of being trusted by their organisation (Penz & Duggleby 2012). These researchers concluded that limitations of their second study were reduced by following a thematic analysis of findings from the earlier study (Penz & Duggleby 2012). However, it was noted that only female nurses from similar cultural backgrounds were recruited (Penz & Duggleby 2011), which may have affected the rigour of the findings.

The expectation of community nurses who carry out multiple roles within their workload featured in Cumming, Boreland and Perkins's (2012) article. In this mixed method study with 34 community nurses, Cumming, Boreland and Perkins (2012) reported that the nurses had multiple roles to fulfil. For example, a little less than half (45%) of nurses had up to 15 different roles in addition to attending to palliative care home visits (Cumming, Boreland & Perkins 2012). The numerical value of the range of primary health care activities underscored the significance of this challenge. However, these other roles were not detailed at all in the article. These authors explored attitudes of this group of nurses and reported the provision of home-based palliative care was accepted as an integral part of their work in the community (Cumming, Boreland & Perkins 2012). However, fulfilling multiple roles often resulted in heavier workloads than other teams working in larger, urban based community services.

As reported by Penz and Duggleby (2012) and Arnaert, Seller and Wainwright (2009), some RNs felt resigned to working with heavy workloads. Finding time to attend to home-based palliative care visits added significantly to their already busy and demanding workloads. One approach utilised by RNs in Arnaert, Seller and Wainwright's (2009) study was to reorganise the timing of home visits. Visits to palliative care patients were scheduled at the end of the RNs' day to ensure there was adequate time without needing to rush away to another home. However, this initiative often resulted in RNs working unfunded overtime (Arnaert, Seller & Wainwright 2009). Another strategy employed by a nurse in Penz and Duggleby's (2012) study was to focus on how changes could be implemented rather than on organisational constraints. These constraints could include not having enough equipment, funding and time.

Marchessault Legault and Martinez (2012) identified more challenges in their findings from a Heideggerian interpretive phenomenological study. The aim of the study conducted in Quebec, Canada explored the experiences of RNs who provided home-based palliative care while conducting a wide range of other task-oriented care in the community. Eight RNs participated in the study. While the interviews were unstructured, three main themes and 13 subthemes provided evidence of extensive data analysis. Minor reference is made in the paper to RNs ' specific experiences, in contrast to the focus on the nurses' role in establishing and providing care for the patient and family (Marchessault, Legault & Martinez 2012). A brief account is provided in the article of the struggle some nurses encountered to transition between caring for general and palliative care patients because each group had very different needs. This challenge was combined with feelings of guilt if there was an extension of time spent with the palliative care patients that reduced time spent with other patient groups (Marchessault, Legault & Martinez 2012).

Articles by Cumming, Boreland and Perkins (2012) and Kaasalainen and others (2014) considered the impact of there being only a small workforce of nurses in some rural areas. This may mean there are very few qualified RNs to attend to all aspects of community nursing, including the support of patients who wish to receive palliative care at home (Cumming, Boreland & Perkins 2012). The confidence of the nurses in these studies in providing palliative care in a remote area of Australia was limited because their work involved caring for diverse patient groups. For example, midwives were required to provide community-based post-natal support as well as visiting patients dying at home and attending to general clinical tasks for others (Cumming, Boreland & Perkins 2012). Adding to the diversity of patient groups, Kaasalainen and others (2014) found community-based nurses who conducted home visits for palliative care patients were also required to attend to various administrative tasks, answering phone calls and sending faxes. The inclusion of all these tasks required the RNs to work unpaid overtime. These challenges were reported within the broad theme of the nature of rural nursing (Kaasalainen et al. 2014).

The methodology in Reed, Fitzgerald and Bish's (2017) study followed a nursing theory and pragmatic approach that focussed on the research question of how district nurses advocated for patients' end-of-life care choices. In doing so there was scant report of a wide range of lived experiences from the RNs who participated. However, it was noted that these district nurses needed to invest a lot of their own personal emotional energy to ensure patients' wishes in end-of-life care were upheld. The main driver of this personal emotional investment on the part of nurses was a high level of frustration and anger because of deficits in organisational resources, and a belief the organisation did not understand their role (Reed, Fitzgerald & Bish 2017).

A lack of education

The fourth subtheme to emerge from the literature was the maintenance of an adequate knowledge base, specifically in regard to the specialty area of palliative care nursing. The challenges RNs experience in accessing professional development emerged in six articles (Rosenberg & Canning 2004; Cruickshank et al. 2010; Cumming, Boreland & Perkins 2012; Marchessault, Legault & Martinez 2012; Kaasalainen et al. 2014; Spelten et al. 2019). As previously reported (Section 2.6.1.2), barriers to accessing educational forums include the long distances RNs need to travel (Rosenberg & Canning 2004). Likewise, the cost of program registration is expensive and the ability to secure time away from clinical workloads is not easy. Low numbers of RNs & ENs in remote areas mean the possibility of no other nurses to provide backfill (Rosenberg & Canning 2004). Rosenberg and Canning's (2004) study design was limited owing to data only being gathered from a 12-item open-ended survey with no follow-up interviews or focus groups being conducted. While qualitative data from the open-ended questions was read and re-read by the research team to identify themes, only three themes were included in the article. The authors referred to three tables with quantitative data to report participants' experiences in accessing educational forums. The first table listed just five participant excerpts related to professional development. Some challenges were: RNs holding multiple roles; meeting the needs of many different patient groups, including palliative care; difficulties in accessing education about palliative care specifically, although motivated and supported by their employer to attend forums and conferences. The second table listed different modes of education and strategies to support future forum planning, and therefore did not report participants' voices. The third table was a brief collation of excerpts that described participants' experiences of attending the workshop (Rosenberg & Canning 2004, p.170). The results and discussion section of the article were brief therefore did not convey an in-depth analysis of the RNs and ENs experiences in attending educational forums (Rosenberg & Canning, 2004, p.170).

Similar challenges were reported from a study conducted in Canada by Marchessault, Legault and Martinez (2012). This study recruited eight general community nurses in one province of Canada to participate. Participants admitted that they struggled to maintain their knowledge and skills in providing specific, evidence-based palliative care practice. Alarmingly, one nurse said that she had not attended an educational update for five years (Marchessault, Legault & Martinez 2012). The researchers reported in one paragraph that a lack of education negatively affected the nurses' confidence in the care they provided (Marchessault, Legault & Martinez 2012).

Cruickshank and others' (2010) study identified a nurse who had confided to her interviewer that when a patient was in a terminal phase of an illness, she had difficulty remembering how to set up equipment such as a syringe driver. As previously mentioned, knowledge of current medications and the knowledge needed to monitor the syringe driver's functioning can be a challenge. Organisational deficits and a lack of regular educational updates all contributed to RNs' lack of knowledge, although these RNs demonstrated their resourcefulness by seeking the support of colleagues (Cruickshank et al. 2010).

The need to feel equipped for the work required in the provision of home-based palliative care also featured in the primary research article by Cumming, Boreland and Perkins (2012). Their study presented findings where 10 Community Nurses were invited to complete a questionnaire and participate in phone interviews. Their experiences were in rural and remote areas of the far west of NSW, Australia. Some descriptive analysis was undertaken. These authors reported that although 90% of the participating nurses had attended education forums on a range of clinical topics recently, more professional development was needed on how to care for palliative care patients (Cumming, Boreland & Perkins 2012). A range of educational developmental opportunities were shown to be available and were listed in a detailed table that provided a clear summary of the numbers of the nurses who felt equipped in various areas of their practice. These skills included RNs feeling professionally and personally prepared to work with palliative care patients and being able to discuss spiritual matters with patients and provide bereavement support to families. Cumming, Boreland and Perkins (2012) reported that most of the community nurses who participated in their study had contact with SPCSs (see Glossary). During these contacts the RNs were able to seek advice about patient care needs, which assisted in mitigating the lack of formal educational programs. The last subheading in the table listed some barriers to education, including workload, staff backfill, funding, lack of transport, little technology and isolation (Cumming, Boreland & Perkins 2012). A succinct summary of the feasibility of various educational initiatives was provided in a fourth table, with qualitative analysis employed to extend understanding of nurses' lived experiences The most feasible mode for educational updates was reported as being online learning, and attending conferences was deemed the least practical way to achieve regular upskilling. Some participants in this study conveyed to their researcher that retaining knowledge about providing emotional and spiritual support to patients and family members was more challenging than management of distressing physical symptoms (Cumming, Boreland & Perkins 2012).

In contrast, Kaasalainen and others (2014) stated that Community Nurses struggled with feelings of inadequacy in the nursing management of distressing physical symptoms that patients experienced throughout the trajectory of their terminal illness. Additionally, RNs were not always confident in their knowledge when they needed to be educators for patients, family and other supporters. For example, talking to family and the patient about a change in the focus of care from curative to comfort care could be challenging (Kaasalainen et al. 2014).

Marchessault, Legault and Martinez (2012) agreed that when a GP had not explained the terminal nature of a disease to the patient and family, it was difficult to prepare a patient for the dying process. Marchessault, Legault and Martinez (2012) also found patients not wishing to talk about or acknowledge the terminal nature of their disease could present challenges for some nurses in being able to engage in open and honest conversation. The challenges of keeping up-to-date in knowledge and skills, dealing with multi-layered community connections, insufficient time, travelling vast distances and inadequate education resulted in these nurses experiencing a range of emotional responses. Nurses' emotional responses as described in Table 2.1 will be presented in the next section of this chapter.

2.6.1 Nurses' emotional responses

In 12 out of the 14 retrieved articles, RNs reported that they experienced a range of positive and negative emotional responses while caring for terminally ill patients at home in their own rural communities (Wilkes & Beale 2001; Rosenberg and Canning 2004; Arnaert Seller & Wainwright 2009; Cruickshank et al. 2010; Penz and Duggleby 2011; Cumming, Boreland & Perkins 2012; Marchessault Legault & Martinez 2012; Penz & Duggleby 2012; Tunnah, Jones & Johnson 2012; Reid 2013; Kaasalainen et al. 2014; Spelten et al. 2019). These emotional responses included feeling rewarded or frustrated. Sometimes the nurses experienced feelings of hope; at other times, the polar opposite of hopelessness. Feelings of fear were also evoked for some as they went about their work. The emotional response of feeling rewarded for their work will be reported in the first subtheme to follow.

Feeling rewarded

Feeling rewarded was reported in 11 articles (Wilkes & Beale 2001; Rosenberg & Canning 2004; Wilkes & White 2005; Cruickshank et al. 2010; Cumming, Boreland & Perkins 2012; Marchessault, Legault & Martinez 2012; Penz & Duggleby 2012; Tunnah, Jones & Johnson 2012; Reid 2013;

Kaasalainen et al. 2014; Spelten et al. 2019;). The RNs experienced positive emotions when they received expressions of gratitude from patients and their families (Cruickshank et al. 2010): for example, a family's appreciation when their loved one's symptoms were relieved when a syringe driver was set up at the right time (Cruickshank et al. 2010). Penz and Duggleby (2012) claimed that RNs were the recipients of the community's respect for the work they did in patients' homes.

Feeling valued by families was also identified as a factor in feeling rewarded by RNs in Cumming, Boreland and Perkins's (2012) study, and Spelten and colleagues' (2019) study. Wilkes and White (2005) found families reported that nurses were a source of trust through the difficult time of caring for a terminally ill loved one, as these nurses understood not only the specific needs in the management of distressing physical symptoms, but also the culture of a rural community—a culture that included being aware of how to go about their work in an unobtrusive way in patients' homes. Nurses' feelings of reward also stemmed from being proactive in advocating for their communities' needs, as well as being aware of other health care professionals' needs. Reward was linked to the experience of high levels of professional achievement and high job satisfaction. Professional fulfilment was briefly described in studies by Cruickshank et al. (2010) and Marchessault, Legault and Martinez (2012). Some nurses felt energised when an episode of care for a patient and family was successful. However, as reported earlier in this chapter, recording of nurses' lived experience in Cruickshank et al. (2010) was overshadowed by numerous excerpts from family and patients' perspectives, so the RN's voice was not clear. In Marchessault, Legault and Martinez's (2012) study, RNs were similarly confident in their ability to care for their patients, particularly in the assessment of patients' needs and the development of patient-centred care plans. Although adjusting care plans as patients' needs changed was considered a challenge, it was also a rewarding part of the RNs' work.

Despite the pressure from management of the organisation to carry out many other tasks, the provision of palliative care in patients' homes is rewarding (Cruickshank et al. 2010; Cumming, Boreland & Perkins 2012; Tunnah, Jones & Johnson 2012; Reid 2013; Kaasalainen et al. 2014). RNs are required to coordinate many aspects of patients' care, which involves scheduling medical visits, setting up volunteer support and liaising with allied health services (Kaasalainen et al. 2014). For example, care workers who provide personal assistance for patients in showering, bathing and general hygiene needs require supervision by these community nurses (Cumming, Boreland & Perkins 2012). Additionally, RNs enjoy working collaboratively with allied health services: for example, making a referral for an occupational therapist to assess and then arrange for equipment to support a patient's declining mobility. This may take several days to a week or more (Cruiskshank et al. 2010; Kaasalainen et al. 2014). RNs have reported that working in a multidisciplinary team to ensure patients received holistic care is very rewarding, particularly in endeavouring to support a patient's wish to die at home. The results sections in several articles included evidence that RNs considered the coordination of home-based palliative care for terminally ill patients in their own communities as a privilege (Cruickshank et al. 2010; Penz & Duggleby 2012; Tunnah, Jones & Johnson 2012; Reid 2013). Tunnah, Jones and Johnson (2012) claimed RNs felt rewarded when patients were kept comfortable in their final days of a terminal illness. Three excerpts refer to the reward of a well-coordinated home-based service. High job satisfaction was achieved when patients were kept comfortable with good symptom management. It was then the RNs felt they had really made a difference, which led to feelings of being privileged to be able to contribute to quality patient care. However, in Tunnah, Jones & Johnson (2012), reporting of the results was combined with the discussion section; therefore, little explanation was given of the included excerpts.

Reid's (2013) article concluded that despite many challenges, RNs found being part of the care team for terminally ill children was an honour. It is a pity that more emphasis was not given to the reporting of these positive experiences earlier in this article. The results section of the article foregrounds experiences like feeling unprepared to care for terminally ill children, poor coordination of home-based services and upholding professional boundaries in small, ‘tightly-kit[*sic*] rural communities’ (Reid 2013, p.544).

Penz and Duggleby (2012) also identified that being an invited guest in a patient’s home is very rewarding for RNs. The detailed data in their table of results relating to challenges and rewards of providing home-based palliative care in rural communities was further reported in the results section under the heading of ‘Feeling valued and respected’ (Penz & Duggleby 2012, p.369). Having an adequate knowledge of palliative care, a sense of professional and personal autonomy, and being respected by their patients and co-workers all contributed to nurses experiencing feelings of reward.

Rosenberg and Canning (2004) briefly reported that nurses in their study felt they had the necessary skills to coordinate patient care and educational programs. This aspect was viewed as a positive affirming experience. Educational forums provided them with vital updates in clinical practice, professional support and networking, all of which encouraged them to continue the provision of home-based palliative care in their rural communities.

Kaasalainen and others (2014) concluded that despite numerous difficulties in providing a home-based service—such as large geographical distances, lack of education and heavy workloads—RNs see themselves as valuable members of the care team. Wilkes and Beale’s research (2001) stated one nurse shared that informal support systems consisting of her own family, friends and community associates provided important affirmation about the work she did. Personal inner strength within the character of nurses in Penz and Duggleby’s (2011) study was a factor that contributed to not only the retention of a sense of hope but the achievement of feelings of reward for the work done. Forming close relationships with the primary caregiver in each family was another source of reward for some nurses. Nurses in Marchessault, Legault and Martinez's (2012) study found when they worked to provide quality care through the formation of meaningful relationships with families and patients, they felt rewarded.

While the literature reviewed provides some insight at a basic level into this subtheme of feeling rewarded, more exploration is needed. The lived experiences of nurses providing home-based palliative care in relation to the uniqueness of the life in rural communities from a personal and professional perspective is scantily represented in current literature.

Feeling frustrated

Not all emerging subthemes within the theme of emotional responses were positive in nature; one negative reaction reported in the literature was frustration. Feelings of frustration were prominently reported in nine articles (Wilkes & Beale 2001; Arnaert, Seller & Wainwright 2009; Cruickshank et al. 2010; Cumming, Boreland & Perkins 2012; Penz & Duggleby 2012; Tunnah, Jones & Johnstone 2012; Reid 2013; Kaasalainen et al. 2014; Reed, Fitzgerald & Bish 2017). Reid's (2013) study of ten Community Nurses' experiences found that conflict with other service providers was a major source of frustration. For example, frustration could occur for general community nurses when the case management of the patient was not clearly defined—specifically, when specialist palliative care teams were also involved in direct patient care (Reid 2013). Miscommunication between the teams led to the local community nurses feeling shut out of the patients' care.

In other studies, feelings of frustration originated from a myriad of causes. Frustration occurred when there was inadequate support from medical officers, managers and larger services centre providers. At times it was difficult for RNs to access medical advice (Tunnah, Jones & Johnstone 2012). Furthermore, Arnaert, Seller and Wainwright (2009) reported that the absence of medical advice or educational updates meant some RNs did not have access to the internet in some remote areas to search for up-to-date, evidence-based information. These challenges added to their feelings of frustration as they believed they were overlooked by their organisations.

A lack of educational resources was compounded by shortages of equipment, which also caused frustration. Equipment included hospital-style beds and bathroom aids to assist in the daily care of patients (Tunnah, Jones & Johnstone 2012; Reid 2013; Kaasalainen et al. 2014; Reed, Fitzgerald & Bish 2017). Additionally, equipment that was not well maintained or readily available at short notice—including syringe drivers—led to frustration (Cruickshank et al. 2010).

An RN in Kaasalainen and colleagues' (2014) study reported at times long delays in equipment being delivered from larger regionally based health services. In addition, basic items such as wound dressings could be in short supply. RNs in Cruickshank and others' study (2010) registered feelings of frustration when the assembly of a syringe driver in a patient's home was delayed because the local pharmacy and medical clinic were only open on a part-time basis. Feelings of frustration were paramount because the lack of supplies in rural areas reflected poorly not only on the preparedness of the palliative care service but also on the RN's professionalism.

Similarly, Reed, Fitzgerald and Bish (2017) reported district nurses needed to access guidelines from other organisations on how to undertake the discussion of end-of-life care wishes in such a way that would assist in realising patients' wishes. Their own organisation did not have in place appropriate resources that they could use. This failure affected RNs professionally as they strove to go about providing quality home-based palliative care in their own rural communities.

Wilkes and Beale's (2001) study shared briefly how difficult it was for nurses to work with medical officers who did not agree that a patient's health status was terminal. This lack of continuity in understanding resulted in the palliative approach to care not being initiated, or delayed, comprising patient care.

From another perspective, Cumming, Boreland and Perkins (2012) claimed there was an account of how providing palliative care in homes in rural communities was just one aspect of community nurses' work. As presented previously in this chapter, these authors found general nurses had multiple patient groups to care for (Section 2.6.1.3). Therefore, these nurses felt frustrated when the organisation did not support their willingness to not only care for the palliative care patient group but also work overtime to meet their end-of-life care needs (Cumming, Boreland & Perkins 2012). RNs in Penz and Duggleby's (2012) research reported that feelings of frustration emerged when contact with other nurses was sporadic and employers failed to provide official debriefing following the death of a patient. It was a disappointment that the detail of nurses' feelings of frustration was scantily reported in these nine articles.

Feeling hopeful or hopeless

Another emotional response evident for some nurses was differing perceptions of hope or hopelessness. The emotions of hopefulness or hopelessness were an identified subtheme in five articles (Wilkes & Beale 2001; Rosenberg & Canning 2004; Penz & Duggleby 2011; Penz & Duggleby 2012; Kaasalainen et al. 2014). Penz and Duggleby's (2011) study found that if the RNs felt they had made a positive difference in their patients' care, they experienced a sense of hope. This study considered the professional and personal aspects of the 14 participating RNs, providing some insight into how the nurses derived feelings of hopefulness within their personal selves as well as in their professional role. Understanding themselves as people was shown to be an attribute that contributed to feelings of hopefulness. Retaining a balance between their personal and professional lives was another avenue for retaining hope (Penz & Duggleby 2011). Balance was achieved by an equal investment of time and commitment in their professional roles and achieving life goals in their personal lives. This phenomenon of the location of balance in nurses' lives is not reported in any other of the retrieved articles and is therefore worthy of further exploration.

For other RNs, feelings of hopelessness remained, despite all their efforts to ameliorate it. Penz and Duggleby (2012) recorded under the subtheme of 'managing grief and loss' that feelings of hopelessness were compounded when nurses experienced the death of several patients in a short timeframe. These deaths could include people who were community associates, friends and colleagues of the nurses. Deterioration of patients' wellness also contributed to feelings of hopelessness.

Wilkes and Beale (2001) claimed that nurses could feel a situation was hopeless when a family's physical and emotional fatigue made caring for a loved one at home difficult to continue. Additionally, a situation could seem hopeless when the primary carer's own health needs were not being met, thus impeding their ability to support their dying loved one. Nurses felt overwhelmed, particularly if the family felt duty-bound to continue home-based care beyond their capacity to do so (Wilkes and Beale 2001). Having insufficient resources also contributed to feelings of hopelessness.

Feelings of hopelessness were linked to inadequate staffing. For example, nurses felt it was pointless trying to attend educational forums if no substitute nurses were available to cover home visits (Rosenberg & Canning 2004). Other authors reported that at times RNs experienced not having sufficient clinical staff to help when workloads were heavy (Penz & Duggleby 2011). One RN in a study conducted by Kaasalainen and others (2014) was dismayed by organisational changes that affected her work in a small community. Some other services like home support workers had been centralised to larger regional centres, the result being that decreased numbers of personal care workers were available to assist with palliative care patients requiring support services at home in smaller communities. The flow-on effect was that community nursing teams were required to cover the work usually done by these relocated care workers (Kaasalainen et al. 2014). Furthermore, the restructure of services affected RNs' ability to respond to changes in patients' status efficiently. The newly established centralised community health service hubs were located further away from some outlying communities; therefore, frequency of visits declined while the cost of freighting equipment and supplies to homes had increased significantly—a cost incurred by the family (Kaasalainen et al. 2014). These occurrences resulted in feelings of hopelessness for nurses striving to provide quality palliative care service.

Infrequent contact with doctors and medical services who were aware of terminally ill patients being cared for at home added to nurses' feelings of hopelessness (Kaasalainen et al. 2014). The failure of GPs to hand over patients to other doctors on duty out of hours or during leave periods meant there was a lack of continuity in patient care. All these external factors influenced the quality of service the nurses provided and heightened their sense of hopelessness as they worked to provide a satisfactory home-based palliative care service.

Feeling fearful

The final emotional response to emerge from data to be reported in this chapter was fearfulness. Less than half of the retrieved articles—that is, five studies—reported that nurses experienced feelings of fear. These fears included a lack of the knowledge required to provide appropriate nursing care, particularly when there were long periods of time between caring for a palliative care patient (Wilkes & Beale 2001; Arnaert Seller & Wainwright 2009; Cruickshank et al. 2010; Marchessault, Legault & Martinez 2012; Penz & Duggleby 2012). Intermittent involvement in providing palliative care was compounded by the lack of educational updates. For example, RNs feared they would not recall information about the range of medications used in setting up a syringe driver or remember how to set up and manage this device (Cruickshank et al. 2010). Fearfulness was also experienced at times when RNs were in the presence of a patient dying, particularly if they were alone (Arnaert Seller & Wainwright 2009). Furthermore, inexperience in providing home- based palliative care could evoke feelings of fear, with the report that their first experience of a patient dying at home could be terrifying (Arnaert Seller & Wainwright 2009). RNs also feared the witness of displays of emotion from their patients or family caregivers.

Wilkes and Beale (2001) found nurses could be the target of angry emotional outbursts as family struggled to come to terms with the impending death of their loved one. Outbursts of anger were not presented extensively in this research article, except to include that such displays of emotions could result in fear of visiting that home again. Others agreed: Marchessault, Legault and Martinez (2012) cited one nurse who had experienced an outpouring of anger from family and patients. The sudden display of anger and sadness caused the RN to not only experience fear but also a sense of powerlessness. Furthermore, the lack of adequate staff for a range of community-based services could mean that support from other health professionals for the patient, such as social workers, may be limited or not available, leaving nurses to deal with such emotional displays the best way they could as they worked alone (Marchessault, Legault & Martinez 2012). Penz and Duggleby (2012) suggested that it was important for nurses to understand their own values and beliefs regarding death to counteract negative emotions such as fear. This suggestion, though, did not account for the rigours of caring for terminally ill patients being compounded by working in isolated settings in rural or remote locations.

While several emotional responses were reported in these articles, there was a superficial coverage of the effects of such lived experiences on the professional and personal lives of the nurses. Most disturbingly, the effects of witnessing distressing emotional displays from patients and families such as anger and fear needed to be further researched.

2.7 Summary

Scrutiny of 14 articles retrieved from an extensive literature search revealed several themes and subthemes. The research question considered across the literature pertained to nursing in rural communities. Those RNs who lived and worked in the same community accepted the occurrence of intertwined relationships between their family, social groups, sporting clubs and professional associations as a normal part of living in rural communities. However, these connections presented some challenges for the RNs as they provided home-based palliative care. The preservation of patient confidentiality was one aspect of their work that was particularly challenging. Little evidence was reported about the effects such close associations had on those who were providing home-based palliative care services. Living in rural and remote areas in any country presents community nurses with geographical challenges that extend past long distances to the tyranny of travel in bad weather conditions and on poorly maintained roads. Accessing nursing supplies and equipment and maintaining contact with medical and allied health services is limited at times because of patients' homes being located in isolated settings. Furthermore, accessing educational forums is impeded by long distances. Most nurses reported that the provision of home-based palliative care was professionally and personally rewarding. However, frustration occurred when there was of a lack of resources, time, and minimal support from other health care services. Likewise, nurses reported the experience of a pendulum effect of feelings of hopefulness and then hopelessness as they provided care, owing to shortages in supplies and professional support. The most disturbing emotion was fear: not only fear of being in the presence of a dying patient while working alone in an isolated setting, but also fear of not being able to provide an adequate service.

While the findings from the literature afford some insight into the lived experience of nurses working and living in rural communities, there remains a paucity of research that delves into what it is really like to be involved in the provision of home-based palliative care. Reviewed literature indicated governments and researchers predominantly focused on improving models of care for patients and their families. However, the voices of RNs were not recognised as an important part of any research endeavour.

The next chapter presents the rationale and process followed to engage the philosophical hermeneutics of Gadamer (1975/2013). Also, the data analysis method of Diekelmann, Allen & Tanner (1989)—which underpinned an expansive qualitative exploration of the nurses' lived experiences—will be explained.

CHAPTER 3: METHODOLOGY

3.1 Introduction

Chapter 3 will discuss the methodological approach adopted for this study, following Gadamer's phenomenological thinking. Later in this chapter, the strong links between Gadamer's phenomenology philosophy (Gadamer 1975/2013) and the chosen seven-stage data analysis by Diekelmann, Allen and Tanner (1989) will be presented. To explore the lived experiences of these nurses in this setting of care, it was necessary to follow a qualitative research approach. Gelling explained:

> Qualitative research is an approach to scientific inquiry that allows researchers to explore human experiences in personal and social contexts and gain greater understanding of the factors influencing these experiences. (2015, p.43)

The lived experiences of participants could not be quantified. Rather, the qualitative paradigm provided a process of identifying themes and subthemes from data (Creswell 1994; Crotty 1996). As Braun and Clarke (2006) explained, a theme is a pattern reoccurring across several transcripts. Identifying themes provided a systematic basis for recording a collation of lived experiences. Phenomenology is placed within the qualitative research methodology. Byrne (2001) explained that a phenomenological approach assists in finding meaning in the lived experience. Pascoe (1996) reflected that since the mid-1960s nursing knowledge experienced an evolution into the scientific realm of knowing; however, at the same time increasing numbers of researchers within the field of nursing identified the need to understand more about the human needs of patients and nurses (Byrne 2001; Jones 2001; Fleming, Gaidys & Robb 2003; McConnell-Henry, Chapman & Francis 2009). The goal of qualitative research is also used to inform and shape holistic nursing theory and practice into the future. McConnell-Henry, Chapman and Francis (2009) explained that within nursing practice lie phenomena which need to not only be identified but also to be understood for meaning to emerge. Identifying themes and subthemes in a qualitative descriptive reporting framework contributes to understanding; deeper analyses such as the methodology of phenomenology offer more of a critical appraisal of lived experiences (Crotty 1996). Although this research is not classed as a 'critical' approach following the lead of critical theorists (Lincoln & Denzin 2000, p.1056), Crotty (1996, p.5) claims the 'goal of phenomenological inquiry goes beyond identifying, appreciating and explaining current and shared meanings. It seeks to critique these meanings.'

As a nurse researcher with experience in the clinical specialty of palliative care, I wanted to gain new understandings of the lived experience of other nurses in this field. The phenomenological philosophy of Gadamer provided concepts with which to answer the research question—that is, what are the lived experiences of nurses providing home-based palliative care in rural communities? Concepts within this phenomenological philosophy from the work of Gadamer (1975/2013) include: ontology, historicity, fusion of horizons, belonging to tradition, finding meaning from language and texts, and understanding and finding meaning from data. As the primary researcher I particularly welcomed the concepts of historicity and fusion of horizons because, as stated above, I had lived the experience of providing home-based palliative care in rural communities. The result in acquiring new understanding from other RNs' lived experience would be that I not only found their truth but also the meaning of my own journey—in particular, the uniqueness of working in a rural setting of care of patients in their own homes.

Before adopting the philosophical methods of Gadamer for this study I explored the beginnings of phenomenology. Several philosophers had key roles in the foundation of phenomenology, including Edmund Husserl (1859–1938), Martin Heidegger (1889–1976), Hans-George Gadamer, Maurice Merleau-Ponty (1908–1961) and Paul Ricoeur (1913–2005). This chapter commences with a brief overview of these phenomenologists, followed by justification in support of Hans-George Gadamer's as the preferred philosophy for this study.

3.2 Choosing a phenomenological framework

Within this research, to gain new understandings, the interview process consisted of several open-ended questions relating to participants' lived experience of providing home-based palliative care in rural communities. In listening to each participant's responses, I also retrieved background demographic information of each nurse. This information provided context to his or her lived experience and will be reported in Section 3.6 of this chapter. In pursuit of gaining a deeper insight into this phenomenon the process was aided by acquiring an understanding of the genesis of some philosophical thinkers, particularly those from the phenomenological tradition.

Reading a wide range of reference sources revealed the first generation of phenomenological philosophers came from a number of countries in the nineteenth and twentieth centuries. These European countries included the Netherlands, France, and Germany; then, a later movement of emerging phenomenologists began in North America (Crotty 1996). My attention was drawn to philosophers' work in Germany as a pathway to acquire an understanding of the origin of Gadamer's philosophy.

Phenomenology emerged from social and political unrest in Germany before, during and after the First and Second World Wars (Crotty 1996). Prior to this era, Western philosophy was founded preceding and after 424 by philosophers such as Socrates, Plato, and Aristotle. (Allen 2013). Philosophies of these pioneers were based on religious teaching and ideals from natural sciences. For example, Socrates, Plato, and Aristotle all strove to influence their societies by the enrichment of their fellow citizens through new philosophical beliefs (Ross 1995; Moore 2007; Crisp, 2014; Shields 2014; Mason 2016). However, philosophers from the nineteenth century wanted more than philosophical beliefs based on the natural sciences and religious teachings (Gadamer 1975/2013; Husserl 1975; Heidegger 1977).

3.2.1 Edmund Husserl: The German movement

Edmund Husserl was the first intellectual scholar in Germany to pursue a new philosophy and is therefore considered the father of the emerging methodology of phenomenology. Initially, Husserl's intellectual interests were in the areas of mathematics and natural science, with his first work in the field of phenomenology published in 1913 (Bossert & Peters 1975; Hopkins 2014). Through his philosophy, Husserl believed that to preserve the integrity of knowledge one needed to invest in logical thinking (Husserl 1975; Hopkins 2014). Aided by his interest in the structure of mathematics, Husserl believed pure logic was 'the science of the ideal "conditions of the possibility" of science generally' (Husserl 1975, p.4). However, to understand logic there was a need to have insight into meaning. He believed understanding was only achieved by categorising different types of logic (Pivčević 2013). Furthermore, Husserl felt that the integrity of knowledge went beyond natural sciences, so his work turned to the inclusion of objectivity (Jonkus 2014; Hopkins 2014). His philosophy considered how objects from a person's life were relevant and how each contributed to intentional consciousness (Husserl 1960; Pivčević 2013).

Edmund Husserl also believed that objectivity in the world was influenced by a person's environment, which contributed to how he or she saw the world (Applebaum 2012). Husserl endeavoured to understand the connections between experience and the essence of things, and in so doing, phenomenology emerged (Husserl 1975; Tymieniecka 2009). Drawing on processes in mathematics, Husserl went on to frame his thinking around the reduction of consciousness (Husserl 1960; Mohanty 2008). Husserl believed the reduction of consciousness was about 'beliefs in the actual existence of the objects of experience' (Crotty 1996, p.59) and allowed new knowledge to emerge. Categorising concepts of logic became known as 'bracketing', and within this process, aspects such as personal lived experiences of the researcher were not given consideration in the process of gaining of new understanding and finding meaning (Crotty 1996). In the context of the present study, I believed bracketing was problematic because of my strong alliance with and experience in the field of palliative care nursing. Hence, I went on to explore the second philosopher to rise to notoriety in Germany, Martin Heidegger.

3.2.2 Martin Heidegger

Heidegger was a pupil of Husserl. He, too, wanted more than a philosophy based on natural sciences and religious beliefs, so his philosophy focussed on the human experience of living in the world (Heidegger 1977). Heidegger worked alongside his teacher Husserl for some time and agreed with some of Husserl's thinking in relation to the human experience as it was lived. However, he differed in how to explore lived experiences (Heidegger 1977; Dowling 2007). Heidegger's work *Being and Time* concentrated on thinking within the fields of metaphysics, mathematics, the essence of truth and the origin of art. Heidegger focussed on the meaning of origin as 'that from which and by which something is what it is and as it is' (Heidegger 1977, p.149). Heidegger held three principles in relation to living life as a human being: each person is self-interpreting*;* individuals must declare clearly who they are as people, as one's own self cannot be divorced from meaning; and meaning can change over time as it is constrained by culture, history and language (Heidegger 1962; Crotty 1996).

Heidegger believed that it was important to understand what being in the world meant (Heidegger 1962, 1977). He concluded that being was present in everyday life through a person's language and metaphysical existence (Heidegger 1977; Casati 2019). The word *dasein* in the German language was translated into English as *being-there* (Heidegger 1962, 1977). Gorner (2002, p.19) explained Heidegger's work as: 'Dasein understands its own being (existence), but in understanding its own being it at the same time understands the being of entities other than itself.' Heidegger (1977) believed that the interpretation of time was the horizon from which understanding of being was possible. The concept of time was a mere foundation upon which to base an understanding of being.

However, Heidegger's quest was primarily centred on understanding of being rather than time (hence his opus, *Being and Time*; Heidegger 1962).

Unlike Husserl, Heidegger was not concerned about bracketing the researcher's own experiences in life to understand the meaning of others' experiences. It was considered, therefore, that Heidegger's phenomenological thinking could assist in answering the research question. In this study however, the basic tenets of Gadamer's philosophy appealed by virtue of their analytical processes.

3.2.3 Hans-Georg Gadamer

Gadamer's work was influenced by his teacher, Heidegger, and other philosophers including Husserl and Plato (Gadamer 1975/2013, 1986). As a child Gadamer had a shared interest in the natural sciences with his father. However, Gadamer was also interested in poetry, language and music and as his philosophy developed these aspects of his life were included. Gadamer also drew on examples from the senses, in particular sense of taste, to illustrate and explain that lived experiences were individual (Gadamer 1975/2013).

As a child he followed the Protestant Christian beliefs of his mother's family, but turned away from these beliefs as a young adult. Nevertheless, elements of his previously-held faith beliefs also featured in his work (Gadamer 1986). Gadamer held a doctorate in philosophy and his interests in art (aesthetics), drama (play), poetry and music were well represented in his works and publications; most notably, in *Truth and Method* (Gadamer 1975/2013; Grondin & Plant 2003, Turnbull 2004; Hamlin 2016).

Gadamer believed that understanding occurred through language; language was the medium where each horizon was expressed (Gadamer 1975/2013). It was the philosophical thinking about historicity that emerged strongly in Gadamer's philosophy. Gadamer believed that people needed to acknowledge that as they lived in the world their own history was created, which in turn created pre-judgements within new experiences (Gadamer 1975/2013; Pascoe 1996; Austgard 2012). Gadamer (1986) explained that pre-judgement was 'historical consciousness' (Gadamer 1986, p.11). He believed conversations embracing historical consciousness allowed new understanding and perceptions to arise (Gadamer 1975/2013, 1986). Gadamer's philosophy explained that one could not be removed from tradition because both history and tradition gave context to the world in which one lived (Gadamer 1975/2013). The value of historicity was truly seen when new understanding was derived from the fusion of horizons with another's experience (Gadamer 1986; Dowling 2007). That is, the phenomenon of a fusion of horizons occurred when insight into another person's lived experience was present because the listeners had similar experiences in their past. Historicity (one's history) and fusion of horizons had an important part to play in acquiring understanding, which led to finding meaning and truth. This belief was in stark contrast to Husserl's approach of excluding or bracketing out past experiences (Crotty 1996). As a researcher, my interest in adopting Gadamer's phenomenology for this study stemmed from being free to allow my history and tradition to be vehicles in acquiring new understanding and finding meaning from other nurses' lived experiences.

One concept Gadamer adopted from his teacher, Heidegger, was the use of hermeneutics. In particular, the hermeneutic circle was useful in achieving understanding (Gadamer 1975/2013; Clark 2008). The hermeneutic circle was the process of understanding parts and language for the whole of the dialogue to be understood. However, understanding of the whole of a text was reliant on understanding the parts as well. Gadamer was steadfast in believing that from new understandings meaning was found, which then exposed the truth of the lived experiences (Gadamer 1975/2013, 1986). However, the truth could not be absolute because truth changed over time. Gadamer's philosophy offered an expansive field of methodology to explore the lived experiences of nurses providing palliative care in patients' home in the rural setting. Nevertheless, to provide further exploration of phenomenological thinking Husserl, Heidegger and Gadamer were not the only phenomenological philosophers considered for this study.

3.2.4 Maurice Merleau-Ponty: The French movement

Merleau-Ponty followed Husserl's reduction and bracketing practice in the interpretation of data (Merleau-Ponty 1962). Merleau-Ponty's initial works considered the nature of perception and existential fundamental structures in life lived and applied experimental psychology, Gestalt psychology. He then moved to the integration of a phenomenological approach into his works in the realm of the relationship between the consciousness and nature (Merleau-Ponty 1962; Dowling 2007). However, Merleau-Ponty aligned his philosophy with Husserl's bracketing. For this study this would have meant excluding my own tradition, historicity and fusion of horizons, whereas Gadamer encouraged these concepts to assist in answering the research question.

3.2.5 Paul Ricoeur

As a final step in determining which philosophical methodology to adopt for this research, I also considered the work of another French philosopher, Paul Ricoeur. Ricoeur's writing initially centred on the concept of the structuralist tradition (Zielinska 2010). His belief was that to understand a person's experiences in the world there needed to be a combination of the phenomenological description and the hermeneutic interpretation, as did Gadamer and Heidegger's philosophies (Merleau-Ponty 1962; Ricoeur 1994; Zielinska 2010; Reynhout 2013). For the most part, Ricoeur's beliefs built on Heidegger's philosophy (Ricoeur 1994; Crotty 1996; Reynhout 2013). There were also minor connections with two French philosophers. However, Ricoeur's work also focussed on text, just as Gadamer drew on language via text to aid in hermeneutic interpretation (Ricoeur 1994; Debesay, Nåden & Slettebø 2008; Petrovici 2013). In opposition to Gadamer, within Riceour's philosophy the pre-understanding of the researcher was not considered necessary in the acquiring of new understanding. Again, this bracketing of my own experience was considered a limiting element in this research study. The expansive philosophies of each phenomenologist were difficult present comprehensively in short sections in this chapter. However, this thesis was underpinned by Gadamer's philosophy that has been describe on pages 57-59.

Figure 3.1: A pictorial illustration of differences and similarities between phenomenological philosophies of Edmund Husserl, Martin Heidegger and Hans-Georg Gadamer, with the minor overlaps of Maurice Merleau-Ponty and Paul Ricoeur's works noted by the broken outer line of the fourth circle.

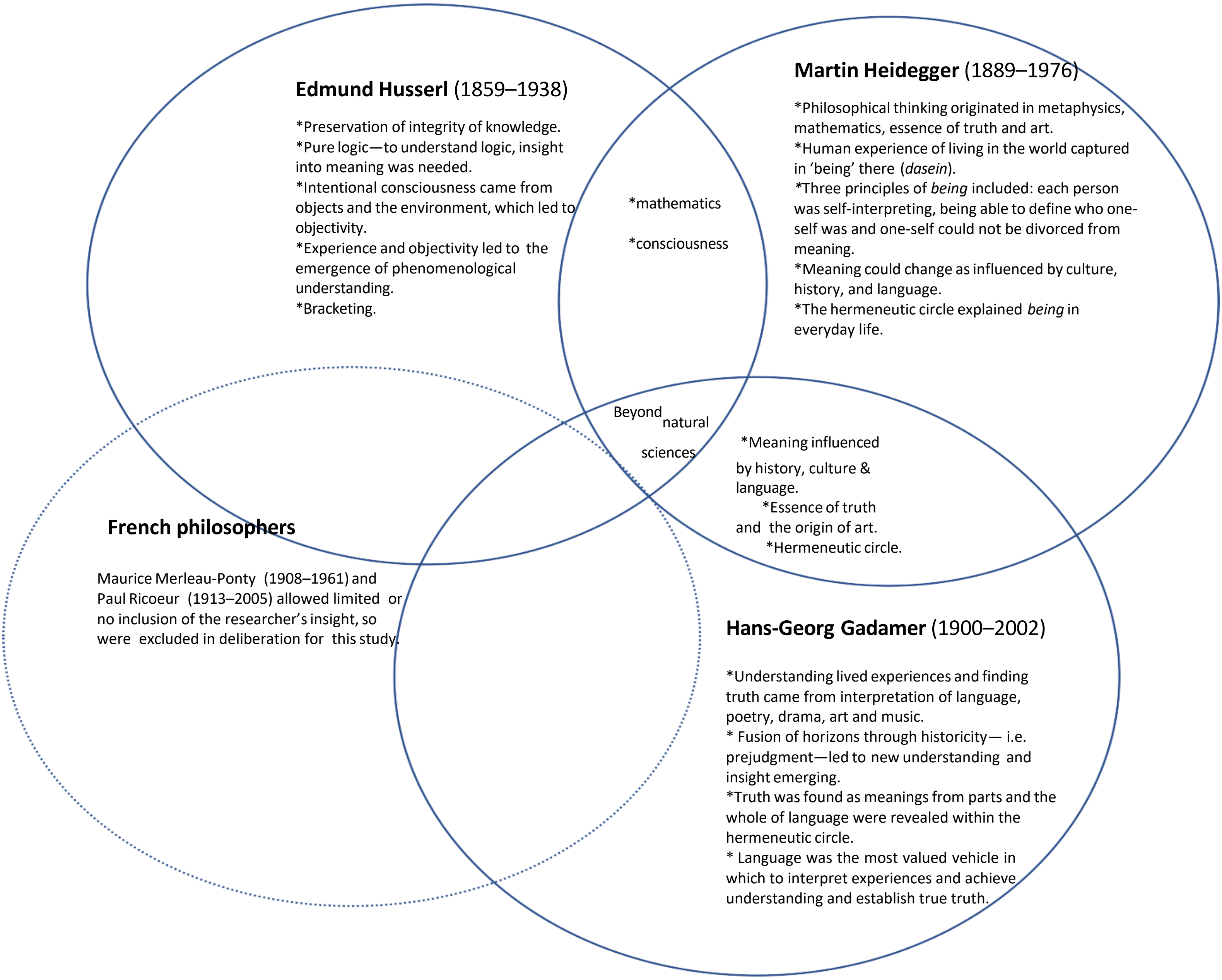


Figure 3.1 provides a synopsis of the key concepts from three foundational phenomenological philosophies to emerge from Germany, including Edmund Husserl, Martin Heidegger and Hans Georg Gadamer.

The three large circles in Figure 3.1 provide a pictorial representation of the three main phenomenological thinkers considered for this study. Each circle details main concepts of their philosophies.

- **The top left-hand circle** presents Edmund Husserl’s concepts of preservation of integrity of knowledge and categorising logical concepts leading to understanding but meaning needed to be found. Intentional consciousness originated from objects and the environment in which a person lived.
- The concept of objectivity emerged, then experience and essence of objects led to a phenomenological understanding.
- **The top right-hand circle** summarises the key concepts from Martin Heidegger’s phenomenological philosophy. His foundational thinking originated from mathematics, like Husserl, as illustrated by the overlapping circle between them. Heidegger’s philosophical thinking also originated in metaphysics, seeking the essence of truth and the origin of art.
- Heidegger’s concepts developed around the thought that human experience of living in the world was captured in ‘being-there’—that is, *dasein*. There were three principles of being: self-interpretation, defining one-self and meaning of oneself.
- The hermeneutic circle was a way of gaining understanding of ‘being-there’ in everyday life. As detailed in the circle between Edmund Husserl and Martin Heidegger, consciousness of self was foundational in both philosophies.
- **The circle at the bottom of the Figure** presents key concepts of Hans-Georg Gadamer’s phenomenological philosophy. For Gadamer, understanding lived experiences and finding truth came from interpretation of language and the arts such as poetry, drama, art and music. Fusion of horizons through historicity—that is, pre-judgement—also assisted in achieving understanding as new insights emerged. Truth was found as meanings from parts and the whole of language were revealed within the hermeneutic circle. Gadamer concluded that language was the most valued vehicle in which to interpret experiences and achieve understanding and to allow truth to emerge.

- Gadamer and Heidegger shared the concepts of meaning being influenced by history, culture, and language. There were no clear overlapping concepts between Gadamer and Husserl, demonstrating the ongoing development of phenomenology throughout the nineteenth and twentieth centuries.
- **The shape in the centre** shared by all three philosophers illustrates the new, emerging realm of phenomenology, which came from beyond the natural sciences.
- **The circle with broken outer lines** presents the philosophies of French philosophers including Maurice Merleau-Ponty (1908–1961) and Paul Ricoeur (1913–2005). The broken lines illustrate minor links with the three German philosophers.

The next section of this chapter offers a rationale to support the choice of Gadamer's hermeneutic phenomenology, which will be explained further.

3.3 Hans-George Gadamer's *Truth and Method*: the philosophy of choice

There are several reasons why Gadamer's phenomenological approach was chosen as the theoretical framework for this research study. Firstly, I considered Gadamer's philosophy best suited to answer the research question; his thinking accommodated an in-depth exploration of the lived experiences of RNs who provided home-based palliative care in rural communities for patients who wished to die at home. The value of the inclusion of the pre-judgement of the researcher as the interpreter of language could not be understated as I, too, had lived experiences from my past clinical practice.

Gadamer's phenomenological philosophy promoted that understanding came from language within the text. Gadamer drew from his passion for the arts as a vehicle for searching for truth, such as illustrations from drama, art, music and written works in poetry (Gadamer 1975/2013, 1986). Gadamer (1986) explained that art allowed meaning from lived experiences to be presented, rather than art being a way of directing a person to find meaning.

Gadamer also explored philosophical thinking from the example of drama. He suggested each play had players who had their own roles to play, each bringing interpretation to the play as individuals (Gadamer 1975/2013, 1986; Grondin & Plant 2003). However, sometimes a player was also part of the audience while being part of the play. In essence, watching as a spectator, as lived experiences occurred at the same time the person lived new experiences as a player leading to the acquisition of new understanding, truth and meaning (Gadamer, 1975/2013). He extended his thinking to each person being part of the play of the world. As the researcher, this analogy resonated with my previous clinical experience. As I listened to participants share their experiences, I connected with the language that was used. I understood phrases that nurses used to explain certain aspects of their work just as one may connect to a musical arrangement, a scene from a play or a piece of poetry from the past. At times I felt as if I was still a player on the field of palliative care, while at other times I was the spectator, as I visualised the setting and events within a story being shared. My own experience enhanced understanding: however, new insights transcended in unexpected ways. Gadamer embraced the individualism of lived experiences by using taste as an analogy. The sense of taste was unique to each person (Gadamer 1975/2013). So it would be that participants' experiences would be different to my own. This expanse of realms in which to analyse the descriptions of the lived experience through language assisted in a thorough interpretation of the text.

Furthermore, just as phenomenology is concerned with understanding of experiences, hermeneutics is concerned with the interpretation (Gadamer 1975/2013; Rydé, Strang & Friedrichsen 2008). Gadamer's hermeneutic phenomenology followed a process of understanding parts and understanding the whole of text and the reverse, known as the hermeneutic circle. As parts of the transcribed interviews were explored, new understandings emerged as the whole and parts of the text were re-read numerous times.

The result of this current study was to achieve new understanding about lived experiences of participants. A new understanding was only possible through a thorough and exhaustive exploration of data. Debesay, Nåden and Slettebø (2008, p.58) explained that Gadamer's understanding was aided by 'self-understanding'. Pascoe (1996) agreed with Gadamer that our own pre-judgements assisted in the interpretation of another's lived experience. The aim of this study was to illuminate the meaning of the lived experience of RNs who provided palliative care within the patients' own homes in rural settings. This exploration could only be achieved by looking at parts, as well as the whole lived experience.

I came to understand the nurses' journeys more than they did themselves. In turn, I found meaning in my own journey as a CN who had worked in the same setting of care. However, as Gadamer (2006) guided, truth is never final; rather, it is an ongoing journey of understanding which is never completed.

While Gadamer provided ways in which to explore language within the text in order to see truth and new understanding emerge, he did not provide a stepwise proforma to do so. Therefore, there lacked a process and framework by which to report these findings. It was necessary to adopt an analytic process to follow. Diekelmann, Allen and Tanner's (1989) seven-stage critical hermeneutic analysis was chosen to guide the formatting of emerging themes and subthemes within the qualitative research paradigm.

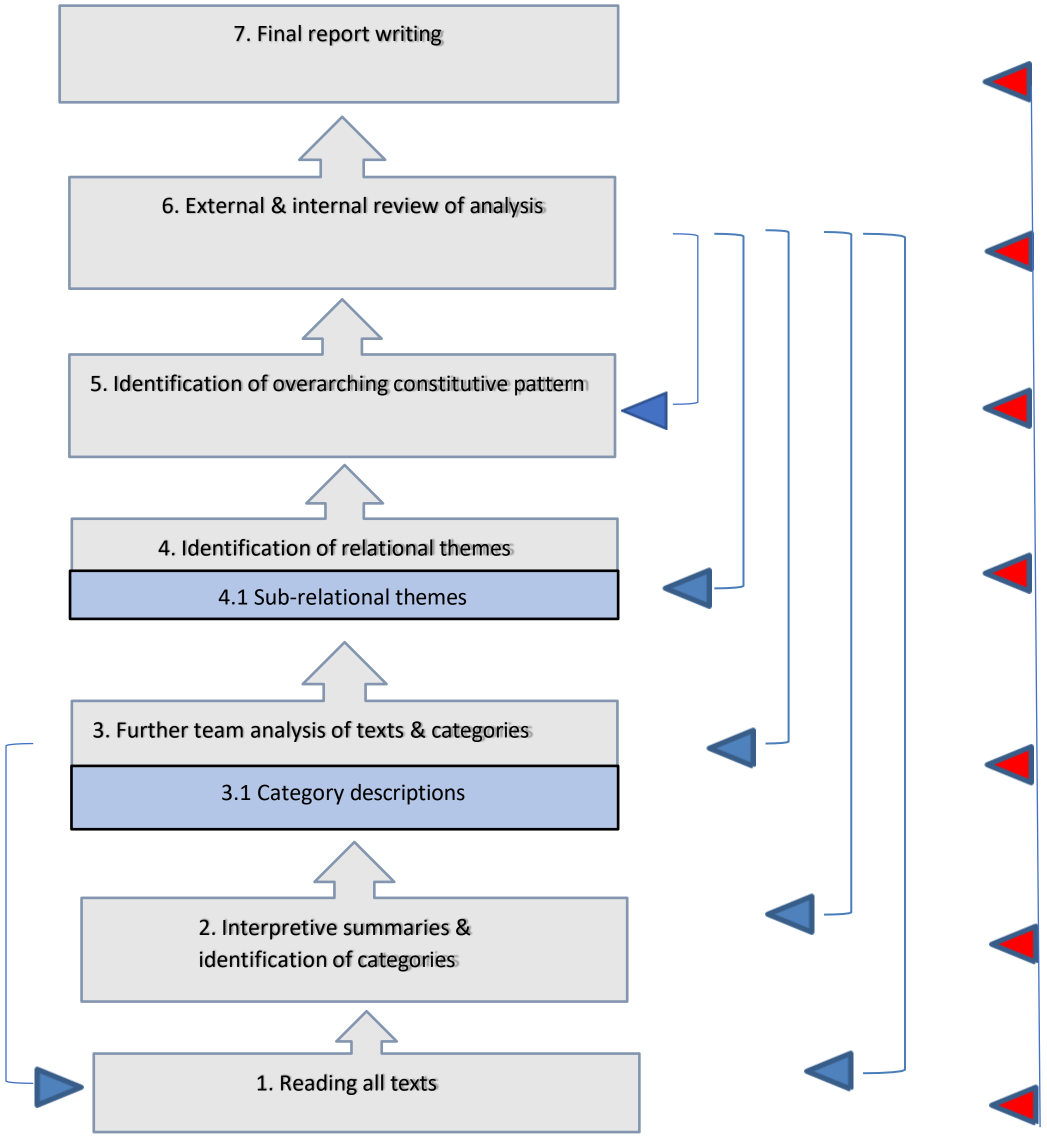
3.4 Methods used in the study

An existing analytical process was available and was used in the report of the results of this study, which explored nurses' lived experiences of providing home-based palliative care. De Chesnay (2014) explained that in nursing research, Diekelmann, Allen and Tanner were the first nurse researchers to follow Heidegger and Gadamer's phenomenological thinking. Diekelmann, Allen and

Tanner's (1989) alliance with Heidegger and Gadamer's phenomenological philosophy captured my attention. They had seen the value in the expanse and depth of philosophers' work in analysing data, but a method was needed to present findings in a systematic way. These earlier nursing researchers designed a method that identified 'categories, relational themes, and constitutive patterns' (Diekelmann, Allen & Tanner 1989, p.11). My interest was raised further as Diekelmann Allen and Tanner (1989) had introduced the method of hermeneutic analysis as a basis to review the accreditation criteria of the Higher Degree Baccalaureate Nursing Programs for the National League for Nursing in The United States of America (Diekelmann, Allen & Tanner 1989). The three texts included in the review were the, Criteria for the Evaluation of Baccalaureate and Higher Dree Programs in Nursing 1983, Policies and Procedures of Accreditation for programs in Nursing Education 1985 and, the Self-Study Manual 1984 (Diekelmann, Allen & Tanner 1989, p.11). This study was within the realm of nursing, and I considered the seven-stage process as a thorough and method of data analysis. I had interviewed numerous nurses, so the data collected was extensive and a hermeneutic style analysis linked well with my chosen phenomenological philosopher of Gadamer.

In the appraisal of the three texts in the Baccalaureate Nursing Program, the research team 'included the principal investigator; nurses and non-nurses as well as faculty skilled in interpretative research; students and clinicians' (Diekelmann, Allen & Tanner 1989, p.11). The research team for this study consisted of myself as the primary researcher, a principal supervisor and an associate supervisor. Both supervisors had nursing backgrounds with research interests in aged care, spiritual care and palliative care. Each of Diekelmann et al.'s stages were necessary for decisions to be made in the identification of emerging categories, relational themes and an overarching constitutive pattern. Figure 3.2 provides a pictorial representation of the process.

Figure 3.2: Diekelmann, Allen and Tanner's (1989) seven-stage data analysis with extensions within stages three and four to include category descriptions and sub-relational themes. The addition of the red coloured arrow on the right illustrates that within the qualitative phenomenological methodology of this current study analysis was an ongoing process, including in the seventh stage of report writing.



In the first stage, Diekelmann's team of researchers read all three texts to achieve an overall understanding of the writing (De Chesnay 2014). After each interview in this study the audio-recording was transcribed by the primary researcher immediately or as soon as was practicable to do so. At monthly meetings with my supervisors, the transcribed data from each interview was discussed. In Diekelmann's analysis the second stage involved each researcher writing interpretive summaries from the texts, supported by excerpts. Categories were then identified from these summaries (Diekelmann, Allen & Tanner 1989). A category was the title given to several subthemes that related to each other within one main theme or succinct group. The term 'category' is used in the third stage of Diekelmann, Tanner and Allen's (1989) process. In this context, a category denotes the initial organisation of large quantities of data. Then further higher levels of analysis takes place as explicit and implicit 'themes' emerge (Diekelmann, Tanner & Allen's 1989; Creswell 1994). Throughout this third stage the researchers from the National League of Nursing met regularly with the investigator to discuss the similarities and differences they each discovered in the text as highlighted in their summaries (Diekelmann, Allen & Tanner 1989). A similar process was adhered to in the present study as I proceeded with writing interpretive summaries from each interview. The early identification of themes and possible categories were discussed with the supervisors at our monthly meetings. Diekelmann's team of researchers re-read and analysed each document and considered each category separately, then reported similar and differing understandings from those of the principal investigator. A consensus was reached within the group by returning to the reading of the original texts as illustrated by the arrow on the right side of Figure 3.2. Rigorous discussions occurred between supervisors and me as we grappled with emerging categories. Re-reading of all 16 interview transcripts and interpretive summaries was needed numerous times over several months to clarify any differing opinions.

The value of the hermeneutic approach was evident—that is, to understand the whole, attention was required at the same time to the parts within each transcript, as well as across all transcripts. It also became apparent during rigorous discussions that a description was needed for the emergent categories. A description would aid new in-depth understanding of each category. Therefore, as illustrated in Figure 3.2, adding a description to each category took place in Stage 3 of Diekelmann, Allen and Tanner's (1989) process of data analysis.

In the fourth stage Diekelmann, Allen and Tanner (1989) identified themes that were present in all texts. These ideas were grouped and recorded as relational themes (Diekelmann, Allen & Tanner

1989). Excerpts were extracted from the original documents to support each relational theme. In the research of Diekelmann, Allen and Tanner (1989), regular discussions were held in team meetings until a consensus was achieved within the group. Analysis of data in this study followed the same process. However, the need to again extend Diekelmann, Allen and Tanner’s (1989) analytical process became apparent. The report of an extensive quantity of rich qualitative data would be aided by the creation of sub-relational themes within each relational theme across all categories. While the identified relational themes remained the same across all categories, the sub- relational themes differed. Ongoing review was required throughout this exhaustive process, which saw some initial sub-relational themes and description of categories change as re-reading of data, writing and in-depth discussions at supervision meetings continued over an extended period.

As Diekelmann and her team continued their appraisal of the three documents, the fifth stage involved applying an overarching constitutive pattern across all categories. This pattern was present in all documents and expressed the relationship between all the categories and relational themes (Diekelmann, Allen & Tanner 1989). According to Polit & Beck (2012, p.568), identifying a constitutive theme ‘forms the highest level of hermeneutical analyses.’ Our research team found this to be a solidifying point in our thorough analysis of data, too. The identified overarching constitutive theme illustrated the truth emerging from the categories, relational and sub-relational themes. New understanding was present in a new and exciting fullness not experienced prior to this stage of analysis.

In Stage 6, consultation with two staff who were experienced in interpretative nursing research was sought for their appraisal of and comment on the entire processes of analysing data. Then, the whole of the research team was given an opportunity to review the process undertaken (Diekelmann, Allen and Tanner 1989). The arrows in Figure 3.2 from the sixth stage detail the process of reviewing the previous five stages of the analytical progress.

In the seventh stage, a final statement was written and reported on categories with corresponding relational themes within the overarching constitutive pattern by Diekelmann and her research team (Diekelmann, Allen & Tanner 1989). Succinct, robust excerpts provided support for all relational themes within each category. Throughout the process of progressing through all seven stages regular meetings between the principal investigator and researchers were held to discuss and achieve an overall agreement, as was the case in Diekelmann's research team (De Chesnay 2014).

As the primary researcher, the author of this thesis identified that an extension of Diekelmann, Allen and Tanner's (1989) process was needed in two of the seven stages to add depth to the analysis. Thus, as detailed in Figure 3.2, two sub-stages were added to the original seven stages of Diekelmann, Allen and Tanner's (1989) process of analysis. Furthermore, the addition of an arrow to all seven stages illustrated that a phenomenological methodology for this study's analysis was ongoing in every stage of the writing up of the thesis.

In this current study, ongoing appraisal and analysis continued in the writing of three results chapters over an extended period. The addition of the red coloured arrow illustrates that in line with a qualitative phenomenological methodology, analysis was an ongoing process through all stages to the write up of results. The research question about the lived experiences of RNs providing home-based care for patients wishing to die at home in their own rural communities was answered. The next section of this chapter provides an overview of this study.

3.5 The current study

Before the study commenced, ethics approval was secured.

3.5.1 Ethics approval process

Ethics approval was obtained from the University and the DoH in one state in Australia. Documentation and letters of support were secured from key people in directorship positions of the participating organisation. Ethics approval was seamless, as the principal researcher who was familiar with the context, I was able to acquaint myself with the organisational structure of the participating health care service. This approach enabled me to obtain approval and support of the appropriate Director at a state level of governance._Permission and final ethics approval was granted, enabling project promotion to proceed (Ethics approval number–332.16; see Appendix 3).

3.5.2 Rigour

May and Pope (1995) outlined some strategies to ensure rigour. Strategies including, a thorough account of the theoretical framework and method used throughout the study, a clear description of context and sampling being clearly described and justified. Generalizability assured by sampling being theoretically comprehensive. A thorough description of how data was collected, recorded, and transcribed were essential. Data analysis was clearly described, multiple checking and reviewing of analysis by multiple researchers ensured reliability. Thorough and expansive reporting of findings supported by direct quotes from study participants (May & Pope 1995) to provide evidence. This study followed a phenomenological methodology guided by Gadamer (1975/2013) further supported by Diekelmann, Tanner and Allen's (1989) method of data analysis. While Gadamer's philosophy underpinned the exploration of the text to ensure understanding was found, Diekelmann, Tanner and Allen's (1989) seven-stage data analysis provided a process that extended past a thematic analysis (Nowell et al., 2017). Throughout all seven stages of analysis Diekelmann, Tanner & Allen (1989) model as illustrated in Figure 3.2 p. 64 required reviewing of all previous stages. This review included rereading of transcripts, category descriptions, relational themes, and sub-relational themes by myself as principal researcher and my two supervisors over an extended period of time. Then as guided by Koch and Harrington (1998, p. 882) the reporting of the results from analysis are 'well sign-posted' in the ensuing three chapters allowing readers to identify trustworthiness.

3.5.3 Project promotion

Promotion was primarily achieved with a wide mailing distribution of information about the research study. These packages included promotional flyers, cover letter, participant information sheets and consent forms (Appendices 4, 5, 6 & 7). Directors from the six Regional Community Health Services throughout the state received these packages via Australia Post. The cover letter requested that the flyers, Participant Information Sheet and consent form be passed on to all the Directors of Community Health Services throughout the state in which the study took place. From there, it was requested that the information be made available to all community nursing and community based SPCSs.

Interested RNs were provided with the University email address of the primary researcher as the initial contact point. Once an email was received from a potential participant, the primary researcher then made contact by replying, or by phone if the participant provided a number. A mutually suitable face-to-face or phone interview date and time was scheduled. The primary researcher confirmed the arranged interview two to three days prior to the scheduled day and time with any changes needed to be made. If needed, the primary researcher contacted the corresponding community health service to arrange the use of a designated office area to ensure the privacy of the interviewee.

3.5.4 Interview questions

The interview questions were derived from the objectives of this study. Reading of literature relating to qualitative research methodology was undertaken to ensure the formatting of questions was correct (Bolderston 2012; Irvine, Drew & Sainsbury 2012). Further reading about how to conduct semi-structured interviews was also undertaken (Doody & Noonan 2013; Ogden & Cornwell 2010). Interview questions (Appendix 8) were discussed with the principal and associate supervisors at regular meetings, with revisions and changes made accordingly.

3.5.5 The interview process

Each interview commenced with an open-ended question about living and working in a rural community. Then, the interviewee was asked to describe what it was like to care for patients who wished to die at home in his or her rural community. The third and fourth questions focussed on exploring how the care for dying patients at home affected participants' emotions; what it was like to work in the presence of the patient who was living with a heightened sense of mortality. The final two questions gave participants the opportunity to share how these experiences had changed them as a nurse and as a person.

Each question was followed by an opportunity to expand on any responses previously provided: 'Can you tell me more?' The final question gave the participant time to share any other experiences they did not cover in the first six questions. Each interview was concluded by the primary researcher, who expressed thanks and gratitude for the participant's giving of their time and asked if they wished to have any follow-up debriefing or counselling through the official capacity of their organisation (Appendix 6).

Following recording of each interview using an MP3 voice recorder, transcribing of each took place. All data was stored on a password protected laptop computer. Hard copies of transcripts were then placed and held in a locked filing cabinet to ensure safe storage of all data.

The final section of this chapter will present some demographic information about the participants. This information underpins the process of the consideration of the person within the professional self and the professional within the personal self, which are featured as the relational themes in the next three results chapters.

3.5 Demographic information

Demographic information was gathered from the transcripts of each participant's interview. It provided background context to the findings to be reported in the next three chapters. The demographic information included the participants' employment, qualification status and years of nursing experience.

3.5.3 Participants' employment, qualification, and years of experience

Table 3.1: Demographic information of participants

Participants	Nursing qualifications	Years of nursing experience in palliative care
Leo	SPCS-RN, CN	> 10 years
Ruby	SPCS- RN, CN	< 5 years
Betty	SPCS- RN, CN	> 10years
Amy	SPCS- RN, RN	< 5 years
Pippa	SPCS- RN, CN	6–10 years
Deb	SPCS- RN, CN	6–10years
Jane	CNS- RN	> 10years
Jess	CNS- RN	< 5 years
Mia	CNS- RN	< 5 years
Kerry	CNS- RN	> 10 years
Leah	SPCS- RN, CN	6–10 years
Tanya	SPCS- RN, CN	6–10 years
Mark	SPCS- RN, NP	6–10 years
Tracey	SPCS- RN, CN	> 10 years
Julie	SPCS- CN, CNS	6–10 years
Leonie	SPCS- RN, NP	6–10 years

Note. Demographic information of participants, Nurse Practitioner (NP) Registered Nurse (RN), Clinical Nurse (CN) employed in a Specialist Palliative Care Service (SPCS) or Community Nursing Service (CNS), qualification and years of experience (pseudonyms were used for all participants to ensure anonymity). No registered midwives participated in this study although they were included on the Promotional Flyer (see Appendix 4; Glossary).

To establish a professional profile of participants it was necessary to ascertain whether they worked within a SPCS or a community nursing service (CNS). To participate in this study the criteria required that each person had attained a Bachelor of Nursing Degree and registered with the Australian Health Practitioners Regulation Agency (AHPRA) (2023), see glossary, as a RN. Additionally, participants who were part of SPCS held either a CN or NP qualification. Table 3.1 provides a summary of the participants’ status. To maintain the confidentiality of participants, each nurse was allocated a pseudonym as noted alongside the numerical recording number of each interviewee.

All participants held qualifications as an RN. Nine participants were also CNs, and two nurses held an NP status in Palliative Care. Twelve participants were employed in SPCSs and five participants worked in general CNSs, with one participant working part-time as a specialist palliative care on a needs basis as well. The range of years of experience in community-based palliative care ranged from less than five years to between six and 10 years and more than 10 years. Four participants had less than five years’ experience, with seven participants’ experience between six and 10 years. The remaining five participants had more than 10 years’ experience in this specialist field of nursing.

3.5.4 Other vocations, hobbies, and interests

It was important for participants to explain other vocations and interests they had in their lives outside of their role of being a nurse. As will be reported in the Results over the next three chapters, these other vocations were pivotal to how each nurse went about responding to families who required palliative care in their communities. In their response to the interview questions, participants provided information about their hobbies and interests in life. Other non-nursing vocations included being a business partner, farmer and a shearer. Community interests included: supporting and participating in local sporting activities, attending church services and events, supporting local schools, attending social groups, and enjoying leisure activities (for example, walking, bike riding and having coffee with friends). Participants also spoke openly about significant people in their lives, immediate and extended family.

3.6 Summary

This chapter has presented the philosophical and methodological approach of this study. It has provided the rationale for the choice of a qualitative approach and the adoption of the phenomenological philosophy of Gadamer's *Truth and Method* to guide the interpretation of the rich data gathered. Sixteen RNs reported their lived experiences of providing home-based palliative care for patients who wished to remain in their own rural communities and to die at home.

The method chosen to analyse data was Diekelmann, Allen and Tanner's (1989) comprehensive, seven-stage critical hermeneutic process. Extensive, in-depth analysis of the transcribed interviews resulted in the emergence of an overarching constitutive pattern, categories, relational themes and corresponding sub-relational themes. This process was then extended to adding a description of each identified category. An additional stage was added, providing sub-relational themes to present the richness of data. The application of Diekelmann Allen and Tanner's (1989) method of data analysis involved multiple readings of transcripts and interpretative summaries. Regular discussions occurred with the research team until consensus was achieved regarding the overarching constitutive pattern, categories and relational themes. Revisions were made as the writing of findings and the discussion proceeded. This extensive hermeneutic process of examining the parts in order the understand the whole and analysis of the whole to bring new understanding to the parts resulted in finding truth as it emerged from data.

The final section of this chapter presented demographic information about each participant. This information provided the context for the professional self and personal self within each participant, thus setting the scene for the report of their lived experience in the provision of home-based palliative care for patients in their rural communities who wished to die at home.

PREAMBLE TO THE RESULTS CHAPTERS 4, 5 & 6

Preamble

The next three chapters provide the reader with a report of the data analysed from interviews with 16 RNs who participated in this study.

Diekelmann, Allen & Tanner's (1989) extended method of analysing data. Finding balance emerged as the overarching constitutive pattern. As the RNs went about their work in the provision of home-based palliative care, finding balance between their professional and personal lives was an ongoing process. This balance occurred within three defined environments (here classed as categories): the community, the health care service, and the home. The setting of a rural community itself evoked unique experiences, and the participants shared stories and examples that differed from what may have occurred if they lived and worked in urban areas. Nurses' experiences as employees of a care health service from which home-based palliative care support services originated were complex. Furthermore, these experiences were influenced by the uniqueness of each individual rural community. The most significant impact on participants' experience was working in the environment of patients' homes. They acknowledged that they were an invited guest in this setting.

These results are now presented in a systematic fashion, guided by Diekelmann, Allen & Tanner's (1989) extended method of analysing data to streamline the reading and to evoke new understandings of the lived experience of nurses who participated in this study. Each chapter will address one of the three environments, aligning with the second stage of Diekelmann, Allen and Tanner's (1989) analytical process, in which categories were identified (p.72). Chapter 4 presents the results from the first category: that is, the environment of the community. Chapter 5 provides evidence of the participants' experiences for the second category, as employees of a health care service. These two chapters provide a foundation for the final results chapter, Chapter 6, which examines what it was really like to care for a patient wishing to die in their own home.

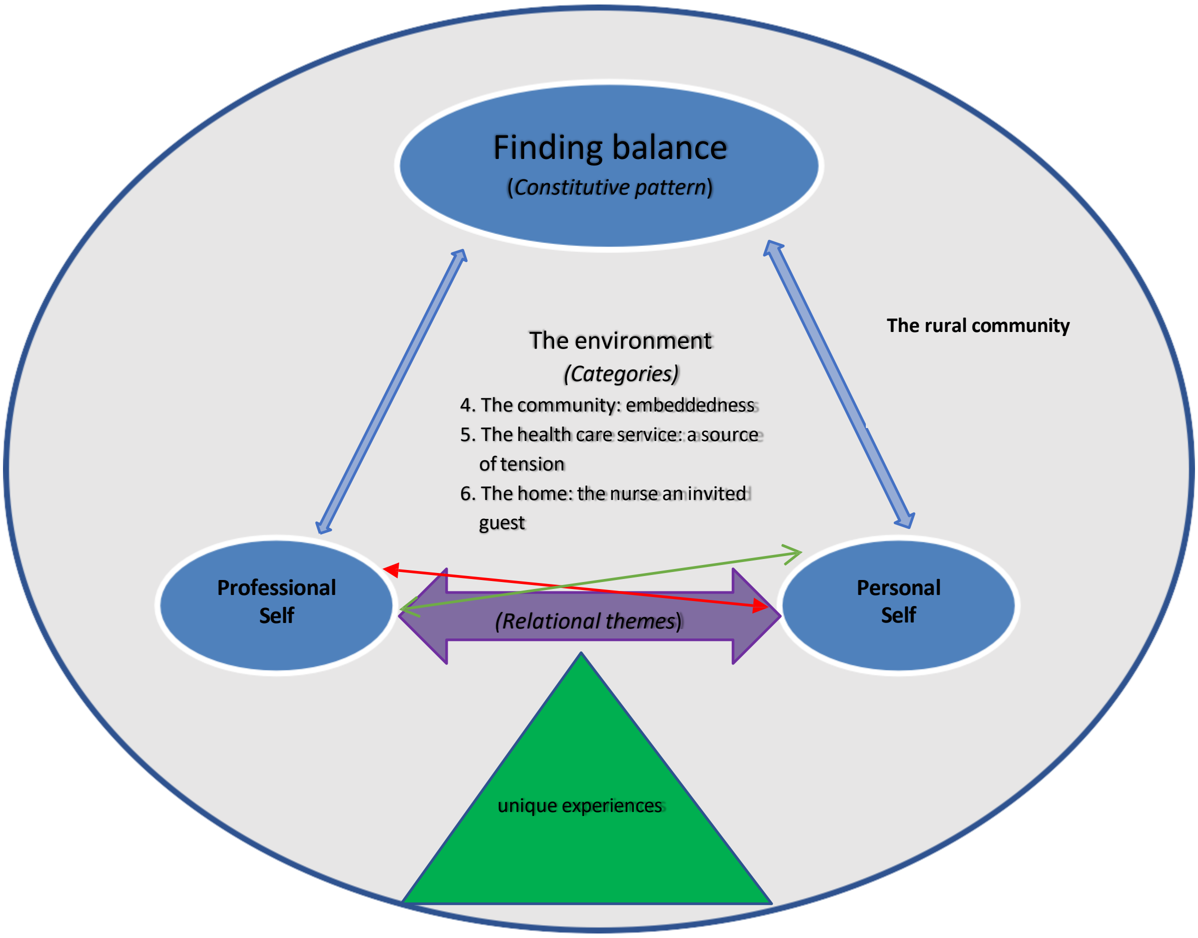
The influences of Gadamer’s philosophical thinking are apparent in these results as I identified with many of the participants’ experiences. As guided by Gadamer (1975/2013), a fusion of horizons occurred as I listened to participants’ stories. New insights emerged as the hermeneutic process of understanding continued—that is, understanding parts of the texts to understand the whole and vice versa. This process continued through the exhaustive analysis, writing, and rewriting of the findings (Gadamer 1975/2013). Rather than being a barrier, my own pre-judgements and historicity became vehicles in allowing the language within the text to challenge, deepen and extend my own understanding (Gadamer 1975/2013).

Figure 4.1 provides a pictorial image of the in-depth analytic process as informed by Diekelmann, Allen and Tanner (1989). The first version of this model provides a structure for presenting the findings of this study. In the seventh chapter, the discussion of the findings, a second, revised version of this model is presented (Figure 7.1), signifying a shift in the significance of these three environments (categories) that highlights the dominance of the home.

Finding balance

Figure 4. explains the multifaceted components of participants' lived experiences.

Figure 4.: Model of the constitutive pattern, categories and relational themes



Note. This model illustrates the evidence that emerged from analysis of the data. The overarching constitutive pattern, categories (numbering aligning with the *three results chapters*) and relational themes are presented in this pictorial model and are underpinned by the unique experiences of living and working in a rural community.

The outer shape of the diagram encompasses the rural community in which the overarching constitutive pattern of finding balance emerged. Data analysis revealed that there were three categories—the environments of: (4) the community, (5) health care service and (6) the home. Extending Diekelmann, Allen and Tanner's (1989) Stage 3, each environment was accompanied by its own description denoting the lived experiences of participants. These three environments and unique descriptions are listed below:

- The community: embeddedness
- The health care service: a source of tension
- The home: the nurse an invited guest

As reported above, the three environments represent the categories according to the second stage in Diekelmann, Allen & Tanner's (1989) analytical process (Figure 3.2). The first category represented communities where participants lived and worked, or just worked. Each community was unique. However, by the very nature of being located in a rural area there were common factors contributing to similar experiences for many participants in this study. The most dominant description to emerge from the environment of rural communities was 'embeddedness'. This connoted a place where relationships overlapped, there were community responsibilities and reciprocal relationships, and this embeddedness was apparent for all 16 participants. The second environment of the health care service was a source of tension that participants reported within their professional roles as RNs. The third and most noteworthy environment was the patient's home. The RNs were an invited guest. In patients' homes, they were primarily a visitor in this private care setting.

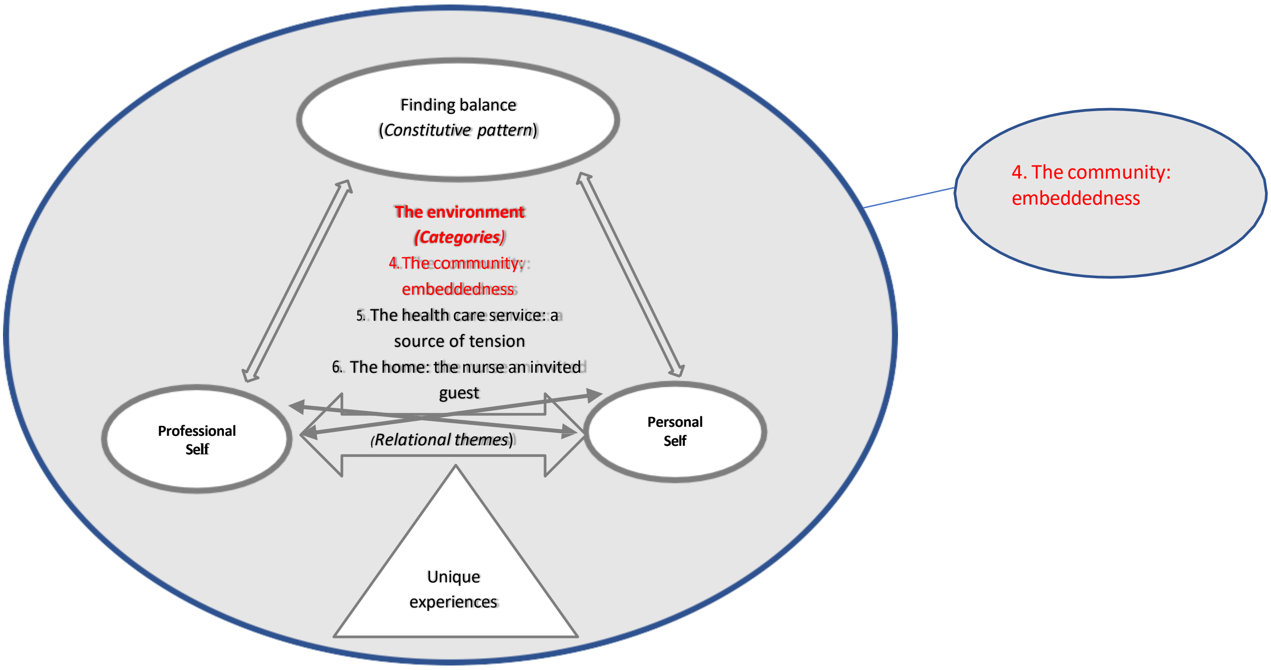
In illustrating the process of finding balance between the emergent relational themes of professional self and personal self, the central aspect of Figure 4.1 depicts a see-saw image consisting of a triangular base with a two-way arrow balanced at its tip. At each end of the arrow two small oval shapes represent firstly, the professional self on the left-hand side, and secondly, the personal self on the right-hand side. A dominant purple arrow is level between the two oval shapes, illustrating times when participants found balance between their professional and personal lives. However, the inclusion of two thin coloured arrows must also be noted. The green arrow depicts a heavier weighting of the professional self on the pivoting base. This tilt illustrates that at times, participants' professional self was weighted more than the personal self. Then the opposite can be seen by the red coloured arrow, which represents times when the personal self was weighted heavier than the professional self. This variation in the tilting of these two arrows represents times when participants experienced a fluctuation between either their professional or personal selves being more dominant than the other. Therefore, the process of finding balance between the professional and personal lives of each participant was ongoing within the complex matrix of each environment in which they worked and lived. Underpinning this see-saw image is a green triangular base representing the unique experiences that occurred; experiences that would not have occurred in a metropolitan community setting. The reporting of participants' experiences in living and working in a rural community will now be presented.

CHAPTER 4: THE COMMUNITY

4.1 Introduction

This chapter reports on the first category of the environment of the community. It demonstrates the unique experiences of participants who lived and worked in rural communities. Participants experienced varying degrees of embeddedness within these communities.

Figure 4.1: A smaller greyscale model of Figure 4. highlighting the environment (category) of the community.



Note. This Figure guides the reader as to the results reported in this chapter. As detailed by the external oval shape and the red coloured font the environment to be reported is the community.

Table 4.1 below provides an overview of the overarching constitutive pattern, category with its description, two relational themes with corresponding sub-relational themes to be reported in this first results chapter.

Table 4.1: A summary of the constitutive pattern, relational and sub-relational themes within the environment (category) of the community

Finding Balance (Constitutive pattern)	
4.2 The community: embeddedness (Category with description)	
Relational themes with corresponding sub-relational themes	
4.2.1 Professional self	4.2.2 Personal self
4.2.1.1 Overlapping relationships	4.2.2.1 Accepting responsibility
4.2.1.2 Feeling comfortable or challenged	4.2.2.2 Feeling pressured
4.2.1.3 Maintaining confidentiality	4.2.2.3 Reciprocal relationships

4.2 The community: embeddedness

The term 'embeddedness' captured participants' experiences of what it is was like to live and work in a rural community. Figures 4. and 4.1 depicts the environment of the rural community as the foundational setting of this study. That is, the type of community that participants in this study were from. Community embeddedness occurred in many ways as participants conducted both their personal and professional roles as community-based nurses who provided palliative care for patients who wished to die at home. As seen in Table 4.1, the first relational theme, 4.2.1 'professional self' had three corresponding sub-relational themes. Firstly, *overlapping relationships,* which described a range of unique experiences participants had as they lived and worked in a rural community. The second sub-relational theme reports participants' *emotional responses* of either feeling comfortable or challenged as they lived and worked in the same rural community. Then the last and third sub-relational theme represents the challenges participants had in *maintaining* their patients' and families' *confidentiality* as they went about their work and private lives.

The second relational theme in Table 4.1 was 'personal self', which also shared three corresponding sub-relational themes. Firstly, *accepting responsibility* as a member of a rural community will be reported. Secondly the sub-relational theme of *feeling pressured* will report on participants' challenges in finding balance between being an active community member and a dedicated health care professional. The third sub-relational theme, *reciprocal relationships* will provide an account of participants' personal commitment to their communities in providing a professional home-based palliative care service. The first relational theme of *professional self* will now be presented.

4.2.1 Professional self

Overlapping relationships are perhaps unique rural communities. In this study, relationships overlapped in numerous ways as community members conducted their work and private lives.

Overlapping relationships

Overlapping relationships between participants' professional and personal lives occurred in several ways. One participant who was well-known within her community explained her experience of living and working in the same rural town. Kerry said:

> I have a bit of an overlap, a bit of a grey area, when I am working, and I am not working because you do know most people … I personally don't see that as a problem though. (Kerry, p.1)

In this excerpt, Kerry accepted the intermeshing of her personal and professional life as a normal part of living in a rural community. There was no clear delineation between these two roles and this occurrence was not an issue for her.

Similarly, Leonie had a long history of living in the same community. She shared:

> [I have] lived in this community all my life … I've got a familiar name like my surname is well-known in the community and the family that I am connected to, so they know you intimately … often they know you before you come into the home. (Leonie, p.2)

Leonie was well-known in the community, in which she had grown up. At interview she stated she readily accepted that there were occasions when her professional self would overlap with her personal self. This embeddedness was considered a unique and expected part of living in a rural community. For Leonie, living and working in a rural community was about finding a balance between her well-established professional self and her personal self.

Working with overlapping relationships in the community was explained further by Jess:

> I think it can be positive in being a face that they recognise in terms of going in and giving care so when I go into that home, they have a point of reference. Even if they don't know me, they might know someone in my family. You know we usually have a mutual connection which really helps in engaging. (Jess, p.2)

Jess reported that previous connections with families had a positive outcome for the patients she visited. Even when patients and their primary caregivers did not know her, some connection may be made with members of her extended family. Jess considered this foundational knowledge as a tool to assist her to establish a therapeutic relationship with each patient and family.

Julie illustrated the concept of overlapping relationships further:

> [because] of the small nature of our community … [when we] received a [particular] referral … we tried to engage with the family without success … one of her daughters was in the same class as my children, so at football one day I had a quiet word [with a family member]. (Julie, p.1)

Julie was able to take advantage of overlapping relationships in her community to engage in a non-threatening way with a family needing palliative care support. Her concern for the family's regard was a valuable way of demonstrating she was a caring community member, as well as a discerning professional nurse. In speaking unobtrusively with a family member at a community event, Julie demonstrated that sometimes her professional self was more heavily weighted than her personal self. Julie was never off duty from her professional role in her community.

The next participant explained more about the realities of living and working in a rural community.

> I suppose it is [about] going on to live my own life knowing that I will run into people who are carers and people that I know. I do care for people that I know directly and indirectly. (Pippa, p.2)

Pippa recognised that there were interconnections between her professional and personal lives, and she accepted community embeddedness as a normal occurrence when living in a rural area. Pippa acknowledged that it was up to her to find a balance between her professional and personal selves as she went about her work and private life.

Amy did not share the same background as these five participants above:

> I first came into the [community-based] palliative care service six months ago, [however] I came here from [name of city] for my graduate program two years ago. It helps me being a relative outsider, [but] I do know what it is like [to be a local community person] because I run into people when I am out and about in town: sometimes patients, sometimes family, sometimes people I work with. (Amy, p.2)

Amy had moved to a rural town having secured a graduate position after completing her Bachelor of Nursing degree at a city-based university. As she commenced working in this rural community, she soon experienced an overlap between her professional and personal lives. Amy quickly gained insight into what it would be like for nurses who had lived in a rural area for a long time, thus discovering a phenomenon not commonly experienced in the city—that overlapping relationships were a unique and accepted part of living in a rural community.

Feeling comfortable or challenged

Participants experienced either feeling relaxed or uneasy when visiting patients' homes in their own rural communities. For some participants, having multi-layered connections in the community was a comfortable aspect of living and working in a rural community. One participant explained:

> probably because I have been in health [care] for such a long time I find I am looking after people [I know], like even those I have delivered as a baby, so often there is an acknowledgement … so it is complicated, but it doesn't bother me that much, you sort of live with it. (Leonie, p.2)

Leonie was generally able to cope with community connectedness. She accepted these contacts had increased over the years and were a unique and comfortable part of living in a rural community. A long-standing nursing career had contributed to this phenomenon as she rotated through several different positions and roles. Betty also found the experience of living and working in the same a rural area over many years as being comfortable:

> I have worked and nursed in this community for 38 years ... this [town] [name given] as opposed to small towns [names given] and then you have got the farmers [that is] the rural component so we work across a wide range of people … I find it really easy, I think that is because I have worked and nursed in this community for 38 years. (Betty, p.1)

Betty was a well-established community member, not only in the large regional town where she lived but also in the surrounding district. Betty generally felt at ease with having multiple community associations. In contrast, living outside of their work community provided a partial buffer between their professional roles and private lives for other participants. Leo explained:

> I don't live in this region I live in [name of neighbouring rural area], so I am not a community member as such, not part of school, social setting … [However] when you have looked after hundreds and hundreds of families … in a small community you are going to run into people and you are bound to meet people who you have had contact with before. (Leo, p.1)

A physical distance between where Leo lived and worked provided the benefit of some delineation between his professional role and personal life. However, over time he had noticed an increase in the number of connections he had developed in his work community. Leo generally felt comfortable about occasional chance meetings with members of families he had supported in the past.

Jane also lived outside of her work community and explained some other advantages.

> I live in (name of another community) so this town is not my community. In saying that I have worked here for 15 years. I have a level of anonymity which I think is probably to my advantage on many occasions, [going on to provide an example], for other nurses [who] work in their own communities they will have contact with patients' family in places like the supermarket … I don't get baled-up, that is a real bonus! (Jane, p.1)

Jane pointed to other benefits of living away from the community where she worked. In her work community she adopted the identity of a health care professional. Jane was comfortable being recognised in her professional role by local people. However, she did value being able to go about her own life without interruption from chance meetings with patients' families. Jane acknowledged the challenges her colleagues who lived locally had in never being able to guarantee that their private lives were not disrupted. Mark agreed:

> I live in an outer metropolitan area and commute here ... so I am an hour away … I am not here on weekends … in some ways that can be a useful thing as a nurse … I might just see them on my lunch break. (Mark, p.3)

For Mark, living away from the town where he worked brought a welcomed divide between his professional role and personal life. Mark entered his work community bearing the title of a palliative care nurse. However, there were occasions on which he did have contact with people he knew or had known within his role previously.

Tracey had a slightly different experience to those participants mentioned above.

> Well, I live [name of place] 25 minutes away [however] I have relatives down here, so I know some people; generally it is great. (Tracey, p.1)

Tracey mostly felt comfortable with the connections she had between her personal and professional life. She welcomed opportunities to have contact with her extended family and their associates as she went about her work. However, other participants reported some situations in their communities were at times quite challenging.

Mia reported:

> Sometimes [working in a rural area] is really challenging because you know that person or you might have worked with someone or you might be friends with their grandchildren, in a way it is nice that they know someone and it makes them feel a bit more comfortable. (Mia, pp.1–2)

Living in a rural farming community meant some of the patients Mia supported would know her from social, family or farming associations. While it was comforting for the families, Mia found these intertwined relationships uncomfortable. Leonie also experienced challenging situations:

> I have been through a marriage breakup and so sometimes there are places I don't want to go and sometimes people don't know, and they ask questions about my husband, so that personal stuff can be difficult. (Leonie, p.2)

Leonie admitted that at times she was challenged with the intensity of community embeddedness. Finding balance between her professional self and personal self caused Leonie some anxiety—for example, when she met people who were not aware of changes in her personal circumstances.

Tanya also shared an example of when close community connections affected her work:

> Being in a small community a lot of people know each other or are related and that can be trouble in a way. We recently had a man out at [name of town] and we were trying to get services out there, we tried to get personal care staff out there to do bed sponges … we were going through all the service providers … some people were available [but] they did not want to go in because they knew the family. (Tanya, p.2)

In this situation, community embeddedness affected Tanya's professional capacity to provide home-based support for some families. It was difficult to find staff who were willing to be involved in a patient's care because of their own family or community connections.

Maintaining confidentiality

Participants reported the complexity of maintaining the confidentiality of patients and families they were supporting. Betty found *s*ocial interactions within the community could pose difficulties. She explained:

> As a nurse in the community, you must be very, very aware of confidentiality. [For example] I go to a quilting group and there was one lady there whose son-in-law had cancer and she knew I was involved but so did the rest of the people at the table. So they know what I am … she asked me a question … and I said 'look I can't really chat to you about that … I hate talking work outside,' … so I shut down pretty quickly. (Betty, p.4)

Betty had developed skills in upholding families' confidentiality by not engaging in conversations about patients she was supporting when she attended social groups in her community. One such skill was to kindly state that she did not like to talk about her work. This stance provided Betty with a professional boundary and thereby protected herself and the families she was supporting.

Intertwined relationships within Betty's community not only illustrated community embeddedness but also the uniqueness of living in a rural setting.

Pippa agreed:

> I can't talk about anything even without names that will identify [patients] … so that is my experience of living in your own community; you do not talk about your work. (Pippa, p.2)

Pippa refrained from speaking about her work in all social settings. She recognised that finding balance between her professional and personal selves was an ongoing challenge. This occurrence was a normal part of working and living in a small, close-knit rural community. It was relatively easy for people to make links between herself as the palliative care nurse and families receiving support services at home. Nurses working larger metropolitan areas may not be so exposed to this level of community embeddedness.

Deb elaborated:

> Sometimes relationships continue with people because you see those people … some people want to engage but that can be a bit challenging because you see them in a public place. (Deb, p.2)

Deb acknowledged that during and after providing nursing support for patients and their families, incidental contact with them was part of each person's normal daily life. Deb was aware that in greeting or conversing with bereaved family members in a public place she could compromise their privacy. However, at times Deb felt she should stop and converse with them. Deb knew that if she did not engage with the family member it would appear that she was not a caring nurse and community member. This is another example of the unique experiences for nurses who work and live in rural communities.

Kerry agreed that it was difficult to know when and where to engaged with a family in a public space.

> I can think of a few people that I have looked after at home and when people are dying at home it is quite an intense situation for families … then a couple of weeks later I am in Foodland pushing my

> trolley and you know the spouse is there and you know you make a decision, do I engage, or do I keep going with the shopping? (Kerry, p.1)

Kerry grappled with trying to maintain confidentiality because she also wanted to convey her ongoing kind regard for the family. Kerry had to make a choice between engaging with the family and comprising their confidentiality or passing them by and risk being seen as insensitive.

Jess shared a similar situation:

> It can be challenging in terms of maintaining confidentiality, especially when there is a lot of people involved in that person's care. You see that family down the street, and they are asking quite personal information in a space where other people might over-hear. It can be difficult to be sensitive … [to] maintain that confidentiality … I've not experienced that anywhere else, here people seem to be quite open about it. (Jess, pp.1–2)

Jess had been taken by surprise by the boldness of people asking about patients for whom she was caring. She was quite taken aback by the nature of their inquiry, not having encountered such directness while working in other professional settings. Mia added further insight:

> they don't want to seem nosey and they really care … they know you are seeing them, you just say '*I am really sorry but I can't say*', usually they will not pry but it is hard because we might have heard something about a referral before I even go there … you know [for example] I shear sheep, so when I am shearing you hear it, you hear everything in the shearing shed! (Mia, p.2)

Mia found most people were caring and discerning community members. As a nurse who lived in a small farming community, it was to be expected that people's misfortunes—including declining health—would be known by others, particularly when she was working in her other vocation as a shearer. Mia heard conversations in which she could not participate, or as other participants reported, she needed to shut down any questions or conversations relating to her professional role as a community-based nurse.

Amy concurred:

> A while ago I received a referral for one of my best friends' grandfather. I went around to her house one day after I had visited her grandfather. Her parents said, '*we thought you were the palliative care girl, we thought you would have contact with us.'* It had only been two days since he had been discharged … so I thought I would give them time to settle in back at home. My friend's parents were not happy when I explained I couldn't discuss the patient's care with them when I was not at work … they wanted to ask

> things about symptom management, it was a bit tricky and my friend apologised saying, '*Oh I am so sorry'.* I said, 'it is okay, I've got used of those questions.' (Amy, p.2)

Amy was mindful of her professional responsibility to maintain confidentiality. However, when challenged by community members in a social setting she experienced some pressure to engage in conversation. In the short term Amy struggled to find balance between her professional role and personal life as she adjusted to living and working in a rural community. Amy experienced the disappointment of the friend's family for her lack of willingness to share information about their loved one—another experience of the reality of embeddedness in a rural community.

In summary, participants had varying levels of embeddedness according to how long they had lived and worked in the community. Some participants were comfortable with the relationships within the community, while others reported reasons why these connections could cause concern. Some difficulties arose in maintaining patient confidentiality as participants went about their private lives within the community. At times, this resulted in a heavier loading of their personal self as they grappled with retaining respect as a caring community member as well as a responsive professional nurse who provided home-based palliative care for terminally ill patients in the community.

4.2.2 Personal self

The second relational theme to emerge from data was the personal self (Table 4.1). The environment of community was multi-layered, with members being involved in numerous social, sporting and professional fields. It was, therefore, vitally important that participants acknowledged their communities' acceptance of them as health professionals. However, alongside this acceptance came the responsibility to be seen as active, committed community members.

Accepting responsibility

Being well-known in the community came with unspoken but expected responsibilities. The participants were grateful for the communities' acceptance of them as nurses and community members. However, this acceptance could result in the need to respond to a diverse range of community responsibilities.

Deb experienced a strong sense of civic responsibility:

> For me it was about when I finished my degree … working where I live, because often rural communities can be quite disadvantaged in accessing services. (Deb, p.1)

A strong connection to her childhood community had underpinned Deb’s wish to return to work there after she completed her Bachelor of Nursing degree. She wanted to be part of the solution of providing a quality health care service to her rural community. In doing so, Deb felt she was giving back to the community where she grew up. She was able to balance her professional work in her chosen field of nursing and her personal preference of living in the rural town.

Tracey told a story to illustrate what accepting community responsibility meant to her:

> You are driving up a dirt road and we had a cow out, I had a student with me, there was a calf out on the roadside, and I said, ‘come on out you get’ and she said, ‘is this what you do in the country?’ She was a city girl [with laughter], so we herded the calf back into the paddock and then we go and find the farmer! It is not strictly nursing sometimes [giggle] you know if someone comes along and hits that calf that would not be good. (Tracey, pp.1–2)

Tracey knew it was important to demonstrate to the nursing student that community responsibility was a normal part of being employed by a health service in a rural area. Accepting this responsibility would result in receiving gratitude from the farmer whose income came from raising livestock. Finding balance in this situation was about accepting the responsibilities that came with being a responsible professional person, as well as being a caring community member. Stopping to help a farmer on the way to a patient’s home was a unique experience for the student nurse; an experience that would not have occurred during a clinical placement in a metropolitan setting. Community embeddedness was evident within Tracey’s professional and personal self and there was ready acceptance of this phenomenon.

From a different stance, Mia reported the importance of supporting her fellow farmers' wish to return home to die after discharge from a metropolitan hospital. Mia shared:

> Take the farmers they have been on the land all their life and they just **want to come home** [spoken loudly] … so yeah it is nice to do that for them … they sort of deserve that! (Mia, p.1)

In this excerpt, Mia explained that just as it was important for people living in metropolitan areas to be able fulfil their wish to die at home, it was equally important for people from rural areas to be given the same opportunity. Mia's role as a community member was to support others who wanted to be home. In this situation, Mia's personal self was more heavily weighted than her professional self because she understood the farmers' deep connection to the land. Finding balance was about acknowledging her personal insights into the farmers' wishes and her professional ability to support them.

Deb agreed:

> I think it is more about being able to do this work where people want it, support that choice of them dying where they want to die. (Deb, p.1)

Deb supported patients' wishes to die at home. She accepted the responsibility of striving to provide a service in her community to accommodate patients' choice to do so. Ruby shared the same strong view that each community had a responsibility to care for their own members, particularly when they were dying:

> [Some authors say] it is the '*social capital of your community*' how you look after your dying people. It is not hard, it is the easy bit, you [the patient] is not lining up for a diagnosis, or a toxic course of chemotherapy, all that is done! (Ruby, p.2)

Ruby saw that it was part of her personal community responsibility to contribute to the care of people who were dying in her town. In so doing, she would build community capacity to care for other terminally ill patients in the future. This stance was thus about strengthening community resources.

Kerry also reported that taking on the responsibility to bring a patient home within her professional role was a vitally important part of her personal responsibility to the community:

> I think if they have been in hospital [in the city] I think they prefer not to go to the local hospital because if they go there, they [may] not get home. It is our responsibility to get them home. (Kerry, p.1)

A rural community's natural networks of support were invaluable in ensuring patients wanting to die at home could do so. Interestingly, Kerry thought that if patients were transferred back from a metropolitan-based health service to the local hospital as a half-way house, then this step may impede the patient reaching home. Kerry was confident that if patients were discharged from city hospitals to return to their homes, then the community supports together with the local health care services were able to fulfil patients' wish to die at home.

Tanya shared a story about the same sense of responsibility from a different rural community:

> We had a man [and it was] just after Christmas they had just gone into the hospital. He was very confused, he had a syringe driver [but] they were not giving him Midazolam because they, the family wanted him to be awake and talking … His wife [said to me], '*I have promised him he could go home, be on his veranda and look over at the river, I promised him!'* So, we decided [community nurses] let's do it and organised the next morning to get him home … he came home, and I was like, '*How is this going to work?'* because there was no one else, the wife [said] she could cope saying the family in [name of the city] had their own lives to live. Anyway, others did come, [so] they ended up with about 20 people in the house! ... they [family] picked him up and put him in wheelchair and sat him on the veranda and she [his wife] had tears in her eyes and she said, 'this is exactly what I wanted.' (Tanya, p.3)

For Tanya, this unique experience was about accepting her professional and personal responsibility to assist fulfilling a lady's promise to take her husband home. Finding balance was evident in Tanya's investment of her professional self to see this patient's wish come to fruition. In doing so the local community would learn of this nurse's work and commitment to her community.

Feeling pressured

The next sub-relational theme reports the participants' experiences of feeling pressured within their personal selves. Several participants explained how different circumstances occurred in their professional self that resulted in feeling pressured within their personal self. Leo explained:

> I‘ve worked here for 16 years … I am getting to the point that I may be caring for a husband or wife of someone I care for five or ten years ago, a second family member [or] I go to a new client’s home for the first assessment, and they say, ‘heard all about you!’ no pressure! … Then we have a laugh. (Leo, p.1)

Leo laughed off the precedent set by work he had done in the past. He acknowledged that encountering families from previous episodes of home-based palliative care was an accepted and unique outcome of working in the same rural community over many years. Leo could see evidence of how he had become embedded in his work community. The result was that his work community had accepted him as an honorary member.

Deb reported that her feelings of being pressured could be self-propelled:

> I think it is a pressure that you put on yourself … I just want to do my best … it is when you have to look after people you know socially or their partners … do they want me because they know me in a different context so there is a merge of professional and personal things. I imagine that you don’t get that so much in the larger metropolitan areas. (Deb, pp.2–3)

Deb recognised the professional pressure she experienced may have been self-imposed to feel she was upholding a good personal reputation in her community. Deb assumed this level of pressure was a unique characteristic of living and working in a rural community, quite unlike living in a city. There was a tension between her professional and personal self because she wanted to give the best of herself to her community while upholding her professional standing. She was unwittingly living with a deep level of community embeddedness.

Jess agreed:

> sometimes I find it hard to know how to help in caring, for example, they [the family] can be under a lot of stress and yet [still] want to do what the dying person wants … you are not sure what is appropriate and what advice is helpful … it makes me feel really bad as a person. (Jess, p.3)

The care needs of the patient and family were not always clear. At times, Jess struggled to find solutions to help relieve the stress experienced by the family. She felt pressured to respond in the most appropriate way professionally. This emotional reaction resulted in Jess feeling inadequate within her personal self as well as in her professional self.

Pippa felt pressured for different reasons:

> I feel pressured at times because people know that I am the palliative care nurse … knowing that I will run into people who are carers and people I know … I am a very private person, I go shopping with my head-down, so I don't run into anybody, so that is my way of remaining disconnected. [To elaborate, she stated] '*I don't know, if they find you and you are feeling vulnerable and they will just unburden themselves onto you so, my way of dealing with that is not to put myself in a position in which they are invited to talk.*' (Pippa, pp.2–3)

Pippa experienced feeling pressured to converse with family and carers outside of her professional role. Consequently, Pippa felt that she had to withdraw from some social settings that may encourage such engagement. For example, when shopping Pippa had developed strategies to minimise interactions with people, resulting in feelings of aloneness and social isolation within her community. Pippa felt her professional self was more heavily weighted in her community than her personal self, so she needed to find ways to protect herself.

In contrast, Mark experienced feeling less pressured because he lived away from the community in which he worked.

> I still bump into people in my working week that I might be directly involved with them … [But] I'm not involved socially, so you're not really *'in it.'* (Mark, p.3)

Mark felt he had a protective barrier from the pressures of his work because he lived outside of the community. He was mostly able to find balance between his professional self and personal self, particularly in a social context outside of his work.

In contrast, the next participant experienced feeling pressured as a result of a well-established therapeutic relationship with a family. Jane shared the following story to illustrate:

> A son and daughter were doing all the caring and one of the brothers was an artist, a mural artist, so, he was [painting] a mural about the family and so everyone had their own thing, so someone had flowers because they did flowers and someone had a dagger because he was always playing with his pocketknife, [and] there was a lobster because he was a lobster fisherman. So, everyone had something on this mural and then he started painting the nurse's hat and I said*, 'what is that?'* and they said, *'that*

> *is yours'* … and I felt really touched and said*, 'oh! That is an honour but no you can't put me up there, I am not family!'* (Jane, p.7)

For Jane, the well-meaning action of the family to include her in their mural caused some alarm. While she acknowledged how privileged she felt to be included in the mural she felt pressured to be a part of the family beyond her involvement as a community nurse. Finding balance was about being a recipient of the family's recognition for the support she had given to their loved one while retaining an acceptable space for herself professionally and personally.

Reciprocal relationships

Embeddedness was demonstrated in several ways as the participants in this study shared more about their intertwined relationships in the communities in which they lived and worked. Amy recognised some differences working and living in a rural community from her previous city-based experiences.

> I've found it very different from *acute care* [in a hospital] in the city, the expectations of the patients in the [rural] community … I think being a younger practitioner sometimes the line can be blurred … it is hard to draw the line and take a step back, I am not their friend. (Amy, p.2)

As a new graduate, Amy experienced needing to develop a new set of professional boundaries. She had experienced the community's expectation to engage as a friend, as well as being their nurse. Finding balance between her professional self and personal self was a new experience for Amy as she settled into a country community. Community embeddedness was an emerging, new phenomenon. The unique culture in rural communities was to contribute throughout her professional role and personal life.

Kerry explained the concept of reciprocal relationships further:

> If people are asking you for help or direction, I would help them as a person because one day I might need their expertise and that is great! (Kerry, p.1)

Kerry acknowledged that being willing to support her community within her professional role was important because some time in the future her family may need help from the community in different ways. A reciprocal relationship was a welcomed and unique part of living in a rural community. Both parties could be equally grateful for the other's assistance as they went about their daily lives.

Deb agreed:

> I guess you create relationships with people … it may sound strange to say you enjoy helping people who are dying but it is a privilege and I think the benefit goes both ways. (Deb, pp.1–2)

Deb welcomed the opportunities that her work as a palliative care nurse provided her in developing professional relationships with people in her community. She felt that the benefit of helping others would one day be returned to her. For this participant, reciprocal relationships in the community were also an accepted and unique experience of living and working in a rural community.

However, Julie cautioned that if she did not support patients' wishes to die at home this hesitancy may have lasting negative impact on her personal life in the community.

> Because we are a small community authenticity is so important … it is not okay just to turn that empathy on just when we work because that can really damage that rapport and when you are in your unprofessional time you can't say*, 'Oh! It is not my workday so don't bother me'.* (Julie, p.3)

Julie acknowledged that the need to respond to requests for support could involve having contact with families outside of her work time. It was important that the community knew she was always approachable. She found balance by being discerning within her professional self and her personal self.

Mia explained more about what reciprocal relationships meant in her community:

> It is hard because you are in the community and you do get called on and the thing is they know your number because like the good old neighbour will say, *'Oh yeah that's their number'* and they are not in the wrong, doing that. But yeah its hard like you know … that they will have to drive an hour to a hospital when they can just ring you … I knew the person well, so I said *'Look, please ring'* because it was not fair to put this lady in a car at 11 o'clock at night. They were just down the road. I would hope that someone would do that for me. So, yeah, like, yeah, like everyone knows everyone … so you head out …

> you want to be there too. I find it is a nice feeling that you can do that for that family … they appreciate you for it, like what goes around comes around. (Mia, p.7)

Mia knew part of fostering reciprocal relationships in a rural community was responding to requests for assistance at any time, even when off duty. Responding to other people's needs was important because as a community member she may need their support in times of personal need in the future.

Ruby expected the reciprocal relationship with the community would extend past her time of employment into her retirement. She explained:

> I feel a voice needs to be given outside of [name of organisation], outside the compound [laugh] … I want to work together [with the community] … to reinstate this service, even grow the service to a 24/7 service. (Ruby, p.4)

Ruby understood the importance of contributing to the community's need to retain a home-based palliative care service for the future. She was committed to supporting the community through non-professional avenues to work towards the goal of increasing the capacity of home-based palliative care services. In doing so she would be thanking her community for their acceptance of her professionally and personally.

4.3 Summary

Participants reported that living and working in rural communities brought some unique experiences. Several participants experienced living and working with overlapping relationships between their professional work and community involvement. Even participants who moved to rural communities from metropolitan areas found that overlapping relationships occurred quite quickly. Most participants were comfortable with these overlapping connections; however, others were challenged by such intense community embeddedness. Interestingly, participants who lived outside of their work community acknowledged that they had a virtual buffer between their professional and personal lives. However, after some years of working professionally in the same communities they also experienced some overlaps as they went about their work.

At times, upholding patients' and families' privacy was challenging. Participants needed to develop their own methods of protecting this. Inadvertently, such initiatives could lead to some participants feeling isolated in their own communities.

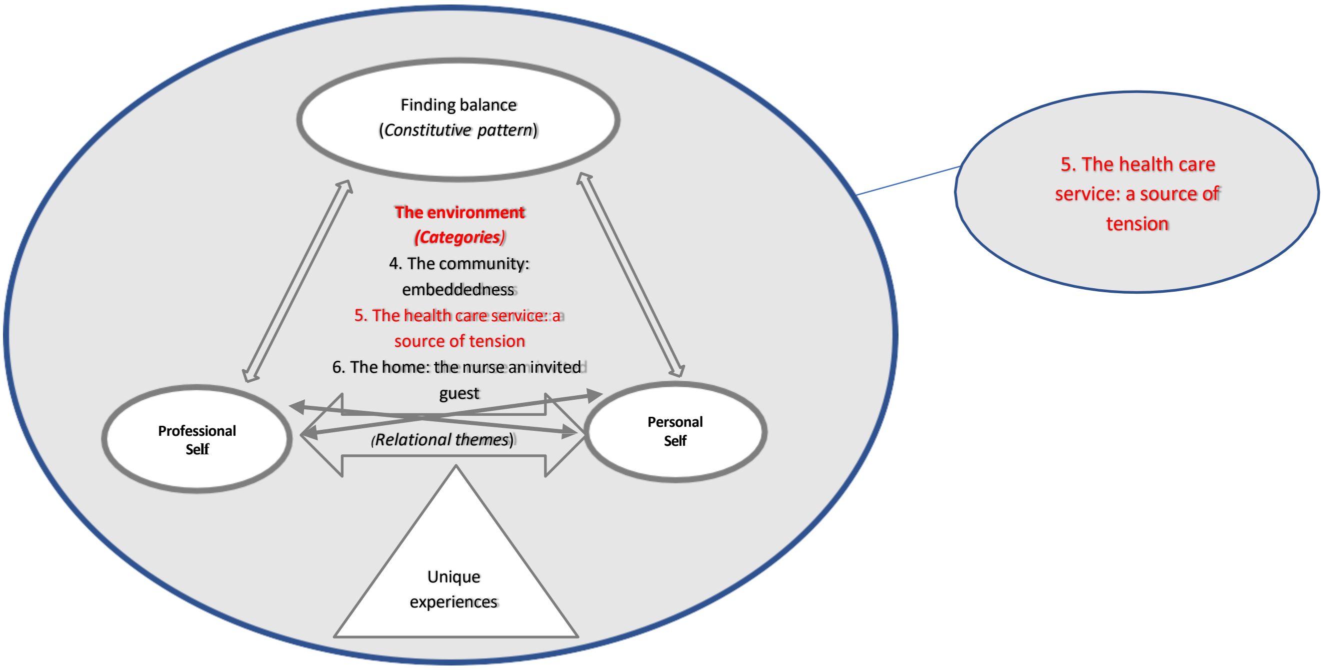
In the second relational theme of personal self, participants reported that they experienced a strong allegiance with their communities. This entailed a sense of responsibility that transcended their professional role; a sense of civic duty to their community. For example, participants were strong advocates for their patients and families, and worked tirelessly to ensure that the very best home-based palliative care service was provided. However, some participants reported that they felt pressured by the community to always be available. Finding balance between working within funded service times and meeting the needs of the community was an ongoing process.

CHAPTER 5: THE HEALTH CARE SERVICE

5.1 Introduction

In this results chapter the second *environment* to be reported that affected nursing care and is guided by the analysis of Diekelmann, Allen and Tanner's (1989) analytical process is the health care service.

Figure 5.1: A smaller greyscale model of Figure 4. highlighting the environment (category) of the health care service



Note. This Figure guides the reader as to the results reported in this chapter. As detailed by the external oval shape and the red coloured font the environment to be reported is the health care service: a source of tension.

In most rural areas of Australia, home-based palliative care services are provided by a local or regionally based health care service. All participants in this study were employed by such a service. The participants were either part of a specialist palliative care team or general CNS (Table 3.1). The main overarching constitutive pattern of finding balance also applied to this environment. In presenting these findings no judgement on the health care service is intended; rather, the data revealed the reality of day-to-day experiences that participants had as they conducted their professional and personal lives. Participants reported that this care was the source of a juxtaposition of positive and negative emotions in their professional and personal lives.

5.2 The health care service: a source of tension

Table 5.1 provides an overview of relational and sub-relational themes within the health care service. The two relational themes of the professional self (Section 5.2.1) and personal self (Section 5.2.2) as reported in the first category, the community (Table 4.1) continued in the second environment of the health care service.

Table 5.1: A summary of the constitutive pattern, relational and sub-relational themes within the environment (category) of the health care service

<table>
<tr><td colspan="2">Finding Balance
(Constitutive pattern)</td></tr>
<tr><td colspan="2">5.2 The health care service: a source of tension
(Category with description)</td></tr>
<tr><td colspan="2">Relational themes with corresponding sub-relational themes</td></tr>
<tr><td>5.2.1 Professional self</td><td>5.2.2 Personal self</td></tr>
<tr><td>5.2.1.1 Fulfilment</td><td>5.2.2.1 Reward</td></tr>
<tr><td>5.2.1.2 Frustration</td><td>5.2.2.2 Anger</td></tr>
<tr><td>5.2.1.3 Confidence</td><td>5.2.2.3 Caring for self</td></tr>
</table>

Participants reported that within their professional lives, the health care service was a source of fulfilment (5.2.1.1) as well as frustration (5.2.1.2), although there were varying degrees of confidence (5.2.1.3) in the work they did. *Polar opposite* feelings of reward (5.2.2.1) emerged, but at other times anger (5.2.2.2) was the prominent emotion. Participants had *unique* ways of caring for themselves (5.2.2.3), with the use of light-hearted responses to the pressures of their work both in their personal and professional lives in their rural communities.

5.2.1 Professional self

As introduced in the first chapter of this thesis (Section 1.4), in rural areas, professional nursing support is provided by community health care services co-located at local hospitals. Participants began each workday at a community health centre and then drove to patients' homes located either within the local community or in the surrounds of a farming district. As presented in the previous chapter, participants held dual roles in their rural communities: they were both healthcare professionals as well as community members. Thus, participants' professional roles could not be divorced from their personal standing in their rural communities. After a time, the status of being a community member also applied to those participants who lived in adjacent rural or outer metropolitan areas. Within their professional selves, the environment of the health care service was a source of tension for these participating nurses.

Fulfilment

Participants recounted examples of experiencing professional fulfilment. One participant spoke with conviction about his work:

> I still can say without a shadow of a doubt that I love the work that I do … I do find it fascinating to be involved with people dying at home, supporting patients, family and carers because it is so mixed, quite unlike my previous clinical roles. (Mark, p.5)

Mark liked the variety his work provided as he met different people from a wide range of social settings. Being an employee of the community-based health care service afforded Mark with professional opportunities he had not experienced in other care settings. For example, Mark found each family had their own way to care for their dying loved one, which differed from working on a clinical ward. This was a sentiment shared by another participant:

> I love this job … we meet up with a lot of people … I have always really enjoyed working with family and people … being with someone at their end-of-life is a privilege. (Betty, p.1)

Betty felt professionally fulfilled caring for patients who were dying at home. She enjoyed meeting different families, and she considered it an honour to do this work.

Other participants elaborated on their feelings of professional fulfilment. Leo shared:

> I can't imagine many other professions that offer this [fulfilment] … this works for me well at a professional level; I reach my potential in this setting. (Leo, p.4)

Leo found working for a health care service that provided home-based palliative care was professionally gratifying. On reflection, Leo conveyed that he felt he was able to use a high level of clinical skills and knowledge in this care setting—a level of professional fulfilment not realised in other clinical areas to date.

The next participant agreed that the work she had done in caring for patients in their own home provided her with valuable professional experience:

> I really love the way that some families totally engage the dying person, [like] putting them in the lounge. [On one visit] the family [were] watching TV and the X-lotto numbers came up and this lady had to write down all the numbers and I am thinking *'Honey, good luck!'* … that was part of what they did on a Saturday evening as a family. (Kerry, p.4)

As a general community nurse, Kerry saw different ways families chose to care for their dying loved ones at home. Their unique family routines continued and as their nurse she felt privileged to support them. Kerry reported professional fulfilment in witnessing how a patient retained some normality amidst the trauma of living with a terminal illness.

A participant from another general CNS acknowledged the professional fulfilment she experienced when she was part of her local team as well as the regional SPCS. Jane explained:

> We have a small team of [general] nurses here and they all, I think, I have the same joys and gratifications that I do in looking after people in their own homes. As for the palliative nature of the service I think that we are relatively well supported by our more specialist team at [name of large regional town] … we use them more as a consultative service. So, it is really the day-to-day services that we are doing, and we only really lean on them for the more complex care issues. (Jane, p.1)

Jane believed that the team of general nurses she worked with all enjoyed supporting patients receiving palliative care at home. Jane considered palliative care was a valuable adjuvant to their general nursing work. Jane also reported that she felt well supported by the consultative advice received from the regionally based specialist palliative care team.

Feeling professionally fulfilled was possible as part of a community-based health care service. In supporting patients' wishes to die at home, participants felt that they were able to achieve professional goals that they would not have achieved in other clinical settings.

Frustration

In contrast, several participants reported feelings of frustration within their professional roles. Within their professional role, some participants reported feeling frustrated about several organisational changes that had occurred in the health care service. An ever-increasing number of administrative tasks was a source of frustration for one participant. Mark explained:

> The bureaucracy can make you [do] all sorts of things that you need to tick off … we spend so much time proving what we do the actual work we do becomes secondary. (Mark, p.7)

For Mark, administrative tasks such as keeping records of all aspects of his work was becoming burdensome and undermined his ability to provide quality patient-centred care. Frustration occurred because Mark felt that the demands of clerical work detracted from having time to use his clinical skills and knowledge at a patient's bedside in a unique setting of care—the home. Similarly, Betty experienced feelings of frustration because she felt her high level of clinical skill was not recognised by the health care service. Betty shared:

> As a specialist palliative care service, we have a role to play in our area and they [the health care service is] trying to make us into generalist nurses because, they say, *'everyone can do palliative care!'* **That frustrates** me because, yeah, everyone can work with palliative care patients, but I think the specialist palliative care services provide a bit extra, a bit more knowledge. (Betty, p.4)

Betty acknowledged that some of the clinical tasks required in caring for patients who were dying at home could be provided by general nurses. However, she felt the management of the health care service did not understand the level of expertise the specialist palliative care team brought to the care of terminally ill patients at home. Betty struggled to find balance between maintaining the use of her specialist skills in home-based palliative care and meeting the new demands of attending to general nursing care visits.

The next participant explained more about the type of work involved in palliative care and the health care service's new approach in the provision of home-based support.

> It [palliative care] is not always task orientated, it can't be measured in time, it needs the time it needs … because how do you say to someone when you are having a deep conversation about how they are going to manage at home or about how they feel about being a burden [to their family] and you say*, 'I am sorry, it is three o'clock, now I have to go to the next client.'* I don't know that is a good way of dealing with it. I don't know if there is a broader understanding about palliation. (Deb, pp.7–8)

Deb spoke decisively about her frustration of having to work within set time frames for each home visit. She felt the health care service did not understand the intricacies of providing palliative care for patients dying at home. For example, at times it was not appropriate to rush out of a home after an allocated time; rather, it was important to allow patients time to talk about their fears and concerns. For Deb, this model of service provision detracted from the very ethos of palliative care. She struggled to find balance between providing two very different types of community nursing.

Ruby, too, voiced her frustration about a deficit in the level of service available to her local community compared with previous years. She said:

> I think we need a 24/7 service; it is too hard … it is frustrating! My approach was that if someone had a syringe driver, I would always ring in the evening despite what the rules said because my view was that they needed that support. I would ring them in the morning and night and then visit during the day … the more they wanted to succeed the more support you need to give them to stay home. For some people that was everything but now we have management who say we just need to send them to hospital. I don't think that is where we are at, we should be the opposite because we know it is cheaper to keep people home. (Ruby, p.4)

As a specialist palliative care nurse, Ruby wanted to support patients to realise their goal of completing their lives at home. However, a recent reduction in funding for an out-of-hours service frustrated Ruby. Ruby felt driven to find ways to continue supporting patients despite these cutbacks. These constraints in service provision highlighted an imbalance between her professional and personal self. As a community member she could appreciate the need for an out-of-hours palliative care service, yet within her professional role, she was officially restricted from providing this.

Another participant spoke of her frustration about diminished levels of home-based SPCS in her community.

> I think it can be frustrating at times … **well** [spoken loudly] we have had a lot of changes and I guess our service has changed a lot from when I initially started. We had a 24/7 on call service. We had the capacity to take a phone call at one o'clock in morning, you were able to go to keep that person in their home but that has all changed. We don't have that same capacity now [softly spoken] … it would be wonderful if we had nursing 24/7, but we don't have that. I think that sometimes that is a bit of a barrier. So, you can be limited to what you can provide ... I would say that palliation is 24/7, you know, it is not between 8 and 4. (Deb, p.1)

Deb found the recent restructure of the health care service had a noticeable impact on the level of home-based care nurses were able to provide to patients and their families. She reflected on the level of service experienced in the past and compared it to what was currently available. The demise of the seven-day-a-week palliative care service caused deep frustration.

Similar feelings were reported by a participant from a general community nursing team:

> [It] can be frustrating … you don't have the resources and you [feel like you have] failed them. We can't get the staff or the funding, you can't get … like you have to have a GP involved; you and they need to be on the same page. And if they are not, it is not going to work. And that is when the family possibly pick up a lot more [of the] caring responsibility because you can't. The nurses will go out of their way [though] to help but it can't be every weekend. (Mia, p.3)

Mia was frustrated that she was unable to offer more support to the families who wished to care for their dying loved ones at home. At times she felt the families were left to manage the best way they could with very little help from the health care service. However, from the health care service's point of view Mia acknowledged it could be difficult to find enough staff to provide adequate support. In addition, if medical services were limited it was even more difficult to successfully provide out-of-hours support for families. Mia grappled with finding balance between being a responsive employee of the health care service and a caring community member in a small rural community with limited services.

In contrast, Leonie's frustration originated from the unrealistic expectations of the government and the local community in the level of health care service available:

> I have a bit of frustration around the expectations of the people who are actually dying in their own home and sometimes that is a bit of a juggle, isn't it? … because it is quite complicated really … we are not a 24-hour service, we are a 5-day-a-week service and planning for all the possibilities over the weekend. Palliative care services [are expected] to keep them at home, and quite rightly so, like the Grattan Institute [states] there is a percentage of people who want to die at home and in [the name of the health care service] there is a KPI [key performance indicator] for that … Yeah, it is huge, you haven't got GPs who do home visits so you haven't got the medical support. (Leonie, pp. 3–4)

Leonie was frustrated by the Federal Government's expectation that a certain number of patients should receive home-based support to die at home each year. Specialist nurses, like Leonie, who worked in community-based health care services in rural communities, felt beholden to achieve these goals. Regarding the community, Leonie felt there was little appreciation for the complexities involved in her work. She considered that the level of funding support available from Medical Practices and the National Key Performance Indicators (KPIs) for palliative care services were in conflict. As outlined in the introductory chapter of this thesis (Section 1.3.3), the expectation of the community that a Level Two palliative care service should be available on a seven-day-a-week basis was incongruent with the level of funding available in these regional areas. Leonie felt there was a lack of knowledge and insight by the consumers, as well as the overarching government body. The uniqueness of this situation was heightened by Leonie's deep involvement in her community over many years, as previously reported in the first results chapter of this thesis (Section 4.2.1.1). Leonie experienced ongoing tension between her professional self and personal self as she tried to achieve the expectations of the health care service, government and her community.

However, another participant reported that some recent organisational changes within the health care service were positive initiatives. Tracey said:

> I am a great believer that when we go into a home it is not about me being Florence Nightingale and stripping them of what they [the family] can do. It is about how can I facilitate what is going on? We were a 24-hour service, now we are not; we just break it [the care episode] down to the terminal phase which I think is much better because you don't disempower people … I like that we are not an emergency service. (Tracey, p.2)

Tracey considered that the restructure in the health care organisation provided clearer guidelines for services provided by palliative care nurses. Under the new service structure, the family and patient were encouraged to remain in control of their care. The family were then encouraged to seek extra support in the final phase of their loved one's illness as needed. To work within this new service structure was not a source of frustration for her as an employee of the organisation. Tracey was able to balance the recent organisational changes by working collaboratively with other services in serving her town within her professional role and as a community member.

In sum, feelings of frustration were evident as a result of organisational restructures and community expectation. Participants were clearly upset about not being afforded the same level of funding as enjoyed in the past. However, one participant was able to be resourceful in working within the new service structure to meet the needs of patients and their families receiving palliative care at home.

Confidence

As reported in the previous section, there were contrasting experiences of this sub-relational theme; some participants felt self-assured in their work, while at times others lacked confidence. For two participants, providing palliative care in patients' homes in a rural community was a new experience. Mia shared:

> I used to do a lot of reading and asking questions, the girls in the *regional team* (specialist palliative care team) probably got sick of me. I think when you start visiting people you really have to spread yourself, it is not hard to do but you have to make sure that you have things in place for when they are ready to talk about it. I can't sort of go, *'Oh I will go and find out for you'* or *'I'll do it next week'.* You have to be really prepared, so I would go and find out. (Mia, p. 4)

Mia acknowledged that she did not feel confident when she started working in this specialised area of nursing. She recognised that she needed to prepare by proactively seeking information about the patient care she needed to provide. Mia would check with nursing staff on the wards at the local hospital, community health service and at other times contact the specialist palliative care team in her region. Over time her confidence grew. Mia had come to her position as a general RN having moved into a new community. She not only had her professional role to establish but also her personal standing in the local community. Finding balance was about establishing herself within the local and regional health care service, as well as in the community.

A second inexperienced participant reflected.

> I first came into the [community] palliative care service six months ago … [So]I am probably hard on myself. If I don't get it right the first time, I might get cross with myself, but you know in this role you can't get something right all the time. (Amy, p.7)

Settling into a new field of nursing was demanding. Amy's lack of confidence was exacerbated by her own self-propelled expectation to succeed in her new professional role; a role quite different from others she had observed as an undergraduate nursing student. In stark contrast, she found working in patients' homes highlighted a need to develop a different set of critical thinking skills. Working autonomously was a daunting and challenging experience for a new graduate.

In contrast, the next participant was confident that she had the necessary experience and local knowledge to secure the resources needed to provide home-based palliative care in her community. Jane said:

> It is [my] first-hand knowledge, how I can get equipment, how I can source things … I can get those things … you know the inside information, like which chemist stocks the drugs or who does not stock the drug. (Jane, p.2)

Jane had valuable knowledge of local services and networks of support to ensure the home-based palliative care was provided efficiently. This knowledge then contributed to enhancing the work she did in patients' homes as an employee of the health care service. This was a clear example of how a participant was able to find balance between her professional self and personal self.

Deb also spoke of feeling confident in providing an appropriate level of support for patients and families:

> I think it may make you find a way to go about things, that you might challenge the system's boundaries to try, and I guess that comes a little bit with the mentors that I have had along the way. It more about,

> ‘Oh! How can we achieve that’ rather than ‘we can’t do that’. It’s about ‘how can we find a way to support this person?’ (Deb, p.2)

In this excerpt Deb expressed her confidence in knowing the needs of the patients and families she was supporting. She was not afraid to take action that may challenge the service provision guidelines of her employing health care service if it meant supporting her patients and families to remain at home. Deb demonstrated her confidence by reassuring patients and families that a home-based palliative care service could be provided. In this way, she upheld her personal responsibility as a caring community member and as a resourceful employee of the health care service.

Leah also felt confident in her knowledge base and embraced opportunities to educate other health professionals. Leah shared:

> Not long ago we did a talk [education session] with one of the medical clinics just about, you know, if you are going away for a weekend or a long weekend make sure you hand your palliative care clients over to someone else and let us know. So, things have been running a bit more smoothly. Yeah, we try to have a good relationship with the doctors but that can be difficult because you have got so many different towns. You know, we have five different towns we look after so you have five groups of different doctors. It is challenging keeping in touch with all of them, and then, you might have a couple of doctors in a town that you have never met before because they have never had a palliative client. (Leah, p.6).

Leah recognised that one unique aspect of working in a rural setting was the need to collaborate with several medical clinics across different communities. Having a diverse range of medical services meant there were challenges in maintaining continuity of patient care. She felt confident in the knowledge her team had to extend their work to include in-service education for doctors in several communities in her area. This level of confidence brought balance between Leah’s professional self as an employee of the health care service and as a community member.

In contrast, despite the support from the health care service and medical services one participant found it was sometimes challenging to meet patients’ needs. Deb shared:

> If it is a challenging death in terms or not being able to control the symptoms, I find that hard because of the feeling of wanting to do more and the distress that the family get from that. The effect is ‘Oh we have not done well enough?’ Sometimes it does matter what you do [but] you can’t fix it all [very softly]

> … just how could we have done better? I think it is more about […] I wish I knew a bit more about that or […] what can I learn to make that better next time? (Deb, pp.3–4)

In this excerpt Deb was honest in admitting that even as a specialist palliative care nurse she could experience a lack in confidence because caring for dying patients could be unpredictable and challenging. Deb was afraid that her lack of confidence in the management of patients' complex symptoms could affect her reputation within the community more so than the health care service. The unique situation was that sometimes in rural communities the personal role of the nurse was more heavily weighted that the professional role because of interlinking relationships, as reported previously in Section 4.2.2.1.

One participant confidently acted as a conduit between metropolitan and local medical services. This conduit ensured seamless transition of care for patients returning home from city-based hospitals. Jane explained:

> Sometimes you must smooth the waters with the communication or the lack of communication between the GP and the specialists. The specialists in [name of city] don't understand the limited service that we have down here. (Jane, p.2)

Jane was confident in her knowledge of the local services available to patients and their families. She readily recognised that metropolitan palliative care services may not be aware of the limited services available in a rural, community-based organisation. Jane's level of confidence was evident as she liaised with the city-based services to provide information about local community networks that could assist when there were gaps in funded health care services. In this way, the levels of confidence the participants reported varied according to their professional experience, level of awareness about home-based services available and resources in their communities.

5.2.2 Personal self

The second relational theme focussed on how participants found balance within their personal selves. As previously reported, participants' personal lives could not be excluded from intrinsic links to their professional roles. Data revealed that in addition to participants feeling professionally fulfilled, they also experienced personal reward from their work.

Reward

Feelings of personal reward came from various experiences as participants provided home-based palliative care. One participant vividly described his feelings of being personally rewarded:

> This work is my soul food ... deeply satisfying, the interactions [thoughtful pause]. Yeah, the interactions between people … deep connections with patients, deep compassion and love. It's almost like there is a part of me that is open to that special moment in palliative care, not that I try to do anything to make it happen … when it happens often enough that it makes it really rewarding and keeps me going, yeah, there is purpose, meaning and realness. (Leo, p.4)

For Leo, there was an overflow of professional satisfaction from his work into his personal life. His professional work also gave him emotional nourishment as a person, and that feeling of reward propelled him to continue in his professional capacity. There was therefore a balance between Leo's professional achievements and sense of wellbeing in his personal life.

Another participant concurred. Mark explained:

> As soon as I get to go inside a home and engage, I come to life. That is what I love doing, you can make a difference there. (Mark, p.7)

Mark expressed his appreciation at being invited into each patient's home. He experienced a sense of being valued within his professional role and felt he made a difference. In the setting of the home, Mark felt that he could contribute in a positive way to the family as they cared for their dying loved one. The next participant explained further; Leah shared:

> I find it a really rewarding … be able support people in their dying wish to die at home. I have lots of people, say to me, 'How do you do it?' So, I guess I feel blessed that I can do it. Many people say*, 'I would never be able to that'* and nurses say*, 'I could never do what you do*.' So, like I say to nurses working in ED [Emergency Department] and delivering babies, *'I could never do what you do'.* (Leah, p.1)

Leah found palliative care to be a field of nursing that encouraged her to develop a specific set of new clinical skills. In so doing, she found her work brought personal reward, too. Working in each patient's private space of their home had awakened emotional responses not experienced in other care settings. Leah acknowledged that she felt comfortable in the environment of the home just as other nurses preferred practicing in other clinical settings.

Jane also felt rewarded after caring for a patient who wanted to die at home:

> You have a sense of euphoria! Yes, you really do because you know end-of-life care is quite manic often behind the scenes … you have actually done a good job … that is no mean feat … there is nothing more rewarding! (Jane, pp.4–5)

In this excerpt, the reward of having achieved a dying patient’s wish to remain at home overshadowed the challenge and busyness of care coordination. Jane’s contribution was not only professionally fulfilling but also personally rewarding.

After only a short time in her position as a palliative care nurse, Mia, too, expressed feelings of jubilation in what could be achieved in supporting patients to complete their lives at home.

> I have found the most rewarding job that I have ever done … there is a sense of connection with them … if you are willing to take an interest in people you kind of get that respect. (Mia, p.2)

Mia had experienced a level of human connection with the patients and their families that she had not felt before in any other role. Home-based palliative care nursing had helped Mia to connect with her new community in a unique way. As a result, she experienced a balance between her professional and personal selves. Amy confirmed these feelings:

> It is really rewarding to meet someone and give them some strategies … there are just so many things you can do. (Amy, p.1)

Amy’s personal reward came from the empowerment she gave to the family to enable them to care for their loved one in their own way. Her professional role involved gently providing nursing support as requested by the patient and family. In this way, she discovered how she could balance her professional role with her own personal attribute of resourcefulness. Another participant who had many years of experience in nursing agreed:

> Yeah, like I would not like to do anything else! I often think to myself, what would it be like to be … and there is nothing … it's rewarding … Yeah, like you see people at their best in the worst situation. (Leonie, p.5–6)

Leonie considered this field of nursing to be the most rewarding part of her career. She marvelled at families' abilities to care for their dying loved one amidst many challenges. To witness how families navigated the unchartered waters of living with a terminal illness was a privilege.

These participants experienced feelings of personal reward from their professional work. Being invited into patients' homes, working collaboratively with family and allowing new clinical skills to develop in this unique care setting were high points in several participants' careers. However, in the next sub-relational theme, a disparity became evident between the positive response just reported and the strong emotion of anger that emerged from the data.

Anger

Feelings of anger were reported by participants for several reasons. Frustration experienced within participants' professional selves transferred to feelings of being affronted on a personal level. Some participants expressed their anger at some recent organisational changes. Mia, for example, reported:

> Yeah, I received a phone call on a Friday evening to tell me! [The funding had ceased.] I was so angry I stopped community nursing altogether and went back to shearing for a while. (Mia, p.6)

In this excerpt Mia was not only angry about the funding being ceased for her palliative care position but also the way this news was given to her. For Mia, the approach taken by the health care service made her so angry that she stopped working as a community nurse and returned to her other vocation of shearing for a period. Not only was Mia's professional career challenged but also her personal reputation in her farming community. The community knew Mia was a nurse who cared for patients who wished to die at home. The health care service had caused her a level of embarrassment on a personal level in the community and the surrounding farming district—a unique occurrence that would not have been not seen in a metropolitan setting. Mia's professional self was more heavily weighted prior to the funding cut. However, after the cessation of funding Mia's personal self was propelled into prominence as she tried to salvage her reputation in the community.

Anger about inadequate funding to provide a service to outlying communities was experienced by Betty:

> Here in [name of a large regional community] there are community nurses who go out and cover seven days a week, they can do that here right! In the regions they don't have enough nurses to even work Monday to Friday so anything outside of those hours … they need to source a person who can be on call. Often the only person available is the same community nurse, so the patient has not been able to die at home. That makes me angry! (Betty, p.5)

Betty expressed her anger that a seven-day-a-week support service could not be extended to families and patients who lived outside of the larger regional town in her area. As a consultative specialist nurse, Betty felt that this shortfall in funding reflected on her professional abilities and on her personal reputation in her community. Finding balance was a challenge because within her professional self Betty was a representative of the health care service and also a community member. In surrounding smaller towns and farming areas, generalist community nurses are often the only nurses available to attend to any out-of-hours work, including calls for end-of-life care support. Betty felt the impact this gap in service provision had on her professional and personal reputation in her community and in the surrounding district.

Another participant was angry about the difficult times some patients had experienced in receiving care through the wider health care services. Pippa said:

> a lot of time things that have happened leading up to them knowing they have a life-limiting illness, it has been really rocky, they have had a really bad time through the health system of being diagnosed ... it makes me angry that they have had to go through that. (Pippa, p.3)

In the excerpt above, Pippa felt angry that patients had experienced difficulties in navigating the complexities of the health care system as they sought medical treatment. Consequently, Pippa felt a need to compensate for these bad experiences as she established a therapeutic relationship with the patients and their families. Pippa understood that as an employee from a health care service she represented all professional services. Pippa knew that her work had the potential to affect her personal standing in the community positively or negatively.

Administrative work was a source of anger for Leo:

> [They are] more concern[ed] in ticking the boxes to make sure that it is all done! While palliative care is about making sure [there is] access to services, equipment, medical input [and] symptoms [are well managed]. [You] need to know when to call a GP or ambulance … other things drive me insane, [for example] writing policies, attending meetings, is not me, I come to work; other work like this [points to paperwork on his desk] is soul destroying. I sometimes go home feeling really flat! (Leo, p.3)

While Leo embraced working in patients' homes supporting those who were receiving palliative care, he admitted that the administrative side of his role was an annoying interruption. He understood completing documentation was a necessary part of his professional work. However, Leo reported some of the expectations of the health care service were unrealistic. Leo struggled to find a balance between these two aspects of his work. This anger spilled over and affected his personal self as well as his professional self.

In contrast, the next participant wanted more involvement in some aspects of administrative work. Mark explained:

> The system that you are working in actually does need to trust your judgement! Yeah, that is right and when I talk about putting in extra support … it would be good if we could do that easily … but no [refers to the home care packages (HCPs), on which see Glossary] … it makes me angry. (Mark, p.8)

Mark felt he was not trusted by the health care service to make decisions about how funding for additional home-based support was allocated. The recently implemented central referral point for additional funding through the HCP excluded Mark from being involved in the administration of any additional funding for home-based palliative care. This exclusion evoked an emotional response of anger. It was interesting to note Mark's strong emotional response of feeling personally affronted by this role being removed from his service coordination tasks. Although Mark chose to commute to work in a rural community from an urban setting over a number of years, he knew that his work community considered him an honorary local member. Therefore, any impact on his professional role may affect his personal standing in his work community, tarnishing his reputation.

Another source of anger was a lack of acknowledgement by the organisation for the work the nurses did.

> You know we are all human and you do make mistakes, but we do our best in palliative care to relieve suffering but sometimes it is difficult. I don't think we are acknowledged enough as a palliative care specialist and that makes me cross. (Tanya, p.4)

Tanya conveyed feelings of anger about not receiving acknowledgement of her professional skills in navigating the complexities of coordinating services in providing home-based palliative care in her community. This coordination was not just about fulfilling professional responsibilities but also those of her own community. Tanya felt her employer did not fully appreciate that nurses working in rural areas needed to find a balance between providing a professional service while being loyal to their own communities.

The next participant's feelings of anger came from interactions with some of her colleagues:

> I can become angry if I see a clinician being judgmental and very intolerant or critical [of patients]; that really irritates me … I get angry when I see other clinicians using their own filters to look at situations. (Pippa, p.6)

Pippa encountered a lack of empathy from some workers within the health care service who were also involved in supporting patients who wished to die at home. The workers' lack of discernment and understanding disappointed Pippa. There was a level of personal as well as professional grievance experienced by this participant. Furthermore, inaction by some medical services incensed other participants. Ruby described her feelings of:

> *Righteous indignation and compassionate outrage because*, '*how dare you not write an order for pain relief for a patient … how dare you not!'* [Raised voice] so you write them a letter and they don't reply. (Ruby, p.3)

Ruby was angry because she felt unsupported by the local doctor. Her resentment increased when a letter she had written did not result in action. She knew that a good professional relationship with the local doctor was pivotal in providing an efficient community-based palliative care service. Finding a balance between her professional role as a palliative care nurse and her personal goal to be an efficient, caring community member through her work was challenging to achieve at times. Ruby's own zealous personality was evident in the level of emotion experienced in this situation. Again, as seen in the previous excerpt, the display of anger was about a patient's suffering not being addressed by a person in a professional position. These experiences caused a level of personal distress for participants Ruby and Pippa.

The juxtaposition of emotional responses between a sense of reward and feelings of anger revealed participants' passion for their work. Participants' professional commitment to provide home-based palliative care within restricted parameters collided with a personal sense of duty to their communities.

Caring for self

In this third and final sub-relational theme, participants relied on their own personal ability to care for themselves. Caring for self was assisted by using a light-hearted response to the sadness and rigours of their work. One participant reported that working with other professionals in the health care service who had similar sense of humour helped. Leah reflected:

> we have a counsellor that works two days a week with me, so we talk about a lot of stuff, we do lots of jokey things, you know, we keep the mood light, so it is not too heavy all the time … we don't dwell on all the bad stuff and all the sad things because it is sad, there is a lot of sad stuff. (Leah, p.2)

Leah acknowledged her work in palliative care could be emotionally draining. Working with a colleague who shared a similar light-hearted approach to their work was a proactive way of coping.

For Leah it was important to find balance by being light-hearted while she was in the presence of so much sadness; as she together with her colleagues witnessed families grappling with the reality of a loved one's impending death.

Another participant was also comforted by the use of humour at work. Amy said:

> I think I have always had a warped sense of humour, but it has gotten a little bit darker [giggle] … I work with [name of colleague]; she has the most wonderful sense of humour … I think you have to. (Amy, p.7)

Amy, too, found working with a nurse who had a sense of humour helped to lighten the mood. Amy appreciated her mentor's use of humour as a way of releasing the pressures they experienced. Self-care strategies such as being light-hearted were vitally important in sustaining these nurses in their professional capacities.

Ruby also relied on her own humour to stay light-hearted:

> When you first meet people, you are trying to do the paperwork and they are quite resistant to your questions … yeah, this is not a social visit … the request to visit came from the doctor … most people don't understand. Oh, I just laugh. I am just resilient and have a warped sense of humour. (Ruby, p.2)

Ruby understood patients and their families' hesitancy in accepting her support. She did not take offence in these situations; rather, Ruby maintained a light-hearted approach. Ruby understood a family's need to protect their privacy because the knowledge of a loved one's illnesses could be quickly known throughout a rural community. People would soon see that Ruby was visiting the home in her professional capacity as a palliative care nurse. Ruby demonstrated her professional and personal discernment for families as she explained how she could support them as they navigated the unchartered territory of caring for a terminally ill loved one.

Taking a pragmatic approach with the use of humour helped another participant remain positive. Pippa explained:

> So, people you care for die! [Higher tone of voice with loud laughter] so I don't get any feedback about what they think about me [laughter]! Unlike the midwives or even the diabetes clients I don't have my clients coming up to me in the street saying, *'How are you going?'* (Pippa, p.7)

Pippa's humour was a useful way of dealing with the realities of being a palliative care nurse. The reality was that all her patients died; thus, there were no opportunities to receive patient feedback about the care she gave. While her use of humour explained some of the sad reality of her work, she knew the sobering fact of living in a rural community was that she would have incidental meetings with grieving family members. Pippa knew the feedback from these families would reflect on her professional and personal life.

Relying on her own interests outside of work helped Tracey to care for herself. She said:

> I am a farmer and so I am out with the animals and so that is my stress relief, they make me laugh and having said that I have been very proactive for many, many years on emotional things. Over the years I have done all sorts of *weird and wonderful* things [laugh] like women's networks in my community. (Tracey, p.4)

Tracey drew on her personal life on the farm caring for her animals to restore normality to her world. Interacting with her animals was a source of releasing tensions that accumulated in the presence of death. Her animals' antics were a valuable source of pleasure as Tracey went about caring for their simple needs. She also found being active in the community through social groups helped her to remember that many people lived in good health. Tracey reported that these community groups were a valued source of laughter and cheer. Finding balance between professional work and her personal interests assisted Tracey to maintain a positive approach in life.

5.3 Summary

Participants' work was a source of both positive and negative experiences. The health care service was a source of mixed feelings, of professional fulfilment and frustration. Experiences such as developing different sets of professional skills in the unique setting of the home were fulfilling. In contrast, inadequate levels of funding and reductions or cessations of community-based palliative care services caused deep levels of frustration. Varying levels of confidence were also experienced by participants as they went about their work. New graduates and younger, less experienced participants found caring for dying patients at home was daunting, while other participants reported that confidence in utilising their knowledge of local community resources and professional experience assisted in coordinating quality home-based palliative care.

In the relational theme of personal self, the flow-on effect of experiencing professional fulfilment was evident. Participants gained feelings of personal reward. However, feeling rewarded was tempered by feelings of anger when participants felt personally affronted by a lack of funding and resources. Most participants understood that funding constraints affected health care services in many rural areas, so drew on their own resources to mitigate any gaps in service provision. The use of humour was one important way of dealing with the pressures and demands of nurses' professional roles.

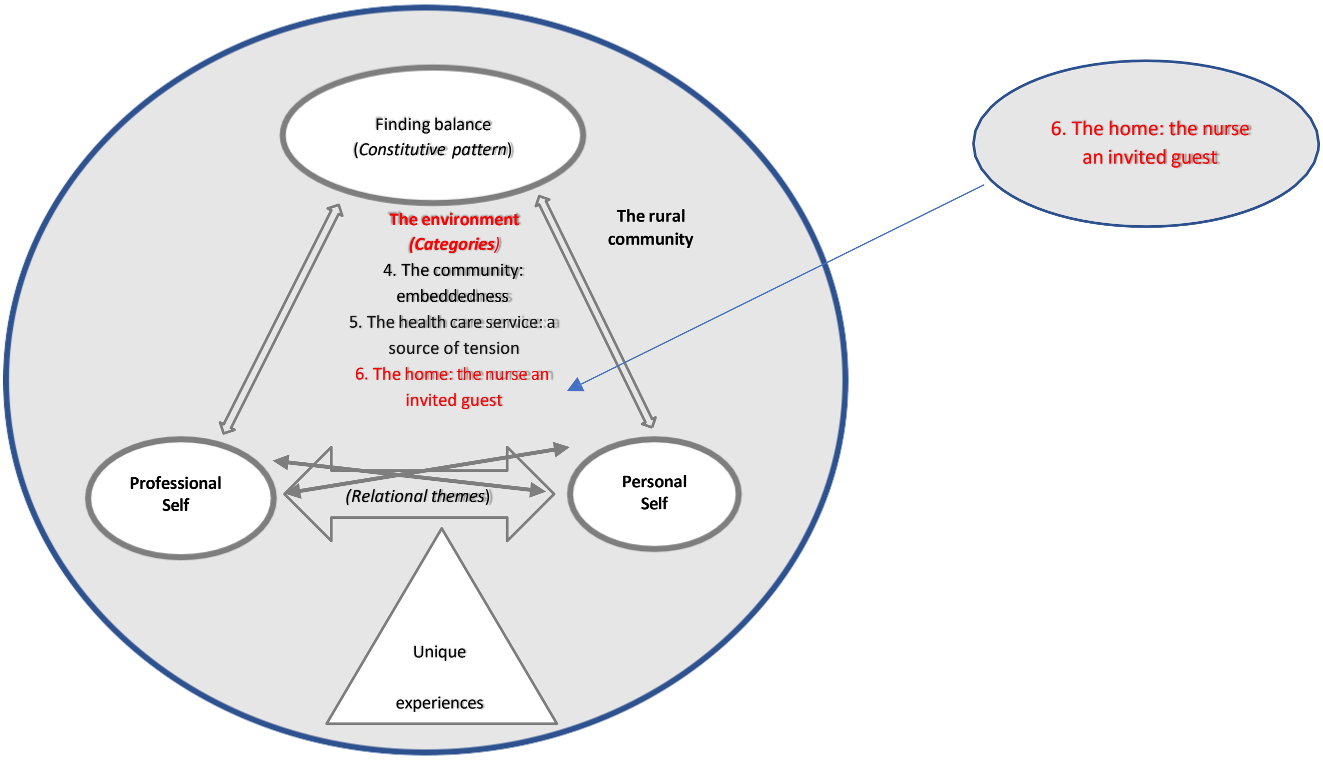
The influences of the environments of the community and health care service have been reported in Chapters 4 and 5, respectively. These two environments (categories) have set the scene for new understandings to emerge from the most prominent environment: the home. This third environment will be reported in the next and final findings chapter in this thesis.

CHAPTER 6: THE HOME

6.1 Introduction

The home is the third environment, as illustrated in Figure 6.1 below to be reported in the results section of this thesis. The data identified that the home was the most important environment out of the three categories to affect participants' experiences. While participants went to each home within their professional role, they were invited guests in the private space of another family. The home influenced how palliative care was administered in partnership with the family. The rural setting meant that the participants may be caring for people they knew from their own communities. At times, neighbours, business associates or extended family members

Figure 6.1: A smaller greyscale model of Figure 4. highlighting the environment (category) of the home with its unique theme of the nurse being an invited guest. This Figure guides the reader as to the results to be reported in this chapter.



Note. This Figure guides the reader as to the results reported in this chapter. As detailed by the external oval shape and the red coloured font the environment to be reported is the home.

6.2 The home: the nurse an invited guest

As established in previous chapters of this thesis, participants in this study were part of either a community-based specialist palliative care team or general nursing service. These RNs all reported that providing palliative care in the home was very different to looking after patients receiving end-of-life care in the hospital setting. Rather than being a clinical space, the home was the private living space of each patient and his or her family. Therefore, there was a stark difference in the manner in which these nurses approached their work. Furthermore, not only was the physicality of each house different, but the daily routines, customs and traditions of each family varied. The table below provides a summary of the constitutive pattern, category, relational and associated sub-relational themes to be reported.

Table 6.1: A summary of the constitutive pattern, relational and sub-relational themes within the environment of the home

Finding Balance (Constitutive pattern)	
6.2 The home: the nurse an invited guest (Category with description)	
Relational themes with corresponding sub-relational themes	
6.2.1 Professional self	6.2.2 Personal self
6.2.1.1 Balance of power	6.2.2.1 Parallel grief journeys
6.2.1.2 Decisive care coordination	6.2.2.2 Spiritual awareness
6.2.1.3 Being a non-intrusive presence	6.2.2.3 Emotional investment

Finding balance between the relational themes of the professional and personal self occurred within three emergent sub-relational themes each. Within their professional roles, participants quickly identified that there was a different balance of power in the home compared with working in a hospital-based clinical care space. Participants also reported that their work required efficient and decisive coordination of care to support each patient and family according to their individual wishes. However, in doing so these nurses needed to remember that they were invited guests, so they adopted non-intrusive ways of being present in the home.

In the second relational theme of personal self, the impact of working within the private space of another family emerged. Participants reflected on their own personal experiences of caring for a loved one in the past. Some participants recognised that their own awareness of spirituality was heightened when working in the environment of the home. The emotional investment required was also reported as being more significant in the home compared with other clinical spaces.

6.2.1 Professional self

The first relational theme in the environment of the home focussed on participants' professional self. The way participants went about their work in the environment of the home differed from working in other care settings. Of importance was that the RNs in this study acknowledged that there was a different power dynamic in the home.

Balance of power

One participant readily identified there was a vast difference. Leo explained:

> I go there as a guest. I am a professional [but] the dynamic is different than in a hospice or hospital.
> (Leo, p.3)

Leo acknowledged that the patient and family held the balance of power in their home. The dynamic was different to that in a hospital; therefore, his professional approach needed to adapt to working in another's private space. An invitation needed to be extended to him to enter the home within his role as a specialist palliative care nurse. Betty agreed:

> It is not a given, you have to sit down and actually say 'can I have your permission to speak with you today?' … it is their home, their territory, they rule what happens there and we are the invited guests.
> (Betty, p.2)

After being invited into a patient's home, Betty found that it was necessary to seek consent to engage in conversation with the patient and family. Then, because the family had the balance of power in the care of their loved one Betty found taking time to engage in conversation at the beginning of each visit was vitally important in acknowledging this stance.

Kerry, another participant elaborated:

> [I] have to adapt to where they are at and want, they expect. Like not what I would expect to happen … [be] more adaptable maybe because you are in their environment because I think when they are in hospital, they are at the mercy of the system whereas at home they have a bit more weight. (Kerry, p.5)

Kerry acknowledged that patients and their families had freedom to do things their way because they were in their own space, the home. She was keenly aware that she needed to be invited into this space by the family. She intuitively adapted her nursing practice to how the family wished to care for their loved one. Finding balance involved observing ways in which she could apply her clinical knowledge and skills to complement the family's routine.

As a new graduate, Amy quickly noted the difference between in working in a home from a ward. She remarked:

> It is nice to see patients being able to live the way they have always lived. They can have the routine that they have always had whereas in hospital the routine can seem a bit forced, and it seems a bit unnatural for them. (Amy, p.2)

Amy had observed that patients were able to retain some normality in their day-to-day lives at home. On reflection, Amy appreciated that patients receiving care in a hospital were bound to adhere to the clinical routines of a ward—routines that did not align with a family's way of living at home. The home gave the patient and his or her family freedom to make decisions according to their way of caring for their own loved one.

Ruby elaborated:

> I feel very privileged because you are allowed in that separate space … the privilege of going into the home is extraordinary [because it's their] home it is their last bastion, isn't it? For lot of them they have been mangled through the health system they have lost their power…. you really need to affirm with them that their power stays with them and that it is a negotiated result. (Ruby, p.1)

For many patients, their home was a welcomed sanctuary away from clinical routines of a hospital. The home was a place where patients and their families felt safe and had a sense of belonging. Home was a safe haven where the patient and family could grapple with the realities of a terminal illness. Ruby considered it an honour to receive an invitation to be involved in the patient's care. To establish her professional self, Ruby needed to respect the family's wish to retain control of how care was given to their loved one. However, receiving consent to enter a patient's home as an invited guest could not be taken for granted. Ruby went on to explain:

> When you first meet people, you are trying to admit them, do the paperwork, they are quite resistant. One man said*, 'It is really bad form wanting to come into my home and talk about my wife dying'* … yeah, but I am a guest, [but] this is not a social visit', [I replied] '*we have arranged this meeting at the request of your GP to see if we can assist you in you in looking after your wife'.* (Ruby, p.2)

Ruby reported that when a family was not ready to accept her clinical input, she delayed her offers of support while she gently explained her professional role. It was important for Ruby to respect a different balance of power—that is, it was the family's right not to accept the help she was offering.

In contrast, Mia found that most farming families living in outer regional areas seemed to readily accept help so their loved one could stay at home. Mia shared:

> I do find in a small rural community people can get their head around it [caring] more, like sometimes in town people can't get their head around it, about caring for someone. I find the further out [of town] they live the more they seem to get it, like giving injections when you have never done that and they kinda like [said] *'I've done it for the cattle, I can do that'.* They want them home, so they are going to do that. (Mia, p.2)

The family knew that to care for their loved one at home they would need to undertake some nursing tasks. They recognised that some clinical skills needed were like looking after sick livestock. Furthermore, the family were prepared to take on the added responsibility of caring for a loved one at home so that they could continue to look after the livestock and attend to the daily tasks of running their property. Mia understood that the alternative of driving long distances to visit their loved one in a hospital was unsustainable for these farming families. Finding balance for Mia involved understanding families' position as a fellow farmer, which enhanced how she went about developing a therapeutic partnership of care with them.

As presented above, the participants reported distinct differences between the clinical setting of care and the home. The participants recognised that being involved in caring for dying patients at home was on an invitational basis, whereas in a hospital setting, giving care was expected. Finding balance between professional self and personal self involved employing sensitivity to patients' and families' wishes and making the appropriate offers of support at the right time.

Decisive care coordination

Participants also shared about their experiences of being ready to take decisive action in coordinating patient care in the home. Coordination of home based services differed greatly from providing care for patients in hospital, where resources were readily available. Home- based care required efficient coordination of services.

Definitive action encapsulated the manner in which participants went about coordinating the care required by a patient and family in the home. Taking quick action was aided by knowing where and how to link into professional and community services to ensure that appropriate support was forthcoming in the patient's home. Jane described her professional role well in the following excerpt:

> They know who the movers and shakers are pretty quickly, and I am not shy. [For example] Like someone has a GP who goes on leave for a week, and no one knows about them [the patient] and then suddenly they deteriorate rapidly, and we need to start a skip pump, and no one has laid eyes on them and then I am ringing up and saying we need a skip pump and we need it now. Oh, Hooley Dooley! OK! Get me a doctor, get one out here now! Can you come? If you can't, we need a script. Then all the processes like they may have been on Fentanyl and titrating that in the skip pump and then you need to go back to a half-reduced dose and then you know, we are teaching families to give subcutaneous boluses [laughs louder] to get us through so we can titrate better for the next day. (Jane, p.3)

As an invited guest, Jane's role was to work efficiently with the local health care services to ensure care could continue in the home. For example, when a patient's regular doctor was on leave a relieving medical officer needed to be contacted quickly should a subcutaneous infusion of medications be indicated by an escalation of distressing symptoms. Jane was able to utilise her established linkages with medical and health care services and her clinical knowledge to source the appropriate equipment and pharmaceutical supplies to provide the patient with ongoing care at home.

Sometimes, coordination of home-based palliative care commenced while patients were in hospital. After receiving a referral for community-based palliative care, nurses would meet and talk with patients about their wish to go home. Amy explained:

> I recently had a patient die in her own home. She was admitted to hospital, but she was adamant that she wanted to go home. She needed home oxygen, so I organised that and she went home with her granddaughter who became her carer. She was only home two and half weeks before she passed away, but she passed away the way she wanted to. She had her whole family around her, she was comfortable. I think that was fantastic! (Amy, p.4)

Amy was able to carry out the necessary background work efficiently, resulting in the family and patient's wish to go home being upheld. Being proactive at the outset of this fledging therapeutic relationship was instrumental in setting the scene for the type of service that patient and family could expect in their home. In rural communities, news of how a nurse went about coordinating a patient's care was noticed and appreciated.

The next participant also spoke about being proactive in assessing her patients' needs. Kerry elaborated:

> [Caring at home] is a drain on the family sometimes and you need to help them on the journey like [being] a gatekeeper for how many visitors come to the house because, you are an outsider you can see what is happening and how they are managing … I sort of take the lead from what is happening. (Kerry, p.2)

Once accepted into the home as an invited guest, Kerry's work was to monitor how the family were coping with the demands of caring for their dying loved one. Kerry's role took on the form of observing what was happening, then acting decisively on the family's behalf in suggesting ways of managing the numbers of people visiting the home at any given time. In this situation the presence of the community in the home was a vital link to ensure the family received the support they needed. Balance was found between Kerry's professional self and personal self because she had insight into the patient's and family's care needs as well as understanding the community's need to be there to help (to be discussed further in the next chapter, Section 7.2.1).

On another occasion, Kerry and Mia conducted a joint care coordination visit to another patient's home. Kerry explained:

> She [Mia] had been looking after her for a long time. I came in when she was bedbound [to help]. Mia had gone [from the room] and the lady asked for her and said, *'I am ready to go, I am ready to go'*. So, I stayed for a while, Mia had gone to the front door, then she must have realised that something was happening [and she returned to the room] and it was not very long and she [the patient] said *'good-bye and thank you for everything'.* (Kerry, p.6)

Kerry was attuned to the patient's need to talk and responded by staying longer at her bedside. Kerry's delay in joining her colleague at the door alerted Mia to come back into the bedroom. Together they spent time with the lady while she expressed her gratitude. Kerry's astute decisive action was evident as she responded to the lady's need to talk.

Betty explained that her approach included being aware of external factors that may affect the care of the patient:

> On a 40-degree day and there are some people whose wives don't drive so they [the patient] are the ones doing the driving … they are so stoic. In this role I think you have to be an advocate, and it doesn't worry me picking up the phone and speaking to anyone in [name of a city]. (Betty, p.10)

Betty was vigilant in identifying the needs of her patients and advocating for them. In this situation, Betty needed to take decisive action to alert a specialist team in the city of the risks involved in a patient and carer driving long distances during extremely hot weather—a phenomenon unique to rural communities, quite unlike metropolitan areas, where such long-distance travel is not required.

There were various ways in which participants were involved in being aware of the patient's changing care needs. These changes can occur from the time of referral to the coordination of ongoing home-based care and advocating with external city-based services. While participants' professional roles were vitally important in care coordination of home-based palliative care, their work needed to be congruent with upholding that status of being an invited guest in that private space. All aspects of nurses' work were noted by the rural community in which they lived and worked.

Being a non-intrusive presence

A skill that participants acquired with years of experience working in homes was to be present in a non-intrusive manner. Quietly taking note of the features and decor of the home was one way to gather information about the lifestyle of the patient and family. Deb explained how the home and family provided clues about what care could be required:

> The thing about being home is if you have a good carer or partner, I think the needs [of the patient] can be catered for a little better … I think that the person that is there most of the time knows the person intimately so they can get what they need … When you go into someone's home you see things about their life. You have a greater opportunity to understand that and understand how they have lived and perhaps why they want to die the way they want to die. And I think you have a better picture of who they were as a well person [at home] … you don't get that in the acute setting. (Deb, pp.4&7)

Deb found capable family caregivers were the main vehicle in meeting the patients' physical, emotional, psychological, spiritual and psychosocial needs. The physicality of the home provided some important information about the patient and the family. The information gleaned from conversations with the primary caregiver assisted Deb in identifying the patients' potential needs.

Ruby explained further:

> '*I am here to loan you my strength when you need it*' … you try to be a steady point in the whirlpool that the client and family are in. [Going on later to explain], '*my job is to get you safely to the doorway [of death] and through the other side … and I will give you the care that will get you there'.* (Ruby, pp.3&4).

The home itself provided a haven from the rigours of hospital-based treatments and care. At home, the family were attuned to their loved one's needs without interruption from the noise and activities of a hospital ward. For each patient, their home was a private place in which to conclude life. Ruby's quiet presence in the home provided an additional a source of strength for the family as they continued to care for their dying loved one. In upholding the status of being an invited guest in the home, this participant allowed her patients to make their journey with a life-limiting illness on their own terms.

Betty agreed:

> We need to stand back, we will not push our way in … we make sure that we are there [in] a supportive [way] but we are not intrusive … we need to know when to back off. (Betty, p.2)

Betty saw her role as being an encourager; a giver of affirmation while she provided clinical nursing support in an unobtrusive manner as it was needed. At times, Betty recognised that her support was not needed. It was then appropriate to step back and allow the family to care for their loved one as they wished.

Being non-intrusive was also reported by Jess:

> [Home-based care] … it's a less intrusive way of providing care … people needing palliative care are generally under a lot of stress so it is nice not to be so much in their face … we can be a little more in the background. (Jess, p.1)

Jess thought it was important to acknowledge that caring for a dying loved one at home could be very stressful for the family. Within her professional self, Jess was developing skills in not forcing unwanted care onto the patient. She understood how important it was to remain approachable at all times as the family continued to care for their dying loved one in their own way.

Leonie found that providing a family with education about the care needed by their loved one was one way of not being intrusive:

> I think we train our carers really well; they feel empowered and a lot of them say they are able [to do things like] adjust the Morphine. They don't have to wait that half an hour [like in hospital] while you find the keys [to the DDA cupboard]. (Leonie, p.4)

Leonie found that upskilling the family with the necessary knowledge about how to respond to their loved one's needs empowered them. She could then step back and allow the care to be given. For example, in giving medications to relieve pain, being at home provided the family freedom to give immediate care without the delay associated with adhering to hospital protocols. Leonie's professional skills enabled the family to be primary carers while her personal discernment for them gave balance in a non-intrusive care approach as a guest in their home.

Amy agreed:

> When they are at home, they may need us once and awhile … with dying at home they seem to be more adaptable and they seem to have better support networks for each other. (Amy, p.4)

Amy recognised the abilities and willingness of family to care for their loved one at home. The home environment also encouraged families' natural support networks from the community to be involved as part of the primary care team. For this participant, being a counterpart in the support team with the family rather than being the primary care giver was the most appropriate approach. This approach to patient care enabled nurses to stay on the side-lines while remaining alert to the family's changing needs.

In summary, the home environment is a unique setting of care where the role of participants within their professional selves was to provide care as invited to do so; to allow the patient and his or her family to retain the balance of power, and to take decisive action as required while maintaining a non-intrusive presence in the home. In this private care setting participants found balance by allowing their personal self to add value to their professional self.

This chapter will now report on the lived experiences of participants for the final time within relational theme of personal self as they provided home-based palliative care for patients wishing to die at home in their shared rural community.

6.2.2 Personal self

Several participants recalled their own personal experiences of caring for a terminally ill loved one at home; memories that influenced how they went about their work in this private space of another family. The physicality of the home brought many emotions to the forefront. However, participants experienced a stark difference between being an invited guest within patients' homes and being a family member. In some instances, though, as members of a rural community, participants could be intrinsically connected to the families they were supporting.

Parallel grief journeys

In the interviews, participants were asked open-ended questions relating to their emotional responses to caring for dying patients in their own rural communities. Several participants spoke about how their work in providing home-based palliative care reminded them of their own personal experiences of caring for a terminally ill family member at home. These personal encounters enhanced—as well as challenged—the participants' care approach as the invited guests in their patients' homes.

Three participants spoke about the death of their mother. Jane shared:

> My own mother died at home, and I was in my own teens … she had a terrible death at home in lots of pain and she did not get the care that she required. I can say that now I have a better insight into it. So, I look after every patient as though it was my mum or my dad and I want the absolute best for them and I want the family to feel as though their loved one is having the best care that they can have. (Jane, p.2)

The confronting death of her mother as a teenager set Jane's resolve. She vowed never to see another dying patient experience distress as her mother had endured. Jane's personal experience had a deep impact on her professional work as she went about caring for patients wishing to die at home.

A second participant found a new source of strength when caring for a family who reminded her of her own grief journey. Julie explained:

> there was a family where things were very much the same as when my own mother passed away. There was a girl the same age that I was when my mother was dying and I found that I was actually pleased

> when I was with the family and on reflection, I was quite comfortable that I was able to work in a professional manner. (Julie, p.4)

The death of her mother at such a young age was devastating for Julie. However, this personal experience provided valuable insight in the journey of another family. Julie was able to use her own experience to provide a compassionate professional self within her role in the home environment. She was surprised about her ability to maintain her professionalism in a situation that mirrored her own personal grief journey. Importantly, Julie found balance between her professional self and personal self in her life and her work by drawing on both of these aspects of her life.

Betty, the third participant, spoke about the difficulties of being separated from her own family who lived overseas:

> I went through a difficult time. In five years I lost five relatives on the same side [of family] in England to cancer, including my mum. I was going through a really tough time … it is funny that working with these patients here helped me through that. I am sitting here [in their homes] thinking, well someone over in England is doing that for my uncle, cousin you know, and my mum. So, I think it gives you a different perspective when you have lost someone. (Betty, p.6)

Betty was comforted knowing that her own loved ones, including her mother, were supported by community-based hospice nurses in her home country while she provided similar support to the patients in her community. An emotional balance was found as she journeyed with her own grief and supported patients and their caregivers in her own community.

The death of an extended family member was a painful childhood memory for Mia:

> It is weird because Grandad was in mum and dad's house … in a box [coffin] … like he was there for two days … as a kid I found that really confronting … people would come in and he was in the dining room … it was how it was done, it was a Station thing because they were buried on the Station. It was a practicality thing. It is funny because now if I ever got unwell, I would want to be home. I have lived in the city, and I liked that, but I like the idea of being at home. I would not have been able to do this role if I hadn't had that experience. (Mia, p.8)

For Mia, it was only as an adult that she understood the significance of her childhood memory of a loved one dying at home. The experience gave her insight into the experiences of the patients and families she now supported in her new rural community. Mia found balance as she drew from her personal experience to bring comfort to families she was supporting in her professional role as a palliative care nurse. She understood the significance of farming families wanting to care for their dying loved one at home. It reflected a deep connection to their land, a place that had belonged to generations of the same family. A place of belonging and therefore the right place to die.

Mark shared about how caring for his father at home had a direct impact on his professional life:

> [I] had my own personal experience of looking after someone prior to becoming a nurse … I did care for my own father … back in the nineties [1990s] … [It was] quite a profound experience. I was 35 years old then. I would say it was a spiritual experience … so I certainly invest with people when I am with them. (Mark, pp.1,4&5)

The experience of caring for his father was a deeply spiritual time in Mark's life. In caring for his own father, emotions were awakened in ways that he had not experienced before. He had witnessed what death looked like for someone he was very close to. The death of his father propelled Mark's passion to work in facilitating other families to care for their own loved ones in similar meaningful ways. His work fulfilled both professional and personal goals in his life.

In contrast, Tracey had a traumatic experience of a loved one's death:

> My own twin brother was killed … I was training as a psychologist when my twin was killed … but I went nursing after that. I think there was an emotional connection there, yeah, well it makes sense, you know, like making sense of death and having connections with it. So, I am sure without a doubt that personal experience helps me in my nursing role now. (Tracey, p.6)

Tracey's journey with the death of her twin as a teenager had lasting effects on her professional as well as on her personal life. She changed her profession to care for others in ways that she had been forbidden to do for her own loved one. Tracey went on to share more about the impact that losing her own brother had on how she supported another grieving twin in her professional role. She explained:

> I actually got to nurse a twin, she was 50 years old … she [the patient] happened to be dying when I was on [duty] and her twin sister did not get there in time. See, I didn't see my own brother, I went to the Burns Unit, I didn't get there. He passed away and I wanted to go up, but they said no.
>
> So, I walked in, and the twin died, her sister just grabbed hold of me and sobbed her heart out. So, she was sobbing, and I was sobbing … see, I was not there [for my twin]. I don't think I believed he had died for about two years. So, when I had this opportunity to be with this twin it was so sad, we just sat on the floor and drank coffee and we talked about her life, and I talked about some of my stuff, and it was incredible the similarities between us as twins. So, it was the twin thing, and when I spoke to her later, she said it gave her courage. (Tracey, p.7)

In Tracey's account of supporting another family, in particular, a twin, she oscillated between being her professional self and her personal self as she dealt with some of her own unresolved grief. Tracey's insight into the grieving twin's specific needs came from her own personal experience. In this situation the reality of human suffering was the connection between two grieving twins rather than the therapeutic relationship between a nurse and a family member. Balance was found in the giving and receiving of comfort from her professional and personal self.

Spiritual awareness

In this second sub-relational theme participants explained how their understanding of spirituality influenced the professional care they provided in the environment of the home as invited guests. The home presented a different dimension in terms of spiritual care for participants because it was a not a clinical space. This space was a personal space that belonged to individual families. For some families, home was indeed a spiritual place in which final days of living occurred. In this study, gaining insight into participants' own understanding of spirituality was important to analyse the experiences they had in providing home-based palliative care in their own rural communities.

Leo said:

> [I have] spent many years finding out what life was really about … I feel pretty good about life ... I [like to make] a difference … this is my belief system. (Leo, p.4)

For Leo, spirituality was about having purpose and meaning in his life. He wanted to make a difference in people's lives. Being involved in the care of patients dying at home as an invited guest provided opportunities for him to do so. Leo found balance in his life by helping people in positive ways within his professional self, and in turn this role gave his personal life meaning.

Leah concurred:

> [Spirituality is in] valuing life … you know, that bucket list … I just want to live life to the fullest and do things that I enjoy and not just work my life away and have regrets down the track. Because you don't know when you may get sick. I guess doing this role you see it so much. I see people my own age with cancer, and you think*, 'Oh, my gosh'.* (Leah, p.8)

Leah realised the importance of embracing life. For Leah, spiritualty was being true to what was important to her. It was imperative to pursue these goals with determination and not waste precious living time. Finding balance was about succeeding within her professional self while feeling fulfilled in her personal self. In doing so, Leah was mindful of guarding her personal goals by not allowing her professional work to dominate her life's achievements.

Having a Christian-oriented faith gave purpose in life for a number of other participants. Julie shared:

> My own world view is that I have a strong Christian faith, so I don't have a fear factor with death as such. Dying is something that we will all share one day, and we will all die despite what our culture believes … I can talk to the family about those important things and can help facilitate those final goodbyes. (Julie, p.4)

Julie's faith guided the way she supported her patients and their families. She was able to talk with family and patients with confidence because she herself did not fear death. Being an invited guest in each patient's home was not taken for granted but permitted Julie a sense of freedom to speak freely about spiritual issues as invited to do so. Julie found balance between her personal faith and being willing as a nurse to support families in whatever spirituality was for them.

Jess agreed:

> I am aware of my own mortality, and I am not afraid of it, because I am a Christian I know where I am going, and I believe in Jesus, and I believe that when I die, I will be in heaven and that is not a scary thing. So, I think dying is quite freeing … so I am not afraid of it. I have prayed together with patients who share my beliefs and they have found that helpful … being able to care for someone on that

> spiritual level is really helpful because I think spiritual care is part of our role. I think people are really looking for that spiritual connection in their death. (Jess, pp.3–4)

Jess conveyed assurance in her belief of an eternal afterlife in heaven. For Jess, her faith provided clear guidelines on how she could support the spiritual needs of her patients. As an invited guest in the patients' homes Jess experienced a connection with people who shared the same beliefs. Finding balance was about allowing her professional role to be enhanced by her personal faith.

Mark also spoke of how his faith enabled him to connect with patients:

> I have a strong Christian faith and I believe that the work that I am doing now is in essence a 'calling'. I feel like there is grace for me to be doing what I have been doing, God's grace … I have talked about my own beliefs [but] my Christian faith is very much my own beliefs, there is never an occasion where I am trying to put my values and beliefs on anyone … but you need to ask those questions … I like to engage in that and find out their beliefs because for me being on the death bed is a great unknown, none of us have been on that process before. (Mark, pp.5–6)

Mark described his work in palliative care as spiritual work as well as a professional career. As an invited guest in the home, he felt free to share his faith in supportive, non-threatening ways if requested by the patient or family. For Mark, there was no clear delineation between his spirituality and his role as a nurse. He experienced harmony between his professional self and personal self. This inner peace provided Mark with a freedom to sensitively explore what spirituality meant for the patients and families who he supported.

Previous hardship in Pippa's private life underpinned her emotional response:

> I do feel really sad … I have had to find strength to put one foot in front of other and keep going … it is the reality that my life has been like this, and it adds to my ability to do my job … yeah, it [faith] does help. (Pippa, p.7)

Pippa admitted that she had many struggles in her life. She understood how life was challenging for patients and their families. She related to other people who found that sometimes it was difficult to keep going. However, Pippa recognised that her faith had helped her deal with past traumas in her own life. In turn, these experiences and faith contributed to supporting patients and their families face the realities of living with a life-limiting illness. These experiences helped her to find some balance in the professional and personal areas of her life.

Ruby held a different belief system:

> I have always been interested in comparative religions and spirituality; [there] are some interesting variants but you always come back to the middle of the road … [I] have always been interested in death as a normal part of life and this concept is so natural so yes, I am very comfortable in that space. (Ruby, p.2)

Ruby considered spiritual awareness as a vital part of her work as a palliative care nurse. For Ruby, it was not about having any particular religious practice. Comparative religious beliefs provided her with a sense of freedom to adopt beliefs and thoughts that were right for her. Ruby was comforted by an ability to change her sympathies as she needed while supporting patients who were dying at home. These beliefs brought balance to her personal self and her professional self.

In this sub-relational theme of spirituality, participants found balance between their own personal belief systems and allowing these understandings to add depth to their professional selves. Participants brought their own life values and spirituality into the home environment as invited guests. The intimacy of the home heightened the nurses' own spirituality in mostly positive ways, affirming the nature of care they provided for the patients and their families as invited guests in that private space.

Emotional investment

Working in the private space of the home evoked a myriad of strong emotions for participants. Participants reported that there, they invested emotionally both on a professional and personal level. This investment did not come without an emotional cost. As community-based nurses, participants were required to work in the unfamiliar surroundings of each patient's home as an invited guest. Sometimes, constantly needing to adjust to working in different patients' homes resulted in feeling ill-at-ease. Mia, for example, was quite apprehensive:

> Oh, that is really hard because a lot of the time you push your own emotions away, you don't want to touch on it because you don't want to get upset about it. (Mia, p.2)

Mia had developed a strategy of not thinking too much about how she felt in order to maintain control of her emotions. Mia found it was safer not to allow herself to display any feelings of sadness in the presence of patients and their families. Another strategy Mia used was to focus on her professional role rather than allow personal feelings to emerge. As an inexperienced palliative care nurse, Mia found balancing the demands of her professional work with her personal needs difficult at times.

Sometimes, participants felt overwhelmed by the responsibilities of meeting complex needs of patients. Leonie confessed:

> If I had any emotion, it would be anxiety about managing symptoms: 'is the patient going to be able to remain in their own home? Is this going to be too much carer stress? … Am I going to get it right? Is this doable?' (Leonie, p.3)

As an NP, Leonie was anxious about meeting all the expectations of her professional role. Leonie understood the success of an episode of home-based palliative care reflected on her professional skills and her personal reputation in the community. Her work demanded a high level of emotional investment to meet all the requirements of the health care system, her community and individual families.

Likewise, the complex needs of patients and their families demanded a high emotional investment for the next participant. Leah explained:

> I find listening to families and carers is very taxing mentally. You know, at the end of the day you go 'oh! My gosh' … it is getting everyone in the family on the same page. You know, quite often you have people in denial saying that a miracle is going to happen, 'my wife is going to get better', when I know "**no, she is not"**! Working out what you can say … [some] people you can say and be blunter with them and other people you have to tip-toe around, so it is working that out … I actually find the symptom management

> is the easy part of the job … the mental side of it [with] all the family dynamics and all those things are actually very taxing. (Leah, pp.3–4)

The responsibility of caring for the emotional needs of family members was exhausting. Leah found the clinical tasks of reviewing the patients' symptom management was usually straightforward, but the work of caring for the emotional needs of the families was particularly challenging. The home environment was the families' own private space and as an invited guest Leah had to carefully navigate how to support each individual family member. In this situation, Leah's professional self was overshadowed by her personal emotional investment.

Caring for her own family added another dimension to her work. Leah went on to explain:

> [I have] supported my own relatives; that calls for extra energy … you get through that … I am tired because they are always tired and worn out. (Leah, pp.1&5)

For Leah, witnessing the exhaustion of a family was tiring, particularly when they were her own extended family. Finding balance between her professional role and personal needs was really challenging in this situation because Leah was a family member as well as the palliative care nurse. Her personal self was more prominent to her extend family, but her professional self was also needed. Knowing how and when to offer her professional knowledge and skills was challenging. Within her professional role Leah was an invited guest in the home even though she was a family member, requiring a complex mix of balancing her professional self and personal self. This, too, was a unique experience of living and working in one's own rural community.

Being a witness to a raft of emotion in patients' own homes was also challenging for Ruby:

> Well, it is sometimes hard; you hardly open the door without the emotion pouring out at you and you think, 'OK' … you need to stay strong … do a bit of centring technique, virtual protection stuff. (Ruby, p.3)

Ruby adopted the approach of being prepared for the unexpected when she arrived at patients' homes as an invited guest. It was Ruby's own depth of character within her personal self that helped her to find balance as she invested her professional self into the situation. Ruby was able to draw on her own self-care techniques to maintain control in a distressing situation within her professional role.

Leo shared the following story to illustrate further:

> I met a client this morning [long pause], a 47-year-old. She has an 11-year-old daughter, the father had been in jail on and off for 25 years … [She has been] on steroids, symptoms like lots of energy, not sleeping [but] but now is sleeping 20 hours a day. [She] wakes up feeling nausea, emotional, she was crying for the first time this morning … she was upset and sobbing, starts talking about her daughter how she loves her and wants to create memories with her, her mother [who was in the room too] left sobbing. I felt the emotion coming up in me, I felt on the edge of tears myself.

Leo went on to explain:

> it is okay to cry with patients as long as it is not about you … it demonstrates you care, your presence, empathetic therapeutic relationship. (Leo, p.2)

In this situation Leo allowed himself to invest emotionally on a personal level, but he was also aware of remaining professional. He did so by not allowing his emotions to become the focus of the experience. Finding balance between his personal self with his own emotions and being the empathetic nurse was a skill that Leo had gained after a number of years of nursing experience. Leo was aware that the environment of the home evoked these strong emotional responses. In his professional self, Leo was willing to share in the sadness present in the room as the lady expressed her wishes to create beautiful memories for her daughter.

Mark also spoke of being present in the presence of suffering:

> I feel like there is grace for me to be doing what I have been doing, God's grace, and people may not have an understanding of that, but I have an understanding of it ... I certainly give of myself. There are professional boundaries of course but no person can watch a person suffering and it not have an effect … [It is] very much part of life. (Mark, p.4)

In his work Mark relied on his faith to give him strength to connect emotionally with his patients. He recognised that his work was more than establishing a therapeutic relationship with his patient; there was the vital element of investing emotionally with another person who was suffering existentially as well as physically. Mark acknowledged that witnessing a fellow human's suffering did affect him emotionally. However, he accepted that this emotional response was a normal part of supporting someone who was dying. Finding balance was about working alongside of one's emotions as a person and as a professional nurse.

Several participants spoke of skills they employed in containing their emotions during home visits. Tracey said:

> Well, while I am here it is your story, it is not my story. You know when you walk into a patient's home, '*this is all about you*' … I can't help them if I am bawling my eyes out. (Tracey, p.4)

For Tracey, being an invited guest in the home required delineating between the two journeys occurring—that is, the family's and her own—a strategy that was vital in establishing an emotional safety net for herself within her professional self.

Jess agreed:

> I feel I can remove myself in that I think I am fairly pragmatic that way, in that, we all face death at some stage and none of us knows when that might come. (Jess, p.3)

Jess was realistic. In this excerpt she acknowledged that death would be faced by everyone. As a fellow human no one could predict when a journey with tragedy or ill health would occur. As a general community nurse her professional role provided some emotional protection. She was an invited guest in patients' home to support them. This generalisation together with her own spiritual awareness assisted Jess to find balance between her professional and personal self.

In contrast, Tanya found caring for a patient who was terrified about facing death very difficult.

> We recently [had a] lady with Motor Neurone [disease] … she was in denial even to the stage when the speech pathologist said she could not eat anymore … every morning you would go out there and it was eight weeks in the end [sigh] … she would always wake up with like absolute depression, like as soon as her eyes were open she was back to reality of what was going on, she was the real matriarch, the head of the family … and she was suddenly without control over anything. It was just horrible … she was a very religious lady … her husband read from the Bible all the time, but you would get out there and if

> you were there first thing in the morning you could hear her from outside the house, howling. It was despairing; it was horrible; it was just horrible. (Tanya, p.5)

While remaining professional in the care of this lady, Tanya acknowledged her struggle to control her own emotions. The rawness of the patient's despair was distressing on a personal and professional level. Although in the familiar surroundings of her own home, this lady who had held a dominant position in her family grappled with her mortality and pending death. For Tanya, witnessing this existential distress was really challenging. The brutality of these emotions spilled out of the house as the nurses arrived each day to provide care.

Mia also shared an emotionally distressing account of a patient dying at home:

> I was working alone on a Friday, of course, [arrived at a home in a remote setting when the patient has just died] … so to deal with it I went outside and asked the wife if she wanted me to sit there for a while, so I sat there for ages because I did not know what to do. Yeah, so I rang the doctor … that GP was good enough to come out. I was there for four hours because the wife did not want me to go … so I waited 'til the family came from the city … How do you leave a little lady in a farmhouse in the middle of nowhere? You kinda don't … I felt useless out there just patting the dog and the dog just stared and stared—see, it was his dog! (Mia, pp.1,3&4)

Mia experienced feeling challenged to staying in control of her emotions as she found herself in an unfamiliar situation. Arriving at a home shortly after the patient had died was a confronting new experience for Mia. She felt ill-prepared in how to respond apart from contacting the local doctor. Mia had insight into the grieving lady's needs at that moment because she also understood what it was like to live in the outer reaches of a regional area. Mia knew it would be some time before family would arrive from the city. Her personal self was more prominent in this situation as she offered to stay at the isolated farm to provide company for a grieving lady. Balance was found in firstly attending to her professional tasks and then investing emotionally. The remoteness of the patient's home added to the feelings of isolation experienced by Mia—a unique occurrence for nurses working in rural communities, unlike the city setting where other natural and professional support would be more readily available.

In contrast, a family's acceptance of the impeding loss of their loved one assisted Deb to stay in control of her own emotions:

> Some people I have come across are really at peace with their life and really accepting, in a sense and I think that is a real privilege to see that and see their calmness. (Deb, p.1)

Deb reported that it was a privilege to witness a family's acceptance of the impending loss of their loved one. Deb was comforted both professionally and personally by the family's quiet assurance. Leo concurred, feeling emotionally uplifted by his work in caring for patients who wished to die at home:

> This setting [the home] has allowed me to express my ability, my skills, being a clinician and myself as well … I don't need to think about what other nurses think … I am being my truest self, does that make sense? (Leo, p.3)

Leo's lived experience was to find meaning in his professional and personal selves. Working in a patient's home allowed him the freedom to develop a deep sense of self within his professional role and personal life, something he had not experienced in any other work setting. Similarly, Deb concluded:

> [It is] a really intimate experience, when you are in someone's home and they are able to die in the setting of their choice … family are in their own environment … life goes on around the person and I think that can be really beautiful. (Deb, p.1)

Deb found that witnessing a patient dying at home was a profoundly unique and personal experience. The environment of the home accentuated the normality of dying as the family continued their daily routines while caring for their loved one.

Pippa spoke of another emotion:

> I feel very privileged to be able to enter people's homes to provide assistance. [It] certainly makes me feel empathy toward people experiencing really challenging times. (Pippa, p.1)

Pippa felt privileged for the opportunity to enter patients' homes because it gave her an insight into other people's journeys with terminal illness. As an invited guest she was able to find balance between her professional self and her personal self by respecting being in the private space of the home. Pippa had gained a deep sense of compassion for people living with a life-limiting illness.

From a different stance, Jane experienced feelings of jubilation:

> I am elated, I am nothing but elated. We have managed to have someone die at home with their family, comfortable with everyone around them and that is what the person wanted. Oh my God, you can't give that experience to everyone ... I don't know anyone who has not enjoyed having their loved one at home, everyone loves being there! (Jane, p.10)

Jane was clearly ecstatic that her team of general community nurses contributed to the care of a patient who wished to die at home. All their work in coordinating services resulted in the patient being surrounded by family until the moment of death in the privacy of their own home. Finding balance was about contributing to a successful episode of care at home, and as a result, Jane experienced feelings of exhilaration and accomplishment within her professional and personal self.

The emotional investment of participants resulted in both positive and negative memories. For several participants, the reality of working in a patient's home in the presence of death was a new and overwhelming experience. For other participants, their professional responsibilities of meeting all the needs of the patients, families and health care service weighed heavily on them. Participants experienced feeling tired and weary as they endeavoured to meet all the demands. In contrast, feelings of being professionally and personally emotionally uplifted were reported. These feelings gave rise to finding professional and personal meaning in life while providing home-based palliative care in one's own rural community.

6.3 Summary

Within participants' professional roles it was evident from the data that there was a stark difference in how they went about their work in patients' homes compared with working in a hospital setting. As invited guests in the home, nurses found that they needed to respect each family's wish to retain the balance of power in how the care was provided to their loved one. Coordination of care needed to be decisive and efficient, while not being an intrusive presence in the private space of the home. Within their professional role many participants expressed feeling honoured to support patients who wished to complete their lives at home.

Personal experiences of grief in the past motivated some participants to strive to provide the best care they could for their patients. Spiritual awareness was reported as being heightened as a result of working in the non-clinical care setting of the home. Such an awareness underpinned an emotional investment of one's personal self in comforting and supporting another fellow human as they grappled with existential matters of impending death. A myriad of emotional responses emerged as participants shared feelings of anxiety, weariness, exhaustion, reward and exhilaration. All of these described in depth what it was really like to provide home-based palliative care in rural communities, where relationships were intertwined and multi-layered.

The next chapter will analyse the main findings from the Results section of this thesis by discussing the complex lived experiences of participants in this study. This discussion will draw on the phenomenological insights of Gadamer to deepen understanding about the true meaning of these lived experience, thus confirming participants' extraordinary quest to find balance between their professional self and personal self.

CHAPTER 7: DISCUSSION

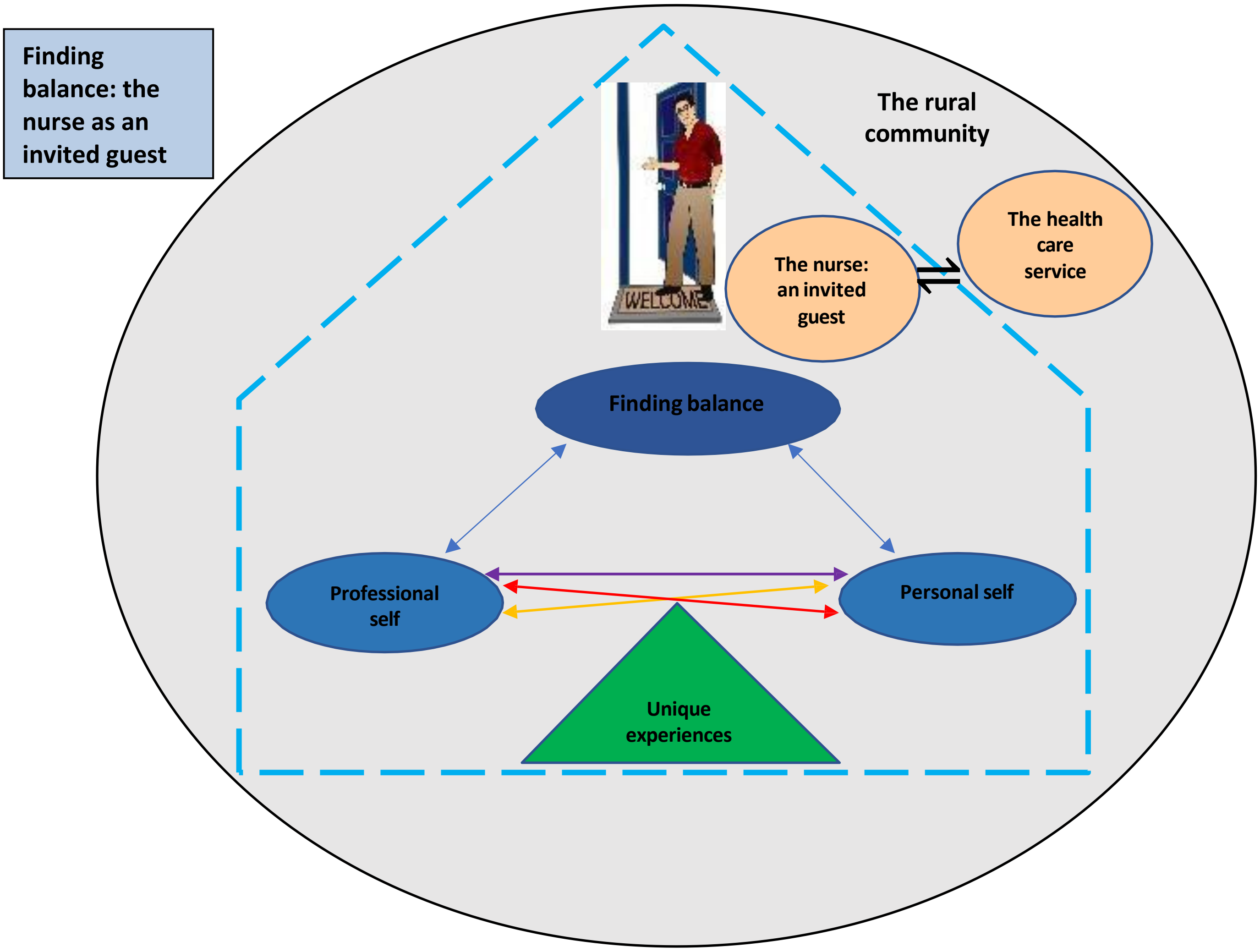
7.1 Introduction

This discussion chapter draws together relational and sub-relational themes as identified under the constitutive pattern of ‘finding balance’ within the environments of the community, health care service and the home. Importantly, *the environment of the community is the foundation of this study* given that the research question drew participants from rural communities. It is not surprising therefore that the nature of living in a rural community is interwoven into the environments of the health care service and the home. The central argument of this thesis does not concern palliative care *per se*; rather, it follows the phenomenological approach of Gadamer (1975/2013) in understanding the essence and meaning of the lived experiences of these RNs, who provide specialist care within patients’ homes in rural communities. The analysis of data followed Diekelmann, Allen and Tanner’s (1989) seven-stage process as presented in Chapter 3 (Figure 3.2, p.64), which guides the discussion of these findings under the emergent overarching constitutive pattern of ‘Finding balance: between the professional self and personal self’.

The home was the most prominent environment to emerge from the data. The changes in the balance of power together with the RN’s status as an invited guest in the home demonstrated the difference between nursing terminally ill patients in a hospital care setting and the private dwelling place of another. Furthermore, the homes visited by participants in this study were in a rural town or a farming district. The community itself was represented in these homes when relatives, friends, neighbours, business associates, sport and community club members were present.

Therefore, a modified version of the model presented at the beginning of Chapter 4 (Figure 4.1) guides this discussion. The previous model depicted finding balance as the overarching constitutive pattern as participants provided home-based palliative care in rural communities. That model included three environments (categories) in which balance was found, including the community, health care service and home. Within these three environments the process of finding balance took place between the professional and personal self of each participant.

Figure 7.1: A modified version of the model as depicted in Figure 4. illustrating the significant findings of nurses' experiences of providing home-based palliative care in rural communities.



The modified model of Figure 7.1 illustrates the lived experiences of participants in this study. The light grey shading within the outer circle represents the environment of the rural community. This environment was influenced by unique cultures and customs of each rural community in which participants were employed. In the model, the dominant environment of the home occupies most of the space within the circle of the rural community (blue broken lines). Notably that same background colour as depicted in the outer circle of the community is seen within the home, indicating that the community was within the home as much as the home was in a rural community. The perforated lines outlining the shape of the home signify permeability: the community was present within home, supporting families caring for their dying loved one, and the patient and family within the home remained actively present in the community.

A focal finding of participants being invited guests is represented by the image of a nurse entering the home. Placement of this image at the apex of the house is indicative of the importance this status bestowed upon the nurse. The participants’ employer, the health care service, is represented by an oval shape located within the outer circle of the rural community. Continuous arrows between this oval shape and the nurse indicate that as a provider of palliative care, the health care service was also present in the home. Furthermore, the nurse moved continuously between the home and the health care service as the representative of the family and organisation.

The shape of the home encapsulates the overarching constitutive pattern of finding balance. Under this constitutive pattern are two relational themes: the professional self and personal self of participants. These oval shapes are connected by several two-way arrows on a pivoting base. The red two-way arrow between these two relational themes illustrates that at times, the personal self of participants was more heavily weighted than the professional self. The yellow two-way arrow represents lived experiences in which participants’ professional selves were more heavily weighted than their personal selves. The level purple arrow shows that on occasion, a balance was found between the participants’ professional selves and personal selves.

The triangular shape on which the arrows pivot represents unique experiences which occurred from working in patients’ homes—experiences that would not have occurred while working in a hospital or other care settings. Furthermore, some experiences were unique to living and working in communities located in rural areas, quite unlike metropolitan areas.

A phenomenological exploration of the lived experience of participants in this study was guided by Gadamer's (1975/2013) philosophy, in which truth was sought. Gadamer's (1975/2013) philosophy also utilised historicity of the researcher in a process known as 'fusion of horizons':

> The horizon of the present is continually in the process of being formed because we are continually having to test all our prejudices … Hence the horizon of the present cannot be formed without the past … *Rather, understanding is always the fusion of these horizons supposedly existing by themselves*.
> (Gadamer 1975/2013, p.317)

Gadamer (1975/2013) explained that understanding another's world was indeed assisted by one's own similar experiences in the past. A fusion of horizons occurred when the historicity of one person identified with another's lived experience. In this research, I drew on my own past experiences of being a CN in palliative care who worked in rural communities. From this connection new understandings were formed. In a continual movement between reading the whole and parts of texts the hermeneutic circle of understanding was not a static phenomenon, but a constant process throughout an exhaustive analysis of data and writing of this thesis.

Before proceeding to discuss the lived experiences of participants as invited guests in the home, this chapter will consider the experiences of participants as employees of the health care service as reported in Chapter 5. In doing so, the participants' lived experiences within the home will be illuminated to reveal new understandings. The influences of living and working in a rural community provides the foundation from which these unique experiences occurred.

The sections in this discussion chapter are listed below:

7.2 The health care service: a source of tension

7.2.1 Balancing professional and personal responsibilities

7.2.2 Establishing professional and personal boundaries

7.2.3 Adapting to changes

7.3 The nurse: an invited guest in the home

7.3.1 Establishing a professional role while being personable

7.3.2 Professional role propelled by personal grief

7.3.3 Professional and personal emotional investment

There were three areas in which participants endeavoured to find balance between their professional and personal selves while being in the employment of a community-based health care service. Firstly, they needed to balance their professional and personal responsibilities. Secondly, establishing boundaries to facilitate this balance was equally apparent in the data as participants provided home-based palliative care. Thirdly, participants found they needed to be adaptable as recent restructuring in health care services determined the level of nursing support they could offer in patients' homes.

In the dominant environment of the patient's home, the RN upheld the status of being an invited guest by being personable while establishing their professional role. Additionally, some participants found their own previous personal experiences of caring for a dying loved one influenced how they undertook their role. Then the home itself demanded a different level of professional and personal emotional investment compared with working in other care settings. Participants found that the experience of being employees of a health care service in a rural setting led to tension in their role.

7.2 The health care service: a source of tension

As depicted in Figure 7.1, the arrow from the health care service to the nurse indicates that a representative of the employer was present in each home via the professional self of each participant. The health care service influenced the level and range of support provided for patients and families in the home. Being an employee of the health care service required each participant to fulfil his or her professional responsibilities, but there were also community obligations to be met.

7.2.1 Balancing professional and personal responsibilities

In this study, participants were committed to fulfil their professional responsibilities to their employing health care service. Similarly, they were dedicated in their contribution to the communities in which they lived and worked. Participants had developed a strong allegiance with their community over long periods of time. They understood that living in a rural community came with expectations of caring for other people who lived there too, particularly when people were going through challenging circumstances such as droughts, floods, fires, and ill health (McManus et al. 2012). This allegiance extended to striving to improve the range of health services available to the community, including home-based palliative care. Osburn Wooldridge (2007), in her dissertation exploring the lived experiences of nurses coordinating community-based hospice care services in provinces in Canada, agreed that there was a deep commitment to caring for others in rural communities. In fact, Osburn Wooldridge found that the smaller and more remote a community, the deeper the commitment to care for its members.

In this study, responding to requests for palliative care support was vital in improving the community's capacity to care for its own members. One participant was so incensed that the funding for her part-time position had ceased that she left this profession all together for a time (Section 5.2.2.2). She considered the cessation of funding to be not only a slight on herself as a nurse but also on her community in being deemed not being worthy of such a service. Mackenzie, Louth, and Goodwin-Smith (2019) in their study about the importance of community-based services in the viability of small towns reported that in rural areas of Australia, many communities had experienced the closure of local schools and businesses such as banks and rural suppliers. Therefore, the impact of any health care service downgrade only added to the demise of businesses in small communities. Other authors add to this view that some outer regional and remote areas of Australia have been severely affected by increasingly scant health services, including home-based palliative care. This decline results in patients from rural communities being more likely to die in hospital than their city counterparts (Kirby et al. 2016; Rainsford et al. 2018). In the recently released report 'Roadmap of Palliative Care services in Australia 2022–2027', the peak non-government advocacy body, PCA (2022d, p.23) described accessing home and community-based palliative care services in regional areas as a 'postcode lottery'. This organisation added that people living in outer regional areas access only half the level of Medicare Benefits Schedule (MBS) funded services [see glossary] as those residing in major cities as of 2019–2020 (PCA 2022*d;* DOH&AC 2022). Participants reported significant gaps in service provision in their regional areas.

Participants in this study defended their communities' need for home-based palliative care. RNs that participated in this study held a twofold goal: one being the retainment of professional positions, and two being the upholding of an acceptable level of services in the community. This level of commitment aligned with the Australian Government DoH's (2018) National Strategy for improving access to palliative care for all Australians—a strategy that acknowledged that home- based, person-centred care contributed to better quality of life for all terminally ill patients (DoH 2018). Furthermore, a recently released report demanded that there be an immediate increase in the numbers of nurses providing palliative care in all settings, including regional areas (PCA 2022d). In this study the overlap of community and organisational obligations were powerful motivators to fuel participants to work tirelessly to provide a high standard of home-based palliative care service at both a local and regional level.

As illustrated in Figure 7.1, the walls of the home were permeable. The community was in the home as much as the home was in the community. There was a natural osmosis between these two environments. Similarly, there was a natural osmosis between the professional and personal selves of the participants; the two could not be separated. As employees of the health care service, participants endeavoured to fulfil the requirements of their organisation in the provision of professional nursing care for patients wishing to die at home. They could also be actively involved in supporting each family's need as community members.

Mills, Birks, and Hegney (2010, p.33) stated that the culture of rural nursing is 'living their work' as they emphasised that all aspects of nurses' lives were intrinsically connected—that is, their professional work as providers of health care services and their personal lives as consumers. As a past palliative care community nurse the concept of community embeddedness and living one's own work was evident for me as I had lived this experience. In this research, Gadamer's (1975/2013) historicity was a vehicle to assist in understanding another's world. New knowledge emerged as data revealed what it was like as a community member who resided in a rural setting. There were many layers of responsibility.

Participants in this current study had multiple roles to play in supporting patients wishing to die at home. They could be a neighbour, friend, co-member of a community group or an extended family member. Participants reported within their professional roles that it was a privilege to serve their own community with quality home-based palliative care. This sense of privilege extended to participants who lived away from the community in which they were employed. Over time they acquired the same sense of responsibility in their work communities as their colleagues who lived locally. However, participants were realistic about the level of health care available in rural communities.

Deficits in rural health care services caused by funding constraints and service restructures were commonplace. For example, participants understood that it was not always possible to receive regular debriefing. As explained in Chapter 1 (Section 1.3.3), funding for palliative care positions is determined from a mix of federal and state government sources according to population. Therefore, many smaller communities represented in this study only had part-time positions. Participants from the specialist palliative care teams based in larger regional centres were responsible for providing home-based care locally and consultative support to Level One services across several smaller communities within a geographical area. In doing so, these specialist nurses worked alone across several towns and farming areas—an occurrence considered an expected aspect of working in non-metropolitan areas. Working autonomously was also commonplace for nurses from general community nursing teams.

At times, participants were able to work with other general community nurses, social workers or allied health practitioners. It was on these occasions they reportedly valued debriefing about the rigours of caring for terminally ill patients. As colleagues they would converse freely about challenges in the care of neighbours, family members, friends, or well-known community members. During these conversations participants found the use of humour was a valuable way of debriefing and lightening their mood.

Blanchard and others (2014, p.50) suggested that the use of humour in the workplace was a 'sense making' mechanism. Participants reported that it was common sense to reach out to colleagues and existing avenues of support within their own community-based health care organisation rather than waiting for an official debriefing session. For example, one participant valued conducting home visits with a colleague who was a social worker. As they drove to each home and then back to their local community health service, they would share challenges they were experiencing in caring for their patients, interspersed with jokes.

Gadamer's philosophy acknowledged that understanding the meaning of life could occur through *sensus communis*. Gadamer explained this concept as 'common sense, connected to the human ideal of eloquentia—elements already present in the classical concept of wisdom, [but also to] "Talking well" (*eu legein*)' (Gadamer 1975/2013, p.18). Humour was aligned with *sensus communis,* from which wisdom manifested. Participants found the use of humour and wit facilitated truthful and eloquent expressions about the reality of lived experiences. This in turn, helped to balance their professional and personal responsibilities.

7.2.2 Establishing professional and personal boundaries.

The essence of the lived experiences of nurses providing palliative care in patients' homes in rural communities was about embracing a common-sense approach in all aspects of their work, including how they went about upholding their professional and personal boundaries. Upholding professional and personal boundaries when working in rural communities was challenged by unique idiosyncrasies of that environment. The true nature of being a member of a rural community became evident as participants shared stories and examples about the challenges encountered daily as they went about providing palliative care.

Several participants reported that they were challenged by community members' questions relating to the health status of patients who were not relatives. Community members regularly inquired about other people's wellbeing out of genuine concern. These conversations could occur in public spaces—a challenge unlikely to be experienced in a city area. As community embeddedness deepened, participants found that it was difficult to avoid conversations relating to the welfare of their patients in social settings and public places. Pesut and others (2012, p.294) acknowledged there was a 'profound blurring' between the personal and professional lives of nurses working in rural communities. These authors went on to suggest that the obligation to engage with others in the community could outweigh the imperative to abide by professional guidelines (Pesut et al. 2014). The NMBA's guidelines for professional conduct acknowledge there are complexities for nurses working in rural areas (NMBA 2018). These guidelines do not provide strategies for mitigating such challenges. However, participants in this current study were able to describe how they minimised disclosure of confidential patient information: for example, by shutting down any conversations about patients and their families when they were at social events. Some participants avoided talking about their work at all in social settings. When other participants were conducting their own private lives in the community they actively sought not to engage with people.

Participants' professional boundaries were also challenged when the patient and family asked personal questions about their (the RN's) own lives. This aspect was particularly so for participants who had grown up in a rural community, where there were multiple layered and overlapping relationships. At times, withdrawing from some social functions led to some participants feeling isolated within their own community. Such extreme strategies would not be necessary for nurses working in larger semi-urban and metropolitan settings.

To date, the literature only reports on nurses working in geographically isolated or remote rural communities experiencing feelings of loneliness (Cumming, Boreland & Perkins 2012; Pesut et al. 2012; Reid 2013; Edvardsen, Lorem & Mehus 2020). Pesut and others (2012) together with Reid (2013) found geographical isolation certainly contributed to community nurses' feelings of isolation, while Cumming, Boreland and Perkins (2012) reported physical isolation combined with a lack of resources and education resulted in nurses feeling alone. A more recent study by Edvardsen, Lorem and Mehus (2020) demonstrated that a nurse who provided palliative care in rural areas who had irregular contact with medical services or other health practitioners could have compounded feelings of working in isolation. However, these studies do not report loneliness as a by-product of separating oneself from the community to uphold professional boundaries. As discussed above, this was a practice that some participants in this current study found necessary to protect their patients and themselves.

Alone-ness also resulted from a lack of other available professional staff to support patients who wished to die at home. At times, non-professional as well as professional staff were related to families who required home-based palliative care support. For example, one participant reported that in the coordination of home-based palliative care she was unable to find enough professional carers to attend to a patient’s care. This shortfall occurred because some of the professional carers were related to a family. In this circumstance, the palliative care nurse and one other colleague needed to work additional hours outside their funded positions on weekends. This not only resulted in the nurse working beyond her hours of employment but also in her feeling alone in the care for this family. Kirby and others (2016) found that local community resources were pivotal in mitigating workforce shortages. However, they did not take into account that overlapping relationships in rural communities could contribute to shortfalls in availability of professional staff, an occurrence considered regrettable but unavoidable in a small rural community.

7.2.3 Adapting to changes

Spelten and colleagues (2021) reported that families caring for a terminally ill loved one at home in rural communities readily acknowledge and appreciate the adaptability of palliative care service providers in ensuring quality of care was provided. Recent changes at a management level of several health care services have resulted in some specialist palliative care teams being required to attend to general community nursing visits as well as supporting patients at the end of life. General nursing visits involve completing specific tasks within a predetermined timeframe during each home visit. Feelings of frustration emerged as participants spoke of feeling deprived of the time they needed to provide holistic care for patients needing palliative care.

Participants spoke vehemently about wanting to stay longer at a dying patient’s bedside should there be a need to do so. Some nurses felt the management of their health care service lacked an understanding of the work involved in providing palliative care; in particular, the ethos of providing person-centred care according to the needs, values and cultures of each individual patient and family (PCA 2018; WHO 2020; International Council of Nurses [ICN] 2021; PCA 2022d). Smith and

Porock (2009), in their study that explored the needs of community nurses, found that increased general workloads were indeed contrary to meeting the needs of dying patients. Forrest (2012) suggested that meeting quotas of home visits each day was reflective of a business model of service rather than a person-centred approach to care. Participants from Level One and Two services concurred that the nature of a palliative approach required a holistic focus rather than completing tasks within a predetermined timeframe. For example, some participants reported that during some home visits, patients may indicate their wish to speak about their fear of dying or regrets for decisions made in the past. However, at times a severe lack of time impeded participants' ability to listen for as long as the patient needed to talk.

PCA together with Departments of Health in each state of Australia provide specific guidelines on the role of specialist palliative care teams (PCA 2018; NSW Health 2020; Government of South Australia (SA) 2021; Queensland Health 2021). These services are funded to provide specific consultative care for patients with complex care needs. Therefore, these specialist services should be free to do so without dealing with the demands of other patient groups. The changes in service provision as reported by some participants in this current study did not align with the current Australian Government DoH's (2018) description of the role of Level Two specialist palliative care teams. The service guidelines for Level One services also need to be extended to acknowledge the specific needs of this patient group. Furthermore, participants reported that the system for applying for additional funding for home-based palliative care support also had changed.

Several participants who had worked for extended times in their positions reflected on how home-based palliative care was provided in the past. For example, larger regional palliative care services had funding to provide out-of-hours home-based care and the administration of this funding was undertaken by the specialist teams. In recent years there has been an introduction of end-of-life care packages being administered through the national program, 'myagedcare'. This program is the single referral point for any patients requiring community-based support services (Australian Government 2021). This centralised referral process has removed the role of specialist palliative care teams overseeing the allocation of additional funding for families caring for a loved one in the terminal phase of an illness. Furthermore, participants are now no longer involved in the assessment of patients' needs or consulted about the specific care required beyond the initial referral process (DoH 2020; Australian Government 2021; Australian Government 2023). This exclusion has reportedly caused delays in providing additional support for patients and their families in times of high need. In turn, these delays reflect on the quality of health care service being provided. This system failure unwittingly reflects poorly on participants professionally and their standing in their community on a personal level.

The national roadmap 2022–2027 for improving palliative care services in Australia recommends that all referrals for additional home-based funding through the 'myagedcare' portal system be given an urgent classification to mitigate long waiting times (PCA 2022d). An option within the national prioritisation system is to be established to address palliative care referrals that are given the highest priority level for assessment for any patient with a 'terminal diagnosis of less than six months' (PCA 2022d, p.27).

Other funding changes have occurred as well. Part-time funding for a general community nursing position to include some hours each week to dedicate to the needs of palliative care patients has been stopped. The way this cessation of palliative care funding was insensitively communicated resulted in the resignation of one participant from her position as a general community nurse. Thus, another service—that is, the general CNS—was affected by the loss of a staff member. The ramifications of the loss of funding not only reflected poorly on the health care service but also on the RN as a community member. In essence, one service in a small rural community had been lost and another depleted.

McManus and others (2012) pointed out that maintaining services in rural areas was pivotal in fostering the local economy and strengthening the resilience of the people who lived there. However, their study only considered the perceptions of one group of people: the farmers. The present study provides insight into the experiences of RNs who were involved in a wide range of businesses and support networks in their communities. Thus, it has provided evidence that declining health care services affects all aspects of community life in inner and outer regional areas of Australia.

Some participants found that the community's expectations of their service could be unrealistic. A participant from a large regional community reported that some families expected to receive the same level of support available in a metropolitan-based Level Three palliative care service. City-based Level Three services comprise large teams of specialist CNs, medical practitioners and allied health staff with extensive training in palliative care (PCA 2018). These teams provide consultative support for patients experiencing extenuating challenges in symptom management as well as supporting acute care services, hospices, and Level Two palliative care services (PCA 2018). Some regional community members assumed home-based palliative care support was available 24 hours a day, seven days a week. This expectation led to participants feeling pressured to provide the same level of service that was available in a metropolitan area.

Additionally, participants' anxiety originated from the guidelines for the provision of palliative care on a national level in Australia. The Grattan Institute provided these guidelines (Grattan Institute 2021). In 2014, authors Swerissen and Duckett in a report published by the Grattan Institute outlined the national commitment to increase the capacity of palliative care services in communities to support more people to die in their preferred place of death, namely, their home. This paper reported that while 70% of Australians surveyed in 2000–2002 by Foreman and others (2006) indicated that their preferred place of death was at home, less than 15% realised their wish to do so. Swerissen and Duckett (2014) suggested that to achieve similar proportions of home-based deaths as other countries such as New Zealand, Ireland and the United States of America, services in Australia would need to increase home-based support by at least another 15%. Participants in this current study, which included an NP, were anxious about being expected to achieve these proportions of home deaths in rural communities. These benchmarks assumed that support from medical practitioners, home-based nursing and allied health services were available over a seven-day week.

Spelten and others (2021) identified that there were several workforce related barriers preventing keeping patients at home, the largest being a severe shortage of GPs. PCA (2022d, p.23) reported that while 82% of GPs in Australia are involved in caring for palliative care patients, 31% of these doctors 'lack confidence in providing this care because of patient complexity, inadequate training and insufficient resources.' Some participants in this current study readily recognised the need to provide local doctors with educational forums about palliative care and set about doing so as part of their specialist role. However, Spelten and colleagues (2021) and PCA (2022d) have not considered the vital role that NPs play in mitigating medical labour force shortages. Additional funding for palliative care specialist teams and NPs is required to improve levels of service in regional areas of Australia.

7.3 The nurse: an invited guest in the home

While system changes evoked strong responses of frustration and anxiety for some participants, these emotions dissipated as they as they entered each home. The home provided a setting of care in which participants became their true selves both in within their professional and personal lives. As previously discussed in this chapter, the environment of the community was in the home as much as the home was in the community. It was, however, the home—as illustrated in the modified model in Figure 7.1—that was the dominant environment. Participants entered patients' homes as invited guests within their professional role. As they entered the home, this status brought with it unique complexities in how participants went about their work.

7.3.1 Establishing a professional role while being personable

In this section of the discussion chapter, findings to be discussed relate to how the participants established their professional role as an invited guest. First, the patient and family extended an invitation to visit them at home. Second, once the nurse arrived at the home, it was important to be granted permission to enter this private space. Third, time was invested in formal introductions with the family and patient through conversation. Introductory conversations included an explanation of the nurses' professional role. However, in rural communities it was also important to allow personal connections to be made with the nurse. People in rural communities valued being able to make connections between their nurse and themselves, friends, relatives or business associates. This request was considered part of the family's need to get to know and trust the person they were inviting into their home. For participants in this study, finding ways to work amidst these reciprocal relationships was an ever-present preoccupation.

Gadamer (1975/2013) explains that in recounting lived experiences, language within a text could describe one as a spectator watching a play or alternatively transport one as an actor preforming on stage. At times I felt like a spectator as participants recounted their lived experiences. At other times I felt an affinity with participants in such a way as to be an actor in the play itself. This phenomenon occurred as a fusion of horizons emerged when I recalled my own experiences of patients making connections with my family.

McManus and others (2012) similarly found that the culture of a rural community revolved around acquainting with each other, regardless of the circumstances. At times, participants reported that establishing their professional role was delayed by the expectation of the patient and family to engage in reciprocal conversations. Finding balance between being personable and professional was not always easy: as one participant explained, she found some families' questions about her personal life quite invasive and that they deflected from her primary role as an RN conducting a thorough nursing assessment of the patient's and family's care needs.

The NMBA (2016) provides guidance in the claim that the fundamental role of any RN is the assessment of the patient and their family's needs. The cornerstone of implementing person-centred nursing support in all care settings is a thorough, holistic assessment of the patient's care needs. In home-based palliative care the physicality of the house itself assisted in this process. Rowles (1983) explained that the home provided clues about the family's traditions, culture and history. McGarry (2003) described the home as a display window of a person's identity. The home framed the personhood of each patient and family. Within this study, participants recognised that a quiet and unobtrusive gathering of information from the home environment guided their patient-centred care. Furthermore, quiet observation of how the family went about their everyday routines while caring for their dying loved one provided additional clues as to the type of support they may need.

Participants found that they were unable to make any assumptions as to what their involvement in patients' care might be. Rather, gentle conversation with the patient and family about how they were coping was pivotal in making appropriate offers of assistance. Griffiths, Ewing and Rogers (2012) reported in their study with community nurses that relaxed conversation and quiet observation of the surroundings were key components of an assessment process. Suggestions could then be made and the family would either accept or reject these offers of support. Griffith, Ewing and Rogers (2012) found taking time to engage in conversation was an important tool in forming a trusting therapeutic relationship with the family and their dying loved one. Establishing a partnership with the patient and family was an important part of providing palliative care in the home. Sometimes, participants found that drawing from their own background knowledge of a family assisted in knowing possible care preferences. For example, knowledge of the family's natural support networks in the community aided the coordination of home-based services.

Reed, Fitzgerald and Bish (2018) have claimed that previous knowledge of families provided nurses with a deeper understanding of patients' needs. Participants in this current study agreed. However, they found being an invited guest in the home determined how involved they became in the patient's care. There is a paucity of literature reporting on the concept of RNs being invited guests in patients' homes; just three studies conducted in Europe and Canada briefly report this notion. Firstly, Öresland and others (2008) suggested that all nurses working in community-based services were guests in the patients' homes. Their study reported that nurses had either a professional or an invited guest status, concluding that it was unlikely these positions could be combined. Another article authored by Wälivaara, Sävenstedt and Axelsson (2013) concluded that in establishing a caring relationship with patients in the homecare setting, nurses needed to behave like guests. However, Wälivaara, Sävenstedt and Axelsson's (2013) article did not expand by explaining more about what this behaviour might be. Another research report debated that while a nurse was a guest in the home fulfilling the status of a visitor, she or he could also be an 'ethical intruder' (Santos Salsa & Cameron 2010, p.659). For example, to locate the room where the patient was (after entering the home as an invited guest) there was a need to seek guidance from the family. However, in situations when patients lived alone some direction could only be sought by announcing one's arrival at the home verbally, and then following the direction of the reply.

Data from this study challenged the stance that community-based RNs were not able to balance the status of being an invited guest and carrying out a professional role in patients' homes. Participants found balance by being mindful that they were present in another's world—that is, the home—while they went about their work. How participants conducted themselves professionally in this private space was imperative to the success of maintaining the status of being an invited guest.

General guidance on how nurses should conduct themselves within their professional roles is provided by the NMBA. The professional code of conduct for nurses working in Australia (NMBA 2018, p.11) stipulates that all nurses need to acknowledge an 'inherent power imbalance' in all therapeutic relationships with a patient and his or her family. However, it does not indicate which party had the ultimate control. In this study, participants resoundingly claimed the family was in control. For example, at times within their professional role they were not invited to enter a home to provide palliative care support. This refusal needed to be respected as participants sensitively explained the support available and then waited for an invitation to become involved. Oudshoorn, Ward-Griffin and McWilliam (2007) agreed that in home-based palliative care, the family had balance of power over how and when care was provided for their dying loved one. However, they cautioned that the nurse may exercise power in their knowledge base of disease trajectories and clinical care needs. They suggest that both parties needed to work collaboratively to provide appropriate holistic care for the patient (Oudshoorn, Ward-Griffin & McWilliam 2007). In this current study participants experienced sharing the balance of power was a continual process that involved reviewing one's professional role while remaining personable in the private space of their patients.

Another important component of continuing to provide a quality home-based service was caring for one's personal self, which in turn sustained one's professional self. Self-care was acknowledged as an integral aspect of participants' lived experience of working within the private space of a patient and their family's home.

7.3.2 Professional role propelled by personal grief

At times, the environment of the home reignited personal memories of caring for a dying loved one in the past. Participants' personal experiences of caring for a dying loved one featured prominently in the findings—experiences that evoked both positive and negative emotions. Participants shared their stories about caring for their own dying loved one. Traumatic experiences such as having insufficient medical support drove one participant to work tirelessly in coordinating home-based palliative care, so no other family had to endure similar deficits. Another participant recalled his experience of caring for his father at home as a deeply spiritual journey and wished to provide the same opportunity for other families. These experiences enriched participants' zeal for their work and gave them insight into the needs of patients and families they were supporting. This work went beyond a professional role to making a connection with another's human suffering. As Gadamer (2006) would put it, there was a fusion of horizons between participants, patients and their family as they journeyed with them within their professional role.

For some participants, having an insight into the generational connection to one's farming land added understanding of a farmer's wish to die at home. Some participants understood farmers' connections to their land and their desire to die at home because they, too, came from families who worked and lived on properties. Kitchen, Williams and Chowhan (2012) found that not only were families intrinsically connected to the land they had worked for many years, but they were deeply committed to continuing the legacy of their forefathers to ensure that the land was passed on to the next generation of family. For example, one participant in this current study shared about the death of her own grandfather on her family's large cattle station. This experience gave her insight into the importance of supporting a patient's wish to return from a city hospital to die at home on his own property. Returning home enabled this man to connect to his land for a final time and complete his life's journey with a sense of belonging.

Devik, Hellzen and Enmarker (2015, p.4) reported people in rural areas were 'deeply rooted' in where they lived. Therefore, dying at home was connected to a sense of rightness. As providers of palliative care and as community members, participants were committed to providing holistic care for their patients to die at home regardless of the geographical location (WHO 2020). The experience of being invited guests in each home highlighted the importance of their role in accommodating this need to die at home.

Adding to the complex mix of community responsibility and fulfilling a professional role was caring for patients who were known to them. Unique experiences for several participants extended to caring for their own relatives. In these circumstances, finding balance between their personal grief and professional role was complex and demanding. The personal and professional cost of caring for one's own family or significant person was profound. On a personal level, participants were mindful of wanting the very best care for their loved one while knowing at times limited services were available. Pesut and others (2012) agreed the emotional cost for nurses caring for dying loved ones was substantial. These authors explained that an exceptionally high level of relational skills was required when caring for one's own family member as the health care professional (Pesut et al. 2012). These skills were not taught but acquired by drawing on one's own attributes and understanding of life.

Reed, Fitzgerald and Bish (2018) reported that nurses' prior knowledge of a patient and their family assisted in achieving therapeutic emotional intelligence, or having insight and understanding of the family's possible needs and what support may be required. However, Reed, Fitzgerald and Bish's (2018) study failed to acknowledge challenges from multiple overlapping connections in rural communities, such as needing to care for one's own family, neighbours, friends or business associates simultaneously. In these situations, a nurse's grief was two-fold, they grieved as nurses and as community members. More research needs to be conducted into this phenomenon to fully understand the short and long-term impact this work has on the professional and personal lives of nurses providing home-based palliative care in rural communities.

7.3.3 Professional and personal emotional investment

Working in the private space of a patient’s home does not occur without emotional investment. Participants found that as they stepped into another’s world—that is, the home—they were challenged in ways not experienced when working in the clinical environment of a hospital ward. As discussed above, within their professional role participants recognised that they were an invited guest and they therefore relinquished some of the power in how care was provided. For example, participants reported they could never assume the level of their involvement in the direct care of the patient. Rather, making suggestions about the patient’s care occurred as part of ongoing conversations from one visit to the next. Engaging in conversation required an investment of time. Participants found that as invited guests in the home they needed to be personable in their approach, for example, by making time to engage in conversation about community news. Willingness to participate in conversation was part of the culture of living and working in a rural community.

Walshe and Luker (2010) in a review of literature found that being authentic was a valued characteristic for all nurses involved in providing palliative care. A professional attitude that was bedded within the forming of good therapeutic relationships with patients and their families. This current study supports this view, finding that investing time in forming and maintaining therapeutic relationships contributed to the provision of quality home-based palliative care. Participants knew the time needed to support these families was difficult to estimate. The emotional investment required was to honour the time that each visit needed to attend to a clinical review of patients’ care needs as well as listen and support families in various ways. Fjørtoft and others (2020) in their discourse analysis of homecare nursing cautioned that the work of nurses in home-based services was increasingly dominated by organisational, task-oriented work. This development in service provision was antithetical to the provision of quality care because there was less time to engage therapeutically with patients and give routine care. As discussed in Section 7.1.3 of this chapter, the findings of this study concurred with Fjørtoft and others (2020); participants reported that the timeframe of each visit could not be determined by the completion of tasks only.

This said, the home as a setting of care did provide a professional freedom despite limitations of time. Participants described feelings of coming alive in their professional roles. They experienced freedom to meld together professional skills with their own personalities without worrying about judgement from other nurses. In working autonomously participants were able to form unique therapeutic partnerships with patients and families. Walshe and Luker (2010) highlighted that general community nurses who were involved in providing home-based palliative care found it was a role that they could own; a role that was not defined by the completion of a task. They were able to utilise clinical skills and their own knowledge of the community to care for their patients. In doing so they gained the acceptance and appreciation of the family, which in turn helped to dispel feelings that their work was undervalued by the health care service.

Participants spoke of experiencing love for their patients and work. This investment of love was more than establishing a therapeutic connection with the patient; rather, it was the bond between two fellow human beings. Weinstein (1986) explained that to love a patient was to care for them holistically. Harrington (2006) clarified that altruistic love was a demonstration of a human connection with the whole person. Caring for another as you would a family member encapsuled these nurses' approach in patient care. The home provided the context for the giving of this love. Love was expressed as participants sat with their patients, listening to their fears and concerns. Kind regard was shown by allowing the family to go about their lives as they wished without judgement as they cared for a dying loved one.

Participants also found the death of a patient at home was more personal than in a hospital ward setting. The pain of grief was keenly felt as participants reported seeing first-hand the rawness of a family's and community's grief in that private space. At times, the sadness was overwhelming, particularly for younger or less experienced participants. Even experienced nurses sometimes found displays of anger and fear confronting to witness. Being in the presence of such suffering and grief required a high level of emotional investment. Spelten and others (2019) agreed that although nurses experienced high levels of reward from their work the emotional investment required was at times very taxing. The impact of over-investing emotionally was not reported in-depth, though, because participants in Spelten and others' (2019) study included experiences of family members as well as nurses. Reward, privilege, and honour were reported but Spelten et al. (2019) did not go as far as to identify love as an emotion.

The love that participants in this study expressed for their both their work and their patients was woven into caring for their own community and simultaneously linked to balancing their professional and personal responsibilities as discussed in Section 7.2.1. This love could result in participants grieving deeply before and after a patient's death. Although Spelten and others' (2019) study was conducted in a rural setting, there was no mention of how nurses dealt with their grief as they cared for someone they knew well from their community. In this current study grief could be multi-layered because participants were intrinsically connected to their patients as community members, friends or relatives as well as being a nurse. Spelten and others (2019) did report that support from colleagues and any counselling offered by the health care services was highly valued. Recently, PCA (2022c) released a series of short video clips on its website providing information about self-care planning and strategies for all health care professionals. However, the unique needs of nurses working in rural communities are not specifically identified. More research needs to be conducted into the specific emotional support needed by nurses who are providing home-based palliative care in rural communities. For example, as discussed in Section 7.2.1, participants in this current study relied on the use of humour in the absence of professional debriefing support. More research could align with planning and improved bereavement support for all clinicians involved in the provision of palliative care in Australia in the immediate future, as outlined by PCA's roadmap 2022–2027 (PCA 2022d).

The final aspect of patient care that participants found demanded a high level of emotional investment was providing spiritual care in the home care setting. Spiritual care could be personalised within the context of the home. This setting of care provided the patient and family freedom to express their spirituality in their own way without fear of judgement. However, participants needed to be ready to invest deeply in supporting their patients' spiritual expressions. Devik, Hellzen and Enmarker (2015) reported that from a patient's perspective, having a nurse who was willing to invest in a personable relationship determined the therapeutic value of the home itself. Nurses' caring attitude, spiritual awareness, and willingness to work in this private setting contributed to patients finding meaning in their final days of life. The home provided participants with evidence of what was important in life for the patient and family. In turn, participants gained an appreciation for embracing all that life had to offer themselves. The home itself provided patients and their families with a level of spiritual comfort not experienced in other care settings such as a hospital ward. Some participants drew comfort and strength from their own faiths; faiths that stripped away the importance of the professional position they held by acknowledging as fellow humans that death was a reality for everyone.

Participants experienced feelings of high professional achievement from being invited into another family's home at a very private time. However, this privilege and honour did not come without professional and personal cost, as discussed above. Working in this setting of care demanded relinquishing some power, taking time to care, loving their patients and work as well as being willing to be spiritually challenged about the meaning of life. Resoundingly, participants spoke of their gratitude at being given the honour of caring for patients in their chosen place of care, their home. Investing in one's work resulted in feelings of professional and personal accomplishment. Their work resulted in the reward of a patient's wish to die at home coming to fruition. Thus, a balance between professional achievement and personal reward could be achieved in most situations.

The experience of providing home-based palliative care for patients wishing to die at home in rural communities gave meaning and purpose in participants' professional and personal lives. In discussing the findings from this study an interpretation was achieved resembling the closing of Gadamer's hermeneutic circle at a particular time (Gadamer 1975/2013; Rydé, Strang & Friedrichsen 2008). In beginning this study, my past lived experiences (pre-judgement) in this field of community-based palliative care brought with it some insight into participants' experiences. However, as guided by Gadamer's illustration of each person's sense of taste as unique, participants' experiences were individual and therefore differed from my own (Gadamer 1975/2013). Thus, new understandings emerged. Just as time never stands still, neither does the process of interpretation of the text and language of lived experiences. However, in the realm of undertaking a research study, there must be an endpoint.

7.4 Summary

This chapter has discussed and contrasted findings of this study with the literature. Providing home-based palliative care in rural communities was about finding balance between participants' professional and personal selves. This balance transcended three environments: the community, the health care service and the home.

Being employed by a community-based health care service afforded participants the opportunity to serve the community through their professional roles. Participants found their professional role rewarding and fulfilling. However, restructuring of home-based nursing services caused some participants frustration and angst. A pinnacle of frustration and anger emerged from the insensitive way funding for palliative care services was reduced or ceased in one small rural community.

Working in the home was unique because this setting of care was the private space of the family. The nurse felt as the primary caregiver, the family held the balance of power. Therefore, participants described their status in the home as being an invited guest. As a guest, involvement in a patient's care was sought through a series of conversations with the family. It was necessary to work in partnership with the family in providing care for each patient. As participants cared for community members they knew well, the emotional investment needed was high. They cared for neighbours, business associates and extended family members.

Finally, it was the environment of the home that provided participants with a sense of freedom to blend professional skills with their individual personalities. These lived experiences within the home provided participants with feelings of being privileged and honoured to work in this private space. In essence, finding balance between the professional and personal self was an ongoing process as these RNs continued to provide home-based palliative care in rural communities.

CHAPTER 8: CONCLUSION AND SUGGESTED STRATEGIES

8.1 Introduction

This chapter presents a synopsis of the study undertaken and provides concluding points from the findings as guided by the phenomenological thinking of Gadamer. A thorough engagement with Gadamer's philosophy has been the vehicle in closing the hermeneutic circle of understanding. From this approach, new understanding has emerged of the lived experiences of RNs providing home-based palliative care in rural communities. However, it should be noted that according to Gadamer, truth has been illuminated at a particular time and place. It cannot be absolute because, Gadamer argues, truth changes over time (Gadamer 1975/2013).

Providing palliative care in the home is not unique to inner and outer regional rural communities. Similar services are provided in remote, semi-urban and metropolitan areas (AIHW 2021; DoH 2021a; PCA 2022a). Nevertheless, this study showed the uniqueness that arose for nurses who resided and provided care or had a long-standing working presence in a rural community.

Participants' lived experience was to find a balance between their professional and personal lives. This balance involved providing a professional nursing service as an employee of a health care service and being a supportive, responsive, caring community member. At times, participants were professional caregivers for people related or connected to their own family. The first section of this chapter will revisit and present concluding points from the interpretation of the data in this study according to Gadamer's philosophy in his magnum opus, *Truth and Method*.

8.2 New understandings

The participants were oriented toward caring for their own community in a specific way; caring for patients with a terminal illness who wished to die at home. The findings from this study emerged from an interpretation of the text as seen at a particular time by me as the primary researcher. Gadamer's phenomenological thinking guided this exploration into the lived experiences of 16 RNs who participated in this study.

Gadamer (1986, p.68) in his essay about composition and interpretation in relation to poetry posed the question 'what then is interpretation?' His answer was that interpretation was 'certainly not the same as conceptual explanation. It is more like understanding or explicating something' (p.68). Gadamer went on to explain that interpretation could involve pointing to something, such as an indicator or a sign. Then it can also point out the meaning, that is, a sign that is self-interpretation. Both aspects of interpretation were linked to each other. I believe my interpretation of data from this study achieved both aspects of interpretation. As Gadamer eloquently concluded, new meaning 'points in a direction rather than to an endpoint' (Gadamer 1986, p.68).

The following sections present new understandings that emerged from the interpretation of data. As illustrated in Figure 7.1, this study took place in the setting of rural communities. The nature of living and working in a rural community was unique. Accordingly, provision of home-based palliative care in these areas was distinct from other settings such as metropolitan areas.

8.2.1 Acknowledging the nature of rural living

Data revealed that for these RNs living and working in rural communities, their professional and personal lives could not be divorced from each other. There was an intrinsic melding together of their work and their allegiance to their community. After a time even RNs who lived away from communities in which they worked experienced what it was like for their colleagues who lived locally. They, too, experienced an overlapping of their professional and personal lives as engagement in their work community deepened.

The intermeshing of professional and personal relationships was a normal and integral part of rural living. It was both an advantage in understanding specific needs of their patients and families, and a challenge in upholding professional and personal boundaries. Rural nurses wanted to care for their own people as invited to do so: neighbours, friends, relatives, business associates, social and sporting club members. However, this commitment was more than serving their community. These nurses wished to contribute to building the capacity of their rural communities. As reported by Mackenzie, Louth and Goodwin-Smith (2019), building community-based services in country areas is vitally important in maintaining the viability of small towns. Furthermore, being proactive in caring for patients who wished to die at home was about ensuring adequate and equitable services were provided equally the level of support available in metropolitan communities.

People living in rural areas had strong links to their land and homes. Being home brought with it security, peace, purpose and a completion of life when death was approaching. These RNs understood and were living this phenomenon alongside the families they supported. The home itself held spiritual meaning and the presence of nurses assisted in facilitation of spiritual care and understanding. Each home was unique, not only in its physicality but also in the culture and customs of the family who lived there. Each RN needed to respect and work with these practices to ensure that they provided holistic, patient-centred palliative care.

8.2.2 Finding balance

Finding balance was identified as the overarching constitutive theme that permeated every aspect of RNs' professional and personal selves. This endeavour involved balancing professional responsibilities as employees of a health care service with loyalty to their rural community. They strove to adjust to recent changes in the delivery of home-based nursing services while upholding principles of palliative care. These RNs accepted that some shortfalls in service delivery were present and mitigated these deficits by utilising non-professional, local, community-based support networks. Validation of the importance of their professional role was lacking and they considered recent reductions in funding and changes in service delivery as a slight on their specialist knowledge and skills. In some instances, the appreciation expressed by the families of the patients was unmatched by the health care service that employed them.

Receiving recognition from the health care service about the uniqueness of providing home-based palliative care in one's own rural community would be affirming and empowering. In many instances, as identified above, the nature of working and living in a rural community is unique. Adding to this uniqueness is the privilege of caring for patients in their own homes throughout their journey with a life-limiting illness. Participants voiced their need to be understood and acknowledged by the health care service just as they were by the community. The acknowledgement given by the community was about their dedication and commitment in providing quality home-based palliative care despite many challenges.

8.2.3 The home: the nurse an invited guest

As these RNs shared about working in the private space of patients' homes, further new understanding emerged.

The home as the care setting was the most prominent environment to emerge from the data. Providing palliative care in the home required a different approach to working in a hospital setting because nurses were invited guests in that private space. Acknowledging and understanding the nature of living in rural communities was the important backstory to providing appropriate home-based palliative care support. As summarised in the previous two subsections, 8.2.1 and 8.2.2, new insight into the uniqueness of living and working in a rural community formed new understanding of why RNs approached their work in patients' homes the way they did.

As an invited guest it was necessary to engage in a series of conversations with the family and the patient. These conversations established connections concerning how each RN belonged to the community. Making connections was the foundation of establishing trusting therapeutic relationships with the patient and family. Being granted permission to enter the home and being willing to engage in conversation were important components in establishing a partnership of care with the family. This partnership included acknowledging that the balance of power in care provision was with the family because the home was their own private space. There was a natural osmosis of community within the home and vice versa. Within their professional capacity these RNs needed to embrace the presence of community members within the home because they were a vital part of the primary care team for the patient.

Working in the home provided nurses with a heightened sense of personal self because there was freedom to meld together professional skills with their own personalities—a phenomenon not experienced in other care settings such as a hospital. Feelings of being rewarded, honoured and privileged to be allowed to work in the private space of patients' homes emerged. All these emotions accumulated in an ongoing process of finding balance between professional self and personal self.

8.2.4 Moving forward

Data did reveal practical and supportive ways in which appropriate government departments could improve the delivery of palliative care in rural communities. The Australian Government Department of Health's (2018) strategic plan aims to improve palliative care services for all Australians needing to access this service. Therefore, future strategies must include initiatives to improve support for nurses working in rural communities providing home-based palliative care.

8.3 Suggested Strategies

As guided by Paley (2017) the aim of phenomenological methodology in nursing research is about identifying meanings from data. Following Gadamer's philosophical thinking has been the vehicle in achieving new understandings of the meaning from the lived experiences of the 16 Registered Nurses. The aim of this study has been achieved. Concluding with new understandings from a specific period in which data was gathered, analysis and reported. However, it should be remembered that according to Gadamer the hermeneutic circle is an ongoing process thus meanings are not static but evolve over time (Gadamer 1975/2013). While this study was not about palliative care *per se*' participants spoke of the health care, structure and included funding changes that impacted them, as they were employees of the health care service. In making the following suggested strategies it is acknowledged that in doing so the parameters of a phenomenological framework are tested. The intent of these suggested strategies is to complete this thesis by informing policy makers at all levels of government as to the support needed by RNs providing home-based palliative care in rural communities.

8.3.1 Suggested support for Level 2 SPCS in regional areas of Australia

- Retain funding for Level 2 services in regional areas of Australia (PCA 2018).
- Fund a 24-hour on-call service with capacity to provide a seven-day-a-week service as required.
- Consult SPCS throughout assessment processes—the National Prioritisation System via the 'myagedcare' portal (see pages 158-159)—for specific needs when allocating additional funding to patients in the final six-month period of their illness (PCA 2022d).
- Expand the professional collaboration between regional community-based medical services and palliative care NPs.
- Immediately increase the number of palliative care nurses and NPs in regional areas in line with PCA (2022d) recommendations. This initiative will assist in mitigating the lack of medical services with limited expertise in palliative care.
- Quarantine RNs from SPCS teams for palliative care home visits only, allowing for quality of service to be maintained and improved.
- Retain part-time palliative care services in medium sized communities (as per population basis) because:
    - the presence of nurses ensures referrals are made and responded to in a timely manner.
    - visibility in the community promotes palliative care.
- Recognise that a palliative care service is more than the clinical tasks required in the homes

because it:

- contributes to the education of the patient, family, and community.
- builds community capacity by supporting informal carers and community organisations who in turn assist by mitigating gaps in formal services.
- builds community capacity by the appointed specialist nurses and NPs being actively engaged in education for other health care professionals such as allied health workers, general community nurses and local medical officers.
- rationalises the loss of rural businesses in small rural communities.
- provides a consultancy service for smaller outlying communities staffed primarily with general CNSs.

8.3.2 Suggested support for Level 1 general community nursing services providing palliative care in regional Australia

Support to include:

- An allocation of funding to be held at local or regionally based Community Health Services to support a ‘pop up’ approach in implementing a palliative care service on a needs basis.
- Funding to be retained and rolled over into the next financial year if not utilised in recognition that the need for palliative care services may peak some years and then not be required for a time.

  - receive assistance from regionally based specialist palliative care teams in assessment of needs for additional funding and implementation of extra home-based support services.
  - all general community nurses to receive baseline training in palliative care and regular twice-yearly education through formal workshops with regional specialist palliative care teams.
  - community nurses to receive consultative support from specialist palliative care nurses and/or NPs as requested and required.

8.3.3 Suggested professional grief support for nurses providing home-based palliative care in inner and outer regional areas in Australia

Recognise that grief support comes from within each individual team and facilitate customised support. In addition:

- The current 1300 673 122 24-hour clinical support number for rural nurses to be extended past the Department of Health SA 2020 Grants Program (SA Health 2022b) to include emotional and bereavement support for nurses providing home-based palliative care. Trained counsellors with background knowledge of palliative care nursing in rural areas to be part of this phone support service.
- Short videos to be developed and included in nursing resources sections of existing well-recognised national non-government peak advocacy body's (PCA's) website. Unique challenges of providing home-based palliative care in rural areas to be acknowledged. Link to additional support to be provided as suggested through the national 1300 673 122 number.
- Rural palliative care services to expand so relief staff are funded to enable nurses to take bereavement leave after caring in a professional capacity for a close friend, associate or relative

8.4 Limitations of this study

This study was conducted in inner and outer regional areas of one state in Australia. Therefore, the lived experiences of nurses providing home-based palliative care in areas classified as metropolitan, remote and very remote areas of Australia were not reported. Creswell (1994) guided that even though the 'uniqueness of a study within a specific context' (p.159) could prevent replicating it exactly in another setting, 'the researcher's positions-the central assumptions, the selection of informants, the biases and values of the researcher' could assist (Creswell 1994, p.159). Some insight into participants' experiences was present throughout this study because of my own previous experience in providing home-based palliative care in rural communities. However, my engagement with participants was guided by carefully constructed and open-ended research questions to ensure expression of their lived experiences was presented, and that I had faithfully reported their own voices. Additionally, the interpretation and analysis of data were shaped by Gadamer's (1975/2013) phenomenological thinking and by extending Diekelmann, Allen and Tanner's (1989) seven-stage process. As Gadamer guided, truth emerged from the language within the text. However, the truth presented here is not absolute because participants' views may change over time.

8.5 Strengths of this study

Adhering closely to the philosophy of Gadamer in allowing the fusing of horizons to emerge as data were analysed (Gadamer 1975/2013), together with the exhaustive reading of transcripts, other relevant academic literature and regular discussions with my supervisors over an extended period new understandings to occur. The movement between understanding and re-reading texts within each transcript further facilitated the closing of the hermeneutic circle.

Following the seven-stage data analysis by Diekelmann, Allen and Tanner (1989) was a comprehensive and detailed method of engaging with the text and language within it. This seven-stage process employed regular review of the previous steps undertaken and resulted in a thorough method of analysis. Furthermore, extension of stage 3 and 4 afforded inclusion of comprehensive data. Again, regular review with my supervisors ensured that consensus was achieved. Thus, the findings of this study were presented in a robust, systematic way.

A wide range of rural communities have been represented in this study within the inner and outer regional areas in the one state of Australia. The 16 participants who willingly took part of the qualitative study provided a copious amount of data. This richness was characterised by the stories they told and their willingness to be open and honest about their individual successes and failures. Participants were willing to become vulnerable as they shared their intimate personal experiences about what it was really like as to be involved in this field of nursing in their own rural communities.

8.6 Future research directions

Research into the lived experiences of other medical and health care professionals including allied health services, family and medical practitioners would add to the understanding of caring for patients wishing to die at home in rural communities. It could be that family carers have very different experiences to nurses. As illustrated in the sixth chapter of this study, participants reported that in the home, the family held the balance of power. Exploration of the phenomenon of being an invited guest in the home from the perspective of Allied health workers and GPs, would also contrast or confirm the concept of family holding the balance of power. A similar study in other countries could provide some contrasting lived experiences as well as confirmation of the key findings from this study.

8.7 Summary

The lived experience of RNs providing home-based palliative care in rural communities is more than just about the work they did. Rather it was about the ongoing process of finding balance between their professional self and personal self. This phenomenon was demonstrated as these RNs found they were invited guests in each patient’s home because it was the private space of another family. As such, a different balance of power existed to that in a usual clinical setting; therefore, forming a trusting therapeutic partnership with the patient and family was paramount. The intermeshing of personal and professional lives within rural communities added to the complexities of the lived experiences for the 16 participating RNs in this study. This was a case of ordinary nurses providing extraordinary home-based palliative care in rural communities. These findings provide evidence to inform government and non-government departments and agencies: evidence about the resources needed to meet the Australian Government’s pledge to afford all Australians who are terminally ill and wish to die at home adequate services and support to do so.

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WHO—*see* World Health Organization

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APPENDIX 1: CASP QUALITATIVE RESEARCH APPRAISAL TOOL

10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising a qualitative study:

Are the results of the study valid? (Section A)
What are the results? (Section B)
Will the results help locally? (Section C)

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

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

These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Critical Appraisal Skills Programme (2017). CASP (insert name of checklist i.e. Qualitative Research) Checklist. [online] Available at: *URL*. Accessed: *Date Accessed.*

Screening Questions

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

☐Yes ☐Can’t tell ☐No

HINT: Consider

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

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2. Is a qualitative methodology appropriate? ☐Yes ☐Can’t tell ☐No

HINT: Consider

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

Is it worth continuing?

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

☐Yes ☐Can’t tell ☐No

HINT: Consider

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

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

☐Yes ☐Can’t tell ☐No

HINT: Consider

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

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

☐Yes ☐Can't tell ☐No

HINT: Consider

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

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

☐Yes ☐Can't tell ☐No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
  (a) Formulation of the research questions
  (b) Data collection, including sample recruitment and choice of location

How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration? ☐Yes ☐Can't tell ☐No

HINT: Consider

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

8. Was the data analysis sufficiently rigorous? ☐Yes ☐Can't tell ☐No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?

- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

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9. Is there a clear statement of findings? ☐Yes ☐Can't tell ☐No

HINT: Consider

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

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10. How valuable is the research?

HINT: Consider

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

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APPENDIX 2a. RESULTS OF CASP APPRAISAL

Article 1

Cruickshank et al 2010 **‘**Using Syringe Drivers in palliative care within a rural, community setting: capturing the whole experience’ *International Journal of Palliative Nursing* vol.16, no.3, pp.126-132

1.Was there a clear statement of the aims of the research? clearly stated: to understand the impact of syringe drivers in the rural community setting. Considering the impact on patients’ carer and community nurses.

2.Is a qualitative methodology appropriate? Heidegger’s phenomenology. Cruikshank et al (2010, p.129) record the experiences reported by nurses included the practical aspects such as accessing medications, working in isolation, distances to cover and supporting other nurses if not so familiar with the use of the pump. The only positive experience reported related the commencing the syringe driver at the right time and this positive experience was linked to the patient and carer rather than the nurse (Cruikshank et al 2010, p.129). Later in the discussion section the over- coming of all the challenges of setting up and maintaining a pump in the home was to be equated to ‘a feeling of a ‘job well done’ for the nurses’. There is no further exploration of this as a meaning of being. It could however be considered a brief glimpse of a manifestation of the experience as is the central theme of hermeneutics. Thus, it could be concluded that the chosen methodology for this study sparingly if at all illuminating the experience of the nurses.

3.Was the research design appropriate to address the aims of the Research? The explanation given was, the overall purpose of the study being to ‘explore expectations and experiences of informal carers, patients and community nurses in relation to the introduction of the syringe driver’(Cruikshank et al 2010, p.127). The report section had a strong focus on the combined experiences from all participants.

4.Was the recruitment strategy appropriate to the aims of the research? Yes. The sample size was very small i.e., four patients, eight carers and twelve nurses. The difficulty of recruiting very ill patients and stressed, grieving relatives was acknowledged. Explained the importance of the researchers having extensive experience not only in nursing research but also in palliative care and the specific needs of this group of participants. All community nurses working across the region were invited to participate in a focus group.

5.Was the data collected in a way that addressed the research issue? Interviews for the carers and patients were conducted at a mutually suitable time. The article does not detail the content of the interviews in a sample of the questions posed to confirm that the approach according to the chosen methodology of phenomenology was followed. The articles does not report on the time or location of the focus groups for the nurses other than to record that 26 people responded to a letter of invitation and two groups were held with ‘six to eight people in each group’. It is interesting to note that the nurses were not included in the one-to-one interview process of this study.

6.Has the relationship between researcher and participants been adequately considered? Support for participants at all stages of the study were put in place. Researchers considered the challenges of participation during the journey with a terminal illness or in the bereavement phase. Patients were able to choose the time and place for interviews to take place allowances were made of their abilities to communicate on these occasions. Focus groups were chosen to encourage group discussion and interaction between nurses who worked in diverse rural locations throughout the region. Information about the study was introduced to the patients’ and carers via the nurses involved prior to the researcher making contact. Close contact between the community nurses and the specialist palliative care nurses throughout. One author or researcher is noted as being listed as a Community Palliative Care Specialist Nurse

7.Have ethical Issues been taken into consideration? Noted as obtained at a local level however specific location details of which region in Scotland are not given or the name of the ethics committee or governance department. As previously mentioned, consideration was given to the vulnerabilities of the patient and carers however no factors identified in challenges for nurses as participants. Consent was obtained prior to get focus group meeting.

8.Was the data analysis sufficiently rigorous? The articles does not indicate how the recorded data was checked for accuracy. Once familiarization of transcripts was achieved qualitative data analysis software was used it code the emerging themes and subthemes. Only one small broadly formatted table summarizes four of the emerging themes relating to the patient and carers experiences and expectations of having a syringe driver commenced and the authors suggest that these were all directly linked to the nurses involvement. This does not illustrate the nurses experience though (Cruikshank *et al*., 2010, p.128). The title of this table is in relation to the community nurses' use and training for the carer and patient. The results section of the article is denoted with one direct quote from a patient and three direct quotes from carers under a subheading of symptom control, with no mention of nurses responses. The second sub heading with the broad title of Final stages of life broadly reports on all participants responses in the relief from a number of distressing symptoms. Although noted as important for all participants including the nurses there were three direct quotes from the carers and one from a patient with none included from the nurses directly. The experiences of dealing with geographical challenges was illustrated with two direct quotes from community nurses and similarly the discussion about working in partnership had strong representation from the nurses responses and excluded any responses from patients and carers. Although the results section is easy to read and direct quotes bring to the fore the individuals responses there is perhaps scope for a much more detailed table to summarize all the themes and sub themes from this study. A list of questions included in the focus group and patient carer interviews would provide additional opportunity to determine if all the goals of the study had been achieved.

9.It there a clear statement of findings? The conclusion sates that this study 'explored the experiences of patients and carer…[While] also sought to understand the role of the community nurse in supporting patients and carer. It could be said that the role of the nurse would be only one aspect of the nurses' experience so perhaps the study was heavily swayed with the experiences of the patient and carer. The authors went on to suggest that these study has considered the holistic experience in that the introduction of a syringe driver may be at a time when the needs of the patient and carer are paramount and the introduction of this piece of equipment provides nurses with the opportunity to explore and discuss other end-of-life care issues. No discussion of creditability of the findings were read in this original research article.

10.How valuable is the research? Influences for practice section of the report does not correlate to the aims of the study instead the need for non specialist nurses to receive regular mandatory training in the use of syringe drivers and awareness of the written information available for use for patients' and carers is highlighted. And to ability of the nurses to engage in open conversation with carers and patients and the use of a syringe driver. There is no discussion on transferability of the findings into other populations or locations.

Article 2

Arnaert A, Seller R& Wainwright M 2009 'Homecare Nurses' Attitudes Toward Palliative Care in a Rural Community in Western Quebec,' *Journal of Hospice and Palliative Nursing*, vol.11, no.4, pp.202-2008

1.Was there a clear statement of the aims of the research? Yes, to explore homecare nurses attitudes towards palliative care in a rural community in Western Quebec. Thought to be important because not many studies conducted and published in this area – needing to give the Canadian perspective. Most of the literature relating to rural communities comes from Australia, although only one reference given to support this claim.

2.Is a qualitative methodology appropriate? Yes, Qualitative research design – involving face to face interviews and one focus group.

3.Was the research design appropriate to address the aims of the Research? Yes, semi structured interviews conducted over 40 minutes with each participant, audio taped and transcribed

4.Was the recruitment strategy appropriate to the aims of the research? Maybe - Five community nurses with vast experience (15-28 years of experience) in community nursing. Does not say exactly how the participants were invited to take part in this study other than to say that they all worked for one organisation

5.Was the data collected in a way that addressed the research issue? Yes, face to face interviews and one focus group? Out of the five participants the number of attendees at the focus group is not reported in the article. Examples of the open-ended questions posed in the individual interviews and focus group are provided. It was explained that the 'Interviews were to explore participants' attitudes in-depth, while the focus group served to increase the breath of the data already obtained.

6.Has the relationship between researcher and participants been adequately considered? Maybe – each individual interview and focus group was conducted by the same interviewer. Consideration was given in the presentation of demographic data in group format to ensure anonymity of participants from a small community. Interviews and focus group conducted in two languages as per need, English and French. Direct quotes from participants are coded S1-S5

7.Have ethical Issues been taken into consideration? Yes, as above and approval obtained from at a regional level and with the University conducting the research project

8.Was the data analysis sufficiently rigorous? First two authors recoded a random sample of 30 % of data. Used coding guidelines developed by first author, stated 'An interrater reliability of 95% was achieved'(Arnaert, Seller & Wainwright 2009,p.204). Thematic analysis is used, a constant comparative method and a reference was provided. It could be suggested that although six main themes were identified that the data maybe insufficient due to small sample size, that is 5 nurses. Unsure if any data could be considered as contradictory in this type of data collection. Audit trail kept and informal member checking with participants to address researcher/s bias

9.It there a clear statement of findings? Yes, six themes extracted clearly listed under a heading of Findings. Each theme is then reported in detail using each theme as a subheading that is, experiencing community embeddedness, maintaining patients' quality of life, experiencing emotional and physical isolation, acknowledging the need for professional development, and dealing with organizational issues.

Article 3

Wilkes, LM & Beale B2001 'Palliative care at home: Stress for nurses in urban and rural New South Wales, Australia,' *International Journal of Nursing Practice*, vol.7, no. 5, pp.306-313.
NB The first study published in 1998 reported on community nurses descriptions of stress when caring for palliative care clients at home in an urban area of NSW. Following an educational forum held in a rural area it was identified that nurses working in rural areas were stress in this care provision as well. A second study in the rural area was conducted to provide explore if there were any differences between the urban and rural areas.

1.Was there a clear statement of the aims of the research? Yes Aim 'to compare stress experienced by urban and rural community nurses working with palliative-care clients in the home' (Wilkes & Beale 2001).

2.Is a qualitative methodology appropriate? Descriptive studies?

3.Was the research design appropriate to address the aims of the Research? Maybe - No discussion on how authors decided to use data from the two-part project

4.Was the recruitment strategy appropriate to the aims of the research? Maybe (more information required e.g., across multiple organisations etc) 80 questionnaires posted to nurses working in both areas. 20 questionnaires returned and 7 nurses from urban area volunteered for in depth interviews. From the rural area (north coast site) only seven nurses worked there, and all completed the survey. Five of which were involved with the interview progress as well.

5.Was the data collected in a way that addressed the research issue? Collected in two parts, questionnaire and then a tailored interview. Interview questions were based on participants' answers in the questionnaire. Examples given, 'Please describe' and' Please complete the following statement….'.(Wilkes & Beale 2001, p. 307)

6.Has the relationship between researcher and participants been adequately considered? Yes, the same person interviewed all participants. Only research team knew the names of participants, no ID was during analysis or reporting processes. No

participants required counselling in follow up from taking part in the interview process. **7.Have ethical Issues been taken into consideration**? Yes, Ethics approval from the participating university, and area health services involved. Written consent from all participants **8.Was the data analysis sufficiently rigorous?** Maybe Ethnography v4.0 software to code segments of text. Both authors textually analysed the data for emerging themes. Each author coded the data independently. Common themes from the two cohorts of nurses were extracted and compared and description complied. Articles both do not detail any critical appraisal from an independence source. **9.It there a clear statement of findings?** No, Table 2 summarises major themes listing subthemes under each however it is not clear which listing applies to urban and which to rural sectors. Reading of the results section findings were easily identified with any quotes and finding from rural nurses clearly noted from urban setting nurses. **10.How valuable is the research?** Adding to the body of knowledge about occupational stress of nurses working in the home environment providing palliative care. Suggested that the findings cannot be generalized but does not give reasons why**.** Limitations – sample disparity rural nurses only nurses with any post graduate certificates in palliative care so differences in educational level between rural and urban nurses. Small sample size and recall of nurses could not be clarified **Article 4** Kaasalainen, S Brazil K, Williams, A, Wilson D, Willison, K, Marshall D, Taniguchi A, Phillips C 2014 Nurses' experience providing palliative care to individuals living in rural communities; aspects of the physical residential setting, *Rural and remote Health*, vol.14, no.2, pp.2728-2740. A follow up study from a larger study in which the patterns of nurses practice, self-efficacy, multidisciplinary teamwork, and perceived barriers to providing effective palliative care was explored.	**1.Was there a clear statement of the aims of the research?** Yes, to explore nurses' experience providing palliative care to individuals living in rural communities; aspects of the physical residential setting. Particular focus physical residents equating to the home. The influence of the physical nature of rural communities in broad terms **2. Is a qualitative methodology appropriate?** Yes, to gain a deeper sense of the experiences (Kaasalainen et al 2014, p. 2730). **3.Was the research design appropriate to address the aims of the Research? Yes,** 'Qualitative descriptive design to explore nurses' experience providing palliative care in rural communities' Consider Rural context by ensuring participants cared for patients at least 80 kms away from the nearest large city with population of 1000,000 >, less than 150person's per square km with total are population of / < 10000. **4.Was the recruitment strategy appropriate to the aims of the research?** Yes 'Sought the perspectives of rural nurses only for this study' **5. Was the data collected in a way that addressed the research issue?** Yes, Semi structured interview guide Table 1 with examples. Member checking, investigator triangulation use to minimize any idiosyncratic biases. Saturation was reached by interview number 21. **6. Has the relationship between researcher and participants been adequately considered?** ' A trained interviewer conducted the interviews' No explanation of relationship to the participants though **7. Have ethical Issues been taken into consideration?** Yes, University and Nursing organization **8. Was the data analysis sufficiently rigorous?** Yes coded and labelled, categorized. Independent coding then any discrepancies reviewed by two investigators and discussed until consensus reached. **9. Is there a clear statement of findings? Yes.** Table –characteristics of the sample, headings include: nature of rural nursing, nursing role, impact of physical residential

setting. Interspersed with direct participant quotes to expand of aspects of nurses' experience under these headings.

10. How valuable is the research? Authors suggest in the conclusion that the findings would assist in informing decision maker about issues that rural nurses face in providing end –of –life care in the home. Limited by being only conducted in one community – the culture of which may impact on generalization.

Article 5

Reid, F 2013 'Lived experiences of adult community nurses delivering palliative care to children and young people in rural areas' *International Journal of Palliative Care Nursing,* vol.19, no.11 pp. 541-547.

1.Was there a clear statement of the aims of the research? Yes Broadly 'highlight some of the challenges perceived by rural community nurses when delivering palliative care'

2. Is a qualitative methodology appropriate? Yes, Phenomenological design

3.Was the research design appropriate to address the aims of the Research? 'Best to explore these individual, diverse, and subjective lived experiences'. Rural setting 65> miles from a general hospital.

4.Was the recruitment strategy appropriate to the aims of the research? All staff invited to participate – 6 DN & 4 Palliative Care CNCs.

5. Was the data collected in a way that addressed the research issue? Maybe, interviews conducted by the author, semi structure interviews, no example questions provided.

6. Has the relationship between researcher and participants been adequately considered? No – the author is the interviewer. Possibly open to biased but may have the insight required as a paediatric oncology nurse.

7. Have ethical Issues been taken into consideration? Yes, NHS research ethics committee and University, participant consent and confidentiality was assured

8. Was the data analysis sufficiently rigorous? Analysis using Latent inductive content analysis which noted the participants audible cues e.g., sigh, tears changes in tone = adding weight to the analytical process. Coding and cross coding used 'distilled into related and recurrent emerging topics – thematic approach.

9. Is there a clear statement of findings? Yes, four 'interrelated overlapping themes'. Emotional preparedness, navigating the professional road, becoming part of the family& everybody's business. Multiple direct quotes from nurses to illustrate findings

10. How valuable is the research?
A beginning insight in to the true human experience however while still interwoven into discussion the human experiences was over shadowed by reverting to the issues e.g. education for generalist nurses in EoL care for children, organisation complexities. Recommendations for practice- emotional stress in nurses should be recognised by managers and health-care commissioners'

<u>Article 6</u>

Rosenberg JP & Canning, DF 2004 'Palliative care by nurses in rural and remote practice,' *Australian Journal of Rural Health*, vol.12, no.4, pp.166-171

1.Was there a clear statement of the aims of the research? Yes, to evaluate experiences of nurses providing palliative care in rural and remote communities. To develop professional strategies to support these nurses.

2. Is a qualitative methodology appropriate? Mixed method study. Registered & enrolled nurses attended a two- day professional development workshop. Semi-structured survey with 23 items on a four- point Likert scale measuring perception of rural & remote practice. Twelve open-ended questions to obtain qualitative descriptions about key concepts.

3.Was the research design appropriate to address the aims of the Research? Yes, semi-structured survey. 23 items measuring perceptions of the nature of rural and remote practice, the provision of palliative care in these settings and the appropriateness of various professional development strategies.

4.Was the recruitment strategy appropriate to the aims of the research? Yes, all participants who attended the workshop received a survey in the mail

5. Was the data collected in a way that addressed the research issue? Collected from attendees at an educational workshop.

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

7. Have ethical Issues been taken into consideration? Confidentiality assured in relation to reporting of findings in survey letter sent to attendees.

8. Was the data analysis sufficiently rigorous? Summary of fixed response items, mean and standard deviations calculated however no detail of tool used. Qualitative analysed using a thematic method

9. Is there a clear statement of findings? 17 surveys received (55% response rate). Three tables present findings of fixed response items: Table 1: professional Development; Table two Support and Guidance and Table 3 evaluation of workshop. The supporting text of results are very brief.

10. How valuable is the research? Of limited value with some insight into issues pertaining to service provision in providing home-based palliative care in rural areas. Key issues: multiple roles, access to education, geographical distances, professional isolation, staffing constraints and time allocation contributed to levels of job satisfaction. Article focused on strategies for ongoing professional development.
Limitations – generalisation restricted owing to evaluation of one forum and self-reported data, therefore limited descriptions of attitudes and self-perception

Article 7

Penz K & Duggleby W 2011 'Harmonizing hope: A grounded theory study of the experience of hope of registered nurses who provide palliative care in community setting', *Palliative and Supportive Care*, vol. 9, no.3 pp. 281-294.

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

Specific aims listed in the abstract included: describe their hope experience, develop a reflexive understanding of the processes of their hope and construct a substantive theory of hope of palliative care RNs.

2. Is a qualitative methodology appropriate? Yes, because a theory was to be constructed from data collected quote Penz & Duggleby (2011) 'a constructivist grounded theory approach…was used to achieve the specific aims of the study.' Definition of Grounded theory Creswell 1994 p. 12 '
The researcher attempts to derive a theory using multiple stages of data collection and refinement and interrelationship of categories of information

3.Was the research design appropriate to address the aims of the Research? Yes, to construct a theory in response to (i.e., reflexive) the phenomenon while considering or being present to the social context in which the study is conducted.

4.Was the recruitment strategy appropriate to the aims of the research? Yes. Ensured that RN currently working in palliative care were invited to participate.

5. Was the data collected in a way that addressed the research issue? Purposeful sampling used to recruit RN who provide palliative care services in community settings in a western Canadian province. Contact made with 3 key professionals to assist in identifying potential participants. Clear inclusion criteria included in the article i.e. RN who provided direct palliative care in community services, RN employed in the province from a variety of geographical locations, have experience according to the key contact people, are practicing in the rural or urban locations (no further details of the geographical province given i.e. descriptions of population or expanse of the area)& are willing to participate in the study. Recruitment also via poster displays at a palliative care conference in the province. Demographic information collected via information package and combined with consent to participate. Open ended telephone interviews were conducted due to geographical expanse (to ensure a broad sampling across the region) of the province. Participants were requested to complete a daily journal for 1-2 weeks. Interview took notes and written memos

6. Has the relationship between researcher and participants been adequately considered? Not detailed as such

7. Have ethical Issues been taken into consideration? Yes, approved by an institutional behavioural ethics review board. Explained to participants via telephone contact and an information package was mailed to each participant including details of journaling to be done by participants.

8. Was the data analysis sufficiently rigorous? Maybe, an interview guide was used however no specific information about which guide. Description of the nature of interview questions e.g. how the RNs defined hope, what it meant to them personally, how hope may influence the care of their patients, the positive and negative influences of hope. Journaling instruction (what gave them hope today, what took away their hope). Notes taken during telephone interview. *Interviews not recorded though*. Notes on participants changes in tone of voice etc taken. Researchers made memo notes through data collect to assist in capturing researchers thoughts and new ideas to pursue. Transcribed using verbatim. Theoretical sampling used; further questions were developed. Contradictory findings - Contrast cases i.e., two participants expressed they did not have a lot of hope, so this was considered to challenge to current theory. Data collection continued until saturation was reach –until no new categories emerged during interviews. Credibility – using participants' own language. Originality –through theoretical sampling using constant comparative methods and references to literature. Resonance and usefulness addressed by confirming the theoretical processes with the participants when possible, providing descriptions of the theory as were found to be in the data that grounded/imbedded.

9. Is there a clear statement of findings? Yes table 1. Harmonizing hope, transcripts, incidents, categories and concepts. Headings social context of hope, definition of hope for nurses – RNs, main concern – keeping hope e.g. life and work challenges, Basic social process – creating harmony socially when others (patients and Family) thoughts differed. 'finding a sense of balance between two opposing or differing views' so they could move forward in the care relationship. Direct quote from participant to illustrate this point. Model of harmonizing hope in Figure 1 4 components with dot points under each and detailing the linkages between each Waves like arrows depicting the highs and lows of the experience of harmonizing hope. Each sub process if then expanded in explanation in the results section of the article.

10. How valuable is the research? May have significance for other palliative care nurses and nurses in general. Future research into hope for health care professionals. Hope may influence RN ability to provide high quality care hope may sustain them and act as a buffer in dealing with things like the lack of resources.

Article 8

Tunnah K, Jones A & Johnstone R 2012 Stress in hospice at home nurses: A qualitative study of their experiences of their work and wellbeing, *International Journal of Palliative Nursing* vol.18, no.6, pp.283-289.

1.Was there a clear statement of the aims of the research? Yes, Explored the home nurses' experiences and feelings of caring for palliative care and dying patients. To identify key issues that contribute to stress in the community across a large rural are in Northwest Wales.

2. Is a qualitative methodology appropriate? Yes, qualitative to explore people experiences in their own setting. Not so sure of full use of the grounded theory though. This was said to be used to categorise the data into themes however not model developed.

3.Was the research design appropriate to address the aims of the Research? In part yes see comments above

4.Was the recruitment strategy appropriate to the aims of the research? A team of hospice care nurses delivery palliative care in the community. Informed of the study at team meetings. Invited individually by college and first author. No discussion why some but not chose to participate or ethics approval. All worked in the care setting for at least 12 months.

5. Was the data collected in a way that addressed the research issue? Setting discussed briefly in first sentence under the heading of participates

10. How valuable is the research? Expanding the understanding of the nurses experience although again returning to common themes of working in isolation, distances, organisational constraints. Develops understanding and could provide new ways to support nurses in this setting. Future research is needed to explore the 'importance of nurses knowing themselves, more comprehensive understanding long-term impacts [these lived experience have] on the practical and personal lives of community palliative care nurses is necessary).

Article 10

Marchessault, J, Legault, A & Martinez A-M 2012, Providing in home palliative care within generalist caseload: A chance for nurses to reflect on life and death, *International Journal of Palliative Nursing*, vol.18, no.3, pp. 135-141.

1.Was there a clear statement of the aims of the research? Yes, to understand the experiences of homecare nurses providing palliative care within a generalist case load

2. Is a qualitative methodology appropriate? Yes, A Heideggerian interpretive phenomenological methodology (revealing human experience, understanding the why, the role of self in interruption find original reference) – the experience and perception of the participant

3.Was the research design appropriate to address the aims of the Research? Yes, Justified by stating that the participants are not very advanced but the authors do not stated in what way they are not advanced.

4.Was the recruitment strategy appropriate to the aims of the research? Fairly casual, Areas chosen in Quebec where palliative care was integrated into home care. Presented at a team meeting only. Nurses had to contact researcher if interested. Only 8 nurses did so.

5. Was the data collected in a way that addressed the research issue? Unstructured individual interviews. An interview guide developed for the study

6. Has the relationship between researcher and participants been adequately considered? First author – Head nurse from a Palliative care unit in a major hospital city area

7. Have ethical Issues been taken into consideration? Only sought from the Health & Social Services Centre where the study took place. Names are used in direct quotes of participants, unsure if fictitious names.

8. Was the data analysis sufficiently rigorous? Briefly detailed. Followed the 5-step phenomenological approach proposed by Giorgi 1997. Full transcripts analysed by first author and then reviewed by second and third author. Contradictory data not considered in article. Potential of own role and bias not detailed

9. Is there a clear statement of findings? Results section Three themes and 13 subthemes detailed into table 1 page 137. Three themes were used as main heading in results section. Well set out with regular participant quotes. The results report on the support given to the patient and family- being committed to care provision, developing a relationship, dealing with patient reactions and family. Concern about quality of care, complexities of caring in the home, relieving symptoms, developing skills and expertise. Personal development from being in the presence of death- experiencing many emotions, receiving help, personal reaction to death, feeling satisfied in care provided, growing personally and professionally

10 How valuable is the research? Themes of the personal journey can be found in the direct participant quotes however the authors remarks and comments revert back to professional issues and challenges mainly for example after a quote about personal and professional growth the authors comments are about the reflection on the nurses own professional practice. That both their life experience and their nursing experience allowed them to provide patients with better support. A closing comment in the final sentence suggests that it was more important to have professional boundaries in order to protect the nurses personal lives with no acknowledgement of the impact of that personal life.

Article 11

Cumming A, Boreland F & Perkins D 2012, Do rural primary health care nurses feel equipped for palliative care? *Australian Journal of Primary Health*, vol 18 no.4, pp.274-283.

1.Was there a clear statement of the aims of the research? Not particularly clear but present in the abstract and the introduction. Explore the experiences of rural primary health care nurses to in rural and remote NSW who are required to provide palliative care as part of a generalist role. How they feel and about caring for palliative care patients how well equipped they feel and what they education and support needs are.

2. Is a qualitative methodology appropriate? Not detailed specifically as a qualitative study (under Qualitative analysis heading (quantitative and qualitative analysis are presented together'). Methods section gave information related to the study population in 14 rural and remote health services in the former Far West Area health Service

3.Was the research design appropriate to address the aims of the Research? Not able to determine- survey only, mailed questionnaire. Ten participants were interviewed by phone, selected to maximise diversity of geographical isolation, nursing roles time worked in rural and remote communities and attitudes about palliative care.

4.Was the recruitment strategy appropriate to the aims of the research? All community PHC nurses who provide palliative care. No details of how these nurses were identified.

5. Was the data collected in a way that addressed the research issue? In part, low participation rate. Explicit methods not given. Just stating 'interviews were in-depth and semi structured. Survey and interview questions based on objective and aims of study, no examples provided.

6. Has the relationship between researcher and participants been adequately considered? In limitations section researcher familiar with are and nurses and there was a pre-existing professional relationship

7. Have ethical Issues been taken into consideration? Consent form included in information pack but no details of approval from any ethics committee, just reported as the appropriate Ethic Committee.

8. Was the data analysis sufficiently rigorous? Brief details of analysis –descriptive analysis using Excel 2000, interviews transcribed and analysed using inductive thematic analysis (Braun & Clark 2006)

9. Is there a clear statement of findings? Maybe Appendix 1 provided coding tree, from interviews with main and subthemes numbered. Other tables provided quantitative data relating to demographics and numbers of nurses who felt equipped to deal with various aspects of palliative care. Tables 3 & 4 related to educational needs of the nurses. Strong focus on educational needs of nurses being the solution of equip these nurses providing palliative care in rural and remote communities in Australia.

10 How valuable is the research? Did report some feelings however not the prominent themes of author discussion. Some lived experiences such as some felt professionally and personally equipped in particular better equipped for physical care provision than spiritual care. Discussion section reverted back to the issues of professional development, being equipped, having access to education indicating that as suggested by Robinson et al 2009 'knowledge influences the willingness to provide palliative care'(p. 280) but nurses not interested in palliative care did not attend education forums/opportunities.

Article 12

Wilkes, L & White, K 2005, 'The family and nurse in partnership: providing day-to-day care for rural cancer patients', *Australian Journal of Rural Health,* vol. 13, no. 2, pp.121–126.

1.Was there a clear statement of the aims of the research? Yes, to explore family and nurse partnerships in meeting the needs of rural cancer patients receiving palliative care.

2.Is a qualitative methodology appropriate? Yes

3.Was the research design appropriate to address the aims of the Research? Yes, Cross sectional qualitative study.

4.Was the recruitment strategy appropriate to the aims of the research? Yes, palliative care nurses in group 2.

5. Was the data collected in a way that addressed the research issue? Yes, semi structured interviews with each participant.

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

7. Have ethical Issues been taken into consideration? Yes, participating university and all health services involved.

8. Was the data analysis sufficiently rigorous? Yes, IBM software package Ethnograph V4.0. Inter view transcripts coded by both researchers. Independent coding and identification of categories.

9. Is there a clear statement of findings? Yes, in section, what this paper adds. Previous knowledge of family assisted in quickly establishing therapeutic relationships. Nurses acknowledged the demanding role family had in caring for their loved one and continuing farm work. Late referral for palliative care support were commonplace due to families' stoic approach in life. There was a lack of essential services in rural locations (farms). Therefore, the role of specialist nurses was vital in accessing resources, equipment and medications. **Limitations –** none acknowledged.

10. How valuable is the research? Contributes to knowledge of the importance of nurses working with the culture of each family when offering palliative care support at home.

Article 13

-

Reed, F, Fitzgerald, L & Bish, M 2016 'Rural nurses experiences of successful advocacy for person centres End-of-life choice, Journal of Holistic Nursing, vol.35, number 2, pp. 151-164

1.Was there a clear statement of the aims of the research? Aim –clearly stated How do nurses advocate for Rural Australian end-of-life care goals? **The goal/ objective -**To develop a holistic practice model for district nurses to inform person- centred end-of-life advocacy

2.Is a qualitative methodology appropriate? Yes, Nursing theory combined with pragmatic approach **focuses on an individual decision maker within an actual real-world situation.** The process of undertaking a pragmatic study is first to identify a problem and view it within its broadest context. This leads to research inquiry, which seeks to better understand and ultimately solve the problem.

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

4.Was the recruitment strategy appropriate to the aims of the research? Yes, 7 nurses participated in 2014

5. Was the data collected in a way that addressed the research issue? Yes narrative and phone contact to set up individual interviews – 1 hour

6. Has the relationship between researcher and participants been adequately considered? Yes, considered distance and available of participants contributed to lengthy time between writing of reflections and in person interviews 3-23 days. Respect for employing agency given consideration, researcher use an encouraging stance which stimulated rich detailed accounts, talking freely.

7. Have ethical Issues been taken into consideration? Yes

8. Was the data analysis sufficiently rigorous? Reflection on written answers, audio recorded interviews, transcribing by primary researcher. Used NVivo QRS 10 qualitative data analysis, - sorting of paragraph, phases, and words. Themes examined using mapping tools in the program to indicate connection and relative importance. Use of thematic analysis by Attride- Stirling 2001 clarified meanings. Check by research team and referring back to data. Participants reviewed analysis and confirmed findings as true.

9. Is there a clear statement of findings? Yes

Being willing to invest in person centred care through involvement, emotional energy, and autonomy. Knowing how to advocate within a professional role while drawing on personal knowledge of family, local resources, and the community. Feeling supported by self and others to achieve patient goals in care.

10 How valuable is the research? Highlights the lived experience of nurses on one particular aspect of caring for patients requiring end-of-life care
Limitations – only 7 participants. Only one group of Health Professionals and from one state in Australia
Further research in using a survey to gather data from a larger sample of District Nurses nationally.

<u>Article 14</u>

Spelten, E, Timmis, J, Heald, S & Duijts A 2019 'Rural palliative care to support dying at home can be realised; experiences of family members and nurses with a new model of care,' *Australian Journal Rural Health*, vol.27, no.4, 336-343.
1.Was there a clear statement of the aims of the research? No
Aim What was the experience of nurses and family caregivers of the dying process at home

2.Is a qualitative methodology appropriate? Yes, mix method with demographic data collected as well.

3.Was the research design appropriate to address the aims of the Research? Not really – nurses were only involved at the end of the project

4.Was the recruitment strategy appropriate to the aims of the research? Family members were only contacted after 6 weeks from the death of their loved one. No specific detail on how nurses were recruited. The four division one nurses available in the particular town the project was conducted were conducted – targeted invitation.

5. Was the data collected in a way that addressed the research issue? Yes, face to face interviews

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

7. Have ethical Issues been taken into consideration? Yes

8. Was the data analysis sufficiently rigorous? Deductive thematic analysis was employed – two domains focussed on experience with the palliative care service and secondly the process of dying at home. Implementation of the palliative care service and its sustainability. The use of ipads were reported as helpful for families to feel supported and for the nurses to stay updated with patient's changes in status. The intense support at the beginning of an episode of care was complex and further impacted by needing to travel long distance to visit home. Good communication with other health professionals and medical staff in good coordination of home-based services. Reward was experienced as nurses received deep appreciation for their work from families. Great camaraderie between nurses but debriefing was only available adhoc from the health care service but was highly valued.

9. Is there a clear statement of findings? One small section in the second table in the article is dedicated to the emergent themes from interviews with the nurses.

10. How valuable is the research? Provides some insight into nurses lived experiences. However only in relation to service provision per se'. A participant group with only nurses would further highlight challenges and rewards

APPENDIX 2b: SUMMARY TABLE OF RETAINED ARTICLES FROM CASP APPRAISAL OF PRIMARY RESEARCH LITERATURE

Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
1. Cruickshank et al. (2010) Scotland, United Kingdom	To explore the experience of patients, carers and nurses. To explore the role and experience of the community nurses in setting up syringe drivers and use of same in the home for patients receiving palliative care in rural communities.	12	Heidegger's phenomenology 4 patients, 8 carers and 12 community nurses. All community nurses working across the region were invited by letter.	Syringe drivers gave an opportunity to relieve and manage distressing symptoms, enhancing a trusting relationship between patient, carers and nurses. Infrequent use of syringe drivers affected the nurses' currency in knowledge base, including providing patients and carers with information about the pump, knowledge gaps in a range of medications and likely actions or interactions. Challenges included accessing medications out of hours, a workload influenced by geographical challenges, teamwork and limited out-of-hours service. However, timely intervention in commencing the syringe driver was rewarding work. **Limitations –** no reference to limitations relating to nurse participants; only patients and family members (difficult to interview at a sensitive time).
2. Arnaert, Seller& Wainwright (2009) Western Quebec, Canada	To explore homecare nurses' attitudes towards palliative care in a rural community.	5	Qualitative semi-structured face-to-face interviews and one focus group. Thematic content analysis.	Nurses' attitudes influenced by community embeddedness, accepting responsibilities, maintaining patients' privacy and quality of life, infrequent collaboration with multidisciplinary teams, emotional and physical isolation, large geographical distances, need for professional development and dealing with organisational issues. **Limitation** – generalisation of results may not be possible because each community has its own unique characteristics.

Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
3. Wilkes & Beale (2001) New South Wales, Australia	To compare stress experienced by urban & rural community nurses working with palliative care patients in the home.	12	Qualitative descriptive study. Seven nurses from an urban region of Sydney and 5 nurses from a costal rural area north of Sydney. Interview via invitation from a postal open-ended survey.	Stressors included role conflict & definition in the community, family dynamics, heavy workloads, impact of community connections, no debriefing opportunities, little education to uphold currency of skills in palliative care nursing and large geographical distances. **Limitations –** the two groups of nurses not having similar knowledge & skills; small sample size; unequal qualifications between the urban and rural nurses, selective recall may have influenced the study results.
4. Kaasalainen et al. (2014) Ontario, Canada	To explore the impact of the physical residence (i.e. the home) in rural communities.	21	Qualitative descriptive design. Semi-structured telephone interviews. Data was analysed using thematic content analysis.	Nurses working in rural areas were part of the community. Challenges included maintaining patient confidentiality, dealing with organisational changes, large distances, poorly maintained roads, inclement weather, supporting and educating carers, accessing resources, medications, working with multidisciplinary teams, working in isolation, relationships with family, multiple administrative tasks and supporting impoverished families by undertaking non-nursing work. **Limitations** – Data collected in one province of Canada. Nurses participating in this study were from just one agency.

Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
5. Reid (2013) Scotland, United Kingdom	To highlights challenges as perceived by community nurses involved in the home care of terminally ill children and young people in rural regions.	10	Phenomenological design Sampling – all nurses of one health services were invited to participate. Semi- structured interviews by the author using thematic data analysis	Challenges included: nurses felt underprepared emotionally, had no specific palliative care education when under- or post-graduates so currency of practice was difficult, navigating organisational issues, family and community connections, stress, pressure of multiple roles, role confusion when specialist teams were involved, supporting family, maintaining job satisfaction, large geographical areas and isolation. **Limitations** – homogenous group, all trained in UK, same culture, ethnicity and gender, possibly affecting transferability to other rural international contexts.
6. Rosenberg & Canning (2004) Queensland, Australia	To evaluate experiences of nurses providing palliative care in rural and remote communities. To develop professional strategies to support these nurses.	31	Mixed method study. Registered & enrolled nurses attended a two-day professional development workshop. Semi-structured survey with 23 items on a four-point Likert scale measuring perception of rural & remote practice. Twelve open-ended questions to obtain qualitative descriptions about key concepts.	Key issues: multiple roles, access to education, geographical distances, professional isolation, staffing constraints and time allocation contributed to levels of job satisfaction. Article focussed on strategies for ongoing professional development. **Limitations** – generalisation restricted owing to evaluation of one forum and self-reported data, therefore limited descriptions of attitudes and self-perception.

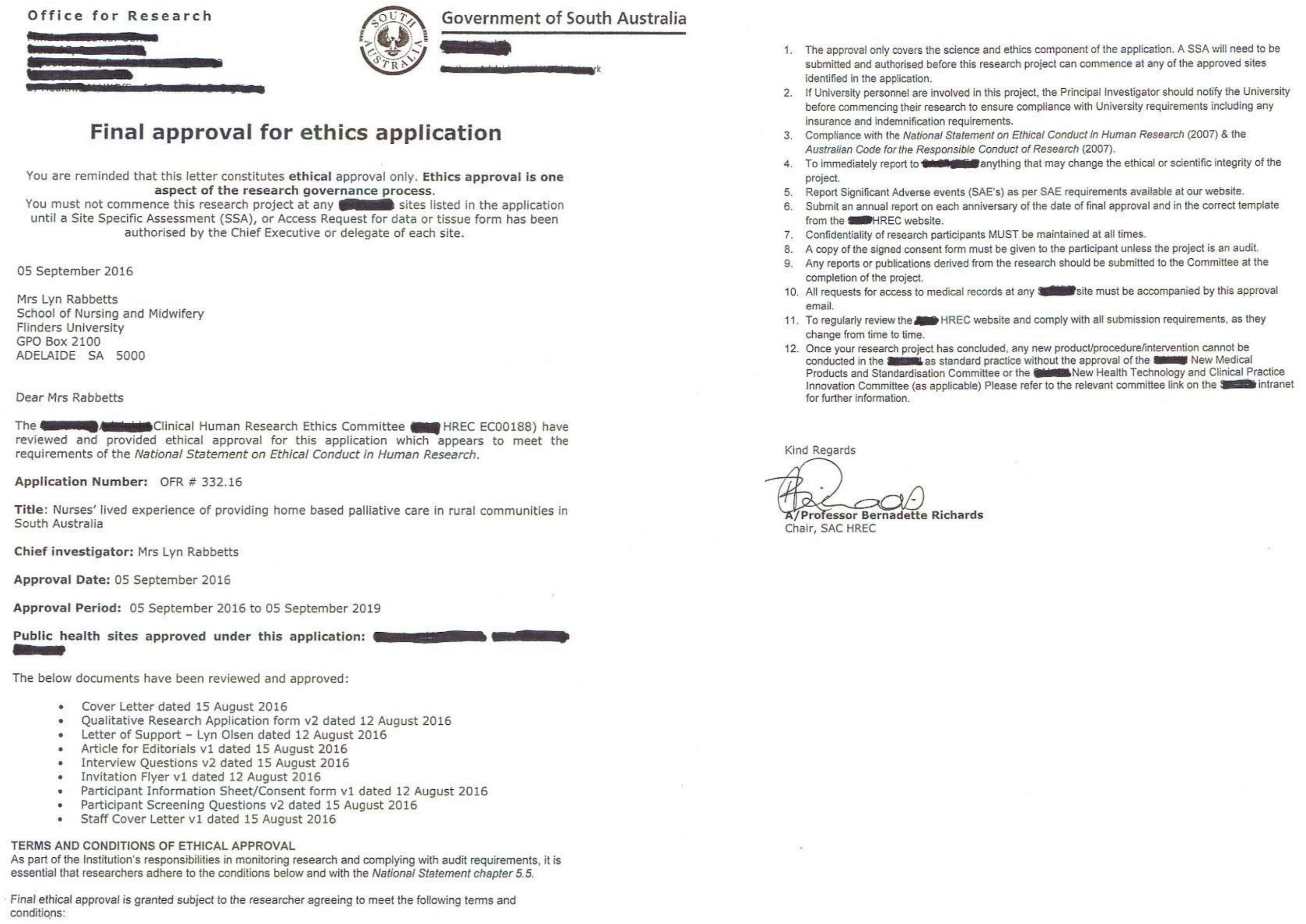
Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
7. Penz & Duggleby (2011) Saskatchewan, Canada,	To describe RNs' hope experience, understand the processes of hope for these nurses and construct a theory of hope of palliative care RNs in the community setting (rural and urban).	14	Qualitative constructivist grounded theory study with purposeful sampling. RNs currently working providing direct care in the community setting, working in a province in a variety of geographical locations, experienced RNs. Recruitment via phone and poster displays. Phone interviews and journal entries.	A theory in development. Harmonising hope theory to assist with understanding the importance of hope for RNs. Hope assisted in perseverance, and in dealing with day-to-day challenges in caring directly for the patient and in working with health care service issues. Using hope, nurses could see connections with others by considering the 'bigger' picture and make a difference while considering others' hopes and concerns. In doing so, nurses could remain true to their own values. **Limitations** – Only female RNs participated. All were aware of the topic of hope so their interest in this area may have influenced their responses.
8. Tunnah, Jones & Johnson (2012) Northwest Wales, United Kingdom	To explore the feelings and experiences when providing palliative care in the community setting. To identify issues that contribute to the stress for nurses working in primary care across the region of Northwest Wales.	11 (10 nurses; 1 care worker)	Qualitative methodology.	Job satisfaction played an important part in the levels of stress experienced. Conflict with colleagues such as communicating with multi-disciplinary teams and GPs, working in isolation, inadequate preparation for patients' deaths, heavy workloads, lack of resources and peer support increased stress. Coping strategies identified included taking time out, self-care such as exercise or relaxing activities, and seeking support from work mates and family on a regular basis. **Limitations**- study included a small team of hospice-at-home nurses. Interviews conducted by project manager – some responses may have been inhibited. Some anonymity of participants

Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
				may have been lost because of each of the three authors being involved in the research project.
9. Penz & Duggleby (2012) Saskatchewan, Canada	To analyse the significant work-life experiences for RNs who provided palliative care in the home in rural & urban settings.	14	Grounded theory; thematic analysis of the context of the hope study.	Themes that emerged included a strong 'sense of self', while having strong ability to advocate, having compassion, resilience, being able to be flexible in working hours and focussing on solutions rather than on organisational constraints. Working independently in the community. Feeling resigned to working in a system that did not understand the nature of palliative care nursing, including a lack of official debriefing following a patient's death. Feeling valued and respected by communities and families who were managing their own feelings of grief and loss. **No further limitations** noted because of drawing from existing data from a previous study by Penz & Duggleby (2008–2009; published findings in 2011).
10. Marchessault, Legault & Martinez (2012) Quebec, Canada	To understand the experiences of home care nurses providing palliative care within a general case load in one district.	8	Heideggerian interpretive phenomenology – unstructured individual interviews.	Three themes and 13 subthemes. Main themes: supporting the patient and family, concerns about providing quality of care, personal development from being confronted by death. **Limitations**- first author's limited experience in conducting interviews and phenomenological analysis.

Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
11. Cumming, Boreland & Perkins (2012) New South Wales, Australia	To explore the experiences of rural primary health care nurses to determine how well equipped they felt in providing palliative care in patients' homes in remote settings.	34 nurses returned a survey, 10 nurses were interviewed by phone.	Mixed method survey-style design with follow-up one-to-one phone interviews. Descriptive analysis.	Experiences included: nurses fulfilled multiple roles such as attending to post-natal visits, general community nursing and palliative care in patients' homes. Some nurses were required to care for their own family and friends. Accepting reciprocal responsibilities in the community was challenging at times. Most nurses reported their work was rewarding. Nurses who did not enjoy being involved with palliative care were committed to providing quality care. Although most nurses had attended education program recently, more was requested. Attending education was difficult because of geographical distances and a lack of staff to backfill. Organisational support was important. **Limitations** included the researcher being well-known to the participating nurses. This may have inhibited responses from some nurses.
12.Wilkes & White (2005) New South Wales, Australia	To explore family and nurse partnerships in meeting the needs of rural cancer patients receiving palliative care.	10 nurses & 17 family members.	Cross sectional qualitative study.	Previous knowledge of family assisted in quickly establishing therapeutic relationships. Nurses acknowledged the demanding role family had in caring for their loved one and continuing farm work. Late referral for palliative care support were commonplace due to families' stoic approach in life. There was a lack of essential services in rural locations (farms). Therefore, the role of specialist nurses was vital in accessing resources, equipment and medications. **Limitations –** none acknowledged.

Author(s), year and location	Aim	Sample size	Methods & sampling	Major findings / limitations
13.Reed, Fitzgerald & Bish (2017) Victoria, Australia	To understand how nurses from rural health services advocate patients end-of-life care goals. To develop a holistic practice model for district nurses to inform person- centred end-of-life advocacy.	7	Nursing theory combined with a pragmatic approach.	Being willing to invest in person-centred care through involvement, emotional energy and autonomy. Knowing how to advocate within a professional role while drawing on personal knowledge of family, local resources and the community. Feeling supported by self and others to achieve patient goals in care. **Limitations –** small group of participants and research project was conducted in one state of Australia.
14.Spelten et al. (2019) Victoria, Australia	To understand the experience of nurses and family caregivers of the dying process at home in one rural community.	4	Phenomenological approach to data analysis. Mixed method in data collection.	Implementation of the palliative care service and its sustainability. The use of iPads was reported as helpful for families to feel supported and for the nurses to stay updated with patients' changes in status. The intense support at the beginning of an episode of care was complex and further affected by needing to travel long distances to visit homes. Good communication with other health professionals and medical staff assisted efficient coordination of home-based services. Reward was experienced as nurses received deep appreciation for their work from families. Great camaraderie between nurses. Debriefing was only available ad hoc from the health care service but was highly valued. **Limitations** – small sample size of nurses, therefore data collected was not extensive.

APPENDIX 3: ETHICS APPROVAL LETTER



Office for Research
[redacted]

Government of South Australia
[redacted]

Final approval for ethics application

You are reminded that this letter constitutes **ethical** approval only. **Ethics approval is one aspect of the research governance process**.
You must not commence this research project at any [redacted] sites listed in the application until a Site Specific Assessment (SSA), or Access Request for data or tissue form has been authorised by the Chief Executive or delegate of each site.

05 September 2016

Mrs Lyn Rabbetts
School of Nursing and Midwifery
Flinders University
GPO Box 2100
ADELAIDE SA 5000

Dear Mrs Rabbetts

The [redacted]/[redacted]Clinical Human Research Ethics Committee ([redacted] HREC EC00188) have reviewed and provided ethical approval for this application which appears to meet the requirements of the *National Statement on Ethical Conduct in Human Research.*

Application Number: OFR # 332.16

Title: Nurses' lived experience of providing home based palliative care in rural communities in South Australia

Chief investigator: Mrs Lyn Rabbetts

Approval Date: 05 September 2016

Approval Period: 05 September 2016 to 05 September 2019

Public health sites approved under this application: [redacted] [redacted] [redacted]

The below documents have been reviewed and approved:

- Cover Letter dated 15 August 2016
- Qualitative Research Application form v2 dated 12 August 2016
- Letter of Support – Lyn Olsen dated 12 August 2016
- Article for Editorials v1 dated 15 August 2016
- Interview Questions v2 dated 15 August 2016
- Invitation Flyer v1 dated 12 August 2016
- Participant Information Sheet/Consent form v1 dated 12 August 2016
- Participant Screening Questions v2 dated 15 August 2016
- Staff Cover Letter v1 dated 15 August 2016

TERMS AND CONDITIONS OF ETHICAL APPROVAL
As part of the Institution's responsibilities in monitoring research and complying with audit requirements, it is essential that researchers adhere to the conditions below and with the *National Statement chapter 5.5.*

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. The approval only covers the science and ethics component of the application. A SSA will need to be submitted and authorised before this research project can commence at any of the approved sites identified in the application.
2. If University personnel are involved in this project, the Principal Investigator should notify the University before commencing their research to ensure compliance with University requirements including any insurance and indemnification requirements.
3. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007).
4. To immediately report to [redacted] anything that may change the ethical or scientific integrity of the project.
5. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.
6. Submit an annual report on each anniversary of the date of final approval and in the correct template from the [redacted] HREC website.
7. Confidentiality of research participants MUST be maintained at all times.
8. A copy of the signed consent form must be given to the participant unless the project is an audit.
9. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.
10. All requests for access to medical records at any [redacted] site must be accompanied by this approval email.
11. To regularly review the [redacted] HREC website and comply with all submission requirements, as they change from time to time.
12. Once your research project has concluded, any new product/procedure/intervention cannot be conducted in the [redacted] as standard practice without the approval of the [redacted] New Medical Products and Standardisation Committee or the [redacted] New Health Technology and Clinical Practice Innovation Committee (as applicable) Please refer to the relevant committee link on the [redacted] intranet for further information.

Kind Regards

A/Professor Bernadette Richards
Chair, SAC HREC

APPENDIX 4: PROMOTIONAL FLYER

Flinders
UNIVERSITY

Research Project

INVITATION TO PARTICIPATE

Nurses' experience of providing home-based palliative care in

rural communities in [redacted]

Are you a Registered Nurse or registered midwife who has been involved in caring for patient/s receiving palliative care at home in rural [redacted]? Would you like to share your experiences?

Each nurse will be provided with the opportunity to participate in an interview for approximately 50 minutes with the researcher at a time that is mutually suitable. No travel or cost will be incurred.

This study has been reviewed by the

[redacted] ***Clinical Human Research Ethics Committee***

For further information please contact:

Mrs Lyn Rabbetts, PhD student, School of Nursing & Midwifery, Flinders University, SA.
Email: lyn.rabbetts@flinders.edu.au

APPENDIX 5: COVER LETTER

[Date]

[Staff details]

Dear staff,

Please find attached/ enclosed information relating to the research project that I am currently undertaking for my PhD study. This project is titled:

Nurses' experience of providing home-based palliative care in rural communities in South Australia

This project has been endorsed by [redacted], Executive Director, Nursing & Midwifery Services, Country Health SA. Ethics approval has been secured through the [redacted] Clinical Human Research Ethics Committee ([redacted] HREC) lead committee under the single review model for ethics. The National Ethics Application Form section one and two and the Site-Specific Assessment (SSA) has been completed and approved.

Each of the six Regional Directors of Country Health SA were invited to pass on the promotional flyers and information to the Directors of the Regional Community Health Services and Directors of Nursing of regional hospitals. It would be appreciated if this information could flow through to the community nursing teams and specialist palliative care teams throughout [redacted], please?

Thank you for your kind consideration of my request and please do not hesitate to contact me with for any further information about my research study.

Yours sincerely,

Lyn

Mrs Lyn Rabbetts RN MPC
PhD Candidature
School of Nursing & Midwifery
Flinders University
Bedford Park campus
Sturt Road, Bedford Park 5042
South Australia
Postal address
GPO Box 2100
Adelaide 5000
South Australia
Email: lyn.rabbetts@flinders.edu.au

APPENDIX 6: PARTICIPANT INFORMATION SHEET

Flinders
UNIVERSITY

Participant Information Sheet

Health/Social Science Research

Flinders University of South Australia

Title	Nurses’ experience of providing home-based palliative care in rural communities in [redacted]
Short Title	*Providing home-based palliative care*
Protocol Number	*332.16*
Principal Investigator	Mrs Lyn Rabbetts
Location	Country Health, SA

Part 1: What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called ‘Nurses’ experience of providing home-based palliative care in rural communities in [redacted]’. You have been invited because you are working either in a community nursing service or a regional palliative care service involved with providing palliative care.

This Participant Information document informs you about the research project. It explains the processes involved in taking part. Knowing what is involved will help you decide whether you will participate.

Please read this information carefully. Ask questions about anything that you do not understand. Before deciding whether or not to take part, you might wish to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide you want to take part in the research project, you will be asked to sign a consent form. By signing it you are informing me that you:

- understand what you have read
- consent to take part in the research project
- consent to be involved in the research described

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

2 What is the purpose of this research?

To explore the experiences of nurses providing home based palliative care in rural communities in [redacted].

While the literature provides evidence of studies undertaken into the service provision of palliative care, nurses' perspectives on the experience of providing palliative care are underreported. In particular, no studies within rural [redacted] and in the home-based care setting are available. Data collected from this study will provide:

- An insight into the complexities of this care setting for nurses
- New understanding will contribute to informing organisational sustainability and capacity building of the community nursing workforce providing palliative care in patients' own homes in rural [redacted].

3 What does participation in this research involve?

- If you decide to take part in the research project the researcher will contact you by phone or email and ask you a number of questions to determine your eligibility to take part. Answering these questions will take 1–2 minutes.
- If the screening questions show that you meet the requirements, then the researcher will arrange a mutually suitable date and time for a face-to-face interview.
- The interview will be held in a private office area at your local community health service or district hospital.
- The researcher will contact you by phone or email 2–3 days prior to the agreed time to confirm your availability and again on the day of your interview should you require this.
- If a face-to-face interview is not convenient then arrangements will be made with you for a phone interview at a mutually suitable time.

- If the screening questionnaire shows that you cannot be in the research project, the researcher will discuss this with you.

The interview

- The researcher will ask you 6–7 semi-structured questions, allowing you time to share your responses. You may be invited to give examples or elaborate further from time to time. Time will be given at the end of the interview for you to provide any additional comments or clarify any of your responses.
- Total time required for an interview will not exceed 50 minutes.

In line with qualitative research principles all efforts will be undertaken to ensure the trustworthiness of the analysis of data collected from purposeful sampling.

There are no costs associated with participating in this research project; nor will you be paid.

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

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with professional staff or your relationship with [redacted]

5 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time. If you decide to withdraw from the project, please notify the principal researcher before you withdraw. If you do withdraw, you will be asked to complete and sign a ‘Withdrawal of Consent’ form; this will be provided to you by the researcher.

6 What are the possible benefits of taking part?

I cannot guarantee that you will receive any direct immediate benefits. However, this research study will contribute to informing future organisational sustainability and capacity building of the community nursing workforce providing palliative care in patients’ own homes in rural South Australia.

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

It is not expected that you will experience any emotional distress. However, should you feel that any questions are upsetting please indicate this to the researcher. Should you wish not to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff independent of the researcher. This counselling will be provided free of charge from [redacted] – Employee Assistant Program – [redacted] [redacted] [redacted].

8 What happens when the research project ends?

The results from this research project will be reported in a thesis, which will be available online from the Flinders University Library or in hard copy. Original research articles will be published in peer-reviewed journals. Results will also be presented at research symposiums and conferences.

Part 2: How is the research project being conducted?

9 What will happen to information I provide?

Interviews will be recorded using an MP3 voice recorder and notes will be taken by the researcher. The recording will be transcribed by the researcher and data stored on a secured, password protected computer. All recordings will be coded with a participant number and date. Your name will not be visible or evident in the transcripts or in the thesis. Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

In accordance with relevant Australian and/or [redacted] privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the researcher. You also have the right to request that any information with which you disagree be corrected. Please inform the researcher named at the end of this document if you would like to access your information.

10 Complaints

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

11. Who is organising the research?

This research project is being conducted by *Mrs Lyn Rabbetts, PhD candidate, School of Nursing & Midwifery, Flinders University*[redacted]

12. Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been

approved by the HREC of [redacted].
This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems related to your involvement in the project, you can contact the researcher.

Name	*Mrs Lyn Rabbetts*
Position	*PhD student candidate of Nursing & Midwifery, Flinders University*
Email	*lyn.rabbetts@flinders.edu.au*

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	[redacted]
Position	*Director, Office for Research*
Telephone	[redacted]
Email	[redacted]

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC name	[redacted]
HREC Executive Officer	[redacted]
Telephone	[redacted]
Email	[redacted]

APPENDIX 7: PARTICIPANT CONSENT FORM

Consent Form

Title	Nurses' experience of providing home-based palliative care in rural communities in [redacted] [redacted]
Short Title	*Providing home-based palliative care*
Protocol Number	*332.16*
Coordinating Principal Investigator/ Principal Investigator	Lyn Rabbetts
Location	[redacted]

Declaration by Participant

I have read the Participant Information Sheet.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

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

Name of Participant (please print) ______________________________

Signature ______________________ Date ______________________

Declaration by Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† (please print) ______________________________

Signature ______________________ Date ______________________

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

APPENDIX 8: INTERVIEW QUESTIONS GUIDE

Interview Questions

1/ Can you describe for me your experience in caring for palliative care patients in their own homes in your own /rural community?

How does/did that make you feel?

Can you tell me more?

2/ Can you describe for me what it is like to live and work in the same community when you are involved in providing palliative care?

How do you deal with this?

Can you tell me more?

3/ Can you describe for me the effects of caring for a dying patient in his/her own home on your own emotions?

How do / did you deal with these emotions?

Can you tell me more?

4/ Can you describe for me the experience of facing the mortality/ death of patient/s in their own homes?

How do/ did you deal with these responses?

Can you tell me more?

5/ Can you describe for me how these experiences may have contributed to changing you as a nurse?

Can you tell me more?

6/Can you describe for me how these experiences may have contributed to changing you as a person?

Can you tell me more?

7/ Is there anything else you would like to share?

Thank you