

The influence of place of death and rural residency on the ‘good death’

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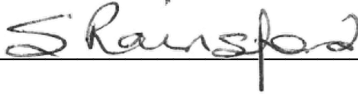
A thesis submitted for the degree of Doctor of Philosophy of
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Statement of authenticity

I, Suzanne Rainsford, declare that this thesis, submitted in fulfilment of the requirements for the award of Doctor of Philosophy, Medical School, College of Medicine Biology and Environment, The Australian University, is the product of my own work. All assistance received in preparing this thesis has been acknowledged and/or referenced. This thesis has not been submitted for qualifications at any other academic institution.

Signature of PhD candidate 

Acknowledgements

It is with immense gratitude I thank the many people who assisted me along the thesis journey. Without their support, encouragement and willingness to participate, completion of this thesis would not have been possible.

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Abstract

Background

Achieving one's preferred place of death is often considered, within palliative care, as a proxy for a 'good death'. To date, most place of death studies are quantitative and reflect an urban view. The objectives of this study were to explore the concept of the good death from the experiences and perspectives of rural patients with a life limiting illness, and their family caregivers, within the Snowy Monaro region of New South Wales, Australia; to determine the influence of place of death and rural residency on the 'good death'.

Methods

This thesis was a mixed methods study, comprising

1. Two systematic and one scoping literature reviews, exploring rural place of death, the rural 'good death', and end-of-life care from the experiences and perspectives of rural patients and family caregivers.
2. An ethnographic study utilising open ended interviews with 11 rural patients with life limiting illness, 18 family caregivers, and six clinicians (medical and nursing).
3. A cross-sectional study of cause and place of death for all people who died in the Snowy Monaro region between 1st February 2015 and 31st May 2016 (n = 224).

Results

Of the 224 deaths recorded, 138 (62%) were due to an illness amenable to palliative care. Seventeen (12%) of these deaths occurred at home, in a private residence; 52 (38%) occurred in the usual place of residence. Residential aged care was considered home for some residents. Home was the initial preferred place of death for those interviewed. Over time, dying in a safe place became more important than dying at home. A 'safe death' emerged as the central theme of a 'good death'.

Home is more than the material structure. It represents connection to the land, family, and memories, all elements that underpin its value as a safe place. Rural residency helped maintain home as a safe place (e.g. privacy on the farm); however, these same features quickly rendered home an unsafe place of death (e.g. isolation). The roles of the

rural hospital and residential aged care in end-of-life care are unique, and their familiarity within one's community often makes them a safer alternative to home, and substitutes for in-patient hospice.

Conclusion

Most Snowy Monaro residents do not die at home, yet a 'good death' is achievable. Many elements of the 'good death' are not unique to rural residency; however rural perspectives on place of death are often contrary to the urban view. A death at home does not ensure a good death. The task for all those providing and supporting end-of-life care is to ensure all places for dying can deliver the 'safe death' no matter where the illness trajectory dictates that the person dies.

Publications arising from this research

1. Rainsford, S., MacLeod, R.D., & Glasgow, N.J. (2016). Place of death in rural palliative care: a systematic review. *Palliative Medicine*, 30(8), 745-63. doi:10.1177/0269216316628779.
2. Rainsford, S., MacLeod, R.D., Glasgow, N.J., Wilson, D.M., Phillips, C.B., & Wiles, R.B. (2016). Rural residents' perspectives on the rural 'good death': a scoping review. *Health and Social Care in the Community*. doi: 10.1111/hsc.12385. [Epub ahead of print, 19 September 2016].
3. Rainsford, S., MacLeod, R.D., Glasgow, N.J., Phillips, C.B., Wiles, R.B., & Wilson, D.M. (2017). Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic literature review. *Palliative Medicine*; 31(10): 895-912. doi: 10.1177/0269216316685234.

Conference oral presentations

1. Rainsford, S., MacLeod, R.D., Glasgow, N.J. (2016). *Does dying at home matter most?* 22nd Hospice New Zealand Palliative Care Conference. 14-16 September 2016. Auckland, NZ.

Conference posters

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2. Rainsford, S., Phillips, C., Glasgow, N., MacLeod, R., Wiles, R., Wilson, DM. (2017). *Place of death does not determine the 'good death' for rural family caregivers. An ethnographic study*. 15th World Congress of the European Association for Palliative Care, 18 - 20 May 2017, Madrid, Spain.

3. Rainsford, S., Glasgow, N., MacLeod, R., Phillips, C., Neeman, T., Wiles, R. (2017). *“I want to stay home and die on the farm.” The actual place of death in a rural setting.* 15th World Congress of the European Association for Palliative Care, 18 - 20 May 2017, Madrid, Spain.

Author contribution to publications

The systematic and scoping literature reviews were my original idea. I developed the research questions for each publication. I conducted the systematic reviews; developed the search terms and inclusion criteria; conducted the database searches, review of titles, abstracts, and full texts, quality assessment, charting, thematic analysis, and back calculations (Publication 1). I wrote the peer reviewed articles, and responded to the reviewers' comments.

NJ Glasgow (Chair of supervisory panel): co-authored all papers and conference presentations arising from the thesis. Independently reviewed some identified abstracts; independently verified data extraction and quality assessment; reviewed manuscript drafts prior to submission.

RD MacLeod (Supervisor): co-authored all papers and conference presentations arising from the thesis. Independently reviewed all identified titles and some abstracts; independently verified data extraction and quality assessment; reviewed manuscript drafts prior to submission.

CB Phillips and RB Wiles (Supervisors): Independently reviewed and assessed content, data extraction and quality of a portion of identified abstracts. Reviewed co-authored manuscript drafts prior to submission.

DM Wilson (External advisor): Offered advice on conducting a scoping review; independently reviewed and assessed content and quality of a portion of identified abstracts. Reviewed co-authored manuscript drafts prior to submission.

T Neeman (ANU Statistical Consultancy Unit): Provided advice on quantitative data analysis and reporting.

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Abbreviations

ABS	Australian Bureau of Statistics
ACI	Agency for Clinical Innovation
ACP	Advance care planning
ANZSPM	Australian and New Zealand Society of Palliative Medicine
APoD	Actual place of death
CCF	Congestive cardiac failure
CDH	Cooma District Hospital
CHH	Clare Holland House (out of region inpatient hospice)
CN	Community nurse
CNC	Clinical nurse consultant
COPD	Chronic obstructive pulmonary disease
CVA	Cerebral vascular accident
DON	Director of nursing
EoL	End-of-life
EoLC	End-of-life care
ERP	Estimated resident population
ESRF	End stage renal failure
FACHPM	Fellow of the Australasian Chapter of Palliative Medicine
FCG	Family caregivers (family member or person identified by patient as primary informal caregiver)
FTE	Full-time equivalent
GP	General practitioner
GWNSW LHD	Greater Western New South Wales Local Health District
HREC	Human research ethics committee
ICU	Intensive care unit
HCP	Health care professional
LGA	Local government area
LHD	Local health district
LOS	Length of stay
MCCD	Medical Certificate Cause of Death
MCCR	Monaro Committee for Cancer Research.
MND	Motor neuron disease

MPS	Multipurpose service
MRHS	Monaro Regional Health Services
NSW	New South Wales
PCN	Palliative care nurse
PoC	Place of care
PoD	Place of death
PPoC	Preferred place of care
PPoD	Preferred place of death
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
QODD	Quality of death and dying
RAC	Residential aged care
RACF	Residential aged care facility
SAH	Subarachnoid haemorrhage
SNSW LHD	Southern NSW Local Health District
TCH	The Canberra Hospital
UPoR	Usual place of residence
WHO	World Health Organisation

PART 1: RESEARCH INTRODUCTION

CHAPTER ONE:

INTRODUCTION TO RESEARCH STUDY

‘Approaches to death and dying reveal much of the attitude of society as a whole, to the individuals who compose it’. (Dame Cicely Saunders, foreword to Oxford textbook of Palliative Medicine. Doyle et al. 1999)

Introduction

The World Health Organisation (WHO) defines Palliative Care as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness’ (WHO, 2004). One goal of palliative care is to enable people to die in their preferred place, with the literature suggesting home is the preferred place for most (Gomes et al., 2013). However, most people don’t die at home, with most deaths in the developed world occurring in institutions, such as hospitals and residential aged care facilities (Broad et al., 2013; Cohen et al., 2015). Some even suggest that a hospital death is suboptimal (Earle et al., 2003), and imply that a ‘good death’ is a death that occurs at home.

Having lived and worked in the rural Snowy Monaro region of New South Wales (NSW), Australia, for the past 25 years, I have observed that most of my dying patients and acquaintances, died in the local district hospital. While a few remained home, until death, most of these terminally ill residents had remained home until symptoms, or family inability to cope, rendered home inappropriate. It was taken for granted they would transfer to the local hospital to die. Over the years, from my personal and professional perspective, the local rural hospital has been a very appropriate and supportive place to die. However, recently in Australia, and in many developed countries, a discourse has emerged in the popular media and in the professional literature about encouraging home deaths by increasing the support to help people die at home, respecting patients’ choices, and reducing the number of expected, often expensive, deaths in hospitals. As I pondered this dilemma, I wondered why the rural

hospital had seemed appropriate for the people I had encountered, and if rural patients and their family caregivers (FCGs) have a different perspective on hospital deaths and what it means to ‘die well’. And so, the basis of my thesis was conceived. The principal questions to be answered through this research study are: (1) what is a rural ‘good death’? and (2) what is the influence of place of death and rural residency on the ‘good death’?

This introductory chapter firstly outlines my personal world view on place of death (PoD) (Section 1.1), as it is important from the outset that I declare any researcher bias I may bring to this research study. This is followed by a statement of the research study objectives (Section 1.2). Section 1.3 provides an overview of the research methodology. The chapter concludes (Section 1.4) with a brief overview of the successive chapters contained within this thesis.

1.1 Researcher world view

I grew up in the city. I don’t remember my first introduction to death, as I was a toddler when my last living grandparent died. Grandma lived with us, adding to the business of a household with five children. Eventually, our wise general practitioner (GP) suggested that respite in a nursing home should be considered, so Dad and Mum could take a well-deserved family holiday, a break from the exhausting daily responsibilities before the arrival of their sixth child. Grandma never returned home; she died a few weeks later. I have a sense Mum always regretted, even felt guilty for, not having cared for her mother at home in the last days of her life.

After graduating from medical school, in the mid-1980s, I spent the then obligatory two years as a junior hospital doctor, before stepping out into general practice. My interest lay in sports medicine, caring for young, healthy, and fit patients. After six months working at an elite sports medicine clinic, I eagerly headed off to the NSW Snowy Mountains (Australia), to become a rural GP, working in the ski fields. I have vague memories of caring for a few patients with cancer. In those days, there was no formal palliative care, nor was there much discussion with patients as to their preferences re place of care or death. If patients had stable symptoms and merely ‘faded away’ they remained at home. Alternatively, and more commonly, they were admitted to the district

hospital, over 60 kilometres away. Elderly patients, who could no longer care for themselves at home, were admitted to the local residential aged care facility (RACF).

Life in the ski fields was challenging, but fun. However, 1997 was, to quote Queen Elizabeth II, my '*annus horribilis*'. The year started with the tragic death of my teenage niece in a car accident. This was followed a few weeks later with the destruction, by fire, of the house of elderly friends. A landslide in the ski village of Thredbo, in which several of my patients died, followed a few months later. Despite the amazing community spirit and camaraderie in such tragic circumstances, suddenly the gloss of working in the mountains was lost. An opening became available to work on a tropical island, over two thousand kilometres away, just off the coast of Townsville in far north Queensland.

It was during my time on the island that I was exposed to the difficulties of providing palliative care in an isolated area. We weren't really that isolated, just a 20-minute ferry ride to the mainland, between the hours of 6am and 9pm. I was the only GP caring for a population of 3000, eight kilometres off shore. There was a public hospital outpatient clinic staffed by a nurse and resident on-call doctor, as well as one ambulance officer. After-hours emergencies could be transferred to the mainland by police launch, providing the waters were calm.

I don't remember the exact details, as I have done well to block out the trauma of looking after Joe, a 65-year old man (names and details have been altered). He lived with his wife, Jane who was in her early 60s. His regular GP was on the mainland. Joe had recently been diagnosed with pancreatic cancer and had spent a few weeks in Townsville hospital, for pain management. One afternoon I received a frantic phone call from Jane, asking me to visit. Joe was in terrible pain. The first time I met Joe he was thrashing about in bed and vomiting. He was unable to take his oral pain medication. I finally settled him with an injection, most likely pethidine and metoclopramide, which was standard practice at the time. Joe had told me he was not going back to hospital, where he was just a patient in a large public ward. He wanted to remain home, on the island. I made a few calls to the newly established pain management clinic who had cared for Joe during his admission. The impression was that Joe was a 'difficult case' and his pain had not been adequately controlled. A new medication was suggested, but

really “you’re on your own...good luck.” The community nurse looked to me for guidance, but nothing seemed to help Joe. At times, all we could do was ‘just be there’ for Joe and Jane. About 4 weeks after first meeting Joe, I received a call from Jane at about 2am. Joe was in a lot of pain, could I come quickly? Joe died 10 minutes later, just before I arrived. At that point, I didn’t want anything more to do with palliative care. I had failed Joe and Jane.

I returned to the Snowy Mountains and joined a general practice in Cooma, about 100 kilometres from the ski fields. I managed to avoid palliative care. I had not applied for accreditation at the 30-bed district hospital. I lost contact with patients once they became ‘palliative’. Once admitted to hospital, ongoing care was provided by the admitting GP. Then one day Beth came to see me.

Beth was 40 years old. She had grown up in Cooma, and until recently had been living and working in the city. She had been diagnosed a few years earlier with cancer. Unfortunately, the cancer had metastasised. Beth had brought her husband and young family back home, to spend her last few months with her mother and brother. Beth was complicated...she had fistulas, multiple ‘ostomies and stents. She was not absorbing her opiate tablets. Although a challenge, caring for Beth was different to Joe. Beth wanted to stay home, no matter what she faced, and we succeeded in respecting those wishes. Beth died at home a few months later, surrounded by her family. This time there was support - a great palliative care community nurse, a wonderful palliative medicine specialist on the end of the phone in Sydney, GP colleagues in the practice, and an array of drug options. This ignited my desire to pursue palliative care. Despite Beth’s family and the palliative care nurse saying I “did well”, I knew I could have done things better.

In between these two significant patients I also had the opportunity to witness palliative care in a more personal way. My elderly dad had cancer, and died suddenly during one of his frequent admissions to a large private Sydney hospital. He had been cared for, both at home and in hospital, by a palliative medicine specialist. Dad did not want to die at home. To him the hospital was a familiar and safe place. Dad didn’t want home ‘turned into a hospital’ with beds and equipment. He didn’t want Mum to have the full responsibility of caring for him during his frequent pain episodes. He had one respite

admission in the nearby hospice, but this was not a safe place for him. Sharing a four-bedded room meant Dad and Mum grieved each time a 'room-mate' died.

In 2012, 25 years after graduation, I started palliative care specialist training. It was always my intention to return to my rural town once training was completed. In mid-2014, I returned to Cooma and started a private, part-time palliative medicine practice, offering consultations in the surgery, private homes, hospital and RACFs.

Much is talked about the 'good death' and preferred place of death (PoD). From my perspective, Joe did not have a 'good' death, despite being at home, in his preferred place. From my perspective, Beth's death was not 'good', things could have been done better. Her pain could possibly have been better managed in hospital. That is not the perception of the family or the palliative care nurse. For them, it was difficult because symptoms were not easily controlled, but 'good' because she died at home. They had felt extremely supported by their palliative care nurse and doctor. In the end, Beth had a 'good enough death' (McNamara, 2004). The family were satisfied and appreciative of the effort that was made to keep Beth at home. My dad died in a private tertiary hospital - that was the right place for him; much better there than at home or on a four-bed ward at the hospice. During my palliative care training, I looked after Jimmy. He was 26 years old, and died in a side room, not hooked up to life support machinery, in the intensive care unit (ICU) in an acute tertiary hospital. My palliative care team said his death in ICU was not 'good', and that we had failed him. But, it was the right place for someone young, who had an acute onset of respiratory distress, who wanted to fight until the end, until all possible active treatments had been exhausted.

From my perspective, formulated through personal and professional experience, the PoD should suite the circumstances, and be the most appropriate place at the time, for the patient and their family. Place of death is dependent on each person's needs and coping ability. While it is imperative to respect a person's autonomy and wishes, as health care professionals (HCPs) we need to not only listen to our patients, but also offer information, advice, and guidance to assist them in making good decisions. I personally question the value of enquiring of one's preferred PoD too far ahead of time, because it is impossible to know what the scenarios will be. Asking people for their preferences risks giving the impression their preference will be honoured. If the

preferred place is not achievable, or available, there is often a sense of disappointment, or even guilt held by the family. I've seen families struggle trying to keep a promise made to a patient; I've seen patients struggle not wanting to disappoint their family by leaving home and going to a hospital or hospice. I've seen and experienced HCPs' disappointment and a knowing better care could have been provided in an alternative place. I've seen 'good' and 'bad' deaths at home, in hospital, in RACFs, and even in the inpatient hospice.

Readers of this thesis may ask why I have indulged in writing about my experiences. I have chosen to undertake an ethnographic study, and this methodology is open to researcher bias. It is therefore important I declare my history and my position, to be transparent.

From my perspective, issues surrounding patients and FCGs' preferences are not the only contentious areas. National and international studies report the actual PoD often from death certificate data; however, this only provides the actual PoD, not the reasons for determining the place. The data show the predictors for PoD, but again, not the reasons. The data do not indicate whether decedents were cared for at home, only to transfer to hospital for the final hours or days before death. Also, many people have seen or heard of a family or friend dying at home, peacefully in their sleep. If they relied on that one experience, they may falsely believe a home death, in any situation, is uncomplicated and peaceful. Healthy population surveys are potentially meaningless if the respondents have no personal experience of inadequately controlled symptoms, or carer burden, fatigue, sacrifice, and responsibility often associated with a home death.

As previously stated, this research study was partly undertaken to answer my own questions. As a rural palliative medicine specialist, I want to ensure my practice is evidenced based and patient focused. My patients are rural residents. Do they, as the literature suggests, want to die at home? Do they, as the literature suggests, believe the small, rural community hospital is an inappropriate place to die? Am I, and my local HCP colleagues failing our patients by not facilitating more deaths at home? Is it possible for rural residents with a terminal illness to achieve a 'good death', regardless of where they die? If so many Snowy Monaro residents are dying in the district hospitals or local RACFs, does more need to be done to improve the quality of the

dying experience within the institutions, for the patient, their FCGs, and the staff? As I delved deeper into the literature it became apparent that not only were there limited studies reporting from the experiences and perspectives of patients and their FCGs, but also the rural voices were significantly under-represented. As I pondered my questions, the objectives of this research study were formulated.

1.2 Research objectives

The primary objective of this research study was to explore the concept of the good death from the experiences and perspectives of rural patients with a life limiting illness, and their FCGs, within the rural Snowy Monaro region of NSW, Australia. The secondary objectives were to determine the influence of PoD and rural residency on the ‘good death’, and to explore the meaning behind the PoD preferences and decision-making process. These perspectives were contextualised by describing the actual PoD of Snowy Monaro residents, and by exploring the factors associated with PoD.

The following section provides an outline of the approach utilised to conduct this research study and to address the research objectives.

1.3 Research methods

This thesis used a mixed methods approach. The research study was informed by a number of systematic reviews of the literature. The actual PoD of Snowy Monaro residents was described after analysing population death survey data, over a 16-month period. It was important to have participants in this study describe their experiences in their own way, and so a qualitative component was utilised based on ethnography. Ethics approval was obtained from two independent human research ethics committees (HREC).

1.3.1 Literature review

Two systematic and one scoping literature reviews were undertaken, using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) and PRISMA-Scoping Review guidelines (Equator Network, 2016). These literature reviews, now published in peer-reviewed journals, (1) *Place of death in rural palliative care: a*

systematic review (Rainsford, MacLeod and Glasgow, 2016); (2) *Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic literature review* (Rainsford et al., 2017); and (3) *Rural residents' perspectives on the rural 'good death': a scoping review* (Rainsford et al., 2016), highlighted the paucity of rural end-of-life studies, and the lack of findings reporting the experiences and perspectives of rural patients, with a life limiting illness, and their FCGs. They also illustrated the challenge of finding a single rural voice, as currently there is no international consensus on the definition of 'rural', with significant heterogeneity across rural studies. The identified rural studies, consistent with urban studies, reported that most people with a life limiting illness do not die at home. However, there were inconsistencies, with most studies reporting rural residents were less likely to die in hospital than urban residents, while a few studies reported the opposite. The literature suggests the 'good death' is subjective, and dependent on individual perspectives and priorities. Dying in one's preferred PoD is one feature of a 'good death'; however, there is insufficient evidence to determine the absolute importance of PoD in facilitating a 'good death'. Most rural locations do not have a dedicated inpatient hospice unit, with rural hospitals often acting as a substitute for inpatient hospice, albeit without a specialist multidisciplinary palliative care team.

The scoping and systematic literature reviews identified gaps within the current rural literature, worthy of further research. The research setting and methodologies are outlined in the following sections, with detailed descriptions provided in Chapters Three and Four.

1.3.2 Study setting

The setting chosen for the study was the Snowy Monaro region, located in south eastern NSW, Australia. This covers an area of 15,162 km² with a population of 20,218 (ABS, 2017a). It is serviced by the Monaro Regional Health Service. Cooma is the regional centre and largest town, with a population of 6742 (ABS, 2017a). There are several other smaller towns and communities, and many farms.

1.3.3 Ethnography

A qualitative approach, utilising open-ended interviews as the prime method of data collection, was chosen to ensure sufficient depth and detail to fully understand each

participants' personal experience (Patton 2002, pp. 16-17). Wilson et al. (2009a) report that rural residents consider themselves to hold unique perspectives on death and dying, and end-of-life care (EoLC). Therefore, this research study explores the influence of rural culture and PoD on the concept of the good death, achieved through an ethnographic approach.

Data were collected in 42 interviews. While the focus was to gain the perspectives of patients and FCGs, local HCPs (palliative and community nurses, and GPs) were also interviewed. In total, 35 participants (11 patients with a life expectancy of less than six months, 15 of their FCGs, three additional bereaved FCGs, and six local HCPs) were interviewed. Potential patient participants were identified by the local palliative care nurse or GPs. After participants provided informed consent, they were interviewed using a semi-structured interview format. Over time, recruitment became more purposeful, to ensure the participants represented a cross-section of the region, in terms of degree of rurality, cause of death, place of care (PoC), and PoD. The interview topics were based around the patients and FCGs' care needs, support, meaning of the 'good death', and preferred PoC and PoD. The interview schedule and my approach deepened over the course of the study, as questions were asked surrounding an issue raised by a previous participant. Interviews were audio-recorded and transcribed verbatim. Data were analysed using thematic analysis techniques.

1.3.4 Population death data survey

While it was essential to gain deep understanding of the 'good death' and PoD within the Snowy Monaro region, it was also important that the data obtained through qualitative methods were placed within a regional context, and on a background of actual current practice. Unfortunately, I was denied access to the regional death data held by the NSW *Registry of Births, Deaths and Marriages* (for reasons explained in Chapter Four, Section 4.5.3) and therefore, death data were initially collected from the local funeral director, local newspaper obituary and funeral notices, and funeral announcements on local radio. As data collection began, it became apparent that data relating to decedents residing in the Bombala area were missing, due to adjacent out-of-region funeral directors being engaged, and lack of obituaries published in the once weekly '*Bombala Times*'. An amendment was made to the ethics approval to recruit additional informants, including the director of nursing (DON) or nursing managers of

local residential aged care (RAC) and inpatient health facilities. The websites of out-of-region funeral directors were also scrutinised. Waiver of consent from decedents' next of kin was granted by ethics committees, on the basis that names and addresses were not collected from the funeral directors and facilities, and the use of any data was de-identified. Demographic data, including sex, age at death, marital status, last place of residence, PoD, and cause of death, were collected over a 16-month period, for 224 deceased residents. It became apparent conflicting information was provided in some obituary notices, with the last address of some long term RACF residents reported as their previous private residence. Therefore, a further amendment was made to the ethics protocol to permit DONs to provide the length of stay for their deceased residents, identified through obituary and funeral notices. Data were initially charted descriptively. Cross tabulations by PoD and key demographic data were performed. Bivariate logistic regression was undertaken to identify factors that may influence the actual PoD.

1.4 Challenges specific to this study

There were several challenges, both ethical and practical, that required attention during the preparation and data collection stages of this research study. Some issues were addressed during the HREC application phase, and others, like the Bombala death data mentioned in the previous section, required an amendment to the ethics approval. The main issues (researcher bias and potential recruitment coercion), related to my dual position of researcher, and palliative medicine specialist practicing within the Snowy Monaro region. Specific strategies were implemented and are discussed in Chapter Four, Sections 4.4. 1, and 4.7.

1.5 Thesis structure

This thesis is organised into four parts, comprising nine chapters.

Part 1: Research introduction

In **Chapter One** I have provided the background to this thesis, and my own world view. As previously reported, one measure of the success of quality palliative care is to enable people to die in their preferred place, with the literature suggesting this to be home for most people. A death at home is considered by some advocates of palliative care to be

central to the concept of the good death. However, the current viewpoints regarding PoD are mostly urban focused, and obtained from healthy populations or healthcare professionals. In this chapter, I declare my personal and professional perspectives on PoD, and my thought processes in developing the objectives of this research study.

Part 2: Research preparation, methodology and methods

Chapter Two sets out the background rural literature relating to the rural ‘good death’, and rural EoLC and PoD. The chapter begins by describing the discipline of palliative care, the concept of the good death, and the challenges in defining ‘rural’. This is followed by a summary of the findings of my published scoping and systematic literature reviews, and their relevance to rural residents’ perspectives on the ‘good death’, PoD in rural palliative care, and rural EoLC. The methods utilised in conducting these reviews are outlined in Chapter 4 (Section 4.2). These reviews demonstrate the paucity of rural EoLC research, especially from the experiences and perspectives of rural patients and FCGs.

Chapter Three describes the setting, both in terms of location and target population. As each rural community is unique, it is important that a visual image is created for the reader. This chapter describes the Snowy Monaro region: the location, demographics, history, and current medical services. The target population is briefly introduced. The chapter concludes with a discussion surrounding the challenges faced in recruiting participants to end-of-life research.

Chapter Four introduces the research questions to be answered, and the methodology and methods underpinning the research study. This chapter concludes with a discussion surrounding the ethical issues relevant to the research: the role of the researcher, researcher bias, transparency, imbalance of power, limitations of the study, and research rigour.

Part 3: Results

Chapter Five describes the actual place of death of Snowy Monaro residents, between February 1, 2015 and May 31, 2016. In total, 224 deaths were identified. The chapter begins with a description of the socio-demographics, cause of death, and PoD for all 224 deaths. While the focus of this thesis is the palliative subset, a brief description of

the cause of death and PoD for the non-palliative subgroup (those who died unexpectedly of an acute condition) is provided. This is followed by a description of the data related to the ‘palliative subgroup’ (those residents who died of an advanced chronic condition considered amenable to, but not necessarily receiving, palliative care).

Chapter Six describes the actual and preferred place of death for the 15 patients identified through the interviews, and explores the meaning of, and issues surrounding, place of care and death, as described by the participants (patients, FCGs, HCPs). The chapter begins with a vignette, Gwen’s story, which highlights the issues faced by the participants and the events that necessitated a move away from home. Like most of the participants, home was Gwen’s initial preferred PoD; however, due to changing circumstances, (disease progression, carer unavailability, significant symptoms, loss of mobility, lack of 24-hours, seven-days-a-week professional support at home), home became unsustainable, and her preferences changed. I then explore the actual and preferred PoD for all 15 identified patients. The meaning of home is explored through the experiences and perspectives of the participants. I explore the congruence between actual and preferred PoD, and the congruence between preferences of patients, FCGs and HCPs. While home was the preferred PoD for most, home was not the actual PoD for the majority. Most accepted the change providing the new place was a ‘safe’ place. This chapter argues that PoD is only one element contributing to a ‘good death’ and that a ‘home death’ should not be a gold standard, or a measure of the success, of palliative care.

Chapter Seven presents the findings relating to the participants’ perspectives on the ‘good death’. The chapter begins with Ivan’s story, which illustrates a ‘good’ rural death at home on the farm. However, while dying at home added to the ‘goodness’ of Ivan’s death, it wasn’t the only influence. This chapter explores the difficulty of defining the ‘good death’ as each participant holds a different view. I then explore the factors associated with a ‘good death’, as described by the participants. A ‘safe’ death emerged as the central theme and essential component of a ‘good death.’

Chapter Eight explores the influence of rural residency on the ‘good death’, PoD, and safety. The chapter begins with Marianne’s story, which highlights the factors that can facilitate or hinder a ‘good death’ and dying in one’s preferred PoD. Each patients’

place of residence is described. This is followed by a discussion on how the rural participants viewed themselves, compared to urban residents. I then explore the factors associated with rural residency that impact negatively on the ‘good death’ and PoD (travel distances, lack of local specialist services, local medical expertise, and allied health support, lack of all-hours in-home formal support). Finally, the benefits of rural residency are explored (personalised care, community support, friendships with HCPs, lifestyle and convenience).

Part 4: Discussion and conclusions

Chapter Nine presents the discussion, conclusions and implications of the research presented in this thesis. The findings of this original research are discussed within the context of the existing literature. The limitations of this research study are discussed, followed by my reflections on my role throughout the study. The implications for policy and practice, and further research, are discussed.

PART 2: RESEARCH PREPARATION, METHODOLOGY AND METHODS

Introduction to Part 2: Research preparation, methodology and methods

Part 2 of this thesis contains three chapters. Chapter Two discusses the current rural literature relating to place of death, preferred place of death, the concept of the good death, and end-of-life care from the experiences and perspectives of rural residents. Two systematic and one scoping literature reviews were undertaken, with the findings presented in this chapter. These literature reviews were considered to be research in their own right, therefore the review methods are reported in Chapter Four.

As each rural region is unique, Chapter Three is devoted to describing the setting for this research study, the Snowy Monaro region of New South Wales, Australia.

This was a mixed methods research study, using systematic and scoping literature reviews, ethnography, and a quantitative death data survey. Chapter Four states the research objectives, and discusses each of the methodologies, and methods used to collect, record and analyse the data.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The primary objective of my thesis was to explore the concept of the good death from the experiences and perspectives of rural patients, with a life-limiting illness, and their family caregivers (FCGs), within the rural Snowy Monaro region of NSW, Australia. The literature suggests the ‘good death’ is dependent on context and individual perspectives. Therefore, the secondary objectives were to determine the influence of place of death (PoD), and rural residency on the ‘good death’, and to explore the meaning behind the PoD preferences and decision-making process.

This literature review was iterative, commencing in mid-2014, in the earliest stages of my thesis, and continuing until the thesis was in the final draft. Initially, a broad view of the literature was taken, and while many excellent studies relevant to the ‘good death’, PoD and end-of-life care (EoLC) were identified, most were either urban focused or failed to identify the rural perspective in mixed rural/urban geography studies. It became apparent, that to find the rural perspectives, a more focused and systematic approach to the literature was required. This culminated in the completion and publication of one scoping review: *Rural residents’ perspectives on the rural ‘good death’: a scoping review* (Rainsford et al., 2016); and two systematic literature reviews: (1) *Place of death in rural palliative care: a systematic review* (Rainsford et al., 2016), and (2) *Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic literature review* (Rainsford et al., 2017). The scoping and systematic literature reviews may be considered research in their own-right, yet form a significant part of my overall literature review. Therefore, the methods utilised in conducting these reviews are outlined in Chapter Four (Section 4.2), and the findings are included in this chapter, rather than in Part 3, Results. To avoid duplicating the detailed tables containing the extracted data, only a summary table of the studies identified in each review, including the updates, is included in this chapter (Table 2.1, 2.2, 2.3, and 2.4). A copy of the published papers, including the full data extraction tables, can be found in Appendix 6.

When I commenced this literature review, the most recent identified comprehensive review of rural palliative care was published in 2009 by Robinson et al. An additional rural palliative care systematic review was published by Bakitas et al. in October 2015. Both reviews highlight that most rural research has been focused on rural palliative and health care services (intervention studies, needs assessment, program planning and evaluation, education and finances), and professional attitudes, education and practices. While it is vital that research seeks novel ways to improve the accessibility to, and quality of, palliative care to rural residents, gaps in the rural literature remain. There is a paucity of studies documenting rural patients' and FCGs' experiences; the influence of rural place and culture on patient experiences; understanding PoD in rural settings; and the challenges of recruiting rural and remote participants to studies.

Chapter structure

This literature review begins by describing the discipline of palliative care (Section 2.1) and the concept of the good death (Section 2.2), as these are fundamental to my research topic. The lack of consensus regarding rural definition is acknowledged (Section 2.3) as this contributes to the challenges faced in conducting and comparing rural research. This is followed by a summary of the findings of my scoping (Section 2.4) and systematic (Sections 2.5 and 2.6) literature reviews, and their relevance to my research study. A brief comment is made regarding current Australian rural studies (Section 2.7). This chapter concludes with a summary of the overall literature review findings (Section 2.8).

2.1 Palliative Care

The World Health Organisation defines Palliative Care as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness' (WHO, 2002, p. 84). As such, palliative care addresses physical, psychosocial and spiritual needs, and mandates this approach is the right of every person regardless of where they live:

Palliative care

- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.

- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Enhances quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, 2002, p. 84).

2.1.1 Origins of palliative care

During the Middle-Ages the term '*hospice*', derived from the Latin *hospitium* [hospitality] and *hospes* [guest, stranger or foreigner] (Doyle et al., 1999, p. vi), was used to describe a place of rest for travellers and pilgrims to Europe and the Mediterranean. These hospices were run by religious orders who offered hospitality to travellers, and people who were ill or dying. During the 19th century, the hospice re-emerged in the United Kingdom and France as institutions run by religious orders caring for people who were terminally ill, as well as providing accommodation for the incurable and destitute (Doyle et al., 1999; Palliative Care South Australia, 2016).

The modern day hospice dates from 1967 with the opening of St Christopher's Hospice, London, established by Dame Cicely Saunders (1918 - 2005). With advances in health care and medicine, the focus of care was directed towards those who could be cured. Saunders became deeply concerned about the suffering (physical symptoms including pain, spiritual and psycho-social distress) of those who could not be cured. The term 'palliative' (from French *palliatif*, or medieval Latin *palliativus*, from the verb *palliare* 'to cloak'), used to describe the care provided to the terminally ill, was first used in 1975 by a Canadian Surgeon, Balfour Mount, to avoid the stigma attached to 'hospice' as a

place for the destitute (Palliative Care South Australia, 2016). Today the terms ‘hospice’ and ‘palliative’ are used at times synonymously, and at times differently in various parts of the world. In Australia, ‘hospice’ usually denotes an inpatient facility and ‘palliative’ an approach to comfort-oriented care, aimed at maintaining quality of life.

The term ‘Palliative Medicine’ was adopted in Great Britain in 1987, when palliative medicine was recognised as a sub-speciality of medicine to undertake ‘the study and management of patients with active, progressive and advanced disease for whom the prognosis is limited and focus of care is on quality of life’ (Doyle et al., 1999, p. 3). Traditionally, palliative care has been provided by GPs, and while they are well skilled (Mitchell, 2002), specialist palliative care multi-disciplinary services have been established, mostly in highly urbanised areas, especially for complex cases. In September 1999, the Australasian Chapter of Palliative Medicine was established within the Royal Australasian College of Physicians. The Chapter has the responsibility for providing training and continuing professional development for Palliative Medicine Physicians and Specialists in Australia and New Zealand (Cairns, 2007).

2.1.2 Contemporary palliative care

Palliative care has traditionally been associated with care of those with end-stage incurable cancer. Australia, consistent with all developed countries, is facing a huge increase of an aging population (Productivity Commission, 2013) as the ‘baby boomers’ age, and more people are expected to die from a non-malignant disease. In 2015, ischaemic heart disease was the leading underlying cause of death in Australia, followed by dementia, cerebrovascular disease (including stroke), cancer of the trachea, bronchus and lung, and chronic lower respiratory diseases (ABS, 2015). Internationally, the challenge now for palliative care is to ensure all patients with any life limiting illness (including organ failure, frailty, dementia and cancer), where life expectancy is 12 months or less, have access to quality EoLC (Mitchell et al., 2010; Bausewein, 2017).

Studies suggest that people living in rural and remote areas receive less than optimal care because they have limited access to specialist multidisciplinary palliative care services (Lynch, 2013) and therefore require special consideration. In Australia, there are both national and state palliative care strategies addressing the current challenges, with the aim of achieving 24-hour-seven-day access to specialist palliative care teams

either face-to-face, by telephone or more recently by telehealth (Chi & Demiris, 2015). At a national level, the Australian Government funds a range of national palliative care projects, primarily focusing on education, training, quality improvement and advance care planning. National policies are population based (Palliative Care Australia, 2003) with the goal to reduce the number of patients presenting to emergency departments and dying in hospital. While this may be appropriate in urban settings, where there are the options of inpatient hospice/palliative care and community based specialist teams, some rural studies have suggested that rural community hospitals may be an appropriate place for EoLC (Payne et al., 2004). When available in rural communities, residential aged care facilities (RACFs) are significant providers of EoLC. With the doubling in the Australian population aged over 65 years by 2050 (Australian Government Treasury, 2010), and the predicted increase in dementia and other chronic illnesses, RACFs will become even more significant providers of EoLC (Australian Institute of Health and Welfare [AIHW], 2015).

Each Australian state and territory is responsible for the delivery and management of palliative care within its own jurisdiction. As the study is being conducted in New South Wales (NSW), only this state's plan will be described.

In 2012, the NSW Government committed an additional \$35 million to improve access to community care and support for people requiring EoLC, and their families and carers. The NSW Ministry of Health (2012) developed a plan 'to increase access to palliative care (2012-2016)' aimed at 'honouring people's choices about the end of their lives' by enhancing services, expanding the skills of multidisciplinary teams providing such care, and involving families more directly in the provision of care. In introducing this plan, the then Minister for Health and Minister for Medical Research, Jillian Skinner, stated the outcome aim was for 'more people to have a real choice about being able to die at home in an environment of love and comfort provided by those closest to them' (p. 4).

One of NSW Government funded initiatives is the '*Last-days-of-life home support service*' (NSW Ministry of Health, 2013). In 2013, the HammondCare Consortium, comprising HammondCare, Sacred Heart Health, and Calvary Health Care Sydney, successfully won the tender to provide palliative care home support packages throughout seven Local Health Districts (LHDs) in NSW: Central Coast, Far West,

Murrumbidgee, Northern Sydney, South East Sydney, Southern NSW, and Western NSW. Silver Chain provides services in other areas. These in-home packages can be mobilised quickly and offered on a tailored basis.

The NSW Agency for Clinical Innovation (ACI), a clinician-led organisation, was tasked with developing new models of care, aimed at improving patient outcomes, and building workforce capacity. One of their agendas is to expanded community-based palliative care services, especially in rural areas and for special needs populations, with the aim to increase the rate of home deaths by expanding support for families and carers. In December 2015, '*The Blueprint for Improvement*' was launched (NSW ACI, 2015). This is an online resource to guide service providers and LHDs in constructing their own localised model of care. At the time of completing this literature review, no reports on the outcomes of the initiatives were available; however, it is predicted that with increased support, providing it is tailored to the needs of individuals and communities, rural residents will have genuine choice regarding their EoLC and PoD. The goal is to increase the rate of home deaths, and therefore allow more rural residents achieve a 'good death'.

On the 12th June 2017, the NSW Premier, Treasurer, and Minister for Health announced an additional \$100 million for palliative care services, over the next four years, would be funded in the 2017 - 2018 NSW State budget. This funding will go towards palliative care training for 300 nurses and allied health staff, 300 scholarships for rural and regional staff to enhance palliative care skills, an additional six palliative care specialists in rural and regional areas, and two specialist positions to provide relief to other specialists in rural and regional areas (NSW Government Media Release, 2017).

2.1.3 Advance care planning

With an aging population (with many living with chronic co-morbidities), advances in healthcare technology capable of prolonging life without necessarily improving quality of life, and increasing health care expenditure (NSW Government, 2012) further Government strategies are being developed. Advance care planning (ACP) is one process to help people formulate and communicate their healthcare preferences during future incapacity (Palliative Care Australia, 2008). By documenting choices regarding future treatment, preferred PoC and PoD, families and healthcare professionals can be

assisted in ensuring palliative care is relevant to individual patients. As such, the Australian Government (Australian Health Ministries Advisory Council, 2011) has developed a national framework to support programs that encourage ACP.

2.1.4 The quality of palliative care

In the preface to the 2004 WHO booklet ‘Palliative Care: the solid facts’, Dame Cecily Saunders states:

Palliative care begins from the understanding that every patient has his or her own story, relationships and culture, and is worthy of respect as a unique individual. This respect includes giving the best available medical care and making the advances of recent decades fully available, so that all have the best chance of using their time well (p. 7).

While patients will often ‘fight to survive’ most will do so only if the extension of time maintains dignity, and an acceptable quality of life. However, quality is subjective and based on an individual’s experience, expectations and values. In 1999, Singer et al. suggested five domains to measure the quality of dying (adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving sense of control, relieving burden, strengthening relationships with loved ones). Two years later, Patrick et al. (2001) argued quality death and dying is the congruence between a person’s preferences for dying and the moment of death, and the reality of circumstances, as reported by others. They suggest quality is based on adequate pain and symptom control, and patient autonomy, and developed a 31-item model measuring the quality of death and dying (QODD). This model, the most widely published and validated multi-item measure available (Hales et al., 2010, p. 127), is based on six conceptual domains: symptoms and personal care, preparation for death, moment of death, family, treatment preferences, and whole person concerns (Patrick et al., 2001, p. 717).

While maintaining patient focus, the Australian and New Zealand Society of Palliative Medicine (ANZSPM), an organisation for palliative medicine physicians, specialists, trainees, general practitioners and other medical practitioners with an interest in palliative care, have developed a document for Quality EoLC assessment and planning. They consider five domains of EoLC essential:

1. Symptom management (holistic & multidisciplinary)
2. Advance care planning
3. Carer support
4. Coordination and integration of care
5. Terminal phase (last 7-10 days of life) - timely recognition of the 'dying phase' and developing documented '*Terminal Phase Plans*' to adequately manage patients in their terminal phase and support their families, loved ones & carers (ANZSPM, 2014, pp. 7-8).

The literature suggests one endpoint of quality palliative care is a 'good death'; however, Proulx and Jacelon (2004) suggest that a 'good death' cannot be measured quantitatively. A 'good death' implies there can also be a 'bad death'; however, who decides what is 'good', as one person's death is viewed through so many different lenses - the patient, the family/carer, the doctor, the community/palliative care nurse, the community and everyone else involved (Holdsworth, 2015; Meier et al., 2016). Regardless, the 'good death' is a central palliative/hospice concept and will be explored.

2.2 The 'good death'

2.2.1 Evolution of the concept of the good death

While death is inevitable as we are all "fellow- passengers to the grave" (Dickens, A Christmas Carol; Stave 1: Marley's Ghost), achievement of a 'good death' is one of the objectives, if not the sole aim, of palliative care. Kellehear (2008) argues that the term 'good death' has 'two commonly cited derivatives'. The first is derived from the Greek words *eu thanatos* from where the word 'euthanasia' is derived; *eu* meaning "good" and *thanatos* meaning "death", that is to die well, or to die suddenly and gently, painlessly, and easily. The second Greek derivative, more aligned with the palliative care movement, is *kalos thanatos*, that is to die 'beautifully or in an ideal or exemplary way...not sudden ...but well prepared by the dying person...A dying that conforms to the wider community expectation of making death as positive and meaningful as possible to as many people as possible' (Kellehear, 2008, p. 90).

Philippe Aries, often considered a pioneer in the writing of social history, published a set of lectures in which he reviewed 'Western attitudes toward death from the middle

ages to the present [early 1970s]' (Aries, 1975). Kellehear (2008) and Aries (1975) describe the changes over time in the concept of the good death, and their arguments are summarised in the remainder of this sub-section.

In pre-modern times, while dying was expected at a younger age compared today, the manner and timing of death was often sudden and unpredictable, usually the result of accident, war, infection, or childbirth. Personal awareness of death was brief, as the dying person, for example, bled to death. Kellehear (2008) argues that much of the Stone-Age dying process was considered to take place 'after death', as the deceased passed from one world to the next, and transitioned from one social role to another, for example father to ancestor, or chief to god, as depicted in cave drawings. This after-life otherworld journey, thought to be at the time treacherous, was undertaken alone and without support of family and friends. Inheritance was the grave goods supplied by the survivors, to assist in a safe journey, or to prevent the deceased from returning and tormenting the survivors. Farewells were possibly ambivalent as it was uncertain if the dead would return as a protector or as a 'haunting ghost'. It is difficult to know what was considered a 'good death' in these times; however, it seems the dying person played a minor role, if any role, with Kellehear (2008) suggesting a self-awareness of imminent death, albeit very brief, or the quality of the grave gifts provided by the family and community were the influencing factors.

The concept of the good death is dynamic, having evolved over time in pace with urbanisation and health care technology (Aries, 1975; Kellehear, 2008). Over time, the concept of the good death progressed from having a self-awareness of impending death, to having the ability to self-prepare for death (the 'tamed death' Aries 1975); followed by a 'managed death' (Howarth, 2007), whereby the doctor, priest (or equivalent) and lawyer became important in assisting the dying person to ensure all final tasks (physical, emotional, financial, spiritual and social) were completed. Today, this could include the preparation of an advance care plan and/or directive, or the appointment of a surrogate decision maker (enduring power of attorney) who can make health care or financial decisions on the dying person's behalf if they are unable to voice their own preferences. This allows the dying person to manage their own death in advance. Once only an 'otherworld' experience, death became a 'this world' experience with a shift from the deceased being the beneficiary of grave gifts to the one who bequeathed

inheritance to the survivors. The otherworld journey became more of a moral issue as death became ‘a ritual organized by the dying person himself, who presided over it and knew its protocol’ (Aries, 1975, p. 11). Depending on religious beliefs, the pre-modern Western death required the dying person to have time to brood over the sadness of dying, pardon those close to him, confess his sins to God and ask for absolution. Having lived a good life, provided a suitable inheritance for survivors, taken opportunity to put things right and ensuring one’s world was not left in chaos (Kellehear, 2008, p. 88) helped secure a safe passage for the deceased.

In comparison, according to Kellehear (2008, pp. 92-93), a ‘bad’ death involved a sudden or violent death (including suicide), dying alone or away from homeland, dying young or in childhood, dying without an heir or not having a proper burial. Lack of self-awareness of one’s impending death and the inability to prepare a smooth transition of material wealth to one’s heirs was also considered a ‘bad’ death.

Dying was once a public affair, occurring at home and supported by the community. Over time, dying has become increasingly private and medicalised, hidden away in institutions, the ‘forbidden’ death (Aries, 1975) or ‘death that is seen not to happen’ (Walters, 2004, p. 405), such as in hospitals or nursing homes (Gomes & Higginson, 2008) despite studies indicating home now has again become the preferred place (Gomes et al., 2013).

2.2.2 Contemporary ‘good death’

The contemporary ‘good death’, at least in the developed world, is what Walters (2004) describes as a ‘controlled death’. With medicalisation of dying, advances in medical technologies and the ability to prolong life, without necessarily maintaining quality of life, the ‘good death’ is now one of the main aims of the palliative care/hospice movement. However, some argue the contemporary notion of the ‘good death’ is idealised, ‘limits spontaneity’ (Cottrell & Duggleby, 2016) and puts ‘pressure on a dying person to be a ‘good patient’ (Proulx & Jacelon, 2004, p. 116). While death is a normal end to life (WHO, 2015), one could argue that many deaths are not entirely ‘good’ due to the nature of the illness (Holdsworth, 2015), the age of the dying person (Counts & Counts, 2004; van der Geest, 2004; Huy, 2007; Dilger, 2008) and individual persons’ perspectives. The goal should be to achieve the ‘best possible death given the

circumstances’ (Holdsworth, 2015, p. 839). McNamara (2004) argues the term ‘good death’ be replaced with ‘good enough’ death, due to the frequent disparity between patient, family, and health providers’ points of view. As palliative care becomes ‘individualised and eclectic’ (ibid, p. 929), consensus regarding the ‘goodness’ of a death is not always possible. Today, most people expect to ‘die very much in the same way they have lived’ (ibid, p. 930), thus satisfying realistic expectations of the dying person (Raisio et al., 2015).

The move towards autonomy and control, particularly in Western medicine, has created tension between stakeholders who often hold different priorities and expectations towards end-of-life care (Holdsworth, 2015). A study by Steinhauser et al. (2000) reported consistent high ranking of pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, and being treated as a ‘whole person’ across all stakeholders (patients, families, and care providers including clergy and volunteers). However, this same study reported considerable variation between stakeholders in regards to place of death, being mentally aware, not being a burden, having funeral arrangements in place, and coming to peace with God. While EoLC must reflect the needs of the dying person and their carers, ideally it must also reflect the needs of the community (Cottrell & Duggleby, 2016). In 1996, Kearl argued that death becomes ‘good’ when it also serve the needs of survivors – the family and the wider community. While there are strong similarities between countries in regards the ‘good death’, in developing countries ‘poverty shaped how people died’ (Grant et al., 2011, p. 5) and beliefs and rituals surrounding dying remain a mix of tradition and contemporary.

2.3 Challenges in defining rural

As the focus of my research study is to explore the concept of the good death within one rural context, it is important to find the voice of rural patients and FCGs (Bakitas et al., 2015). To ensure palliative care services are ‘embraced by community members’ (ibid, p. 462), and ‘to remain socially relevant, end-of-life care ideally must reflect the needs of the dying individual.... within diverse cultural and geographic areas’ (Cottrell & Duggleby, 2016, p. 26). Studies consistently report that rural folk perceive themselves as different to urban residents and clearly hold distinct views on what it means to die

well (Wilson et al., 2009a, 2009b; C Robinson et al., 2010; Spice et al., 2012). Gessert et al. (2015) reported independence, stoicism, and fatalism to be common traits found in rural residents. Compared to urban residents, there is sometimes greater pressure placed on residents living in small communities, to conform to social expectations and norms.

However, rural researchers are challenged in their search for commonalities. Firstly, despite an increase in rural palliative care research, including in Australia (C Robinson et al., 2009), studies remain limited. Secondly, and possibly more importantly, there is no universal rurality index or international consensus on rural definition. With a lack of homogeneity of health services and cultural context, it is difficult to compare results, not only between countries, but also within countries. This challenge is greater when comparing studies from developed and developing countries where priorities vary significantly.

The definition of rurality 'is a multifaceted concept ... and frequently relies on stereotypes and personal experiences' (Hart et al., 2005, p. 1149). Definitions have been based on population size, population density or demographics; distance from urban centres and services; or defined as a specific 'culture' (ibid 2005). For example, since the early 1990s four different geographic classifications have been developed in Australia (AIHW, 2004): Rural, Remote and Metropolitan Areas (RRMA) classification, Accessibility/Remoteness Index of Australia (ARIA), Australian Standard Geographical Classification (ASGC), and Modified Monash Model (MMM). The rural town of Cooma, (population 6742 [August 2016], 115 kms from the nearest major urban area) provides an example of conflicting rural definitions. Depending on which classification is applied, Cooma is considered 'rural' based on population size (RRMA) or 'inner regional' based on the road distance to accessible services (ASGC). The classification has significant implications on funding, service provision and financial incentives to attract general practitioners to areas of need. In the rural studies identified in my PoD systematic review, rural populations ranged from <1000 (Burge, 2005; Papke & Koch, 2007); to <9999 (Goodridge et al., 2010b); with rural towns ranging from 2000 (Escobar Pinzon, 2011) to <28,000 (Herd, 1990). Rural areas typically have fewer health and social services as compared to urban areas (Downing & Jack, 2012) with some included studies described as having access to large county

hospitals (Axelsson & Christensen, 1996), inpatient hospices and residential aged care, while others had limited medical facilities (Yasumura et al., 2000).

Notwithstanding the limitations in the current rural literature, rural people believe they have some unique perspectives on and concerns about dying, end-of-life care and the ‘good death’. While it could be argued that the concerns raised by rural participants are not dissimilar to urban dwellers (desire for autonomy and good quality EoLC), a narrative review of eight studies by Kirby et al. (2016, p. 1) described rural residents as ‘more accepting of death and less likely to intervene to delay death’ and concluded that the ‘palliative needs of rural and remote residents are related to context ...and are shaped by reduced access and availability of services’. This is supported by the findings of my systematic literature review, which identified substantial differences in the provision of care due to distances and the reality that sometimes people must move away from their community to receive the care required.

Rural people have a deep concern for their community and its members (Kirby et al., 2016). Strong relationships and informal community services are important factors that facilitate care within rural communities. Pesut et al. (2010, p. 190) reported in their study that:

Participants spoke eloquently of the benefits of their rural lifestyle including physical beauty, privacy, and accessibility of recreational activities. The level of support provided by community members was an important factor in why individuals valued rural life.

It is this value of rural life that contributes to the quality of EoLC, as death and dying is an individualised experience with cultural, religious and political values and beliefs influencing the quality of dying (Cottrell & Duggleby, 2016). Facilitators and barriers to receiving EoLC in rural/remote settings, and the influence of rural place and culture on EoLC experiences were two objectives of my scoping review.

2.4 Rural residents' perspectives on the rural 'good death': a scoping review

As discussed previously, many of the viewpoints and research findings on the 'good death' reflect the urban voice (Robinson et al., 2009; Bakitas et al., 2015); however, rural folk perceive themselves as different to urban residents (Wilson et al., 2009a, 2009b). A scoping literature review was undertaken exploring rural residents' perspectives. The methods are described in Chapter Four (Section 4.2.1). The literature search, conducted from 2nd January 2016 to 28th February 2017, identified 20 papers, reporting on 17 studies and one systematic review (Table 2.1). A copy of the published paper, including tables containing the data extracted from the initial identified studies can be found in Appendix 6. A summary of the findings is included in this section of my literature review.

The included articles were published between 2000 and 2015, with data collected between 1981 and 2013. Rural perspectives were reported in articles from both developed and developing countries. While all studies were described as rural, there was no standardised definition of rurality. Locations were heterogeneous. All the eligible studies were qualitative in nature, using focus groups, interviews, written surveys, clinical encounters and community observations. The exact number of participants is unknown as two anthropological studies included whole communities (Counts & Counts, 2004; Easom et al., 2006). Of the 751 identified rural participants, 84 were rural patients, 68 rural FCGs, 323 rural HCPs, 153 rural residents, 83 rural community leaders and 40 rural health administrators and policy makers. Of the identified informants 20% were patients or FCGs and of these 76% were African. HIV/AIDS (considered a stigmatised disease) or cancer accounted for most terminal illnesses in Africa. Of the 19 patients in developed nations, 17 had cancer, one dementia and one cerebral vascular disease.

The concept of the good death was widely acknowledged in both developed and developing countries, and referred to the death event, the dying process, the meaning of death or the after-death concept. The identified studies illustrated that the 'good death' is subjective, with priorities based on personal, cultural, social and religious perspectives. However, despite the diversity, common themes were identified. The

themes surrounding the contemporary rural ‘good death’ included being pain free, maintaining dignity and autonomy in decision making, having support of family, and providing opportunity for the dying person to “sort out” personal affairs (Raisio et al., 2015; Davies et al., 2016; Meier et al., 2016).

Table 2.1: Studies included in rural 'good death' literature review

First Author	Publication Date	Country	Method	Diagnosis	Informants	Quality
Arnaert	2009	Canada	Interviews (ITV), focus groups (FGD)	-	5 Homecare nurses	Medium
Beckstrand	2012, 2015	USA	Written survey	-	236 Nurses	Medium
Biggs	2014	Canada	Semi-structured ITV	Dying	10 Dying Patients, 8 FCGs	High
Counts	2004	Papua & New Guinea	Field work; Observations	-	Community	Low
Cruickshank	2010	Scotland	Patient- ITV; FCG- Bereavement nurse- FGD	-	4 Patients, 8 FCGs, 12 nurses	Medium
Devik	2013	Norway	Narrative ITV	Cancer	5 Cancer patients	Medium
Dilger	2008	Tanzania	Field work	HIV/AIDS	HIV patients	Low
Easom	2006	USA	Mixed: Written survey; ITV	-	9 Nurses	Low
Felt	2000	USA	FGD	-	Community	Medium
Grant	2003	Kenya	Semi-structured ITV	Cancer, HIV	32 Patients (cancer, AIDS), 24 carers	High
Grant	2011	Uganda, Kenya, Malawi	ITV	-	33 Patients, 27 FCGs, 36 HCP, 25 volunteers, 29 leaders (community)	Medium
Gysels	2011	Africa	Systematic review	-	-	-
Huy	2007	Vietnam	FGD	-	Farmers	Low
Joarder	2014	Bangladesh	ITV	Elderly	8 Elderly villagers	Medium
Knight	2014	England	ITV	-	4 Clergy	Medium
Van der Geest	2004	Ghana	Fieldwork observation, ITV, FGD.	-	Farmers	Medium
Veillette	2010	Canada	ITV, FGD	-	Community	High
Wilson	2009a, 2009b	Canada	ITV, FGD.	-	Community, HCP, policy makers	High

Abbreviations: ITV: interviews; FGD: focus group discussions; FCG: family caregiver; HCP: healthcare professionals; (-) details not provided; informant number reported when provided.

Consistent with the WHO mandate (2002, p. 84), and urban studies (Holdsworth, 2015; Raisio et al., 2015; Davies et al., 2016; Meier et al., 2016), rural residents identified five dimensions considered important for facilitating a ‘good death’ – physical, emotional, social, spiritual, and cultural. The dominant theme, from both developed and developing countries was that a rural ‘good death’ is one that is peaceful, free of pain and without suffering. The themes describing the rural ‘good death’ parallel the urban view, and include a ‘controlled’ death, with control over symptoms, place of death, decision making, manner of death, and independence (Felt et al., 2000; Counts & Counts, 2004; Dilger, 2008; Wilson et al., 2009a, 2009b; Veillette et al., 2010; Knight, 2014); a ‘timely’ death (Counts & Counts, 2004), that is a death coming ‘naturally and after a long and well- spent life’ (van der Geest, 2004, p. 899) and ‘hopefully in my sleep’ (Felt et al., 2000, p.405) after having had opportunity to say goodbye to family; a ‘dignified’ death by maintaining identity, self-worth, integrity and control (Wilson et al., 2009a; Devik et al., 2013); a ‘social’ death, such as to die within the community with family present (Wilson et al., 2009a, 2009b); and a ‘noble’ death such as through enduring the situation (Grant et al., 2003; Devik et al., 2013). Two articles (van der Geest, 2004; Knight, 2014) acknowledged the difficulty of defining a ‘good death’, as it is dependent on individual interpretations, perspectives and priorities.

Place of death was considered in terms of geographical location (community), and physical space (home, hospital, residential aged care). The strong connection to one’s rural/remote community meant dying within one’s rural locality was identified as a critical element in achieving a ‘good death’. While the literature reports that PoD, in terms of physical space, is one measure of a contemporary ‘good death’, a number of authors suggest that place is only one factor, and a ‘home’ death is not universally or necessarily the most important determinant of a ‘good death’ (Biggs, 2015; Hoare et al., 2015; Davies et al., 2016). If it is not possible to die at home surrounded by family, then it is important to die within the rural community (Wilson et al., 2009a, 2009b; Veillette et al., 2010; Biggs, 2015) as ‘the good rural death is an outcome of rural community values’ where ‘some would prefer to have less care and fewer services’ (Veillette et al., 2010, p. 163) than leave their community.

While 20 papers were reviewed, due to heterogeneity across locations, cultures, participants and research studies' objectives, there is currently insufficient data to generalise rural residents' perspectives and what it means for them to 'die well'.

2.5. Place of death in rural palliative care: a systematic review.

In 2004, the World Health Organisation (WHO, 2004, p. 17) released a report stating that meeting individual preferences for place of care and death should be the ultimate measure of the success of the palliative care provided. In doing so, the WHO urged policy makers to encourage health services to inquire of people their preference for, and monitor the wishes of seriously ill people concerning place of care and death, and routinely monitor PoD as one interim measure of success. The inference being that congruence between preferred and actual PoD is a fundamental component of the 'good death'.

Cross-national studies in developed countries (Cohen et al., 2010) report most people, including Australians, (Howat et al., 2007; Swerrisen & Duckett, 2014) die in hospital. In 2013, Gomes et al. published a systematic review reporting that home was the preferred place of care and death for 31-87% of patients, 25-64% of carers and 49-70% of the general public; median percentage 54% (Broad et al., 2013). Some studies report a shift in deaths away from hospital (Wilson et al., 2009c) towards home (Burge et al., 2003) and care homes (Houttekier et al., 2011), while others report the opposite (Mystakidou et al., 2009; Tang et al., 2009; Yamagishi et al., 2012) with a prediction that by 2030 home deaths in the UK will have decreased by 42% and institutionalised deaths increased by 20% (Gomes & Higginson, 2008).

As my research study is rural focused, it is important to determine if preferred and actual place of care/death are different for rural residents. Healthcare resources, including palliative care, are less available in rural areas, with reports indicating rural residents are less likely to die at home than urban residents. This could imply that rural residents are also less likely to have a 'good death.' However, rural residents' preferences for PoD are not clearly reported. A systematic review was undertaken to review the rural data. The methods used for this review are described in Chapter Four (Section 4.2.2.1). A copy of the published paper, including the original data extraction

tables, can be found in Appendix 6. A literature search, conducted from 1st September 2014 to 28th February 2017, identified 44 papers, reporting on 39 separate studies. All studies were included in this review, irrespective of their quality (Table 2.2, Table 2.3).

The rural studies were heterogeneous in terms of rural definition and participants, with wide variations reported in rural home death rates. Overall, home death rates ranged from 12% in Sweden (Axelsson & Christensen, 1996) to 81.7% in Taiwan (Lin & Lin, 2007), with cancer patients having the greatest chance of dying at home (Costantini et al., 2000; Lin & Lin, 2007). Three Australian rural studies reported home death rates of 18.1% (Burns et al., 2015), 19% (Howat et al., 2007), and 26.7% (Crawford, 2000). Except for two UK studies (McCall & Rice, 2005; Thomas et al., 2003, 2004), more than 50% of rural participants expressed a preference for dying at home. Home was the preferred place for 25% of participants (cancer patients) in the two UK studies; however, Thomas, Morris and Gatrell (2003) reported an additional 33% of participants selected 'home or hospice' as their preferred place, an option not available in other studies. Consistent with urban dwellers, rural residents wanted to die at home, surrounded by family and friends (Veillette et al., 2010) and in the case of Indigenous Australians, connected to their land and family (McGrath, 2007); however, most deaths occurred away from home. While hospital was the commonest PoD in some studies, (New Zealand 21.5% (Smyth et al., 2010); Canada 76.2% (Burge, 2005; Burge et al., 2003), a study in rural South West Scotland (Black et al., 2016) reported PoD was significantly dependent on cause of death. In Black's study, between 2000 and 2010 there was a decline in home deaths and an increase in the number of deaths occurring in institutions; however, most cancer deaths occurred in the specialist palliative inpatient unit within acute hospitals. Increasing age was a strong negative predictor for a home death, with RACFs the commonest place of death for patients with dementia.

Table 2.2: Studies included in actual place of death literature review

First Author	Publication Date	Country	Informant	Diagnosis	PoD	Home death	Quality
Aabom	2005	Denmark	Death certificates	Cancer	Home vs institution	29%	Medium
Axelsson	1996	Sweden	Death certificates	Cancer	Home, hospital, RACF	12%	High
Black	2016	Scotland	National mortality register.	Palliative	Acute hospital, cottage hospital, RACF, home.	All deaths: 25% Cancer 27.8% Dementia 9.5% Respiratory 17.6% IHD 43.7%	Medium
Burge	2003; 2005	Canada	Death certificates	Cancer	Hospital vs out-of-hospital	23.8%	High
Burns	2015	Australia	Bereaved relative ITV	Terminal illness	Hospital, home, hospice, RACF	18.1%	High
Carroll	1998	Scotland	Single practice medical records	Cancer	Home, community hospital, residential home, hospital or hospice	30%	Low
Castillo-Guzman	2013	Mexico	National records	Cancer	Home, hospital, other	69.4%	Medium
Catalan-Fernandez	1991	Spain	Relative face-to-face Q	Cancer	Home or hospital	65.9%	Medium
Cohen/ Houttekier	2008/ 2010	Belgium, Netherlands, England	Death certificates	Cancer	Home vs outside home	Belgium 28.2%, Netherlands 39.1%, England 20.7%	High
Constantini	2000	Italy	Regional mortality register	Cancer	Home or hospital (incl. RACF)	53.4%	High
Crawford	2000	Australia	Death certificates	Cancer	Home or hospital	26.7%	Medium
Escobar Pinzon	2011a 2011b	Germany	Relative; written survey	All	Home, hospital, palliative care facility, aged care home, elsewhere	43%	Medium
Gatrell	2003	England	Mortality data	Cancer	Home, hospital, hospice, elsewhere, NH/retirement home	aOR 1.334 95% CI 1.139-1.562 Urban home=1	High
Goodridge	2010b	Canada	Service files	COPD or lung cancer	Home, hospital, aged care	15.4%	Medium
Herd	1990	England	FCG ITV	Cancer	Home, hospital	53%	High

Table 2.2 continued

First Author	Publication Date	Country	Informant	Diagnosis	PoD	Home death	Quality
Higginson	2017	England	Death records	COPD	Hospital, home, hospice (inpatient), nursing home, care home/residential home, elsewhere.	Rural hospital COPD: OR 0.93; 95% CI 0.92-0.94 Urban hospital =1	Medium
Howat	2007	Australia	PC service records	Palliative care	Home, hospital, RACF	19%	Medium
Hunt	2001	Australia	Cancer registry	Cancer	Hospital, hospice, Home, NH	aOR 3.5 (95% CI 3.03-4.04) urban home=1	High
Jayaraman	2013	Canada	Death certificates	All	Home, extended care facility, hospital or other.	20.2%	High
Lavergne	2015	Canada	Linked health and census data	Palliative	In, or out, of hospital. RACF excluded	26.6% out-of-hospital	Medium
Lazenby	2010; 2012	Botswana	Death certificates	All	Home or hospital	38.3%	Medium
Lin	2007	Taiwan	Death certificates	cancer	Home or hospital	U6:78.4% U7:81.7%	High
Lopez-Campos	2013	Spain	Death certificates	COPD	Home, hospital, hospice, other	aOR 2.8 (95% CI 2.46-3.16) urban home =1	Medium
McNamara	2007	Australia	Death certificates	Palliative	UPoR, hospital, RACF, hospice. Other	Rural aOR=0.74 (95% CI 0.61-0.91); Remote aOR=1.03 (95% CI 0.75-1.41) City UPoR=1	Medium
Papke	2007	Germany	Death certificates	Cancer	Home, hospital, RACF	Small town: aOR 1.54 (95% CI 1.29-1.82) Large town home=1	Medium
Smyth	2010	NZ	GP postal survey	Palliative care	Home, hospital, hospice, RACF	46.2%	Low
Thomas	2003	England	FCG/HCP bereavement ITV	Cancer	home, hospital, hospice, elsewhere	25% (n=8)	Medium
Yasumura	2000	Japan	FCG ITV	Palliative	Home, hospital	47.7%	High

Table 2.3: Studies included in preferred place of death literature review

First Author	Date	Country	Method	Diagnosis	Informant	Study	Home PPD	Quality
Carroll	1998	Scotland	ITV/ Medical notes audit	Cancer	GP	Retrospective	PPoD:77% (audit)	Medium
Champion	2015	Australia	Case note review	Palliative	Notes	Retrospective	100%	Low
Choi	2005	South Korea	Survey	Cancer	Patients/ FCG	Prospective	Patient 47%; FCG 51%	Medium
Foreman	2006	Australia	State Survey	-	Population	Prospective	71.1%	Medium
Fukui	2011	Japan	National survey	-	Population	Prospective	51% (PoC)	Medium
Gu	2014	China	FTF survey	Cancer	Patients/ FCG	Prospective	60.4%	Medium
Howell	2011	Canada	FTF ITV	Advanced disease	Patients	Prospective	80%	High
McCall	2005	Scotland	FTF ITV	Cancer	Patients	Prospective	25% (PoC)	High
McGrath	2007	Australia	FTF ITV	Palliative	Patients, FCG, HCP	Prospective	-	Medium
Shih	2015	Taiwan	Postal Q	-	Population	Prospective	79%	Medium
Thomas	2003, 2004	England	FTF ITV	Cancer	Patients	Prospective	25%; home or hospice 33%	High
Veillette	2010	Canada	ITV, FG	-	Community	Prospective, retrospective	-	High
Wilson	2013	Canada	Telephone survey	-	General public	Prospective	74.9%	Medium

Abbreviations for Table 2.2 and Table 2.3: PPD: preferred place of death; GP: general practitioner; FCG: family caregiver; HCP: healthcare professional; PoC: place of care; ITV: interview; FTF: face-to-face; Q: questionnaire; FG: focus group; (-): item not reported.

RACE: residential aged care facility; IHD: ischaemic heart disease; COPD: chronic obstructive pulmonary disease; UPoR: usual place of residence; OR: odds ratio

Compared to urban residents, there were inconsistent experiences between rural locations. Rural residents in South Australia had a greater chance of dying at home [aOR 3.5; 95% CI 3.03, 4.04] (Hunt et al., 2001) than urban residents. Likewise, in a study by Higginson et al. (2017), rural patients with end stage COPD were less likely to die in hospital than patients residing in urban locations (OR 0.93, 95% CI 0.92, 0.94). However, a Canadian study by Lavergne et al. (2015) reported no significant difference in the odds of dying in hospital for urban and rural residents.

The qualitative studies provided meaning to the actual PoD. Deciding on PoD was found to be a complex process, in which wishes and preferences were not necessarily the same. While wishing to remain home, the participants in the study by McCall and Rice (2005) accepted a home death may not be possible, due to ‘concern about their carer and not wanting to become a burden’ (p. 543). For these patients, hospital became their preference, and possibly a substitute for inpatient hospice care.

Factors influencing PoC/PoD in rural settings were not clearly identified in the included studies, but when reported, include patients’ functional status and clinical condition, carer and social networks, and health-system facilities. The uniqueness of individual rural communities was evident. Locations with stronger traditional cultures and values exhibited the highest numbers of home deaths, or the strongest preferences for home deaths; however, these locations often had less access to hospitals, hospices and RACFs.

As previously stated, the congruence between preferred and actual PoC and PoD has been mooted as a quality outcome for palliative care (Patrick et al., 2001), with health policies aimed at enabling people to die in their preferred place (Dept. Health [UK], 2008; NSW Ministry of Health, 2012; Hoare, 2015). Based on the current literature, the assumption is that for most people, the preferred PoC and PoD is home, being in ‘familiar surroundings in the company of close family and/or friends’ (Dept. Health [UK], 2008, p. 9). With only two studies reporting the actual and preferred place of death, there is insufficient data to draw any conclusions as to the degree of congruence within rural settings.

One limitation of most studies included in the systematic review, was that they were either population surveys reporting hypothetical preferences of healthy people, or retrospective bereavement interviews/questionnaires of families and carers. Few studies collected preferences directly from patients, explored the impact of incongruence in preferred and actual PoC/PoD on patients and FCGs, or addressed the reliability of the retrospective informants. A non-rural study by Agar et al. (2008), suggests PoC is not a ‘euphemism’ for PoD. McCall and Rice (2005) reported that their rural patients changed their preferences as illness progressed. A recent non-rural study by Hoare et al. (2015) suggests that it is not possible to state accurately what proportion of cancer patients prefer to die at home due to the extent of missing data, as studies have frequently omitted to report preferences from those people with no preference or who have not been asked. Other non-rural studies report PoD is not necessarily a dominant concern of the dying person (Steinhauser et al., 2000) and a hospital death is not necessarily a ‘bad’ death (Gott et al., 2004). Meanwhile, Menec et al. (2010) suggest rural residents are disadvantaged by the lack of inpatient facilities, and that rural hospitals act as a substitute for inpatient hospice.

Due to the limitations of the current rural studies, it remains unclear if the ‘push’ to increase the rate of home deaths in rural settings is justified, or even if it is appropriate to use achievement of preferred PoD as a measure of the quality of palliative care, and the ‘good death’. While Seal et al. (2014) reported some FCGs experienced adverse effects when their family member was unable to die at home, in their preferred place, a recent Japanese family bereavement study (Miyajima et al., 2014) reported that failing to die in a patient’s favoured place was not a contributing factor in complicated family grief. This Japanese study suggested that having come to terms with life’s unanswerable questions, being surrounded by family and community, and quality bereavement support were more appropriate outcome measures. Providing a person’s universal need for security, significance and self-worth are met at the end of life, then being in relationship and surrounded by significant people may be more important than the PoD. Robinson et al. (2010) suggest that a death at home is not necessarily the most appropriate or desirable place in rural settings, due to often limited palliative care resources, especially after-hours. Current studies are reporting on the significant, and often overlooked, burden and cost (financial, physical, and emotional) to FCGs caring for a family member at home (Gott et al., 2015). Despite informal support of rural

communities, travel distances and limited resources often increase the burden and cost to rural FCGs. Patients may only be able to die well, and have a ‘good death’ if they leave their home or farm to die in the rural hospital.

While achieving one’s preferred PoC and PoD may appear to be an easy outcome to measure, an easy box to tick on data collection, it would be helpful to explore the meaning behind, and the significance placed on the decisions made by patients, and the experiences and perspectives of rural patients and FCGs in end-of-life care.

2.6 Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic literature review

The second systematic literature review aimed to describe the EoLC experiences of rural patients and FCGs; to identify facilitators and barriers to achieving a ‘good death’ in rural/remote settings; and to describe the influence of rural place and culture on EoLC experiences. The methods for this systematic review are described in Chapter 4 (Section 4.2.2.2). The literature search, conducted from 2nd January 2016 to 28th February 2017, identified 32 articles, reporting on 26 separate studies from both developed and developing countries, and one systematic review (Kirby et al., 2016). A copy of the published paper, including the original data extraction tables, can be found in Appendix 6. A summary of the findings, including a summary table of the studies identified in the original and updated literature searches (Table 2.4), is provided in this section of the chapter.

Consistent with my two previous literature reviews, heterogeneity between studies was demonstrated in rural definitions, settings and degree of isolation. Three studies (Lockie et al., 2010; Johnston et al., 2012; Dembinsky, 2014) included remote locations. Twenty studies were qualitative; four quantitative; two mixed methods; and one was a systematic review (Kirby et al., 2016). Participants included patients with cancer and non-cancer diagnoses. FCGs were either actively caring for a family member or bereaved.

Table 2.4 Studies included in rural perspectives on end-of-life care literature review.

Author	Year	Country	Method	Diagnosis	Informant	Quality
Brazil et al.	2013, 2014	Canada	Telephone survey	Palliative Care	FCG- active (44) and bereaved (26)	High
Dale & Johnston	2011	Scotland	Semi-structured ITVs	Lung cancer	Patients (6)	High
Darer et al.	2015	USA	Written survey	Palliative Care	NOK- bereaved (672)	Medium
Dekker et al.	2012	South Africa	Questionnaires, and ITVs	HIV, TB, cancer, RF, pneumonia	Patients (45); HCP (20)	Low
Dembinsky	2014	Australia (Indigenous)	Medical Anthropology- informal ITVs, ethnography	Breast ca	Patients (10), FCGs (4), non-carer family (6), HCPs (5)	High
Devik/Wiik	2013/2011	Norway	Phenomenology, narrative ITVs	Cancer	Older patients (71-79years; n=5)	High
Devik et al.	2015	Norway	Phenomenology, narrative ITVs	Cancer	Older patients (71-92years; n=9)	High
Devik et al.	2016	Norway	Semi-structured ITVs	Cancer	FCGs (bereaved; n=10)	Medium
Duggleby et al.	2010, 2011	Canada	Grounded theory; Open-ended ITVs	Cancer	Patients (6); FCGs (bereaved; n=10)	High
Duggleby et al.	2014	Canada	Written survey	Cancer	FCG (active; n=122)	Medium
Grant et al.	2011	Uganda, Kenya, Malawi	Photographic ethnography, ITVs, direct observation	Advanced illness	Patients (33), FCGs (active [17] & bereaved [10]), leaders (29), staff (61).	Medium
Hansen et al.	2011	USA	Semi-structured ITVs	Cancer, chronic illness	FCGs (bereaved; n=23)	High
Hatcher et al.	2014	Australia	2 serial semi-structured ITVs	Cancer	FCG (active; n=6)	Medium
Herce et al.	2014	Malawi	Structured and open-ended ITVs	Kaposi sarcoma, HIV, cancer	Patients (36) FCGs (active; n=11) Included 9 dyads.	Medium
Howell et al.	2011	Canada	Longitudinal; validated assessment tools	Advanced disease.	Patients (95)	Low
Johnston et al.	2012	Scotland	Serial ITVs	Cancer	Patients and their FCGs(n=20)	Medium
Kelly et al.	2009	Canada	Phenomenology, ITVs	Not specified	FCG (Aboriginal), bereaved (10)	Medium
Kirby et al.	2016	Multinational	Systematic review	Cancer and non-cancer	8 studies	Medium

Table 2.4 continued

Author	Year	Country	Method	Diagnosis	Informant	Quality
Lockie/Pesut	2010/2010	Canada	Semi-structured ITVs; written questionnaire	Cancer	Patients and FCGs (n=15)	High
Mixer et al	2014	USA	Semi-structured ITVs	Life limiting illness	Patients and/or FCG (active or bereaved) n=11	Medium
Ostertag & Foreman	2008	USA	FGD	>50% cancer or HF	FCG (bereaved, n=19), HCP (53), volunteers (9)	Medium
Payne et al.	2007	UK	Semi-structured ITVs	Cancer or advanced disease	Patients ≥65years (18) and FCGs (11)	High
Pesut et al.	2011, 2014	Canada	Ethnography, ITVs, observation	Not specified	Rural residents (95) included FCGs (25)	High
Reece et al.	2014	USA	ITVs	Terminal illness	Patient (1), FCG (10), hospice care givers (9)	Low
Revier et al.	2012	USA	Phenomenology; 2 interviews	Not specified	FCG (6)	Medium
Tamannai et al.	2015	Cameroon	Semi-structured ITVs	Paediatric Burkett's lymphoma	Patients (3); FCG (7)	High
Williams et al.	2013	Canada	Participant daily journal; narrative enquiry	Cancer	FCG (active), n=23	Medium

Abbreviations: ITV- interview; FGD-focus group discussion; FCG-family caregiver; HCP-health care professional; HF-heart failure; TB-tuberculosis; RF-renal failure

2.6.1 Patients' experiences and perspectives.

Rural patients identified several important features associated with maintaining quality at EoL, and emphasised the importance of not giving up (Dale & Johnston, 2011; Devik et al., 2013; Devik et al., 2015; Wiik, 2011); finding meaning in life (Devik et al., 2015), while living life (Dale & Johnston, 2011); and maintaining dignity (Dale & Johnston, 2011; Devik et al., 2013; Grant et al., 2011; Johnston et al., 2012), independence (Dale & Johnston, 2011; Devik et al., 2013; Devik et al., 2015; Duggleby et al., 2010, 2011, 2014; Johnston et al., 2012) and normality (Dale & Johnston, 2011; Devik et al., 2013; Johnston et al., 2012). This required most patients to redefine 'normal' (Dale & Johnston, 2011; Devik et al., 2013; Duggleby et al., 2010; Johnston et al., 2012; Wiik, 2011), come to terms with change (Devik et al., 2015; Duggleby et al., 2010; Johnston et al., 2012), [often with resignation (Dale & Johnston, 2011) or struggle (Devik et al., 2013)], while making the most of every day (Dale & Johnston, 2011). Patients described how they lived with exhaustion and stress (Devik et al., 2013; Duggleby et al., 2010, 2011; Wiik, 2011) often while balancing hope and despair (Devik et al., 2013). While a patient's deteriorating physical condition increased their dependency on others, most continued to fiercely defend their independence (Duggleby et al., 2011; Johnston et al., 2012) for as long as was possible. Some patients talked openly about impending death, while holding onto hopes and dreams for the future (Devik et al., 2013; Johnston et al., 2012; Wiik, 2011); while others described enduring life bravely, despite being too exhausted to enjoy life (Devik et al., 2013; Wiik, 2011).

2.6.1.1 Maintaining dignity

Patients maintain dignity by refusing to be defined by their illness (Dale & Johnston, 2011; Devik et al., 2013; Duggleby et al., 2010, 2011; Johnston et al., 2012) and searching for hope (Devik et al., 2013, 2015; Duggleby et al., 2010; Grant et al., 2011; Johnston et al., 2012) as 'hope is the key to enduring distress' (Devik et al., 2013, p. 785). Many patients were reluctant to ask for help, as they were afraid of becoming a burden (Dale & Johnston, 2011; Devik et al., 2013; Duggleby et al., 2010, 2011; Johnston et al., 2012) and/or losing independence (Devik et al., 2013; Duggleby et al., 2011). One Norwegian patient found hope in pursuing life-prolonging chemotherapy despite losing dignity through side-effects (Devik et al., 2013), while others refused chemotherapy to maintain their quality of life (Johnston et al., 2012). None of the participants spoke directly of euthanasia.

2.6.1.2 Preparing for death

Preparing for death, such as funeral planning, ‘without loss of hope or the desire to keep living’ was important for some patients. (Johnston et al., 2012, p. 1622). Some patients found comfort in preparing themselves and their families for impending separation (Dale & Johnston, 2011). This was achieved through activities such as funeral planning and completion of wills.

2.6.1.3 Pain control

Most participating dying people and families feared pain. In sub-Saharan Africa, pain dominated the lives of patients (Grant et al., 2011; Herce et al., 2014). In one Malawi study, 86% of participants reported pain to be moderate to severe (Herce et al., 2014). Inadequate pain control was reported in four studies from developed countries (Devik et al., 2015; Johnston et al., 2012; Pesut et al., 2010; Wiik, 2011). Participating patients described pain management as important (Devik et al., 2015) and essential for self-care (Johnston et al., 2012). Anticipating medication requirements, when commuting long distances, was an important consideration for some patients (Pesut et al., 2010; Lockie et al., 2010).

2.6.1.4 Formal and informal support

Support of family, friends, community (Duggleby et al., 2011; Herce et al., 2014) and HCPs (Duggleby et al., 2010) was considered essential, and valued. Despite this support and connection, the message from two studies was that patients felt isolated as their disease progressed, ‘I’m part of the community but I feel alone’ (Duggleby et al., 2011, p.2) and having to ‘walk the palliative path alone’ (Wiik, 2011, p. 12).

2.6.2 Family caregivers’ experiences and perspectives

To obtain a broad view of rural EoLC it was important to hear the voice of the rural FCGs, and to explore not just the common views, but to also determine the degree of congruence between perspectives. Family caregivers often felt responsible for ensuring the dignity and comfort of their loved ones during their final days, and spoke of their distress, guilt and anger when circumstances prevented them fulfilling this role (Revier et al., 2012). While rural FCGs took on the responsibility of providing direct care, many also took on the role of managing and coordinating care, while being an advocate for

their family member (Pesut et al., 2014); however, ‘few [were] physically, emotionally, or educationally prepared for the tasks and responsibilities of caregiving’ (Revier et al., 2012, p. 5), especially as the illness progressed (Duggleby et al., 2011).

FCGs experienced a broad spectrum of negative emotions (Williams et al., 2013). If FCGs could find meaning in the situation, by focusing hope on the day-to-day moments (Revier et al., 2012), redefining normal (Duggleby et al., 2010; Williams et al., 2013), connecting and separating (Revier et al., 2012), they were better positioned to cope with the responsibilities, burden of care and transitions in roles (Duggleby et al., 2010). Self-care and maintaining their own quality of life was important; however, Williams et al., (2013, p. 6) reported that FCGs often lacked the ‘time and energy to do everything they needed and to care for themselves.’ To fulfil their caregiver responsibilities, FCGs required support (Duggleby et al., 2011; Pesut et al., 2011, 2014; Brazil et al., 2013, 2014; Herce et al., 2014) from family, friends, neighbours and HCPs and they ‘identified the need of having someone to talk to, and being appreciated by the care recipient’ (Brazil et al., 2014, p. 15).

Some FCGs accepted the role out of obligation (Herce et al., 2014); however, many found meaning in caring for their loved ones (Revier et al., 2012; Pesut et al., 2014), with the burden of care ‘outweighed by ... the satisfaction they derived from having made a meaningful contribution’ (Pesut et al., 2014, p. 130). However, many FCGs become fatigued with full time care, and with the responsibility of providing care to a loved one.

2.6.3 Patient and FCGs’ common experiences and perspectives

2.6.3.1 Communication; accurate and timely information

The greatest support need of participating rural patients and FCGs, in developed countries, was informational. Effective communication between HCPs and patients/FCGs, and within families (Tamannai et al., 2015), reduced pain and distress (Grant et al., 2011), empowered carers to fulfil their responsibilities (Revier et al., 2012), facilitated smooth transitions of care (Hatcher et al., 2014), and allowed patients and families to prepare for death (Johnston et al., 2012; Dembinsky, 2014). Most, but not all (Devik et al., 2013) participants were satisfied with the standard of communication by rural HCPs. However, many participants reported one or more

communication difficulties, such as receiving conflicting or untimely information (Ostertag & Foreman, 2008; Pesut et al., 2014), uncertainty as to ‘which physician was in charge’ (Darer et al., 2015), and not receiving information from the person considered to be the expert (Duggleby et al., 2010; Pesut et al., 2014). While some patients accepted medical advice without questioning (Dale & Johnston, 2011), others considered false hope (Kelly et al., 2009) or poor communication, a lack of respect for the patient and their family (Kelly et al., 2009; Duggleby et al., 2010, 2011) and that ‘not knowing was worse than knowing’ (Johnston et al., 2012, p. 1623). Ostertag and Foreman (2008) reported primary care physicians were highly praised for honesty and presence at the time of death.

2.6.3.2 Formal services

Brazil et al. (2014) reported 82.6% of their participating rural FCGs indicated that formal palliative care services were readily available in the rural locations where they resided, with 68.6% having access to services after hours. While the participants in the study by Pesut et al. (2011) reported that a HCP was always available, these results were not universal. Other rural studies reported inadequate accessibility to care and continuity of care (Duggleby et al., 2011; Wiik, 2011; Hansen et al., 2012; Johnston et al., 2012; Devik et al., 2013), especially after hours (Duggleby et al., 2010, 2011; Hansen et al., 2012; Johnston et al., 2012). Access to HCPs with palliative care training (Duggleby et al., 2010), paid qualified in-home carers (Hansen et al., 2012), after-hours pharmacies or morphine (Grant et al., 2011; Hansen et al., 2012), respite care (Brazil et al., 2013, 2014), and paediatric hospice (Mixer et al., 2014), are often limited or unavailable in rural areas.

Features of care that facilitated quality rural EoLC included personalised care (Duggleby et al., 2010; Hansen et al., 2012); ‘knowing’, and ‘being known’ by the HCPs, and a willingness of HCPs to go beyond their professional care (Pesut et al., 2011). However, loss of privacy and anonymity, and an expectation that friends will always be available were perceived as barriers (Pesut et al., 2011). Some participants reported the quality of care provided was dependent on the personality of the HCP, with difficulties arising if personality conflicts arose, as often no alternative provider was available (Devik et al., 2013).

When care at home was not possible the local community hospital was an acceptable alternative (Hansen et al., 2012; Herce et al., 2014; Mixer et al., 2014). Rural hospitals were considered safe (Hansen et al., 2012), small, convenient, personal, and welcoming. Rural nursing staff were described as caring and compassionate. However, rural hospitals were not viewed positively by indigenous participants in Australia (Dembinsky, 2014) and Canada (Kelly et al., 2009), mainly due to cultural insensitivity.

2.6.3.3 Informal social support - family, friends and neighbours

Nineteen rural studies reported on the informal support provided by family, friends, neighbours and the community, with some participants stating that family is the ‘most important’ factor (Devik et al., 2013, 2015) and essential for culturally congruent care (Mixer et al., 2014). Brazil et al. (2013, 2014) reported that the greatest unmet needs identified by rural FCGs were the tangible or practical needs. Community support was reported to have a positive influence on rural EoLC with one Norwegian participant describing a sense of solidarity, as people took care of each other (Devik et al., 2015). However, not all participants admitted to having happy family relationships (Mixer et al., 2014; Williams et al., 2013). Other rural participants acknowledged that community support cannot be taken for granted and is highly reciprocal. Those participants who had been involved in giving to their rural community often received the highest amount of support from that community (Pesut et al., 2011). Despite the strong sense of community, studies reported that as disease progressed and patients lost mobility and independence there was a sense of isolation, with one participant saying, ‘I am part of my community but I feel alone. Family and friends come to visit me, but I feel isolated as they are unable to understand what is happening to me and my wife’ (Duggleby et al., 2011, p. 2).

2.6.3.4 Emotional support

Strong emotional support was identified as a facilitator of quality rural EoLC and was dependent on good communication, information, the presence of HCPs, support of other patients (Johnston et al., 2012), faith and hope. Hope was maintained through connection with family (Devik et al., 2013), friends, and being linked to something outside the illness (Revier et al., 2012).

2.6.3.5 Spiritual support

Spiritual connection and faith fostered hope (Kelly et al., 2009; Revier et al., 2012; Williams et al., 2013; Mixer et al., 2014) with faith seen as an enabler to persevering in life as death drew near. Faith was reported to be fundamental to rural Appalachians and their transition through EoLC (Mixer et al., 2014). In many rural communities, church support was not limited to spiritual issues, as congregations also provided physical and financial support (Tamannai et al., 2015).

2.6.4 Influence of rural place and culture

Despite diversity in rural settings, rural residency was seen as having positive and negative influences on rural EoLC for both patients and FCGs. Distance was identified as the greatest negative influence. For many participants, commuting for treatment was considered stressful and exhausting (Devik et al., 2013; Duggleby et al., 2011; Lockie et al., 2010); inconvenient (Devik et al., 2013) and expensive (Grant et al., 2011; Hansen et al., 2012; Lockie et al., 2010; Pesut et al., 2010). Travelling impacted negatively on the health of some FCGs (Lockie et al., 2010) and resulted in fragmented care (Duggleby et al., 2011). Some rural participants accepted commuting (Devik et al., 2015) as ‘one of the compromises they have to make for living at home, that is, to live in a place that contributed to their overall health’ (Wiik, 2011, p. 12).

Geographical distance limited accessibility to home-based services as some patients lived outside the boundary for home visits (Hansen et al., 2012), visits were less frequent especially in bad weather (Lockie et al., 2010; Pesut et al., 2010; Dembinsky, 2014) and were often not available at short notice or after hours (Duggleby et al., 2010, 2011; Hansen et al., 2012). However, opinions regarding the effect of distance on the quality of care were divided with some seeing it as a major barrier to rural residents receiving home-based palliative care and therefore achieving a home death (Dembinsky, 2014), and others not viewing distance and rural residency a disadvantage (Devik et al., 2015). However, with advanced illness, the participants’ sense of solitude became one of isolation (Duggleby et al., 2011). Geographic isolation also explained the greater unmet emotional needs of rural caregivers as they usually lacked the support of others going through the same experiences (Brazil et al., 2014).

Mobile phones (Grant et al., 2011), computers and internet access (Devik et al., 2015; Pesut et al., 2010) helped reduce the sense of rural isolation by maintaining contact with distant family and improving access to HCPs; however, these technologies are not available everywhere (Lockie et al., 2010; Pesut et al., 2010). For some patients, a phone call was not sufficient, and did not replace the physical presence of HCPs (Pesut et al., 2010; Hansen et al., 2012).

2.6.5 Meaning of home or ‘home country’

In one study, 46% of patients and FCGs reported their preferred place of care to be “home” (Herce et al., 2014), as ‘being at home is like a brick being in the right place: this is my land and these are my people’ (Devik et al., 2015, p. 7). Many of the rural participants were entrenched in their community and had a strong place attachment (physical, social, and autobiographical). Devik et al. (2015, p. 8) suggest the rural environment had ‘potential to be a source of comfort, security, and identity’, while others reported the urban environment was often viewed negatively (e.g. noisy, unfamiliar, and unknown spaces).

For indigenous rural residents, home or ‘home country’ has special cultural significance. The biggest barrier to using hospital-based palliative care services for these participants was not being able to die ‘in country’. The lack of cultural awareness by HCPs and misperceptions of the concept of palliative care were barriers to accepting palliative care (Grant et al., 2011; Dembinsky, 2014).

2.6.6 Summary of rural end-of-life care from the experiences and perspectives of patients and family caregivers

Consistent with previous reports (Hughes et al., 2004), rural participants in this literature review were mostly satisfied with the EoLC provided to them; however, most were realistic and openly acknowledged their unmet needs. The over-riding themes for patients and FCGs in all locations were ‘living life’; holding onto hope, dignity and meaning; receiving personalised care; being known; and the desire for HCPs to be present, provide reassurance, and honour the choices of patients and FCGs. In sub-Saharan Africa, this was possible once pain was managed. The EoL issues faced in general by patients and FCGs, regardless of where they live (Lynch et al., 2013; Ciemens et al., 2015; Sandsdalen et al., 2015), were raised by the rural participants in

this review; however, there are differences, facilitators and barriers (such as the hardship of distance), unique to rural settings that significantly impact rural EoLC. Quality EoLC facilitates a ‘good death’ in rural settings.

While there is no expectation that resources in rural areas should be equivalent to those available in urban settings (Kaasalainen et al., 2014), some rural HCPs lamented their lack of palliative skills, training and mentoring (Castleden et al., 2010; Goodridge & Duggleby, 2010b). This insufficiency is especially significant in the hospital setting. Rural hospitals often act as a substitute for inpatient hospices (Wilson et al., 2006; Spice et al., 2012), and so EoL services must be integrated into the healthcare provided. (Fink et al., 2013).

2.7 Australian rural studies

While the above review details rural EoLC across heterogeneous rural settings, I had intended to close my literature review by focusing on studies conducted in similar rural settings to that of my thesis, or as a minimum, to report on relevant Australian studies. However, there is a paucity of Australian rural studies specifically focussing on a ‘good rural death’ or preferred place of care and death. The Australian studies have mostly been related to indigenous populations (Diaz et al., 2015; McGrath, 2007) or have included urban and rural residents without sufficiently identifying the rural views (Kirby et al., 2016; Pereira, 2005; O’Connor & Lee-Steere, 2006; Buikstra et al., 2006)

2.8 Chapter summary

In this chapter, I have outlined the current rural research literature relating to the rural ‘good death’, end-of -life care, and place of death. The studies identified are a combination of qualitative and quantitative research. Where possible I have reported the findings from the experiences and perspectives of rural patients, with a life limiting illness, and their family caregivers.

The chapter started by defining the discipline of palliative care (Section 2.1). The origins and development of palliative care were explored. One of the aims of

contemporary palliative care is to assist people receiving EoLC to die at home, if that is their preference. This requires the support of family and a multidisciplinary team of formal and informal providers. Some studies have suggested that a home death implies a ‘good death.’

Section 2.2 described the evolution of the concept of the good death. The concept is dynamic, having changed from the dying person having an awareness of impending death, to the western contemporary ‘controlled’ death. The ‘good death’ is open to interpretation based on personal, social, cultural, political and religious perspectives. Formerly a very public affair, the contemporary ‘good death’ is often hidden away in institutions, such as hospitals and RACFs.

The definition of ‘rural’ was explored in Section 2.3. Currently, there is no consensus on the definition of ‘rural’ making it difficult to compare rural studies and their findings. The current rural studies are heterogeneous in terms of location, population and resources. However, rural residents describe themselves as different to urban residents. There are unique factors that either hinder or facilitate the rural ‘good death’ and determine rural residents’ actual PoD.

Due to the paucity of rural studies, one scoping and two systematic literature reviews were undertaken. The findings of these reviews are reported in this chapter. The findings of ‘*Rural residents’ perspectives on the rural ‘good death’: a scoping review*’ are reported in Section 2.4. The ‘good death’ referred to the death event, the dying process, the meaning of death and the after-death concept. The elements considered essential for a ‘good death’ were those that addressed the physical, emotional, social, spiritual and cultural needs of the dying person and their FCGs. Alternative names for the ‘good death’ included controlled, timely, dignified, social and noble death. There were rural factors that either hindered or facilitated a ‘good death’. Place of death, and in particular, dying at home, was one factor that facilitated a ‘good death’.

Place of death in rural settings was further explored by systematically reviewing the literature. Section 2.5 reported the findings of ‘*Place of death in rural palliative care: a systematic review*’. This review reported on the actual PoD of patients receiving palliative care in rural settings, and the preferred PoD, as expressed by rural patients

and/or their FCGs. Most deaths in rural settings occurred away from home, with most occurring in hospital. The determinants of PoD were similar to those identified in urban locations: patient functional state and clinical condition, carer capacity, social networks and health system facilities and resources. Most rural residents were less likely to die at home than urban residents, and were disadvantaged by rural residency and lack of options. Rural hospitals were considered a substitute for inpatient hospice. Some studies reported PoC and PoD were not necessarily the same, and that people change their preferences along the disease trajectory. Rural residents indicated that PoD was not a major concern of the dying and providing they died within community, home was not essential for a 'good death'.

The findings of the second systematic review, '*Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic literature review*' were reported in Section 2.6. Limited studies were identified. Features considered important for quality EoLC included maintaining dignity, hope, independence and normality; the presence of family and friends; minimising carer burden; timely and accurate information; formal and informal support; physical, emotional and spiritual support; living life, personalised care, and being known. Residents in developing countries had different priorities to those in developed regions, with access to adequate pain control being the greatest unmet need.

This comprehensive and systematic review of the literature has highlighted a significant gap in the current rural literature. Presently, there is a lack of rural end-of-life studies reporting specifically on the 'good death' and PoD experiences and perspectives of rural patients, with a life limiting illness, and their family caregivers. Where experiences and perspectives have been reported, they have mostly related to patients with cancer or HIV/AIDs. The voice of rural patients, dying of advanced chronic non-cancer diseases, are mostly unheard. Therefore, there is insufficient evidence to draw any reliable conclusions on what facilitates or hinders a rural 'good death', or the importance of home as a PoD.

CHAPTER THREE: THE SNOWY MONARO – DESCRIBING THE SETTING AND POPULATION

*He hails from Snowy River, up by Kosciusko's side,
Where the hills are twice as steep and twice as rough,
Where a horse's hoofs strike firelight from the flint stones every stride,
The man that holds his own is good enough.
And the Snowy River riders on the mountains make their home,
Where the river runs those giant hills between;
I have seen full many horsemen since I first commenced to roam,
But nowhere yet such horsemen have I seen.*
(THE MAN FROM SNOWY RIVER by A.B. "Banjo" Paterson, 1890.)

The literature review supports the argument that each rural community is unique. Therefore, it is appropriate to allocate a full chapter to the setting of this research study. A visual image of the setting, created for the reader, will assist in placing the findings of this study, into a meaningful context. This research study is conducted within the Snowy Monaro region of NSW, Australia. Section 3.1 outlines the reasons for choosing this region, and briefly places the Snowy Monaro within the Australian context. This is followed, in Section 3.2, by describing this rural setting – the location, demographics, history, medical services, transport, and community services. Section 3.3 briefly introduces the target population. Section 3.4 discusses the challenges faced in recruiting participants to end-of-life research. The chapter concludes (Section 3.5) with a summary of the chapter.

3.1 Introduction

Being a rural resident and rural medical practitioner, the chosen setting was the location in which I am familiar, the Cooma Monaro and Snowy River Shires (Local Government Areas). To gain a cross-section of views, including those from more remote areas with reduced access to medical resources, the neighbouring Bombala Shire was also included. At the time this seemed appropriate as all three Shires made up the Monaro Health Service, a sub-division of the Southern New South Wales Local Health District (SNSW LHD). As chance would have it, the NSW Government enforced a compulsory

amalgamation of local government councils, and on 12th May 2016, at the end of my data collection period, the three Shires of Cooma-Monaro, Bombala and Snowy River, merged to become the Snowy Monaro Regional Council. This is a diverse region comprising towns, villages and farms with residents engaged in agriculture, forestry, hydroelectric production, tourism (skiing, fishing, mountain biking), National Parks, and a variety of support industries (education, health, policing, local government, tradesmen, hospitality, and retail).

To enable the reader to place this study into the Australian context, a brief description of the Australian population is provided. This is followed by a more focused description of the region under study. The Australian population, as of 18th June 2017, was 24.5 million (ABS ‘Population clock’, 2017b), with approximately two-thirds of the population living in a capital city. At June 30, 2016, the estimated resident population of NSW was 7.7 million people, with just over one third of NSW residents living outside Greater Sydney (Table 3.1).

Table 3.1 Estimated resident population (ERP) by remoteness structure. (ABS Regional population growth, 2017d)

	ERP at 30 June		CHANGE	
	2015 No.	2016 No.	2015-2016 No.	%
NSW				
Major Cities	5675992	5765757	89 765	1.6
Inner Regional	1458267	1473700	15433	1.1
Outer Regional	448098	448862	764	0.2
Remote	30638	30392	-246	-0.8
Very Remote	8344	8231	-131	-1.6
Total	7621339	7726924	105585	1.4
Australia				
Major Cities	16870359	17159014	288655	1.7
Inner Regional	4308519	4357568	49049	1.1
Outer Regional	2086950	2090572	3622	0.2
Remote	321194	319314	-1880	-0.6
Very Remote	204033	202408	-1625	-0.8
Total	23791055	24128876	337821	1.4

3.2 The Snowy Monaro region

The area chosen for the study, the three previous NSW local government areas (LGA) of Snowy Monaro, Bombala and Snowy River Shires, located in south eastern NSW (Figure 3.1), covers an area of 15,162 km² with a population of 20,218 (ABS Census

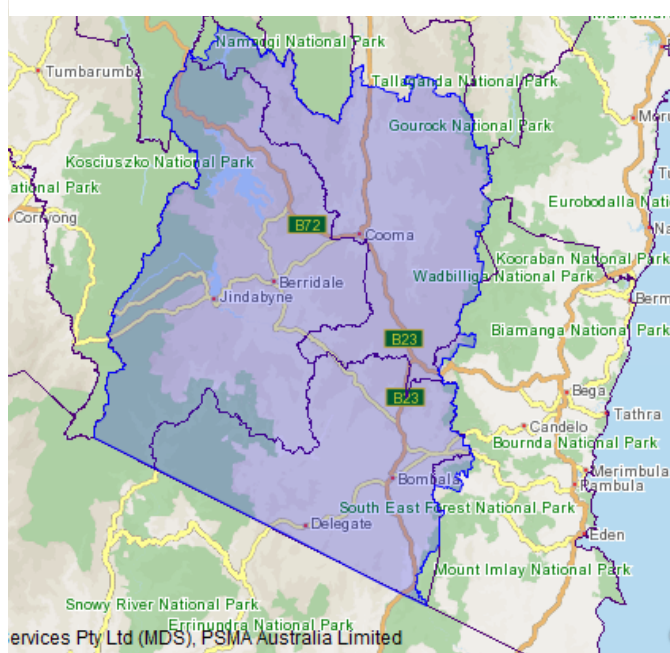
QuickStats, 2017a). The demographic features are reported in Table 3.2. This region is serviced by the Monaro Regional Health Service. This region borders the Australian Capital Territory, and the Queanbeyan-Palerang LGA to the north; the Bega Valley to the east; the Snowy Mountains to the west; and Victoria to the south (Figure 3.2). Cooma is the regional centre and largest town, with a population of 6742 (August 2016). Smaller towns include Bombala (population 1386), Jindabyne (2629), and the villages of Berridale (1197), Thredbo (471), Bredbo (352), Delegate (351), Adaminaby (301) and Nimmitabel (320) (ABS Census QuickStats, 2017a). There are also smaller communities and many farms.

Figure 3.1: Map of NSW with study location indicated by arrow.



The population density ranges from 0.6-2 /km², with an average population density of 1.4 residents per km². The population in the south-western area (Jindabyne and surrounds) increases by approximately 10,000 (Monaro Regional Health Services Plan, 2015) in winter, due to the influx of seasonal workers and tourists during the ski season. This region was chosen for its diverse rural characteristics, absence of a specialist multidisciplinary palliative care service, and my familiarity with the region. Public health services are managed by the Monaro Regional Health Services (MRHS), governed by the Southern NSW Local Health District (SNSW LHD).

Figure 3.2: Map of the Snowy Monaro region



Monaro Regional Health Services (MRHS, 2015, p. 10).

A significant proportion of the Monaro population do not live in the main towns. Approximately one third of Cooma-Monaro LGA residents live outside Cooma, two thirds of Snowy River LGA residents live outside Jindabyne, and half the Bombala LGA population lives outside the Bombala Township (MRHS, 2015).

Table 3.2: Demographic features of the Snowy Monaro residents.
(ABS QuickStats, 2017a)

	Snowy Monaro	NSW	Australia
Males	51.7%	49.3%	49.3%
Median age (years)	43	38	38
>65 years	19.5%	16.2%	15.8%
Median weekly household income	\$1200	\$1486	\$1438
Aboriginal and/or Torres Strait Is. people	2.2%	2.9%	2.8%
Both parents born in Australia	63.2%	45.4%	47.3%

3.2.1 Snowy Monaro history

The rural culture evident today in the Monaro region has been moulded by its history. The Cooma-Monaro Shire land is an ancient plateau running north south about 800 metres above sea level, and bounded on the east and west by rugged mountain ranges,

part of the Great Dividing Range. The name ‘Monaro’ comes from the aboriginal word ‘Monaroo’, meaning high plateau or plain. The tablelands are naturally treeless due to soil types, low rainfall, low temperatures and cold air pooling (Figure 3.3).

Figure 3.3: Monaro Plains, outside Cooma (2016)



Photograph: Suzanne Rainsford

The south-western corner of the Snowy Monaro region is mountainous, and while the elevation is much lower than the mountains in Europe, North America and central Asia, the area is snow covered during the winter months (Figure 3.4).

Figure 3.4: The Main Range, Kosciuszko National Park



Photograph: Suzanne Rainsford

Archaeologists believe that Aboriginal people have been living in the Snowy Monaro region for as long as 20000 years before the arrival of Europeans. The two main tribal groups were the Ngarigo people of the tablelands, and the Wogul or Wolgalu people of the high country. During bad weather it is believed the tribes moved to the warmer valleys. During the warmer months, large-scale inter-tribal gatherings were held in the high country, when tribes travelled from the South Coast to collect the large bogong moths (Plowman et al., 1999, p. 1). Following European settlement, in the 1800's, the number of Aboriginal people declined. Records during the 1840s reported a group of between 500 and 1,382 Ngarigo were frequently seen on the Monaro, however, by 1856 only 166 Aboriginal people were counted in the census, and by 1892 just two remained. It was originally believed the Ngarigo disappeared due to disease and interactions with European settlers, but recent information suggests many moved to the coast and integrated with the coastal clans around Bega and Bermagui (Plowman, 2007). The 2016 census identified 448 Snowy Monaro residents as Aboriginal or Torres Strait Islander, representing 2.2% of the population (ABS Census QuickStats, 2017a). While this study did not specifically include or exclude indigenous participants, this demographic was not collected.

Captain Mark Currie and Major John Ovens carried out the first expedition to the Monaro, arriving on 4 June 1823. It was not long before squatters, shepherds and herdsmen arrived, bringing with them flocks of sheep and herds of cattle belonging to wealthy Sydney landowners. Today, the Monaro is known for its high-quality Merino wool and beef cattle (Figure 3.5). In 1833, the first squatters arrived in the Bombala area and took ownership of what was to become the Bombala Station. The Snowy Mountain area was first explored by Europeans in 1835. Edmund Strzelecki, ascended the highest peak, Mount Kosciuszko, in 1840 and named it after a Polish patriot. High-country stock men followed, using the Snowy Mountains for grazing during the summer months. The town of Cooma dates back to 1842, when John Lambie, Crown Lands Commissioner for Maneroo, constructed a residence and office (Plowman, 2007).

Figure 3.5: Cattle drive on the Snowy Mountains Highway



Photograph: Suzanne Rainsford

The discovery of gold in 1859, on the high plains near Kiandra, boosted Cooma's development. At its height, Kiandra had a population of about 4,000 people, and ran 14 hotels. The gold rush was short lived, ending in the mid 1860's. Kiandra was abandoned, resulting in an influx of people looking for work in Cooma. The town continued to prosper, and by the second half of the 19th century Cooma became the commercial centre for the Monaro.

In 1949, Cooma was chosen as the headquarters for the Snowy Mountain Hydro-electric Scheme, the construction of a world class hydroelectric system supplying electricity and water for irrigation. This quiet rural town was rapidly transformed into a major centre, with the population increasing from 2,000 to 10,000 people. Other new towns sprang up in the surrounding Snowy Mountains. Cooma was the first multi-cultural town in Australia, with two thirds of the Snowy workers being immigrants from war torn Europe, representing 40 countries. The Scheme brought prosperity to the town and region, and confirmed Cooma as the commercial centre of the Monaro.

Following the completion of the Snowy Hydro Scheme, while many workers drifted away, a significant number remained in the region, living in towns, villages and farms. The 'Snowy' people were hardy. I can remember, a few years ago, one elderly German patient recounting stories of her early years in the area. The family (husband and two

small children) arrived from war torn Germany and spent the first 18 months, including two snowy winters, living in a tent, with no electricity, just out of Jindabyne.

Today, Cooma is a busy commercial and tourist centre and the ‘Gateway Capital to the Snowy Mountains’ (Figure 3.6). It is located at the junction of two highways linking Canberra (115 km), the south coast (115 km) and the mountains (100 km). Over the years, the region has become known for its Merino sheep, Angus and Hereford cattle, farming, forestry, and as a popular tourism destination (skiing, fishing, and more recently mountain bike riding). The average resident endures drought, bushfires, summer heat, winter snow and ice, fog, rabbits, foxes, weeds, wool prices up, wool prices down, and many other adversities. Yet this is their home, and for many this is where they want to live and where they choose to die.

Figure 3.6: Cooma; population 6742 (August 2016)



Photograph: Suzanne Rainsford

3.2.2 Medical facilities

The Government Gazette of 1844 records two doctors officially listed for the Monaroo Plains. One held a stock run in the Bombala district. A prerequisite for a Monaro doctor was that he was ‘a strong and capable rider, to be available at any time day or night and be prepared to ride many miles in an emergency’ (Plowman, 2007 p36).

Cooma’s first permanent doctor arrived in the village of 166 people in 1865. A small hospital, built with government and private funds, was opened in 1867. Today, Cooma has a 37-bed public hospital (30 medical/surgical beds and 7 obstetric beds). The hospital has a busy emergency department, day surgery/endoscopy unit, inpatient operating theatre, maternity ward, outpatient oncology and renal dialysis units, physiotherapy (with hydrotherapy pool), pathology and radiology department including

CT scanning. In addition, there is a multidisciplinary community health service including one palliative care nurse (0.9 full time equivalent [FTE]) and one *McGrath Breast Care Nurse*¹ (0.3 FTE) who doubles as a community nurse. Medical cover is provided by local general practitioners. In addition, there are visiting specialists in general surgery, orthopaedics, gynaecology, endoscopy, gerontology and psychiatry. While not having formally designated palliative care beds, two single rooms have been set aside for patients receiving end-of-life care. The former staff meeting room has been beautifully refurbished and renamed the *Mary Green Room*², in memory of Cooma's first oncology nurse who died a few years ago from cancer. When required, this lounge room provides private day and overnight accommodation for families of dying patients. The hospital has on an average 14.3 palliative care deaths/year (range 10-19) from July 2008 to June 2013 (MRHS, 2015).

The Snowy Monaro region has eight General Practice surgeries. Surgeries in Cooma and Jindabyne are open Monday to Friday; practices in smaller towns are part-time. After hours' services are provided by the emergency departments at Cooma and Bombala hospitals. Cooma has two large general practices staffed by 14 FTE GPs. I currently work in Cooma (0.2 FTE) in general practice and as a private palliative medicine specialist. There is no specialist multidisciplinary palliative care team or local inpatient hospice. Most of the end-of-life care is primary palliative care. Cooma has two residential aged care facilities (RACF) (72 beds and 40 beds) offering respite and permanent high level care placement.

Bombala has a multi-purpose service (MPS) with an inpatient facility (seven medical, one palliative care and ten RACF beds), community health services and a part-time general practice. The Bombala MPS has limited medical support, especially after hours. Most acute or serious injuries or illness are transferred to either Cooma Hospital, or the Bega Regional Hospital. Bombala also has a privately run RACF with 32 beds.

¹ McGrath Breast Care Nurses are sponsored by the McGrath Foundation, to help individuals (and their families) experiencing breast cancer by providing physical, psychological and emotional support. This support is available for free, from the time of diagnosis, and throughout treatment and end-of-life.

² Mary Green Memorial Palliative Care Family Room. Opened in 2015, on the main ward of Cooma Hospital, adjacent to the two single rooms set aside for EoLC. Funded by MCCR, in honour of Mary Green, the first oncology unit nurse. In 2012, she lost her battle with cancer. Facilities include a sofa bed, TV, equipped kitchenette and dining suite. This room is for the use of families of palliative care patients.

Delegate, 35 kms south of Bombala, towards the Victorian border (Figure 3.7), has a MPS with a nine-bed RACF. The emergency department is nurse led and offers basic first aid. The palliative care nurse, based in Cooma, visits Bombala weekly and Delegate weekly, when required.

Figure 3.7: Delegate; population 351 (August 2016)



Photograph: Suzanne Rainsford

Despite strong campaigning by the locals, currently there are no inpatient facilities or after hours' medical services, in Jindabyne. The general practitioners conduct their practice from two private medical practices. Community health services, from Cooma, are available in a purpose-built facility, including palliative care (nurse) home visits. The closest inpatient hospital is Cooma (1-hour drive in good weather). There is a 14 bed RACF in Berridale (half way between Cooma and Jindabyne). As previously mentioned, the population of Jindabyne swells by 10,000 during the winter months. Travel times in winter increase due to ski traffic, fog and icy roads.

Other medical practices in the Snowy Monaro region are located in the winter ski resorts of Thredbo and Perisher Valley (Figure 3.8). The medical centres in Thredbo and Perisher are open during the winter season. Thredbo medical centre is also open during Easter and summer school holidays.

Figure 3.8: Sharp Street Surgery, Cooma and Perisher Valley Medical Centre.
(Photographs: Suzanne Rainsford)



The palliative care and community nurses are available to visit all homes within the region; however, the degree of isolation dictates the frequency of visits. While some oncology patients receive their chemotherapy in Cooma, there are no visiting oncologists. Most patients requiring specialist medical care travel to Canberra, although a small but significant number travel to Bega (114 km from Cooma) or even further away to Sydney (450 kms) or Melbourne (620 kms). Patients requiring tertiary medical care are transported to The Canberra Hospital, either by road or retrieval helicopter.

Most of the palliative care within the region is provided jointly by the general practitioners supported by the palliative care Clinical Nurse Consultant (CNC). While there is a multidisciplinary community health service, currently there is no counsellor, social worker or palliative care pastoral care worker. After completing my training and gaining Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM) I now offer a part-time (0.2 FTE) private palliative medicine consultancy service in Cooma. The closest specialist multi-disciplinary team and specialist palliative care inpatient hospice are in Canberra (115 kms). New state and commonwealth government initiatives were implemented after completion of my data collection. There is now a *HammondCare* in-home package³ available to assist patients and their FCG in the final days of life (MacLeod et al., 2015); an after-hours telephone palliative care advisory

³ HammondCare Palliative Care Home Support Program - provides free, non-means tested end-of-life care for patients who wish to remain at home. A package of up to 48 hours of specialised supportive palliative home-based care, day or night, is provided by specially trained community care workers who work as part of the existing multidisciplinary team. <http://www.hammond.com.au/services/palliative>

service; and an ambulance after-hours palliative care plan. These initiatives have the potential to improve the quality of palliative care in rural areas, especially after hours. The telephone advisory service is available to patients, families, and healthcare providers, both in community and hospital settings. A systematic literature review by Mitchell (2002) reported the majority of palliative care in the community is provided by GPs; however, while patients and FCGs were appreciative of the care provided, GPs often felt inadequate and unsupported. The telephone advisory service is one step towards providing specialist support in rural areas.

3.2.3 Transport

As in any rural region, distances and transport compound the issues of isolation. In Cooma, the train line from Sydney opened in 1889, but closed in 1989. The train has been replaced by a bus, the *Transborder Express Trainlink*. This bus travels by road from Bombala to the Canberra railway station (four hours), from where a train line runs directly to Sydney (four hours). The bus travels from Bombala (and return) three days a week, via Jindabyne and Cooma, to Canberra train station, where taxis are available for transfer to the Canberra airport. There is also a daily bus service from Bega via Cooma to Canberra. Cooma currently has a small airport with one flight to Sydney, Monday to Friday. Additional flights are available during the ski season. Due to the frequent fog, flights are often delayed. Unless a small town lies directly on the bus route, the only available public transport is the local school bus. Residents in Adaminaby needing to use public transport can travel to Cooma, for the day, by school bus.

The additional medical costs of travel and accommodation are partly offset by a government funded *Isolated Patient Transport and Accommodation Scheme*. This provides a small reimbursement of travelling costs, providing the patient travels over 100 kms to the nearest medical service. In addition, for a small fee, patients can use the subsidised *Health and Community Transport Scheme* to attend medical appointments and treatments, within the local region, Canberra and Bega. Holders of a Veteran Affairs gold card have access to taxis, with the fare paid in full by the Department of Veterans' Affairs.

3.2.4 Community services

Like most rural regions, Snowy Monaro is known for its many volunteer and community organisations. The hospitals are supported through community auxiliaries and volunteers. One organisation worthy of note, mainly due to its unique contribution to the cancer community, is the *Monaro Committee for Cancer Research Inc. (MCCR)*⁴. This organisation was started by a group of local women, after the death of a young local mother in 1996. She had battled cancer for five years. The original aim was to hold major fundraisers in the Monaro district with funds distributed to cancer research and support for local cancer care facilities. Locally these funds have been used to purchase equipment and provide financial assistance for cancer patients either undergoing treatment or receiving palliative care. MCCR was a significant lobby force behind the opening of an outpatient oncology unit in Cooma, and used their funds to equip and furnish the unit. This has reduced the travelling burden for some oncology patients, as they can alternate their treatments between Cooma and Canberra.

3.2.5 Snowy Monaro region summary

I hope by now the reader has a clear impression of the rural setting for this original research. In some ways, it is a ‘typical’ Australian rural region, full of resilient, hardy characters; and yet in many ways it is unique. It is a diverse region. Some areas, such as Cooma, are well resourced and in relative proximity to a tertiary hospital. Yet other locations, such as Delegate and Ingebyra on the Snowy River, are far from resources. Some places are accessible in summer, but isolated in winter. Some places are easily accessible by car, and yet for the weak and frail a 30-minute car journey is agonising.

3.3 The target population

The Snowy Monaro residents are a heterogeneous group. Some participants are sixth and seventh generation Monaro farmers; others immigrated to Cooma during the ‘Snowy’ days; some followed their hearts during courting days; some came for work; while others are new comers - they just decided, it would be a nice place to live (Figure

⁴ Monaro Committee for Cancer Research. Not for profit community fundraising organisation. Funds cancer research, financial aid for local families coping with cancer, local health facilities e.g. equipment provided to the oncology unit. <<http://mccr.org.au>>

3.9). The interviewed participants will be introduced in the following chapters. In the remainder of this chapter I will discuss the challenges in recruiting palliative care patients to research.

Figure 3.9: Great Diving Range, view from outskirts of Cooma



3.4 Challenges in recruiting palliative care patients to research

Challenges in recruiting palliative care patients to research have been well documented in the literature (Agar et al., 2013; Rainsford et al., 2014; Wohleber et al., 2012). Traditional views in palliative care have considered it unethical (De Raeve, 1994) to recruit terminally ill patients to research, in the belief they are too vulnerable, too unwell, too exhausted, or lack sufficient cognitive capacity to provide informed consent. As dying patients have little to gain personally from participating, health care professionals often become protective, acting as ‘gatekeepers’ to exclude these patients in the belief they would find any request to participate as intrusive (Bullen et al., 2013; Ewing et al., 2004). Members of human research ethics committees (HREC) also hold reservations about providing approval to recruit such participants, and place strict guidelines on how to proceed. However, recent studies argue this is not necessarily the case (Ross & Cornbleet, 2003; White & Hardy, 2010). In response to the suggestion that a recorded interview be stopped, due to the personal nature of the conversation, one

patient interviewed by Kleinman (1988, p. 148) replied, “No don’t. This helps me feel I will leave something behind.” Gysels et al. (2012, p. 1) concluded in their literature review that ‘ethical concerns regarding patient participation in end-of-life care research are often unjustified’ and that providing studies are carefully designed and executed, most palliative care patients and their FCGs find participation a ‘positive, therapeutic experience’. This was certainly my experience during the interviews I conducted. One bereaved FCG appreciated being involved. His wife had complex pain issues, and when her cancer pain was finally brought under control by the specialist palliative care team in Canberra, with a combination of second and third line medications, the local GPs would not listen to her plea not to change the medications. No one had listened to his wife. Theirs was a story “*that needs to be told*” (Andrew, husband of Elaine), and now finally some months after her death he had an opportunity for “*someone to hear [their] story.*” (Andrew).

However, concerns about ethics (Casarett, 2005) are not the only barrier to recruiting palliative care patients. There are logistical issues that impede recruitment. The disease trajectory of palliative care patients means they frequently present with complex symptoms, including extreme mental and physical fatigue, and poor performance status. Of those who do consent to participate in research, patient attrition becomes a hurdle, as patients often die or become too unwell to continue in studies.

Recruiting FCGs can also be challenging. They are often too busy, stressed or overwhelmed with the burden of care (Brazil et al., 2013). The research proposal, discussed in the following chapter, had provision to conduct longitudinal interviews. While this was possible with a couple of patients and their FCGs, the anticipated number was not achieved. The daughter of one patient (Bruce) consented to be interviewed but was not present at the initial interview with her parents. Her elderly mother became distressed when Bruce, no longer able to remain home for EoLC, was admitted to a RACF. She lived on a farm and moved into town with her daughter, to enable daily visits to her husband. The daughter became over-burdened with concern for both parents, transporting her mother to and from home and the RACF, and running a small business. On many occasions she stated to me, as her father’s palliative medicine specialist, she was barely coping. It was inappropriate to ask her for an interview.

One of the inclusion criteria for this study was that potential participants had some knowledge of their prognosis. This also impeded recruitment as some patients who were identified as suitable either did not know or did want to believe their life expectancy was short. Some were so focused on controlling the disease they did not want to talk about dying.

The challenges in recruiting palliative care patients to research are amplified in rural settings. Urban studies have a larger pool of potential participants from which to recruit. If a potential rural participant declines to participate, especially if they reside in the more remote area, there is often a significant period to wait until another suitable participant is identified. Despite the barriers, there is emerging evidence to suggest conducting research in palliative care is feasible (Gibbons et al., 2013) especially if strategies are implemented to ameliorate these problems during the development phase of a research project (Bullen et al., 2013; Fischer et al., 2011).

3.5 Chapter summary

This chapter has described the setting for this research study, and outlined the challenges faced in recruiting palliative care patients to research. The setting is a diverse rural area. The following chapter outlines the methodology and methods chosen to conduct this rural research study, and discusses the strategies used to overcome the challenges faced in recruiting terminally ill patients. The reader will also be introduced to the rural participants who are well placed to describe their experiences and perspectives on rural end-of-life care, the ‘good death’ and place of death.

Figure 3.10: Monaro Dorper lambs



CHAPTER FOUR:

RESEARCH DESIGN AND METHODOLOGY

Introduction

This chapter introduces the research questions to be answered, and the methodology and methods that underpin the research. The overall research plan explored the concept of the good death, and the influence of place of death (PoD) and rural residency on the ‘good death’, from the experiences and perspectives of rural patients and their family caregivers (FCGs). This was achieved by using two types of research (i) scoping and systematic literature reviews, and (ii) mixed methods original research.

The overall project had three stages: preparation and ethics approval; data collection; and analysis and write-up. The research objectives and questions guiding this thesis are stated in Section 4.1. One element of the preparation stage was my literature review, as discussed in Chapter 2. The preliminary literature review was enhanced by a more systematic review of the literature, resulting in the completion and publication of one scoping review (*The rural good death: a scoping review*) and two systematic literature reviews (*Place of death in rural palliative care: a systematic review*; *Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic review*). Section 4.2 discusses the methods that guided these literature reviews. In Section 4.3 I present my arguments for the theoretical framework and chosen methodology underpinning the original research: mixed methods incorporating ethnography and quantitative analysis. Section 4.4 outlines the qualitative methods, including recruitment and consenting of participants, data collection (interviews), and data analysis. Section 4.5 outlines the quantitative survey data collection and analysis. In Section 4.6 I reflect on my role as a researcher, and the influence of my background and perceptions on the data collection and analysis. A brief discussion on the limitations of this study follows in Section 4.7, before concluding with my arguments that validate the rigor of this research (Section 4.8).

4.1 Research objectives and questions

The primary objective of this research study was to explore the concept of the good death from the experiences and perspectives of rural patients with a life limiting illness, and their FCGs, within the rural Snowy Monaro region of NSW, Australia. The secondary objectives were to determine the influence of PoD and rural residency on the concept of the good death, and to explore the meaning behind the PoD preferences and decision-making process. The hope was, that by identifying the essential features of the ‘good death’, and the meaning of PoD, in this rural setting, more informed decisions and actions can be considered for inclusion in the palliative EoLC offered in this region.

The literature frequently reports the importance of placing qualitative data into context. The perspectives obtained through the interviews were therefore contextualised by describing the actual PoD of Snowy Monaro residents, and by exploring the factors associated with PoD.

To address the objectives, six questions were explored through this research study:

1. What is a ‘good rural death’?
2. What is the influence of PoD on the ‘good rural death’?
3. What is the influence of rural residency on the ‘good death’?
4. What is the meaning of ‘place’ when deciding preferred PoD?
5. Where do Snowy Monaro residents die?
6. What factors influence the PoD? For example, are residents living on farms less likely to die at home than residents living in town?

4.2 Systematic and scoping reviews

The starting point for this research was a general review of the literature, as reported in Chapter Two, to identify gaps within the current literature that would help determine the objectives of this study. While some might argue that systematic literature reviews are not ‘research’, I have taken the stance that systematic reviews are in fact research, as they answer a research question, and follow strict methodological guidelines for data

collection and reporting. At the 15th World Congress of the European Association for Palliative Care (Madrid, May 2017), the Editor in Chief of *Palliative Care*, Professor Catherine Walshe, on presenting the ‘2016 paper of the year award’ to the authors of a systematic review, stated “*reviews are research too*”.

As previously noted, my initial literature review was sufficient to inform the development of my research protocol and ethics application; however, due to the dearth of identified rural studies, a more systematic approach was later undertaken, resulting in one scoping and two systematic literature reviews. All three reviews were substantially my own work; however, all my supervisors contributed to the publications, in varying degrees, as stated on page viii of this thesis. The three reviews are now published and a copy can be found in Appendix 6. I performed an update of the reviews (to 28th February 2017) without any external assistance. The database updates identified all three of my published reviews; however, my reviews were not included in the studies added to the final literature review.

4.2.1 The rural ‘good death’: a scoping review

My initial intention had been to undertake a systematic review exploring the concept of the rural good death, from the perspectives of rural residents, in order to answer the research question “What is a ‘good rural death’?” However, due to the very small number of relevant articles identified, a scoping review approach was chosen.

Currently, there is no standardised definition or methodology for scoping reviews (Peters et al., 2015) so the definition commonly applied is that first described by Mays et al. and cited and used by Arksey and O’Malley (2005, p. 5). They describe a scoping review as one that aims:

To map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before.

The protocol used in my review was based on the methodological framework first described by Arksey and O’Malley (2005), enhanced by Levac et al. (2010), Daudt et al.

(2013) and Colquhoun et al. (2014), and later refined by the Joanna Briggs Institute (JBI, 2015). The original (Arksey & O'Malley, 2005) and modified (Levac et al., 2010) frameworks consist of six stages (JBI, 2015):

1. Identifying the research question by clarifying and linking the purpose and research question.
2. Identifying relevant studies by balancing feasibility with breadth and comprehensiveness of the scoping process.
3. Study selection using an iterative team approach to selecting studies and extracting data.
4. Charting the data by incorporating a numerical summary and qualitative thematic analysis.
5. Collating, summarising and reporting the results, including identifying the implications for policy, practice and research.
6. An optional consultation exercise between stakeholders.

In recent years, scoping reviews have become increasingly popular. To ensure scoping reviews are valid and reliable, Tricco et al. (2016) have identified the need for standardised reporting guidelines. However, at the time of my scoping review no guidelines existed. Therefore, the reporting of my scoping review was based on the 2016 scoping review published by Tricco et al., the team developing the standardised reporting guidelines, the Preferred Reporting Items for Systematic Reviews and Meta-Analysis-Scoping Review (PRISMA-ScR) guidelines (Equator Network, 2016). While quality assessment is not a requirement of the JBI guidelines, it was included in my published review (Levac et al., 2010; Daudt et al., 2013); however, the optional consultation stage was omitted.

4.2.1.1 Eligibility criteria

Scoping reviews have a broad approach and include any existing literature, including both published (primary research studies, observational studies, reviews) and relevant unpublished (grey literature) articles, regardless of study design, discipline or quality. To answer my scoping review research question, I developed eligibility criteria, using the Participants, Concept and Context (PCC) acronym outlined in the JBI guidelines (2015):

- *Participants*: Rural residents, including rural patients with a life-limiting illness, rural FCGs, rural HCPs and the wider rural community, as these are the most appropriate to provide the rural perspective. No age filter was applied.
- *Concept*: The principal concept under review was the ‘good death’ in a rural setting, as described through the personal experiences or perspectives of rural residents; collected by interviews, surveys or extensive field work observations. The term ‘good death’ was either used explicitly or implied.
- *Context*: Rural or remote; all countries and territories were considered; no standardised definition of rurality was used. Articles that included urban and rural data were considered providing the rural data were clearly identifiable.

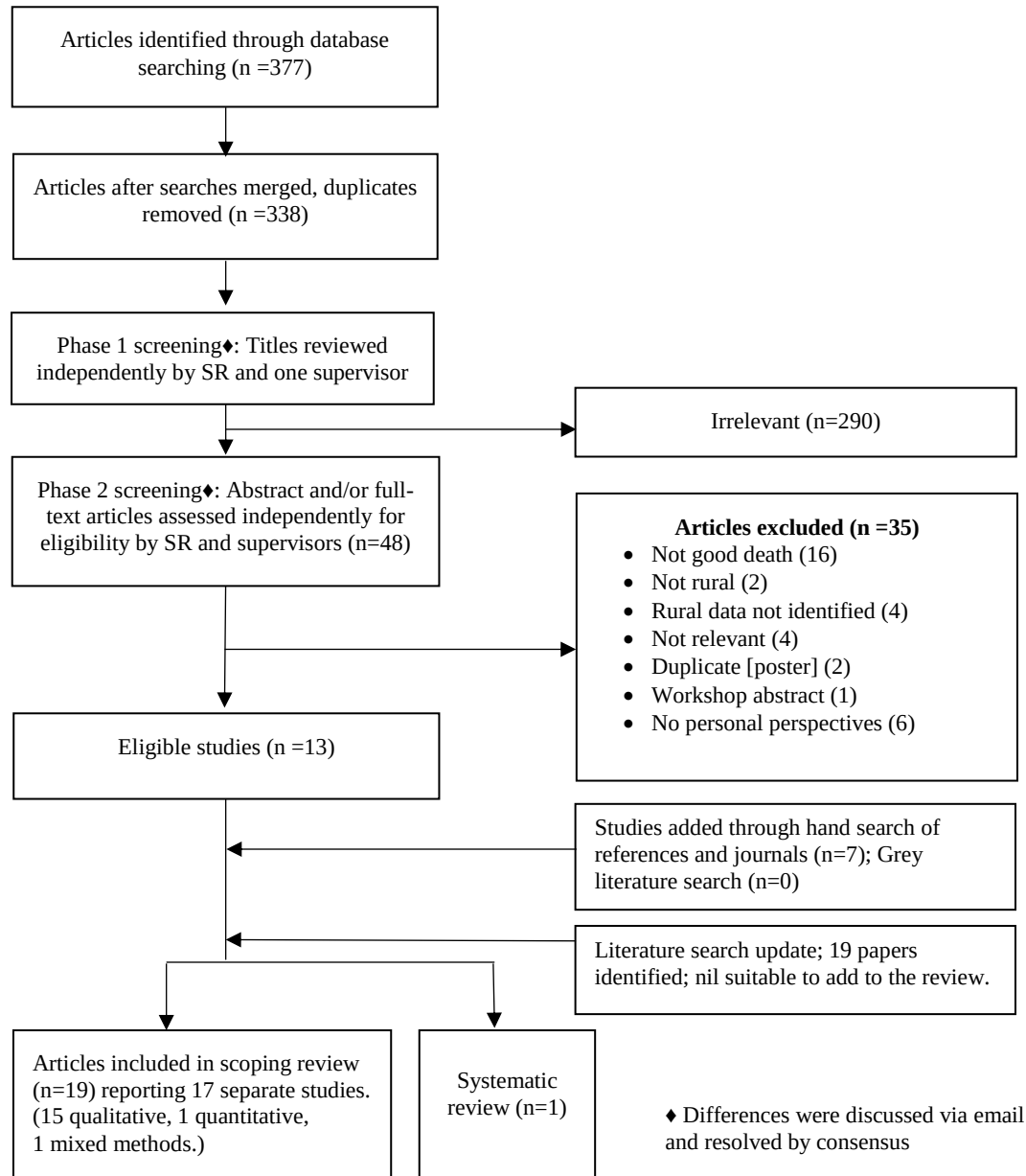
4.2.1.2 Information sources and search strategy

Five electronic databases (PubMed, CINAHL, Scopus, PsycINFO, and Web of Science) were searched from 2nd January through 14th February 2016. A literature review update was undertaken in early March 2017, by accessing the same data bases and searching for articles published from 15th February 2016 to 28th February 2017. An iterative process was used with “peaceful death” omitted from the original search. The following keywords and Medical Subject Heading (MeSH) terms were used in the final search: (“good death” OR “managed death” OR “good enough death” OR “tamed death” OR “dying well” OR “peaceful death”) AND (Rural OR Remote). All study designs were included; no date filter was applied; only English language papers were included.

The initial search identified 377 articles. These were downloaded to ENDNOTE X7, merged and duplicates deleted (338 articles). The reference lists of all retained articles were scanned for additional studies. Recent issues (July 2014 - Jan 2016) of eight relevant journals (Palliative Medicine, Journal of Palliative Medicine, Palliative and Supportive Care, Australian Journal of Rural Health, Journal of Rural Health, Social Science and Medicine, Health and Place, and Death and Dying) were hand searched. Cochrane Library, CareSearch database and OpenGrey repository were searched for grey literature. Authors of three studies reporting mixed geographical data were contacted; however, rural data were not specified, and so these three articles were excluded from the review. The literature search update followed the same format and identified 19 papers, including my own published paper. On review of titles and

abstracts no suitable papers were found to add to this scoping review. The remainder of the selection process is illustrated in the flow chart (Figure 4.1).

Figure 4.1. Flow diagram of scoping review selection process including reasons for exclusion.
(Source: modified flow chart as described by Moher et al., 2009)



4.2.1.3 Assessment of quality

To ensure valuable insights reported in lower quality studies are not excluded, the current scoping review methodological guidelines do not require a formal quality assessment of eligible articles. However, a quality assessment was conducted in this review to assist in validating the quality of the literature informing my report. After an initial assessment was made, my four supervisors independently assessed each paper. Differences were discussed by email and resolved by consensus. All eligible articles

were retained in this scoping review, regardless of their quality. Some high-quality studies received a lower score, as the assessment was based on aspects relevant to the rural ‘good death’, and not of the study per se. All studies identified for the scoping review were rated to be of low, medium or high quality based on a simple scoring system described by Hawker et al. (2002) and modified by Gomes et al. (2013). Two additional items were added to account for the rural ‘good death’ focus: (1) clarity of rural definition and (2) validity of informant (prospective=2, retrospective =1, well community=0). The scoring card can be found in Appendix 2.

4.2.1.4 Synthesis

The synthesis included both a quantitative analysis of the actual scoping review and a qualitative analysis of the content of the included articles (Appendix 3). A thematic analysis of the content was conducted by downloading the eligible articles into NVivo-10, and coding for major themes. Findings were reported narratively. Due to heterogeneity within a small number of studies, a meta-analysis and analysis according to informants were not possible. Some informant groups had only one study identified. The qualitative results of the scoping review were described in Chapter Two (Section 2.4). The published paper can be found in Appendix 6.

4.2.2 Systematic reviews

Two systematic literature reviews were conducted identifying both quantitative and qualitative studies, and were undertaken utilising the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Shamseer et al., 2015).

4.2.2.1 Place of death in rural palliative care: a systematic review

The first systematic literature review, “*Place of death in rural palliative care: a systematic review*” was conducted between September and December 2014, by searching four electronic data bases (PubMed, PsycINFO, Scopus, and CINAHL) using the following keywords and Medical Subject Heading (MeSH) terms: (choice OR prefer* OR decision) AND (palliative OR end-of-life OR terminal) AND (care OR death) AND (place OR location OR site) AND (Rural). A date filter was not applied, and all published English language, peer reviewed research articles were identified. Having found 82 manuscripts, the search was widened by limiting the keywords to (“place of death” OR “place of care”) AND (Rural), on the presumption rural data may

be embedded in population studies. The two searches were downloaded to ENDNOTE X7, merged and duplicates deleted. The reference lists of all included studies were scanned for additional articles. The literature search was updated in early March 2017, using the same databases and keywords, and date limitation of January 2015 through February 2017. Issues (June 2013 - February 2017) of six relevant journals (Palliative Medicine, Journal of Palliative Medicine, Journal of Pain and Symptom Management, Palliative and Supportive Care, Australian Journal of Rural Health, and Journal of Rural Health) were hand searched by myself. Relevant articles, found incidentally or identified by PubMed monthly updates (January 2015 – February 2017), were also included. One corresponding author (Thomas et al., 2003) provided a copy of their completed report containing specific rural data. One hundred and thirteen articles were identified in the original search, with 40 being eligible for inclusion. An additional 38 papers were identified in the database search update. After removing duplicates and those irrelevant by title and abstract, four additional papers were included (Figure 4.2).

Selection criteria

Each identified study was assessed against predetermined inclusion criteria, and were included if they fulfilled the following conditions:

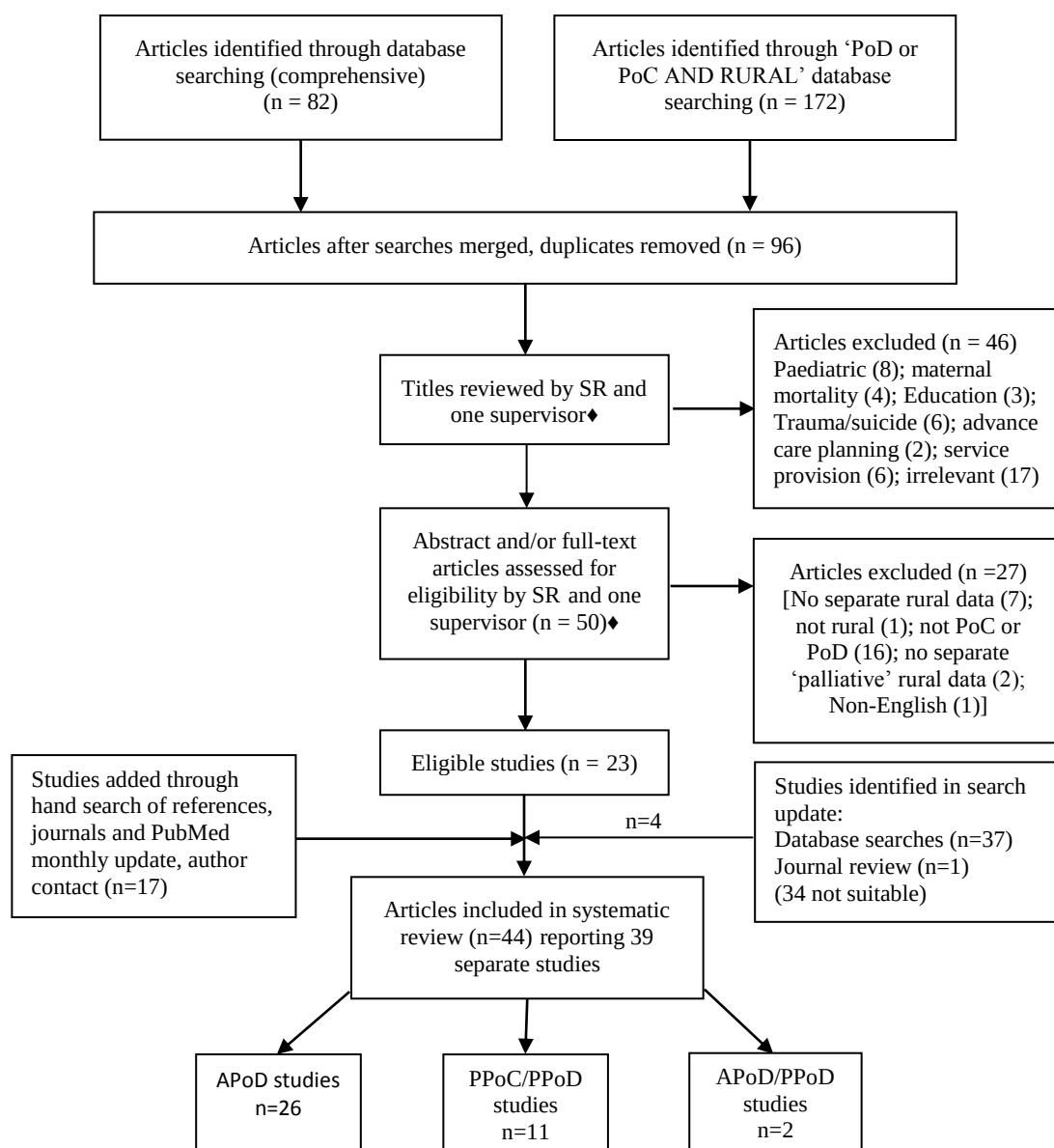
- Preferred and/or actual place of death/care reported as either part of the research aim or findings.
- Participants included rural, regional or remote residents (no standardised definition of rurality was used).
- Rural data were clearly identifiable.
- Cause of death included a palliative condition (malignant and non-malignant), or the survey included preferences indicating the participants had current or hypothetical life-limiting illness.
- The article indicated a research study had been conducted with method and results described.
- While this systematic review excluded paediatric palliative care the age filter (≥ 19 years) was not applied in the initial search as different cut off ages were used, ranging from 15 to 19 years.
- Both qualitative and quantitative studies were included.

Studies were described in terms of country, date of publication, populations (including palliative condition), design, rural description and assessment outcome. Two main categories were identified, actual place of death (APoD) and preferred place of care and/or death (PPoC/PPoD), with results summarised in two separate tables.

A quality assessment of each paper was conducted. One of my supervisors independently assessed a random selection of six studies (17%). Differences were discussed by email and resolved by consensus. Different scales were used to assess the quality of the quantitative and qualitative studies. Mixed studies were assessed using both scales. The quality assessment tool outlined previously in the scoping review, was used for the qualitative studies (Appendix 2). The scale suggested by Khan (2001, as cited in Gomes & Higginson, 2006), and modified by Gomes et al. (2013) was used for the quantitative studies.

Quantitative data were manipulated into a common format and where possible, algebraic back calculations were performed to determine the percentage of actual or preferred rural home deaths. Where the adjusted odds ratio (aOR) was reported, the rate of a rural home death was compared to urban (aOR of urban home death=1). Thematical analysis of the qualitative data regarding PoC/PoD are reported descriptively. Due to heterogeneity, a meta-analysis was not possible. Findings are reported in Chapter 2 (Table 2.2 and Table 2.3 summarise the included studies). The full data extraction tables can be found in the published paper in Appendix 6.

Figure 4.2: Flow diagram of selection process for 'Place of death in rural palliative care: A systematic review.'



PoD: place of death; PoC: place of care; APoD: actual place of death; PPoC/PPoD: preferred place of care/death.
♦ Differences were discussed via email and resolved by consensus

4.2.2.2 Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic review

The second systematic literature review, “*Rural end-of-life care from the experiences and perspectives of patients and family caregivers*” was conducted in January 2016, again by searching four electronic databases (PubMed, CINAHL, Scopus and Web of Science) using the following keywords and Medical Subject Heading (MeSH) terms: (“palliative care” OR hospice OR “terminal care” OR end-of-life OR “end-of-life care”) AND (Rural OR Remote) AND (patient OR family OR carer OR caregiver) AND (perspective OR experience OR opinion OR view). An initial date filter of January 2006

through January 2016 was applied to include an overlap with the last published systematic review (C Robinson et al. 2009). This allowed for any missing submitted, but unpublished studies to be included. One article (Payne et al. 2007) was identified and included.

The reference lists of all included studies were scanned for additional articles. A hand search of recent issues (July 2014 - January 2016) of six relevant journals (Palliative Medicine, Journal of Palliative Medicine, Journal of Pain and Symptom Management, Palliative and Supportive Care, Australian Journal of Rural Health, and Journal of Rural Health) was also undertaken. An updated search of the previous databases and journals was undertaken, in early March 2017, using a date filter of 1 February 2016 to 28 February 2017. Sixty-six additional potential papers were identified in the databases, including two of my published papers. No relevant rural studies were identified in the updated hand search of journals (Figure 4.3).

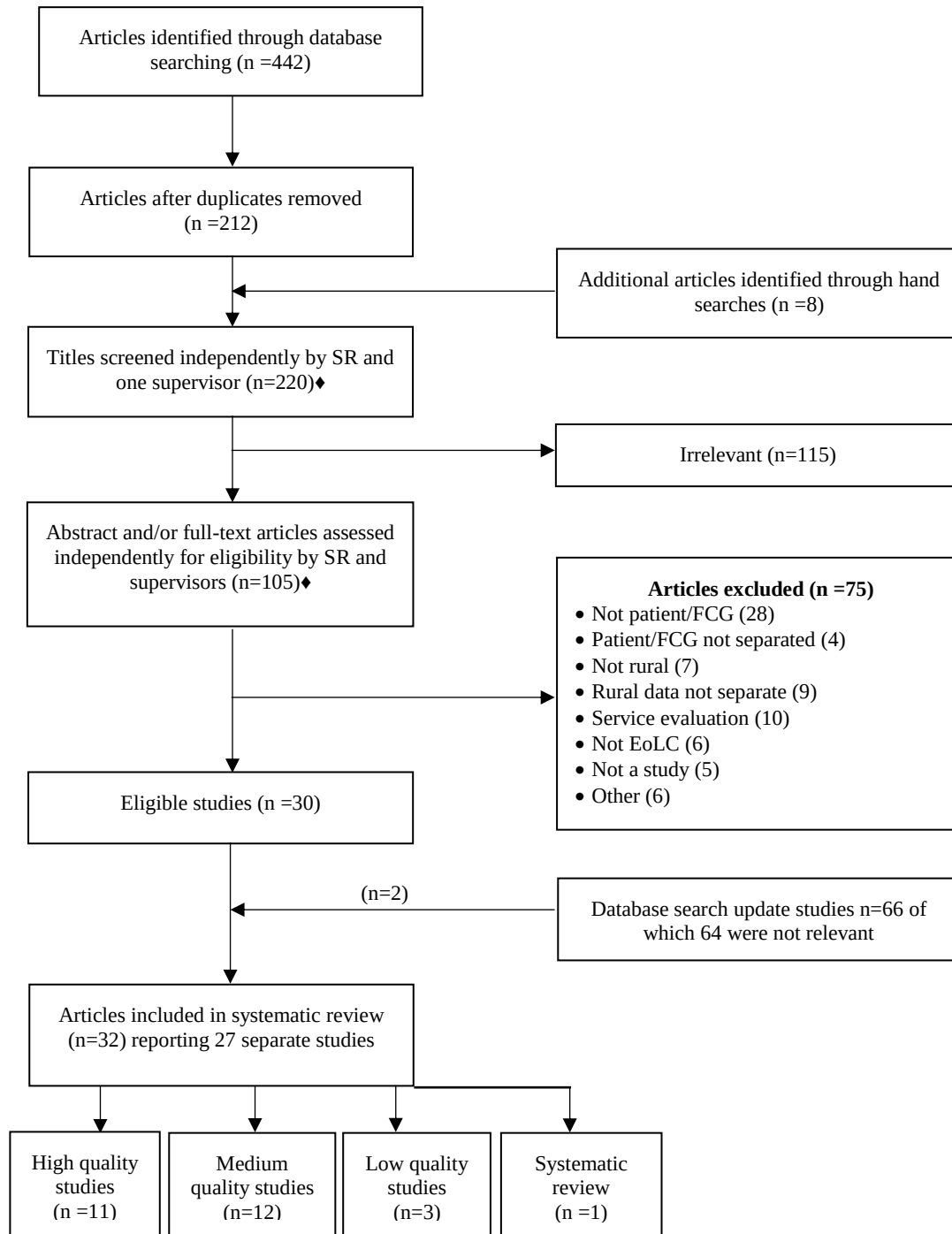
Studies were included if they were consistent with the following inclusion criteria:

- Rural or remote residents (no standardised definition of rurality was used).
- Participants were receiving palliative or EoLC for malignant or non-malignant illnesses.
- Data pertained to patients' or FCGs' experiences or perspectives on EoLC, collected from interviews or surveys.
- Both qualitative and quantitative studies were included.
- No age filter was applied.
- Only published international English language, peer reviewed research articles were considered. Articles that included urban and rural data were included, providing the rural data were clearly identifiable.

Rejected studies were either clearly irrelevant or those that addressed the topic in general but failed in one or more of the inclusion criteria. After an initial quality assessment was made, verification was shared independently by the five co-authors. The previously outlined scoring card was used. Differences were discussed by email and resolved by consensus. While low quality studies were excluded from the published systematic review, all studies, regardless of quality, were retained for my thesis literature review (Table 2.4, Chapter 2).

Study findings were coded into four categories: (1) patient perspectives; (2) FCGs perspectives; (3) facilitators and barriers to receiving rural palliative EoLC; (4) influence of rural place and culture on EoLC. Each category was analysed thematically and reported descriptively.

Figure 4.3: Search flow chart ‘Rural end-of-life care from the experiences and perspectives of patients’ and family caregivers’: A systematic review’.



Source: modified flow chart as described by Moher et al. (2009) Abbreviations: FCG- family caregiver; EoLC- end-of-life care ♦ Differences were discussed via email and resolved by consensus

4.3 Theoretical framework and methodology of the mixed methods research study

While previous studies have utilised written questionnaires and surveys (Patrick et al., 2001), such as the ‘Quality of death and dying questionnaire’ (Curtis et al., 2000), in-depth qualitative interviews are more appropriate to investigate the participants’ perspectives and viewpoints on the ‘good death’ as:

One of the great advantages of qualitative methods is that they enhance the capacity not only to describe events but to understand how and why the same events are often interpreted in a different, sometimes even conflicting manner, by different stakeholders (Sofaer, 1999, p. 1106).

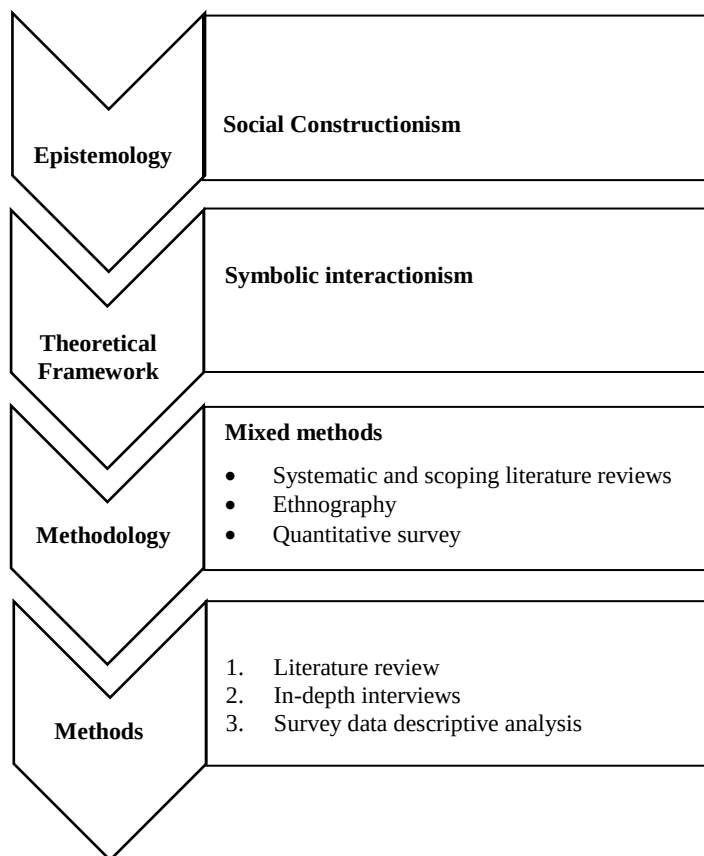
The secondary aims of this research were to determine the influence of PoD, and rural residency on the concept of the good death, and to explore the meaning behind the PoD preferences and decision-making process. Again, this information is best captured in open-ended interviews. To complement the fieldwork, and to place the interview data into context, I also completed a descriptive study of current practice, addressing the questions ‘Where do Snowy Monaro residents die?’ and ‘What factors influence place of death in this rural setting?’ My research therefore, used a mixed methods approach, combining ethnography methods (detailed in Section 4.4), to gain a deeper understanding of, and the reasoning behind the actual or preferred PoD, with descriptive analyses from the survey data (detailed in Section 4.5).

The theoretical perspective, or philosophical stance, informing the methodology and epistemology (the theory of knowledge embedded in the theoretical perspective, and thereby in the methodology) is symbolic interactionism, developed by Herbert Mead (1863 -1931), in which people create meaning based on their interactions with others. The meaning of events and behaviours arises from an individual’s interpretation. Behaviour, therefore, is not necessarily based on objective truth, but on what a person believes to be true. Interpretations of the same event can vary from person to person (Crotty, 1998). Symbolic interactionism, in turn, reflects the fundamental epistemological stance adopted by this research, social constructionism:

Truth or meaning comes into existence in and out of our engagement with the realities in our world.... meaning is not discovered, but constructed...different people may construct meaning in different ways (Crotty, 1998, pp. 8-9).

Constructionism is based on the view that reality is based on knowledge. Knowledge is formulated through social context, and it is this context that dictates the way people view or construct ‘their world’. Interactions between people and ‘their world’ constructs meaningful reality. Therefore, there is no single or true interpretation of events, only meaningful or useful interpretations. Social constructionism infers that ‘without culture we could not function.... We depend on culture to direct our behaviour and organise our experience’ (Crotty, 1998, p. 53). The theoretical framework is illustrated in Figure 4.4.

Figure 4.4: Theoretical framework and methods underpinning the complete research study.



4.3.1 Ethnography

Qualitative research, utilising interviews and observation, is interpretative and studies ‘things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them’ (Denzin and Lincoln, 2005, as cited in

Grbich, 2015, p.40). There are perceived differences between rural and urban cultures, and the influence of rural culture on the 'good death' and place of care/place of death is best explored through an ethnographic study. Ethnography specifically 'deepens the understandings of cultures and culturally based concepts' (Wilson et al., 2009a, p. 21). In this study, ethnography provided deep insight into the participants' perspectives on the rural 'good death', the meaning behind PoD preferences and decision making, and the influence of rural culture and values on the 'good death' and PoD within the Snowy Monaro region.

Ethnography, a research method developed by anthropologists to describe and understand foreign cultures, is used to understand groups of people living within society (e.g. the marginalised or invisible). As summarised by Patton (2002, p. 81), 'The primary method of ethnographers is participant observation... [along with] extensive fieldwork in which the investigator is immersed in the culture under study.' Variations in cultures are recognised by gaining and describing 'the understandings and meanings constructed by people as they undertake daily activities' (Grbich, 1999, p. 159).

Becker et al. (2004, p. 269) suggest that traditional ethnography defines 'social problems that have either not been recognised or have fallen off the radar screen...because the presence of this problem contradicts cultural norm.' In this study 'cultural norm' is the culture of palliative care, as studied from an urban perspective, where urban residents requiring EoLC usually have access to a specialist multidisciplinary palliative care team. Becker et al. (2004, p. 271) also argue that:

Ethnography has the capacity to develop different ways of thinking about a social universe that is often taken for granted, to explore and make real the experience of people who have gone through hardship, through loss...and possibly even a triumph against all expectations.

Within qualitative research there are two main schools of thought regarding the positioning of the researcher. Grbich (1999, p. 5) suggests some would say 'the researcher can participate in, and document, the 'outer' world with minimal intrusion' while others believe 'the perceptions of the researcher and other participants in the 'socially constructed' world are intricately interwoven'. Ethnographic researchers are

conscious of the potential for bias in all research, as every aspect, starting from the research question, design, methodology, selection, analysis, conclusions and responses to ‘ethically important moments’ (Guillemin, 2004), are influenced by our values and beliefs, background and motives, and are open to subjective interpretation (Ulin et al., 2005). Essential components of ethnography are transparency and reflexivity (Rice et al., 1999). Reflexivity is a process of critical reflection by the researcher. It is important that the researcher is able to stand back, at every stage of the research, and take a critical look at their own role in the whole research process.

Researcher influence is not just limited to my personal world view, but my very presence within the study, and my personal framing. ‘Rigorous qualitative research is honest about the role of the researcher in the project’ (Rice et al., 1999, p. 41); however, despite all attempts, no researcher can be totally unbiased. Steps (described later) were taken in my research, starting at recruitment through to the final writing, to minimise my potential bias in collecting, analysing and reporting the research results.

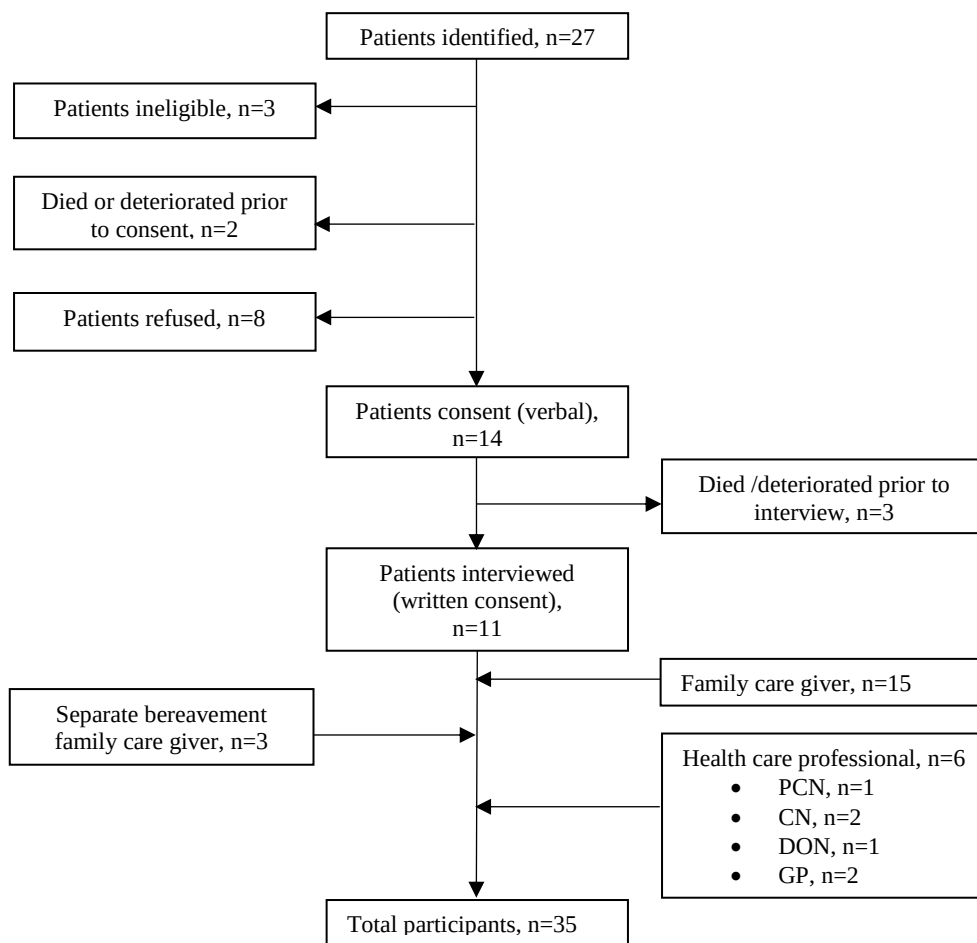
4.4 Ethnographic component

A qualitative approach, utilising open-ended interviews as the prime method of data collection, was chosen to ensure there was sufficient depth and detail to fully understand each participants’ personal experience (Patton, 2002, pp. 16-17), and to enlighten the interpretations of the quantitative data. While there is limited data on EoLC from the experiences and perspectives of patients and their FCGs, I felt it was important not to exclude the local rural health professionals (palliative care nurse [PCN], community nurse [CN], residential aged care facility director of nursing [RACF DON], and general practitioners [GPs]), as a cross section of viewpoints would facilitate triangulation and thus provide a more accurate picture of the realities of the rural ‘good death’.

4.4.1 Recruitment

To ensure a cross-section of experiences and perspectives, three groups of participants were recruited for the ethnographic study: patient and FCG dyads; local health care professionals (HCPs); and bereaved FCGs, whose family member had died up to twelve months previously (Figure 4.5).

Figure 4.5: Recruitment flow chart for interviews



Abbreviations: PCN- palliative care nurse; CN- community nurse; DON- residential aged care facility director of nursing; GP- general practitioner.

*For 1 consenting patient the FCGs were interviewed first, but the patient became too unwell before they could be interviewed

Recruitment for interviews was conducted through direct invitation. Twenty seven potential patient participants, who fulfilled the inclusion criteria (Table 4.1) and triggered a “no” response to the ‘surprise question’, “would you (the referrer) be surprised if this patient were to die within the next 6 months?” (Gold Standard Framework, 2011), were identified by the palliative care nurse (19), community nurse (1), one RACF DON (2), two GPs (3) and myself (2). Except for the purposely selected bereaved family members, who received their invitation by mail, most FCG participants were present at the time of patient invitation. The three absent FCGs were identified by the patient, and with patient consent, were contacted at a later time. Over time, recruitment became more purposeful, as I tried to ensure a cross-section of participants representing all three shires, different degrees of rurality, both cancer and non-cancer diagnoses, and those receiving care at home, hospital and in a RACF.

Table 4.1 Inclusion criteria for interviews

Patient	Family caregiver	Bereaved family caregiver
- Life limiting illness - Life expectancy ≤ 6 months - Awareness of prognosis - ≥ 18 years - Snowy Monaro resident - English speaking - Capacity to provide consent	- Family member or person identified by patient as primary informal caregiver - ≥ 18 years - English speaking - Capacity to provide consent	- Next of kin identified in obituary notice - Deceased relative was a Snowy Monaro resident - Relative died of a life-limiting illness - ≥ 18 years - English speaking - Capacity to provide consent

Before commencing any interviews, the objectives and processes of the research were discussed with the PCN, CN, DON and a principal GP in each of the general practices. I personally made a presentation during a lunchtime meeting to the two GP practices in Cooma. The nurses and GPs were phoned, and invited to be interviewed, after the patient had died. Strategies for maintaining confidentiality were discussed (real names and ages have not be used in any report). Recruitment strategies ensured voluntary participation. Conflict of interest was addressed by advising each GP when one of their patients had consented to participate. This was not just a courtesy, but provided opportunity to assure the GP I would not be taking over the care of their patient, unless I received a formal referral at a later date.

In accordance with the ANU and GWNSW LHD ethics requirements, on the two occasions where I directly approached one of my current patients to invite them to participate, a third party (practice nurse) conducted the consenting process to ensure there was no coercion, on my part, to participate. At the time of recruitment, one of my current patients identified by another GP, declined to participate.

Once identified by the recruiter, the patient gave verbal consent to be contacted directly by phone. I responded to all identified potential participants who had given verbal consent, with the exception of two who died unexpectedly, prior to making contact. The reasons for not participating included not wanting to talk about dying, and being too busy travelling for treatment. One Asian FCG of an interested Anglo-Saxon patient, identified by the palliative care nurse, hid the paperwork from the patient as she felt it was culturally inappropriate to talk about dying.

4.4.2. Participant consent

Before commencing interviews, participants were provided with a detailed participant information sheet (a copy can be found in Appendix 4), outlining the objectives of the study, the interview process, the topics to be covered, and the way their information would be managed and stored. Participants were assured they were free to withdraw at any time, up to the time of thesis submission or journal publication. Participants completed a signed consent form before commencing the interview. An iterative process of consent was undertaken. At the start of each interview I gained verbal consent to proceed, and at the end of each interview the participant was asked if there were any details they wanted deleted. At the start of each interview, the patient and their FCG were reminded that I was interviewing them as a researcher, and not as their treating doctor. As such, the participants were not to assume I knew anything about their illness and its management; that I would not be providing advice; and that I was not implying there would be a change in their clinical management by asking certain questions. For example “Have you considered moving to a nursing home?” did not imply that was my intention as their treating doctor. Despite my best intentions to allay patients’ concerns, one patient did become upset, as he thought I was trying to send him to a nursing home. His GP spoke to him at length the following day, and assured him he was remaining in the hospital for EoLC. In other interviews, a few patients and FCGs teared up when telling their story. In these instances, I gave them time in quietness, sometimes pausing the recording. I was careful to ensure they were ready, and agreeable, to continue the interview. The information sheet provided the contact details of a counselling service (Beyond Blue) if they felt they required additional support. To my knowledge this was not required by any participant, and in fact a number of bereaved FCGs commented on how therapeutic it had been to talk about the death of their relative.

Between three and six months after the patient had died, all FCGs who had previously consented were contacted by either phone or mail, to arrange a follow-up bereavement interview. In respect for the FCGs’ grieving, they were not contacted immediately after the death. However, the literature reports that if too much time has elapsed, then issues of memory may impact the validity of the recall (Addington-Hall & McPherson, 2001). Despite all FCGs previously consenting, this aspect of the research proved to be difficult. Of the 15 FCGs, only five agreed to be interviewed, with another who talked openly about his experience, during my follow up phone call, but declined a formal

interview appointment. My failure to contact the remaining bereaved FCGs, (two had moved away, two did not return my phone calls, two had returned to their interstate and overseas homes, and the remainder were uncontactable) is consistent with previous studies (Bakitas, 2008, p. 7). Two bereavement interviews were face to face, the remaining three were conducted over the phone.

While patients and FCGs are the main group ‘missing’ in rural studies, I felt it important to also gain the views of the nurses and GPs directly involved in the care of the patient. The PCN was aware of who had consented to participate as she was the primary recruiter. The relevant GPs had also been contacted, to advise them of their patient’s participation. After the patient had died, I again contacted the nurse and GP, and invited them to be interviewed, for them to express their perspective on the EoLC, death and PoD. Two GPs agreed, however a third did not respond to my invitation. I was the primary treating doctor for three patients. At least one nurse or DON agreed to be interviewed for each patient.

The third group of participants was a purposely selected group of bereaved relatives, chosen because their story was possibly outside the stories of the recruited patients. During my patient interviews none had died in the out-of-town hospice, so my search of the obituary notices selected three FCGs whose family member had died in the Canberra hospice. I also selected three FCGs whose family member had lived on a farm and died in the local hospital; one whose wife lived in a village and died in the Bombala MPS; a younger man who was cared for and died of a palliative illness at home; and an elderly man who was transferred from the tertiary hospital to die in the local rural hospital. Of nine invitees, four responded, with one regretfully advising that they were still grieving after 12 months, and unable to participate.

All consenting participants are residents of small rural communities, and it is possible, despite the use of de-identified data and aliases, they might be recognised through their role, stories and quotes. Permission to include quotes and stories was included in the consent process.

4.4.3 Interview participants

Table 4.2 lists all the participants, and describes the demographic features of the patients (interviewed and identified in obituary notices). Names and ages have been changed to preserve participants' anonymity, though ages are within five years of the true age.

4.4.4 Data collection - the interviews

This research used open-ended interviews. I refrained from using a structured interview format, as I wanted to explore deeply the views, perspectives and experiences of the participants (Patton, 2002, p. 4), and wanted to be sufficiently flexible to allow the participants to set the direction of the discussion. I did however, have a set of prompt questions, adapted from those described by McCall and Rice (2005) (Appendix 5) to assist in the interview process. On a few occasions, I referred to the prompts early, especially if the interviewed stalled; however, it was more common for me to glance over the list at the end of the interview, to ensure all major points had been addressed.

The interview topics were based around the patients' illness, care, needs and support (what was good, what could be done better), where they would prefer to be cared for in the last weeks and days, and if they had a preference for PoD. As the interviewing stage progressed, my approach to the interviews became more iterative and more focused, as I would specifically ask questions surrounding an issue raised by a previous participant. I wanted to determine if the issue raised was specific to one participant or more generalised. As I became more confident, and where appropriate, I asked specific questions relating to the 'good death'. "You have no doubt heard of someone living a good life, what do you think would make a good death?", and in the bereavement interviews "did....die well?" or "did ... have a good death?" In some interviews I asked more general questions around the topic, as I had a sense the concept may not have been readily received. I also asked about the benefits and challenges of rural residency on EoLC and PoD.

Table 4.2: List of participants and demographic features of the patients (interviewed and identified in obituary notices).

Patient	Sex	Age	Marital	Diagnosis	Residence	Place of death	Interviewed family care-giver	Interviewed health care professional
#1 Gwen	F	81	Widowed	CRC	Town	RACF-respite	Daughter (Louise); Lived 500km away	DON
#2 Cheryl	F	56	De facto	GBM	Town, RACF	RACF (LT)	Partner (Pat)	NIL
#3 Marianne	F	62	Married	Myeloma	Farm	Home	Husband (Peter)	GP , CN
#4 Kevin	M	75	Married	Sarcoma	Town	Home	Wife (Deedee) Daughter (Susan)	PCN
#5 Ray	M	74	Married	Lung ca	Town	CDH	Wife (Clare)	PCN
#6 Ryan	M	56	Married	Lung ca	Rural residential	Home	Wife (Carol)	PCN
#7 Barbara	F	92	Widowed	Frailty	Town - RACF	RACF (LT)	Son (Rodney) Lived 400km away	NIL
#8 Bruce	M	85	Married	CRC	Farm	RACF EoLC	Wife (Diane)	NIL
#9 Dorothy **	F	84	Married	Pulmonary Fibrosis	Town-RACF	RACF (LT)	Daughters x2 (Rhonda, Simone)	NIL
#10 Ivan	M	83	Widowed	Leukaemia	Farm	Home	Son (Paul); daughter (Amanda-interstate)	GP CN
#11 Stuart	M	55	Single	Pancreatic ca	Town	BMPS	Brother (Fred); lived 500km away; retires and stayed with Stuart for last weeks)	PCN
#12 George	M	62	Divorced	Lung ca	Village	BMPS	Sister (Betty); lived in separate dwelling on property	NIL
#13 Leanne *	F	55	Partner	Breast ca	Farm	CDH	Partner (Daniel)	NIL
#14 Elaine*	F	60	Married	Breast ca	Town	Hospice	Husband (Andrew)	NIL
#15 Gordon *	M	72	Married; wife in RACF	Cerebral lymphoma	Town	CDH; transfer from TCH for EoLC	Son (Nathan)	NIL

* Patient not interviewed (identified in obituary notice); ** Patient not interviewed as too unwell;
Abbreviations: RACF=residential aged care facility; LT= long term (permanent resident); HCP= health care professional; CRC=colorectal cancer; GBM= Glioblastoma multiform; DON= director of nursing; GP=general practitioner; CN=community nurse; PCN= palliative care nurse; CDH= Cooma hospital; ca= cancer; BMPS=Bombala multipurpose service; TCH=The Canberra Hospital; EoLC= end-of-life care.

Where possible, interviews were conducted at the place of residence (private home or RACF); however, a few interviews were conducted in hospital. On one occasion, a patient was admitted to hospital on the morning of my pre-arranged interview. Despite my hesitancy to interview the patient and his wife, on what was a distressing day, both were eager to keep to the interview schedule. I kept the interview with this patient as short as possible (15minutes). Two bereavement interviews, identified through obituary notices, were conducted at my place of work. I had not met the men before and felt it more professional to conduct the interviews in a more 'public' space. With the exception of three bereavement phone interviews, all interviews were conducted face to face, as meaning is not just the words but also the non-verbal clues, the facial expressions, gestures in response to the words spoken, details that can only be observed in interviews. This meant for one outlier I travelled 270 km round trip from my home to conduct the interview.

In total, 42 interviews, lasting a total of 22.8 hours, were conducted, between 20th April 2015 and 24th November 2016. The interviews lasted from six to 78 minutes, (average 33 mins). The time spent with patients was determined by their physical condition. Time spent with FCGs was determined by their availability. For example, a follow up interview with Gwen's daughter lasted just eight minutes, as she was concerned about leaving her mother on her own. The interviews were mostly individual, with two joint interviews with both patient and FCG present. I had intended to conduct a follow up interview with each patient; however, most patients became too unwell, or it was not possible to find a mutually convenient time, especially those living further away from Cooma. Two patients died while I was overseas on holidays.

At the start of each interview, I re-affirmed that the interviewee consented to participate, and for the interview to be audio recorded. Participants were reminded they could stop the interview at any time. I did not take any notes during the interview; however, wrote an entry in my personal journal (my feelings, the environment, physical condition of the patient, interruptions) once back in my car.

The interviews were conversational and open-ended, however, became more focused as I wanted to explore further issues raised in previous interviews. At the completion of the interviews I gave the participants' opportunity to raise any issues they felt had not been

covered, and to delete anything they did not want recorded. All interviews were audio recorded, and transcribed verbatim. After transcribing, participants were assigned an alias. Recorded interviews were deleted from the recorder after transcribing.

Downloaded interviews, transcriptions and notes are kept on my password protected laptop. A backup copy is kept on an external hard drive. As per the standard ANU policy, these files will be kept for five years after publication.

4.4.5 Analysis of qualitative data

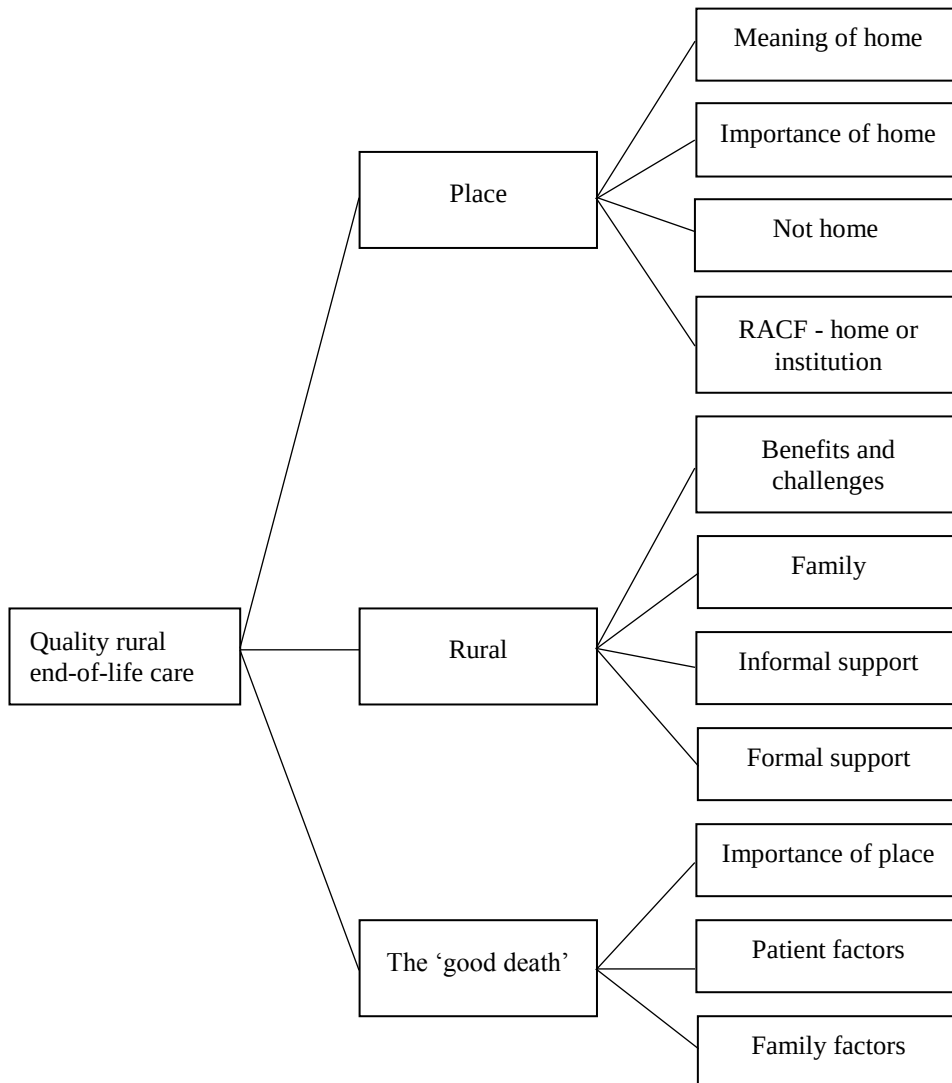
Transcribing was a time consuming process, made more difficult by my elementary typing skills. Transcribing of a one hour interview took up to eight hours to complete; however, it provided opportunity to become embedded in the data and reminded me of the emphasis placed on words, and the emotions displayed during the interviews. It was during the transcribing process that I began initial analysis. However, after transcribing the first five interviews I employed a known and trusted local online transcribing service. On receipt of the transcripts, interviews were listened to and errors corrected. The transcripts were re-read, then down loaded to NViVo-10. Data analysis was undertaken using thematic analysis, which involved the identification, analysis and reporting of patterns, themes and interrelationships within the data (Patton, 2002, p. 41). In the two occasions I was able to conduct follow-up interviews, issues clouded in uncertainty were clarified.

After becoming intimately familiar with the data, a coding tree was developed. Often qualitative research is conducted by a team, where members would independently code the data, then compare and discuss similarities and differences, in order to gain a consensus. However, as this research is a PhD thesis, the coding was substantially carried out on my own, with general guidance provided by one supervisor with extensive experience in ethnography. After determining the three main themes (place, rural/community, and 'good death'), coding was inductive (discovering patterns and themes) rather than deductive (analysing data according to a predetermined framework) (Patton, 2002, p. 453). Each major theme was classified into sub-themes (Figure 4.6).

Separate chapters are devoted to each of the major themes. The use of direct quotations has been used to explore the sub-themes in the following results chapters, as they are:

A basic source of raw data in qualitative inquiry, revealing respondents' depth of emotion, the ways they have organised their world, their thoughts about what is happening, their experiences, and their basic perceptions (Patton, 2002, p. 21).

Figure 4.6: Coding tree



4.5 Quantitative component

This study had some secondary questions, and in order to answer the questions, ‘Where do Snowy Monaro residents die?’, ‘What factors influence the PoD?’, and ‘Are residents living on farms less likely to die at home than residents living in town?’, the inclusion of a survey method was necessary. Ethics approval was granted as previously reported.

4.5.1 Quantitative methods objectives

A formal quantitative approach allowed me to describe the PoD of residents within the Snowy Monaro region, both systematically and explicitly. It also allowed me to present the data visually (charting) and mathematically (frequencies and logistic regression) in order to identify patterns within, and relationships between the influencing factors associated with dying at home or in one's usual place of residence (UPoR). These patterns may not be obvious from the qualitative interviews, due to the small sample size. Death data were collected from a variety of local informants, including funeral directors, residential aged care and inpatient health facilities, local newspaper obituary and funeral notices, and funeral announcements on local radio. An explanation of the data collection and analysis is provided later in this chapter.

4.5.2 Recruitment

The final group of participants in this original research, were the informants of the population PoD survey data. The primary informant was the local funeral director. I had approached him, prior to gaining HREC approval, to seek his interest in participating. Once ethics approval was obtained, he was formally invited to participate and was issued with an information sheet and consent form, (copy in Appendix 4). He was advised that participation was voluntary, and that he could withdraw at any time, until publication of the data. It was made quite clear to the funeral director that, as the only 'local' funeral director, his identity would easily be recognised by anyone familiar with the region and reading this thesis or future journal publications.

As data collection began, it became apparent that data relating to decedents residing in the Bombala area were missing, due to adjacent out-of-region funeral directors being engaged, and lack of obituaries published in the once weekly '*Bombala Times*'. An amendment was made to the ethics approval to recruit additional informants. As there are no resident GPs in the town, most deaths in the Bombala district, regardless of PoD, are certified at the local hospital (Bombala MPS), before the body is transported to the undertakers' mortuary. There was also conflicting information, provided in the obituary notices, on some long term RACF residents, with the obituaries reporting their last address as their previous private residence rather than the RACF. This fact was highlighted during a conversation with one DON. A further amendment was made to the protocol to permit DONs to provide the length of stay for their deceased residents,

identified through obituary and funeral notices. Contact with the informants was in person or via email or phone.

Waiver of consent from decedents' next of kin was granted on the basis that names and addresses were not collected, and the use of any data was unidentified. The majority of decedents had previously been identified either in local newspaper obituary notices or funeral announcements on local radio.

4.5.3 Quantitative data collection

Death data were collected from 1st February 2015 through 31st May 2016. Denominator data on numbers of deaths were obtained from consenting informants (local funeral director (personal contact and website), Bombala MPS and RACFs), and from obituaries and funeral notices in local newspapers, on local radio, and adjacent out-of-region funeral directors' websites (Table 4.3) After contacting the NSW *Registry of Births, Deaths and Marriages* by email, to seek advice as to how best to access data contained in the official death certificates, I was referred onto the Australian Bureau of Statistics (ABS). The ABS advised that their Causes of Death dataset does not contain the actual place of death beyond the state or territory the death was registered. For ethical reasons, mainly relating to privacy and consent, I was unable to personally access copies of the *Medical Certificate Cause of Death* (MCCD) held by the local hospitals, funeral directors, RACFs and GPs. Cause of death was therefore determined by data provided by the consenting informants taken from their official records. De-identified data on date of death, age at death, sex, place of death, cause of death, and last place of residence (farm, village, or town) was supplied by the informants. RACFs also provided decedents' length of stay. Duplicate records were deleted by cross checking obituary and funeral notices with data received from the consenting informants.

It was my intention to collect data over a 2-year period. At the start of data collection there was a widely circulated, twice weekly local newspaper, the '*Monaro Express*', publishing obituary and death notices, from which data on 'last place of residence' and marital status were collected. Without notice, the newspaper ceased publication in mid-May 2016. At the time, many obituary and funeral notices were not published in the remaining weekly local paper "*The Monaro Post*", due to its small circulation, and distribution after many funerals had taken place.

Table 4.3: Informants of the Snowy Monaro death data

Informant: Total deaths, N=224	n (%)
Local funeral director and local newspaper	122 (54.5%)
Local funeral director (direct and website)	48* (21%)
Adjacent out-of-region funeral directors' websites	8 (4%)
Local newspapers (no other informant)	25 (11%)
Local radio only (no other informant)	2 (1%)
BMPS nursing manager or RACF DON	18 (8%)
Qualitative bereavement interview	1 (0.5%)
*Includes 4 deaths identified only on website; BMPS- Bombala multi-purpose service; RACF residential aged care, DON director of nursing. 161 deaths (72%) were available in the public domain.	

4.5.4 Quantitative analysis

The population PoD data was entered into IBM Statistical Package for Social Sciences version 22 (SPSS-22), for ease of recording and analysis. Demographic data were collected on date of death, sex, age at death, marital status, last place of residence, PoD, and cause of death. Marital status was only available from newspapers, resulting in missing data for 31.7% of decedents. Marital status was classified into married/de facto/widowed/single/unknown; for the logistic regression model, marital status was dichotomised into partnered (married/de facto) and un-partnered (widowed/single). It was not possible to determine if decedents were living alone or with others, or how long patients were cared for at home before transferring to a hospital or RACF.

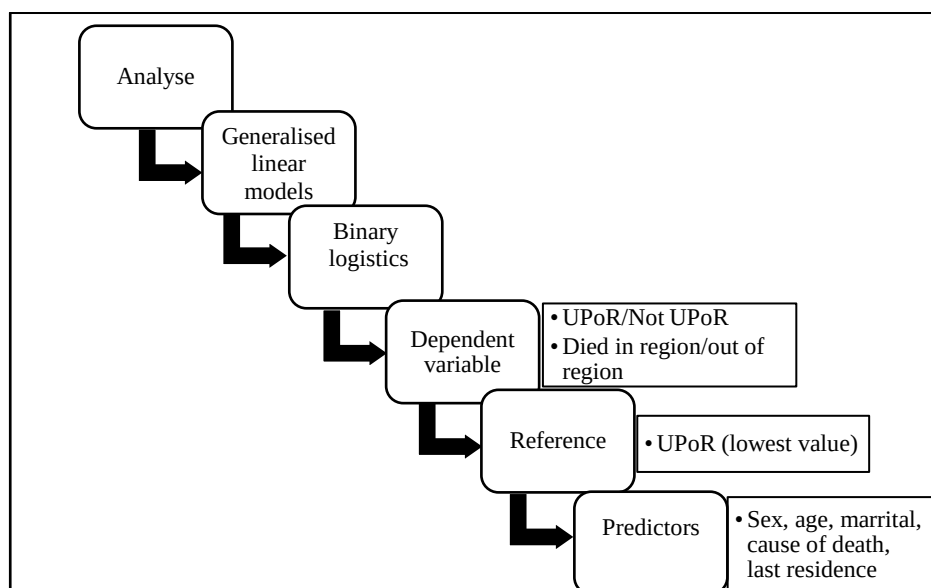
Place of residence was categorised according to the degree of rurality, which reflected the availability of health services. Only the towns of Cooma and Bombala were classified as 'town', as they contained GPs, rural hospitals and RACFs. The remaining region was classified as 'small towns' (with GPs), 'villages' (no GPs); or 'farm'. Cause of death was separated into 'natural' or 'external' (accident, suicide, homicide) causes. Of those deaths considered to be 'natural', decedents were dichotomised into 'palliative' or 'non-palliative'. The palliative subgroup consisted of decedents who had died of an advanced chronic condition. These included advanced frailty (Gomez-Batiste et al., 2014), and the 10 conditions, considered by McNamara et al. (2006) to be amenable to palliative care (cancer (solid and haematological), chronic cardiac failure (CCF), end stage renal failure (ESRF), liver failure, chronic obstructive pulmonary disease (COPD), motor neurone disease (MND), Parkinson's disease, Huntington's disease, dementia, and HIV/AIDS). In this study, there were no deaths due to Huntington's disease or

HIV/AIDS. While other studies (Gomez-Batiste, *ibid*) have included chronic cerebral-vascular disease in the palliative subgroup, as it was uncertain if deaths due to cerebrovascular accident (CVA) were acute or chronic they were excluded from the palliative subgroup. It is unknown which, if any, of the decedents in the palliative subgroup were identified by their health professionals as 'palliative' or if they were receiving palliative care at the time of their death.

Data were initially charted descriptively. Cross tabulations by PoD and key demographic data were performed. Bivariate logistic regression was undertaken to identify factors that may influence the actual PoD, in particular dying in one's UPoR, and within region. Independent variables used in linear regression modelling were derived from studies reported in my literature review, and consistent with factors emerging from the original research qualitative data analysis.

The outcome variable was place of death: private residence, local hospital, out-of-region hospital, out-of-region (Canberra) inpatient hospice, RACF, other (road, workplace), and unknown. RACF decedents fell into two groups: those who were permanent residents (length of stay (LOS) ≥ 3 months), for whom the RACF was their 'usual place of residence' (UPoR); and those admitted for respite or transferred from their private residence for end-of-life care (LOS < 3 months). For this study UPoR referred to either a private residence or long term RACF. The final dependent variables were 'dying in UPoR' or 'not dying in UPoR', and 'dying in region' or 'dying out of region'. Pearson Chi² tests were used to determine if any of the independent variables were associated with PoD. Exact p-values were calculated whenever there were any expected cell counts less than five. For large contingency tables, Monte Carlo simulation was used to estimate exact p-values. P-values less than 0.05 were considered to be statistically significant. Bivariate logistic regression was conducted using the model outlined in figure 4.7. Multivariate logistic regression was unachievable.

Figure 4.7: SPSS modelling for logistic regression



Abbreviations: SPSS=Statistical program for social sciences; UPoR=usual place of residence

4.6 Ethical considerations

Both qualitative and quantitative research received ethics approval from two human research ethics committees, the Australian National University (ANU) and Greater Western New South Wales Local Health District (GWNSW LHD) Human Research Ethics Committees. Site specific approval was also granted by the Southern New South Wales Local Health District (SNSW LHD) to conduct the research within SNSW LHD facilities, and to interview their staff and patients. A copy of the ethics approvals can be found in Appendix 1.

4.7 The role of the researcher

Research does not occur within a vacuum, instead the researcher brings to the study/interview their own insights, opinions and beliefs formulated from personal experience. To maintain rigor within the study the researcher must remain reflective:

The qualitative analyser owns and is reflective about [their] own voice and perspectives; a credible voice conveys authenticity and trustworthiness; complete objectivity being impossible and pure subjectivity undermining credibility, the researcher's focus

becomes balance - understanding and depicting the world authentically in all its complexity while being self-analytical, politically aware, and reflexive in consciousness (Patton, 2002, p. 41).

Throughout each step of this study I have tried to be transparent and as objective as possible; however, the circumstances under which this study was conducted were inherently open to bias. Firstly, I am the only palliative medicine specialist in the region and a long term resident, over 25 years. Secondly, one of my supervisors is also a long term resident and medical practitioner in the Snowy Monaro region. As such, we are well known and (hopefully) respected. This had potential to create bias in recruitment and a sense of participant coercion. As previously noted, a third party conducted the consent process for any of my current patients. A few patients declined the recruiters' invitation to participate. In contrast, Gwen, whose story is told in the preface to Chapter Six, was extremely keen to participate. Gwen had metastatic cancer. Living in a country town meant I was not just her GP, but our paths also crossed socially. Long before I had gained ethics approval for this study, Gwen had heard of my project and asked if there was anything she could do to help me with the study. She offered to be interviewed, and wanted to "*be a help. That's the main thing*". While waiting for ethics approval, Gwen asked on numerous occasions, "*when are you going to interview me?*" When the green light was finally given, Gwen was participant number one. To appease the ethics committees' fear that recruitment could be seen as coercion, I arranged for our practice nurse to complete the consent process.

During interviews there was an imbalance of power: interviewer/doctor versus interviewee/patient. I tried to be transparent and trustworthy in conducting the interviews by reinforcing the fact that during the interviews I was a researcher and not a doctor, and would not be making any comment or giving advice on management. The ethics committees also clearly stated that I could not use any information I had prior knowledge of, or that had not been obtained in interviews. This meant that I could not access the medical notes, of not only the interviewees but also to fill in missing data collected for the death statistics component of the study. This was a two way restriction, and in one case I was unable to share potentially significant information I had gathered from a confidential patient interview, with family and health providers during a management related family meeting.

While I was involved in the management of only three patients at the time of recruitment and interview, as circumstances dictated I was actively involved in the management of an additional five patients prior to their death. While this may not have influenced the collection of data, there is potential for my knowledge of the timing and circumstances of each one's death to influence my analysis and write up of my report, because, as one university lecturer told me, "*You cannot un-know what you already know*" (Dr Graham Fordham, Senior Lecturer in Social Foundations Medicine, Medical School, ANU College of Medicine, Biology and Environment, 2015). Likewise, of the three previously bereaved relatives, I had been involved in the care of two of their family members.

4.8 Limitations

The limitations of this study are described in detail in the final chapter of this thesis. However, I believe it is fitting to acknowledge at this point, limitations that were identified early in the development stage of this research, as a direct result of my conflict of interest. As a medical practitioner, my primary aim is to ensure symptoms are managed, and that patients are comfortable and settled. Therefore, there is potential risk of my pre-conceptions influencing the findings. In Chapter One, introduction to this thesis, I talked about my own personal and professional experiences with dying persons, and that my belief is that home is not necessarily the best PoD. While some patients and their FCGs will compromise 'best care' and comfort to remain home, this is not my value. Escalating pain is more readily addressed in hospital than at home, especially out on farms. I have tried to put my beliefs aside, listen to, and honestly portray the views expressed by the rural patients and their FCGs. For that reason, I have included long quotes and narratives in Chapters Six, Seven and Eight.

4.9 Rigour of the research

The central focus of this study was on finding meaning behind the quantitative data describing the actual PoD within the Snowy Monaro region. This was undertaken using an ethnographic approach. In many ways, qualitative research has polarised the scientific world, over issues such as validity, reliability and objectivity (Patton, 2002,

p. 93). Even qualitative researchers are polarised into those who ‘emphasise the importance of rigorous qualitative research and those who regard “rigour” as inappropriate’ (Grbich, 1999, p. 61). One of the criticisms of qualitative research is that the analysis is subjective and influenced by researcher bias. Kuper et al. (2008) suggest the most important component for the reader to assess the rigour and relevance of qualitative research is to have a strong understanding of the methodological approach and methods utilised by the researcher. I am quietly confident that, after reading my literature review, the previous chapter describing the setting, and this chapter explaining the methodological approach and methods for collecting and analysing data, the reader will be confident that the results of this study will be valid, reliable and objective. I have attempted to systematically approach all aspects of this research.

While it is important that all work I present in this thesis is substantially my own, in order to satisfy the rigorous standards required for systematic and scoping literature reviews, my supervisors willingly assisted in the validation of the included studies. One supervisor independently assessed all the titles of identified papers. All my supervisors independently reviewed a portion of the retained abstracts. However, I conducted the literature searches and independently undertook every step of the literature review process.

Sampling strategies for the qualitative component were appropriate for the study objectives. While the focus of this research was on patients with a life limiting illness and their FCGs, in order to gain perspectives on the ‘good’ rural death through different lenses, the HCPs were also interviewed (also known as triangulation). This allowed comparison and corroboration of data. Recruitment did not initially use a sampling frame, but as recruitment progressed it became purposive, seeking to incorporate a diverse range of participants. Data collection was over a period of time, with a few participants being interviewed more than once. In order to ensure authenticity in reporting, I have provided quotes to represent the participants’ views and perspectives. As reported in the preceding section I have, to the best of my ability, honestly and transparently acknowledged by bias in all components of this research.

Rigour in the collection, analysis and reporting of the quantitative data was enhanced by collecting whole population data over a 16 month period. When it became apparent that

much of Bombala Shire data were missing from the records of the local funeral director, the protocol was amended in an attempt to capture as much data as possible. Adoption of a mixed methods approach meant that PoD data obtained in the bereavement interviews could be validated.

This chapter has presented the theoretical framework underpinning my research. The methods used to collect and analyse data have been described, and the participants introduced. This completes Part 2 of the thesis, the report on the literature review, preparatory, and data collection and analysis phases of the research study. The results of this research study are reported, discussed and argued in Part 3, consisting of four chapters. The quantitative data are presented in the next chapter (Chapter Five). The qualitative data collected from the interviews are then presented separately, in the three chapters that follow (Chapters Six, Seven and Eight).

PART 3: RESEARCH STUDY RESULTS

Introduction to Part 3: Research study results

Part 3 of this thesis reports the quantitative results and qualitative findings. The concept of the good death, place of death (PoD), and rural residency, are discussed, as described by the participating patients, family caregivers, and healthcare professionals. Four major themes emerged, with a chapter devoted to each theme.

Chapter Five provides the context for the qualitative data, by describing the actual PoD of Snowy Monaro residents, between February 1, 2015 and May 31st, 2016. These data tell us where the residents died, but do not provide any insight into the reasons that determined each PoD.

Chapter Six discusses the meaning and importance of place of care and death, from the experiences and perspectives of the participating patients, and their FCGs and rural HCPs. The primary objective of this thesis was to explore the concept of the good death, therefore, Chapter Seven is allocated to the participants' narrative on the 'good rural death', including their perspectives on the influence of 'place' on the 'good death'. Chapter Eight discusses the influence of rural residency on the PoD and the concept of the good death.

Each of the three qualitative results chapters (Chapters Six, Seven, and Eight) begins with a vignette, the story of one participating patient. This sets the scene for what is discussed in each chapter. The issues raised by each highlighted patient are woven through the remainder of the chapter. The body of each chapter contains long narratives, provided by the participants. As a palliative medicine specialist and researcher, my interpretations are open to my biases. To maintain transparency, it is important for the reader to 'hear' from the participants, rather than from my paraphrasing. Rather than numbers, aliases (names and ages have been changed) have been used to introduce the participants, as they are real people, and valued members of my community.

Part 3 begins by describing the actual PoD of Snowy Monaro residents.

CHAPTER FIVE: PLACE OF DEATH OF SNOWY MONARO RESIDENTS

Introduction

This chapter describes the actual place of death (PoD) of Snowy Monaro residents, between February 1, 2015 and May 31, 2016. The chapter begins by describing the socio-demographic features, cause of death, and PoD for the full data set (Section 5.1). While the focus of this thesis is the palliative subgroup, Section 5.2 briefly describes the cause of death and PoD for the non-palliative subgroup, i.e. those who died unexpectedly of an acute condition. Section 5.3 describes the data related to those residents who died of an advanced chronic condition, considered amenable to palliative care. The results specific to RACF deaths are reported and discussed in Section 5.4.

5.1 Description of all deaths

Over the 16-month data collection period, death records of 224 Snowy Monaro residents were collected. One hundred and ninety (85%) died as a result of ‘natural’ causes, and five (2%) of ‘external’ causes. The external causes of death included one death from injuries sustained in a motor vehicle accident, one suicide, one drug overdose, one homicide, and one death in a house fire. Natural deaths included 52 (27%) from an acute or ‘non-palliative’ condition and 138 (73%) from a ‘palliative’ illness. The cause of death was unknown for 29 (13%) residents.

Table 5.1 describes demographic features and PoD of decedents. There were no significant differences between the palliative and non-palliative groups in relation to their likelihood of dying in their usual place of residence (UPoR) or dying in the region. Except for one neonatal death (excluded from the analysis), the age at death ranged from 20 to 101 years. Four residents were 100 years or older. Most decedents (66%) lived in Cooma or Bombala, i.e. one of the two towns with a hospital. The 66 deaths in RACFs comprised two groups: 51 permanent residents (77%) and 15 short stay residents [those admitted for either respite, or transferred from their private residence or hospital for end-of-life care (23%)].

Table 5.1: Decedents' demographics and place of death

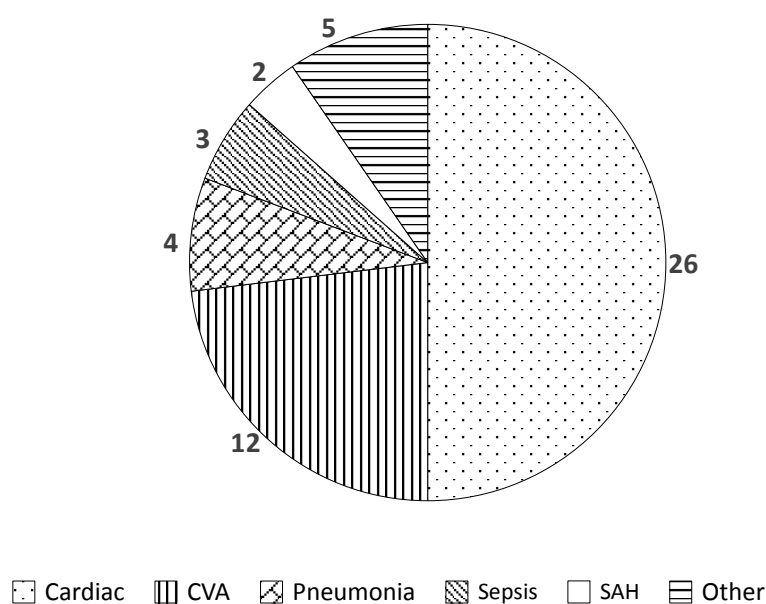
	All deaths n=224 [#]	Palliative n=138 (62% *)	Non-palliative n=52 (23%*)
Sex			
Male	116 (52%)	75 (54%)	23 (44%)
Female	108 (48%)	63 (46%)	29 (56%)
Age (years)			
≤39	3 (1%)	0	1 (2%)
40-49	6 (2.5%)	4 (3%)	1 (2%)
50-59	13 (6%)	9 (6.5%)	2 (4%)
60-69	31 (14%)	20 (14.5%)	5 (9.5%)
70-79	53 (24%)	37 (27%)	9 (17%)
80-89	69 (31%)	43 (31%)	19 (36.5%)
≥90	46 (20.5%)	24 (17%)	15 (29%)
unknown	3 (1%)	1 (1%)	0
Marital			
Partnered ⁺	82 (36%)	65 (47%)	10 (20%)
Unpartnered [‡]	71 (32%)	43 (31%)	21 (40%)
Unknown	71 (32%)	30 (22%)	21 (40%)
Place of residence			
Farm	33 (14.5%)	24 (17%)	2 (4%)
Village (no GP)	18 (8%)	10 (7%)	5 (10%)
Small town (GP, no hospital)	17 (7.5%)	8 (6%)	6 (11%)
Town with GP and hospital	147 (66%)	91 (66%)	39 (75%)
Unknown	9 (4%)	5 (4%)	0
Place of death			
Private residence	42 (19%)	17 (12%)	14 (27%)
Local hospital	82 (36.5%)	64 (46%)	17 (32.5%)
RACF ^{##}	66 (29.5%)	44 (32%)	14 (27%)
Tertiary hospital	16 (7%)	8 (6%)	5 (9.5%)
Hospice (out of region)	4 (2%)	4 (3%)	0
Other place	5 (2%)	1 (1%)	2 (4%)
Missing data /unknown	9 (4%)	0	0
Died in UPoR			p= 0.41♦
Yes	93 (41.5%)	52 (38%)	23 (44%)
No	122 (54.5%)	86 (62%)	29 (56%)
Unknown	9 (4%)	0	0
Died within the region			p=0.89♦
Yes	191 (85.5%)	122 (88.5%)	47 (90%)
No	21 (9.5%)	14 (10%)	5 (10%)
Unknown	12 (5%)	2 (1.5%)	0

[#] 'All deaths' includes unknown cause of death (n=29;13%) and external causes (n=5, 2.2%); * percentage of all deaths; + Partnered= married/de facto; ‡ Unpartnered= single, widowed, divorced; ##RACF= residential aged care facility, includes permanent and respite/short stay residents; GP=general practitioner; UPoR= usual place of residence, includes private residence and permanent placement ≥ 3months in RACF; %= column percentages. ♦P values for dying in UPoR and within region >0.05 (by Pearson χ^2 test for differences in proportions between palliative and non-palliative groups;2x2 table, unknown excluded)

5.2 Non-palliative subgroup

Of the 190 natural deaths, 52 (23% of all deaths) were considered to be due to a non-palliative condition (Figure 5.1). Of these, half were due to a cardiovascular cause (cardiac arrest or acute myocardial infarct). The remaining causes were cerebrovascular accident (CVA), pneumonia, sepsis, subarachnoid haemorrhage (SAH), and five of another cause (abdominal aortic aneurysm, seizure (epilepsy), fractured neck of femur, bowel obstruction and aspiration). Where cause of death was reported to be due to a CVA, the decedent was classified as non-palliative, as it was not possible to determine if they died of an acute event. It is therefore possible that some CVA survivors may have been incorrectly classified and could have been considered ‘palliative’.

Figure 5.1 Cause of death of the non-palliative subgroup, n=52

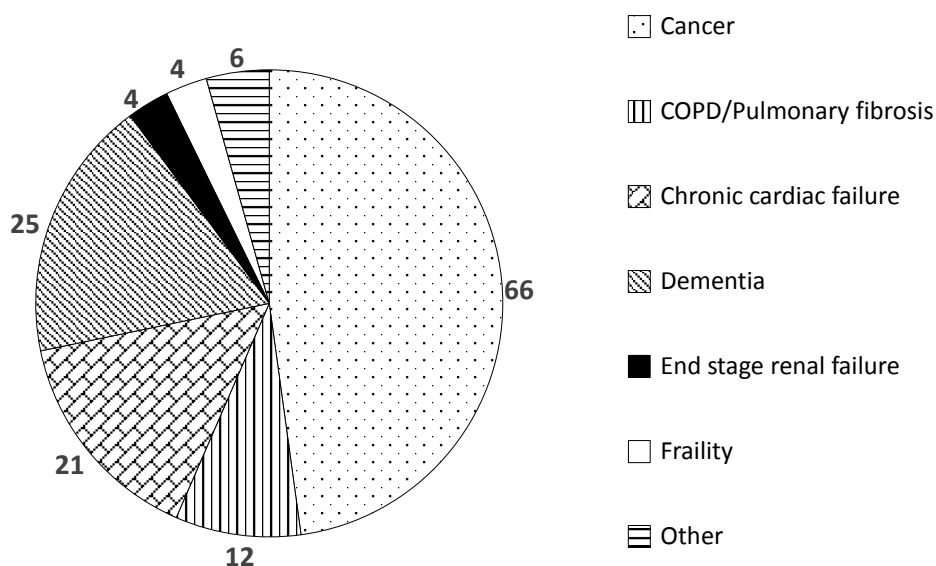


Place of death for the non-palliative subset was evenly distributed between private residence, local hospital and RACF. Just under ten percent died in the out-of-area tertiary hospital in Canberra. As the local hospitals are staffed by general practitioners, with no intensive care, cardiac care, interventionists, specialist anaesthetists or onsite surgeons, serious, unexpected acute conditions are transferred to the Canberra Hospital.

5.3 Palliative subgroup

The focus of this thesis is the palliative subgroup, consisting of decedents reported to have died of an advanced chronic condition considered amenable to, but not necessarily receiving, palliative care. There were 138 (62% of all deaths) in the palliative subgroup. In this study, the causes of death amenable to palliative care included cancer (solid and haematological), chronic cardiac failure (CCF), end stage renal failure (ESRF), liver failure, chronic obstructive pulmonary disease (COPD), motor neurone disease (MND), dementia (McNamara et al., 2006), and advanced frailty (Gomez-Batiste et al., 2014). Full details of the statistical methods are found in Section 4.7.1 of the Methods Chapter. Cancer was reported as the cause of death for 66 (48%) of the palliative deaths. Seventy-two (52%) non-cancer causes of death included chronic obstructive pulmonary disease (COPD) or pulmonary fibrosis; chronic cardiac failure (CCF); end stage renal failure (ESRF); and ‘other’. The ‘other’ category included liver failure (five) and motor neurone disease (one) (Figure 5.2).

Figure 5.2 Deaths caused by a condition amenable to palliative care, n=138



In the palliative subgroup, ages ranged from 40 years to 100 years; median 79 years. Consistent with my literature review, most patients who died of a condition amenable to palliative care, died in a place away from their private residence. The ‘other’ category

related to one resident with chronic heart failure who died while staying at a community respite cottage.

Of the 138 palliative deaths, 17 (12%) occurred at 'home' in a private residence and 121 (88%) occurred in an institution (hospital, hospice or RACF). In regards the out-of-region hospital, eight died in the tertiary hospital, 115 kilometres from Cooma. There were no reported deaths in out-of-region private hospitals, Bega Regional Hospital, or other tertiary hospitals.

5.3.1 Place of death according to cause of death

In this sample, cause of death included cancer and non-cancer diagnoses. Deaths due to COPD, CCF, ESRF, dementia, frailty, liver failure and MND were recorded in the advanced non-cancer chronic conditions amenable to palliative care category. In Table 5.2 the 'other' category includes liver failure and MND. There were no deaths due to Parkinson's disease, Huntington's disease or HIV/AIDS.

Table 5.2 describes the PoD, by socio-demographic features, for the palliative subgroup. Nearly half of all palliative deaths occurred in the local hospital, one-third in a RACF, one-in-eight in a private residence. People who died of cancer were more likely to die in the local hospital, while people who died of non-cancer causes were more likely to die in a RACF (Monte Carlo simulation exact $p=0.001$). Of the non-cancer causes of death, people with dementia were the most likely to die in a RACF (Monte Carlo simulation exact $p=0.04$). No residents over the age of 70 years or with a non-cancer diagnosis died in the out-of-region hospice. Across the palliative subgroup, 125 (91%) died within the region.

5.3.2 Place of death according to degree of rurality

No deaths occurred in a village private residence. The results suggested that people living on farms, and in villages and small towns were more likely to die in hospital. People living in Cooma or Bombala were more likely to die in a RACF or the local hospital. However, when the Monte Carlo simulation test was applied, no statistical differences were found. Three farmers died in a RACF; however, it was not possible to determine how many farmers had moved permanently to a RACF (Table 5.2).

Table 5.2: Place of death for the palliative subgroup by socio-demographic characteristics. N=138

	Total number of deaths (% of total)	N (%) occurring at a private residence	N (%) occurring at a local hospital	N (%) occurring at an out-of- region hospital	N (%) occurring at the out-of- region hospice	N (%) occurring in a RACF *	N (%) occurring at another place	p-value♦
All palliative deaths	138	17 (12%)	64 (46%)	8 (6%)	4 (3%)	44** (32%)	1 (1%)	
Sex								
Male	75 (54%)	12 (16%)	38 (51%)	4 (5%)	-	20 (27%)	1 (1%)	0.069
Female	63 (46%)	5 (8%)	26 (42%)	4 (6%)	4 (6%)	24 (38%)	-	
Age (years)								
40-49	4 (3%)	1 (25%)	1 (25%)	-	1 (25%)	1 (25%)	-	0.039
50-59	9 (6.5%)	4 (44.5%)	3 (33.5%)	1 (11%)	1 (11%)	-	-	
60-69	20 (14.5%)	4 (20%)	12 (60%)	2 (10%)	1 (5%)	1 (5%)	-	
70-79	37 (27%)	7 (19%)	18 (48%)	3 (8%)	1 (3%)	7 (19%)	1 (3%)	
80-89	43 (31%)	1 (2%)	19 (44%)	2 (5%)	-	21 (49%)	-	
≥90	24 (17%)	-	10 (42%)	-	-	14 (58%)	-	
unknown	1 (1%)	-	1 (100%)	-	-	-	-	
Marital status								
Partnered ⁺	65 (47%)	9 (14%)	33 (51%)	4 (6%)	2 (3%)	16 (25%)	1 (1%)	0.315
Unpartnered [†]	43 (31%)	4 (9%)	17 (39.5%)	1 (2.5%)	2 (4.5%)	19 (44%)	-	
Unknown	30 (22%)	4 (13%)	14 (47%)	3 (10%)	-	9 (30%)	-	

Table 5.2 continued

	Total N	Private residence	Local hospital	Out-of-region hospital	Out-of-region hospice	RACF *	Another place	p-value
Residence								0.126
Farm	24 (17%)	5 (21%)	12 (50%)	3 (12.5%)	1 (4%)	3 (12.5%)	-	
Village (no GP)	10 (7%)	-	8 (80%)	-	-	2 (20%)	-	
Small town (GP, no hospital)	8 (6%)	3 (37.5%)	5 (62.5%)	-	-	-	-	
Town (GPs+ hospital)	91 (66%)	9 (10%)	35 (38.5%)	5 (5.5%)	3 (3%)	38 (42%)	1 (1 %)	
Unknown	5 (4%)	-	4 (80%)	-	-	1 (20%)	-	
Cause of death								
Cancer	66 (48%)	9 (14%)	38 (57.5%)	5 (7.5%)	4 (6%)	10 (15%)	-	0.001
Non-cancer	72 (52%)	8 (11%)	26 (36%)	3 (4%)	-	34 (47%)	1 (2%)	
Non-cancer	N=72	n=8	n=26	n=3	n=0	n=34	n=1	0.04
COPD	12 (17%)	3 (25%)	5 (41%)	2 (17%)	-	2 (17%)	-	
CCF	21 (29%)	1 (5%)	10 (47%)	1 (5%)	-	8 (38%)	1 (5%)	
Dementia	25 (3%)	-	4 (16%)	-	-	21 (84%)	-	
ESRF	4 (5.5%)	1 (25%)	2 (50%)	-	-	1 (25%)	-	
Frailty	4 (5.5%)	1 (25%)	2 (50%)	-	-	1 (25%)	-	
Other§	6 (8%)	2 (33%)	3 (50%)	-	-	1 (17%)	-	

Abbreviations: *RACF= residential aged care facility (includes both permanent (35) and short-stay residents (9)); GP=general practitioner; COPD= chronic obstructive pulmonary disease; CCF= chronic cardiac failure; ESRF= end stage renal failure. Presented percentages are row percentages except for Column 2 “total number of deaths” (column percentages). ** 1 resident died in an out of region RACF. § Other= 5 liver failure and 1 motor neurone disease, (no deaths due to Parkinson’s disease, Huntington’s disease, or HIV/AIDs; + Partnered= married/de facto; † Unpartnered= single, widowed, divorced.

♦ Monte Carlo simulation test, exact p-values less than 0.05 indicate an association between place of death and the factor of interest.

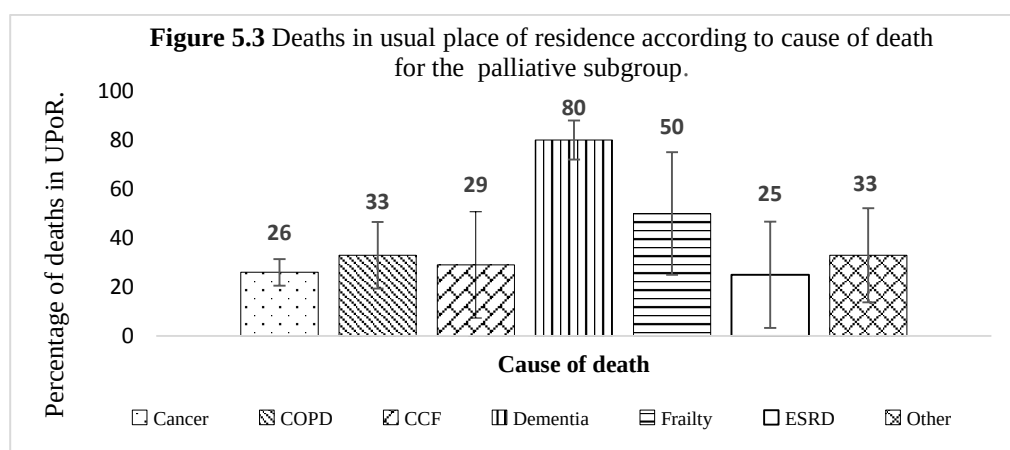
5.3.3 Deaths in usual place of residence

As previously noted, PoD was initially separated into six categories, with RACF deaths including those of both permanent residents and those admitted for respite or transferred from home or hospital for end-of-life care. As will be discussed in Chapter Six, some long-term residents of RACFs considered the facility to be their ‘home’ and not an institution. Therefore, the category ‘private residence’ does not represent all the deaths that occurred at ‘home’. When permanent RACF residents’ deaths in their facility were combined with deaths in a ‘private residence’, the number of deaths occurring within an ‘institution’ decreased from 88% to 62%. The term ‘usual place of residence’ (UPoR) included private residences and RACFs for permanent residents. Thirty-five (49%) of non-cancer and 17 (26%) of cancer deaths occurred in an UPoR. The following chapter discusses the rural participants’ experiences and perspectives on PoD, including RACFs.

5.3.4 Factors influencing death at usual place of residence

The binary logistic regression model found no statistically significant associations between sex, age, or marital status and dying in one’s UPoR (Table 5.3). The bivariate logistic regression showed that people with a non-cancer diagnosis were more likely to die in their UPoR than those who died from cancer (odds ratio (OR) 2.73, 95% CI 1.33, 5.60; $p=0.005$), with 84% of those with dementia dying in a RACF.

Figure 5.3 charts the percentage of deaths occurring in UPoR according to cause of death, and the error bars indicating the 95% Wald Confidence Interval. Those living on farms and in small towns were less likely to die in their UPoR than town dwellers (OR 0.31, 95% CI 0.11, 0.89; OR 0.31, 95% CI 0.10, 1.01 respectively; $p 0.016$).



5.3.5 Factors influencing death within region

A binary logistic regression model using ‘dying within region’ as the outcome variable found no statistically significant associations between sex, age, marital status, or cause of death, and dying within region. The model suggested that farm dwellers were less likely to die within region than town residents (OR 0.55 95% CI 0.15, 1.96). No small town residents died out of region; therefore, it was not possible to estimate the odds ratio for small town residents dying within region (see ‘not estimable’ (NE) Table 5.4).

Table 5.3: Odds ratio estimates and 95% confidence limits of factors associated with dying in usual place of residence and in region, for the palliative subgroup.

	Dying in usual place of residence		Dying within region	
	OR	95% CI	OR	95% CI
Sex				
Male (n=75)	0.86	0.43, 1.7	2.04	0.63, 6.57
Female (n=63)	1		1	
Age (years)^p				
≤64 (n=22)	0.53	0.18, 1.52	0.22	0.05, 1.03
65-84 (n=66)	0.57	0.26, 1.21	0.79	0.18, 3.50
≥85 (n=49)	1		1	
Marital				
Unpartnered (n=43) [‡]	1.51	0.68, 3.35	0.99	0.26, 3.74
Partnered (n=65) ⁺	1		1	
Cause of Death^{§p}				
ESRF (n=4)	0.96	0.09, 9.87	NE	NE
COPD (n=12)	1.44	0.39, 5.40	0.79	0.15, 4.21
Dementia n=25	11.53	3.72, 35.50	3.79	0.46, 31.58
Frailty (n=4)	2.88	0.38, 22.08	NE	NE
CCF (n=21)	1.15	0.39, 3.45	3.16	0.38, 26.52
Cancer (n=66)	1		1	
Palliative type^p				
Non-cancer (n=72)	2.73	1.33, 5.60	2.68	0.79, 9.18
Cancer (n=66)	1		1	
Residence^a				
Farm (n=24)	0.31	0.11, 0.89	0.55	0.15, 1.96
Small town (n=19) [◆]	0.31	0.10, 1.01	NE	NE
Town (n=91)	1		1	

Abbreviations: OR=Odds ratio; CI= confidence interval; ESRF=end stage renal failure; COPD= chronic obstructive pulmonary disease; CCF=chronic cardiac failure; NE= not estimable; + Partnered= married/de facto; ‡ Unpartnered= single, widowed, divorced; § excludes ‘other’ causes; ◆Small towns with GPs/no hospital; p= p-value <0.05, indicating an association between dying in UPoR and factor of interest. First column excludes ‘unknown’ (see table 5.2 for percentages of missing data).

5.4 Deaths in residential aged care facilities

During the data collection period, 65 decedents (29% of all deaths) were identified as permanent RACF residents (median length of stay 25 months, range four -168 months). Ages ranged from 69 to 101 years, median 88 years. Of these residents, 51 (78.5%) died at the facility (Table 5.4). In total, 66 deaths occurred in a RACF, including eight (12%) whose cause of death was not available. The length of stay before death, for the 15 admitted for respite or EoLC, ranged from one day to just short of three months.

One RAC resident died in the out-of-region tertiary hospital (cause of death not available as referred to the Coroner). Nearly 30 percent of the palliative subgroup within the Snowy Monaro region died in a RACF, and more than one third were due to dementia (Table 5.4). Dementia is rapidly becoming one of the main causes of death in Australia (ABS, 2015), with many dementia sufferers residing, and therefore dying, in RACFs (Black et al., 2016).

Table 5.4: Characteristics and PoD for all permanent RACF residents, n=65.

Total n=65 (29% of total deaths)	
Sex	
Male	27 (41.5%)
Female	38 (58.5%)
Age (years)	
60-69	1 (1.5%)
70-79	8 (12.5%)
80-89	30 (46%)
≥90	26 (40%)
Marital status	
Married	16 (24.5%)
Widowed	27 (41.5%)
Unknown	22 (34%)
Place of death	
RACF	51 (78.5%)
Local hospital	13 (20%)
Tertiary hospital	1 (1.5%)
Died in UPoR	
Yes	51 (78.5%)
No	14 (21.5%)
Type of death	
Palliative	42 (65%)
Acute/non-palliative	15 (23%)
Unknown	8 (12%)
Palliative deaths n=42	
Cancer	8 (19%)
Non-cancer	34 (81%)

<i>Table 5.4 continued</i>	Total n=65
Non-cancer palliative death n=34	
COPD	2 (6%)
Dementia	22 (65%)
Frailty	1 (3%)
CCF	8 (23.5%)
Other	1 (3%)
Non-palliative death n=15	
Cardiac (AMI)	4 (27%)
CVA	3 (20%)
Sepsis/pneumonia	5 (33%)
Other	3 (20%)
Abbreviations: PoD= Place of death; RACF=residential aged care facility; UPoR= usual place of residence; COPD=chronic obstructive pulmonary disease; CCF= chronic cardiac failure; AMI= acute myocardial infarction; CVA=cerebrovascular accident (onset unknown).	
Non-palliative cause of death: Other= bowel obstruction, ruptured aortic aneurysm, fractured femur.	

5.5 Palliative deaths, excluding permanent RACF residents

During the data collection period, more Snowy Monaro residents died in hospital (43.5%) than at home (19%), in their private residence, reflecting the general trend noted in the literature for rural patients to die in hospital rather than home. One significant inconsistency in the literature is the definition of ‘home’ and ‘institution’, especially when permanent RACF residents have been included in the reported findings. While not specifically a rural study, McNamara and Rosenwax (2007) dichotomised PoD into ‘UPoR’ (private residence and permanent placement in RACFs), and ‘place other than UPoR’. However, most previous studies have considered RACFs to be ‘institutions’ and therefore, not ‘home’.

While the aim of the quantitative component of this study was to determine where Snowy Monaro residents die, the large number of permanent RACF residents who mostly reside in one of the two towns, and die in their UPoR, is one of the reasons for the preponderance of town residents not dying in hospital. A secondary analysis of the data was undertaken on the palliative subgroup, by excluding permanent RACF residents, to determine where non-RACF residents die. (Table 5.5).

Table 5.5: Socio-demographics of palliative sub-groups: including, excluding, and exclusive of permanent residential aged care facility residents.

	All Palliative N=138*	Palliative subgroup, excluding permanent RACF residents; n=92	Palliative subgroup: permanent RACF residents only; n=42
Sex			
Male	75 (54%)	57 (62%)	16 (38%)
Female	63 (46%)	35 (38%)	26 (62%)
Age (years)			
40-49	4 (3%)	4 (4%)	0
50-59	9 (6.5%)	9 (10%)	0
60-69	20 (14.5%)	18 (19.5%)	0
70-79	37 (27%)	31 (34%)	6 (14%)
80-89	43 (31%)	20 (21.5%)	21 (50%)
≥90	24 (17%)	9 (10%)	15 (36%)
unknown	1 (1%)	1 (1%)	0
Marital♦			
Partnered	65 (47%)	51 (55.5%)	14 (33%)
Unpartnered	43 (31%)	26 (28.5%)	17 (41%)
Unknown	30 (22%)	15 (16%)	11 (26%)
Place of residence§			
Farm	24 (17%)	24 (26%)	0
Village (no GP)	10 (7%)	7 (8%)	2 (5%)
Small town (GP, no hospital)	8 (6%)	7 (7.5%)	1 (2.5%)
Town with GP and hospital	91 (66%)	52 (56.5%)	38 (90%)
Unknown	5 (4%)	2 (2%)	1 (2. 2%)
Place of death			
Private residence	17 (12%)	17 (18.5%)	0
Local hospital	64 (46%)	54 (59%)	7 (17%)
RACF	44 (32%)	9 (10%)	35 (83%)
Tertiary hospital	8 (6%)	7 (7.5%)	0
Hospice (out of region)	4 (3%)	4 (4%)	0
Other place	1 (1%)	1 (1%)	0
Died in UPoR			
Yes	52 (38%)	17 (18.5%)	35 (83%)
No	86 (62%)	75 (81.5%)	7 (17%)
Died within the region			
Yes	122 (88.5%)	81 (88%)	41 (98%)
No	14 (10%)	11 (12%)	1 (2%)
Unknown	2 (1.5%)	0	0

*total N includes 4 with incomplete data; RACF= residential aged care facility; ♦ Not possible to determine if decedent was living with partner; § Not possible to determine RACF place of residence prior to transfer to RACF; GP=general practitioner; UPoR= usual place of residence; column percentages.

When permanent RACF residents were excluded from the data analysis, there were no statistically significant associations between UPoR and cause of death ($p=0.501$) or degree of rurality ($p=0.926$).

5.6 Limitations

While the data collected are representative of the regional population, there are several limitations to be acknowledge. Firstly, official death certificates were unavailable, and while strategies were in place to maximise the data collection, it is possible that an unknown, though presumably low, number of deaths were missed. While there are limitations to the accuracy of data obtained through official death certificates (Brameld et al., 2017), without access to these certificates, verification of cause of death and interval between onset of the condition directly leading to death, and death itself, was lacking. It is therefore possible that residents who died of prolonged effects of a cerebrovascular accident/stroke, were incorrectly excluded. However, the data provided by the various informants were taken directly from the Medical Certificate Cause of Death completed by the attending medical officer.

Secondly, because the data collection was regional, the sample size is small. With a total of 224 deaths, generalisability is questionable. However, the collection of regional data is both a strength and a weakness. The Australian Bureau of Statistics data (ABS Regional Stats, 2017c), last updated on 31 March 2017, reported 749 deaths in the Snowy Monaro, in the five years between 2011 and 2015. Using these data, approximately 200 deaths would be expected over any given 16-month period. Any missing records could include deaths of residents that occurred outside the region or those requiring a coroner's autopsy, and where no local funeral service was held. According to the funeral director, only a couple of families withheld consent for the death details to be released. It is possible that these deaths were still included in the audit with data obtained from newspaper obituary or funeral notices.

As this study was a component of my PhD thesis, data collection was time limited. After 16-months of data collection, this component of my research came to an abrupt halt. Without warning, the main local newspaper ceased publication in May 2016. I had been gaining vital information from the obituary and funeral notices to supplement, and

cross check, the information provided by the funeral director. This reduced my collection period by 6-months, and therefore reduced the sample size. It is unknown if the results would be replicated over a different or longer period. While the results represent where people died in the Snowy Monaro region between February 1, 2015 and May 31, 2016, they may not be generalisable to all rural regions, or even to this region over a different time period.

Other limitations include the omission of data relating to income, occupation, and informal carer support. The results do not indicate decedents' preferences for PoD, family caregivers' satisfaction with PoD, the degree of symptom or carer burden, or the number of residents that received most of their care at home only to move to hospital at the very end-of-life. To comply with both HRECs' requirements, I am unable to add decedents' details not obtained through the approved sources. In general terms, some of the RACFs' residents moved from their farms months or years before their deaths. Therefore, their last place of residence was recorded as the RACF, and their farm or village status changed to 'town'. It is possible the data collected do not accurately reflect the previous degree of rurality of some of the RACF residents. While their new UPoR was the town RACF, many would still consider their farm to be their 'real' home.

Despite the limitations, these results describe where residents of the Snowy Monaro Region died during the same period I conducted the qualitative interviews. These quantitative data provide a context in which to place the narrative data obtained through interviews with patients with a terminal illness, and their FCGs and rural health care professionals.

5.7 Chapter summary

This chapter has described the actual PoD of Snowy Monaro residents, between February 1, 2015 and May 31, 2016. This was a population survey, with 224 deaths identified. Nineteen percent of all deaths occurred at a private residence, 29.5% in a RACF, and 44% in hospital; 85% of deaths occurred within the region. While not all patients with end-stage cancer, or an advanced non-cancer chronic diagnosis were necessarily receiving palliative care, 138 Snowy Monaro residents (62% of all identified deaths), died of a condition considered amenable to palliative care. For this palliative

subgroup, 12% died at 'home' in their private residence, and 88% died in an institution (hospital, RACF, or out-of-region hospice).

Highlighting the importance of terminology, when the term 'UPoR' was used rather than 'private residence' to depict 'home', 38% of the palliative subgroup, including RACF permanent residents, died in their UPoR (private residence or RACF), with 62% dying in an institution (hospital, hospice or respite RACF). These results are consistent with previous studies that report most people die at a place other than their 'home' or UPoR (McNamara & Rosenwax, 2007; Cohen et al., 2015).

Residence, or degree of rurality, was the main factor influencing PoD for the palliative sub-group, in this region and is consistent with studies included in my '*Rural place of death: A systematic review.*' Access to health-system facilities, often lacking in more rural and remote regions, is a key factor. Cause of death was an influencing factor in dying in one's UPoR, but not dying within region. In contrast to the systematic review findings, age, sex, and marital status were not predictors of PoD. It is possible these results do not reflect the true picture as some RACF residents may have moved from their farm more than 3 months prior to their death.

The importance of rural 'community' is well reported in the literature. Dying within the region was possible for 91% of residents. The data do not indicate if dying out-of-region was by choice or circumstance; however, without a local specialist palliative care inpatient hospice this may have been the preferred PoD for four residents. Conversely, the absence of a local inpatient hospice could mean the local rural hospital and RACFs are considered a substitute for inpatient hospice, and if it is not possible to die at home then it is important to die within the rural community (Wilson et al., 2009a; Veillette et al., 2010; Biggs, 2015).

Having determined where terminally ill Snowy Monaro residents die, the findings illustrate that more residents die in hospital and RACFs than at 'home' in their private residence. What does this mean? The results do not indicate decedents' preferences for PoD, congruence between preferred and actual PoD, the reasons behind preferences, the changing preferences over the course of the patients' illness, family caregivers' satisfaction with PoD, the degree of symptom or carer burden, or the number of

residents that received most of their care at home only to move to hospital at the very end-of-life. The following three chapters place these data into context, by exploring the meaning of ‘place’, the influence of ‘place’ within the concept of the rural good death, and the influence of rural residency on the ‘good death’ and PoD.

CHAPTER SIX: PLACE OF DEATH AND THE MEANING OF PLACE.

The most important thing is where he's going to be looked after the best.

(Betty, sister of George)

Gwen's story

As Gwen's GP, I was the one she consulted when she first developed symptoms. Preliminary investigations were undertaken locally, and she was found to have a cancer in her bowel. At her request, Gwen was referred to a Sydney surgeon, as it would be more convenient to stay with her daughter, both before and after surgery. She was relieved that chemotherapy was not required. Two years later, she developed liver metastases, and again consulted the Sydney surgeon. After further surgery, Gwen was referred to a Sydney oncologist. While it was convenient to be managed in Sydney for surgery, it quickly became apparent it would not be convenient to travel 500 kms to Sydney every few weeks for treatment. Chemotherapy was administered in Cooma, under the guidance of a Canberra oncologist. Gwen tolerated the chemotherapy, but the cancer progressed. She had chemo therapy four days before my interview. While hoping for more time, Gwen accepted palliative care with the aim of maintaining her independence and quality of life.

I met with Gwen at her home on 20th April, 2015. It was a grand, but uncluttered home, just on the edge of town. The home had been built by her late husband, as had most of the timber furniture. The house was immaculate. Gwen looked so comfy sitting in her large leather arm chair. This had obviously been their 'family' home and was filled with photos and other happy memories of her late husband and now adult children. Photos of grand-children were scattered throughout the home.

It was no surprise that 'home' was emphatically her preferred place of care and death. It was obvious 'home' was very important, not just the physical building, but also the emotional and spiritual tie to family. Her home was comfortable, a place where she was in control. When first interviewed, Gwen could not "*see any problem where I can't stay at home.*" She already had home help and plans for future support. Family and friends

would “*rally around.*” There would be no need to even consider an alternative, and definitely not aged care. Gwen was familiar with the local nursing home - it had been built by her husband. Gwen herself visited regularly to help feed the residents and sit with those without family, as they died.

Unfortunately, three months after the initial interview, Gwen suddenly lost the use of her right leg and arm. She was admitted to the local hospital; investigations revealed brain metastases. She remained positive and while “*coming into hospital was not what we had planned*” she “*accepted it.*” Control of nausea was her main concern. Gwen now wanted to be in the place best suited to controlling symptoms, while clinging to the hope of returning home. Radiotherapy in Canberra did not have the hoped-for outcome. While she experienced small improvements, with no family in Cooma, Gwen was pragmatic, “*I mean I can’t go [home] now and I’m prepared to try whatever happens...I really want to get home...but I’ll accept whatever happens.*” Gwen was transferred to the residential aged care facility for ongoing rehabilitation. The hope was that given more time she would gain sufficient mobility to return home, albeit with lots of community services. She continued to plan her ‘going home’ and what help would be required. She was conscious of not wanting to be a burden on her family in Sydney, and friends in Cooma. After three weeks, Gwen’s improvement stalled. She rapidly deteriorated. Gwen never spoke about going home again.

Gwen had a lovely single room at the nursing home. It looked out onto the garden and distant hills. The room was adorned with family photos. Her favourite hymns were often heard on the small CD player. Her family visited from Sydney, often for days at a time. Initially, between family and friends there was always someone with her during the daytime. As her body physically deteriorated and she became frailer, the family asked friends not to visit. During the night Gwen was often restless. A change in rooms was considered so she would be closer to the nurses. This suggestion caused great distress to Gwen’s daughter, “*I didn’t want her moved...this is her room now...it’s Mum’s home now.*”

On an afternoon in December, while her son was briefly out of the room, Gwen died, two months after being admitted to the aged care facility. Everyone knew Gwen wanted to die at home. Her daughter was ambivalent about the impact this had on the quality of

her dying. Gwen was comfortable, well cared for, safe and in familiar surroundings, but not at home. On reflection her daughter said, *“I think I was happy at the time with the decision because she couldn’t have lived [at home] by herself.”*

Introduction

Gwen’s story highlights many issues surrounding the actual and preferred place of death (PoD). Her story demonstrates the issues around disease progression, unexpected events and scenarios, where remaining in one’s initial preferred PoD is not always possible. The new place becomes the accepted PoD.

This chapter unpacks some of the issues surrounding place of care (PoC) and PoD, as narrated to me by the research patients (i.e. those interviewed directly and those introduced by the three bereaved family caregivers (FCGs)), their FCGs and their rural health care professionals (HCPs). The chapter begins with a description of the actual and preferred place of care and death of the research patients. I then explore the meaning of home, hospital, residential aged care facility (RACF) and hospice in relation to PoC and PoD, and the congruence between actual and preferred PoD, and between the preferences of different stakeholders.

6.1 Actual place of death

The previous chapter described where Snowy Monaro residents died. Consistent with those quantitative findings, of the 15 research patients identified in this qualitative component of my research study, more died at a place away from their private residence, (local hospital [five], hospice [one], RACF [five]), than at their private residence (four). Of the five who died in a RACF, three were permanent residents and two had been admitted for end-of-life care. None of the patients died in an out of region hospital. One patient (Gordon) was transferred from the tertiary hospital intensive care unit (ICU) to die in the local rural hospital.

While these data tell us where the patients died, they do not indicate patient or FCGs’ preferences, nor where they received the majority of their end-of-life care. The data do not provide any understanding of the meanings attributed to PoD. It was only through

the rich data obtained through the interviews that a true understanding of PoD could be constructed. As will become apparent in the remainder of the chapter, the reality is that many participants moved between preferences, dictated by the trajectory of their illness.

6.2 Preferred place of death

The interviewed patients, except for two, initially stated their preferred PoD to be their private residence. One of the exceptions, Barbara, had lived in a RACF for a number of years, and considered this to be ‘home’ and her preferred place to die:

This is home now.... I'm with people who know me, you know, and it's quite happy here. I am quite happy here. (Barbara)

George, who lived in a separate dwelling in his sister's backyard, stated his PoD would be either the hospice in Canberra or the local hospital. George highlighted a common theme amongst the interviewees, and consistent with the work done by Agar et al. (2008): place of care is not a euphemism for PoD, and often these are two separate, and different, places. Most patients indicated a short hospital admission would be acceptable if they required specific symptomatic treatment, such as a blood transfusion, providing they could return home as quickly as possible. Regardless of where they died, they wanted to remain home for as long as possible:

I'd like to stay here [at home] as long as I can get myself about a bit and look after myself. But when it starts to get a bit too hard, on [my sister] especially, that's when I would go [to hospital or the hospice]. (George)

George's sister, Betty, did not want him to die at her home. She had nursed her parents at home and found the burden of care too physically and emotionally draining. So in George's case, his personal preference was overshadowed by his sister's decision not to care for him at home, and his willingness to respect her wishes:

I don't know, it sounds horrible, but I just can't do it again. I just can't nurse someone to the end again, it's just too much. (Betty, sister of George)

Two of the three non-participating patients (i.e. their FCGs participated only in a bereavement interview), had indicated a preference for PoD to their FCG. The third patient (Gordon, who I will discuss later) had become unwell suddenly, without discussing end-of-life goals with the family. According to one FCG (Andrew), his wife wished to die in the out-of-region hospice because:

She didn't have confidence in me to be able to manage the stuff right ... Elaine was a nurse, and I'd work out the medications and everything my way, and I had tables drawn up and the whole thing, but as she got sicker she got more confused and less confident that I was doing the right thing. She would have been happy if there was somebody looking over my shoulder that could say, "Oh yeah, he's doing it right." (Andrew, husband of Elaine)

Another patient, Leanne, had told her partner that she wanted to die in the local hospital rather than on the farm. It is uncertain if this decision was guided by her concern for her partner, or reflected her own wishes:

We talked about things as things went along and...I'd made the decision that I didn't want her to die in the house. And I think Leanne probably was thinking along the same lines as well...I didn't want that lingering memory flashbacks in my head of her lying dead in the bed. I mean I can still picture her in the hospital and I'm just glad that that memory's not in [the bedroom]. (Daniel)

However, when the time came to leave the house, Daniel struggled to phone the ambulance, for he knew Leanne would not return home. Daniel recalled the conversation with his partner before making the call:

Leanne had to tell me three times to ring the ambulance. She said, "Have you made that call yet?" (Laughs) and I said, "No". So then the third time she said, "Get the phone and make it and do it here where I can hear" So yeah that was I guess just a realisation that things were not so good. And I know when she did go in [to hospital, the GP] said if you feel you get a little bit stronger ... you can go home for a day or so. And she just said, "No I'm not going back there, I'm

not going through that again.” So obviously, even though she put on a brave face when she was leaving it was fairly tough on her. (Daniel)

Drawing out the preferences from the participants was not a straightforward matter and highlights the limitations of only asking a single question in a survey or questionnaire. While some patients gave an emphatic initial answer in stating their preferences, usually “home”, most qualified their response during the interview. While hoping to remain home, most were prepared to wait and see how circumstances unfolded:

Depends on how bad the pain was or his hallucinations and things like that. If he was to go into a coma he would probably be better off in hospital and I’d stay at the hospital. I mean hospital’s great, but only if he needs it. And if he was in really bad pain, yes. (Carol, wife of Ryan)

Amongst this rural group, the preferred PoD did not only refer to the physical building. Except for Elaine, who chose to die in the Canberra hospice, some 115 kms from home, all participants wanted to die within the local community. George had moved from Canberra five years previously, so the option of dying in the Canberra hospice was not totally ‘out of region’. For some, dying in the local hospital softened the disappointment of not dying at home. While Ivan did die at home, he summed up the importance of remaining in the community:

Well I’m part of [the community]. So why would I put part of myself somewhere else? You are what you are because you make your life where you are. (Ivan)

Gordon’s family arranged a transfer, for end-of-life care, from the intensive care unit (ICU) in the tertiary hospital to the local rural hospital. The family wanted him back home in town. Home as a physical building was not the focus. ICU was a distressing place for the family. Gordon had not regained consciousness and was dying. The family wanted their father out of ICU, away from the tertiary hospital, and back into the familiar surroundings of the local hospital, “*where he could die peacefully*” and they would be supported by familiar hospital staff.

Preferred PoD was often a place where patients felt valued. Barbara was a long term resident in one of the region's RACFs. Visits from family were limited, as none of her children lived nearby. She agreed to relocate to a Sydney RACF, so at least one son could see her more frequently. However, leaving her community was not a good decision and she became "*homesick for [the nursing home] and that's why she went back [to Cooma], she wanted to go back...so in the end it was really where mum was happiest,*" (Rodney, son of Barbara).

While Gwen had earlier travelled to Sydney for surgery, so as to be with her daughter, placement in a Sydney RACF was never an option. Louise knew that if Gwen could not die at home then it was important she remain in her community, surrounded by friends:

I would never have taken her to Sydney, she's got all her friends here, and she's familiar with here and knows everyone. I know how hard it was for her when she was in Canberra for those 5 days, she really missed having people she was familiar with looking after her, so I would never have moved her to Sydney...If I'd had to move her to Sydney that would have been awful for her, I think that would have broken her heart actually. (Louise, daughter of Gwen)

This desire to die in community was not universal. Elaine chose to leave her community in order to die in the place she felt was most equipped to manage her symptoms:

Her choice was [the Canberra hospice], after having such a good experience [previously]...The pain control team there is very, very good. (Andrew discussing wife's preferences)

Each participant had a preference for where they, or their family member, lived out their last days, and where they died. They all had legitimate reasons for their preferences. The following sections of this chapter explore the meaning behind each place identified by the participants as a place to die.

6.3 The meaning of home

Most patients, including the permanent RACF residents, stated ‘home’ to be their preferred place of care and place to die. While patients and FCGs identified home as the physical building, the words and gestures suggested home was more than that and was a place of security, memories, identity and control. Many of the interviews were conducted at people’s homes, and just visiting where people live gave me an appreciation of what ‘home’ meant. Often I could hear the birds singing, the sheep bleating in the paddock, the neighbour mowing the grass or the sound of silence. Hearing his son on the tractor gave Ivan a sense of connection to the everyday running of the farm:

Ivan: I like lying here in this bed. I’ve got a lovely view out the window, and the garden. I’ve got my cat. And I got my two dogs with me. And my chooks there. So it’s a perfect set up. And then I can ring Paul [son] up and say, what have you been doing Paul [on the tractor today]?

Interviewer: So even though you’re in bed you’re still part of the activities on the farm?

Ivan: Very much part of it.

For Ivan and Bruce, home was the generational family property where they and their FCGs felt a connection to the land and a continuity with the past:

It’s sort of about who we are really, which might sound silly, but a city person wouldn’t have that connection with place that we have. We’ve been here six generations now, so when we look at things around the farm, like if I look out there I can see a pine tree, I know my great grandfather planted that. I go to the post office and the holly trees out the back, my great grandmother planted those.... Yeah, so we’ve got connections all over the place. (Paul, son of Ivan)

For others, home was also the place for keeping important memories, “*if anything important was done it was always done here [on the farm]*” (Bruce). After regular home visits, spanning more than two years, the community nurse observed that

Marianne's identity as a mother was embedded in the home. The farmhouse was full of memories of children growing up:

That property was where she'd done her mothering, where she'd educated her children, because she didn't send them to school, so for her that was her world really, so for her dying in that setting was I would imagine very important to her. (Marianne's community nurse)

At times the words used to describe 'home' were paradoxical. On one hand 'home' was described as peaceful, unregimented and yet it was a place where patients, like Marianne, felt in control:

[Home is] a controlled space that Peter [husband] and I have control of, where as soon as we go into a hospital we're in somebody else's controlled space. That's what immediately springs to mind. (Marianne)

Proximity to town contributed to the 'controlled space' and the security of home. While living on a farm had disadvantages, as will be discussed in chapter 8, Peter appreciated the isolation that the farm provided.

This is a good location because it's a nice place to be, if you've got to be sick, you know, you're not in suburbia, stuck in a street with people calling in all the time. I mean, you can manage the visitors [at home]. (Peter, husband of Marianne)

For most patients, quality of life was maintained if they could compensate for the loss of control over their disease, and its effect on their bodies, with some degree of stability and 'normality' in other aspects of their life. Many participants, like Ray and Carol, spoke of being able to continue normal activities at home:

Well probably being in surroundings that you know, not having to depend on too many people to do things, like going to the toilet and things like that, just little things. (Ray)

*We spend a lot of time at night just talking in bed. Just cuddling and talking.
We've always done that anyhow but more intense now. (Carol, wife of Ryan)*

The close connection to a 'place of memories' facilitated the representation of home as a place of independence and individuality, two qualities that Gwen fiercely protected before her physical deterioration forced her to transfer to a RACF:

Home means everything to me... I'm a homely person, I've always been home and family, and it is more personal, its more... it's more intimate and I think that you can, when I say relax I don't mean relax, but you can feel more comfortable at home, you can do what you feel you should do. (Gwen)

Home was not simply the physical building, and did not refer to a 'private residence' for all the patients. Three of the patients were permanent residents of a RACF; two were short term residents. The presence or memories of family did not necessarily define 'home'. For Barbara, who had left and then returned to the local RACF, the facility was her physical, emotional, and spiritual 'home', a place where she felt she was treated as an individual. Her family did not visit regularly, and yet when she left Cooma to be more accessible to her son, she pined for her former 'home':

At first she was doing very well and we thought [we've] found the right place...Big relief... but we noticed her health started to deteriorate and it wasn't so much her physical health, ... it was getting her down, and she said, "I want to get out of here." (Rodney, son of Barbara)

So after "a couple of weeks ... I thought, no I don't have to put up with this kind of nonsense, I'll go back home. I call this [Cooma RACF] home... this is home to me." (Barbara)

Morris and Thomas (2005) observed that while home is a familiar place, where patients and their FCGs strive to maintain a sense of normality, it becomes 'less normal' as the familiar space is altered to accommodate the various supports required to keep the patient at home. Kevin's community nurse observed that Kevin and his family accommodated the 'new normal':

Because Kevin had been so sick for such a length of time it was normality for them... to have him... at home. I know it sounds a bit bizarre. But it was normal, it was part of their normal life, he'd been like that for so long (laughs). The progression to end stage was very normal, not much had changed. He might not be responding as much, but the physicality of having him in a bed and caring for him in a bed, normal. And maybe that's why it [went so well] ... it was what he wanted and that's what Deedee said to me. She said "thank you, that's what Kevin wanted and thank you for being able to help us with Kevin and provide his wish." So she was certainly very grateful of that. (Kevin's community nurse)

Home was often idealised and portrayed as an unproblematic place, and while the primary preference for most, home was also offered as a default from unacceptable alternatives or places considered problematic. For Gwen, institutions were viewed as impersonal; for Kevin's daughter, hospitals were too noisy; Peter was concerned about the loss of control in a hospital setting and the staff's inability to manage his wife's medications:

I have thought about [the alternative to home] but it does not appeal to me in any way, because it's not personal. If you go to a nursing home, or where ever you go to, it's not personal...If you're in an institution you've got to abide by the rules of that institution. (Gwen)

[Dad] likes quiet, peace and solitude, so I think a hospital where people are in and out and it's busy, [means] he wants to be [at home]. (Susan, Kevin's daughter)

There are so many things about hospital care that don't suite this disease state, unless she was completely unconscious, and then it wouldn't matter, but whilst she was conscious she would suffer terribly with the anxiety and worry about "will my medication be on time, will I have someone to do this and do that?" We'd be at the point of having a family member sitting with her in hospital when we could be doing it at home. (Peter, Marianne's husband)

However, home is not without problems. Morris and Thomas (2005) observed that normality, security and personal control found within the familiar environment of home can quickly become disrupted. When symptoms escalate and access to medical help is not readily available, especially after hours, or the burden of care becomes too great, the safe home can quickly become an isolated place, where patients and FCGs feel abandoned, and FCGs become overwhelmed with the responsibility of caring. Even when things seem to be working well, caring for someone at home is exhausting for the carers. In the following quote, Ivan's son describes the exhaustion faced by his sisters in providing the physical care for their father. He also illustrates the challenges faced by FCGs in making medical decisions without a clear understanding of the medical details:

There is stress on family relations, everybody's under pressure, exhausted. It is exhausting, there's no let up. Dad would be up six times a night... I eventually worked out a roster. One [sister] would do night shift, one would do day shift. They were doing eight hour shifts toward the end, to try and rest, so it's physically exhausting from that aspect. Another difficulty is managing all the information, so who's right and who's wrong, medicine's not a perfect science – should we be doing this? Should we be doing that? What's got to happen here? What's got to happen there? And managing that is difficult... One of the biggest issues was just understanding what's going on, the information from [everywhere], trying to process it without the background and being able to speak the language, let alone understand. (Paul, son of Ivan)

Symptom management is often more difficult at home, especially in rural areas where medical and nursing backup is often not available, especially after hours. While Marianne settled in the last few hours before her death, her GP considered hospital to be the only option had her terminal agitation persisted:

I think the fact that they didn't have medical staff there to provide reassurance and intervention as necessary was certainly challenging... She became more agitated over the next few hours and there was no medical person there to intervene and help them with that.... If we hadn't been able to [make her comfortable], she would have had to have come into town. I mean you couldn't have her distressed in her last hours. That would have been awful. I mean that

would be a very distressing thing... you couldn't possibly have kept her at home in the discomfort and the distress. No that would have been cruel to do that to her and to the family. (Marianne's GP)

Ryan and Carol were both keen for Ryan to be cared for and to die at home. From past experience, through caring for a relative, they had the image of Ryan slowly slipping away, peacefully at home with friends and family all around. The tranquillity of this image unravelled when Ryan became acutely confused and agitated.⁵ The palliative care nurse describes a scene of chaos and distress when she arrived at their home on the morning Ryan died:

Things were going well leading up until his death. They...had seemed to manage well, and I think his wife was quite controlled. But the morning of his death, when he became agitated, extremely breathless, the oxygen that we had in place wasn't enough, the pain, he had pain, extreme pain. I think everything... all his symptoms exacerbated at about early morning. I think they had been like that for quite some time, probably maybe from about two a.m. until we got there ...about ten o'clock... We had anticipated ...so the drugs were all there.... I think [Carol] was quite frightened at his agitation, so if we'd both not been able to be there and start the drugs I think she would have been relieved to have gone back to hospital, because she would have been... relieved to see him more comfortable, wherever that took place.

I spoke to [Carol] on the phone the next morning, and I said, "I'm so sorry that Ryan died on the floor." But, I was very happy when we got [Ryan] back into bed because he looked really peaceful and [Carol] was then able to lay with him. And [Carol] said, "I was just so happy to be able to lay there all day with him, and that is what I'm remembering." So that made me feel better. (Palliative Care Nurse/Ryan)

⁵ This was one occasion that I was present at the death in my role as the palliative care doctor. I also lived down the road, and as luck would have it I was home when Ryan's sister phoned me to visit urgently.

Most participants spoke of the importance of continuing social engagement with extended family and friends. This was often considered a vital support for the patient and the FCGs. In the following quote, Carol expressed the important role played by maintaining social contact at home, and the challenges of maintaining this support if Ryan was hospitalised:

When you're home you can have a house full of people and they can come and go at different times. Not all the time, but then you've got the support with you the whole time. Where in a hospital you haven't...and you're more aware of making noise and disturbing other patients. Where at home, you know I can have family in their caravans come and stay in spare rooms, put mattresses on the floor. You could have the house full. Not necessarily disturbing his sleep, but they can pop in from time to time, but they're also there for me when I need a bit of a break as well...you just can't do that in a hospital. (Carol, wife of Ryan)

Not all participants wanted their home to be “full of people.” A few months before Marianne died she became gravely unwell. At the time, all the family were called home. Their home was full of adult children, their partners and Marianne’s grandchildren. With no one with medical or nursing experience, the home became chaotic. Marianne did improve, and life returned to normal for another few months. On reflection, Marianne’s husband said:

The home can't become the social hub, it has to become a private hospital where there is only one family member and they're here to care for her, not to talk to others, or to socialise with other family members or catch up or anything like that so that Marianne only has to cope with one person coming and going and looking after her...if I'm not here. (Peter, husband of Marianne)

While most participants identified home as their preferred PoD, the decision was complex, dynamic, and often required much negotiation between the patient and their FCG. In many instances, the role of the HCP was to help navigate through the options. The meaning of home, as described by the participants, was consistent with the ten features identified in Despres’ (1991) literature review, and is more than just the material structure. For the research participants, home was a place of security and

control; a reflection of one's self, value and status; a place of permanency, continuity, and a place to belong; a place of memories; relationships; the centre of activity; and a refuge from the outside world. All 15 research patients remained home for some time during their illness, yet only four died in their private residence. The following sections of this chapter describe the alternatives to home.

6.4 Hospital as the place of death

Two patients were interviewed in hospital, with the remaining patients providing reflections on their previous admissions, or on their hopes and fears for possible future admissions. Their experiences included the local rural hospitals, as well as tertiary hospitals in Canberra and Sydney. Five of the research patients (George, Leanne, Ray, Stuart and Gordon) died in one of the two rural hospitals. Their FCGs discussed, in the bereavement interviews, their experiences of hospital end-of-life care. While mostly positive, there were some significant challenges and disappointments; however, all said the hospital was the right place for their family member to die, and if faced with a similar situation they would again chose the hospital as their preferred PoD.

Patients were transferred to hospital for two main reasons: (1) symptom management and (2) to relieve the carer of burden and responsibility. This second reason was either pre-planned, as in the case of George and Leanne, or became necessary during the illness trajectory. For a home death to be successful, symptoms need to be well managed, and the FCGs need to be confident in their ability to care:

I thought for Kevin he was certainly very comfortable... he had a very supportive family that worked really well as a team. His main care provider, Deedee his wife, was very happy in that role. She was very good at keeping accurate records (laughs) which made it easier for us [nurses] ...So yes I felt that [home] was the right place for Kevin to be, yeah. And I felt the family and the carers were very, very happy with Kevin being there too, and in their role as well. (Community nurse)

While hospital was not the preferred PoD for the four patients who died at home, during the interview process they all indicated that the local hospital was a genuine alternative

if symptoms could not be managed at home, or if their carer was not coping. Ivan had decided to leave that decision “*entirely to my doctor.*” One GP, speaking in general terms, felt that too much emphasis was placed on achieving a home death and that often hospital was the more appropriate place:

I think that [patients] don't realise the stress that it can put on their carers and I think there's probably times they can actually suffer more than if they were in a hospital environment where the professionals can respond to the rapid changes in their need for pain relief in particular, which you just can't offer at home on a 24/7 basis. (GP)

My first interview with Ray was during an emergency hospital admission due to increasing breathlessness. Ray was hoping to return home, but after two failed discharges, home was looking more unlikely. Ray was aware of the stress on his wife, and eventually her wellbeing became more important than getting home. Ray did not return home, and in the second interview he told me was now “*more sensible about not going home...as there was no way Clare could care for me now.*” Clare was relieved in his acceptance of the hospital:

I panic... I've had enough. He's had enough and I've had enough, so the nurses and the doctors can look after him here...I get very tired....The hospital can do more for him than I could at home because I... you know, I haven't got the oxygen that he needs...he's better off here. (Clare, wife of Ray)

While it is acknowledged that rural hospitals lack the palliative care resources and expertise of the larger city hospitals (Lynch, 2012), the Snowy Monaro hospitals have their own standout features that partially make up for any deficiencies. Patients and their FCGs spoke of the personal treatment by all the staff. The hospital was a familiar place where some had worked and knew “*most of the staff*” (*Nathan, son of Gordon*), a place where children and grandchildren had been born, family had been cared for, and former family members had died, the place they turned to whenever a crisis arose.

One GP recounted a recent interesting experience:

I had a patient die in hospital...his wife was actually in hospital at the time with a problem with her hip, so she was up one end of the ward and then they called her to his room, and she was with him when he died, which was nice.

The following quotes by Ryan, Clare and Stuart illustrate their experiences and perceptions of rural hospitals. Ryan had recently spent a few days in Cooma Hospital, for symptom management; Ray and Stuart were local hospital inpatients at the time of interview:

I prefer [the local hospital], because I just like... country hospitals...and country people.... I feel they're more compassionate. They're not as highly staffed so there's more personal interaction. In the big hospitals there's that many nurses and doctors that you don't get to know them or their name or personality... there's a definite difference between the country hospital and the city hospitals. (Ryan)

You get along better in the smaller community hospital rather than busy, busy [city] hospitals. The hospital has been very good to us. I don't think he'd get any better care than what the hospital's doing for him here. (Clare, wife of Ray)

It's much better [here]. Canberra's really busy and because it's a teaching hospital there's people coming and going all the time. Everybody wants to have a look. (Stuart)

While most participants highly praised the nursing staff, all the staff contributed to making the hospital more personal. Stuart's brother, Fred, had come from Sydney to care for Stuart. He was impressed by the country hospitality:

All the staff, the tea ladies, the boys that bring lunch and everyone, the whole thing seems to be done in a very respectful way... and then when you meet them out in the grounds having their lunch or something, they chat. (Fred, brother of Stuart)

Ryan even laughed about the advantages of knowing the kitchen staff:

I know [the assistant] in the kitchen quite well. I've known her for sixteen years...she's a partner of one of my mates. She come in and ask me is there anything special (laughs) I wanted on the diet and so ordered some scrambled eggs for a change, and all of a sudden I'd get scrambled eggs whenever I wanted them. Yeah, little things like that...you wouldn't get that in a big hospital. (Ryan)

This notion of 'knowing' and 'being known' (Pesut et al., 2011) by the staff was an overriding expectation of all the participants. Leanne and Daniel had a great rapport with Leanne's GP and community nurse, both of whom visited her on the farm, 30 kms from town. What occurred after Leanne died in hospital was unexpected, especially in a small rural hospital, and caused great disappointment amongst the family. The doctor involved was the overnight medical officer, a GP rostered to work in the emergency department and ward. He was unknown to Daniel and had not been involved in Leanne's care:

Just one thing I was a bit disappointed about. One of the nurses was in there just after Leanne died. She just came in and checked her and she said "I'll have to get the doctor to certify everything". So we waited there for probably 20 minutes... and then the doctor come to the door but he didn't actually step into the room, he just went to the door and he asked was the nurse in there. We said "no" and he went back to the desk, and then we waited another 20 minutes, and then we went out and said to the nurse, "You know the doctor hasn't been." "Oh yeah he's already signed off", but he didn't go into the room...which was a bit disappointing...I would have thought he would have, might have offered some condolences or something. He didn't even look at Leanne. (Daniel)

The familiarity with staff did, on occasions, have its downside:

I love the oncology unit... you know people there, you go, you chat, you talk it's really friendly and lovely and I used to love going but [the nurse] would [speak] at the top of her voice. It wasn't a private thing

and I didn't feel comfortable at all... Other patients, we can chat and talk and staff shouldn't say anything. They are actually there to do a job. (Marianne)

With only a small number of staff, when conflicts arose, there was often no alternative health provider to turn to. This conflict with a staff member eventually caused Marianne to cease local treatment, “*I couldn't take it anymore*” opting to continue treatment in Canberra. Other participants also had negative experiences in the local hospital, often surrounding the prescribing and administration of medications. Andrew spoke of the inexperience of medical staff in dealing with high dose opiate pain medication; Susan spoke of the delays experienced when her father required medication:

But they wouldn't [give her what she needed] because they're not trained in [the medication] or the methodology. (Andrew, husband of Elaine)

In hospital you can't give the medication as the carer, you can't be in charge of their pain... let's say [Dad] might need the lolly [fentanyl lozenge], but you might ring the buzzer, wait ten minutes, then they have to go and unpack the lolly and even then Dad was showing them how to unpack the lolly. I think it's quicker at home because within three seconds of Dad saying, “Can I have something?” [he gets it], and he knows how to open the lolly better than the nurses in the hospital. (Susan, daughter of Kevin)

However, this negative experience was not universal across all patients as expressed by Ryan:

If I needed anything for pain... Not a problem... They were always there, yeah. Excellent service. (Ryan)

The delay in receiving medication was also indicative of the low staffing levels, not unique to rural hospitals, “*it's the same everywhere*” (Ray). While the level of care was perceived as mostly good, families sometimes felt the care lacked expertise compared to city hospitals, where care seemed “*more proactive rather than reactive*” (Daniel, partner of Leanne). Some families also felt the need to remain with their family

member, even overnight, to ensure they were adequately cared for and received timely assistance:

I guess [the care] was good....they're all busy...like you know Leanne's breakfast had arrived but she wasn't able to open anything or eat it so that was a bit of a wakeup call to the rest of us... then we just said, well someone should go and sleep there every night and be there for whatever she needs. (Daniel, partner of Leanne)

This need to stay with their family member was for some an inconvenience and one reason some FCGs preferred to continue care at home:

But I really think that [a hospital admission] would just be more hassle because we'd still want to be there, one of us there all the time or two of us there all the time, so that's actually much less convenient. (Susan, daughter of Kevin)

With no formally designated palliative care beds, Cooma hospital does have two rooms set aside for palliative care patients, with facilities for families to stay overnight in the *Mary Green Room*. Despite some families perceiving the overnight stay in hospital an inconvenient necessity, for some families, having the ability to stay overnight was a privilege and lessened the disappointment of their family member not receiving end-of-life care at home. One GP describe his experience with a family who were able to be with their husband/father when he died in hospital:

His wife said she couldn't really cope and, we've got this room upstairs that was furnished by the MCCR [Monaro Committee for Cancer Research] and the family were there, she was with him, and the kids lived [out of town] so they were actually in the hospital and it was a very good hospital death... they, physically, couldn't have done it at home. (GP)

One theme, throughout the interviews, was the importance of maintaining personal routines and normality, regardless of place of care. While hospitals were considered a '*controlled space*' where routines and policies were adhered to, the hospital policies often were not sympathetic to individual preferences.

As a controlled space, and in consideration for other participants, some felt the hospital was not a congenial place to maintain social interactions. Ray was concerned about his noisy grandchildren visiting:

All the grand kids can come into the house. If they come here [hospital] (laughing) they'll wreck the place, they're little 'ferals'! (Ray)

The lack of privacy in hospitals was perceived to inhibit intimacy between couples. For Ryan and Carol, it was important they have “*that special time... [when] we're not interrupted... that quiet time, that personal time.*” Ryan died at home and the time Carol spent with Ryan before the funeral directors came was important, as narrated by the palliative care nurse:

And for [Carol] to be able to spend quite significant hours, because [Ryan] stayed in the home until about seven o'clock...until the daughter arrived, so she was able to lay with him. They were in their own bed. [In hospital] it would have been possible for a little while, but it's still a foreign environment, a hospital environment...And people coming in and out of the room, or noise...Yeah, just hearing that background hospital noise, even with your door shut. And I think that after a little while [the nurses] would have been suggesting that Ryan go down to the morgue. (Palliative care nurse/Ryan)

Despite the challenges and disappointments with the local hospitals, the FCGs of the five patients believed the hospital was the right place of death:

Hospital was the best place...yeah I think so. (Daniel, partner of Leanne)

Even though he wasn't at home. I thought it was good actually because I don't think we could have coped at home...So, I think [Stuart] did it for us. He probably thought right, I know them up at the hospital, I know everyone there ... I'd rather die there where they can look after me than expect my brother and sister to do it for me. (Fred, brother of Stuart)

After a month long stay in intensive care in Canberra, Gordon was transferred to the rural hospital to die. While returning home was considered, the better option was a transfer to hospital. His death in hospital was managed professionally, compassionately and personally:

He was given a private room where he could die peacefully, with his family around him and I think that was as dignified as it could be. He had people tending to him... he was off the drugs, but I think he was just getting oxygen...if we wanted to have him home in our house then we probably could have, but we'd made a decision that he was just as well off being there [in hospital] as being at home...it would have been harder having him at home, because we would have had to do all the work...it was fine in Cooma [Hospital], so why not stay. (Nathan, son of Gordon)

In contrast to the well managed hospital death of Gordon, all did not end well for George. The reader will recall that in respect of his sister's wishes, George's preferred PoD was hospital. George had had a number of admissions to hospital, the last admission the result of a delirium. All through his illness, George had known he was to die in hospital; however, in his confused state he wanted to go home. He became agitated and at times combative, especially after his sister's visits. Possibly due to the inexperience of rural staff and the lack of specialist palliative care advice, the staff at the small rural hospital requested that Betty stop visiting. I will let Betty tell the rest of the story:

George wasn't really happy in hospital. He wanted to come home... [When I visited he'd say] "I want to go home" and I'd say, "Well, you can't come home." "Why can't I come home?" "Because they're not going to release you and 'cause you've got cancer and you're dying and you need to stay here." They stopped us from seeing him, from the end of April to, he died on the 9th of May. We didn't see him in that time... 'cause I used to upset him every time he'd see me. He'd get upset because I wouldn't take him home.

At ten o'clock I got a phone call from the nurse, who told me that she walked into George's room and he was a bit blue, so they put him in bed and they put

him on a syringe driver and she said, "Now, that doesn't mean he's going to die today. It could be three weeks' time or whatever." Twelve o'clock I got a phone call telling me that he'd passed away... I mean, I wasn't there, I didn't see him, so...obviously, his condition had changed, so the fact something had changed to prompt them to change his management. I mean, what she said is that sometimes people will change and will go on for a few days, so she's right and she's wrong, but yeah, she was wrong.

He passed away on his own, which he didn't want to do. We'd already prearranged that when his time was up or getting close to being up, I would be there with him because he said he didn't want to die on his own. "I will be there for you. I will hold your hand until you pass away" and he said, "You promise?" and I said, "I promise." But I didn't get the chance to do that.

(Betty)

When I interviewed Betty, three months after George died, she was finally coming to terms with the guilt and trauma of not being with her brother when he died. She knew she could not have cared for George at home, but she was disappointed she had been stopped from visiting. Betty was left wondering if things would have ended differently if George had been transferred to the out-of-region hospice.

Not all research patients admitted to the local hospitals for symptom management or carer distress remained there for end-of-life care. When their prognosis was estimated to be more than a couple of weeks, and they were unable to return home, then the only option for Gwen and Bruce, was transfer to one of the six local RACFs.

6.5 Residential aged care as the place of death

Five participants died in a residential aged care facility (RACF). Three were permanent residents, for whom the facility had become their 'usual place of residence'. Gwen was admitted for respite and rehabilitation, and Bruce was transferred from hospital for end-of-life care. For Barbara, introduced previously, the RACF had become more than just the physical building, it was also her 'home'. While Cheryl wished she could be at home rather than in the aged care facility, she "*sort of*" accepted the placement and had

made it more homely by bringing in “*some furniture and stuff*.” Dorothy, on the other hand, struggled with her placement; the facility was not her true home. All of these participants had moved to the nursing home, not from choice, but because their health and/or social circumstances meant they were no longer able to be cared for at home:

She never wanted to be put in a nursing home...but unfortunately she needed 24 hour care and it just wasn't something I could do. (Rhonda, daughter of Dorothy)

Two RACF research patients were widowed (Gwen and Barbara); three were married (Cheryl, Bruce and Dorothy). While Cheryl's husband was willing to care for her at home, her condition required round the clock nursing care, not available in her out-of-town residence:

If she could move she could walk, she wouldn't be here and could leave, that's the unfortunate part about it, she could be at home....but, we wouldn't have the equipment for a start, like she's got to be lifted in and out of the chair all the time with the lifter and that takes virtually two people, so you would have to have someone with you all the time. (Pat, husband of Cheryl)

The remaining residents had either no partner or the partner had their own health issues making it impossible to provide care at home:

Well there is Dad and he's 91 and has mild dementia. Up until Mum went to hospital I was coming over all day and being with them all day. But ...I got sick so I couldn't keep on doing it...because of her behaviour it was becoming really unsafe for her [at home]. (Rhonda, daughter of Dorothy)

Families often struggled with the decision to admit their family member to care. Hospital was a more acceptable place than a RACF. The patients' medical condition was seen as the reason for admission to hospital, the patient required medical care that was not available at home; the family's withdrawal of care, desertion or shirking responsibility was the perceived reason for admission to a RACF, and this was often associated with a sense of abandonment and guilt:

I felt it hard because I thought I was letting [mum] down, see, after all the time looking after her that I actually let her down by putting her in a nursing home... When I told her that's what we had to do, she said "I know it's not your fault", ... but I don't know whether she fully understood. (Rhonda, daughter of Dorothy)

According to one RACF director of nursing (DON), residents take on average 3-months to settle into their new environment, and Dorothy had only been there two weeks. Bruce was transferred to the RACF from the local hospital. He had a mild dementia that worsened as his cancer progressed, making it impossible, and unsafe for him to return home to his elderly wife. During his 2 month stay he never settled, the facility never became home, his family never resolved their guilt. In contrast, Barbara had lived in aged care for a number of years. According to Barbara and her son, Rodney, there are a number of features that make a RACF stand out. Number one is the staff:

Some of the staff there [in Sydney], you could tell it was a job and their attitude was quite different, so I think the number one thing that makes a nursing home better, is... the staff, it's like the foundation of it. (Barbara)

Décor and the airiness and all that, and the layout, come in second. I think the big thing with [the Cooma nursing home] is its staff are really dedicated. I can't think of one person there that I'd say was not doing their job. (Rodney, son of Barbara)

Staff aside, if the RACF is to become home, then it is important to make it less institutionalised and more homely. Rodney and Fred described their experiences of nursing homes in Sydney:

It was dull, it was depressing... I just thought, the designer has missed the mark. The painting, the paint inside, the walls and décor, was all that dark coffee colour. (Rodney, son of Barbara)

When I go into nursing homes, when I used to visit Mum, the nursing home just smelled. And it had a kind of depressive side to it... and everything associated

with death...On the whole I think probably rural nursing geriatric care in some ways is better than in the city. (Fred, brother of Stuart)

One theme that was often voiced, was that country RACFs are staffed by community members, people who know the residents and whom the residents know. For many new residents it is a familiar face that helps them to settle in:

The staff really care, because they know the residents. That's the difference between rural and city, is that the staff themselves have grown up and lived with them. They know them, so they do the death [the way they] think [the resident] would want. (DON)

From my experience with nursing homes in Sydney, I think there's much more community here and the staff knew mum and... in a way it can be really supportive that they kind of knew her. (Louise, daughter of Gwen)

Just like rural hospitals, rural RACFs are part of the community. This can work for or against its reputation. If something is done well then the facility is held in high regard; if there are gaps in care then the whole community knows. The family members who were interviewed commented that at times “*they were really quite short-staffed*” (Louise, daughter of Gwen), and in particular short of qualified nursing staff. This became more of an issue when the resident was unable to call for help themselves and relied on FCGs to assist:

We wait a long time when the buzzer's pushed for help, for the pan or for pain medication. I think the staff probably do as best as they can but there's times when I'm very frustrated by how long it takes to have someone come. (Rhonda, daughter of Dorothy)

I don't think the nurses read up so much 'cause a lot of them don't understand mum's got macular [degeneration] ... they tend to shout at her and I think well she's not deaf, she's blind. Mum does get a bit of a pip in her when they start. (Simone, daughter of Dorothy)

However, Cheryl's husband did not see that staff shortages were an issue at his wife's facility. Compared to their experiences in a city hospital, Cheryl was well looked after. Pat felt very confident in the level of nursing care:

I can go home at night and sleep knowing she's well looked after. When she was in Sydney I'd be worried every 5 minutes wondering if she is being looked after. So much turnover of staff in those hospitals up there, not regular, they come from the agency and you never know who, never see the same one twice. (Pat, husband of Cheryl)

It was only possible to interview two FCGs in the bereavement period; however, both felt that the facility was the right place to die. All the residents died in a safe environment. They were all well cared for. They died in a RACF because home was no longer safe for them:

It was the right place, she was surrounded by friends, but also not only staff and patients but there was other friends within the town who used to come and see her...so she felt good about that. (Rodney, son of Dorothy)

I was happy at the time with the decision because she couldn't have lived [at home] by herself, and at the time we didn't know how long she had. (Louise, daughter of Gwen)

While FCGs would consider a transfer out of the facility to hospital "if they could do something" (Louise, daughter of Gwen), none of the residents or their FCGs wanted to be transferred out of the facility for end-of-life care:

I wouldn't want her moved to hospital or anywhere else. I know a lot of people do die in a hospital but if you've got the option I don't think that's a nice place to die (crying). Not that there's ever a nice place to die, you know what I mean, but I would rather her be here. It's just more clinical in a hospital... if she's comfortable it's not like they can do anything. (Louise, daughter of Gwen)

While by no means perfect, the overall level of satisfaction with the regional RACFs was high:

I don't know how they could actually improve it here. It's about the top of the tree, the nurses are all great, everyone associated with the [facility] are all great. (Pat, husband of Cheryl)

6.6 Out-of-region inpatient hospice as the place of death

For this discussion, 'hospice' refers to the specialist multidisciplinary palliative care inpatient unit across the border in Canberra, Australian Capital Territory, 115 kilometres from Cooma, and 200 kms from Bombala. None of the interviewed patients identified the hospice as their preferred place of care or death, although Marianne and George considered it an option. In order to gain a perspective from at least one FCG whose family member had died in the hospice, three FCGs were identified from obituaries in the local paper. One bereaved FCG, Andrew, responded to my request for an interview.

For Andrew's wife, the out-of-town hospice was her preference. From Andrew's perspective it was because Elaine felt safe there. She had complex pain issues and over the years this had been poorly managed by both the local hospital and the tertiary hospital in Canberra. Prior to her death, Elaine had been admitted to the hospice on two occasions for pain management. This was a place she trusted and believed it was the only place that would keep her comfortable:

She didn't have to worry about anything. It was all pretty much taken care of. She was back on pain management...she was still in a lot of pain, however, it was a lot better than what things were. She was in a quiet environment where she could, I suppose basically withdraw from the world, and there was always one of us with her. And in [the hospice], if she was in need of anything you hit the button and within a couple of minutes you could get it. (Andrew, husband of Elaine)

Other patients and FCGs acknowledged the expertise of the hospice, in relation to pain management:

I imagine that [the hospice] would do a much better job [in pain management] because that's what they're devoted to, they're focused on. They have palliative care doctors and nurses. (Susan, daughter of Kevin)

[If I had major pain issues] I'd go to [the hospice]. I think I would just make a choice to go where the specialists would keep me comfortable. (Marianne)

For most participants, the hospice was not an option, mainly because of its location out of region. For one FCG, the concept of 'hospice' was a city institution where families could hand over their responsibility of caring for their family member, *"In Sydney, you'd just disappear into a hospice."* (Amanda, daughter of Ivan)

Except for Betty (who had a distressing experience with her brother's hospital admission), and Elaine (who preferred to die in the hospice), the need for a rural hospice was not identified, as most participating residents had confidence in the existing regional support. Marianne, whose story will be told in the preface to chapter 8, was ambivalent towards the hospice.

6.7 Congruence between actual and preferred place of death

All the participants identified a place they or their family member would prefer to die. There was congruence between actual and initial preferred place for six research patients. While I was unable to interview all the bereaved FCGs, there were legitimate reasons for patients having to move from their preferred PoD. The views expressed in the interviews suggested that the patients and their FCGs accepted the move, at the time.

6.8 Concordance between preferences of patient, family caregiver, and healthcare professionals

Consistent with the findings reported by Davies et al. (2016), there was good concordance between patients and their FCGs around preferred PoD. For the patients and their FCGs, the preferred PoD usually meant the place where the patient felt safe and could maintain their identity, value and control. Initially this was their ‘home’ or their private residence. Except for George, the patients’ and FCGs’ preferences were the same, with the FCG making every effort to achieve the preferred PoD:

He would prefer to stay at home, he’s a home person ... he loves being home, so we try our best and use all the facilities and support to keep him at home as long as possible. (Deedee, wife of Kevin)

In discussing the options for PoD, some FCGs indicated that if the circumstances changed, for example pain became unmanageable, they would explore all the alternatives. However, most FCGs felt the final decision to move from home would be left to the patient: *“I think we would just leave it up to [Dad]”* (Susan, daughter of Kevin). The GPs and nurses were more pragmatic. While wanting to respect patients’ choices, they saw their main role as controlling symptoms. The two GPs, palliative care nurse, and community nurses all gave examples of incongruence between patients’ and FCGs’ preferred PoC and PoD. In some situations the FCG accepted the patient’s wishes, at detriment to themselves and the patient:

[Place of death] is important, but it’s not the only factor that I would think about. And I’m not really talking about Ivan in this particular case, but quite often people make these decisions and the families just can’t cope with it, and so when the patient gets to a certain point the families, despite the fact that they wish to die at home, the family are just completely falling apart, and you end up bringing them into hospital. Often at that stage, the patient is so unwell and clouded they’ve sort of almost lost contact with where they are, so then it becomes a matter of almost treating the family rather than the patient, ‘cause the patient’s not really aware anymore and sometimes the family are just not physically up to the physical demands of having someone die at home, and

sometimes the family aren't really behind it all, but they've just sort of acquiesced to the patient. (GP)

6.9 Chapter summary

This chapter has described where the 15 research patients died. It has explored the preferred PoC and PoD of the patients, their FCGs and HCPs. All the participants had an initial preference. All the patients, including the RACF permanent residents, stayed at home (or in their usual place of residence) for as long as was possible. Patients were willing to consider alternatives to home for PoC, providing it was short term, to access specific treatments (such as acute pain management or transfusions), and they could return home as quickly as possible. Home (or UPoR) was the preferred place for routine care regardless of the preferred PoD. Home was also the initial preferred PoD for most, and while some were able to die in this place, the majority of patients and their FCGs had to adjust to changing circumstances. Most accepted the change. The meaning of home was explored through the experiences and perspectives of the rural participants. Home is more than the material structure. The most significant features of home include a place of security, control, memories, self value, belonging, relationship, and a refuge from the outside world. If these elements could be found in places other than home then the alternative PoD became 'acceptable', and the new preferred PoD.

The findings reported in this chapter contest the notion that a 'home' death should be a measure of the success of palliative care. Some research patients died well at home, while others died well in the local hospital, RACF, or hospice. Some patients died well in their preferred place. Others, like George, did not die well in their place of choice. Place of death is only one element contributing to a 'good' death. The following chapter explores further the rural concept of the good death.

CHAPTER 7: THE RURAL ‘GOOD DEATH’

Ivan’s story

Ivan’s death, according to his GP, “*was one of the most positive death experiences*” he’d been involved in. Ivan had been living with chronic leukaemia for 8 years or more. Two months before I interviewed Ivan, his leukaemia transformed into an acute form, with a very poor prognosis. Ivan was a 5th generation Monaro sheep farmer. He lived on the family property, where he was born over 80 years ago. The property held many happy, but also tragic, memories. Of his three adult children, two had moved away. His son remained on the property, where he lived with his own family.

The farm was about 15 kilometres from town: close enough for Ivan to be actively involved in his church and community, but far enough away from the hustle and bustle of town. The farm house was cosy, and adorned with items that reflected Ivan’s love for his family and his love of life. Ivan was embedded in the community and embedded in the deep tapestry of his farm. Five years earlier, Ivan drew up his advance care directive. His plans were to live a long, productive, healthy and happy life, and when the time came, to avoid machines and futile life prolonging interventions, and to die on the farm. His intentions had not changed.

Once his leukaemia transformed, Ivan was admitted to the oncology isolation ward at the tertiary hospital. This was an unfamiliar environment. He longed to be home, surrounded by nature and “*all the trees.*” Ivan was far from home, the place where he could “*paint and find peace with God.*” Ivan made the decision that for him there would be no more futile treatments in cold sterile isolation wards. He was going home.

It was a wet Monday morning when I interviewed Ivan. He was very frail but willing to tell his story. There was a sense of calmness throughout the home. Ivan lay in bed looking out the large double French doors that opened directly onto a secluded, shady cottage garden. This was obviously a special place on the farm. A place to sit and relax after a hot, tiring day on the tractor or chasing sheep, a place protected from the howling

snowy winds. The farm dogs were asleep on the mat outside the glass doors. We talked about his illness, his hopes, his faith and his artwork.

It was obvious that Ivan could no longer care for himself. It took all his energy just to sit up in bed to take a sip of water. He could still say his “*prayers in the morning*” but could no longer “*drag himself to church on Sundays.*” His adult children had all come home to care for their father. They had not lived together for many years, and with three individual adult personalities, they found themselves tripping over each other and becoming exhausted (physically and emotionally) in their attempt to do the best for their father. They harnessed their collective strengths and “*eventually worked out a roster*”. This allowed Ivan’s son, Paul, to continue working the farm, and the others to take turns having ‘timeout’, to rest and gather their strength to face whatever lay ahead. With limited energy and still “*lots to do*”, the family ensured Ivan’s energy was spent on important things, like spending time with family and in the garden.

Team work was essential if Ivan was to remain home. A combination of friends and health care professionals supported the family. Paul described “*an endless stream [of] Community Health troops*” which at times became overwhelming. While each person was keen to help, at times Paul felt there was a lack of co-ordination or a blindness to “*the overall picture.*” Ivan was dying, he didn’t need dietary advice to build up his strength. There were endless phone calls, and a steady stream of visitors who never came empty handed. The kitchen was overflowing with homemade cakes, biscuits, soups and casseroles. The community nurse visited. Fortunately for Ivan, his GP was a family friend, so distance was no barrier for home visits.

Ten days after my interview, Ivan had a particularly restless night. He suddenly became confused and agitated, most likely the result of a cerebral haemorrhage. The family were exhausted. The girls needed to get away, to renew their strength, so took a drive in the countryside. The GP dropped by on his way out of town. It was obvious to him that Ivan was dying. Medications were arranged, but before the community nurse arrived at the home, Ivan died. Ivan died at home, in his own bed, in his son’s arms. This is what Ivan and the family had hoped for. This was a good rural home death.

Introduction

Ivan's story illustrates that a 'good' rural death is possible. It is a powerful story of family, home and community. Ivan's death illustrates the meaning and importance of home, as described in the previous chapter. For Ivan, home was a place of security and control; a reflection of himself, his values and status; a place of permanency, continuity, and a place to belong; a place of memories; relationships; the centre of activity; and a refuge from the outside world. Having explored my participants' preferences for PoD, and the meanings they ascribe to these places, this chapter explores the position PoD holds within the concept of the good death. Dying at home added to the 'goodness' of Ivan's death, but it wasn't the only feature. Security, maintaining identity, self-value, personal control and normality, and continuing to live while dying were contributing factors. Absolute PoD is meaningless unless it is placed into context.

This chapter, explores what it means to die well in the rural Snowy Monaro region, from the experiences and perspectives of a sample of the residents. I begin by drawing out what is meant by the 'good death' among this population. The factors patients, family caregivers (FCGs) and health care professionals (HCPs) consider to be important in defining the 'good death', namely symptom control, place of death, the presence of family, informal and formal support from the community, autonomy and spirituality, are discussed. I describe the way previous experience moulds the expectations as to what a 'good death' should look like, and changes in perspectives over time. This chapter concludes by exposing the core element of the rural 'good death' as described by the participants.

7.1 What is a 'good death'?

Ivan's story illustrates a 'good' rural death from the perspectives of his son, who was present at the time of death, and his GP, who was absent. What made it 'good'? After all, a beloved father died in the midst of acute agitation. There was no medical presence at the time of death. The GP had left; the community nurse was away preparing medications. For some participants in this study, the 'good death' related to the time of death, for others it was the weeks leading up to the death.

A 'good death' might be defined by its rapidity:

The only good dying I can think of is quick (laughs). But possibly just being very comfortable, no pain and just at peace. (Carol, wife of Ryan).

Despite his illness and weakness, Ivan was able to continue living while he was dying. He was able to participate in his normal activities, albeit much slower and for shorter periods of time. Except for the last few hours, he remained lucid. In the following quote, his GP highlights the importance of maintaining physical and cognitive capacity until the time of death:

It was fairly rapid and he had capacity, right up 'til the day he died. He could still get out and about and do things and I saw him at a family birthday, it would have been probably...ten days before, and he was out and about and quite active and visiting people and it was really only the last day that that stopped. So he went from being sort of quite active, so in that respect, he didn't have a prolonged period of being bed-bound. But that was just lucky, I suppose.
(Ivan's GP)

Ivan's rapid death contrasted to Daniel's experience with Leanne. Daniel struggled with the length of time his partner was actively dying. For five days, Daniel sat at her hospital bedside, as Leanne lay in a coma, wasting away, unable to engage in conversation. Daniel's concern was not only for himself but also Leanne:

The last four or five days like it... I guess it seemed as peaceful as it could have been, I don't know. I guess if four or five days had of been two days it would have been better. She didn't get much joy out of just lying there. (Daniel, partner of Leanne)

Other participants felt a 'good' death was a 'timely' death. Ivan was in his 80s. Although he was still active, he had lived a long and productive life. He had children and grandchildren to continue the family line. Other participants felt it important there was time to prepare for death, to face death with a sense of life completion, as in the following quote by a patient:

Knowing I'm ready, everything sorted out...I know we've all got to go so it doesn't matter, I've nearly made 75. (Ray)

Family caregivers reiterated this point about feeling there was no more “work to be done”, with additional concerns that their relative not be overwhelmed by negative emotions:

I suppose a good death for [Stuart] will be [if he can say] “I'm only 55, I have only retired, yes the house and everything I worked on so hard, I won't be able to enjoy it; however, I enjoyed doing everything I've done. I don't have any regret. Of course I'd like to live longer, but I can die now, and fall asleep feeling, gee there was so many good things I enjoyed”. So that would make a good death. And that there's no longer the anger. That there's no fear. (Fred, brother of Stuart)

I believe a good death, when the times comes, he knows himself and he can say what he wants to say with his family. (Deedee, wife of Kevin)

The rural palliative care nurse made the comparison between a ‘good’ death and a ‘good’ birth, and commented on the differences between calm and tranquillity, with everything going along as expected, to chaos, with nothing going as planned or as hoped for:

I personally like to think that they are comfortable, peaceful, everyone around is accepting, and that it's a really nice transition from life to death, a smooth transition...I see it along the lines of birth. If it's a really traumatic birth and it's suddenly this rushing to theatre and a caesarean because things are going wrong, that stays with the parents for, you know for a couple of months, maybe they kind of retell that story, “Oh, it was so scary.” And I always think that about death, too. If it can be a really lovely peaceful transition then that's what you remember. (Palliative care nurse)

For some participants, expectations matched reality, as demonstrated in Ivan's story. Before he died, Ivan's daughter shared her hopes for her scenario of her father's death:

A good death for me would be just to fall asleep [in the garden], in the chair in the sun and ... in a happy situation, like sitting in the sun with the sheep dogs around him and just falling asleep in the chair. (Amanda, Ivan's daughter)

Reflecting on Ivan's death, Ivan's son said:

I mean a death in his own bed and looking out his own window with his own garden, with feeding the chooks two days beforehand, with a brown snake in the garden, 'cause that's what brown snakes do in Australia and with all the family coming and going. (Paul, son of Ivan)

The GP also concurred, that in his opinion, this was a 'good death':

Well I'd say, his death was probably one of the most positive death experiences I've been involved in he died in his son's arms on his bed, I mean, what better way could you go? Like his son had his arms around him when he died, it was quite an experience. I wasn't there at that time, I'd been there just a few hours before and I went there afterwards as well. (GP)

While the experience of death and dying was different for each participant, there were common themes surrounding the 'good death'. These themes were consistent with the literature review in Chapter Two, and revolve around the western concept of a 'controlled' death. The physical, emotional, social, spiritual and cultural aspects of dying were all identified by the participants, and are discussed throughout the following section.

7.2 Factors associated with a 'good death'

The participating patients, FCGs and HCPs reported a set of factors associated with 'dying well' within the Snowy Monaro region. Five major themes were identified that represented concepts the participants considered important for a rural 'good death': symptom control, place of care and death, family presence, community support (informal and formal), spirituality, and maintaining identity and control (autonomy).

These themes all underpin the deep personal need to be valued, to feel secure, and to die in a safe environment.

7.2.1 Symptom control

Good symptom control was identified by all the participants as essential to achieve a 'good death', and was probably the main facilitator. Most participants specifically mentioned the importance of being pain free:

I think the last period as you're leading up to death, I think, should be free of pain. (Rodney, son of Barbara)

To be as comfortable as possible. It's awful seeing [Dad] in pain and feeling like you want to jump to do something and help but you know you can't. (Susan, daughter of Kevin)

Other participants spoke of the need to control other symptoms, as all symptoms, no matter how distressing, have an impact on patients' quality of life. Ivan's recent swollen ankles meant more than just physical discomfort. To maintain dignity, he always dressed well when going to town. While he could wear slippers around the house, this was not an option in town. His daughter reflected on the consequences of this new symptom:

I don't want him to suffer. Like today he's got puffy feet, that's new. And the implications of that is the shoes don't fit. And if the shoes don't fit, we can't... well we can't go to town because that's quite undignified. (Amanda, daughter of Ivan)

Pain and other distressing symptoms were feared, not only by the patients, but also the FCGs. The following FCG spoke openly of how her partner's breathlessness distressed her and how she felt uncertain about best to support him:

Clare: *Seeing him not being able to breath, you can see it frightens him. It would frighten anyone. I mean hold your breath for five minutes and you can see that.*
Interviewer: *And it frightens you too?*

Clare: *And me of course, yeah. We sit there and he tries to catch his breath, and I sit with him. You know, he sits on the reclining chair, that's where he sleeps as well. And I say "take some deep breaths" and... I sit with him and rub his shoulders and he goes, "I'm right now". But I don't know if he is.* (Clare, wife of Ray)

One of the features that helped Ivan to die well was that he maintained a good level of cognition right up until the last few hours. Patients feared the loss of awareness and decision making capacity. However, a relative might be willing to accept some loss of cognition if it meant symptom control could be achieved, as in the case of Stuart:

So I'm hoping to see [Stuart] in an acceptance, peacefulness, no pain of course. Well I don't think there will be, from what the staff have told me of his condition. And at the same time, it's a pity that if they have to give him so many drugs that he just sort of passes out and dies in his sleep. But, I guess if he's not afraid of death he may see it as the next adventure, and that would be great. (Fred, brother of Stuart)

The word 'euthanasia' was not used by any participants, nor was the request for physician assisted suicide made by any patient or FCG. However, for some FCGs, such as Nathan, good symptom management implied not prolonging suffering:

I asked them to give him some more pain relief, but that was just as much to hurry up the process as anything else, I couldn't see any point him lying there possibly in pain, you know, sort of making groaning noises and that. (Nathan, son of Gordon)

A 'good death' meant that life was not prolonged unnecessarily by futile interventions. Peter, Marianne's husband, had watched his wife go through many painful treatments, and while he was grateful for the extra time they had together, he questioned the fairness in prolonging life:

Because the treatment is available it prolongs life, but it prolongs suffering as well. (Peter, husband of Marianne)

Some FCGs spoke of their concerns for their family member based on past experiences. One of Paul's elderly relatives had suffered a protracted death following a stroke. She had lost dignity; she had no quality of life. Paul did not want this scenario for his father. Ivan had made it known on his final discharge from the isolation ward in Oncology, he did not want any further futile treatments. Paul respected his father's decision and autonomy over his decision making:

I watched my elderly relative die.... She had a stroke and was unconscious and she was rattling away full of morphine. And not only morphine but she was dehydrated. I couldn't believe, she looked frightful and I said to the young boy, I now realise he was probably a young registrar, "what do you think you're doing? I wouldn't do that to a sheep".... And that was indicative of our society's inability to deal with death in a humane way. And that was the case of because medical intervention could and medical intervention had kept her alive for weeks as a vegetable. Yeah, and I thought that was cruel. (Paul, son of Ivan)

While most FCGs would prefer that their relative was symptom free, there was an acceptance of compromise. Speaking of Marianne's experience with myeloma, her husband commented on her ability to adjust:

Over time she has come to, well learned to appreciate even though she's unwell, there's still things she can do, relationships to be had and things to be seen through. She has the personality that allows her to make the most of the situation, whereas another person might have got depressed or given up or just lashed out or whatever, through frustration, but she has been able to, she has such an accepting way of coping that she's been able to make the most of it, which is a strange thing to understand because through daily discomfort and pain and everything she's still able to find joy and meaning in little things. She has an acceptance of her fate which should, you know, help us as family to cope with the whole situation. If the person is constantly fighting or afraid to die it would be terrible because just that anxiety has to be taken on. (Peter, husband of Marianne)

Patients also demonstrated their ability to compromise and adjust to the symptoms as the disease progressed. In the following quote, Gwen adopts a pragmatic approach towards her planned whole brain radiotherapy, seeing in her experiences something that could benefit others in future:

You know you're going to get worse but you don't think about that you get on with life. I could sit here all day on my own and think "poor me" but I've never thought "poor me" I just feel that there's a reason for it and through what I'm going through somebody else might be able to be helped. (Gwen)

Many participants equated a 'good death' with a peaceful death. This was more than just being pain free. "Peaceful" implied the patient was comfortable, unaware of the distressing situation, at ease physically, emotionally and spiritually:

Mum had a good death, 'cause she was in a coma, so she didn't feel nothing.....just peaceful. That's all I can hope for my brother too, that he's not in too much pain, and he just floats away. (Betty, sister of George)

Good symptom control was essential if someone was to die 'well' at home. For the interviewed HCPs, symptom control was their main objective, and sometimes meant compromising the respect for patient's preferred PoD. After a difficult day trying to control Marianne's pain and restlessness at home (her story is narrated in the following chapter), her GP indicated that if her symptoms had not settled she would have been admitted to the local hospital in town:

If we hadn't been able to [make her comfortable], she would have had to have come into town. (Marianne's GP)

Marianne's community nurse, did not return to see Marianne settled, and was left with a lingering sense of failure as a nurse, as she was unable to control her symptoms:

I saw her certainly at her worst...if I had of arrived 5 minutes before she died and saw her peacefully dying, I would perhaps say "that was a really good death" but my vision's been skewed (laughs) by what I saw before...and that's

put a lasting impression in my head. (Marianne's community nurse)

7.2.2 Place of death

Place of care and death was identified as one factor contributing to a good death. Preferences for PoD and the meanings ascribed to place were discussed in depth in the previous chapter. Here I discuss how PoD and the congruence between actual and preferred PoD fits into the concept of the good death. As reported in the previous chapter, most patients and FCGs initially identified 'home' as the preferred place for care and death; however, 10 of the 15 patients (excluding Barbara who considered the RACF to be 'home') did not die at 'home'. Along the illness trajectory patients frequently had to move away from home. For some, the move reflected a change in preferred PoD, for others the 'new' place was not of their choosing, but became an 'acceptable' PoD. In bereavement interviews with FCGs whose family member had to leave home, it was apparent that the actual PoD did not have a negative impact on the quality of dying. Marianne died at home, in her preferred PoD, however, her husband regretted she did not die in hospital, where medical advice would have been immediately available. He actually considered her home death to be a 'bad' death.

A home death was Marianne's idea, it was not realistic....home was the right place for Marianne...but it was too traumatic for us. (Peter, Marianne's husband)

In the initial interviews, most participants considered home to be a peaceful, unproblematic place. However, some patients indicated they would consider moving away from home if necessary. Frequently, patients who wished to die at home qualified their preference for home with statements such as "*if my symptoms are controlled*" or "*providing the family are coping.*" While patients had discussed their preferences with their FCGs, it appeared not all FCGs were as willing to change their preferred PoD. As an aside to this discussion, it is fitting I add the following personal reflection on the situation that arose for Marianne and her family. One of the personal tensions I had in conducting the interviews was that in guaranteeing confidentiality I was unable to pass information between patients, their FCGs and HCPs. I had been involved in Marianne's care but was away when she died. Marianne had indicated in her interview that while she wished to stay at home to die, she was uncertain if her husband and adult children

would cope with the physical and emotional responsibility of providing 24/7 care. While she had told her family she wanted to die at home, she was actually very open to the idea of receiving end-of-life care in either the local hospital or the Canberra hospice:

Say I was semi-conscious and they couldn't control my bowels...anything like that. If my family can't manage that and I've told all the girls, and the boys too, if it gets to the point where I need full nursing care, like the bed changed because I've soiled myself or stuff like that I don't want to really, I don't think I want to be home if we're at that stage, just for the sake of dignity and I'd feel uncomfortable... and you can't make those decisions 'til they're upon you."

(Marianne)

Peter's determination to keep Marianne at home had a negative impact on his bereavement. He tried desperately to find some positive feature, something he could attribute to a 'good death' or a sense that he and the family had helped his wife to die well:

The ambulance man said "it was fantastic to achieve [a home death]. Usually it becomes too physically and emotionally draining, becomes too hard and most people phone us to take the person to hospital." I suppose we achieved something significant, but it was extremely traumatic. I had to cope, I was the leader. I had to be there for the family... We had a plan, I had to do everything to keep to our plan. Marianne wanted to stay home and then she couldn't tell us what she wanted. (Peter, husband of Marianne)

Actual PoD is often a compromise between honouring patients' wishes and being mindful of FCGs' capacity and ability to provide care and take on the responsibility. Obviously, it is impossible to determine how important the congruence between actual and preferred PoD was to deceased patients; however, as highlighted in the case of Marianne, the FCGs must be considered as it is the FCGs who are left with the long term memories of the death:

Marianne did want to die at home. But... her husband wasn't quite as committed to that, or he was committed to it, because of her sake, but that

wasn't what he would have chosen necessarily, because he found that whole caring aspect quite challenging I think... I mean he doesn't have any sort of health background and so physical care and that type of thing, and also the emotional intensity of being with the one that you love without the backup and support of medical people in your own home. (Marianne's GP)

As alluded to in the previous chapter, the interviewed HCPs appeared much more pragmatic when it came to PoD. While endeavouring to honour patients' wishes, PoD was not considered to be the major contributor to a 'good death':

With any patients, [home] is important, but it's not the only factor that I would think about. (GP)

Ivan, whom we met in the preface to this chapter, did die at home, and on all accounts his was a 'good death'. There is no doubt that home was very important to him and contributed greatly to his 'good death'. His identity, security and self-worth were all embedded in his home and farm. Home was central to his relationships, activities and memories. From information gained in the bereavement interview with his son, there is no doubt that a hospital death would not have been 'good' for Ivan or his family:

I just keep hearing stories again and again that reiterate how lucky we were to have a death like that. I haven't heard of any deaths at home like that, most people end up in hospital, wired up to machinery and far from their home environment. (Paul, son of Ivan)

Most research patients did not die in their initial preferred place. The reader will recall Gwen, whose story was told in the previous chapter. Gwen died in a RACF, the place she least wanted to die. When Gwen's daughter reflected on the quality of her death, the PoD contributed to, but was not the overriding determining factor:

I think she died as well as she could have, if you know what I mean. To her, I think, she would obviously have preferred to be at home, so it's hard for me to say. I think in the scheme of things, I think she did [die well]. (Louise, daughter of Gwen)

Through the experiences and perspectives of the rural participants it appears that while home is the preferred PoD for most people, preferences change throughout the illness trajectory. Some patients died at home, their preferred PoD. Some of these deaths were good; some were not good. Other patients died away from home, either by choice or circumstance. Again some deaths were good; others were not good. While PoD is a contributing factor to achieving a 'good death' it is by no means the most important factor, and in some cases had no bearing on the quality of the dying.

7.2.3 Family

Many FCGs spoke of the importance of being present, if not at the time of death, then the days or hours before. In the initial interviews, a number of FCGs spoke of their hope of being present and their fear of being absent at the time of death. Being present would provide the FCG opportunity to support and comfort their relative, and ensure they did not die alone. Being present also provided comfort to the FCG in their bereavement, knowing their relative was not abandoned and alone. In situations where the patient had been agitated and restless seeing their loved one finally at rest, provided some comfort. This was the last act of kindness they could offer their loved one:

I'd like to be there to say, "don't be afraid, we're here." That's what I'd like to do. Be physically close to him... No, not on his own, and physically I can be there close to him, and for him to hear, "don't be afraid, don't be afraid" ...And of course when he dies, his memory will, he'll still be with us in our thoughts, and every time we touch or see anything that we know he loved, we'll be able to recall him. (Fred, brother of Stuart)

He loved his family and his family was there, so it was a good death, yeah. We had two little grandchildren, so dad's great grandchildren [were also there]. (Nathan, son of Gordon)

One of the fears surrounding a hospital death was that the FCG would not be present at the time of death:

My biggest fear is not being there when he goes. And if he's in hospital there's a ten minute drive, lots of roos, traffic, so you've gotta try and get there in time

before he goes and my biggest fear is not being there, not being able to hold him or hold his hand and telling him “it’s OK, I’ll be alright”. I think that’s my biggest fear, not being there. (Carol, wife of Ryan)

In addition to being present at the time of death, some FCGs thought it important to have opportunity and time to talk with the family. This would require good symptom control and for the patient to retain capacity and awareness:

I think other things would be having family around, if that’s what you want. Like the chance to say goodbye, for him to say goodbye, for us to say goodbye, to express things you never said while you’re alive because you don’t need to say it. Being able to say goodbye, to forgive, to reconcile if you need to, and to be as comfortable as possible. (Susan, daughter of Kevin)

The importance of being present was illustrated by those who were present at the time of death or had spent time with their relative before they died. A few FCGs lived out of area and they all spoke of the importance of making the effort, and sometimes sacrifice, “*cause I more or less did put my life on hold*” (Louise, daughter of Gwen), to spend time with their relative before they died. A number of FCGs left their partners and children, some still at school, behind at home while they came to the Snowy Monaro region to care for their family member:

That’s one thing that I look back on and I don’t regret. That’s one thing I can say, I spent the time with her...I don’t regret [leaving my children in Sydney] when I look back on things, yeah, that’s one thing I’m pleased I did. (Louise, daughter of Gwen)

It was very important that we were there, even though we weren’t there at the precise time, but it was good that we were there and we could be there within minutes after the event, but we’d been there all day. (Rodney, son of Dorothy. After spending all afternoon with his Mum he had gone back to the motel for a short rest).

I don't want to go back [home to Sydney]. I want to stay [with my brother], although I've just left everything in Sydney. But then I've got supportive neighbours. That's my community, it's the neighbours and the church community. But the neighbours keep an eye on the house and everything. So I know I can stay. (Fred, brother of Stuart)

Not all FCGs were present at the time of death. For some this was devastating, compounding grief and guilt. Betty did not want her brother, George, to die in her home and had promised him she would be with him in hospital and hold his hand as he died. Due to his agitated state, the nursing staff had requested Betty not visit, and so, George died alone. In my interview with Betty, before George died, she articulated some hopes that were not to come to pass:

George would want a quiet and peaceful [death], and to see everyone's face for the last time, and then just drift off. I think that would be the best for George. I mean not necessarily his friends, but his family... [The place] isn't important providing there's love. (Betty, sister of George)

Elaine, wished to die in the hospice in Canberra, some 110 kms from home. Andrew, her husband, was able to spend a lot of time with her, but on occasions had to return home to attend to business. It was during one such trip home that Elaine died. Andrew regrets his decision to return home that night, a wrong that can't be put right:

Unfortunately, that night was one of the nights where I came back to sort things out, and went back again. And I made it a short night, I think I left there about ten o'clock at night, and I was back there at seven o'clock in the morning, but she was already gone. So for me, I needed to be there that night. But I can't change that. I could have organised things better, I suppose. (Andrew, husband of Elaine)

In the previous chapter, one of the interviewed GPs spoke about a recent hospital death. The family was from out of town and were staying in the family room on the ward. The man's wife was present when he died; however, his adult children were getting dressed in the family room next door:

I honestly thought that was a very good death... he didn't want to come into hospital, but they physically couldn't have done it at home...I didn't actually think whether it was at home or at hospital made a lot of difference actually, it was more about whether the family is there. Yeah, it was more about who was there rather than where it was. Well his children were not with him the moment that he died, but that didn't seem to make a lot of difference, his wife was there.
(GP)

FCGs also play the role of advocate for the patient. This is a privileged position and works well when “*all the family's in agreement and everybody knows what's going on*” (Paul, son of Ivan). However, at times FCGs priorities differed from the patients', as in the case of Stuart and his sister:

Stuart told the palliative care doctor in Canberra, when I was sitting by the bed, “I know my illness is terminal, and I want quality in whatever time I have left, not quantity.” And that was difficult, because lot of the palliative care interview... was [our sister] saying how she wanted a PICC line delivered. And the doctor said, “well, there's a high risk of infection with these [and he would have to go to hospital] to control that”. And [our sister] had a few ideas...I suppose she just feels she doesn't trust people that they'll look after him properly...And I took Stuart's arm, and I said, “What do you want to do, Stu?” And he turned, and the doctor said, “Yes, a good question. Stu, what would you want?” And that's when he said, “I'd like to go home.” (Fred, brother of Stuart)

While the dying person is central to the concept of the good death, the level of care and support for the FCGs must be acknowledged. If the FCGs are left exhausted, guilt ridden or significantly distressed, complicated grief may result (Miyajima et al., 2014). It is during the bereavement period that the FCGs reconstruct their impression of the death. It is important that FCGs' concerns, objections and reassurances are listened to and validated. Some patients intuitively knew the thoughts and concerns of their FCGs, while others needed to hear them spoken by their FCGs. Most patients' decisions regarding their care were influenced, to varying degrees, by the viewpoint of their FCGs. A successful home death required teamwork:

A person can't just have that right [to die at home] without the cooperation of their loved ones. (Community nurse)

An additional issue for patients and their FCGs was raised by a community nurse. It is difficult to know whether Marianne and Peters' expectations were due to poor communication or their desire to 'hope for the best'. They had been told by Marianne's haematologist that in the terminal phase she would "slip away peacefully, and without pain," despite having suffered with complex pain throughout her illness. This mismatch of expectations and reality had a negative effect of Marianne's dying:

I think she possibly did not have a 'good death' because the family had unrealistic expectations of what was going to be happening as she got further in her illness. I think that the unrealistic expectations set up for failure. When we got to her last few days, because it wasn't what the family had been led to believe by the treating specialist, there was some anger there, which I think made it difficult for the family to fulfil a caring role, because there was so much anger there....And I think that led towards a situation of panic, to be truthful. We did manage to have her pain relatively well controlled, but there was a restlessness and agitation, and when she was demonstrating that restlessness and agitation she wasn't in a fit state of mind to be able to express herself verbally and that made the situation harder for the family, as well as the nurses going in. (Marianne's community nurse)

It inevitably falls upon the rural community to support the FCGs, although distant family and friends may be available to contribute. The support is often equally shared amongst informal and formal networks. Some of the research patients had limited family within the region, so their support was mostly provided by the community.

7.2.4 Community support

In order for someone to have a 'good' death, the patient and their FCGs need to feel supported. Gwen's daughter felt that the large number of friends who visited the RACF, helped Gwen to accept the placement. Gwen had been an active member of the community, so visitors were familiar and ensured she did not feel isolated:

She had so many people that popped in and that was a really positive thing about her being here too, is that people could do that...if she wasn't mixing with people I don't think she would have been as accepting of the situation. (Louise, daughter of Gwen)

Daniel also appreciated the support he received, not only from the local community, but also Leanne's international and interstate friends:

I was just amazed. But yeah [a friend] from the Sunshine Coast and [friends from Canberra] and you know different ones that... spent time here over the eight to ten weeks. Just reflecting on it, it was a good time for us as well. I mean I guess we formed a closer friendship and you know Leanne was here for most of it and she was up for just as much fun while she could still have fun when they were here and... and I guess everyone was making the effort to make it as good a time as possible for her and... and yeah as sad as it all was, it was still nice that we all went through that together. (Daniel, partner of Leanne)

Friends also offered practical support, especially for those who had stored up social capital before they became unwell:

Elaine had a lot of friends in Cooma, and she did a lot of community work. You know she was really well known by parts of the community, and those people were queuing up to do something. I'd have to send them away all the time, there were far too many people. You'd hear a knock on the door, and open the door and there'd be a meal left there. And that sort of thing happened many times. People turned up one day and said, "Right, we're going to clean your windows for you," and they went through the house and cleaned all the windows, you know. It was amazing. (Andrew, husband of Elaine)

All of the participants spoke of the essential support required from health care professionals in making a 'good' death. This support was not just medical advice and management, but also came in the form of friendship, practical support, a listening ear, and often just being there:

I think for someone to feel they'd had a good death would mean that they felt supported through every step of the way, whether that means they'd chosen to die at home or in a facility or in a hospital. (Community nurse)

7.2.5 Autonomy

Autonomy, and respect of patients' choices, were cited as factors contributing to the 'good death'. Most FCGs concurred with Susan (daughter of Kevin), who considered it her responsibility to "*respect [Kevin's] wishes as much as we can.*" Many patients described how the scope of their autonomy narrowed as the disease progressed. Early in the illness, most patients indicated it was important to participate in decisions regarding treatment options and place of care. For Gwen it was important to undergo surgery in Sydney.

All of the participating patients and FCGs expressed their personal preferences, wishes, goals and priorities. One of the benefits of remaining home was to retain autonomy:

[At home], you can do what you feel you should do, whereas if you're in an institution you've got to abide by the rules of that institution. (Gwen)

For some, the fear of losing control caused much distress, "*I've lost control [of my body, the disease and my life] and I'm an emotional wreck*" (Marianne). Likewise, the disregarding by HCPs of patients' and/or FCGs' wishes, was also met with frustration and disappointment.

While most patients and their FCGs accepted the move from home, as death approached, participation in the decision making was important. Gloria accepted the move to the aged care facility, providing she could continue with physiotherapy. Once settled in the facility, Gloria and her daughter rejected the recommendation that she move to a room closer to the nurses' desk:

I asked Mum and she didn't want to move. She's already had to come to hospital and then here [aged care facility]. She's just got this room, and I think moving her again is not really fair, especially as she doesn't want to go. [Louise, daughter of Gwen]

For others, respect for their decisions regarding the final PoC and PoD contributed to a 'good death'. It was Barbara's decision to return to Cooma, despite it being inconvenient for her son to visit, "[Sydney] was getting her down, and she says, 'I want to get out of here'" (Rodney). Ivan's decision to leave the oncology isolation ward and return to the farm, was respected, as was Gordon's family decision to transfer him from the tertiary hospital ICU to a ward bed in the rural hospital.

For some FCGs, the quality of dying was negatively impacted by the pursuit of respecting patients' choices. While some FCGs indicated they would leave the decision making to the patient, "I think we would leave [the decision to go to hospital] up to him" (Susan, daughter of Kevin), some were not given this opportunity as patients became incapable to make decisions. Marianne's family were intent in respecting her previously stated wishes to remain home. As will be discussed in the following chapter, according to Peter, (husband of Marianne), "her ideas were never realistic... I had to do everything to keep to our plan." This sentiment was supported by her community nurse, and unfortunately, "the unrealistic expectations set up [the family] for failure."

While patients, FCGs, and HCPs preferences were often at odds with each other, and preferences changed over time in pace with changing circumstances, a sense of autonomy was maintained providing patients were listened to, and participated in the decision making.

7.2.6. Spirituality

Two patients, Gwen and Ivan, found peace in their Christian faith. While Ivan was no longer able to attend church, daily prayers gave him a sense of contributing to others' well-being:

If you just sat there and watched TV all the time, you're not doing anything for anyone. So this is where prayer is important. The more you keep mixing, and finding people that need prayer, and some of them need incredible prayer just to keep going. And the more you do that, even if you're just a vegetable, and you're in bed praying for other people...you're contributing. (Ivan)

Gwen's faith provided her with a source of spiritual sustenance and strength. Her 'worldly' suffering was a temporary process to be replaced after death with something much greater and more peaceful:

If I didn't have my strong faith I would be a screaming, screaming heap. I know where I'm going and that's the main thing...Peace, I have peace, I don't need to worry about suffering or what lies ahead...one day at a time. My faith gives me a different view, a different outlook on suffering... because I know where I'm going. (Gwen)

The concept of 'worldly' suffering (physical, emotional and spiritual) was also raised by Kevin's daughter, Susan. Her view of a 'good death' was associated with the trust in, and assurance of an afterlife:

I think a good death is one where you have hope beyond death, where even in the midst of your suffering and pain you know that actually death is not the end but the beginning of actually the better life, the way life was meant to be. Life in this world is full of pain and suffering, my dad is facing that at the moment, I think the saddest thing for me is if suffering continues [after death] and there is no kind of reward. (Susan, daughter of Kevin)

Most participants did not disclose any specific religious faith. However, spirituality did not just relate to religious beliefs. Marianne found music to be a spiritual experience:

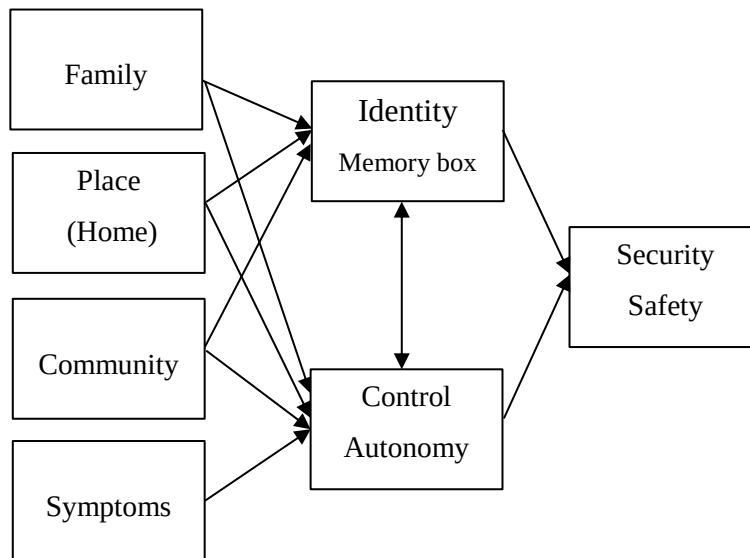
I don't have any fear but I feel a form of grief. I listened to Brook's violin concerto yesterday, it was on the ABC proms concert and I just wept and sobbed through the second movement...because it triggered how grief stricken I am and how emotional I do feel about this part of the journey. At times I think I have come to terms with it and then something like that happens and then I feel very vulnerable and extremely sad (cries). We'd spent the morning with the grandchildren and they're so full of life, and you know I can enjoy all that without feeling grief while I'm there. It's music that triggers things for me, it's always music that triggers me. [It's very spiritual and a] highly emotional, emotive thing. (Marianne)

7.3 The central theme of the ‘good death’

The ‘good death’ for these 35 rural residents was influenced by adequate symptom control (physical, emotional, psychological and spiritual), place of care and place of death (not necessarily home), the presence and support of family and the community, accessible health care professionals and other forms of formal support, spiritual strength and comfort from faith beliefs and other mediums such as music and nature, and maintaining some degree of control over the dying ‘journey’. After synthesising the preceding themes, the central theme on which the ‘good death’ is founded can be summarised in one word, SECURITY (Figure 7.1). A dying person is vulnerable, and in most cases has lost control of their physical body. The disease has taken control. If they can die in a safe physical, emotional, social, and spiritual space, and the FCG feels they have helped create and protect a safe space for their loved one and themselves, then this is a ‘good’ death.

To create a safe space, the patient and FCG need to take back whatever control they can. As the literature review illustrated, a ‘controlled death’ implies control of symptoms, timing and place. This necessitates autonomy and a right to decision making. Autonomy respects identity and self-worth, and maintains dignity. Maintaining relationships with family, friends, HCPs, and the community protects the safe space; but relationships can also create disharmony. In a safe space the patient has the freedom to be who they are - be it the old familiar person or the ‘new’ person created through the illness. For most patients ‘home’ was seen as a safe place; but for many participants, the home quickly became unsafe. All these research patients, except Marianne, supported by their FCGs and HCPs, willingly moved from the ‘unsafe’ place to a safer place.

Figure 7.1: Interaction of themes and the creation of the safe ‘good death’



7.4. Chapter summary

This chapter has explored the concept of the good death in the Snowy Monaro region, through the experiences and perspectives as narrated by 11 rural patients, 15 FCGs, two GPs, one palliative care nurse, two community nurses and one RACF director of nursing. While each stakeholder has an impression of what a ‘good death’ may look like, the ‘good death’ is in the memory of the survivors, especially the FCGs. The ‘good death’ is illusive, and has many different meanings. Many of the contributing elements are not uniquely rural, but are shared across all settings.

For some participants the ‘good death’ referred to the moment of death, and for others, the dying process. Maintaining a sense of normality, and continuing to live while dying was important, and achievable, for many participants. Good symptom control was voiced by all participants to be essential for a ‘good’ death. Symptom control included management of physical, emotional, psychosocial, and spiritual distress of not only the patient, but also the FCG. Place of death was one cog in the ‘good death’ wheel, but not the ‘hub’. While home was the initial preferred PoD for all the participants, a death away from home did not imply a ‘bad’ death. The presence and support of family, both during the dying process and at the time of death, contributed to a ‘good death’. However, when the FCG perceived or experienced a lack of support for themselves, the death was sometimes constructed to have been a ‘bad’ death, even if it occurred at

home. Community support, both formal and informal, helped the FCGs to feel supported, and helped to maintain normality for the patients. A 'good death' was often pictured as a 'peaceful' transition from life to death. However, for some participants, a 'good death' was not possible, with some settling for a 'good enough death' (McNamara, 2009).

The participants' narratives illustrate that the key determinant of the 'good death' is security, and not necessarily dependent on any particular place of death. For some patients, like Ivan, home was a place of security. He died literally in the secure arms of his son. For others, home was not a place of security. In rural Australia, the meaning of home may carry a deeper significance and connection, particularly for people who have lived long on the land. However, isolation and limited resources may make home less safe than in urban settings. The following chapter explores the influence of rural residency on the 'good death' and decisions surrounding place of death.

CHAPTER EIGHT: THE INFLUENCE OF RURAL RESIDENCY ON THE ‘GOOD DEATH’ AND PLACE OF DEATH

Marianne’s story

Marianne was married to Peter. They were not ‘locals’, having both grown up in the city. They preferred the tranquillity of country living. They felt safe in their relative isolation. Twenty years ago they moved from the city, with their seven young children, to the farm. Twenty-five kilometres from town was close enough to be involved in community life, but far enough away to protect their privacy. They were a self-sufficient, independent family. Although not visible, there were neighbours nearby who would respond to any call for help. There were patterns to life that created security. Marianne was the lynch pin of the family; the organiser, the matriarch. Like many of the children on the surrounding farms, Marianne’s children had been home schooled, so home held many happy memories.

Marianne was interviewed in their huge rambling farmhouse. The last two kilometres to the house was on a muddy, and at times, slippery dirt road. It was a lovely winter’s day. The home was cosy; the wood fire in the corner burnt brightly. We sat in a new extension that had been purpose built to ensure Marianne had a cosy place to sit during her final months.

Marianne had been unwell on and off for over five years. She had the type of cancer that cycled through response to treatment to relapse. This cycle continued over the years. Bone pain, at times difficult to control by the local GPs, had been her constant companion. The palliative and community nurses had visited Marianne at home regularly over the five years. While required to travel to Canberra to see her specialist, for the first three years she had received treatment locally in the five-chair, three-day-a-week oncology outpatient unit. Her specialist minimised Marianne’s visits to Canberra by being available by phone. Marianne had loved the local oncology unit; it was small and personal. She appreciated the support she received from the oncology nurse and fellow patients. They were all locals and Marianne felt a connection to the unit. Part way through Marianne’s illness the oncology nurse became ill and resigned.

Unfortunately, Marianne had issues with the new oncology nurse and no longer felt comfortable attending the unit. Marianne and Peter ‘wore a track’ on the road between home and Canberra, a 270 kilometre return trip. The private oncology clinic in the city was adequate, but did not have the personal country feel. In the beginning, regular trips to Canberra were acceptable, even a “nice day out”. However, when her pain escalated the journey became unbearable, but had to be endured as her symptoms and medication regime were too complex for the local GPs and rural hospital.

A few months before I interviewed Marianne I had visited her at home in a professional capacity. She was in crisis. She was very unwell and not expected to last the week. Her adult children came from all parts of Australia. The house was busy with people coming and going. Despite being gravely ill, Marianne continued to direct her care and the household from her bed. After three days, a blood transfusion was arranged in Cooma. This was a miracle. Within a couple of hours Marianne, who had barely enough energy to get to the hospital, was up walking to the bathroom. This had been a “*dry run*” for her dying, some eight months later.

Marianne wanted to die at home. Home was a safe place. Marianne and Peter thought this “*dry run*” had shown them what to expect in a home death. Remaining in their safe place may not be the best option, and might be too stressful and burdensome for Peter and the family. There were “*too many people with no medical training*” staying at the farmhouse. Marianne didn’t want her children toileting and washing her. Maybe the local hospital or the out-of-region hospice would be a better option, but that could also be stressful for Peter. With this immediate crisis over, the family returned to their own homes, but in their absence, the “*kids felt they should be doing more.*” The oncologist reassured Marianne and Peter that with her type of cancer, the last days of life “*would*” be pain free and peaceful.

When Marianne entered the terminal phase of her illness the family all returned to the farmhouse. Three days before Marianne died her GP went on holidays. Before leaving, he handed her care over to one of his colleagues, the husband of one of Marianne’s best friends. The following day Marianne became restless and agitated. The community nurse visited daily. She remained available on-call by phone overnight; after hours home visits were unavailable. Staying on the farm also meant GP home visits were

limited. With a busy day in town, the GP was unable to just “*pop in between patients*”. He was happy to be interrupted with phone calls but there were “*no medical staff to provide [face to face] reassurance and interventions.*” Peter and the family were on their own for most of the time. Peter felt “*unsupported and alone.*” He did not want phone nursing advice or care workers. He wanted the presence of “*qualified medical advice.*” He was overwhelmed by Marianne’s increasing restlessness and agitation. This was not what he had expected and it had been going on for two days. On the third night, the night before Marianne died, medical support was finally available. After finishing at the surgery, their GP friend went to the hospital, where he worked as a visiting medical officer. He collected a syringe driver and medications and drove out to the farmhouse. He stayed with the family until Marianne was settled. In the early hours of the morning the GP returned to his home. Marianne died a few hours later at home, on the farm, surrounded by overwhelmed, exhausted and distressed family.

Introduction

Marianne’s story contrasts to Ivan’s ‘good death’, yet they both died at home on their respective farms. From Peter’s perspective, Marianne’s death was not ‘good’. Due to relative isolation and limited resources home became an unsafe place to die. Marianne’s story illustrates the influence of rural residency on the ‘good death’ and place of death (PoD). The chapter begins with a description of the patients’ place of residence. This is followed by a description of the participants’ perception of themselves as ‘ruralites’. The aspects of rural living that either facilitated (life style, and familiarity with the community, location and institutions) or hindered (distance, and lack of specialist and allied health services, and local expertise), a ‘good’ rural death and determined the patients’ actual PoD are discussed.

8.1 Participating patients’ place of residence

As previously discussed, in the literature review, there are many definitions of ‘rural’, and many different types of rural communities. Even in this study, ‘rural’ was not homogenous, and included towns, villages and farms. Each participating patients’ residence was unique, either in terms of location or the living circumstances. Some patients lived alone, and others lived with a spouse/partner or family member.

Consistent with the quantitative data discussed in Chapter Five, the patients resided in a cross-section of locations and degree of rurality. The majority of decedents identified in the surveyed population palliative deaths, and patients represented in the interviews, lived in a town with GPs and a hospital (66% (91/138) of surveyed deaths; 60% (9/15) of interviewed patients). Farmers accounted for 17% (24/138) of surveyed palliative deaths, and 33% (5/15) of patients identified in the interviews. Of the 15 patients identified in the interviews, seven lived in Cooma (one lived alone; four with their spouse; two in a RACF); two lived in Bombala (one lived alone in a private dwelling; one in a RACF); one lived in his sisters' 'granny flat' in Delegate; and five lived on farming properties located between 10 and 38 kilometres outside Cooma. Three of these farms were on bitumen roads; two were accessed by dirt roads for the last two and five kilometres, making travel difficult in wet or snowy weather. All but one farmer lived with their partner/spouse; Ivan lived on his own, but had an adult son living in a separate house on the property. Bruce lived with his frail, elderly wife, but also had adult family members living independently on the property.

8.2 Rural identity and resilience

The literature argues (Wilson et al., 2009a) that rural people define themselves as different to urban residents, and this was supported by a comment made by Cheryl, when comparing nurses in a Sydney hospital with the nurses in her RACF, *"I'm from the country ... these are my sort of people"*. Amanda and Paul, the adult children of Ivan, made the observation that there is no 'universal' rural characteristic and that 'farm residents' are different from 'town residents'. We were sitting at the kitchen table, drinking tea and munching on the neighbour's homemade biscuits. Ivan was asleep in the adjoining room. We were talking about receiving end-of-life care (EoLC) in the country. Paul suggested that I needed *"to define rural as in living on a farm or living in a country town as being two separate things."* As children growing up on the farm, Paul and Amanda were aware that they were 'different' to the town children:

I went to [the local high school], there was a big difference between the country kids and the 'townies' ... they were just different. (Amanda, daughter of Ivan)

While Amanda found it difficult to explain the exact differences, Paul described how ‘farm’ residents are more independent, resilient and more adept at problem solving. This resilience (flexibility and the capacity to recover quickly from adversity) and self – reliance (the ability to problem solve rather than relying on others) was not necessarily a personality trait but more out of necessity, born out of personal experiences and expectations:

People on farms, by the nature of our business, we have to be able to fix problems, whether it's a sick animal or a broken pump or busted tractor or a bushfire or fence or whatever it is, financial stuff, dealing with business people, we've got to be able to do all those things. And we've got to be able to fix a pump with our pocket knife, if that's all we've got, that's what it takes. Where a town person would ring the mechanic and say "you fix it" and they'll go to the doctor and say "you fix that" ... So it's that sort of practical decision-making that I think country people are probably more adept at than town people. (Paul, son of Ivan)

Rural resilience, and in particular the resilience of farmers, was further described by Paul when I interviewed him after Ivan had died. Paul described how farmers are faced with new challenges every day. They are used to multi-tasking and finding novel ways to solve multiple problems at the same time. The following quote was in response to my question, “Is there a resilience?”

Absolutely, it's about problem solving, so every time we walk out the door we've got to solve problems. So this morning's problem... we've got shearing next week...it's about to rain, the tractor's been left up there [in the paddock], so we're going to have to walk up there today... we don't have to walk, but we're going to walk five kilometres to go and get it, and we'll check some sheep on the way. That solves [two] problems that need addressing. (Paul, son of Ivan)

8.3 Challenges of rural residency

This section discusses the factors associated with rural residency, as narrated by the participants, which impacted negatively on the ‘good death’ and PoD. During the

interviews, each participant was asked if patient care or FCG support had been compromised due to rural residency. Bereavement interview participants were also asked what influence, if any, rural residency had on the quality of dying and the actual PoD of their family member. Almost universally, the immediate response was ‘no’, as illustrated by Gwen and Ivan:

At the moment I can't see any disadvantage living in a rural area...people are kinder, people seem to rally round more, if they can help in any way they will help. (Gwen)

No [disadvantages]. Quite the opposite. (Ivan)

However, when given time to think about the question most participants identified at least one disadvantage, with the majority citing distance and travel. The following quote by Marianne illustrates her change in perspective when given a couple of minutes to consider the disadvantages of rural residency. Both Marianne and Deedee highlighted the consequence of distance when illness prevented further travel - they would lose contact with their specialists:

I honestly can't think of any [disadvantages] Actually, a negative I hadn't actually thought of, the travel you have to put in...what I'm thinking as a disadvantage, if the pain is too much to travel to Canberra...then I'm out of touch with my specialist. (Marianne)

If he isn't strong enough, it is only the travel. Otherwise I don't feel any disadvantages because I feel there is very good organisation and support here [in town]. (Deedee, wife of Kevin)

8.3.1 Distance and travel

As in Marianne's case, all the patients interviewed had received their initial diagnosis locally; however, they had to travel out-of-area to Canberra, Bega or even further away to Sydney, for further investigations, definitive diagnosis or treatment. Gwen and Cheryl travelled to Sydney for some of their treatment. For Gwen, it was by choice, to be near her daughter during and after surgery. Cheryl's sub-specialist treatment was

unavailable in Canberra. While both were initially accepting of the need to travel over 500 kms from home, ongoing treatment and monitoring in Sydney was not sustainable long-term:

I couldn't travel to Sydney all the time because I run [my local business]... We used to get letters to go and visit [the Sydney specialist]. People in the city think you only live around the corner. Sydney hospitals might be good in some respects, but for country people it's not possible to get there. (Pat, Cheryl's partner)

While travelling was mostly acceptable in the early stages of disease, over the course of the interviews it became apparent that the issue of distance and travelling became more significant as the patient became sicker and more fatigued, when symptoms became more troublesome, and when the patient entered the terminal phase. Travelling was not just an inconvenience, it was also associated with physical distress. Travel for those living on farms and in villages often meant a weekly trip to the nearest GP to obtain regular medications. The following FCGs described the problems encountered:

And the distance, 'specially when he's sick, having to get up early hours and go for appointments and scans and things like that and having to do the distance was quite painful with the roads and the snow traffic... That can be quite stressful. So that was a disadvantage ...because it just puts everybody on edge. (Carol, Ryan's wife)

Oh, it was terrible. He'd have about two or three [pain tablets] on the trip in and we're only half an hour away, so it was terrible. (Betty, sister of George who had to travel to the next town to see the GP)

Despite the inconvenience and hardship of travelling, many regarded travel for treatment a price for living in a beautiful place. Early in Marianne's illness her husband considered the travelling a positive, as "*a day out.*" The interview participants included those locally born and those who had moved to the region. Despite their origins, patients and their FCGs equally accepted the compromise that needed to be made, as illustrated by Bruce and Peter:

It was an inconvenience but if you live away from a metropolitan area, well it appears that if you need certain things you have to go to a metropolitan area. I'm willing to travel if [I have to]. (Bruce, generational 'local')

When you live in the country part of the accepted economy is that part of income goes on travel, that's just accepted...the quality of life we have here is so excellent in many different ways, it's a small price to pay. (Peter, husband of Marianne, 20-year 'local')

On occasions, travelling for treatment was put into perspective by describing it in terms of travel 'time' rather than 'distance'. While rural distances to treatment may be longer than in urban areas, due to faster speeds and less traffic on country roads, the time taken is not necessarily greater. Marianne was discussing how 'safe' she felt living on the farm, despite her isolation. She has family living in Canberra and compared travelling at home to travelling in Canberra:

Here you're 20ks but it translates to 15 minutes. In [the city], 5 kilometres translates into 15 minutes.

Due to travel distances, contact with specialists ceased as patients became too unwell to travel or to continue treatment. A number of participants (both patients and FCGs) expressed a sense of grief over discontinuing their contact. One community nurse associated the disconnection with a loss of support for the patient and their FCGs:

There's distances often between where the treating doctors are and where the patient is residing...and I think for someone to feel they'd had a good death would mean that they felt supported [by their specialist] through every step of the way. (Marianne's community nurse)

It's impossible now [to travel to Canberra to see the specialist], and there's no specialist here to come and see him. You know they won't travel here. And that upsets me to think, well he needs to see a specialist, but he [can't] travel all the way to Canberra. (Clare, wife of Ray)

It was an agonising decision... he wanted to have more treatment and we weren't sure if it was appropriate, and it was a [long trip] travelling up...because his mobility was reduced. And I suppose if we had a visiting oncologist here in Cooma, that logistic of travelling to Canberra to be reviewed by an oncologist would mean just travelling [into town]. Well I'm guessing the oncologist would not do a home visit. (Susan, daughter of Kevin)

The previous chapter reported that one factor contributing to a 'good death' was the presence of family at the time of death. The fear of not being present was significant. When FCGs had to travel to hospitals or the out-of-region hospice to be with their family member, the travel distances became more problematic. While rural FCGs had a strong desire to be present at the time of death they had to balance fulfilling their responsibilities at home with maintaining a bedside vigil away from home. The reader will recall, in the previous chapter, Andrew's regret for returning home the night his wife died in the out-of-region hospice. For Daniel and Leanne, the local hospital was their preferred PoD and the fear of not being present was foremost in Daniel's thoughts every time he left the hospital to attend to chores on the farm, some 30-kilometres away:

I guess I wanted to be [at the hospital] and then I'd come home and then I'd think well it could happen in the next four or five hours ...and so it's hard to come away and feel OK in case something happened. (Daniel, partner of Leanne)

I did a lot of going backwards and forwards between [home] and Canberra, I ran into problems when I stayed away from home too long, there were animals and all sorts of things to be done, and things got completely out of hand. And even to the point at one stage where a wild cat had moved into the house... I would come home and do what I needed to do around [home] and fix the things at home, and then gear myself up – the washing, etcetera, and that sort of thing – and then head off. And then I'd spend another three days and two nights [at the hospice]. (Andrew, husband of Elaine who died in the out-of-region hospice)

Distance and travel impacted on most FCGs, regardless of whether they lived locally or away. In the following quotes FCGs describe a number of scenarios they faced while caring for their family member: the out-of-town daughter having to travel to Cooma, leaving her own family; the family who had to travel from Cooma to be with their father in ICU in The Canberra Hospital; the anguish of family trying to decide whether to seek medical help locally or in Canberra; and the costs of travel when there was no family home to stay in when visiting:

If [Mum] was in Sydney it would be more convenient, you know what I mean, it'd be easier without the travel and stuff. (Louise, daughter of Gwen)

It was disruptive; we had to go up to Canberra every day for a month ...It's the time, the fuel. Taking time off work, and it wasn't just one person, it was my brother and my wife and my kids and all that sort of thing, so we wanted [Dad] back in Cooma...A lot of people say, you know, if you're sick you should be in a major centre ... but I'm not really sure. (Nathan, bereaved son of Gordon)

The travelling hurt [Elaine] a lot. So, we would only head for Canberra Hospital in the circumstance where we would consider that if we took her [to Cooma Hospital] she'd probably be put in the ward and transferred to Canberra Hospital anyway. The problem is that it would probably take a day to [be transferred to Canberra], whereas if I just get in the car it's only an hour...but she has to put up with the pain in the meantime, not that she doesn't have the pain when she goes via the ambulance. (Andrew, husband of Elaine)

The tyranny of distance. Every time we went down [from Sydney to visit Mum] we had to stay at least three days to make it worthwhile. We had to fuel the car twice and to pay for accommodation plus food. We used to bring our own breakfast material down, but we always had a hot meal out, and this was costing us on average about eight to nine hundred dollars a trip. So [we] couldn't do it as often as [we] might have liked to. (Rodney, son of Barbara)

As discussed in Chapter Five, PoD was partly determined by where one lived and the degree of rurality, with residents living on farms less likely to die in their usual place of

residence (UPoR) than those living in towns. This was in part a reflection of the availability of, and access to health services. By Australian standards, none of the participating patients were extremely isolated or remote. The furthest distance from the nearest hospital and GP was 38 kilometres, although the distance to some part-time GPs was greater after hours. The role played by distance and travel, in either facilitating or hindering the quality of EoLC, was evident in the interviews. The health care professionals (HCPs) indicated their availability to support patients dying at home, and each other, became problematic the greater the travel distance and the more protracted the terminal phase. The following quotes by a GP and a community nurse highlight their perspectives on travelling distances to reach patients at home:

Kevin lived in Cooma itself, so he was five minutes away. So if there was ever any issue or problem we were only five minutes away. Night time, [his wife] seemed to be very capable...knowing that the hospital wasn't far away, she could phone the nurses at the hospital. I did go on-call the last two nights.
(Kevin's community nurse)

If it had been a protracted illness it could have been quite difficult because he lived 15 kilometres out of town and to get out there and back for nurses was different to if someone was in town. (Ivan's GP)

If it is a long way out of town, then it is really difficult. I remember we had this young lady a few years ago up at [the ski resort], and that was really difficult to access her. It was winter, she wanted to die at home...and I must admit we were not encouraging her to die at home because it was wintertime...it was snowing...and no doctor was going to home visit, and you kind of feel like you're on your own when you're doing that. If you're the one travelling to that faraway distance, and [getting advice from the GP] all by phone, it's difficult for you to feel as supported as you do when you're doing it closer to town.
(Kevin's community nurse reflecting on a previous scenario)

For some out-of-towners, there was a mismatch between their view on the challenges of distance, and those raised by the HCPs. This may reflect the out-of-towners' acceptance of daily travel. When I interviewed Marianne she downplayed her distance to town.

While she was still physically able to travel she was optimistic of the support available; however, during her terminal phase her ‘15 minutes’ became an obstacle to receiving support at home. The following sequence of quotes illustrates the different meanings of ‘15 minutes’. While some GPs were prepared to travel, the final quote illustrates the restriction to travel due to responsibilities in town:

We’re only 15 minutes away, for acute care, for emergencies we have the help, we have doctors who are willing to come out, we have palliative care nurses who are active and willing to come. (Marianne)

[Living on a farm] certainly made it harder, because you couldn’t just duck out there. I mean I couldn’t just sort of pop out. If she’d been living in Cooma I could have said between patients that I could go out for five minutes and just have a quick look and see. But obviously it was a 40 minute round trip, so you couldn’t do that. So her distance... made that aspect of it harder for sure.
(Marianne’s GP)

Because they lived out of town, it wasn’t like you could just pop in the car and see how she was. You had to allocate time. If it’s raining that road can be terrible ...it was 20 minutes, 25 minutes to get out there... we don’t have an evening service, so if we go out there it’s usually a long home visit because we want to make sure we go through everything and make sure everything is in place and everyone’s clear, so it would be a big chunk of your day. (Marianne’s Community nurse)

The thing is I can’t always leave town because I’m on call for maternity...and we’re supposed to be within ten minutes of the hospital... There are doctors that have got anaesthetic call and the emergency doctor can’t get out of emergency for their whole shift, so on the days where we’ve got ‘on call’ responsibilities [we can’t leave town]. (Ivan’s GP)

The participants all eloquently narrated their perspectives on the “tyranny of distance” faced by ruralites. However, distance was not the only factor negatively impacting the ‘good death’ and place of death.

8.3.2 Other challenges of rural residency

8.3.2.1. Lack of local specialist services

While travel distances prevented patients from attending their specialists, especially once they became too unwell to travel, the lack of local specialists and interventions were also considered a disadvantage of rural residency. However, as patients became more unwell, they and their FCGs acknowledged that the need for further complex interventions was no longer necessary, regardless of where they lived:

If a high level intervention would make a difference, you're not going to get it here. So Cooma can't do platelet transfusions 'cause of the short time between extraction and delivery that's required. But that's the only technical issue we've come across...No, the advantages far, far outweigh any disadvantages. (Paul, son of Ivan)

Ready access to specialist services and expertise instilled confidence in some patients. This was particularly true when patients had complex pain issues. A number of patients spoke about the inability of local GPs to manage more complex issues. During a hospital admission in Canberra, Marianne became quite fearful of being discharged and returning home:

I got very insecure, which is very unusual for me cos I'm usually on top of things, and I wanted to stay an extra couple of days [in hospital]. I was frightened to come home because of all the drugs. [My specialist] said, "You've got to go home, you'll be right, you'll be OK" and it was. (Marianne)

8.3.2.2. Lack of local medical expertise

While most had been satisfied with the involvement of their local GP at the time of diagnosis, Susan talked about her disappointment in the delay in diagnosis of her father's cancer, which was not necessarily a rural issue:

The first [disappointment] would be 3 years ago when dad went to a local GP in town, he had a lump, but it wasn't really investigated [until] a year later. That's something we look back on as a disappointment, but of course that could have

happened with a GP in Canberra; I think it just depends on the particular GP.
(Susan, daughter of Kevin)

While most participants praised their local GPs, some felt they lacked the ability to manage complex issues, such as complex pain and high dose opiates. The perceived shortcomings were seen as multifactorial. Some of the inadequacies related to education, knowledge and experience of the GPs. Some participants expressed their concerns over the lack of funding and resources for rural hospitals, and the absence of proper clinical handover by the specialists and tertiary hospitals. A number of FCGs spoke of the lack of continuity of care between treating HCPs. Speaking from first-hand experience, Andrew became quite angry as he spoke of the discontinuity in the care of his wife, Elaine. Fred also voiced his frustration with the poor clinical handover:

The major issues that I can see are the lack of co-ordination and communication between the services. And most especially in the country hospitals there appears to be a big lack of funding... the support of the local GP is obviously critical. As far as I can see, there's very little support for a local GP. They need to be across the sort of treatment that [their patient] had, and the history up to that point, would help a lot. But it just seems to me that the local GP in many cases doesn't even get decent reports or anything. They're not being told. And it's their patient. Their patient comes back and they have absolutely no idea what's happened in the meantime. (Andrew, husband of Elaine)

Canberra just sent him back to [the local] hospital with no proper medical notes. They just sent him home to die, basically, without an adequate handover ... [The GP] said, "Well, we don't have any notes from Canberra. We've got nothing to tell us what's going on." (Fred, brother of Stewart)

8.3.2.3. Lack of allied health support

Limitations in accessing allied health support was cited as a disadvantage of rural residency. Some FCGs lived in cities and commented on the paucity of, or absence of, some services compared to more urban areas. In some circumstances, as voiced by Amanda, this was just an inconvenience; for others, like Gwen, the limitations in private home nursing reduced her chance of returning at home. (As an aside, since completing

my interviews, *HammondCare Palliative Care Home Support Packages*, funded by the New South Wales Ministry of Health, are now available, providing up to 48-hours of in-home end-of-life support by trained care workers (MacLeod et al., 2015)). One RACF director of nursing (DON) felt the lack of counselling support affected both the patient and the FCG:

And we've run out of glucosamine, so I went to the health food store, "oh we've run out, we'll order it." I come in three days later, "oh we haven't... the order got misplaced, and we'll reorder it." And I thought welcome to country town. Not that the glucosamine will make any difference but... (Amanda, daughter of Ivan)

I think the family would have benefited from a counsellor or a social worker. That would have made a huge difference, and then that would have had an impact on Gwen, because she got upset when the family were upset. (DON re Gwen)

While living only 10 kilometres from town, Carol spoke of the difficulty of leaving Ryan on his own, and the difficulty of finding someone at short notice to sit with him. While this did not prevent Carol from running errands, she was always mindful of the time she was away from home:

If I had to leave him on his own I couldn't go for very long...so that would be a problem, leaving someone as sick as he is home on his own. You've gotta organise [home care] in advance... you can't just ring up and say look I've gotta duck into town and do something. They can't just come out, you've gotta have that in place ahead of time. (Carol, wife of Ryan)

8.4 Benefits of rural residency

Despite the challenges faced due to rural residency, all participants stated the advantages outweighed the disadvantages. One of the positives of rural living, voiced by many participants, was the beauty and tranquillity of the rural lifestyle. Some of the participants, like Ivan and Bruce, were born in the region; others had moved there.

Leanne had moved to the area only three years previously. Yet all participants loved the region:

The advantages are really around lifestyle. (Andrew, husband of Elaine)

Leanne was just so grateful to be able to spend her last few years here ... in the peace [and quiet], with the animals, and just walk down the old road if she wanted to. (Daniel, partner of Leanne)

Some participants, like Ryan, who spoke of the “*good clean air*”, believed rural living had positive health benefits. Pat could not contemplate living anywhere else:

I would suggest you wouldn't leave here (laughs), like you couldn't get a better place... as far as living and care goes you wouldn't get it any better than here. (Pat, partner of Cheryl)

A few months before Marianne died, she described feeling ‘safe’ in her isolation. It is interesting to note that during her dying phase, the ‘isolation’ of the farm contributed to home becoming an unsafe place for her family, and limited the availability of medical and nursing support:

I just feel safe...the isolation I love, the fact that I feel really safe in my isolation. (Marianne)

A number of common themes emerged from the interviews that participants perceived to be a unique benefit of rural residency. Each theme facilitated a ‘good’ death and assisted the patient to die in their preferred place.

8.4.1 Personalised care

Many participants spoke of the value of being treated as an individual and receiving personalised care. The concept of ‘being known’ and ‘knowing others’ (Pesut et al., 2011), highlighted as a unique feature of rural hospitals in Chapter 6, was a major benefit of receiving and providing rural EoLC. Some participants commented on the small turnover of rural staff that facilitated personalised care. ‘Being known’ gave Ivan

a sense of acceptance for who he was rather than being known for his illness. For Pat, knowing the staff gave him confidence in Cheryl's care. From Louise's perspective, Gwen's acceptance of her transfer to the RACF was made easier because Gwen knew the staff. It was not just patients and FCGs who benefited from 'knowing' as the work of the community nurse was also enhanced by knowing the other service providers:

You know everyone. There's a sense of freedom I suppose. Oh well freedom to be the person you want to be. People accept you as you are. (Ivan)

[In the Sydney hospital] you're only a number. Here you're recognised as a person. I can go home at night and sleep knowing [Cheryl's] well looked after. When she was in Sydney I'd be worried every 5 minutes wondering if she is being looked after. So much turnover of staff in those hospitals up there, not regular, they come from the agency and you never know who, never see the same one twice. (Pat, partner of Cheryl)

And the fact that you know people, you're working with people, so you know if you need a service you know who you're talking to. It's not a stranger on the end of the phone. The personal touch of a smaller town is really advantageous. (Community Nurse)

However, 'being known' also had a negative side, as illustrated in Marianne's story. A conflict developed between Marianne and a staff member, forcing Marianne to stop attending the local oncology unit. Before her illness, Gwen had been a volunteer in the local RACF. One of the difficulties Gwen faced, after being transferred to the RACF, was allowing other residents see her in her frail deteriorating state:

She didn't ever leave her room, because she felt very self-conscious of the way she was, because she used to see all those people and help out, you know, with feeding and stuff like that...so I think that was in a way a bit detrimental in terms of, she didn't leave her room and...come out into the dining area. (Louise, daughter of Gwen)

8.4.2 Informal community support

Participants spoke highly of the support received from members of their local communities. Support came from neighbours, friends, shop keepers, other patients and community members. Most of the participants believed the community support offered was unique to rural communities and was a significant advantage of rural residency, and would be hard to find in a city. It was this support that particularly helped the FCGs, and was something they appreciated and remembered fondly:

I've lived in the area all my life, and contacts in Cooma I've had forever.... the network spreads pretty fast. For example, one of the ladies in town took Leanne to [a doctor's appointment] one day, [she] just came up and took our car and took her in.... They went and had lunch together and spent a nice afternoon together when I couldn't do it.... There were people there that were ready to put their hand up for whatever... everyone just pitched in. I mean [one friend] would have two lots of washing on the line every day. All little things, but reflecting back on the very, very sad times but some good times had as well.
(Daniel, partner of Leanne)

So [a friend] dropped in with a fruit cake and [another retired nursing friend] came up and gave dad five minutes of nursing care, which delivered more nursing care than all the other nurses put together (laughs)...stick the pillow up this way, get the feet this way and wash his feet 'cause that will make you feel better, or whatever it does. Basic nursing... and there were a lot of people came to visit. (Paul, son of Ivan)

Informal support was mostly direct and practical, such as food, transport and home help; however, some support was indirect, with many providers unaware of the significance of a friendly smile or 'hello':

I think what was nice the other day, [Dad] was in [hospital] all day having a blood transfusion, and people who know you walked past and oh, "hello Ivan", and they came and had a chat. It was nice to see friendly faces when you're in hospital. Whereas you wouldn't get that in Canberra. (Amanda, Ivan's daughter)

Just living in a town where you have your habits. You go to that shop to get your coffee, you get to know people...and when you bump into them you have a chat.... and in general you get to know the staff in the shop, it's very comforting in many, many ways. (Peter, husband of Marianne)

During Ivan's illness, Paul was aware that dying was not just a family matter but involved the whole community. In the following quote, Paul perceives the death of rural residents to be more 'dignified' than urban dwellers. This is partly due to his observation that rural people tend not to die in tertiary hospitals "*hooked up to machinery*". More significant is the community involvement, especially when the dying person is a much loved and respected 'local'.

Country people seem to have more dignified deaths because they've got a more practical understanding of death. Now that could be for two reasons. One is we're rural types and our main [work is] to keep animals alive, and sheep only go for five years and then we've got to get rid of them, so we've got that practical animal aspect. But in the community sense, when someone dies or is dying the whole community knows about it. When there's a funeral, there's a heap of cars up [the road outside the cemetery] and the whole town stands still... Sorry (cries)...And food, people bring us fruit cakes and soup and endless food. And these bikkies are very nice... which is lovely. (Paul, son of Ivan)

The value of community was intensified after Ivan died. In the bereavement interview Paul was eager to show me something. He was "*holding a pile of papers three inches deep*" containing letters and cards from friends and acquaintances:

A lot of these got delivered on the day of the funeral. I know you're asking ... "was he still part of the community in the last few weeks?" ... But he really was part of the community...a hundred and ninety odd people turned up to his funeral. (Paul, son of Ivan)

For Marianne, informal community support was a two-way concept. While undergoing chemotherapy locally, Marianne found mutual support in other patients. Inside the oncology unit a special 'community' of oncology patients existed:

[It was] a communal thing...even meeting somebody new and going “would you like to have a coffee next week?” Or sometimes you meet somebody you click with and you actually want to continue a friendship, the cancer’s actually brought you together and you don’t get that in the city. (Marianne)

When patients became too unwell to travel into town, the community nurse observed that travel distances to farms did not deter friends from visiting:

They had friends that were coming to see them. I mean the distance [out to the farm] didn’t seem to stop their friends, their friends were all very happy to come out and see her. (Marianne’s community nurse)

Another informal support, not previously mentioned, were the local church leaders and members. Three of the patients interviewed talked about the importance of their Christian faith. It was important to Ivan that he continued to attend church; he liked “singing all the hymns”. When that was no longer possible, the Pastor offered to visit him at home to provide spiritual support:

Plan B for church was that the Minister could come out here. (Paul, Ivan’s son)

So there was a lot of church support people, friends of [Marianne] who came and sat with her. (Marianne’s community nurse)

8.4.3 Formal support

Patients and their FCGs received formal support locally, and from specialist units in Canberra and Sydney. There were a number of situations, possibly unique to the rural setting, which assisted three patients to die at home. Unlike the majority of urban medical practices, most rural GPs live in the community where they work. It is only natural that many patients become friends. Strong ties develop between GPs and their patients, and for some patients the GP will be more available than is the standard practice:

I’ve never really practiced in the city, but I imagine that you don’t generally practice in the area that you live, so where you’d probably be practicing, your

patient's wouldn't be people that you'd be socialising with, whereas, here you do, and you sort of go out of your way, I mean, there's patients' that you've known for many, many years who become sort of like friends anyway, and when someone's dying, I mean, that's about it, that's the end of your relationship with them, so you do probably tend to invest more time just trying to get them through that last little bit. (Ivan's GP)

Of the patients interviewed, two were close friends with their GP, with a third patient a near neighbour to their doctor. All three patients lived out of town and died at home with the support of their doctors:

Well Ivan's son is my best friend...it was a privileged position to be in...if he'd had a protracted sort of pre-terminal phase at home, I may well have spent quite a bit of time out there, that I might not necessarily have spent with another patient. (Ivan's GP)

Marianne was a close personal friend...I was very glad to be available for her...and to be able to care for the family... I've never done that previously. I don't expect I'll ever do it again. I think this was a oncer under these sort of unique circumstances really...I mean I wouldn't have done that for anybody else. (Marianne's GP)

Carol rang me at about eight [am] to say, "Can you come up and see Ryan, he's got a lot of pain." And then when I arrived he certainly was extremely agitated and restless, and I think had [the doctor, who was a neighbour] not been there it would have been quite ghastly for me on my own, because we needed to quickly do the drugs and get drugs on-board quickly, and [the doctor] was there writing up the orders as we were doing it. (Ryan's palliative care nurse)

One important formal support service that enable people to die well, regardless of where they lived, were the palliative care and community nurses. If the need arose, the palliative care nurse was available to home visit every resident in the Snowy Monaro region. However, the frequency of her visits was dictated by where the patient lived. Patients living in Cooma had the greatest access to the palliative care nurse. On

weekends, a community nurse was available to home visit. While home visits were not available after hours, on occasions, when someone was close to death, the palliative care nurse or breast care nurse were available for phone advice:

I never have feelings of fear or being too far away from help or anything... I feel [help] is a phone call away, [the palliative care nurse is] a phone call away. Even though I hardly ever [call] I know it's there. I know a person with myeloma in Sydney and he has no visits from palliative care nurses at all...So he only goes to see the specialist, there is no support. I suppose if he asked, but here we didn't have to ask...here I'm overwhelmed by support, it's almost too much. The nurse would be here every week if I wanted her. It's unbelievable, and we live in the country! So to me the advantage is huge, you get immediate care. Even the ambulance came within 20 minutes when we needed it once or twice...like in the city it seems to take longer, so I think we have more than adequate support and I love living here, I wouldn't ever want to move.

(Marianne)

As in the case of the GPs, the nurses are also 'locals' and part of the community. The advantages of 'being known', and continuity of care enhanced a sense of trust in the nurses. For some of the patients interviewed, the same nurse had been visiting and providing support for a number years, often from the time of diagnosis. Andrew's wife, Elaine, had received all her chemotherapy locally. He commented on the flexibility of the local nurses, compared to the urban nurses:

[The local oncology nurse] her knowledge and flexibility when things weren't working right, her sheer knowledge of the thing, and ability to work around things and get things going, is way above what we found in Canberra, where they have the new 'you beaut' facilities. (Andrew, husband of Elaine)

8.4.4 Convenience of rural residency

Despite the travel distances, once in town, there are conveniences often not found in cities. When FCGs are 'time poor', the convenience of parking at the door, and lack of traffic jams was reported as a benefit of rural residency:

In a small town you know exactly where everything is, if you need something you know exactly where to go, shopping is not difficult, you're never held up, you can always park, there's so many practical pluses in living in a place like Cooma. (Peter, husband of Marianne)

8.5 Rural residency and safety

In the previous chapter, the central theme of 'safety' emerged as the main determinant of the 'good death'. A 'safe death' was one that occurred in a safe place. In illustrating the advantages and disadvantages of rural residency, the participants have provided deep insight into how rural residency hinders or facilitates a safe 'good death' by creating safe spaces.

Early in the disease trajectory, creating a safe place of care (PoC) was the focus. While patients remained well enough to travel, the tertiary hospitals and medical specialists contributed to creating a safe space for most participants. The perceived inexperience of local GPs in managing complex issues, such as complex pain, was often negated by consulting with the 'not-so-far away' Canberra specialists. However, some patients and their FCGs (e.g. Cheryl and Pat) did not feel safe in the city hospitals because they were unfamiliar spaces both in terms of location, environment and personnel. Despite the issues surrounding formal handover of care, and providing patients could return home as quickly as possible, most patients were satisfied with alternating their PoC between home and the most appropriate facility to provide the level of care required. Patients were mostly willing to accept admissions to either the local or out-of-region hospitals. Patients and FCGs accepted that rural hospitals could not provide radiation therapy, management of acute oncology conditions such as febrile neutropenia, intensive care, or specialist surgical procedures and interventions. While patients could travel, distances were not a major obstacle to creating and maintaining a safe space.

However, once patients became too ill to travel, or entered the terminal phase, the issues surrounding travel distances intensified. While a medical reason to see oncologists and respiratory physicians no longer existed, for some participants this lack of contact with specialists created a degree of insecurity. For some patients, this deficit in care was adequately replaced by the local health professionals. However, Elaine and Andrew did

not trust the local HCPs to manage her complex pain, and without a local specialist inpatient hospice, they made the decision to not only leave home, but to move out-of-region so Elaine could die in a safe place:

[The out-of-region hospice] turned out to be the best choice for us. In slightly different circumstances it would have been far better to have her at home. But really her pain management was beyond my ability to keep track of and keep up to scratch...I would have stayed home if I thought that I could manage her pain. But things were changing, and I didn't have that confidence....And the local people didn't have a clue. (Andrew, husband of Elaine)

Despite the strong community support and beautiful environment of home, for most of the participants, the safe haven of home became unsafe. Ivan's home remained safe until the end, partly due to the support of his family, friends and HCPs, and the resilience of his farming family. But, the major determining factor was possibly his disease trajectory. Ivan was able to 'live' and participate in life until a few days before he died. His episode of acute deterioration and restlessness lasted only a few short hours. In contrast, Marianne had distressing symptoms for nearly three days. Her home became an unsafe space; however, her husband perceived the local hospital to be more 'unsafe' than home, and so she remained at home. Had their GP friend not visited and supplied the appropriate medication, Marianne may well have died in hospital.

Six of the patients moved from home once home became an unsafe space. Home became unsafe because of symptoms or carer burden. The local rural hospital became a safer space. The lack of all-hours formal support may have been a contributing factor in some circumstances; however, the decision for George and Leanne to leave home was made well before home became unsafe. While there were perceived deficiencies in skills and expertise of the rural hospital HCPs, the local hospital quickly became a safe space for those admitted for end-of-life care. This was no doubt facilitated by the value placed on rural 'community.' The two rural hospitals were considered to be community hospitals where patients received personalised care, where patients and their families were known, and hospital personnel were known members of the wider community.

While rural residents are less likely to die at home than urban residents, and my participants living on farms were less likely to die at home than those living in town, safe spaces were created at home. My sample of rural residents illustrated that rural homes, and especially farm homes, can quickly become unsafe spaces. While not necessarily generalisable, it is possible that rural homes are more likely than urban homes, to become unsafe due to the challenges of providing suitable and sustained services and resources into rural areas. However, when home became unsafe, the two local rural hospitals were more likely than the large tertiary hospital to be perceived as a safer alternative to home.

The previous chapter concluded that PoD was not the main determinant of the ‘good death’. Marianne’s husband and community nurse did not consider her death at home a ‘good’ death. While remaining home contributed to the distressing experience, the inability to overcome the challenges of rural residency was possibly the greatest factor. It is impossible to know the outcome had Marianne lived in town, but specialist palliative care home support would most likely have been available at all hours had she lived in Canberra, or any other large urban area.

I have previously indicated the elements necessary for a ‘safe good death’ (see Figure 7.1 in Chapter Seven). For some participants, like Ivan, the presence of family was strengthened by rural residency as his son lived on the property. For others, like Gwen and Barbara, their families had moved from the rural town and had to travel many hundreds of kilometres to be present at the time of death. For all participants the support of community was powerful throughout their illness. All commented that the level of community support would unlikely have been available in a city. ‘Being known’ and ‘knowing others’ was a unique feature of rural communities, which for most patients helped facilitate a ‘good death.’ The degree of symptom control was variable amongst the participating patients. Those with complex pain issues were the least satisfied with the level of local expertise. All the participants spoke of the importance of receiving personalised care and maintaining identity. Rural residency strongly facilitated this with the generational farmers having the strongest connection to the region. Due to the limited choice in HCPs, resources and inpatient facilities control over many aspects of care was limited; however, most patients and FCGs indicated they did actively participate in decision making surrounding patient care. Where circumstances were

outside their control, for example Gwen who developed an unexpected hemiparesis, patients and their FCGs often took a pragmatic approach with most eventually accepting the change in plans.

8.6 Chapter summary

This chapter has explored the aspects of rural residency that either facilitated or hindered a ‘good’ rural death, and determined the patients’ actual PoD. Each of the participants had different priorities, and held different perspectives. What one participant identified as a barrier, another considered it a challenge that could be overcome. Some of the challenges identified included distance and the need to travel, the lack of local specialists, limited experience and expertise of the local HCPs, and the lack of allied health services. The challenge of travel was not just for the patient attending medical appointments. Distance also resulted in limited availability of formal home support services, and was an additional cost for out-of-town families wanting to visit and be present at the time of death. Despite the challenges, there were many positive features to rural residency that facilitated the creation of safe spaces, including lifestyle, community, personalised care, being known, and the convenience of small towns. While rural residency helped create home as a safe PoC in the early stages of the disease trajectory, these same features rendered home an unsafe PoD. Where participants once relished their isolation and privacy on the farm, this isolation often worked against them when their care needs escalated. The rural culture of community and ‘being known’ facilitated the adoption of hospital as a safe space. While most patients wished they could die at home, when this was not possible, most readily changed their preference for PoD from home to hospital.

This is the final chapter reporting the results of my research study.

PART 4: DISCUSSION AND IMPLICATIONS

CHAPTER NINE: DISCUSSION AND IMPLICATIONS

Introduction

The primary objective of this research study was to explore the concept of the good death drawing on the experiences and perspectives of rural patients with a life limiting illness, and their family caregivers (FCGs). The secondary objectives were to explore the influence of place of death (PoD) and rural residency on the concept of the good death, and to explore the meaning behind the PoD preferences and decision-making process.

One measure of the success of palliative care is to enable people to die in their preferred place. The literature reports 'home' to be the preferred place for most (Gomes et al. 2013), thus implying, a 'home death' is central to achieving a 'good death'. Consistent with the international findings, (Broad et al., 2013; Cohen et al., 2015), most Snowy Monaro residents, including the interviewed patients, regardless of cause of death, died at a place other than home, with most deaths occurring in an institution, such as hospitals and RACFs. When 'home' was reclassified as 'usual place of residence' (UPoR), in acknowledgement of the fact that RACFs are often considered 'home' by many long-term, permanent residents (Cartwright and Kayser-Jones, 2003), most deaths still occurred in an institution. Therefore, if the standard that a home death is central to achieving a 'good death', one could conclude that most residents in the Snowy Monaro, including those who died of a condition amenable to palliative care, did not die a 'good death'. However, this stance was contested by the interviewed participants.

The popular equation of the 'good death' with the at-home death has some limitations. Firstly, data on preferences for PoD have typically been collected using surveys, mostly completed by a healthy population, with limited data reporting the preferences of patients with a terminal illness, and their FCGs. Where patients and FCGs have participated in studies, cancer patients tend to be over-represented. The 42 in-depth semi-structured interviews, in this research study, have provided opportunity for 11 rural patients, with cancer and non-cancer diagnoses, and a life expectancy of less than six months, 18 FCGs and six local HCPs, to describe their experiences and perspectives on what constitutes a 'good death', and the meaning of PoD within one rural setting. These perspectives have

provided texture and meaning to the actual PoD data, collected through the population death data survey.

A second criticism of the current literature is that PoD data have been derived from a single point in time. They do not capture the many patients who received their care at home, only to transfer to an institution for the very last hours or days before death. By conducting longitudinal interviews, with a sample of Snowy Monaro patients and their FCGs, my research findings support those of Agar et al. (2008), and strengthen the argument that PoC and PoD are not necessarily the same, and that preferences change along the disease trajectory. Finally, by conducting this research in a rural setting, rural voices, often unheard within urban focused research, have been placed centre stage. Gott et al. (2013) have recently challenged the popular belief that end-of-life admissions to, and deaths in hospitals are ‘inappropriate’, ‘potentially avoidable’ or even an indicator of sub-optimal EoLC (Earle et al., 2003). Further research by Gott’s team in New Zealand found that being admitted to an acute city hospital has identified benefits for non-Maori patients with palliative care needs (J Robinson et al., 2012, 2017). This view is consistent with the findings in this thesis, that most rural patients, and their FCGs and local HCPs, considered a death in the local rural hospital appropriate, and at times necessary and planned. Depending on their clinical situation, most participants in this research study considered the two rural hospitals an appropriate place to die, and a facilitator of a ‘good death’.

In this chapter I discuss the findings of the death data survey by placing the findings into the context of existing literature. This is followed by a discussion of the themes identified in the in-depth interviews, meaning of place (section 9.2), the ‘good death’ (section 9.3), and rural residency (section 9.4). Limitations to the study are discussed in section 9.5. The importance of researcher reflexivity, outlined in Chapter Four, is discussed further in Section 9.6. Implications for policy and recommendations for further research are discussed in section 9.7.

9.1 Place of death for Snowy Monaro residents

Between 1st February 2015 and 31st May 2016 there were 224 deaths in the Snowy Monaro region, of which 190 (85%) were due to ‘natural’ causes. Of these, 138 (73%) were due to one of the conditions considered to be amenable to palliative care. Cancer

deaths are often over-represented in rural palliative care PoD studies. The data collected in this research study describe PoD for both cancer and non-cancer deaths. Consistent with the current international whole population literature (Broad et al., 2012), the study data highlight the significant reliance on hospitals and RACFs for actual PoD.

In this current study, the overall rate of hospital deaths was 43.5%, RACFs 29.5%, and private residence 19%. In 2012, Broad et al. published an international paper reporting on the PoD for 16.2 million decedents, from 45 populations (including, but not identified, rural populations). The proportion of hospital deaths, in my research study, is consistent with those findings (median 45%, range 40-60%); however, the proportion of deaths in RACFs in my study is higher than the median reported by Broad et al. (median 12%, range 0-20%). My results are consistent with some individual countries identified in their findings: Norway (44% of all deaths occurred in a RACF), New Zealand (31%), and Australia (26%). With no inpatient hospice in the Snowy Monaro, it is not uncommon for patients who are unable to return home from hospital to be transferred to a RACF for EoLC, as illustrated by the cases of Gwen, Bruce and Cheryl. Rural communities are also aging at a faster rate than urban areas, mainly as a result of internal migration with younger family members moving to the city for education and work (Aged and Community Services, 2004). As a result, rural residents are often less likely to have family to provide EoLC at home. This places a greater reliance on RACFs, especially for those aged 65 years and older. Three Australian rural studies (Burns, 2015; Crawford, 2000; Howat et al., 2007) and one Canadian rural study (Jayaraman, 2013), reported home death rates of 18%, 26.7%, 19% and 20.2%, respectively. These are similar to the Snowy Monaro rate of 19%.

Over half of the residents in this study, who died of a palliative condition, died in hospital (52%). The high rate of deaths in hospital, especially in the developed world, has been attributed to the medicalisation and institutionalisation of death (Aries, 1975; Kellehear, 2008). However, as illustrated by the interviewees in this thesis, this is only part of the reason. People are living longer, often with chronic diseases and debilities. Society itself is changing. Previously, mothers stayed home to care for the children, and often their elderly relatives. Today, both parents are often in the workforce. Similar to urban families, rural families are often fragmented, due to family breakdown, or adult children moving away for work. Many adult children in this study were working or

living away, some interstate or overseas, and while some could offer intermittent support, most were unavailable full-time. While Ivan's and Kevin's daughters could return home to help care for their respective fathers, this would not have been sustainable long term. Bruce's daughter lived nearby, but was under tremendous strain juggling a small business and care.

There are large differences between countries in the reported rates of home deaths for cancer and non-cancer decedents (Cohen et al., 2015). While Cohen et al. (ibid) reported residents who died of cancer in England, New Zealand, Canada, and the USA, were more likely to die at home than those who died of a non-cancer cause, this is not consistent with my findings. In the Snowy Monaro, those who died of cancer were more likely to die in hospital (65%) than those of a non-cancer cause of death (40%). Despite cancer patients having a more predictable disease trajectory (Murray et al., 2005), the higher rate of hospital deaths could again be due to the 'rural' effect, and limited formal in-home support, especially after hours.

In the Snowy Monaro, the proportion of home deaths for cancer patients was 14%, and for non-cancer conditions amenable to palliative care 11%, where 'home' implied a private residence. When the term 'usual place of residence' was used to refer to a private residence or permanent RACF, as suggested by McNamara and Rosenwax (2007), the rates for cancer were 26%, and non-cancer 49%. Within the current rural literature, there is great variation in the rate of home deaths across studies, with more traditional regions reporting higher rates of home deaths. Studies in southern Italy (Constantini et al., 2000), Spain (Catalan-Fernandez et al., 1991), and Mexico (Castillo-Guzman et al., 2013) reported home death rates, for residents with cancer, to be greater than 50%; however, in these studies, there was no RACF category, with deaths in RACF either absent or contained in the hospital category. One Swedish rural cancer study (Axelsson & Christensen, 1990) reported a home death rate of 12%, with the remaining studies clustered around 25%. In the Snowy Monaro study, of the 65 permanent residents in RAC, 78.5% died at the facility. This rate was 84% for those with dementia. Therefore, care must be taken when interpreting the rate of 'home' deaths, as most permanent residents of RAC in my study, died at their facility, that is, they died in their UPoR, and for many that was 'home'.

The reason for reporting the rate of deaths at home should determine which terminology is used. If the purpose is to determine the quality and effectiveness of the overall EoLC provided, then UPoR is a more appropriate term, as this rate identifies all who died ‘in place’ and not just those who died in a private residence. However, if the purpose is to inform service providers of the needs within the community for resources to assist people to remain, and be cared for, in their private residence then ‘home’ is the appropriate term. When RAC permanent residents are excluded from the ‘home’ category, this has the potential to skew the data by falsely increasing the rate of deaths within institutions. While the interviewed RACF residents considered the facility to be ‘home’ this may not be true for all residents. With length of stay in RACFs decreasing, as people remain home longer and until all other options have been exhausted, and some older patients (over the age of 65 years) transferring from acute hospitals to RACFs for end-of-life care, Phillips and Currow (2017) have questioned the validity of calling RACFs ‘home’. Further research is encouraged to explore the meaning of ‘home’ for a cross-section of permanent rural RAC residents and their FCGs.

The findings in this thesis demonstrated that cause of death is associated with PoD, especially for those who died in their UPoR. Residents who died of cancer were less likely to die in RAC than those who died of a non-cancer cause. Compared to patients with cancer, residents with dementia were more likely to live in a RACF, and therefore die in their UPoR. Access to health-system facilities, often lacking in more rural and remote regions, was a key factor in determining POD, with residents living on farms or in small towns, with limited or no medical services, being less likely to die in their UPoR than those living in towns with general practitioners and rural hospitals. Inconsistent with the literature, age, sex, and marital status were not predictors of PoD within the Snowy Monaro; however, data on marital status were missing for 32% of deaths.

The results of the PoD analysis raise several questions. Of the residents who died of a condition amenable to palliative care, did the 17 who died at home have a ‘good death’? Did the 72 who died in hospital have a ‘bad death’? Did those who died in a RACF die at ‘home’ or in an institution? These data do no more than provide a snapshot of current practice. While this is important, the quality of care provided and received, the congruence between actual and preferred PoD, the changes in preferences along the

disease trajectory, the meaning behind the final place, cannot be ascertained from the statistical data.

9.2 Meaning of place

All 15 patients, identified through the interviews, had a preferred PoD, with six dying in their UPoR (four at their private residence, and two in a RACF). Consistent with the findings of Agar et al. (2008), place of care (PoC) and PoD were not necessarily the same. There was good congruence between the preference of the patient and their FCG (Davies et al., 2016). Most of the participating patients, supported by their FCGs, accepted the need to alternate between home and hospital for management of symptoms, such as blood transfusions, providing the length of stay was kept to the minimum. Initially, some patients were prepared to travel out of region; however, once the patient became too unwell, and travelling too burdensome, the local rural hospital was considered appropriate for short admissions. Providing people could remain home, for as long as was possible, once home became unsafe, their preferences regarding PoC and PoD changed, and home as the actual PoD became less important than the literature suggests. This illustrates the inadequacy of relying on data obtained from surveys of healthy populations, when many do not have first-hand experience of dying, or caring for someone at home at EoL. In addition, when studies have reported only a one-time preferred PoD, the full story is left untold.

Participants associated home with identity, self-worth, connection, memories, family, social contact, control, normality, and familiarity. More importantly, home was determined to be a safe place (Collier et al., 2015). In 2005, Morris and Thomas linked safety with the 'right place' to die. Over time, the connection of safety with place, has been overshadowed by concepts such as autonomy, choice, avoiding hospitalisation, improving health budgets, and reducing hospital costs. Researchers have begun to explore the often invisible or uncountable cost-shifting from hospital to the FCG, when EoLC is provided at home (Gott et al., 2015; May, 2017; Rowland et al., 2017). Such studies suggest that there are economic advantages to health care institutions, and economical and personal costs for FCGs, in delivering home-based palliative care.

Interviews with families and the dying patients in this thesis indicated that the preferred place is the 'safe place', regardless of its physical location. Once circumstances rendered home unsafe, the participants in this study either chose or were encouraged by their FCGs or HCPs, to leave home. Five transitioned to one of the local rural hospitals, three to a RACF, and one to the out-of-region hospice. The new site of care was mostly accepted, providing the patient and their FCGs perceived the new place to be a safe place. For most patients and FCGs, the move from home did not have a negative effect on the quality of dying. For Marianne, (Chapter Eight), home came to be seen as unsafe by the family and the community nurse. However, hospital was considered to be more unsafe by the family, and so she died at home, but with negative consequences for her husband.

For the patients and their FCGs, home became unsafe for various reasons. The most frequently cited reasons for leaving home were symptom control and carer distress. For most FCGs, being a carer was a privilege and the final act of kindness for their family member; however, some FCGs were overwhelmed by the responsibility, uncertainty, and feelings of inadequacy (Seal et al., 2015). In contrast to the HCPs interviewed in one New Zealand urban hospital study (Gott et al., 2013), who considered admission to hospital for carer inability to cope inappropriate, the HCPs in this current study regarded admission to the local district hospital as appropriate. Ivan's GP, expressing a commonly held view, suggested that patients and their FCGs often suffer unnecessary stress by remaining home, and that hospital admissions should occur earlier and more often. Again, this is possibly the 'rural' effect, as full time medical and nursing support at home is not available, and the hospital is a substitute for in-patient hospice. The rural effect has the potential to render rural homes, especially farms and outliers, more susceptible to become unsafe, earlier and more frequently than most urban homes.

Safety is central to the delivery of healthcare, regardless of place of care. The National Health Performance Committee defines safety in the health care system as 'the avoidance or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered' (AIHW, 2017). In August 2012, the Australian Safety and Quality Goals for Health Care were developed, mandating that 'people receive health care without experiencing preventable harm' (Australian Commission on Safety and Quality in Health Care, 2012). Within the

context of healthcare organisations, Vincent et al. (2014, p. 670) suggest safety is partly achieved by being alert to perturbations [failures in the functioning of the system] and responding rapidly to keep things on track'. Safety in hospitals and other healthcare institutions is often equated with compliance and assurance (Vincent et al., 2014, p. 671).

The interviewees in this thesis described safety in different terms. For them, safety implied protection for the patient, and ensuring a psychological sense of security during an unstable and complex physical process. Most participants in this thesis indicated the local hospitals were an appropriate safe PoD when home became unsafe. If hospitals are to be safe for the terminally ill it is assumed that policies are in place to maintain safety. However, creating a safe place is not just following organisational policies and clinical procedures. Safety is subjective and individualised (J Robinson et al., 2017). Marianne and Kevin, who had complex pain symptoms, did not feel safe in hospital, because they and their FCGs lost control of their medications. While hospital policies surrounding drug administration ensure protection for patients and clinical staff from medication errors, the policies also mean pain medications are often not available immediately, or as quickly as families can respond at home. While organisational policies ensure clinical systems and processes are reliable, the implementation is dependent on 'the capacity of staff to follow safety critical procedures...monitor safety...anticipate and be prepared for problems and threats to safety... detect, analyse, integrate, respond and improve safety' (Vincent et al., 2014, p. 671). For some participants, including the HCPs, the ability of the local hospitals to detect, analyse and respond, made hospital safer than home. This is possibly more significant in rural areas, where there is often no full-time home healthcare and medical support to respond to changes in patients' conditions. Rural hospitals could be perceived as less safe than urban hospitals, due to the lack of specialist palliative care and expertise; however, this was not the perception of the research participants. The familiarity of, and personal attention provided by, the rural hospitals, and the benefit of being known, created a safe place within the rural hospitals. However, this experience was not universal. When the local hospital was perceived as unsafe, Marianne remained home, possibly by default rather than choice, while George and his sister, Betty, suffered in hospital, and Elaine left her community to die in the out-of-region hospice. For patients and their FCGs, safety is not simply following procedures and policies. Safety is aligned with trust. Trust is based on prior knowledge

of the hospital, and dependent on the moment-to-moment experience of care, not only for the patient but also their FCG. Safety is ‘conveyed by the manner of staff, empathy and compassion’ (Vincent et al., 2014, pp. 673-4).

Previous studies have associated acute hospitals with ‘aggressive and futile treatments’, and over medicalisation (Gott et al., 2013). This was not how the participants perceived the two local rural hospitals. Gott reports that acute hospital renal nurses felt the hospital was appropriate for EoLC for their renal patients who, over time had developed relationships with the staff, and become familiar with the hospital. While the participants in my study identified the tertiary hospital as appropriate for specialised, aggressive, and hopefully life prolonging treatments, such as radiotherapy for hemiparesis due to new brain metastases, febrile neutropenia secondary to chemotherapy, intensive care for previously undiagnosed cerebral lymphoma, it was never a familiar or homely place. Despite the presence of specialists and expertise, the tertiary hospital was frequently perceived as unsafe. For most participants, the local hospital was, or became, a safe place, and while some patients chose to remain home, all participants, except Marianne’s husband and Elaine, believed the local hospital to be an appropriate place if the circumstances required an admission.

In the same way, RACFs need to be safe for the terminally ill. Gott et al. (2013) reported families believed a transfer to hospital in cases of acute deterioration showed the staff were providing good care. This was not the perception of the patients, FCGs and director-of-nursing (DON) I interviewed. The participants in the current study thought the RACF could, and did, provide appropriate EoLC, and that the hospital could not have provided different or better care. However, my views have been informed by only three patients, four FCGs and one DON, and none had experienced acute deterioration or significant and uncontrolled symptoms. However, all the RAC participants identified the lack of staff, especially registered nurses overnight, as a negative influence on care, and therefore safety (Wetle, 2005). Gwen’s daughter raised the concern of lack of staff experienced in monitoring pain and other symptoms at EoL. Fortunately, Gwen did not have significant pain before she became unarousable and unable to ask for pain relief. One can only assume this continued until her death, and hope that medication was given; however, the literature reports the frequent under-estimation of pain by RACF staff due to lack of expertise (N Johnston et al., 2016).

Despite this short-coming, Gwen's daughter believed the right decision was made for Gwen to remain in the facility, and that she died a 'good enough' death.

For preferences to be meaningful, there needs to be genuine choice. While the literature reports inpatient hospices are considered by some patients and FCGs as an appropriate alternative to home (Thomas et al., 2004), in this setting there is no local inpatient unit. This potentially accounts for the high percentage of hospital deaths within the Snowy Monaro region. The lack of inpatient hospice possibly had minimal effect on the rate of deaths in RACFs, as dementia was the most frequent cause of death amongst residents, with previous studies reporting most deaths due to dementia are likely to occur in an aged care facility or acute hospital. (Badrakalimuthu & Barclay, 2014). However, for Gwen, who transferred from hospital and died in a RACF, a local inpatient hospice may have been a more acceptable option. Only two interviewed patients, and one identified through the bereavement interviews, considered the out-of-region hospice a genuine alternative to home. Only one participating patient died in the out-of-region inpatient hospice. The hospice was recorded as the PoD for four decedents in the population death data survey; however, it is impossible to determine if this out-of-region place was by choice or circumstance. A number of interviewed participants discussed the hospice, but it was dismissed as an option due to its location out-of-area. The hospice was an unfamiliar place for the remaining participants, and so did not feature in the interviews.

Morris and Thomas (2005, p. 21) suggest PoD is not a matter of individual choice, 'but rather embedded in pre-existing relationships with place and other people'. Home can quickly become unsafe, especially out of hours and the further one lives from HCPs and the hospital. Home is often unsafe for patients with a terminal illness, living on their own, in advanced stages of disease, or if symptoms become uncontrolled. Safety is often associated with rapid access to appropriate symptom management.

Congruence between preferred and actual PoD is an appropriate measure of quality, providing the recording of preferences is kept up-to-date. Except for possibly George, who in his delirium repeatedly requested to return home, all the participants in this study died in their final preferred place, as determined by them towards the end of their terminal illness. This place was mostly not their initial preference. McCall and Rice (2005) suggest that wishes and preferences are not the same, and this notion fits well

with the impression gained through the interviews. For those participants who died away from home, home most likely remained their 'heart preference', while the new place became their 'head preference'. The reality of the circumstances at home dictated a move from home.

Changes in preferences raises concern over the current practice of health data collection. In Australia, systems are in place to record PoD, with these data used to measure the quality of palliative care health services, and to compare services against benchmarks. PoD data are usually dichotomised into died 'in preferred PoD/ not in preferred PoD'. This recording system does not allow for any explanation for changes in preferences or changes in location. If medical records indicate a person's preferred PoD was home, and they died in a hospital or hospice, this is considered by some to be a 'failure' in care, despite the patient remaining home until the very last hours or days. The literature reports some FCGs suffer adverse effects as a result of not honouring requests to die at home (Seal et al., 2015); however, while some FCGs were ambivalent about the move, none of those interviewed in the bereavement period indicated they had failed in their provision of care because their family member transferred to hospital. For three of the participants who died at home, the PoD could have so easily have been different. Ryan deteriorated suddenly with acute confusion and agitation. This was distressing for his family, and would have been unmanageable at home without immediate formal support. It was only by chance that I lived across the road and was immediately available to administer medication. Ivan also developed acute confusion and agitation. Again, it was fortuitous his GP was a friend, and available, on his day-off, to visit the farm. Marianne died at home, only because their friend was a GP and provided medical and emotional support overnight. Under normal circumstances, the ambulance would have been called for all three patients, and they would have been transported and admitted to the local hospital for their last few hours of life. However, with nursing and medical support at home, these brief episodes of terminal restlessness were managed at home. Despite formal support, had the symptoms been prolonged, home support would not have been sufficient, and the professional advice would have been to move from home, which had become unsafe, to the safer option of the hospital.

9.3 The rural ‘good death’

A ‘good death’ was difficult to define for the research participants. Marianne’s story, (Chapter Eight), demonstrates that the concept is subjective, and dependent on personal values, perspectives and priorities. For some participants, the ‘good death’ referred to the dying process, highlighting the importance of living life, while maintaining normality and quality of life. For others, the ‘good death’ referred to the moment of death, or even the after-life. The factors associated with a ‘good death’, among the interviewees, were not uniquely rural and were consistent with those identified in the literature review. They included adequate symptom control, presence of family, support of health care professionals and informal carers, a sense of life completion and acceptance of death, all while maintaining a sense of autonomy and control. Dying at home was initially considered an important factor for all the participants; however, over the course of their illness, home became less important for most (Davies et al., 2016). This contradicts the popular contemporary Western view that prioritises home as the preferred PoD, and associates home with the ‘good death’. It is also unclear if the 100% initial preference for ‘home’ is a genuine preference, or a default due to the lack of alternative locations, such as inpatient hospice.

Congruence between final preferred and actual places of care and death was considered important to most patients and FCGs, and to a lesser degree by the health care professionals. Most participating patients had an idealised, or even romanticised, view of the ‘good death’; however, the realities of the ‘good death’ were, for this study, narratively reconstructed by the FCGs after the death of their family member. For FCGs, the ‘good death’ in reality was sometimes at odds with the idealised notion of a ‘good death’ held by the patient.

In rural settings, relationships between place and one’s self are often stronger than for urban residents, so one would expect that rural people would view dying at home as a major feature of the ‘good death’. However, home as the actual PoD was not as important in reconstructing the ‘good death’ by most FCGs after death. Dying a safe death was central to the ‘good death’. The rural participants, in this study, placed a higher priority on safety than home, with most participants willing to compromise and settle for a ‘good enough death’ (McNamara, 2004), to ensure safety.

9.4 Influence of rural residency on the ‘good death’ and place of death

In a recent narrative synthesis of rural and remote studies, Kirby et al. (2016), reported that reduced access and availability of services in rural and remote areas has a negative influence on outcomes. From some perspectives, for example those of Marianne and George, the lack of alternative PoD which forced hospital to be the default to home, could be seen as a negative outcome. However, as previously discussed, the dependence on the local rural hospital was for most participants, a good outcome. Rural residents are frequently reported to be more resilient than urban residents, more accepting of their circumstances, and more supported by community networks (Kirby et al., 2016). These characteristics were demonstrated in the interviewed Snowy Monaro residents. While Kirby et al. (2016) suggest the rural strengths are ‘counterbalanced by low expectations, “making do” and a reluctance to seek help’ (p. 297), this perspective was not a major feature of the Snowy Monaro participants, with most having high, but realistic, expectations for the care they would receive. For most who had received treatment in urban hospitals, the positives of the rural care outweighed the negatives.

The tyranny of distance, associated with rural residency, could be regarded as a barrier to achieving positive outcomes; however, distance was not necessarily measured by mileage. While commuting for treatment, or travelling to visit patients at home, were costly for patients, FCGs and HCPs, in terms of dollars, time and energy, there were significant benefits in travelling (Pesut et al., 2010), and the inconvenience was accepted by most rural residents in this study. Kirby et al. (2016) reported that rural cancer patients and FCGs had similar types of needs (information and personal interaction with HCPs), and FCG burden, as urban residents. Most of the patients and FCGs spoke of the personal support they received by ‘being known’ by the HCPs and the wider community. While the Snowy Monaro region has unique community supports (MCCR and *Mary Green room*), there was a sense amongst some participants that the community could be more supportive, especially for those living out of town. The literature describes the community as an ‘untapped resource’ (Horsfall et al., 2013).

9.5 Limitations

There are several limitations to this research study. Firstly, the population data were collected over a relatively short period of time. While the data are representative of the whole population, it is uncertain if the results would be different over an extended collection period. Many residents in the Snowy Monaro are involved in seasonal activities, such as farming or winter tourism; however, due to the short data collection period any potential seasonal differences in PoD were not observed. Limitations due to inaccessibility to official death certificates were discussed in Chapter Five. However, with access to a variety of alternate sources, some cross-checking was possible; I estimate that death data were collected for close to all deaths during the 16-month collection period.

The research study's sample size consisted of 35 participants. This is a robust sample size which represents a wide range of residences, modes of dying, causes of death and places of death. I was able to interview some participants repeatedly through the course of their dying, and to triangulate these interview data with interview data from family caregivers and health care professionals. This all helped the data to be valid, though, as with all qualitative research, there is often a generalisability-validity trade-off. The results may not be generalisable to all rural locations, or even those of comparable populations. However, the broader notion of safety being the dominant driver for identification of the best place of death is likely to reflect concerns of dying people in other regions.

While the Snowy Monaro region lacks a specialist multi-disciplinary palliative care team, it is well resourced with health services, and is in close proximity to specialist and tertiary services in Canberra. Therefore, the results are unlikely to reflect the experiences of those living in remote regions. In the absence of a local specialist multidisciplinary palliative care service and inpatient hospice, the perspectives gained in this study may reflect the lack of familiarity of residents with the services offered by specialist teams and inpatient hospice. However, many of the participants were aware of palliative care services and inpatient hospices having looked after family members in other settings.

The literature reports the significance Indigenous peoples place on being connected to land, family and community, the importance of a home death, and the burdens faced with hospitalisation (Gott et al., 2013; McGrath, 2006, 2007; Robinson et al., 2012). Many of the Snowy Monaro Ngarigo people no longer live on-country, though they retain their connection to land (ABC News, 2016). Very few residents identify as Indigenous (Aboriginal and/or Torres Strait Islander people [ATSI]), with the 2016 census reporting the proportion of ATSI in the Snowy Monaro less than the NSW average (ABS Census QuickStats 2017a). Official death records indicate if a decedent identifies as ATSI; however, as discussed in Chapter Four, access to these records was denied. None of the interviewed participants were of ATSI descent, and, due to strict guidelines surrounding recruitment of ATSI persons, ethics approval prevented me from purposefully selecting ATSI participants. Therefore, it is not possible to make any comment or compare my findings to studies reported in the literature relating to the experiences and perspectives of Indigenous rural residents.

9.6 Reflexivity

To enhance the validity of qualitative research, it is essential for the researcher to employ reflexivity, reflecting on how their own experiences and beliefs may have impacted on the collection and interpretation of data. As a Snowy Monaro resident and practicing medical practitioner (palliative medicine specialist and GP), I potentially brought to this study personal and professional bias. There was also the potential for conflict of interest as doctor/researcher. From my perspective, the best place to die is not necessarily home, but I endeavoured to step outside my pre-conceptions and to welcome and reflect on the perspectives of patients and FCGs in their own contexts and settings. In order to keep track and monitor my own perceptions, and to identify the intrusiveness of pre-conceptions, I kept a personal journal throughout the interview process. I present my reflections in the hope the reader of this thesis may have confidence that my professional pre-conceptions have not directed the course of the findings.

One concern of the ethics committees was that as a doctor/researcher, and the only palliative medicine specialist in the region, patients may feel coerced into participating and offering their perspectives. At the start of every interview I reminded the patient

and their FCG that I was acting as a researcher and not their doctor. I also advised that my direction of questioning did not imply anything was, or was not, being considered or would eventuate. Knowing some of the participants added depth to the interviews. Participants were open in their discussions, trust was already established. From my perspective, it was easy to be empathic as I knew, or in some cases I wrongly thought I knew, their personal struggles and what they were going through. It never ceased to amaze me the depth of new information I was privileged to hear; experiences and perspectives that are too lengthy for patients and FCGs to narrate within the time frame of a normal 15 minute clinical consultation.

Rapport was established quickly with all the participants, both known and unknown. All the participants were open and appeared to enjoy the interviews. There was never a sense topics were avoided or responses altered to provide me what participants thought I might want to hear. I was told of things that went well, and things that were done poorly. I was left with the impression that people, especially the bereaved FCGs, appreciated the opportunity to talk, to be heard, and to 'get things off their chest', especially when outcomes were not as planned. Silences were embraced, and were often followed by something profound.

The patient participants were vulnerable and unwell, the FCGs burdened with the responsibility of care, the HCPs were busy. All this had to be considered during the interview process. While Kevin was happy to be interviewed, his wife and daughter did not want Kevin tired out. They requested a copy of the questions before I interviewed Kevin, so he could prepare his responses in his own time. I respected this request knowing that Kevin was so unwell and easily fatigued. His was the shortest interview, and the only one with a set agenda. Having cared for Kevin and his wife for the previous few months meant I could dispense with the preliminary 'chit chat' and just ask direct questions relevant to his perspective on the 'good death' and his preferred PoD. This would have been more difficult had I not had an established rapport with Kevin and his family.

Interviewing patients and their FCGs also had an effect on me, both personally and professionally. During the interviews, I became aware of the participants' expectations, and on a few occasions, as their treating palliative care specialist, I was concerned I

would be unable to live up to their expectations. As Gwen re-encountered her experience, many years ago, of caring for her mother, I knew I could not “*always [be] there, [available] to visit every day [at her] beck and call.*”

Gwen’s sudden deterioration was stressful, not only for Gwen and her daughter, but also for me as a friend and doctor. I was torn between respecting her deteriorating health, and wanting a follow-up interview. My role as her doctor was to navigate Gwen through the decision making and treatment options. However, this was also a significant time in my research as Gwen’s choices regarding place of care had changed suddenly, without any warning. It became obvious her preferred PoD at home would not be achievable. Was it right to request an interview when she was at her most vulnerable? On the second day, I eventually asked Gwen, and without hesitation she agreed to be interviewed the following day, providing she remained well enough. If Gwen deteriorated overnight I would still visit, but just as her doctor. To ensure Gwen had not felt coerced, I sought permission from her daughter, who replied, “*Yes, the distraction might be good for her*”. Gwen was now afraid of what lay ahead, and as her doctor, she was depending on me. I didn’t want to abuse the trust. The next day when I arrived at the hospital, Gwen was waiting for me, and eager to start the interview. It was a difficult interview. Gwen teared up when talking about home. At one point, I switched off the recorder for 10mins, as she spoke confidentially about her family. She told me when we could restart. Gwen had capacity to provide consent. She knew she could decline an interview, something she did when I later requested a fourth interview. Gatekeeping is well documented in the literature (Bullen et al., 2014; Rainsford et al., 2015). It occurs frequently when carers, professional and informal, deny patients opportunity to participate in research, on the assumption they are too frail, or too unwell and therefore need protecting from the burden of research. I knew I shouldn’t assume Gwen was too unwell. Nevertheless, I wrestled with internal conflict regarding the appropriateness of requesting an interview.

There were other issues I found challenging. Despite having confirmed I was conducting the interviews as a researcher and not their doctor, at times I found it difficult when not offering advice or comment on aspects of their management and care. On occasions, I felt my questions forced patients and FCGs to justify their responses and decisions. I often silently agreed with their decisions, but asked delving questions to

ascertain the reasoning behind their decisions. At other times, there was a fine line between maintaining sensitivity, and ‘pushing’ participants to get to the heart of the matter, in my search for the deep meaning and importance of home. In Chapter Four, I discussed the conflict surrounding confidentiality and not being able to share information gained through interviews in clinical situations and family meetings.

Before the interviews, I thought I knew my patients and colleagues well. What I learnt through the interviewing process is that in the busyness of clinical practice, we just don’t have the time to really get to know our patients. We don’t have time to just sit and listen to their hopes, their fears, their experiences and perspectives. There is so much we can learn from our patients and their families, and our colleagues, if only we had the time. My experience illustrates the importance, of researchers not relying on surveys stating hypothetical wishes, but the need for more qualitative studies to gain the perspectives from those living the dying process.

9.7 Implications for policy and practice

The findings of this study illustrate that rural residents do hold unique perspectives on EoLC, which are at times, contrary to the urban view. It is not simply the physical challenges faced, such as travel distances, access to health services, and reduced resources that makes the difference. The uniqueness of ‘rural’ is intangible, often invisible, and associated with a strong sense of community and belonging. In the same way, safety is not just about policies and standards. While urban acute hospitals may be inappropriate, although there is recent evidence suggesting this may not be the case (J Robinson et al., 2012), the rural hospital is more than an urbanised health service. Rural hospitals are staffed by community members; they are a familiar place, and hold a significant position within rural communities. There is an expectation rural hospitals will, and currently do, provide good EoLC for the community.

While continuing to encourage governments and health services to expand resources to support people to die at home, if that is their preference, it cannot be ignored that rural hospitals play a different role to city hospitals; they are often a substitute for in-patient hospice. As such, rural hospitals need to be a safe place. While the participants thought the two local hospitals mostly did a good job, there is a need for improvement. In the

Snowy Monaro, the highly skilled palliative care nurse provides a consultancy service in the community and hospitals. However, she is not available for every shift, and not routinely available afterhours. If the rural hospital is to provide excellent EoLC for all, then every shift should have access to palliative care support. Since I commenced my research study, new resources have been implemented; there is now an all-hours specialist palliative care phone support service. However, this is not the same as having expertise on the ground. One way of addressing this gap would be to find palliative care champions amongst the existing nursing staff. These staff members could be upskilled, and rostered on most, if not all, shifts.

One criticism of the hospital was its strict rules governing administration of breakthrough medications. Even when medications are charted, there are often delays in receiving medications. If breakthrough medication is not provided immediately, pain can easily escalate. Patients and FCGs are often familiar with administering medications at home. Providing the patient, and their FCG, are competent, one recommendation would be for the nurse to draw up, for example, two breakthrough doses, for either self-administration, or in a locked bedside drawer for immediate use by the nurse, when required.

More needs to be done to improve the EoLC in RACFs. Again, most participating Snowy Monaro aged care residents, believed their care was good, with one regarding it excellent. However, we need to ensure these are safe places to receive end-of-life care. The main criticisms related to under staffing, and inexperience in managing symptoms, especially in the unconscious patient. As in the hospital setting, palliative care champions need to be identified, encouraged and upskilled.

While this study has added to the international literature, by exploring the 'good death' and PoD from the perspectives of rural patients and their FCGs, in life-limiting illness, further research is required. From the experiences and perspectives obtained from the interviewees, a 'good death' is a safe death. However, 'safety' is subjective and dependent on one's perspective and priorities. At times, FCGs priorities and perspectives were at odds with those of the patient. HCPs priorities were often focused on symptom management and the desire to relieve the FCG of the burden and responsibility of providing end-of-life care. The 'good death' was often reconstructed by the FGC after the death of their family member.

Place of death was a contributing factor to a ‘good death’; it was not the main factor, and a ‘home’ death was not essential for a ‘good death’. Rural areas are unique, and it may be that the perspectives obtained in this study do not represent the perspectives of other rural or remote regions. National and international collaborative work is needed.

While there are features of rural residency, such as travel distances and limited availability of all-hours health services, that restrict the provision of end-of-life care at home, there are compensating features. Rural hospitals are an integral part of the rural community, and as such have the potential to be a safe place, and therefore an appropriate and acceptable place for rural residents to experience a ‘good death’. Therefore, further research is required to determine what makes a ‘place of dying’ safe from the perspectives of patients and FCGs, and what are the elements of a safe death. If care is to be patient-centred then processes need to be in place to ensure that all places providing EoLC are able to access and deliver this mixture of elements to ensure safety. The participants have illustrated that safety is not just about policies and quality assurance. Therefore ways to develop and maintain trust between the institution, the health care professionals, the FCG, and the dying patient need to be explored. The foundations of good palliative care need to be in place well before the person finds out that death is approaching.

As I complete this thesis, I argue that a death at home should not be a gold standard, or a measure of the success, of quality palliative care. The preferred place is the safest place, and that can’t be decided before time. Attitudes and words need to change. Policy makers need to stop implying that a ‘good death’ is a death at home. Patients and their FCGs need to have genuine options. Home needs to cease being the default because the hospital is not safe. The task for policy makers, administrators, institutions, healthcare professionals, communities, and family caregivers, is to ensure all places for dying are safe.

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APPENDICES

Appendix 1: HREC ethics approvals

Appendix 2: Quality assessment score cards for the scoping and systematic literature reviews

Appendix 3: Numerical summary of the studies included in the ‘good death’ scoping review

Appendix 4: Participant information sheets and consent form

Appendix 5: Interview prompts

Appendix 6: Copies of published papers

Appendix 1: HREC ethics approvals.

From: aries@anu.edu.au
Sent: Tuesday, 24 February 2015 8:57 AM
To: suzanne.rainsford@anu.edu.au
Cc: human.ethics.officer@anu.edu.au; nicholas.glasgow@anu.edu.au
Subject: Human Ethics Protocol 2014/736

THIS IS A SYSTEM-GENERATED E-MAIL. PLEASE DO NOT REPLY. SEE BELOW FOR E-MAIL CONTACT DETAILS.

Dear Dr Suzanne Rainsford,

Protocol: 2014/736
A rural perspective on quality end of life care

I am pleased to advise you that your Human Ethics application received approval by the Chair of the HREC on 24 February 2015.

PLEASE NOTE: The Chair of the HREC has advised the following:
"Approved. The approval of the Greater Western HREC is noted and acknowledged. I do want to thank you, also, for using the Information Sheet template and ensuring that all information required by ANU policy has been included. The GWHREC request for confirmation of permission from colleagues is noted, as is your e-mail offering to remit that information to ANU if requested."

For your information:

1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.
2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.
3. Please notify the Committee immediately if any unforeseen events occur that might affect continued ethical acceptability of the research work.
4. Please advise the HREC if you receive any complaints about the research work.
5. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Kim

Ms Kim Tiffen
Human Ethics Manager
Research Integrity & Compliance,
Research Services,
Ground Floor, Chancelry 10B
Ellery Crescent,
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ACTON ACT 2601
T: +61 6125 3427
F: +61 2 6125 4807
Kim.Tiffen@anu.edu.au or
human.ethics.officer@anu.edu.au

Dear Dr Suzanne Rainsford,

Protocol: 2015/005

PLACE OF DEATH IN COOMA- MONARO, BOMBALA and THE SNOWY MOUNTAINS

I am pleased to advise you that your Human Ethics application received approval by the Chair of the Science and Medical DERC on 23 February 2015.

PLEASE NOTE: The Chair has advised the following:

"Approved. Thank you for the revised documents and the notice to be used in the participant's office to notify his clients of the research occurring. I appreciate the effort to which you have gone to work through the issues raised by the DERC with the participant - thank you."

For your information:

1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved.
Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.
2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.
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4. Please advise the HREC if you receive any complaints about the research work.
5. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Kim

Ms Kim Tiffen
Human Ethics Manager
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12 February 2015



Health
Western NSW
Local Health District

Dr Suzanne Rainsford
PhD Candidate
Medical School
Australian National University
Sharp Street Surgery
COOMA NSW 2630

Dear Dr Rainsford,

**Greater Western Human Research Ethics Committee (HREC)
HREC Project No. HREC/14/GWAHS/122**

A Rural Perspective on Quality End-of-Life Care

Application for Ethical Review

Thank you for responding to the HREC's request for clarification and further information for the above project. The HREC reviewed your responses at its meeting held on 4 February 2015.

The Greater Western HREC has been accredited by the NSW Ministry of Health as a lead committee to provide the single ethical and scientific review of proposals, to conduct research within the NSW public health system. Further, this committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research and the CPMP/ACH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the HREC has granted ethical approval for this research project. The following documentation has been reviewed and approved by the HREC:

- National Ethics Application Form (NEAF) (AU/1/7C7C18) - dated 11/01/2015
- Researcher's Response Template (Deferred Decision) - dated 09/12/2014
- NSW Ministry of Health Privacy Questions - undated, as submitted 11/01/2015
- Study Protocol - version no. 2 - dated 10/01/2015
- Patient Information Sheet - version no. 2 - dated 10/01/2015
- Family / Unofficial Carer Information Sheet - version no. 1 - dated 10/01/2015
- Health Practitioners Information Sheet - version no. 1 - dated 10/01/2015
- Patient Consent Form - version no. 2 - dated 10/01/2015
- Family / Carer Consent Form - version no. 2 - dated 10/01/2015
- Health Provider Consent Form - version no. 1 - dated 05/11/2014
- Patient & Carer Interview Prompts - version no. 1 - dated 05/11/2014

Greater Western Human Research Ethics Committee
Incorporating the Western NSW & Far West Local Health Districts

PO Box 143, Level 1, 230 Henrich Street, BATHURST, NSW 2795
Tel: (02) 6330 6941 Fax: (02) 6332 3140

The project is approved to be conducted at the following NSW Public Health sites:

- Southern NSW LHD
 - Cooma Health & Community Services
 - Bombala Health & Community Services
 - Jindabyne Health Services
 - Berridale Health Services
 - Adaminaby Health Services
 - Nimmitabel Community Services

Please note the following conditions of approval:

- 1 The coordinating investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including any unforeseen events that might affect continued ethical acceptability of the project.
- 2 Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review in the specified format.
- 3 The HREC will be notified, giving reasons, if the project is discontinued at a site before the expected date of completion.
- 4 The coordinating investigator will provide an annual report to the HREC and at completion of the study in the specified format.

HREC approval is valid for three years from the date of this letter.

This HREC approval letter constitutes ethical approval only. You are required to submit a site specific assessment application for each site at which you wish to conduct this project. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. A copy of this letter must be forwarded to all Principal Investigators at every site for submission to the relevant Research Governance Officer as part of the site specific assessment process.

Should you have any queries about your project please do not hesitate to contact the Greater Western HREC Executive Officer on (02) 6330 5941 or via email WNSWLHD-EthicsCommittee@health.nsw.gov.au.

Please quote HREC Reference No. HREC/14/GWAHS/122 in all correspondence.

The HREC wishes you every success in your research.

Yours sincerely



Suzanne Degiorgio
Ethics & Research Governance Officer
Western NSW & Far West Local Health Districts



Health
Southern NSW
Local Health District

Southern NSW RGO
Southern NSW Local Health District
Eden St Offices
Bega Hospital
McKee Drive
PO Box 173 Bega 2550

Telephone: 09 6492 9682
Facsimile: 02 6492 9685

16 March 2015

Dr Suzanne Rainsford
General Practitioner and PhD student
Sharp Street Surgery
PO Box 159
Cooma NSW 2630

CC by email only: Prof Nicholas Glasgow, Dean Medical and Health Sciences, ANU

Dear Dr Rainsford *Suzanne*

HREC reference number: HREC/14/GWAHS/122

SSA reference number: SSA/15/SNSWLHD/5

Project title: A Rural Perspective on Quality End-Of-Life care.

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at Cooma and Bombala (and surrounding smaller services) - community health and palliative care.

Documents reviewed/authorised for use at the site are as follows

- SSA form and signatures (AU/2/705D17)
- Ethical approval letter dated 12/2/15
- Patient and care interview prompts V1, 5/11/14
- Patient information sheet, V2, 10/1/15
- Patient consent form V2, 10/1/15
- Family & unofficial carer information sheet V1, 10/1/15
- Family & carer consent form V2, 10/1/15
- Health Practitioner information sheet V1, 10/1/15
- Health provider consent form V1, 05/11/15
- Withdrawal of consent form V1, 05/11/15
- Protocol V2, 10/01/15
- CV of investigators and supervisors
- Cover letter to research governance officer dated 14 March 2015

The following standard conditions apply to this research project: **you MUST** comply with them. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:



1. Please inform the research governance officer in writing if the project either:
 - a. does not commence, or is
 - b. subject to significant delays in commencing, or is
 - c. discontinued before expected completion.
2. Proposed amendments to the research protocol or conduct of the research which may affect the **ethical acceptability** of the project, and which are submitted to the HREC for review, must be copied to the research governance officer.
3. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing **site acceptability** of the project, must be submitted to the research governance officer.
4. **Serious or unexpected adverse effects** or unforeseen events that are reported to the HREC that approved the study should also be reported to the research governance officer.
5. An annual 'site progress report' should be submitted to the research governance officer. The first will be due one year from the date of this letter. An electronic template for this report is attached with the emailed copy of this letter; templates are also available from the research governance officer at gsahs.ethics@gsahs.health.nsw.gov.au
6. At the completion of your study you are requested to forward a **summary of key findings** to the research governance officer, as well as your final progress report. This may be in the format of a summary report or paper for publication; you may choose to use the template provided.
7. **Monitoring:** as part of the standard monitoring process for authorised research your project may be selected for either:
 - a. A 'site visit', with a small audit component, or
 - b. A 'self audit' which you will be requested to complete and return

If your project/site is randomly selected for either of these you will be given ample notice and instructions.

8. **START date:** Please note that the 'start date' of this project will be recorded as the **date of authorisation (date of this letter)**. Please email the Research Governance Officer at the address below with an alternative date if you wish a different start date to be recorded.
9. There is an expectation that all research will be conducted in accordance with the *NHMRC Code for the Responsible Conduct of Research*, 2007, available at <http://www.nhmrc.gov.au/guidelines/publications/r39>

If you have any queries about this SSA please contact the research governance officer on 02 6492 9682 or email gsahs.ethics@gsahs.health.nsw.gov.au

Yours sincerely

Sally Josh
Research Governance Officer
Southern NSW Local Health District

Encs: Electronic template for Site Progress Report; Final Report Summary Template - by email.

Appendix 2: Quality assessment score cards for the scoping and systematic literature reviews (Hawker et al. (2002); Gomes et al. (2013) and further modified by the author).

1. Quality assessment for rural 'good death' scoping review	
	Score Poor=0 Fair=1 Good=2
Title & abstract Clear description of study relevant to rural 'good death'	
Good background and aims relating to rural concept of the 'good death'	
Appropriate method , clearly explained	
Sample strategy appropriate to aims/ sample size/response rate	
Rigorous analysis Credible (>1 assessor, peer review; quotes; time)	
Ethics addressed	
Reflexivity and aware of own bias	
Clear statement of findings	
Results generalizable ? Transferable to wider rural population?	
Importance to policy and practice	
Rural definition	
Informant: Prospective patient/carer; or HCP currently working =2 Retrospective >6months=1 Well community =0	
Total /24, >70% high quality High ≥ 17 ; med $\geq 10-16$; Low < 10	

2. Quality assessment for rural PoD (actual) systematic review (quantitative)	
	Score Poor=0 Fair=1 Good=2
Design : prospective =2; cross-sectional=1; retrospective=0	
Sufficient description of rural sample	
Adjustments made for confounders	
Representative sample /relevant population	
Explicit inclusion/exclusion criteria	
Rural response rate : >60%=2; 59-50%=1; <50%=0	
Rural variable reliable and objective/reliable and objective assessment tool	
Rigorous, appropriate analysis	
Total /16, >75% high quality High ≥ 12 ; med $\geq 8-11$; low < 8	

3. Quality assessment for rural PoD systematic review (preferred place)	
	Score Poor=0 Fair=1; Good=2
Title & abstract Clear description of study relevant to rural preferred PoD.	
Good background and aims relating to rural preferred PoD.	
Appropriate method , clearly explained	
Sample strategy appropriate to aims/ sample size/response rate	
Rigorous analysis Credible (>1 assessor, peer review; quotes; time)	
Ethics addressed	
Reflexivity and aware of own bias	
Clear statement of findings	
Results generalizable ? Transferable to wider rural population?	
Importance to policy and practice in improving rural PoD	
Total /20, >75% high quality High ≥ 15 ; med ≥ 10 -14; Low < 10	

3.4 Quality assessment for rural end-of-care from perspectives of rural patients and FCGs	
	Score Poor=0 Fair=1 Good=2
Title & abstract Clear description of study relevant to rural palliative patient/FCG perspectives	
Good background and aims relating to rural palliative patient/ FCG perspectives	
Appropriate method , clearly explained	
Sample strategy appropriate to aims/ sample size/response rate	
Rigorous analysis Credible (>1 assessor, peer review; quotes; time)	
Ethics addressed	
Reflexivity and aware of own bias	
Clear statement of findings	
Results generalizable ? Transferable to wider rural population?	
Importance to policy and practice in improving rural PC by listening to patient/FCG perspectives	
Rural definition	
Informant: PT/FCG perspective Prospective: Patient/carer =2 Retrospective >6months=1 2 nd hand perspectives	
Total /24, >75% high quality High ≥ 18 ; med ≥ 13 -17; Low < 13	

Appendix 3: Numerical summary of the studies included in the ‘good death’ scoping review (Chapter 4; Section 4.2.1)

	Developed countries (n=10)	Developing countries (n=8)
Date of publication		
2000-2004	1	3
2005-2009	3	2
2010-2015	6	3
Countries		
Developed (n=10)		
North America	7	0
United Kingdom	2	0
Norway	1	0
Developing (n=7)		
Africa	0	5
Bangladesh	0	1
Vietnam	0	1
Papua New Guinea	0	1
Source of article		
Journal	9	8
Dissertation	1	0
Source discipline		
Palliative/hospice care	7	3
Social Science and Medicine	0	2
Other nursing	2	0
Population Health	0	1
Anthropology	0	1
Cross cultural gerontology	0	1
Theology	1	0
Study objective included “Good death”	4	3
Type of article		
Qualitative (n=17)		
Phenomenological	3	0
Ethnographic	2	1
Open ended written survey	2	0
Anthropological field work	0	3
Not specified	3	3
Systematic review	0	1
Methods*		
Interviews	7	4
Focus groups	5	3
Observations/Field work	0	4
Written surveys	2	0
Clinical observations	0	3
Terminology		
Good death	7	4
Peaceful	0	2
Other	3	1
Bad death	0	1

Appendix 4: Participant information sheets and consent

PATIENT PARTICIPANT INFORMATION SHEET

Principal Researcher: Dr Sue Rainsford (Sharp Street Surgery, Cooma and PhD student ANU)

Associate Researchers: Dr Rob Wiles (Sharp Street Surgery, ANU Rural Medical School, Cooma)
Prof Nick Glasgow (ANU Medical School)
A/Prof Christine Phillips (ANU Medical School)
Prof Rod MacLeod (Hammond Care and Sydney Uni. Medical School)

A RURAL PERSPECTIVE ON QUALITY END-OF-LIFE CARE

You are invited by Sue Rainsford and the associate research team to participate in a study that will form the basis of her PhD research thesis. Before you decide whether or not to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Description and Methodology: The study will explore what factors rural people (patients, families, unofficial carers, general practitioners and palliative care/community nurses) see as important in providing and receiving quality care at the end of a person's life and the advantages and disadvantages of living in a rural area. The study will focus on the priority given by patients and their families to receive care and die in their preferred place. Data will be collected through face-to-face interviews.

Participants: The study will be carried out in south eastern NSW in the 3 local government areas of Cooma Monaro, Snowy River and Bombala. It is hoped to recruit 20 patients living in Cooma, smaller townships and villages, and living on isolated farms. Participants will be patients (and a family member or unofficial carer and their GP and/or palliative care nurse) diagnosed with a life limiting illness and a life expectancy of less than 12 months.

Use of Data and Feedback: The results of this study will be written up in a thesis to be read by examiners and a copy stored in the ANU library. Articles may also be submitted for publication in Medical Journals or presented at national or international conferences.

Voluntary Participation & Withdrawal: Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide **not** to participate, it will not affect the treatment or care you receive now or in the future.

If you wish to withdraw from the study once it has started, you can do so at any time, until the work is prepared for publication, without having to give a reason. If you withdraw from the study, where possible your data including personal quotes will be destroyed however, it may not be possible to destroy all your data from the study results particularly if your identifying details have been removed. With your permission individual quotes may be used in the written report.

What does participation in the research request of you? If you agree to participate in this study Sue Rainsford will contact you to answer any questions, obtain consent and arrange a convenient time and place to visit. The study will involve a 1 hour audiotaped interview. This may be shorter if you are not feeling well. You will be asked questions about your illness, your care, your needs and support (what's good, what could be done better), where you would prefer to be cared for in the last weeks and days and if you have a preference for where you die. After the interview the audiotape will be transcribed. The aim is to discover common and unique threads relating to end of life care in this region. Where possible a follow up interview will be carried out at a convenient time.

For those who would like to participate, Sue Rainsford will also like to talk to your husband/wife/partner or main carer to explore their views on their care needs and support and their preferences regarding your place of care and death. Ideally this will be carried out at a separate time but if you prefer can be done at same time as your interview. The interviews will be audiotaped, transcribed and discussed looking for common and unique themes within the household and the community. Sue Rainsford will also contact this person about 2-3 months after you have died to gain a retrospective view on the care and support you both received.

With your permission Sue will also talk to your GP or palliative care/community nurse to talk about their perspective on your illness and care, and the issues they faced trying to achieve your preferred place of care and death. Again these interviews may be audiotaped, transcribed, coded for themes with results compared to those received from their patient and carer and between health professionals.

If you are interested, a few patients will be invited to be the subject of a case study. This will require a number of interviews over the course of your illness. The purpose is to look more deeply at what it is really like for a rural person to have a life limiting illness, the day to day struggles and blessings faced, how you make sense of your illness, how you adjust to the changes in plans and preferences and what influence rural living has on your care.

If you wish to participate you will be asked to sign a consent form: this will be clearly explained to you by the researcher.

Location and Duration: Interviews will be conducted at your home or another mutually convenient location and last up to 1 hour. For most participants the total time requested of you in this research is 2 hours. For those willing to participate in a case study the total time will be 6-8 hours over a number of months.

Risks: If you decide to participate in the study you need to be aware that talking about your illness and life expectancy can be distressing. The research team has taken steps to minimize any risk to you. Sue Rainsford will be conscious of the sensitive nature of the interviews and your frail physical condition. The interview can be stopped at any time. If you suffer any harm or complications as a result of the study, you should contact the researcher as soon as possible, who will assist you in obtaining appropriate care or counselling. With your permission your GP, nurse or other appropriate person identified by you will be informed of any significant distress you experience. If you require immediate counselling please phone **Beyond Blue on 1300 224 636**.

Every attempt will be made to ensure information is provided in such a way that you cannot be identified however it is possible you may be recognised by your stories or quotes. To minimise this risk neither your name nor any other identifying information will be published and your age will be changed in any written report.

Benefits: The study aims to further our knowledge about rural end-of-life care and preferences of place of care and place of death. Although this study is unlikely to benefit you directly, benefits may be seen in the future through improvements in rural palliative care.

Confidentiality: Any identifiable information that is collected about you in connection with this study will remain confidential and be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results.

Confidentiality of the information collected in connection with this study will be maintained at all times. Consent forms and researcher personal notes will be stored in a secure location. All study data will be de-identified and stored on a password-protected computer. Five years after publication the data will be disposed of by shredding and erasure of computer-generated data

Contact Details for More Information: As mentioned by your GP or palliative care nurse, the primary researcher, Sue Rainsford, will phone you in about a week to discuss the study with you and to answer any queries you may have. If you would like to know more at any stage, please either contact Sue at Sharp Street Surgery, 6455 0000 or email suzanne.rainsford@anu.edu.au or Nicholas Glasgow (supervisor) nicholas.glasgow@anu.edu.au

The ethical aspects of this research have been approved by both ANU and GW Human Research Ethics Committees. If you have any concerns or complaints about how this research has been conducted, please contact

ANU Human Research Ethics Committee. Contact the Ethics Manager, Australian National University, Telephone +61 2 61253427; email: Human.Ethics.Officer@anu.edu.au Quote 2014/736

Greater Western Human Research Ethics Committee (HREC) of the Western NSW & Far West Local Health Districts. Contact The Executive Officer, Greater Western Human Research Ethics Committee, Western NSW Local Health District. PO Box 143 Bathurst NSW 2795 or telephone (02) 6330 5941. Quote: HREC/14/GWAHS/122

The Chief Executive's delegate for the Southern NSW Local Health District (LHD) has authorized this study within the Southern NSW LHD.

Thank you for taking the time to consider this study. If you wish to take part please sign the attached consent form and either send it to: Dr S Rainsford, Sharp Street Surgery, PO Box 159, Cooma 2630 or have ready for collection at the interview.

This information sheet is for you to keep.

FAMILY/ CARER PARTICIPANT INFORMATION SHEET

Principal Researcher: Dr Sue Rainsford (Sharp Street Surgery, Cooma and PhD student ANU)

Associate Researchers: Dr Rob Wiles (Sharp Street Surgery, ANU Rural Medical School, Cooma)
Prof Nick Glasgow (ANU Medical School)
A/Prof Christine Phillips (ANU Medical School)
Prof Rod MacLeod (Hammond Care and Sydney Uni. Medical School)

You are invited by Sue Rainsford and the associate research team to participate in a study that will form the basis of her PhD research thesis. Before you decide whether or not to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Description and Methodology: The study will explore what factors rural people (patients, families, unofficial carers, general practitioners and palliative care/community/aged care nurses) see as important in providing and receiving quality care at the end of a person's life and the advantages and disadvantages of living in a rural area. The study will focus on the priority given by patients and their families to receive care and die in their preferred place. Data will be collected through face-to-face interviews.

Participants: The study will be carried out in south eastern NSW in the 3 local government areas of Cooma Monaro, Snowy River and Bombala. It is hoped to recruit 20 families or unofficial carers of patients living in Cooma, smaller townships and villages, and living on isolated farms. Participants will be patients (and a family member or unofficial carer and their GP and/or palliative care/aged care nurse) diagnosed with a life limiting illness and a life expectancy of less than 12 months.

Use of Data and Feedback: The results of this study will be written up in a thesis to be read by examiners and a copy stored in the ANU library. Articles may also be submitted for publication in Medical Journals or presented at national or international conferences.

Voluntary Participation & Withdrawal: Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide **not** to participate, it will not affect the treatment or care your family member/patient receives now or in the future.

If you wish to withdraw from the study once it has started, you can do so at any time, until the work is prepared for publication, without having to give a reason. If you withdraw from the study, where possible your data including personal quotes will be destroyed; however, it may not be possible to destroy all your data from the study results particularly if your identifying details have been removed. With your permission individual quotes may be used in the written report.

What does participation in the research request of you? If you agree to participate in this study Sue Rainsford will contact you to answer any questions, obtain consent and arrange a convenient time and place to visit. The study will involve a 1 hour audiotaped interview. You will be asked questions about your needs and support in caring for your family member or patient (what's good, what could be done better), and your preferences regarding the patient's place of care and death. Ideally this will be carried out at a separate time to the patient's interview. After the interview the audiotape will be transcribed. The aim is to discover common and unique threads relating to end of life care in this region. Where possible a follow up interview will be carried out at a convenient time.

Sue Rainsford will also contact you about 2-3 months after your family member/ patient has died to gain a retrospective view on the care and support you both received.

Sue will be also be interviewing your family member/patient, at a separate time, to ask questions about their illness, their care, their needs and support (what's good, what could be done better),

where they would prefer to be cared for in the last weeks and days and if they have a preference for where they die.

If for any reason your family member/ patient decides not to participate, with their permission you can participate to discuss your views as outlined above. Likewise, if you decide not to participate the patient can still be involved in the study as we will be discussing their illness and preferences.

A few patients will be invited to be the subject of a case study. This will require a number of interviews over the course of their illness. The purpose is to look more deeply at what it is really like for a rural person to have a life limiting illness, the day to day struggles and blessings faced, how they make sense of their illness, how they adjust to the changes in plans and preferences and what influence rural living has on their care. If you agree you may be included in this longitudinal study.

If you wish to participate you will be asked to sign a consent form: this will be clearly explained to you by the researcher.

Location and Duration: Interviews will be conducted at your home or another mutually convenient location and last up to 1 hour. For most participants the total time requested of you in this research is 2 hours. For those willing to participate in a case study the total time will be 6-8 hours over a number of months.

Risks: If you decide to participate in the study you need to be aware that talking about illness and life expectancy can be distressing. The research team has taken steps to minimize any risk to you. Sue Rainsford will be conscious of the sensitive nature of the interviews. The interview can be stopped at any time. If you suffer any harm or complications as a result of the study, you should contact the researcher as soon as possible, who will assist you in obtaining appropriate care or counselling. With your permission your GP, palliative care nurse or other appropriate person nominated by you will be informed of any significant distress you experience. If you require immediate counselling please phone **Beyond Blue on 1300 224 636**.

Every attempt will be made to ensure information is provided in such a way that you cannot be identified however it is possible you may be recognised by your stories or quotes. To minimise this risk neither your name nor any other identifying information will be published and your age and family member's age will be changed in any written report.

Benefits: The study aims to further our knowledge about rural end-of-life care and preferences of place of care and place of death. Although this study is unlikely to benefit you directly, benefits may be seen in the future through improvements in rural palliative care.

Confidentiality: Any identifiable information that is collected about you in connection with this study will remain confidential and be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results.

Confidentiality of the information collected in connection with this study will be maintained at all times. Consent forms and researcher personal notes will be stored in a secure location. All study data will be de-identified and stored on a password-protected computer. Five years after publication the data will be disposed of by shredding and erasure of computer-generated data

Contact Details for More Information: As mentioned by your family member's GP or palliative care nurse, the primary researcher, Sue Rainsford, will phone you in about a week to discuss the study with you and to answer any queries you may have. If you would like to know more at any stage, please either contact Sue at Sharp Street Surgery, 6455 0000 or email suzanne.rainsford@anu.edu.au or Nicholas Glasgow (supervisor) nicholas.glasgow@anu.edu.au

The ethical aspects of this research have been approved by both ANU and GW Human Research Ethics Committees. If you have any concerns or complaints about how this research has been conducted, please contact

1. ANU Human Research Ethics Committee. Contact the Ethics Manager, Australian National University, Telephone +61 2 61253427; email: Human.Ethics.Officer@anu.edu.au Quote 2014/736
2. Greater Western Human Research Ethics Committee (HREC) of the Western NSW & Far West Local Health Districts. Contact The Executive Officer, Greater Western Human Research Ethics Committee, Western NSW Local Health District. PO Box 143 Bathurst NSW 2795 or telephone (02) 6330 5941. Quote: HREC/14/GWAHS/122

The Chief Executive's delegate for the Southern NSW Local Health District (LHD) has authorized this study within the Southern NSW LHD.

Thank you for taking the time to consider this study. If you wish to take part please sign the attached consent form and either send it to: Dr S Rainsford, Sharp Street Surgery, PO Box 159, Cooma 2630 or have ready for collection at the interview.

This information sheet is for you to keep.

HEALTH PROVIDER PARTICIPANT INFORMATION SHEET

Principal Researcher: Dr Sue Rainsford (Sharp Street Surgery, Cooma and PhD student ANU)

Associate Researchers: Dr Rob Wiles (Sharp Street Surgery, ANU Rural Med. School, Cooma)
Prof Nick Glasgow (ANU Medical School)
A/Prof Christine Phillips (ANU Medical School)
Prof Rod MacLeod (Hammond Care and Sydney Uni. Medical School)

You are invited by Sue Rainsford and the associate research team to participate in a study that will form the basis of her PhD research thesis. Before you decide whether or not to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Description and Methodology: The study will explore what factors rural people (patients, families, unofficial carers, general practitioners and palliative care/community/aged care nurses) see as important in providing and receiving quality care at the end of a person's life and the advantages and disadvantages of living in a rural area. The study will focus on the priority given by patients and their families to receive care and die in their preferred place. Data will be collected through face-to-face interviews.

Participants: The study will be carried out in south eastern NSW in the 3 local government areas of Cooma Monaro, Snowy River and Bombala. It is hoped to recruit 20 patients living in Cooma, smaller townships and villages, and living on isolated farms. Participants will be patients (and a family member or unofficial carer and their GP and/or palliative care/aged care nurse) diagnosed with a life limiting illness and a life expectancy of less than 12 months.

Use of Data and Feedback: The results of this study will be written up in a thesis to be read by examiners and a copy stored in the ANU library. Articles may also be submitted for publication in Medical Journals or presented at national or international conferences.

Voluntary Participation & Withdrawal: Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide **not** to participate, it will not affect the excellent existing relationship between the local researchers and yourself and your practice. If you wish to withdraw from the study once it has started, you can do so at any time, until the work is prepared for publication, without having to give a reason. If you withdraw from the study, where possible your data including personal quotes will be destroyed; however, it may not be possible to destroy all your data from the study results particularly if your identifying details have been removed. With your permission individual quotes may be used in the written report.

What does participation in the research request of you? If you agree to participate you will be asked by the principal researcher, Sue Rainsford, to identify potential palliative care participants for the study. The inclusion criteria includes patients with a life limiting illness < 3-6 months life expectancy (longitudinal case studies <6-12 months); 18 years of age or over; English speaking; capable of providing informed consent; living in the targeted rural region. You will be required to tell the patient (and their carer) of the existence of the study and ask if they would consider taking part. If they would like to know more about the study you will provide them with a participant's information sheet and consent form. You would then gain their verbal consent to pass on their name and phone number to the principal researcher. If they provide a verbal agreement you will need to pass on these details to Sue Rainsford.

After the patient has died, and with their prior permission, you will advise the researcher of the death. You will be contacted by the researcher to talk about your perspective on their illness and care, and the issues you faced trying to achieve their preferred place of care and death. These interviews may be audiotaped, transcribed, coded for themes with results compared to those received from the patient and carer and between health professionals.

If you wish to participate you will be asked to sign a consent form.

Location and Duration: Your initial time commitment for this study is dependent on the number of potential participants you are caring for. As you are only required to mention the study, gain verbal consent to provide their name and phone number to the researcher and forward this information by phone or email the time involved would be about 5 minutes. Post death interviews will be conducted at your surgery or another mutually convenient location and last up to 1 hour.

Risks: If you decide to participate in the study you need to be aware that talking about your management of patients can be distressing. The interview can be stopped at any time. If you suffer any harm or complications as a result of the study, you should contact the researcher as soon as possible, who will assist you in obtaining appropriate care or counselling. If you require immediate counselling please phone Beyond Blue on 1300 224 636.

Every attempt will be made to ensure information is provided in such a way that you cannot be identified; however, it is possible you may be recognised by your stories or quotes. To minimise this risk neither your name nor any other identifying information will be published and your age will be changed in any written report.

As with any research, there may also be risks associated with the research that are presently unknown or unforeseeable.

Benefits: The study aims to further our knowledge about rural end-of-life care and preferences of place of care and place of death. Although this study is unlikely to benefit you directly, benefits may be seen in the future through improvements in rural palliative care.

Confidentiality: Any identifiable information that is collected about you in connection with this study will remain confidential and be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results.

Confidentiality of the information collected in connection with this study will be maintained at all times. Consent forms and researcher personal notes will be stored in a secure location. All study data will be de-identified and stored on a password-protected computer. Five years after publication the data will be disposed of by shredding and erasure of computer-generated data

Contact Details for More Information: If you would like to know more at any stage, please either contact Sue Rainsford at Sharp Street Surgery, 6455 0000 or email suzanne.rainsford@anu.edu.au or Nicholas Glasgow (supervisor) nicholas.glasgow@anu.edu.au

The ethical aspects of this research have been approved by both ANU and GW Human Research Ethics Committees. If you have any concerns or complaints about how this research has been conducted, please contact

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2. Greater Western Human Research Ethics Committee (HREC) of the Western NSW & Far West Local Health Districts. Contact The Executive Officer, Greater Western Human Research Ethics Committee, Western NSW Local Health District. PO Box 143 Bathurst NSW 2795 or telephone (02) 6330 5941. Quote: HREC/14/GWAHS/122

The Chief Executive's delegate for the Southern NSW Local Health District (LHD) has authorized this study within the Southern NSW LHD.

Thank you for taking the time to consider this study. If you wish to take part please sign the attached consent form and either send it to: Dr S Rainsford, Sharp Street Surgery, PO Box 159, Cooma 2630. This information sheet is for you to keep.

PLACE OF DEATH IN COOMA- MONARO, BOMBALA and THE SNOWY MOUNTAINS

PARTICIPANT (FUNERAL DIRECTOR) INFORMATION SHEET (V2 18/2/15)

Principal Researcher: Dr Sue Rainsford (PhD student, Medical School ANU).

Associate Researchers: Dr Rob Wiles (ANU Rural Medical School, Cooma)
Prof Nick Glasgow (ANU Medical School)
A/Prof Christine Phillips (ANU Medical School)
Prof Rod MacLeod (Hammond Care)

(Please note this research project is unrelated to Drs Rainsford and Wiles' association with the Sharp Street Surgery and Cooma District Hospital)

Description and Methodology: This study aims to describe the actual place of death of residents living in the 3 local government areas of Cooma-Monaro, Bombala and Snowy River.

De-identified socio-demographic data including place of death (home, local hospital, other hospital, ACT hospice, residential aged care facility, other) and last place of residence (post code only plus an indication if town, village or farm) and if burial or cremation will be retrieved from all death records held by the one local funeral director (FD) between January 2015 and December 2016 and emailed to the principal investigator at the end of each month. Data will be statistically analysed to determine how many residents in this region die at home.

Participant: Local funeral director (FD).

Use of Data and Feedback: The results of this study will be written up in a thesis to be read by examiners and a copy will be stored in the ANU library. Articles may also be submitted for publication in Medical Journals, presented at national or international conferences or used for teaching purposes. Your name will not be published. A summary of the research will be provided to you at completion of the study.

Voluntary Participation & Withdrawal: Participation in this project is **voluntary** and you may, without any penalty, decline to take part or withdraw from the research at any time until the work is prepared for publication. If you do withdraw every attempt will be made to destroy and not use data previously provided by you; however, this may not be possible as some data provided by you may have been amalgamated with data obtained from newspaper obituaries. At the time of withdrawing you will be given the option of allowing continued use of data supplied by you.

What does participation in the research request of you? You will be asked to email to the researcher by the 5th day of each month de-identified data on local residents who have died in the previous month. To maintain anonymity and confidentiality it will be important you do not provide names or actual home addresses. You will be asked to provide socio-demographic data from your records including date of death, age at death, gender, place of death (home, local hospital, other hospital, ACT hospice, residential aged care facility, other), last place of residence (post code only plus an indication if town, village or farm), cause of death and if cremation or burial. If the data has not been received by the researcher by the 5th of each month the researcher will phone you. If data is still not received by the 12th day of the month the

researcher will phone you a second time. If data is still not received the researcher will not contact you until the 5th day of the next month.

If data has not been received for 3 months and if the researcher has not been able to contact you by phone the researcher will send an email to confirm you have withdrawn from participation. No further contact will be made concerning the project.

Location and Duration: The study is to be conducted in the 3 local government areas of Cooma-Monaro, Bombala and Snowy River between January 2015 and December 2016. (Once ethics approval has been granted you will be asked to backdate the first list to commence January 1 2015)

Risks: While your name will not be identified in any report or presentation, as you are the only funeral director in the region it is possible your identity will be recognised by third-parties. Due to the difficulty of obtaining informed consent from relatives of deceased persons the researchers will provide you with a notice of intent to collect de-identified data to display in your office. The data provided by you will be combined with data obtained from newspaper obituaries.

Confidentiality: Confidentiality will be protected as far as the law allows and your identity will be disclosed only with your permission, or except as required by law. Your name will not be used in published reports. Only the researchers named above will have access to the data you provide. Confidentiality of the information collected in connection with this study will be maintained at all times.

Data Storage:

Where: All study data will be stored on a password-protected computer and external hard drive.

How long: Five years after publication the data will be disposed of by shredding and erasure of computer-generated data from hard drives and external storage devices.

Contact Details for More Information: Any queries regarding the study should be directed to Sue Rainsford, suzanne.rainsford@anu.edu.au mobile: 0408485150 or Nicholas Glasgow (Chair of supervisory panel) nicholas.glasgow@anu.edu.au PH: 6125 2622

Ethics Committee Clearance: The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee. If you have any concerns or complaints about how this research has been conducted, please contact:

Ethics Manager
ANU Human Research Ethics Committee
Australian National University
Telephone: +61 2 6125 3427 Email: Human.Ethics.Officer@anu.edu.au
Approval 2015/005

WRITTEN CONSENT for Participants

A RURAL PERSPECTIVE ON QUALITY END-OF-LIFE CARE

I have read and understood the Information Sheet you have given me about the research project, and I have had any questions and concerns about the project (listed here

_____)

addressed to my satisfaction. I agree to participate in the project. YES ☐ NO ☐

I agree to this interview being audio-recorded YES ☐ NO ☐

I agree to my stories or quotes being used in any thesis, report, publication or presentation providing my name and other identifying details are not used. YES ☐ NO ☐

Signature:.....

NAME:

DATE.....

Please circle to indicate which information sheet you received:

PATIENT FAMILY/UNOFFICIAL CARER HEALTH PROVIDER

Appendix 5: Interview prompt questions

Patient and carer interview prompts:

Interviews will be conversational and semi structured without necessarily direct questioning. Sample prompts for both patient and carer (adapted from McCall & Rice 2005) include:

1. Can you tell me what you know about palliative care?
2. Can you tell me what palliative care services are available locally?
3. If circumstances allowed you to choose, where do you think you would prefer to be cared for? Why would you choose this place?
4. If circumstances allowed you to choose, where do you think you would prefer to die? Why would you choose this place?
5. What do you think you will need to achieve this choice? To receive the best care possible?
6. Under what circumstances do you think you may not be able to achieve your choice?
7. Would you consider an alternative? Where would the alternative be? Why?
8. How would you feel if you had to change your preference?
9. How important is it that you stay at home? (if that is what they have indicated) For you? For your family?
10. Have you ever had to leave home to receive care? How did that feel? Tell me what was good? What was bad?
11. Who helps you at home? (formal and informal carers)
12. What do think contributes to a 'good death'?
13. Do you think you care is influenced by where you live?
positive/negative

Appendix 6: Copies of the published papers arising from this thesis

1. Rainsford, S., MacLeod, R.D., & Glasgow, N.J. (2016). Place of death in rural palliative care: a systematic review. *Palliative Medicine*, 30(8), 745-63.
doi:10.1177/0269216316628779.
2. Rainsford, S., MacLeod, R.D., Glasgow, N.J., Wilson, D.M., Phillips, C.B., & Wiles, R.B. (2016). Rural residents' perspectives on the rural 'good death': a scoping review. *Health and Social Care in the Community*.
doi: 10.1111/hsc.12385. [Epub ahead of print, 19 September 2016].
3. Rainsford, S., MacLeod, R.D., Glasgow, N.J., Phillips, C.B., Wiles, R.B., & Wilson, D.M. (2017). Rural end-of-life care from the experiences and perspectives of patients and family caregivers: a systematic literature review. *Palliative Medicine*; 31(10); 895-912. doi: 10.1177/0269216316685234.

Place of death in rural palliative care: A systematic review

Palliative Medicine
2016, Vol. 30(8) 745–763
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DOI: 10.1177/0269216316628779
pmj.sagepub.com
SAGE

Suzanne Rainsford¹, Roderick D MacLeod^{2,3} and
Nicholas J Glasgow¹

Abstract

Background: There have been many studies on the actual and preferred place of care and death of palliative patients; however, most have been whole population surveys and/or urban focused. Data and preferences for terminally ill rural patients and their unofficial carers have not been systematically described.

Aim: To describe the actual place of death and preferred place of care and/or death in rural palliative care settings.

Method: A systematic mixed studies review using Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines.

Data source: PubMed, PsychINFO, Scopus and CINAHL databases were searched (September to December 2014); eligible quantitative and qualitative studies included preferred and/or actual place of death/care of rural, regional or remote residents; rural data that are clearly identifiable; death due to palliative condition (malignant and non-malignant) or survey of participants with current or hypothetical life-limiting illness.

Results: A total of 25 studies described actual place of death; 12 preferred place of care or death (2 studies reported both); most deaths occurred in hospital with home as the preferred place of care/death; however qualitative studies suggest that preferences are not absolute; factors associated with place are not adequately described as rurality was an independent variable; significant heterogeneity (rural setting and participants), however, many areas had a greater chance of home death than in cities; rural data are embedded in population reports rather than from specific rural studies.

Conclusion: Home is the preferred place of rural death; however, more work is needed to explore influencing factors, absolute importance of preferences and experience of providing and receiving palliative care in rural hospitals which often function as substitute hospice.

Keywords

Palliative care, place of death, patient preference, rural, systematic review, terminal care

What is already known about the topic?

- Most place-of-death studies have been population surveys or urban focused.
- Few studies have focused specifically on influencing factors or absolute importance of place of care and death in rural settings.

What this paper adds?

- Significant variations exist in rural definition, characteristics, available services and preferences.
- Quantitative studies indicate that rural-preferred place of death is home; however, qualitative studies highlight the complexity and fluidity of decision-making that is not reflected in population surveys.
- Rural hospitals may act as substitute hospice.

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Email: suzanne.rainsford@anu.edu.au

Implications for practice, theory or policy

- Further rural-specific studies are required to explore
 - Factors influencing place of care and death.
 - Significance of preferences.
- There is a need to determine actual proportion of rural residents who die in their preferred place.

Introduction

Dying in one's preferred place of death (PPOD) is one outcome defining quality palliative care¹ and 'the good death' with the assumption that a home death is the ideal.^{2,3} The modern day 'good death' infers a 'managed death'^{4,5} with the goal of not only adequate pain and symptom control but also autonomy and respect of patients' and families' wishes. A previous systematic review⁶ reported home to be the PPOD for 31%–87% of patients, 25%–64% of carers and 49%–70% of the general public.

Currently, most deaths occur in hospital^{7,8} with one multi-nation European study reporting hospital rates of up to 91% (Sweden)⁹ and home rates of between 45.4% (the Netherlands) and 12.8% (Norway).¹⁰ The median percentage of all deaths in hospital is reported to be 54%.¹¹ Some studies report a shift in deaths away from hospital¹² towards home¹³ and care homes,¹⁴ while others report the opposite^{15–17} with a prediction that by 2030 home deaths in the United Kingdom will have decreased by 42% and institutionalised deaths increased by 20%.¹⁸

However, a significant percentage of the world's population lives outside a major capital city, for example, one-third of Australia's population¹⁹ yet most studies reporting on preferences for place of care (POC) or place of death (POD) have been population surveys and/or urban focused. One of the difficulties in describing rural preferences is the lack of consensus in defining 'rural.' In general terms, 'rural' implies a geographical area outside cities and urban areas; however, 'rural' can mean different things to different people, both within and between nations. The degree of rurality can be based on population density, size of the community or remoteness as defined by proximity to services provided by capital cities or urban service centres. Since the early 1990s, three different geographic classifications have been developed in Australia: the Rural, Remote and Metropolitan Areas (RRMA) classification, the Accessibility/Remoteness Index of Australia (ARIA) and the Australian Standard Geographical Classification (ASGC).²⁰ Depending on which classification is applied, it is possible for one small agricultural town of <2000 people, 160 km from the nearest major urban area, to be considered 'rural' based on population size (RRMA) or 'inner regional' based on the road distance to accessible services (ASGC).

Despite the difficulty in defining 'rural', studies suggest that rural folk are different to their urban counterparts²¹ and have unique perspectives and concerns about

dying in one's home community²² with each rural location unique and different from the next. New models of care are being developed to expand community palliative care services, especially in rural and remote areas with one recommended outcome being an increase in home deaths;^{23,24} however, there is limited data describing the preferences of terminally ill rural patients and their unofficial carers. To our knowledge, no systematic reviews of international rural studies have been published. The aim of this review is to describe the actual place of death (APOD) and preferred place of care (PPOC) and/or death in rural palliative care settings.

Method

This systematic review of both quantitative and qualitative studies was undertaken utilising the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines.²⁵

Literature search

Between September and December 2014, four electronic databases (PubMed, PsycINFO, Scopus and CINAHL) were searched using the following keywords and Medical Subject Heading (MeSH) terms: (choice OR prefer* OR decision) AND (palliative OR end-of-life OR terminal) AND (care OR death) AND (place OR location OR site) AND (Rural). A date filter was not applied, and all published international English language, peer reviewed research articles were identified.

The search was widened by limiting the keywords to ('place of death' OR 'place of care') AND (Rural) on the presumption that rural data may be embedded in population studies. The two searches were downloaded to ENDNOTE X7, merged and duplicates deleted. The reference lists of all included studies were scanned for additional articles. The researcher hand searched the recent issues (June 2013–April 2015) of six relevant journals (*Palliative Medicine*, *Journal of Palliative Medicine*, *Journal of Pain and Symptom Management*, *Palliative and Supportive Care*, *Australian Journal of Rural Health* and *Journal of Rural Health*). Relevant articles found incidentally or identified by PubMed monthly updates (January–May 2015) were also included. One corresponding author²⁶

provided a copy of their completed report containing specific rural data.

Selection criteria

Studies were assessed against predetermined inclusion criteria and included if they reported the preferred and/or actual POD/POC as either part of the research aim or findings; participants included rural, regional or remote residents (no standardised definition of rurality was used); rural data were clearly identifiable; cause of death included a palliative condition (malignant and non-malignant) or survey included preferences if participants had current or hypothetical life-limiting illness; the article indicated that a research study had been conducted with method and results described. While this systematic review excluded paediatric palliative care, the age filter (≥ 19 years) was not applied in the initial search as different cut-off ages are used, ranging from 15 to 19 years. Both qualitative and quantitative studies were included.

Rejected studies were either clearly irrelevant or those that addressed the topic in general but failed in one or more of the inclusion criteria. The titles of all identified studies were reviewed independently by two researchers (S.R. and N.J.G.). S.R. and R.D.M. independently read abstracts of studies identified by title and full transcripts where further clarification was required. Disagreements were discussed via email and resolved by consensus.

Data extraction

Data from each accepted study were extracted and entered into a table under the following headings: article information (author, year, country, aim); methods (design, setting, participants, rural definition, inclusion and exclusion criteria, rural response rate, assessment and interview question) and results. When provided, predictors of and reasons for preferences were recorded. Data were extracted by S.R. with a second reviewer (R.D.M.) independently assessing a random selection of six studies (17%).

Assessment of quality

The quality of each study was assessed on aspects relevant to rural POC/POD and was not necessarily an assessment of the study per se, resulting in some high-quality studies receiving a low score. All studies were rated to be of low, medium or high quality based on a simple scoring system described by Gomes et al.⁶ and modified by the researcher to account for the rural focus. Different criteria²⁷ were used to assess the quantitative and qualitative²⁸ studies with maximum scores of 16 for quantitative studies and 20 for qualitative. Both tools awarded a score of 2 (Good), 1 (Fair) and 0 (Poor). Items scored for quantitative studies included study design, adequate rural description, representative rural

population, explicit inclusion/exclusion criteria, rural response rate, reliable and objective rural variable, adjustments made for confounders and rigorous/appropriate analysis. Qualitative studies were graded on clear title and abstract, clear aims and background, appropriate method and justification for using qualitative method, appropriate and representative sample, rigour in analysis and interpretation, ethics considered, reflexivity and bias acknowledged, clear statement of findings, generalisability and importance of findings.

The quality assessment was made by S.R. with R.D.M. independently assessing, using the same scoring system, a random selection of six studies (17%). Differences were discussed by email and resolved by consensus.

Data synthesis

Studies were described in terms of country, date of publication, populations (including palliative condition), design, rural description and assessment outcome. Two main categories were identified: APOD and PPOC/PPOD with results summarised in two separate tables. Due to heterogeneity, a meta-analysis was not possible. Findings are reported descriptively.

Data were manipulated into a common format, and when possible algebraic back calculations were performed to determine the percentage of actual or preferred rural home deaths. Where the adjusted odds ratio (aOR) was reported, the rate of a rural home death was compared to urban where aOR of urban home death = 1. Themes regarding POC/POD are reported for qualitative studies.

Ethical approval was not required as this study was a systematic literature review.

Results

We identified 254 articles from the electronic searches. After merging searches and removing duplicates, 96 studies were identified. Following review of titles, abstracts and full texts, where necessary, 23 studies were eligible for inclusion (Figure 1). Of those rejected, all included rural participants; however, five did not separate rural from urban data, seven did not relate to POC/POD and two reported data for all deaths including children and accidents. Hand-searches, review of reference lists and monthly PubMed updates (including May 2015) added 16 additional articles. A total of 39 papers^{10,13,29–65} were reviewed reporting 35 separate studies. One corresponding author supplied their full report²⁶ with data merged with their published paper.⁶² Data extraction for six studies^{29,37,39,55,60,65} required arithmetic calculations of the data by the researcher to enable results of rural POD to be presented as a percentage. There was an initial disagreement on the quality score of two of the six studies selected for checking due to the interpretation of the extracted rural

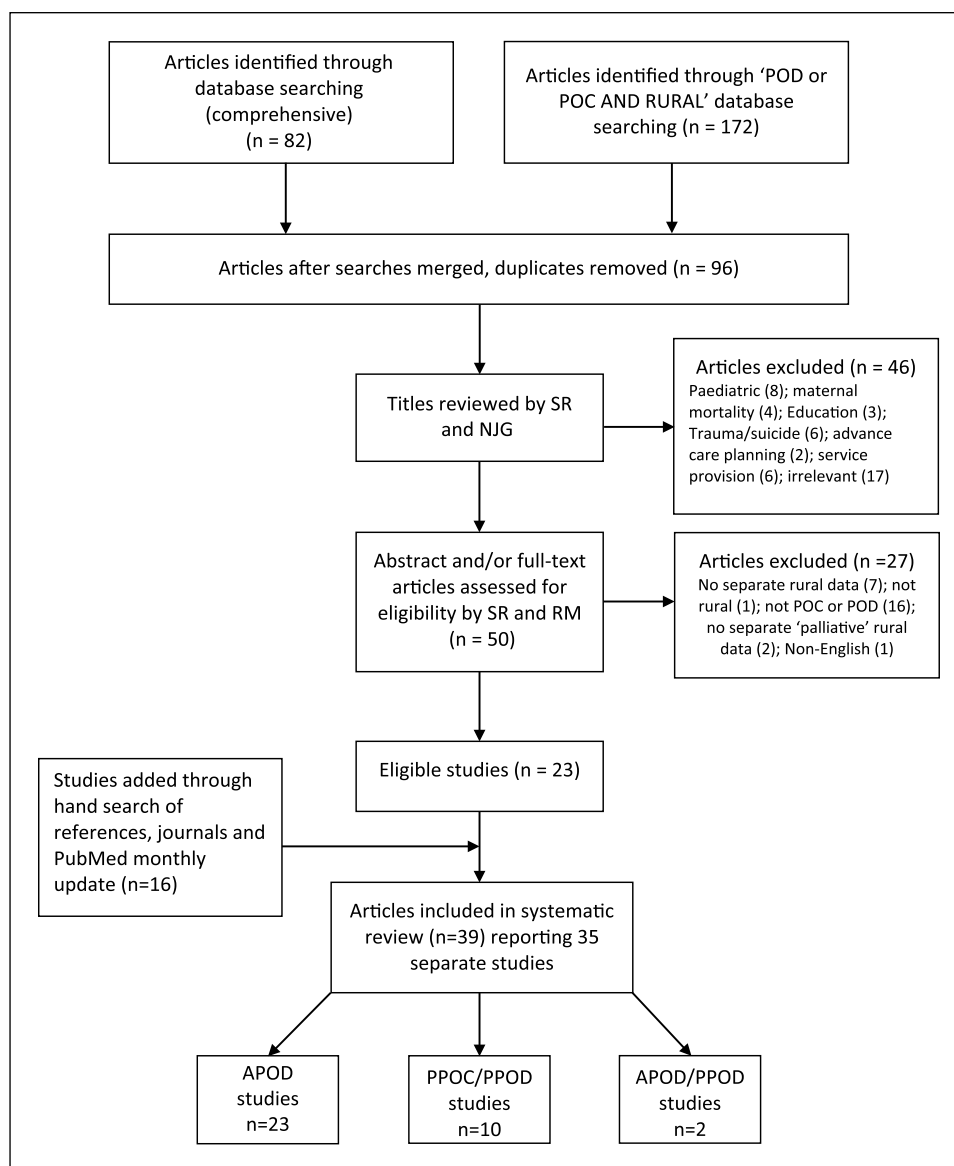


Figure 1. Flow diagram of selection process.

Source: modified flow chart as described by Moher et al.²⁵

POD: place of death; POC: place of care; APOD: actual place of death; PPOC/PPOD: preferred place of care/death.

data. This was resolved by both the researchers reviewing the studies for the second time and applying strict views of the rural aspect resulting in agreement by consensus.

Characteristics of the studies

The studies, published from 1990 to 2015, reported rural APOD ($n=23$, Table 1), PPOD ($n=6$),^{37,40,48,56,60,63} PPOC ($n=3$),^{47,64,65} PPOD and PPOC ($n=1$)⁵³ and both APOD and PPOD ($n=2$).^{26,31,62} Data were collected from at least 278,687 rural residents (sample size ranged from 847 to 199,211³⁸) from 21 countries (three studies did not provide rural participant number^{32,57,59}). Data were collected from Australia (7),^{39,41,48,52,54,56,59} Canada (6),^{13,36,40,42,51,63,64}

England (4),^{10,26,38,57,58,62} Germany (2),^{35,49,55} Italy (2),^{10,34} Scotland (2),^{31,47} Taiwan (2),^{45,60} Japan (2),^{50,65} Spain (2),^{33,46} and one from each of Belgium,^{10,38} Botswana,^{43,44} China,³⁷ Denmark,²⁹ Korea,⁵³ Mexico,³² Norway,¹⁰ the Netherlands,^{10,38} New Zealand,⁶¹ Sweden³⁰ and Wales.¹⁰ One study^{10,38} collected data from more than one country.

A total of 6 studies reported national data,^{32,43–45,60,61,65} 12 reported provincial, state or county data,^{13,29,30,33,35,36,41,42,51,52,55,56,59,64} 9 reported regional data,^{26,34,39,46,48,49,57,58,63} 7 reported a single town or health service/practice,^{31,37,40,47,50,53,54} and 1 reported that data set was multi-regional.^{10,38} Eight studies were described as rural or semi-rural,^{26,31,47,48,50,57,58,61} one regional³⁹ and the remainder were cross-sectional containing rural data. One study reported data

Table 1. Studies describing actual rural place of death.

Study description Rural N/total N	Study design	Decedent diagnosis	Rural description	Results	Percentage of rural patients died at home	Quality
Aabom et al. ²⁹ Funen county, Denmark January 1996–December 1998 Rural N = 927/4386	Cross-sectional death certificates linked with four national and two local registers. POD: home or institution (hospital, RACF)	Cancer	Not provided	Rural POD: home = 29% Urban home deaths = 30% Influencing factors: not described specifically for rural; rural residency independent variable.	29	Medium
Axelsson and Christensen ³⁰ Jamtland county, Sweden 1990 Rural N = 203	Cross-sectional death certificates linked with hospital records. POD: home, hospital, RACF	Deaths from GI tract, breast, urogenital, skin and thyroid cancers	Sparsely populated county	Rural POD: home = 12%, NH = 24%, hospital = 64% Influencing factors: proximity to hospital and short interval between diagnosis and death ^ hospital deaths	12	High
Burge and colleagues ^{13,51} Nova Scotia, Canada 1992–1997 Rural N = 6176/13,652	Cross-sectional, population-based death certificates linked with three administrative health databases. POD: hospital or OOH (included both home and NH). RRR: 97%	Cancer	Population <1000 or population density <400/km ²	Rural POD: OOH = 23.8%, hospital = 76.2% Urban OOH death = 28.2% Increasing trend for OOH death. Influencing factors: not described; rural residency independent variable	23.8	High
Burns et al. ⁵² South Australia, Australia 2001–2007 Rural N = 2205/6849	Randomised, population- based, face-to-face interview surveys with bereaved relatives; annual state government health survey. POD: home, hospital, hospice, RACF	Terminal illness	Postcode areas outside the capital city, >1000 population	Rural POD: home = 18.1%, hospital = 67.5%, hospice = 7.9%, RACF = 6.4% Urban: home = 20%, hospital = 55.5%, hospice = 16.2%, RACF = 8.4% (<i>p</i> < 0.001) Influencing factors: not described; rural residency independent variable	18.1	High
Carroll ³¹ Scotland 1992–1994 Rural N = 82	Retrospective cross-sectional audit of single practice medical records. POD: home, community hospital, residential home, hospital or hospice	Cancer	Semi-rural small town, population = 11,240	Rural POD: home = 30%, community hospital = 17%, residential care = 10%, hospital = 38% hospice = 5% Influencing factors: not reported	30	Low
Castillo-Guzman et al. ³² Mexico 1999–2009 N = 5,338,322 deaths Rural N not provided	Cross-sectional, population- based Mexican National Institute of Statistics and Geography database. POD: home, hospital, other	Cancer	Not provided	Rural POD: home = 69.4%, hospital = 23.6%, other = 7% Urban POD: home = 52.3%, hospital = 43%, other = 4.7% Influencing factors: not described; rural residency independent variable	69.4	Medium

(Continued)

Table 1. (Continued)

Study description Rural N/total N	Study design	Decedent diagnosis	Rural description	Results	Percentage of rural patients died at home	Quality
Catalan-Fernandez et al. ³³ Majorca, Spain April 1984–August 1986 Rural N = 135/335	Retrospective cross-sectional service-based face-to-face questionnaire survey with relatives. POD: home or hospital	Cancer	'Everywhere on the island outside the capital, Palma de Mallorca'	Rural POD: home = 65.9%, hospital = 34.1% Urban: home = 31.5%, hospital = 68.5% ($p < 0.001$) Influencing factors: not described; rural residency independent variable	65.9	Medium
Cohen et al. ¹⁰ and Houttaker et al. ³⁸ Norway, England, Wales, Belgium, Italy and the Netherlands 2002, 2003 Non-metropolitan N = 199,211 ³⁸ /26,4277	Cross-sectional Common European database–death certificates. POD: home versus outside home (hospital, care home/NH), other (hospice in England and the Netherlands), public road, work	Life limiting illness/ cancer	Based on population density	Rural POD: home – Belgium = 28.2%, the Netherlands = 39.1%, England = 20.7% (palliative subset); Cancer deaths: aOR home death urban = 1 Belgium = 2.34, Italy = 2.08, the Netherlands = 1.6, Norway = 1.66, England = 0.9, Wales = 0.71 Influencing factors: not described; rural residency independent variable	20.7 28.2 39.1	High
Costantini et al. ³⁴ Liguria and Toscana Italy 1991 Rural N = 1664/55,759	Retrospective cross-sectional computerised data from Toscana and Liguria Regional Mortality Registers, POD: home or hospital (including NH)	Cancer	Rural municipality <150 inhabitants/ km ²	Rural POD: home = 53.4%; Urban: 43.2%; semi-urban: 60.4% Trend decrease in home deaths. Influencing factors: not described; rural residency independent variable	53.4	High
Crawford ⁵⁴ Kangaroo Island, Australia 1994–1996 N = 15	Cross-sectional death certificates written on Kangaroo Island. POD: home, hospital (30 beds)	Cancer	Island population 4000	Rural POD: home = 27%, hospital = 73% Influencing factors: hospital deaths associated with proximity to hospital, symptom management, carer needs	26.7	Medium
Escobar Pinzon et al. ^{35,55} Rhineland-Palatinate Germany September 2008–January 2009 Rural N = 644/1378	Cross-sectional written survey of relatives; RR: 36% POD: home, hospital, palliative care facility (hospice, hospital, PCU), NH, elsewhere (e.g. work, on holidays)	All deaths (72% had progressive disease). 25 May–24 August 2008	Rural classification: rural municipality <2000 inhabitants, rural town 2000– <5000, small town 5000–<20,000	Rural POD ³⁵ : home = 43%, hospital = 38%, PCU = 6%, NH = 11%, elsewhere = 2%. Large town: home death = 28.4% Influencing factors: not described; rural residency independent variable	43	Medium

Table 1. (Continued)

Study description Rural N/total N	Study design	Decedent diagnosis	Rural description	Results	Percentage of rural patients died at home	Quality
Gatrell et al. ⁵⁷ North West, England 1993–2000 N=6900 (rural not provided)	Cross-sectional; linked mortality data provided by single Health Authority and Office of National Statistics. POD: home, hospital, hospice, elsewhere, NH/ retirement home	Cancer	Not provided; includes semi-rural South Lakeland	Residents of semi-rural area are more likely to die at home (aOR = 1.334), or hospital (aOR = 1.677); less likely to die in hospice (aOR=0.640) or NH (aOR = 0.647) than urban (aOR = 1). Overall POD: hospital = 35%, hospice = 33%, home = 22%, no place of death recorded = 10%. Influencing factors: proximity to hospital or hospice increased rate of dying there	aOR = 1.334 95% CI = 1.139– 1.562	High
Goodridge et al. ³⁶ Saskatchewan, Canada 2004 Rural N = 468/1098	Retrospective cohort study (COPD or lung cancer); Linked data from seven separate service files including vital statistics death file. POD: home, hospital, LTCF	COPD or lung cancer	Rural classification: rural/remote (≤ 9999 population size), small urban or urban (≥ 100,000)	Rural POD: home = 15.4%, hospital = 59%, LTC = 25.6%. Urban home deaths = 16.3%. Influencing factors of POD were not the focus of study	15.4	Medium
Herd ⁵⁸ West Cumbria, England April–October 1987 Rural N = 157	Cross-sectional, semi- structured interview questionnaires with lay carers. POD: home, hospital	Cancer	Semi-rural, small towns (maximum population = 28,000), villages, isolated hamlets and farms	Rural POD: home = 53% Urban: home = 24–41% Influencing factors: distance from hospital and more likely to die at home; reasons for hospital admission: no carer (22%), lay carer unable to continue (45%)	53	High
Howat et al. ³⁹ North Queensland, Australia 2004 N = 270	Retrospective cross-sectional review of medical charts; single palliative care service POD: home, hospital, NH	Palliative care	Regional using the RRMA classification	Rural POD: home = 11.6%, hospital = 55.8%, NH = 0.4%, Unknown = 24% Remote POD: home = 0, hospital = 35.3%, NH = 6%, unknown = 58.9% Metro: home = 23.4%, hospital = 67.5%, NH = 6.7%, unknown = 2.4% Influencing factors: home death – younger, married, colorectal cancer, community nurse involvement	19	Medium

(Continued)

Table 1. (Continued)

Study description Rural N/total N	Study design	Decedent diagnosis	Rural description	Results	Percentage of rural patients died at home	Quality
Hunt et al. ⁴¹ South Australia 1990–1999 Rural N = 7527/29,230	Population-based, cross-sectional South Australian cancer registry. POD: hospital, hospice, home, NH	Cancer	No rural definition	Overall POD: metropolitan public hospital = 25.0%, hospice = 19.9%, country hospital = 16.9%, private residence = 15.8%, metropolitan private hospital = 12.7%; NH = 9.7%; city (low socioeconomic) home death aOR = 1 Influencing factors: not described; rural residency independent variable Rural POD: home = 20.2%, hospital-extended care = 20.9%, other = 6% Vancouver: home = 14.6%, extended care = 27.3%, hospital = 55.8%, other = 2.4% Influencing factors: not described; rural residency independent variable = 52.9%	aOR = 3.5 (95% CI = 3.03–4.04)	High
Jayaraman and Joseph ⁴² British Columbia, Canada 2004–2008 Rural N = 19,428/153,111	Retrospective population-based death certificates. POD: home, extended care facility, hospital or other	All deaths (cancer = 32%, non-malignant progressive disease = 33%)	Postcode		20.2	High
Lazenby and colleagues ^{43,44} Botswana June 2008 Rural N = 10,487/18,869 Rural oldest old N = 1787	Retrospective cross-sectional death certificates; RR: 97.2% POD: home or hospital	All deaths (HIV/AIDS/cancer = 39%; cardiac = 10%; TB = 4%)	Rural categories as identified by the Republic of Botswana's Central Statistics Office	POD: home deaths rural (38.3%), town (29.7%), city (27.1%). Rural home deaths >80 years: 50%–100% compared to overall 27%–94%. Most hospital deaths occurred in cities. Influencing factors: rural home death –female >80 years	38.3	Medium
Lin and Lin ⁴⁵ Taiwan 1997–2003 Rural N = 21,237/18,869	Cross-sectional population-based study; death registration data; RR: 96% POD: home, hospital	Cancer	National standards	Rural POD: Urbanisation 6 – home = 78.4%, hospital = 21.6%, Urbanisation 7 – home = 81.7%, hospital = 18.3% Urbanisation level 1 (city): home = 36.4%, hospital = 63.6% Influencing factors: not described; rural residency independent variable	U6: 78.4 U7: 81.7	High

Table 1. (Continued)

Study description Rural N/total N	Study design	Decedent diagnosis	Rural description	Results	Percentage of rural patients died at home	Quality
Lopez-Campos et al. ⁴⁶ Andalusia, Spain 2010 and 2011 Rural N = 2603/4983	Retrospective observational cohort study; death certificates POD: home, hospital, hospice, other	COPD	Villages and countryside. 17.8% of population	Overall POD: COPD – home = 35%, hospital = 57.6%, hospice = 6.7%, other = 0.7% Non-COPD: home = 33.8%, hospital = 57.5%, hospice = 8.2%, other = 0.6% aOR COPD dying at home: urban = 1; rural = aOR 2.8 (95% CI = 2.46–3.16). Influencing factors: not described; rural residency independent variable	aOR = 2.8 (95% CI = 2.46–3.16)	Medium
McNamara ⁵⁹ Western Australia, Australia 1 July 2000–31 December 2002 N = 13,453 No rural N	Longitudinal (2.5 years) population-based retrospective cohort design; death certificates linked with hospital and palliative care nursing records. POD: usual place of residence (home including long-term residents of RACF), hospital, hospice, RACF (transferred just prior to death) and other place to death	PCS	Rural geographical remoteness ARIA based on access/ proximity to service centres	Overall POD (PCS): usual place of residence = 32%, hospital = 51%, hospice = 11%, RACF = 3%, other = 3%; dying in usual place of residence aOR city = 1. (POD of all deaths: usual place of residence = 35.8%, hospital 48.6%). Influencing factors: not described; rural residency independent variable	Rural aOR = 0.74 (95% CI = 0.61– 0.91); remote aOR = 1.03 (95% CI = 0.75–1.41)	Medium
Papke and Koch ⁴⁹ Sächsische Schweiz, Germany 1997–2003 Town N = 1315 Country N = 1001/2316	Cross-sectional; death certificates; POD: hospital, home, NH	Cancer	Town – district and larger towns; country – smaller towns and villages	aOR town home death = 1; aOR country home death = 1.54 (95% CI = 1.29–1.82; <i>p</i> = 0). In small town and rural locations, POD from ca was equally distributed between home and hospital. Influencing factors: not described; rural residency independent variable	aOR = 1.54 (95% CI = 1.29–1.82)	Medium

(Continued)

Table 1. (Continued)

Study description Rural N/total N	Study design	Decedent diagnosis	Rural description	Results	Percentage of rural patients died at home	Quality
Smyth et al. ⁶¹ New Zealand Rural N = 186	Cross-sectional postal survey completed by rural GPs; RR: 42.2%; POD: home, hospital, hospice, RACF	Palliative care	GP receiving a rural GP bonus identified by New Zealand Institute of Rural Heath	Rural POD: home = 46.5%, NH = 24.8%, local public hospital = 16.7%, hospice = 7.2%; base hospital = 4.8%. Influencing factors for not dying at home: caregiver burden = 42%, symptoms = 25%, patient choice = 11%, investigations = 5%	46.5	Low
Thomas et al. ²⁶ North West England, England October 2000–September 2002 Rural patients N = 12	Post bereavement interviews with carer or health professional. POD: home, hospital, hospice, elsewhere	Cancer	Semi-rural region of Kendall/South Lakeland	Rural POD: home = 25%, hospice = 62.5%, hospital = 0, elsewhere = 12.5% (four alive at end of study: PPOD hospice = 3, undecided = 1). Influencing factors: not rural specific; however, proximity to hospice was one factor; rural residency one variable	2/8 = 25	Medium ^a Data obtained from full report provided by author; small component of a larger study
Yasumura et al. ⁵⁰ Japan January 1986–December 1988 Rural N = 312	Retrospective rural study; face-to-face interviews with carer; RRR: 88.6% POD: home, hospital	Decedent bedridden ≥ 7 days prior to death	Small rural town; population 13,000; no hospital or NH, no physicians, or community palliative care	Rural POD: home = 47.7% (Japanese average in 1990 = 20%); hospital = 35.9%. Influencing factors for home death: age, lack of pain, non-cancer, senility, regular home visits by a public health nurse, living in a three-generational household. Factors hospital death: cancer, higher education and living with spouse	47.7	High

POD: place of death; OOH: out of hospital; RACF: residential aged care facility; NH: nursing home; LTCF: long-term care facility; RRR: rural response rate; PPOD: preferred place of death; GP: general practitioner; GI: gastrointestinal tract; CI: confidence interval; COPD: chronic obstructive pulmonary disease; LTC: long-term care; TB: tuberculosis; PCS: palliative care subset; PCU: palliative care unit; aOR: adjusted odds ratio; RRMA: Rural, Remote and Metropolitan Areas.

^aData recalculated by researcher to enable rural POD percentages to be reported.

from non-cancer patients,⁴⁶ eight both malignant and non-malignant,^{36,38,39,40,50,52,59,61} 8 cross-sectional population data^{35,42–44,48,55,56,63–65} and the remainder reported data from terminally ill patients with cancer. In all, 31 studies were quantitative, 3 were qualitative^{47,48,63} and 1 was mixed.^{26,62}

Heterogeneity

While 15 studies used death certificates to report the APOD, studies were heterogeneous in regard to rural setting, participants, inclusion criteria and assessment. While some studies listed a range of locations for POC/POD (home, hospital, hospice, nursing or care home), others restricted the options to 'home or out of home/hospital',^{10,29,33,34,38,43–45,50,58} or 'hospital or out of hospital'.^{13,51} Long-term placement in a nursing home was considered 'home' for some studies^{13,51,59} and an 'institution' for others.^{29,34} Not all rural locations had the options of community hospital, inpatient hospice or nursing home. A total of 17 studies related to cancer patients and 8 to non-specified terminally ill patients. The definition of rural varied between the studies ranging from small remote, sparsely populated communities to large regional centres within large rural municipalities or provinces. Rural was described as isolated farms, hamlets, small towns or villages,^{31,46,49,58} low level of urbanisation,⁴⁵ 'everywhere on the island (Majorca) outside the capital'³³ and sparsely populated rural provinces.³⁰ One Australian study³⁹ used the RRMA classification and another⁵⁹ the ARIA. Rural populations ranged from <1000,^{49,51} <2000,³⁵ 4000,⁵⁴ 8000,⁴⁰ <9999,³⁶ rural towns 2000–<5000³⁵ and small towns <28,000.⁵⁸ Some studies described as rural had access to large county hospitals (Sweden: 104 beds³⁰), while others had limited medical facilities.⁵⁰

APOD

In total, 25 studies^{10,13,26,29–36,38,39,41–46,49–52,54,55,57–59,61} described the APOD with 2^{26,31} describing both APOD and PPOD. Location of APOD was gained from death certificates or national registries (15),^{10,26,29,30,32,34,38,42–46,49,51,54,57,59} medical records or general practitioner (GP) surveys (3),^{31,39,61} cancer registry records (1),⁴¹ and post bereavement informal carer interview or survey (6).^{26,33,35,50,52,55,58} A total of 14 studies investigated the POD for cancer decedents ($n=40,451$),^{26,29,30–34,41,45,49,51,54,57,58} 6 for terminally ill or palliative decedents ($n=202,184$);^{10,36,38,39,50,59,61} 3 for all deaths ($n=30,550$; cancer or HIV/AIDS accounted for 39%–72% of deaths)^{35,42,43/44,55} and 2 studies reported on decedents with chronic obstructive pulmonary disease (COPD) or lung cancer.^{36,46} Three studies did not provide the number of rural deaths.^{32,57,59} A total of 11 studies were of high quality,^{10,13,30,34,38,41,42,45,50–52,57,58} 12 medium quality,^{26,29,32,33,35,36,39,43,44,46,49,54,55,59} and 2 low quality.^{31,61} The main weaknesses were lack of rural description. Poor-quality

studies had low numbers, with one single practice study³¹ relying on GPs' recollection of APOD.

Table 1 summarises the study descriptions, participant populations, study design and either percentage of rural patients who died at home (or out of hospital) or aOR of rural home death compared to urban.

The rate of home deaths ranged from 12% (Sweden³⁰) to 81.7% (Taiwan⁴⁵); 7 studies reported rates of home death less than 25% (Sweden,³⁰ Canada,^{36,42,51} Australia,^{39,52} England^{10,38}), 10 studies reported 25%–50% (Denmark,²⁹ Scotland,³¹ England,²⁶ Netherlands,^{10,38} Belgium,^{10,38} Australia,⁵⁴ Germany,^{35,55} Botswana,^{43,44} New Zealand,⁶¹ Japan⁵⁰) and 5 studies reported >50% (Mexico,³² Spain,³³ Italy,³⁴ England,⁵⁸ Taiwan⁴⁵). Where a home death was not achieved, most deaths occurred in hospital (New Zealand: 21.5%,⁶¹ Canada: 76.2%^{13,51}). Less than 10% of rural deaths occurred in nursing/care homes or hospices; however, these options, especially hospices, were often not mentioned^{29,32} or not available.^{13,30,33,34,39,43–45,50,54,58} Where results were expressed as aOR, compared to urban home deaths (aOR=1), rural home deaths ranged from 0.74 (95% confidence interval (CI): 0.61–0.91; Western Australia)⁵⁹ to 3.5 (95% CI: 3.03–4.04; South Australia).⁴¹

The highest rates of home deaths were seen in cancer patients (53%³⁴ to 81%⁴⁵); however, one cancer study reported the lowest frequency (12%³⁰). Rates for terminally ill patients (cancer and non-cancer) ranged from 15.4%³⁶ to 47%⁵⁰ and all deaths 20.2%⁴² to 43%.^{35,55}

A total of 17 studies included both urban (city or large town) and rural data. Four studies reported that rural patients are more likely to die in hospital^{13,51,52,57} or long-term care facility³⁶ than urban patients with the out-of-hospital trend less marked in rural locations.⁵¹ The remaining studies reported the chance of dying at home to be greater in rural than urban locations.

Most studies designated rural residency as an independent variable with the seven rural studies briefly reporting factors influencing POD. The factors influencing the decision to transfer from home included proximity to a hospital or hospice,^{25,30,54,57,58} inability of carer to continue,^{54,58,61} increasing symptom burden,^{50,54,61} brief interval from diagnosis to death³⁰ and patient choice.⁶¹ Two rural studies^{39,50} reported that the involvement of community nurses increased the likelihood of remaining home.

PPOC/PPOD

Eight studies described PPOD,^{26,31,37,40,48,56,60,62,63} three PPOC^{47,64,65} and one reported preferences for both places⁵³ (Table 2). In all, 11 studies were prospective and 1 retrospective;³¹ 8 quantitative,^{31,37,40,53,56,60,64,65} 3 qualitative^{47,48,63} and 1 mixed.^{26,62} The quantitative studies collected data from interviews and surveys; qualitative studies used semi-structured and open-ended interviews

Table 2. Studies describing rural preferred place of care and death.

Study description Rural N/total N	Study design	Participant/ informants	Rural description	Results	Percentage (or aOR) of rural residents whose PPOD/C is home	Quality
Carroll ³¹ Scotland 1992–1994 and Oct 1995–September 1996 PPOD Rural N = 82 (pre-audit) and 34 (audit)	Retrospective cross-sectional study; interviews with GPs pre-audit and audit after implementation of matrix to prompt GP to ask PPOD. RRR: pre-audit = 71%; audit = 88%	Decedents: cancer patients Informant: GPs	Semi-rural small town, population: 11,240. 32 km from Aberdeen	PPOD: pre-audit (audit): home = 72% (77%), community hospital = 9% (21%), NH = 5% (0), hospital = 9% (0), hospice = 5% (3%). Influencing factors: not provided	PPOD: 72% pre-audit PPOD: 77% audit	Medium
Choi et al. ⁵³ Seoul, South Korea Dates not given PPOC/PPOD Rural patients N = 79/371 (21%) Rural carers N = 48/281 (17%)	Cross sectional, self- completed, service-based survey Actual questionnaire not provided	Cancer patients and their carers	Not provided	Overall PPOC: home = 53% patients and 49% family Overall PPOD: home = 47% patients and 51% family. Urban home preference aOR = 1 Influencing factors: home – stronger family network and less access to hospital; rural residency independent variable	PPOC home: rural patient aOR = 1.57 (95% CI = 0.94–2.61). Rural family aOR = 1.57 (95% CI = 0.84–2.94) PPOD home: rural patient aOR = 1.65 (95% CI = 1–2.72). Rural family aOR = 2.76 (95% CI = 1.41–5.42) PPOD: 71.1%	Medium
Foreman et al. ⁵⁶ South Australia, Australia 2004 PPOD Rural N = 792/3015 (26%)	Cross-sectional, state-wide population, face-to-face survey (annual health ombudsman survey); stratified by location of residence. Question: where would you like to die if you had a terminal disease, such as cancer or emphysema?	General population: > 15 years	Rural: > 1000 residents	Rural PPOD: home = 71.1%, hospital = 1.7%, hospice = 6.2%, NH = 21%. Urban: home = 69.9%, hospital = 0.4%, hospice = 11.4%, NH = 18.7% ($p < 0.001$). Influencing factors: not described; rural residency independent variable		Medium
Fukui et al. ⁶⁵ Japan March 2010 PPOC/PPOD Rural N = 412/1042 (40%)	Cross-sectional, nation-wide survey; stratified by location of residence. Question: preferences for end-of-life care and death (home, acute hospital, PCU, public NH, private NH) if life expectancy is 1–2 months, no physical distress and needed care assistance	General population: 40–79 years	Rural area: < 150,000 residents	PPOC: urban – home = 49%, hospital = 17.5%, PCU = 22.5%, NH = 11%; rural – home = 51%, hospital = 16%, PCU = 21%, NH = 12%; p -value not significant. Overall PPOD: home = 43%, hospital = 16%, PCU = 20%, public NH = 7.4%, private NH = 0.6%, uncertain = 13.4%. Rural PPOD data not provided. Influencing factors: not described; rural residency independent variable	PPOC: home = 51%	Medium

Table 2. (Continued)

Study description Rural N/total N	Study design	Participant/ informants	Rural description	Results	Percentage (or aOR) of rural residents whose PPOD/C is home	Quality
Gu et al. ³⁷ Shanghai, China December 2007–December 2012 PPOD Rural dyads N = 278/522 (53%)	Prospective, cross-sectional, service-based, separate face-to- face interview questionnaire Question: 'where do you prefer to die if circumstances allowed you to choose at your terminal stage of life?' PPOD: home or hospital Prospective cohort study; face-to-face interview questionnaire; preferences at time of enrolment into study. RR: 83% Question: 'if your condition worsens, what is your hope about where you would like to receive care? + POD (if appropriate)'	Cancer patient/ carer dyad	Not provided	Rural patient PPOD: home 60.4% (urban 45.9%), hospital 32%, family to decide 7%. Carer: overall preference for home = 51.3% (no rural % provided). Influencing factors: culture: rural residency independent variable	PPOD: 60.4%	Medium
Howell et al. ⁴⁰ Canada Impact of shared care model on POD Rural N = 95	Prospective, qualitative, purposive sample identified by GP; semi-structured-taped interviews. Question: 'if everything were possible where would you choose to be cared for in the end stage of your illness?' and 'why would you choose this place?'	Patients; advanced, progressive disease (malignant and non- malignant)	Rural municipality comprising small towns, population = 80,000, served by 60-bed community hospital	PPOD: home = 80%, hospital = 4%, hospice = 1% PPOC data not reported Influencing factors: not provided as POD was secondary outcome	PPOD: 80%	High
McCall and Rice ⁴⁷ West Highlands, Scotland POC decisions Rural N = 8	Prospective, qualitative, purposive sample identified by GP; semi-structured-taped interviews. Question: 'if everything were possible where would you choose to be cared for in the end stage of your illness?' and 'why would you choose this place?'	Cancer patients	Not provided	Rural PPOC: home = 2; no preference but home not possible = 2; hospital as home not possible = 4; PPOC changes as care needs increase. Influencing factors: carer availability and ability patients' wishes may not be their preference due to concern about carer and not wanting to become a burden. Determinants for PPOC: carer resource and support; past experiences with death; communication of wishes	PPOC: 25%	High
McGrath ⁴⁸ Northern Territory of Australia. PPOD N = 72	Qualitative, phenomenological study, open-ended interviews with a cross-section of participants. Question not provided	Indigenous patients (n = 10), caregivers (n = 19); Indigenous and non-Indigenous health care workers (n = 41), interpreters (n = 2)	Rural and remote territory of Australia	Clear articulation of Indigenous people to die at home connected to land and family. Influencing factors: strong cultural reasons given including strong connection with land and community, a belief in 'death country'	Home	Medium

(Continued)

Table 2. (Continued)

Study description Rural N/total N	Study design	Participant/ informants	Rural description	Results	Percentage (or aOR) of rural residents whose PPOD/C is home	Quality
Shih et al. ⁶⁰ Taiwan April 2011 PPOC/PPOD Rural patients N = 76/310 (25%)	Cross-sectional; nation-wide postal questionnaire; stratified by location of residence. Assessment: five-part questionnaire included PPOC/ PPOD (home or not home) both in current situation and hypothetical if physicians or home nursing care services were available	Registered general patients	Not provided. Residential categories were city, town, rural	Rural patients PPOD ^a : home = 79%, not home = 21% City patient PPOD: home = 57%, not home = 43%; $p = 0.005$. Rural PPOC not reported. Influencing factors: not described; rural residency independent variable	PPOD: 79%	Medium
Thomas et al. ^{26,62} North West England, UK October 2000–September 2002 PPOD Rural patients: village/ hamlet N = 12; small town N = 6/41 Rural carer: (Kendall) N = 6/18	2-year longitudinal observational study; face-to- face interviews. Prompt question: 'if your illness gets worse, where would you like to be?' 'Would you like, for example, to go to a hospital, be at home, go to a friend/family, go to hospice, go to a NH, stay where you are now?' (supplied in full report)	Cancer patients (> 18 years; 3 months life expectancy)	Semi-rural South Lakeland (market town Kendall-small hospital); village/hamlet and small town	PPOD: village/hamlet: home = 25%, hospice = 17%, hospital = 0, NH = 8%, home or hospice = 33%, undecided = 17%. Small village: home = 17%, hospice = 50%, undecided = 33%. Influencing factors: overall factors presented but not rural specific; rural residency independent variable	PPOD: hamlet = 25%; village = 17%	High
Veillette et al. ⁶³ Quebec, Canada January–April 2007 'Good death' Rural N = 40	Qualitative, ethnographic study conceptualise the good rural death; individual interviews and focus groups. End-of-life locations: home and hospital	Community members with experience of death and dying in rural communities	Region A: metro- adjacent to Quebec city. Region B: considerable distance from Quebec city	PPOD: home community surrounded by family, and friends; solidarity and support of neighbours, but aware of need for available health care and support services. Several would prefer less care and fewer services than forgo contact with family and friends	Home community	High
Wilson et al. ⁶⁴ Alberta, Canada May–July 2010 PPOC Rural N = 213/1203 (17.7%)	Annual province, wide population-based telephone survey; stratified by location of residence. Question: 'where would you choose to spend your last days of life?	General public: > 18 years	Not provided	PPOC: rural – home = 74.9%, hospice = 11.5%, NH = 1.1%, hospital = 8.2%, unknown = 4.4% Village: home = 53.3%, hospice = 20%, NH = 3.3%, hospital = 16.7%, unknown = 6.7%. City: home = 70.3%, hospice = 15.5%, NH = 1.8%, hospital = 6.1%; $p = 0.4$. Influencing factors: not rural specific; rural residency independent variable	PPOC: rural: 74.9%; village: 53.3%	Medium

POD: place of death; POC: place of care; PPOC/PPOD: preferred place of care/death; NH: nursing home; PCU: palliative care unit; RRR: rural response rate; RR: overall response rate; aOR: adjusted odds ratio.

^aData recalculated by researcher to enable rural POD percentages to be reported.

and focus groups. Preferences were collected for 2531 rural residents, the smallest study⁴⁷ interviewed eight cancer patients and the largest⁵⁶ surveyed 792 members of the general public. Preferences were collected from 680 patients (73% cancer), 351 family carers, 43 health professionals and 1457 members of the general public. Studies were conducted in eight countries (Canada,^{40,63,64} Australia,^{48,56} Scotland,^{31,47} China,³⁷ South Korea,⁵³ Taiwan,⁶⁰ Japan⁶⁵ and England^{26,62}). One setting was described as rural and remote,⁴⁸ three rural,^{40,47,63} one semi-rural³¹ and seven population-based studies included rural participants.^{26,37,53,56,60,62,64,65} Most studies did not provide details of the rural setting only stating rural participants resided in small towns, villages and hamlets or rural areas either adjacent to or some distance from a major city. One qualitative study (phenomenological) explored PPOD for rural and remote Aboriginal people in the Northern Territory of Australia,⁴⁸ another (ethnographic) aimed to conceptualise the good death for Quebec rural francophones.⁶³ One UK study explored factors influencing decisions around POC in the West Highlands of Scotland,⁴⁷ and the other examined the reasons behind cancer patients' POD preferences in North West England.⁶²

Four studies (one quantitative⁴⁰ and three qualitative^{26,47,62,63}) were of high quality, and the remainder studies were of medium quality. The main weaknesses were inadequate rural descriptions, omission of rural response rate and uncertainty as to generalisability of results to other rural locations as participants were either recruited from single health services or members of a specific culture (remote Indigenous Australians). All qualitative studies had clear aims and justifications for study design and reflected on researcher biases.

Eight studies provided the actual question asked to assess preferences.^{26,37,40,47,56,60,62,64,65} One questionnaire offered home/not home as the option,⁶⁰ another home or hospital³⁷ with the remainder being either open-ended or providing a list of options. Cancer patients were asked their preferences if there were no influencing factors such as physical symptoms, carer burden or unlimited provision of home support.

Preference for dying at home

Six quantitative studies reported the preference for dying at home as a percentage,^{26,31,37,40,56,60,62} and one study reported as an aOR compared to urban preferences.⁵³ One qualitative study reported both percentages and themes.⁴⁷ All studies, with the exception of two UK studies,^{47,62} reported more than 50% of rural participants expressed a preference for dying at home. Thomas et al.²⁶ reported home to be the preferred place in 25% of participants; however, an additional 33% of participants selected 'home or hospice' as their preferred place, an option not available in other studies. Home was the PPOD for 60.4%³⁷ to 80%⁴⁰

of patients and 71.1%⁵⁶ to 79%⁶⁰ of the general public. No statistical results were reported for carers. In one study, home was the PPOC for 25%⁴⁷ of patients with home as the PPOC for 51%⁶⁵ to 74.9%⁶⁴ of the general public.

Three studies^{53,64,65} reported both urban and rural preferences for POC as either a percentage or odds ratio with a fourth study⁶⁰ reporting PPOD as a percentage. Results reported that preferences for home were greater in rural than urban areas and only the preferences for POD were statistically significant.

There was clear articulation in all qualitative studies that home was the PPOD 'surrounded by family, and friends'⁶³ and in the case of Indigenous Australians 'connected to land and family'.⁴⁸ The qualitative studies provided meaning behind decision-making, acknowledging that decision-making is complex and 'wishes' and 'preferences' are not necessarily the same. While wishing to remain at home, the participants in McCall and Rice's study⁴⁷ were aware that achieving this may not be possible due to 'concern about their carer and not wanting to become a burden', and so hospital became their preference.

Preference for hospital

With the exception of one study that recorded options as 'home' or 'not home',⁶⁰ all participants were given the option for hospital as an alternate POD or POC. The preference for hospital ranged from less than 4% (England,^{26,62} Australia,⁵⁶ Canada⁴⁰) to 32% (China³⁷). Reasons for preferring hospital included perceptions of better professional care, relief of carer burden and symptom control. Familiarity with hospitals was also reported. Hospitals were not always available within the community, and displacement from community to access the closest hospital was not always acceptable with some participants preferring to forgo symptom management to remain in their community.⁶³

Preference for hospice

Six studies^{25,37,47,48,56,60} acknowledged that inpatient hospices were not available in all locations, therefore requiring patients to travel outside their immediate community or were not offered as an option. Five studies reported preferences for inpatient hospice care with preferences ranging from 1% (Canada⁴⁰), 17% (North West England^{26,62}) to 21% in Japan.⁶⁵

Preference for residential aged care facility

Only 5 studies^{26,31,56,62,64,65} included residential aged care facilities (RACFs or Nursing Homes) as an option with preferences ranging from 1.1% in Canada⁶⁴ to 21% in South Australia.⁵⁶ Many rural locations did not have aged care facilities.

Discussion

To the best of our knowledge, this is the first systematic review of the international literature describing the actual and PPOC/PPOD of rural residents with most rural data embedded in population reports rather than in specific rural studies. The review also highlights the variability in the use of the term 'rural'. Due to heterogeneity in rural locations, individual studies could be considered 'silos'; however, consistency of results was present across a number of studies with death certificates documenting hospital to be the most frequent POD. Results described home to be the PPOC/PPOD; however, the small qualitative studies^{26,47,62,63} highlight the complexity and fluidity surrounding preferences indicating it is not simply a hypothetical decision as suggested by population surveys.

The APOD studies provided a 'snap shot' of current practice by describing and comparing POD across nations through death certificate data, while acknowledging that many developing nations are not represented. While the cause of death (cancer/non-cancer) stated on the certificate could be different to that found at autopsy,^{9,51} any misreporting of POD is unlikely to be significant as many studies included a cross-checking process. In these large studies, rural regions were included as either part of the whole country/state/province or stratified by degree of urbanisation; however, rural response rates were mostly unreported but inferred to be at or close to 100%. Common to previous studies, the rural data do not consider POC, and while hospital is the documented POD, decedents may have spent a significant time at home only to be transferred to hospital at the very end of life.⁶

Consistent with urban studies,^{8,66} most rural residents do have a preference for POC/POD, often home; however, high quality studies reported both the highest and lowest preference rates for a home death. For some, due to remoteness, there may not be a choice as there is no local alternative to home⁵⁰ or the community hospital is underserved.³⁷ Rather than a desire to remain home for whatever reason it may be more an 'aversion to hospital'.⁴⁷ Thomas et al.⁶² and McCall and Rice⁴⁷ observed that there is a difference between 'wish' and 'preference' with preferences changing to accomplish end-of-life care goals⁶⁷ as death approaches, care needs increase or carer burden becomes apparent.⁶⁸ Some patients are willing to sacrifice symptom management to remain home, while others sacrifice their preferred place to reduce carer burden. While surveys provide hypothetical preferences, there is an apparent significant incongruence between actual and preferred POC/POD consistent with urban data. However, reasons behind and absolute importance of preferences are not adequately described, and care must be taken when reporting the proportion of rural people who do not die in their preferred place as one cannot compare the hypothetical preferences of healthy population survey participants with terminally ill patients and their carers who are living the experience.

Factors influencing POC/POD in rural settings were not clearly identified as 'place' was the dependent variable and rural residency one of many independent variables. When reported, influencing factors were consistent with urban findings and included functional status and clinical condition, carer and social networks and health-system facilities; however, one needs to be careful drawing conclusions due to the limited rural data. Rural resilience⁵² and community as a social support network^{69,70} were not described. The uniqueness of individual rural communities was evident with locations exhibiting the highest numbers of or strongest preferences for home deaths being those with stronger traditional cultures and values; however, these locations often have less access to hospitals, hospices and nursing homes.

Previous studies report POC and POD are not synonymous,⁷¹ POD is not necessarily a dominant concern of the dying person⁷² and a hospital death is not necessarily a 'bad death'⁶⁸ with one study⁷³ suggesting rural residents are disadvantaged by the lack of inpatient facilities. Hospices can be an acceptable alternative to home;^{8,26,62} however, no two rural locations are the same and not all rural residents have access⁷³ to an inpatient hospice. When available, the rural community hospital often becomes the alternative to hospice, albeit without specialist multidisciplinary teams, and may be one reason for the higher rate of rural palliative care deaths in hospital in some locations.

If each rural community is unique, the challenge for future research is to find a common thread while avoiding over-generalisation.⁷³ However, trying to respect the wishes of each patient and community, it is not always practical or financially viable to have multiple individual models to suit each location. While ensuring all rural communities are represented using a stratified method of sampling, it is also important to ensure a cross-section of voices are heard within each represented rural community. Future studies could explore the actual proportion of rural residents who die in their preferred place and include qualitative studies with people (patients, carers, community members, rural health professionals) experienced in end-of-life care. While it is important to increase community services to support those who wish to stay at home, improvements in palliative care within community hospitals^{74,75} and RACF should not be overlooked as these places are often substitute hospice and the only alternative to home.

Study limitations

This systematic review had limitations in both completeness of the review and quality of identified studies. Studies not including selection criteria wording in the title, abstract or keywords may have been missed; however, electronic searching was augmented by hand-searching journals and reference lists. The lack of homogeneity and consistency in rural definition meant that studies reported on a variety of rural locations, populations and proximity to health

services with significant differences found in POD not only between regions but within regions.^{34,57} The objectives of most studies were not rural focused, and in some studies, POD was a secondary outcome increasing the risk of misinterpretation or miscalculation of rural data. Other limitations include small rural sample size; absence of documented rural response rate; limited generalisability due to specific populations such as remote indigenous peoples; recruitment bias (single medical practices or hospital clinics, omission of rural patients unable to travel to city cancer clinics and those not associated with palliative care services); reliance on family and health professionals' recall of patient preferences; variations in terminology and options for POD; inconsistency of nursing homes as 'home' or 'institution'; inconsistency in cohorts (cancer/non-cancer/all deaths/general population).

Conclusion

Despite striking variations between and within countries, a significant number of rural residents die in hospital; however, in many locations, they have a greater chance of dying at home than city residents. The PPOD (and care) for most rural residents is home; however, home is not the first preference for all and more work is needed to explore influencing factors, changes in preferences as disease progresses, the absolute importance of preferences, the influence of community on POD and the experience of providing and receiving palliative care in rural hospitals.

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Review

Rural residents' perspectives on the rural 'good death': a scoping review

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What is known about this topic

- The 'good death' is a key objective of palliative care.
- Current viewpoints and research about 'good' deaths reflect the urban voice.
- Rural areas are distinct and as such need to have special consideration.

What this paper adds

- Rural residents in both developed and developing countries report similar themes for a 'good death' as urbanites.
- Rural perspectives are subjective and dependent on rural context.
- Highlights the need for more research regarding rural patient and family caregiver perspectives on what it means to die well.

Abstract

The 'good death' is one objective of palliative care, with many 'good death' viewpoints and research findings reflecting the urban voice. Rural areas are distinct and need special consideration. This scoping review identified and charted current research knowledge on the 'good' rural death through the perspectives of rural residents, including rural patients with a life-limiting illness, to identify evidence and gaps in the literature for future studies. A comprehensive literature search of English language articles (no date filter applied) was conducted in 2016 (2 January to 14 February) using five library databases. Reference lists of included articles, recent issues of eight relevant journals and three grey literature databases were also hand-searched. Twenty articles (for 17 studies and one systematic review) were identified after a two-phase screening process by two reviewers, using pre-determined inclusion criteria. Data from each study were extracted and charted, analysed using a thematic analysis of the included articles' content, and with a quantitative analysis of the scoping review. These papers revealed data collected from rural patients with a life-limiting illness and family caregivers, rural healthcare providers, the wider rural community, rural community leaders and rural health administrators and policy makers. Rural locations were heterogeneous. Residents from developed and developing countries believe a 'good death' is one that is peaceful, free of pain and without suffering; however, this is subjective and priorities are based on personal, cultural, social and religious perspectives. Currently, there is insufficient data to generalise rural residents' perspectives and what it means for them to die well. Given the extreme importance of a 'good death', there is a need for further studies to elicit rural patient and family caregiver perspectives.

Keywords: dying well, end-of-life, good death, palliative care, rural, scoping review

Introduction

Death is an individualised experience with cultural, religious and political values and beliefs influencing the quality of dying. (Cottrell & Duggleby 2016). The 'good death' is one of the main objectives, if not the

sole aim, of palliative care. It is a dynamic concept whose meaning has changed over time in line with urbanisation and advances in medical technologies (Aries 1974, Kellehear 2008). Some argue the contemporary notion of the 'good death', fostered by the hospice/palliative movement, is idealised and 'limits

spontaneity' (Cottrell & Duggleby 2016). Historically, death and dying have moved from an open public activity at home to a more private and institutionalised process, hidden away in hospitals or other institutions such as nursing homes (Gomes & Higginson 2008), despite studies increasingly indicating the home as the preferred place (Gomes *et al.* 2013, Rainsford *et al.* 2016).

The common essential features of the modern 'good death' are thought to include being pain free, maintaining dignity, support of family, autonomy in decision-making for the dying person and opportunity to 'sort out personal affairs' (Raisio *et al.* 2015, Davies *et al.* 2016, Meier *et al.* 2016). However, different stakeholders have different priorities and expectations of end-of-life care (EoLC) (Holdsworth 2015, Davies *et al.* 2016, Meier *et al.* 2016). Ideally, it must reflect the needs of the community and in particular those of the dying person and their carers (Cottrell & Duggleby 2016). One voice that remains largely unheard is that of rural palliative care patients and their families (Bakitas *et al.* 2015).

One challenge in finding the rural voice is the difficulty in establishing consensus on a 'rural' definition. While efforts are made to define 'rural' geographically (based on population density or distance from services), Wilson *et al.* (2009a,b) suggest rural people define themselves as 'rural' and perceive themselves as different from urbanites. Studying rural views of the 'good death' is important because these may differ from urban views (Spice *et al.* 2012). In addition, ageing is more pronounced in rural areas, and rural areas typically have fewer health and social services as compared to urban areas (Downing & Jack 2012). For example, the growth in Australia's population aged 65 years or older is expected to rise by 139% between 2000 and 2030, with a 180% increase anticipated in rural areas (Australian Report 2008).

The purpose of this scoping review was to identify and chart current research knowledge on the 'good' rural death through the perspectives of rural residents, including rural patients with a life-limiting illness, rural family members/informal caregivers (FCG), rural healthcare providers (HCP) and the wider rural community; and to identify gaps in the literature for areas for future studies to better understand the concept of 'good death' for rural people. This review will add to an understanding of the rural perspective on the 'good death' to guide researchers, healthcare professionals and policy makers in future planning and development of rural EoLC.

Methods

Protocol

Currently, there is no standardised definition or methodology for scoping reviews (Peters *et al.* 2015); however, the definition commonly applied is that used by Arksey and O'Malley (2005). The protocol used in this review is based on the methodological framework first described by Arksey and O'Malley (2005), enhanced by Levac *et al.* (2010), Colquhoun *et al.* (2014) and Daudt *et al.* (2013) and later refined by the Joanna Briggs Institute (JBI 2015). The original (Arksey & O'Malley 2005) and modified (Levac *et al.* 2010) frameworks consist of six stages (JBI, 2015).

Despite scoping reviews becoming increasingly popular (Tricco *et al.* 2016), there are no standardised reporting guidelines. Tricco *et al.* (2016) identified the need for guidelines to ensure scoping reviews are valid and reliable. The reporting of this review is based on the 2016 scoping review published by Tricco *et al.* (2016), the team that is developing the standardised reporting guidelines, as well as the PRISMA-Scoping Review (PRISMA-ScR) guidelines (Equator Network, 2016). While quality assessment is not a requirement of the JBI guidelines, it will be included in this review (Levac *et al.* 2010, Daudt *et al.* 2013).

Eligibility criteria

Scoping reviews have a broad approach and include any existing literature regardless of study design, discipline or quality. In order to answer the research question 'How do rural residents describe the "good death" concept within a rural setting?' eligibility criteria were developed to clearly identify the purpose of the review and guide the reviewers in deciding which articles to include.

The eligibility criteria were developed using the JBI (2015) guidelines using the Participants, Concept and Context acronym.

- **Participants:** Rural residents including rural patients with a life-limiting illness, rural FCGs, rural HCPs and the wider rural community as these are the most appropriate to provide the rural perspective. No age filter was applied.
- **Concept:** The principal concept under review was the 'good death' in a rural setting as described through the personal experiences or perspectives of rural residents; collected by interviews, surveys or extensive field work observations. The term 'good death' was either used explicitly or implied.
- **Context:** Rural or remote; all countries and territories were considered; no standardised definition of

rurality was used. Articles that included urban and rural data were considered providing the rural data were clearly identifiable.

Information sources and search strategy

The principal researcher conducted the comprehensive literature search. Five electronic databases (PubMed, CINAHL, Scopus, PsycINFO and Web of Science) were searched from 2 January to 14 February 2016. The following keywords and Medical Subject Heading (MeSH) terms were used in the final search: ("good death" OR "managed death" OR "good enough death" OR "tamed death" OR "dying well" OR "peaceful death") AND (Rural OR Remote). This iterative process had 'peaceful death' omitted from the original search. All study designs were included; no date filter was applied; only English language papers were included.

The initial searches identified 377 articles. These were downloaded to ENDNOTE X7, merged and duplicates were deleted (338 articles). The reference lists of all retained articles were scanned for additional studies. The principal author also hand-searched recent issues (July 2014–Jan 2016) of eight relevant journals (Palliative Medicine, Journal of Palliative Medicine, Palliative and Supportive Care, Australian Journal of Rural Health, Journal of Rural Health, Social Science and Medicine, Health and Place, Death and Dying) for additional articles. The Cochrane Library, CareSearch database and OpenGrey repository were searched for grey research literature. The authors of three studies reporting mixed rural/urban geographical data were contacted; however, rural data were confirmed as not specified, and so these three articles were excluded from this review.

Study selection process

Phase 1 screening (review of titles) was carried out independently by two authors. At least two authors independently screened the abstracts and/or full text of potential articles (see Figure 1 for flow chart). Rejected articles were either clearly irrelevant or those that addressed the topic in general but failed in one or more of the inclusion criteria. Due to geographical distances, differences were discussed via email and resolved by consensus.

Data extraction and charting

Data from each accepted article were extracted by the principal author and entered into a table according to predefined headings (JBI, 2015). Three co-authors

independently read the retained articles and added their comments to the table indicating agreement/disagreement/additions/deletions. Differences were discussed via email. The final version was emailed to all co-authors for verification.

Assessment of quality

The current scoping review methodological guidelines do not require a formal quality assessment of eligible articles to ensure valuable insights reported in lower quality studies are not excluded. However, a quality assessment was conducted in this review to assist in validating the quality of the literature. All eligible articles are retained in this scoping review regardless of their quality.

The quality of each study was assessed independently by four co-authors. Some high-quality studies received a lower score as the assessment was based on aspects relevant to the rural 'good death' and not of the study per se. All studies were rated to be of low, medium or high quality based on a simple scoring system described by Gomes *et al.* (2013) and modified to account for the rural 'good death' focus. Two additional items were included: (1) clarity of rural definition and (2) validity of informant (prospective = 2, retrospective = 1, well community = 0).

Synthesis

The synthesis included both a quantitative analysis of the actual scoping review and a qualitative analysis of the content of the included articles. Both analyses were conducted by the principal author and verified by one of three co-authors. The quantitative analysis is charted and described in frequencies. A thematic analysis of the qualitative content was conducted by downloading the eligible articles into NVivo-10, coding for major themes and reported narratively. Due to heterogeneity within a small number of studies, a meta-analysis and analysis according to informants were not possible. Some informant groups had only one study identified.

Results

Literature search

A total of 377 potential articles were identified from the electronic searches. After merging the searches and removing duplicates, 338 manuscripts were

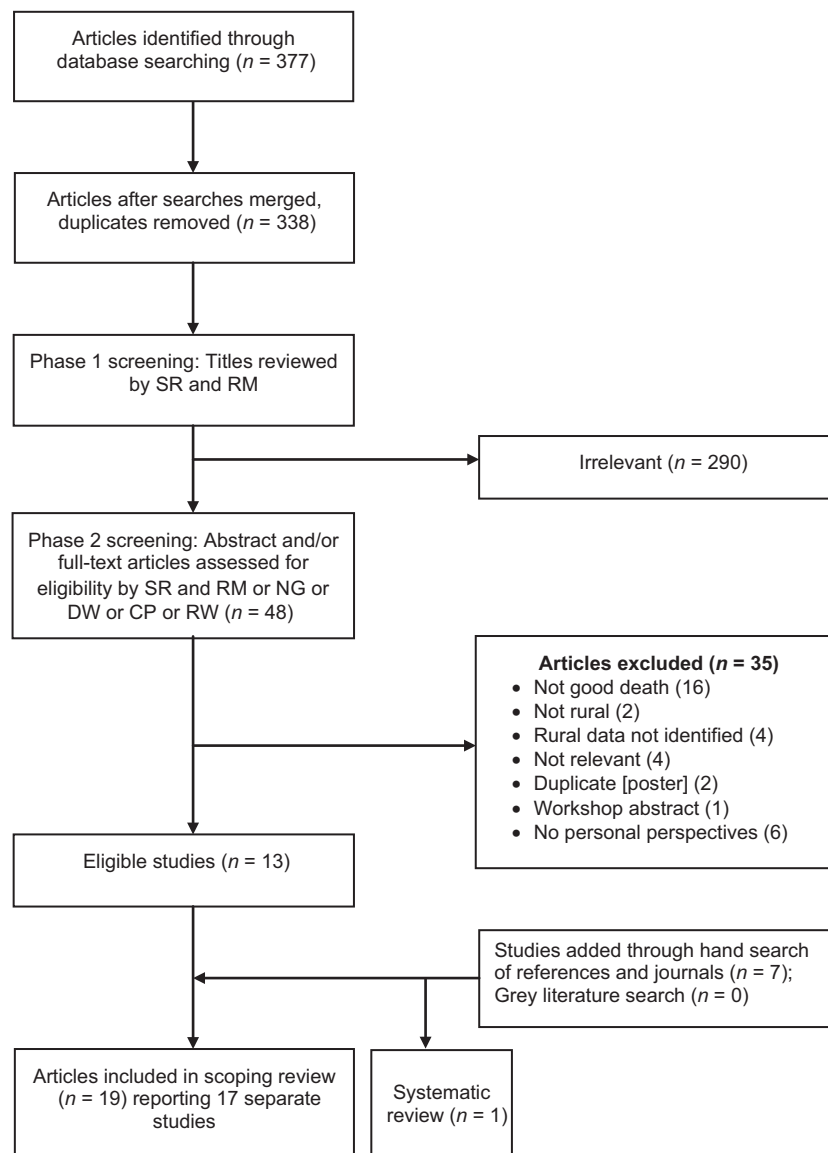


Figure 1 Flow diagram of scoping review selection process including reasons for exclusion.

Source: Modified flow chart as described by Moher *et al.* (2009).

identified and 13 remained after two screening phases (see Figure 1). Hand-searches of journals and reference lists identified an additional seven articles. Consequently, 20 articles reporting on 17 studies and one systematic review were included in this scoping review (see Table 1).

Study characteristics

The included articles were published 2000 through 2015 (see Table 2), with data collected between 1981 and 2013. Rural perspectives were reported in articles from both developed and developing countries –

Canada (5), USA (4), Kenya (2), United Kingdom (2) and one each from Norway, Vietnam, Bangladesh, Papua New Guinea, Uganda, Malawi, Ghana and Tanzania. One study (Grant *et al.* 2011) and the systematic review (Gysels *et al.* 2011) collected data from more than one country in sub-Saharan Africa. One Canadian manuscript (Wilson *et al.* 2009b) compared data collected from two studies (Wilson *et al.* 2009a, Viellelette *et al.* 2010) conducted in different Canadian provinces using the same study protocol. With the exception of two articles (Gysels *et al.* 2011, Knight 2014), all studies were described as rural; no remote communities were specified. No standardised

Table 1 Summary of included studies

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Anaert <i>et al.</i> (2009) Western Quebec (Canada) Rural <i>N</i> = 5	To explore home-care nurses' attitudes towards palliative care (PC) in a rural community. Palliative care journal	5 home-care nurses; all residents of the rural community.	Vast, sparsely populated area geographically isolated with few health or social services. Rural study	Qualitative face-to-face semi-structured ITVs and FGD; thematic analysis.	'If they [the patients] die with dignity and they are conscious right to the end, and they haven't suffered, then ... they have had a good death' [nurse].	Six themes identified: 1 Community embeddedness; 2 Maintaining patients' QoL 3 Multidisciplinary collaboration 4 Emotional and physical isolation 5 Need for professional development 6 Organisational issues.	Medium Small sample size; employed by PC service.
Beckstrand <i>et al.</i> (2012, 2015) Wyoming, Utah, Nevada, Alaska (USA) Rural <i>N</i> = 236	To discover size, frequency, and magnitude of obstacles in providing end-of-life care (EoLC) in rural emergency departments (ED). Emergency nursing journal	52/73 rural hospitals agreed to participate; 236/508 surveys returned by registered nurses.	Small rural communities with critical access hospitals (CAH). Rural study.	Cross-sectional survey design; 57-item survey included 15 demographic, 3 open ended and 39 Likert questions.	To be comfortable and free of pain, the family is able to perform EoL rituals, others are respectful of the patient's dignity, and families have adequate time to say goodbye.	GD = ideal death Obstacles to ideal death in rural ED includes personally knowing the patient or family; lack of privacy for the dying patient due to poor design; issues with family members; unknown patient wishes; nurse/physician power struggle; Phone calls from family, etc. detract from time with patient.	Medium Convenience sample; ED nurses; focus mainly sudden or accidental deaths within the ED.
Biggs (2014) Canada Rural <i>N</i> = 19	To explore how dying persons and their caregivers experience spiritual care in their homes as an aid to dying well and having a GD. To examine effect of rural geography on the experience. Doctoral thesis	10 dying persons and 9 caregivers.	Grey and Bruce Counties described as rural comprising towns of various sizes and farms (no specific details). Rural study.	Phenomenological study and interpretive analysis; semi-structured ITVs.	With spiritual care 'people's needs are fulfilled, their suffering is lessened and there is an increased possibility of them experiencing a good death'.	EoL spiritual care facilitates 'GD' by helping dying persons and their FCG to experience connection and support to people and traditions they consider necessary to die well; provides personal inner resources including hope, comfort, self-worth, strength to cope, and peace of mind. Rural residency contributed positively to their experience of a GD.	High Small sample size limitation is counterbalanced by depth of interviews.

Table 1 (continued)

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Cruikshank <i>et al.</i> (2010) Scotland Rural <i>N</i> = 24	To understand the impact on patient care by use of syringe drivers (SD) in rural communities Palliative care journal	4 terminal patients, 8 informal carers, 12 community nurses.	'Typical Scottish rural community'. Town 15,000 and surrounding rural area. Rural study.	Phenomenological approach; Patient ITVs at home; carer bereavement ITVs; 2 community nurse FGDs.	Good pain relief makes a GD; however, many other issues to consider 'it [syringe driver] helps the pain but that's all it helps' [patient].	Factors influencing good death: 1 Good anticipatory care 2 Symptom management (physical, psychological) 3 Open/honest communication – family and patient EoLC is complex; Community nurse is central to EoLC; Rural challenges include distances and limited staff.	Medium Patients enrolled in palliative care service; had SD at recruitment; biased towards symptom control. Not focused on GD; focused on determining EoLC needs in a rural community
Counts and Counts (2004) West New Britain (Papua New Guinea) Rural <i>N</i> = whole community	'The good, the bad, and the unresolved death in Kaliai' Social science and medicine journal	Authors' observations and interviews with residents.	Isolated NW island; 1000 Melanesian Lusi-Kaliai residents; accessible only by sea. Government clinic operated at Roman Catholic Mission. Rural study.	Qualitative Long-term Anthropological field work (1966–1967, 1975–1976, 1981, 1985). Case studies	'A good death is under the control of the dying person and is the result of the natural process of ageing'. [author]; 'death is either good or bad depending on whether it is the consequence of bad social relationships and causes social upheaval'.	GD = 'peaceful death'; 5 elements: social (at peace with others, mutually); psychological or spiritual (at peace with one's own life and death and 'soul'); timing (natural death/old age); spatial (at home, surrounded by relatives A GD rarely happens; it is a controlled, quiet death of elderly as result of the natural process of ageing. Bad death implies a rupture of social relations and results in the destruction of peace and social order. Combination of traditional and Christian beliefs. Social death versus physical death	Low Observation – researcher bias however data collected over many years. Understanding of good and bad death is very much based on localised cultural constructions and may not necessarily reflect general beliefs and customs. Old study – findings may no longer be relevant.

Table 1 (continued)

Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
To explore and understand lived experience of older cancer patients living alone. Oncology nursing journal	5 older patients with incurable cancer; >70 years; living on their own.	Communities with low-population density; population 920 to 7775. Rural study.	Qualitative; phenomenological hermeneutical approach; narrative interviews.	'Good death' is implied; could be inferred to be a noble death; acceptance comes through maintaining a will to live; the hope to stay alive is not death-renouncing, but rather life-affirming.	Importance of maintaining dignity, identity and value; enduring by keeping hope alive by continuing chemotherapy as a means of delaying death and retaining a positive outlook; maintaining autonomy by mobilising personal resources; not to become a burden on family, friends and services. Challenges: coping with conflicting feelings of hope and despair; navigating alone as patient and self-care provider; living up to expectations of being a good patient; limited control; risk of losing one's identity and value; loss of former life; services not always available in rural areas therefore need to be self-reliant.	Medium Small sample; recruitment bias (polyclinic); patients undergoing chemotherapy; patients living alone.

Table 1 (continued)

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Dilger (2008) Tanzania	To explore how moral perceptions of HIV/AIDS-related illness and death in rural Tanzania are related to social and cultural practices of disease interpretation, patient caring and burial. Anthropology Journal	Young men and women with HIV/AIDS (minor ethnic group.)	Mara Region in Tanzania; rural; borders on Lake Victoria in the west and Kenya in the north; farming and fishing. Rural study.	Anthropological field work; Research 1999–2000.	A controlled, quiet death of elderly as result of the natural process of ageing.	'Bad death' – physical and spiritual with social, cultural and moral components. Suicide is an example of a bad death → negation and rejection of social order; HIV/AIDS is a 'bad disease' inferring a 'bad death' – painful for individuals and their families; premature death breaks continuity of whole families and lineages as young people die without leaving children from 'legitimate relationships'; disturbs social equilibrium and kinship networks; considered a 'final death' as prevents fulfilling of ritual requirements.	Low Field work and case studies with no reporting of methodology; no reflexivity; Results possibly not generalisable due to small ethnic group with specific cultural practices and young age of informants...

Table 1 (continued)

Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Easom et al. (2006) USA Rural N = 9	Convenience sample; 9 rural nurses working in assisted living and nursing home environments	Rural = access; distance >75 miles from large metropolitan area. Rural study.	Mixed study; written questionnaire. In regard GD attitudes: Qualitative: 2 open-ended questions. Q1: 'What is your belief regarding what constitutes a "good death"?' Q2: 'What impact do cultural values have on death and dying?'	To die painlessly, comfortably and hopefully in one's sleep.	Attitudes and perceptions of participants changed in defining what constitutes a 'good death'. Q1: Pre-education: to die painlessly, comfortably, and, hopefully in sleep. Post-education: adding importance of family involvement; Respect and compliance with patient and family wishes. Q2: No change in knowledge and attitudes relating to significance of cultural values on the process of death and dying. • Communication. • Cultural competency.	Low Small convenience sample; Recruitment bias. Pilot study. Not focused on GD-evaluated staff EoLC education programme.
Felt et al. (2000) Kansas, USA Rural N = approx. 50	Targeted communities; purposive selection of active community leaders.	Six rural communities in Kansas. Rural study.	Qualitative; 6 FGDs of 7 to 10 people; discussions recorded, transcribed, reviewed individually; comparisons made between groups → themes identified.	Best scenario for one's own death 'in my sleep' or 'hope it happens quick'; at home or 'someplace comfortable, quiet, and peaceful, with family' and 'loved ones nearby; to 'make peace', to 'forgive and forget', to be honest about what was really happening; permission to die from loved ones very important to a peaceful death.	GD = 'best scenario for own death' Important themes: 1 Freedom and independence 2 Honesty and trust 3 Importance of family 4 The right to information 5 Participants expressed more fear over the manner of death than death itself; fear a technological death as opposed to a good death. Some wanted to die alone after closure with loved ones.	Medium Selection bias; minority groups not represented; script-guided discussion. Focused on determining EoLC needs in a rural community rather than GD.

Table 1 (continued)

Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/ Limitations/ Bias
Grant <i>et al.</i> (2003) Rural Kenya, sub-Saharan Africa Rural N = 56	To describe the experiences and needs of dying hospital patients and their FCG to determine what constitutes a GD in sub-Saharan Africa. Palliative care journal	32 adult patients (cancer or AIDS); 24 carers; mostly Christian however traditional beliefs still strong; identified by hospital doctor; stratified by home and hospital care.	Eastern slopes of Mt Kenya (Meru District). Population density 363/km ² to 65/km ² poverty, drought, poor infrastructure. Population mostly Christian. Rural study.	Qualitative; Semi-structured ITVs; not recorded, hand written notes + impressions and observations; transcultural researcher; multidisciplinary advisory group; multiple data sources; ITVs completion once saturation achieved; constant comparison; thematic analysis.	Dying with dignity or dying well is outside the grasp of most pain, poverty, sense of burden, guilt, and need for basics of life.	High Limited generalisability to sub-Saharan Africa. Selection bias- recruited from hospital. Small sample, single ethnic group; interviews not recorded, however, rigour in recall; cancer/AIDS focus.
Grant <i>et al.</i> (2011) Uganda, Kenya and Malawi Rural N = 162	To describe patient, family and local community perspectives on the impact of three community based PC interventions in sub-Saharan Africa. Palliative care journal	33 patients with advanced illness, 27 family carers, 36 staff, 25 volunteers, 29 community leaders and observed clinical care of 12 patients.	Uganda: mobile PC service 120 km from Kampala; includes fishing communities on Lake Victoria. Kenya: rural, 240 km from Nairobi. Malawi: peri-urban districts of Blantyre. Influence of Christian missionaries. Rural study.	Rapid assessment evaluation; Qualitative; photographic ethnography; rapid evaluation field studies; ITVs with key informants; direct observations of clinical encounters; review of local PC information; data triangulation; thematic analysis.	'To let people die in peace'; 'now patients die with dignity' with a 'sense of hope'. Good death implied	Medium Service evaluation; selection bias; small samples. Palliative care present → may inhibit honest responses.

Table 1 (continued)

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Gysels <i>et al.</i> (2011) Sub-Saharan Africa	To synthesise qualitative research on EoL to inform policy, practice and further research. Palliative care journal	–	Studies relating to the GD were conducted in rural Ghana, Tanzania, and Kenya.	Systematic review	Ghana: Bad death is a death that come too early, or believed to be punishment for sins. Tanzania, Kenya: bad death related to 'bad disease' (HIV/AIDS).	GD versus bad death and stigma. Cultural beliefs impact EoLC for patient, family and community. Ghana: elderly, death welcomed, brings peace and rest. Bad deaths – early, punishment for sin. A good funeral was part of a good death. Tanzania: studies related to stigma attached to HIV/AIDS, associated with immoral behaviour = bad death. Kenya and Tanzania: HIV/AIDS death denied status of ancestors → threatened continuity of clan and community; buried outside the homeland → loss of dignity and complicated bereavement.	Systematic review; methodologically sound not GD focused. Systematic review based on EoLC in sub-Saharan Africa; predominantly HIV/AIDS among young people; Findings not generalisable outside this cohort.

Table 1 (continued)

Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Huy <i>et al.</i> (2007) Vietnam Rural N = approx. 80.	Purposive selection; Farmers, lived in hamlet >5 years.	Commune 6000 –10,000; each divided into a number of small hamlets. Vietnamese folk religion and Christianity. Rural study	Qualitative 9 FGDs (6–11 participants); audio recorded and transcribed; translated in to English; thematic analysis	GD is an 'honourable death'	Types of death: • Elderly (natural process and deserved) • Young (working adults); GD = 'honourable death'; 'Bad death' = death of dishonourable person who had lived a bad life or stigmatised disease (HIV or suicide) • Young death (school aged) • Infant death (either 1 or 12 years) Bad and infant deaths more likely to be unreported due to family stigma and babies not recognised as a 'person'	Low FGDs possibly not appropriate in this culture and may inhibit discussion; not generalisable; no reporting of researcher bias or reflexivity; no indication of participants' personal experience with dying (implied).
Joarder <i>et al.</i> (2014) Bangladesh Rural N = 8	5 male +3 female elderly villagers. Data collected 2008.	Rural village (Kakabo), Savar sub-district 25 km from Dhaka. Mostly Muslim; few Hindu and Christian. Rural study.	Qualitative; purposive sampling; in-depth interviews; daily routines; informal discussions; Participatory Rapid appraisal tool box. Coding and categorising patterns.	Peacefully, without suffering, surrounded by family	Physical versus spiritual death; duality of body and soul. 'Good death' – peacefully, without suffering, surrounded by family. This manner of death was given by God; the result of good actions in life. 'Bad death' = caused by hanging, poisoning, homicide, and accidents; earned through bad deed; bad 'karma'.	Medium Short time interval (3 days); age difference between interviewers and participants (respondents considered interviewers too naive to discuss serious issues); beliefs based on local cultural traditions with religious influences limiting generalisability.

Table 1 (continued)

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Knight (2014) England Rural <i>N</i> = 4	To explore the views of clergy about the constituent elements of a 'good death'.	4 Church of England clergy working in rural or town parishes. (10 clergy including 3 rural, 1 town, 2 suburban; 4 not specified)	Diocese of Worcester. Urban/Rural study; rural data identified.	Qualitative; random sample; structured ITVs using flash cards; thematic analysis and scoring of cards.	Different meanings of 'Good Death' depending on perspectives, cultures; individual concept.	Spiritual care slightly more significant than emotional care and more important than physical care. Social domain lowest priority. Spiritual care: 'to be at peace with God'; 'to say goodbye to important people in my life' Emotional care: 'dignity; sense of humour' Physical care: pain free; 'To have human touch'. Social care: to have my family with me' • Keeping sense of humour + family involvement highly valued; To say goodbye more highly rated than dying at home. • Peacefulness for HCP = absence of distressing symptoms; for the clergy = Maintaining sense of humour, sense of dignity; being at peace with God.	Medium Small sample size; clergy bias; single researcher.

Table 1 (continued)

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
van der Geest (2004) Ghana Rural <i>N</i> = 35	An essay considering 'good death' and 'bad death' in rural Ghana. Social science and medicine journal.	Residents, mostly farmers, of Kwahu-Tafo, southern Ghana.	A rural town; population 6000; farmers and traders. Christian, mostly Roman Catholic. Rural study.	Anthropological fieldwork carried out intermittently from 1994 to 2004. Interviews, participant observations, school questionnaires, FGD.	A good and peaceful death comes 'naturally' after a long and well spent life.	'Good death' = a peaceful death: having finished all business, made peace with others; being at peace with own death; not by violence, accident, fearsome disease, without much pain; at home, surrounded by children and grandchildren; a death accepted by the relatives. 5 aspects: social, psychological, spiritual, timing, spatial. However, 'good death' is ambiguous as quality is open to interpretation by all stakeholders.	Medium Not a study with methods but extensive field work, open to researcher bias. No reflexivity provided; not generalisable; ethics not described.

Table 1 (continued)

	Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/ Limitations/ Bias
Viellette <i>et al.</i> (2010) Quebec, Canada Rural <i>N</i> = 36 (concerning 70 cases)	To obtain perspectives on what constitutes a good death from persons living in French speaking rural Quebec. Palliative care journal	ITV: 25 long-term rural community members with personal or professional experience of death and dying. FGD: 11 healthcare providers, community services and EoL policy makers/ administrators.	Region A: considerable distance from Quebec city. Region B: close to Quebec City. Rural study.	Qualitative ethnography; validation of themes previously identified (Wilson); 25 ITVs; 2 FGD(5 + 6); audio taped; transcribed; coding; themes; iterative; saturation.	'Enjoying a good quality of life while dying (and their family) was essential to a good death'.	GD: four dimensions – physical, spiritual, social and emotional – psychological. Essential elements: 1 Control over physical pain 2 Not being a burden on family 3 Ability to make choices and control over life 4 Being in one's environment, surrounded by family +friends 5 Being spiritually accompanied 6 Good communication 7 Good relationships with care and service providers. Rural Specific: to die in one's own community, reliance on neighbour support. Some would prefer to have less care and fewer services than be removed from community (family and friends). Gaps in available services are limiting factors to a GD.	High Study in 2 small areas of a large province; retrospective views- some of many years; no First Nations; few males; recruitment bias; self-selection.

Table 1 (continued)

Purpose	Informants	Rural definition	Methodology	Good death description	Findings in relation to good death	Quality/Limitations/Bias
Wilson <i>et al.</i> (2009a,b) Alberta, Canada Rural <i>N</i> = 34 To gain a conceptual understanding of the 'good death' in English speaking rural Alberta. Palliative care journal	ITVs: 13 community members with personal or professional experience of death and dying; self-selection. FGD: 21 healthcare providers and policy makers.	Region A: Metro-adjacent; Region B: Non-metro-adjacent. Rural study.	Qualitative ethnography; Document review; site observations; interviews (13); themes validated by 2 focus groups (9 + 12); audio tapes transcribed; coding; themes; iterative; saturation.	The good rural death is contextualised. Dying outside one's rural community is considered a 'bad death'	Four themes: 1 'Rural people are a distinct cultural group' with unique perspectives on EoLC and GD; rural persons need to be in their home community when dying. 2 Deep concern about community and its members; desire to provide highly individualised care aimed at maintaining the dignity and addressing the self-directed care preferences of the dying person. 3 Loose network of carers (paid and volunteer) 4 Unique challenges in developing and maintaining EoL services Rural people have less access to specialist palliative care.	High Limitations not noted however researcher reflexivity and bias is acknowledged; selection bias; small sample.

Findings reported are in relation to good death and do not necessarily reflect full findings of the study.
 ABBREVIATIONS: PC palliative care; ITV interviews; FGD focus group discussion; QoL quality of life; GD good death; EoLC end-of-life care.

Table 2 Characteristics of included studies

	Developed (n = 10)	Developing (n = 8)
Date of publication		
2000–2004	1	3
2005–2009	3	2
2010–2015	6	3
Countries		
Developed (n = 10)		
North America	7	0
United Kingdom	2	0
Norway	1	0
Developing (n = 7)		
Africa	0	5
Bangladesh	0	1
Vietnam	0	1
Papua New Guinea	0	1
Source of article		
Journal	9	8
Dissertation	1	0
Source discipline		
Palliative/hospice care	7	3
Social Science and Medicine	0	2
Other nursing	2	0
Population health	0	1
Anthropology	0	1
Cross-cultural gerontology	0	1
Theology	1	0
Study objective	4	3
included 'Good death'		
Type of article		
Qualitative (n = 17)		
Phenomenological	3	0
Ethnographic	2	1
Open ended written survey	2	0
Anthropological field work	0	3
Not specified	3	3
Systematic review	0	1
Methods*		
Interviews	7	4
Focus groups	5	3
Observations/field work	0	4
Written surveys	2	0
Clinical observations	0	3
Terminology		
Good death	7	4
Peaceful	0	2
Other	3	1
Bad death	0	1

*Some studies used more than one method.

definition of rurality was reported. The research quality assessment is reported in Table 1.

Objectives of the included articles

To explore or describe the 'good death' concept through the perspectives of rural residents was the objective of seven studies (Grant *et al.* 2003, Counts & Counts 2004, van der Geest 2004, Wilson *et al.* 2009a,

b, Viellette *et al.* 2010, Knight 2014, Biggs 2014). Seven studies (Felt *et al.* 2000, Arnaert *et al.* 2009, Grant *et al.* 2011, Gysels *et al.* 2011, Beckstrand *et al.* 2012, 2015, Devik *et al.* 2013, Joarder *et al.* 2014) implied the 'good death' by focusing on quality EoLC. The 'good death' was not the primary objective in the remaining three studies (Easom *et al.* 2006, Huy *et al.* 2007, Cruickshank *et al.* 2010) but was a point of comment by rural participants noted within the article text.

Methods of data collection

All eligible studies were qualitative in nature. Twenty-nine focus groups and 378 interviews were conducted; 245 written surveys were completed; eight clinical encounters were detailed and six communities were observed. Sample sizes ranged from four (Knight 2014) to whole communities (Counts & Counts 2004, van der Geest 2004, Easom *et al.* 2006, Joarder *et al.* 2014). With the exception of one urban–rural study (Knight 2014), all the included studies were classified as being solely rural in focus.

Participants

The exact number of participants is unknown as two anthropological fieldwork studies included whole communities (Counts & Counts 2004, Easom *et al.* 2006). Of the 751 identified rural participants, 84 were rural patients, 68 rural FCGs, 323 rural HCPs, 153 rural residents, 83 rural community leaders and 40 rural health administrators and policy makers. Of the identified informants, 20% were patients or FCGs and of these 76% were African. HIV/AIDS (considered a stigmatised disease) or cancer accounted for most terminal illnesses in Africa. All participants were adults and when reported, their ages ranged from 18 to 94 years. Participants over 80 years of age were interviewed in Canada (Biggs 2014), Bangladesh (Joarder *et al.* 2014) and Kenya (Grant *et al.* 2003). Of the 19 patients in developed nations, 17 had cancer, one dementia and one cerebral vascular disease.

Concept

All the eligible articles reported on the 'good death' from the perspectives or experiences of rural residents. The term 'good death' was used explicitly in eight titles (PNG [1], Africa [2], Britain [1], Canada [4]) and an additional six abstracts (USA [2], Africa [2], Bangladesh [1], Vietnam [1]). For those studies not using the exact term, all implied the 'good death' within the report or used an alternative term such as the 'ideal' death (Beckstrand *et al.* 2012, 2015), 'the

best scenario for one's own death' (Felt *et al.* 2000), an 'honourable death' (Huy *et al.* 2007), 'dying with dignity' (Grant *et al.* 2011), 'dying peacefully' (van der Geest 2004, Grant *et al.* 2011), dying 'the proper way' (van der Geest 2004) and 'facing death in a brave manner' (Devik *et al.* 2013). One study focused on the 'bad death' (Joarder *et al.* 2014). The 'good death' referred to the death event, the dying process, the meaning of death and the after-death concept.

The dominant theme, from both developed and developing countries was that a 'good death' is one that is peaceful, that is free of pain and without suffering. Other themes describing the 'good death' included a 'controlled' death (control over symptoms, place of death, decision-making, manner of death and to remain independent) (Felt *et al.* 2000, Counts & Counts 2004, Dilger 2008, Wilson *et al.* 2009a,b, Viellette *et al.* 2010, Knight 2014); a 'timely' death (Counts & Counts 2004) that is a death coming 'naturally and after a long and well-spent life' (van der Geest 2004, p. 899) and 'hopefully in my sleep' (Felt *et al.* 2000, p. 405) after having had opportunity to say goodbye to family; a 'dignified' death by maintaining identity, self-worth, integrity and control (Wilson *et al.* 2009a, Devik *et al.* 2013); a 'social' death such as to die within the community with family present (Wilson *et al.* 2009a,b) and a 'noble' death such as through enduring the situation (Grant *et al.* 2003, Devik *et al.* 2013). Two articles (van der Geest 2004, Knight 2014) acknowledged the difficulty of defining a 'good death' as it is dependent on individual interpretations, perspectives and priorities.

Despite the challenges of definition, the review team determined that rural residents identified five dimensions they considered important for facilitating a 'good death' – physical, emotional, social, spiritual and cultural dimensions.

Physical (pain and symptom management)

Good pain and symptom control was the overriding factor reported to ensure a 'good death'. Pain relief was central to maintaining quality of life through the dying journey, not only just for the patient but also the FCG (Cruickshank *et al.* 2010).

In both developed and developing communities, physical care also includes human touch (Grant *et al.* 2011, Biggs 2014), 'touching [wounds] helps put a smile on people's faces' (Ugandan nurse; Grant *et al.* 2011, p. 10). In contrast, western participants 'fear a technological death as opposed to a good death' (Felt *et al.* 2000, p. 401), while in Ghana, 'death was peaceful and no medical battle was fought to keep him alive' (van der Geest 2004, p. 902).

While acknowledging the importance of symptom control, participants in two studies (Cruickshank *et al.*

2010, Grant *et al.* 2011) highlighted the need for a holistic approach to the 'good death' including 'emotional, spiritual, social and practical care' (Grant *et al.* 2011, p. 1).

Emotional

Living well while dying (Viellette *et al.* 2010, Devik *et al.* 2013) and maintaining dignity, respect, self-worth, autonomy and possibly also a sense of humour were all reported as essential for facilitating a 'good death'. In order to maintain autonomy, 'the dying person needed to be lucid, to be able to think, and to have enough energy and mental alertness to share their thoughts and feelings' (Wilson *et al.* 2009b, p. 315). The distress of not respecting patients' wishes was voiced by a number of rural emergency room nurses who indicated that 'one obstacle to providing [quality] EoLC is not knowing the patient's wishes regarding the continuation of treatments or tests because of [their] inability to communicate' (Beckstrand *et al.* 2012, p. 16). Research participants from both developed and developing countries felt it was important to know the truth about their illness (Felt *et al.* 2000) so they could be 'at peace with their own death' (van der Geest 2004, p. 908), 'stop chasing [expensive] false hopes' (Grant *et al.* 2003, p. 161) and prepare for death; however, not all families want the patient to know the truth (Grant *et al.* 2003). Fear and anxiety were cited as impediments to peace (Devik *et al.* 2013).

Social

Most rural participants identified the importance of family and community. While a minority wanted to 'die alone, but only after having had closure with loved ones so that death would be peaceful' (Felt *et al.* 2000, p. 405), most rural residents in all regions and cultures said it was important to have family and significant people present because 'the togetherness of the family members makes you feel they love you and are not abandoning you' (Grant *et al.* 2003, p. 163). African participants talked of the important role that family and community plays after death in ensuring specific rituals are carried out. Acceptance of the death by family members and 'permission to die from loved ones [is] very important to a peaceful death' (Felt *et al.* 2000, p. 405).

Ensuring there is no unfinished business or unresolved personal conflicts and reconciliation is vital across rural/remote cultures:

Before one dies conflicts should be ended and enemies reconciled, debts should be paid and promises fulfilled. Someone who has been able to achieve this, is ready for his final departure. He is ... a peacemaker, a person who is respected by others. (van der Geest 2004, p. 908)

The place of death has significance with most rural informants wishing to die 'at home, which is the epitome of peacefulness, surrounded by children and grandchildren' (van der Geest 2004, p. 899) as 'the home or home community ... [is] the only place where the dying person [can] be close to the many people who have meaning for them' (Wilson *et al.* 2009b, p. 316). In Ghana, dying away from home is considered 'bad' and disgraceful; however, partial restoration can be achieved by 'bringing the dead body home' (van der Geest 2004, p. 909). Some participants considered these social elements a low priority and thus relatively unimportant (Knight 2014).

Spiritual

A spiritual dimension was identified as the opportunity to say goodbye (Counts & Counts 2004) and express values and priorities; finding meaning to life and death which can 'help to give a dying person hope' (Biggs 2014) and gaining a sense of dying well (Wilson *et al.* 2009b). Two theological studies (Knight 2014, Biggs 2014) placed the priority of spiritual and emotional peace (maintaining a sense of humour; sense of dignity; being at peace with God) ahead of physical and social care with opportunity to say 'goodbye' to significant people a higher priority than dying at home. Participants from Africa (Grant *et al.* 2003, van der Geest 2004) and Canada (Biggs 2014) remarked on the importance of religious rituals and how they 'experienced the support of spiritual care through spiritual practices such as singing hymns, reading scripture and Holy Communion' (Biggs 2014, p. 124).

One of the most important spiritual elements was the acceptance of death ... that could be reached through a process of dying well. For this state to occur, the dying person needed to find meaning in their life and also meaning in their daily experience. (Wilson *et al.* 2009b, p. 315)

Cultural

The influence of cultural beliefs and values was evident in most articles with rural Kenyan participants illustrating how 'powerful cultural traditions [make] it difficult for social needs to be met' (Grant *et al.* 2003, p. 163). Religion was found to be a component of cultural beliefs and values, with Christian religions most commonly identified (Grant *et al.* 2003, 2011, Counts & Counts 2004, van der Geest 2004, Knight 2014, Biggs 2014). However, in some developing countries, while Christianity has 'greatly influenced' (van der Geest 2004) the concept of the 'good' and 'bad' death, it has not replaced, but instead has been interpreted and applied to traditional beliefs (Grant

et al. 2003, 2011, Counts & Counts 2004, van der Geest 2004, Huy *et al.* 2007). In Vietnam (Huy *et al.* 2007), Papua New Guinea (Counts & Counts 2004), Bangladesh (Joarder *et al.* 2014) and Ghana (van der Geest 2004), the 'good' and 'bad' death concepts were aligned with the circumstances surrounding the death and afterlife, as these significantly impact on the health and well-being of the community, descendants and ancestors. The 'good death' is also one that does not disrupt the life and health of the community (van der Geest 2004). Rural residents in developed countries instead viewed the 'good death' in the light of a bio-medical model, placing greater emphasis on autonomy, the process of dying and minimising any sense of struggle. The afterlife provides the dying person with a 'hope of something more to come' (Biggs 2014). The culture of 'not complaining' was reported in both developed (Devik *et al.* 2013) and developing countries (Grant *et al.* 2003). 'Poverty shaped how people died' (Grant *et al.* 2011, p. 5) in rural sub-Saharan Africa.

Context

The overriding theme is that rural residents prefer to die at home, and when this is not possible then in their rural community (Wilson *et al.* 2009a,b, Viellette *et al.* 2010, Biggs 2014). 'Some would prefer to have less care and fewer services' (Viellette *et al.* 2010, p. 163) than leave their community.

Wilson *et al.* (2009a,b) reported that rural residents recognised unique challenges of providing EoLC in rural areas. These include distance (Grant *et al.* 2003, 2011, Wilson *et al.* 2009a,b, Cruickshank *et al.* 2010), lack of services and personnel (Wilson *et al.* 2009a,b, Viellette *et al.* 2010, Devik *et al.* 2013), emotional and physical isolation for independent HCPs (Arnaert *et al.* 2009), lack of access to specialist palliative care (Wilson *et al.* 2009a,b) and the distress of caring for close friends and colleagues (Arnaert *et al.* 2009, Beckstrand *et al.* 2012, 2015). It was obvious there are many advantages as well, such as the deep concern of community for its members (Wilson *et al.* 2009a,b). The benefits include personal attention (Arnaert *et al.* 2009, Wilson *et al.* 2009a,b, Beckstrand *et al.* 2012, 2015, Biggs 2014) and 'the friendliness and closer-knit nature of a rural setting ... the increased level of concern persons have for one another, and the resources available' (Biggs 2014, p. 139). The rural environment was 'identified as a much quieter and contemplative setting'; however, 'dying outside the rural community is a common and highly problematic issue for rural people' (Wilson *et al.* 2009b, p. 317).

Discussion

Principal findings

This scoping review identified 20 articles describing the concept of the 'good' rural death from the perspectives of a cross-section of rural residents including rural patients with a life-limiting illness, rural family members/informal caregivers, rural HCP and the wider rural community; and identified gaps in the literature for areas for future studies to better understand the concept of 'good death' for rural people. Both developed and developing countries were represented, with most data coming from North America and sub-Saharan Africa.

Despite the challenges of rural definition, and notwithstanding differences in rural locations, cultural perspectives, priorities and expectations, this scoping review found similarities and differences in perspectives with those reported in urban studies. The four elements (physical, spiritual, emotional and social) considered essential by the WHO (2015) to facilitate a 'good death' were identified as pain/symptom control, dignity, preparedness, autonomy and community and are consistent with urban findings (Holdsworth 2015, Raisio *et al.* 2015, Davies *et al.* 2016, Meier *et al.* 2016). However, the context and priority placed on each factor differed between included studies and from urban perspectives (Kirby *et al.* 2016).

While death is a normal end to life (WHO 2015), one could argue that many deaths are not entirely 'good' due to the nature of the illness (Holdsworth 2015), the age of the dying person (Counts & Counts 2004, van der Geest 2004, Huy *et al.* 2007, Dilger 2008) and individual persons' perspective. The goal should be to achieve the 'best possible death given the circumstances' (Holdsworth 2015) or a 'good enough' death (McNamara 2004) to reflect a death that satisfies realistic expectations (Raisio *et al.* 2015).

Locality was also identified as a critical element, with deaths and dying ideally to be connected with the rural/remote community. The literature increasingly reports that place of death is one measure of a contemporary 'good death' as supported by the majority of articles in this review; however as Biggs (2014) suggests, place is only one factor of importance and not necessarily the main one for all people (Hoare *et al.* 2015, Davies *et al.* 2016, Rainsford *et al.* 2016). If it is not possible to die at home surrounded by family then it is important to die within the rural community.

Knight (2014) suggests that the quality of dying is subjective and dependent on whose perspective one is using. Family and friends are thought to perceive a 'good death' has occurred when 'timing, symptom

management and support come together successfully' (Adamson & Cruickshank 2013). Unfortunately due to heterogeneity within a small number of articles, it was not possible to compare the different perspectives of rural informants or to compare with any confidence the views of respondents in rich and poor countries; however, what was apparent is the different expectations as in Kenya one is focused on the 'basics of life' (Grant *et al.* 2003), whereas in Kansas, one fears 'a technological death' (Felt *et al.* 2000). Good pain control is highly ranked in EoLC (Byock *et al.* 2009); however, the difficulty of patients in developing countries accessing basic drugs such as morphine was highlighted.

Wilson *et al.* (2009a,b) found that rural people identify themselves as 'rural' with unique needs from urbanites; and dying in a rural area was reported to have elements that either enabled or obstructed a 'good death'. These elements included distances, isolation, limited services and personnel, strong sense of community and resilience. As such, the findings of this scoping review are diverse, rich and informative, but not uniform across the countries or studies.

Study meaning

While adding to rural end-of-life knowledge by identifying and synthesising the current literature, this scoping review highlights the paucity of information relating to the 'good' rural death especially from the perspectives of dying patients and their family members. Only 20% of the rural informants identified in this review were patients or FCGs, with the majority having a cancer or HIV/AIDS diagnosis, yet 'to remain socially relevant, EoLC ideally must reflect the needs of (all) the dying individuals ... within diverse cultural and geographic areas' (Cottrell & Duggleby 2016, p. 26). It is not just the rural voice that is as yet unheard and unrecognised as unique, but those with a non-malignant diagnosis as well as minority groups within rural communities. However, the findings of this review may be used to inform future researchers and policy makers of the 'quiet' rural voice and guide future planning and development of rural EoLC.

Limitations

This scoping review had limitations in the completeness of the review and the quality of identified studies. Studies not including the selection criteria wording in the title, abstract or keywords may have been missed; however, electronic searching was augmented by hand-searching journals and reference lists. A potential bias in data extraction, synthesis and analysis is

also possible due to most authors being Palliative Medicine Specialists and/or General Practitioners and all citizens of western nations. Currently, there is no broad consensus on scoping review reporting guidelines, which potentially limits the report.

A more serious limitation is the lack of homogeneity and consistency in the 'rural' definition. This meant that studies reported on a variety of rural locations and rural populations. Extremely remote areas were not studied, although some of the rural peoples studied may have been in extremely remote areas with limited health services. Equally significant is the diversity in cultural perspectives. While this is a strength in that it presents a wide range of perspectives on the 'good death', it is also a limitation as it reduces the ability to examine the specific understanding of the 'good death' within diverse cultures.

The objectives of some studies were not 'good death' focused, a factor that increased the risk of our misinterpretation of the findings. Other limitations include small rural sample size; inability to determine perspectives of rural informant subgroups; limited generalisability; recruitment biases; a predominantly Christian or traditional cultural viewpoint; and variations in terminology.

Conclusion

Previous studies have found that rural residents consider themselves rural and as such have unique EoLC needs and challenges. The existence of 20 papers indicates that rural perspectives on the 'good death' are important to consider. The current literature is heterogeneous and thus insufficient to confidently generalise the perspectives of rural residents on the 'good death' and what it means to die well and to avoid dying badly. Rural residents of both developed and developing nations want a dignified death; however, this is largely subjective and thus open to interpretation based on personal, cultural, social and religious perspectives that could be highly individualised, family contextualised or rural community based. Clearly, given the importance of a 'good death', there is a need for further studies, both qualitative and quantitative, to elicit rural person, especially dying patients and family caregivers' perspectives.

Author contribution

SR was responsible for conception; design; acquisition, analysis and interpretation of data; drafting, revising and final manuscript. RDM, DW, NJG contributed to review design. All co-authors contributed to analysis and interpretation of data; revising the article critically

for important intellectual content; and final approval of the version to be published.

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Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review

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Abstract

Background: End-of-life care must be relevant to the dying person and their family caregiver regardless of where they live. Rural areas are distinct and need special consideration. Gaining end-of-life care experiences and perspectives of rural patients and their family caregivers is needed to ensure optimal rural care.

Aims: To describe end-of-life care experiences and perspectives of rural patients and their family caregivers, to identify facilitators and barriers to receiving end-of-life care in rural/remote settings and to describe the influence of rural place and culture on end-of-life care experiences.

Design: A systematic literature review utilising the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Data sources: Four databases (PubMed, CINAHL, Scopus and Web of Science) were searched in January 2016, using a date filter of January 2006 through January 2016; handsearching of included article references and six relevant journals; one author contacted; pre-defined search terms and inclusion criteria; and quality assessment by at least two authors.

Results: A total of 27 articles (22 rural/remote studies) from developed and developing countries were included, reporting rural end-of-life care experiences and perspectives of patients and family caregivers. Greatest needs were informational (developed countries) and medications (developing countries). Influence of rural location included distances, inaccessibility to end-of-life care services, strong community support and importance of home and 'country'.

Conclusion: Articulation of the rural voice is increasing; however, there still remain limited published rural studies reporting on patient and family caregivers' experiences and perspectives on rural end-of-life care. Further research is encouraged, especially through national and international collaborative work.

Keywords

Palliative care, end-of-life care, rural, family, patient, caregiver, systematic review

What is already known about the topic?

- Quality end-of-life care is the right of every person regardless of where they live.
- Rural areas are distinct and as such need to have special consideration.
- Gaps exist in rural end-of-life care research including studies reporting the experiences and perspectives of rural patients and their family caregivers.

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What this paper adds?

- Rural patients and family caregivers experience unique challenges and benefits of rural living.
- The greatest needs of patients and family caregivers were informational (developed countries) and medications (developing countries).
- Influences of rural location on end-of-life care included distances, inaccessibility to end-of-life care services, strong community support and importance of home and 'country'.
- Articulation of the rural voice is increasing, especially in North America.

Implications for practice, theory or policy

- Further research is encouraged to gain the experiences and perspectives of rural patients and family caregivers, especially through national and international collaborative work.

Introduction

Quality end-of-life care is considered the right of every dying person regardless of where they live.¹ Quality end-of-life care is patient-centred care where patients and their primary carer, often a family member, are encouraged to participate, if not direct, care decisions as 'to remain socially relevant, end-of-life care ideally must reflect the needs of the dying individual within diverse cultural and geographic areas (p. 26)'.² Rural areas are distinct and as such need to have special consideration. It is imperative to take full account of the rural experiences and perspectives of those persons and families receiving care to ensure optimal rural end-of-life care.³

Wilson et al.^{4,5} suggest rural people define themselves as 'rural' and as different from urbanites; however, gaining the rural voice is challenging. One significant obstacle in finding a common 'rural' voice is the lack of an internationally agreed rurality index, meaning that results across studies and across countries are not necessarily comparable. Hart et al.⁶ report 'rural' to be a 'multifaceted concept (p. 1149)'⁶ dependent on context. As such, there are inconsistencies in definitions of 'rural' based on population size, density or demographics; or distance from urban centres and services; or as a specific 'culture'.⁶ An additional research challenge is the difficulty of recruiting terminally ill patients and their family caregivers to research⁷ which is magnified by the often small cohort of such patients within small rural communities.

Previous rural palliative care reviews^{3,8} report that rural research is focused on programme planning, integration and evaluation; education; finances; and needs assessments,⁹ with professional providers or administrators as the prime informants. In 2009, Robinson et al.⁸ published a systematic review (studies published from 1996 through 2007) identifying major gaps in the literature including a lack of studies describing end-of-life care through the experiences and perspectives of rural patients and family caregivers and the influence of rural culture on these experiences. Future researchers were encouraged to seek these perspectives in order to provide 'strong evidence to inform

palliative care policy and service development in rural settings (p. 253)'.⁸

The objectives of our systematic review were to search the literature since January 2006 and to (1) explore the end-of-life care experiences and perspectives of rural patients and their family caregivers, (2) identify facilitators and barriers to receiving end-of-life care in rural/remote settings and (3) describe the influence of rural place and culture on end-of-life care experiences. This information will add to the general knowledge on rural/remote end-of-life care and may further assist rural policymakers and healthcare professionals (HCPs) in ensuring that rural palliative care services are relevant to those receiving such care.

Method

This systematic review was undertaken utilising the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.¹⁰

Literature search

In January 2016, four electronic databases (PubMed, CINAHL, Scopus and Web of Science) were searched using the following keywords and Medical Subject Heading (MeSH) terms: ('palliative care' OR hospice OR 'terminal care' OR end-of-life OR 'end-of-life care') AND (Rural OR Remote) AND (patient OR family OR carer OR caregiver) AND (perspective OR experience OR opinion OR view). A date filter of January 2006 through January 2016 was applied with this including an overlap with the 2009 systematic review⁸ to ensure that previously submitted but unpublished studies were included. Two articles (2006 and 2007¹¹) were identified and considered; however, as the 2006 article was included in the previous review, it was excluded.

The reference lists of all included studies were scanned for additional articles. Recent issues (July 2014–May 2016) of six relevant journals (*Palliative Medicine*, *Journal of*

Palliative Medicine, Journal of Pain and Symptom Management, Palliative and Supportive Care, Australian Journal of Rural Health and Journal of Rural Health) were handsearched by the first author (S.R.).

Selection criteria

Studies were assessed against predetermined inclusion criteria and included rural or remote residents (no standardised definition of rurality was used); participants were receiving palliative or end-of-life care for malignant or non-malignant illnesses; data pertained to patient or family caregivers' experiences or perspectives on end-of-life care collected from interviews or surveys. Both qualitative and quantitative studies were included. No age filter was applied. Only published international English language, peer-reviewed research articles were considered. Articles that included urban and rural data were included providing the rural data were clearly identifiable. One author¹¹ of a retained study was contacted to verify participants were rural.

Rejected studies were either clearly irrelevant or those that addressed the topic in general but failed in one or more of the inclusion criteria. Ethics approval was not required for this review of published literature.

Screening of papers

The search identified 450 potential papers. After duplicates were removed, 220 titles were screened independently by S.R. and second author (R.D.M.) against the inclusion criteria. This identified 105 papers for consideration. At least two authors screened each abstract, and when necessary, full texts. Differences were discussed via email and resolved by consensus.

Appraisal and data extraction

Quality assessment of each retained article was made by S.R. with verification shared independently among the five co-authors. Quality was determined on aspects relevant to rural patient/family caregiver perspectives on end-of-life care and was not necessarily an assessment of the study per se, which resulted in some high-quality studies receiving a lower score. All studies were rated to be of low, medium or high quality based on a simple scoring system described by Gomes et al.¹² and modified by S.R. to account for the rural patient/family caregiver focus. As such, two additional items were included as follows: (1) clarity of rural definition and (2) validity of informant (first hand/prospective=2, retrospective family caregiver=1). Only studies rated high or medium were included in this literature review.¹³

Data from each retained article were extracted and tabled by S.R., according to pre-defined categories (see

Table 1). Critical review of full texts against data extraction was shared and undertaken independently among the five co-authors.

Data synthesis

Study findings were coded into four categories: (1) patient perspectives, (2) family caregivers' perspectives, (3) facilitators and barriers and (4) influence of rural place and culture. Each category was analysed thematically and reported descriptively. Due to heterogeneity, a meta-analysis was not possible. Differences in quality assessment, data extraction and synthesis were discussed by email and resolved by consensus.

Results

Overview of findings

Of the initial 450 articles identified and screened, a total of 27 articles^{11,14–39} reporting on 22 separate studies met our inclusion criteria (see Figure 1 for PRISMA flowchart⁴⁰). In total, 19 studies (86%) were conducted in developed countries: Canada (7),^{14,15,22–24,30–32,35,36} United States (5),^{17,26,33,34,37} Australia (2),^{18,27} Scotland (2),^{16,29} Norway (2),^{19–21} and England (1);¹¹ and 3 in sub-Saharan Africa including Malawi (1),²⁸ Cameroon (1)³⁸ and one multi-nation study (Malawi, Kenya, Uganda).²⁵ Three studies focused on indigenous populations (Australia,¹⁸ Canada³⁰ and United States³³). Rural definitions, locations and degree of isolation between studies were heterogeneous; four studies^{18,25,29,31,37} included remote locations. Studies were published between 2007 and 2015; no published articles were identified in 2016. In all, 18 studies were qualitative, 3 quantitative,^{14,15,17,24} and 1 mixed-methods.^{31,32} Qualitative methods were described as ethnographic (4),^{18,25,33,35,36} phenomenological (4),^{19–21,30,37} grounded theory (1),¹¹ and non-specified (9). Studies collected data from interviews (face-to-face (17), phone (1)^{22,23}); surveys (written (3),^{17,24,31,32} phone (1)^{14,15}); focus groups (1),³⁴ and analysis of personal daily journals (1).³⁹ Sample size ranged from 5^{19,20} to 672.¹⁷

Participants included those with cancer and non-cancer diagnoses; active and bereaved family caregivers. A cross section of participant ages was found, with one paediatric study³⁸ and eight studies where all patients (participants or deceased) were elderly (≥ 60 years).^{11,16,17,19–23,26,33} Patient and family caregiver characteristics are reported in Tables 2 and 3.

Three studies explored the experiences and perspectives of patients only;^{16,19–21} eight of family caregivers only;^{14,15,17,24,26,27,30,37,39} eight of both patients and family caregivers;^{11,18,22,23,28,29,31,32,38} and three were community-focused studies including family caregivers.^{25,34–36} One study compared urban and rural perspectives,^{14,15} one the congruence between patient and family caregiver views,³⁸

Table 1. Summary of included studies.

	Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Brazil et al. ^{14,15} Canada	To compare experiences and support needs of urban and rural FCG, to determine importance of and degree of unmet needs Mixed geographical study	140 FCGs (included 70 rural FCGs; 44 active + 26 bereaved) Recruitment: identified by single PC service RR: 29%	Rural = area outside urban (communities $\geq 30,000$ residents); rural and isolated communities in Northeastern Ontario	Cross-sectional telephone survey; demographics; modified validated instruments: CBS-EoL, MSPSS, ECOG; catalogue services available, 25-item carer support need instrument + 5 questions relating to service delivery; analysis-descriptive and inferential statistics; evaluation by location (urban vs rural)	Most important needs for urban (U) + rural (R) were informational; rural FCG: greater unmet tangible needs ($z = -2.59$, $p = 0.01$); emotional support U = R; care perceived as largely accessible to patients' changing needs for U + R respondents (mean accessibility score: 1.7, SD = 0.7 and 1.9, SD = 0.09, respectively, $t80 = 1.31$, $p = 0.20$, 95% CI: 0.12–0.58, $d = 0.29$) Themes: 1. Steadfastly living life; making most of time available, maintaining normality, take life as it comes, not giving up, not becoming a burden on family, maintaining identity and value; one participant indicated no other choice but carry on as normal 2. Family support and separation: support of and concern for family, planning so no unfinished business, anticipated loss, preparation for separation 3. Trust in professionals: some wanted information to make decisions, others content to follow advice without questioning, knowing who to contact for support	Low response rate, recruitment through palliative care service, rural residency diverse, evaluation of single service, bias as over-burdened carers may not have participated, survey directed towards existing service delivery Small sample size, single service recruitment	High
Dale and Johnston ¹⁶ Scotland	To explore and interpret the concerns of patients with inoperable lung cancer, to inform specialist palliative care nursing practice Rural study	Six patients Recruitment: purposive sample; identified by lung cancer nurse specialist Disease: lung cancer	Rural community in Scotland	Qualitative, interpretative constructivist approach, semi-structured exploratory ITVs, thematic analysis Interviewer: researcher nurse, unknown to participants	1. Steadfastly living life; making most of time available, maintaining normality, take life as it comes, not giving up, not becoming a burden on family, maintaining identity and value; one participant indicated no other choice but carry on as normal 2. Family support and separation: support of and concern for family, planning so no unfinished business, anticipated loss, preparation for separation 3. Trust in professionals: some wanted information to make decisions, others content to follow advice without questioning, knowing who to contact for support	Small sample size, single service recruitment	High
Darar et al. ¹⁷ USA	To assess quality of the dying process, identify opportunities for improvement and support strategies for targeting at-risk families Rural study	672 NOK (bereaved) Recruitment: identified from single integrated rural health data, mailed survey, opt-out Diagnosis: All; ESRD, CHF, COPD oversampled RR: 25%	Central and NE rural Pennsylvania	Written survey contained QoDD instrument, GAD-7, PHQ-8, modified Toolkit of Instruments to measure EoLC Quantitative analysis-descriptive, comparisons (chi square, linear regression, p values)	In general, high satisfaction with care teams and providers, lower QoDD experience associated with dying in hospital, receipt of conflicting information, poor co-ordination between HCPs and confusion around which doctor is in charge, NOK depression and anxiety, prolonged illness	Poor response rate, single integrated health system, limited diversity of participating NOK, up to 12 months bereavement (potential recall bias), predominantly White females ≥ 60 years, NOK not necessarily rural	Medium
Dembinsky ¹⁸ Australia	To explore perceptions and use of palliative care services by examining lived experiences of women with breast cancer Rural/remote study	10 patients; 4 FCG, 6 non-carer family members, 5 HCPs Recruitment: Regional Medical Services and Indigenous Women's Support Network Diagnosis: breast cancer	Yamatji country, mid-west region of Western Australia; scarcely populated with few small towns	Medical anthropology, informal ITVs, grounded theory and ethnographic immersion, coded, thematic analysis Interviewer: non-treating researcher	Preparation – to gather family, distribute possessions, set affairs in order, say goodbye To die in country – if one dies outside their country, the spirit is doomed to roam eternally, preventing completion of life-death-life continuum Specific ceremonies and practices surrounding death, for example, ritual cleansing of physical death place inhibits uptake of inpatient care Opportunity for family to remain close to the dying member is important for the surviving family Hospital environment not culturally appropriate Home-based PC limited due to distances, mobile service visit 1–2 times/months	Small sample size, specific cultural issues, only female participants with breast cancer, recruited through single health service, snowballing of participants	High

Table 1. (Continued)

Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Devik et al. ¹⁹ Wilk et al. ²⁰ Norway	To explore and understand lived experience of older cancer patients living alone Rural study 5 older patients, living alone; (3 women, 2 men, aged 71-79); receiving outpatient and life-prolonging chemotherapy Recruitment: identified through oncology polyclinic; initial contact by nurse Diagnosis: incurable cancer RR: 50%	Communities (mountain and coastal), low population density, population: 920-7775	Qualitative; phenomenological hermeneutical approach; narrative ITVs Interviewer: Non treating researcher	Enduring by keeping hope alive, becoming aware that you are on your own, living up to expectations of being a good patient and being at risk of losing one's identity and value Rural distance requires commuting (stressful commuting, being exhausted)	Small sample, recruitment bias (polyclinic), cancer	High
Devik et al. ²¹ Norway	To illuminate and interpret the meaning of receiving home nursing care when being old and living with advanced cancer Rural study 9 older patients (5 women, 4 men); 71-92 years Identified by oncology and cancer care nurses Diagnosis: cancer RR: 50%	A territorial area with scattered settlements, some distance from a densely populated area and where natural resources are the basis for industry and outdoor activity; participants resided where population: 268-5089 (mean 5 inhabitants/km ²)	Qualitative, phenomenological hermeneutical approach, narrative ITVs Interviewer: researcher	Receiving HNC means to continue a familiar and meaningful life Three themes: being content with what one gets (a wish to age in place), falling into place and losing one's place Strong place attachment (physical, social, autobiographical); suggests rural advantageous healthcare environment (comfort, security, identity)	Small sample, cancer, recruitment by home care nurses Strength: researcher reflexivity acknowledged	High
Duggleby et al. ^{22,23} Canada	To explore the context and experience of significant transitions experienced by older rural persons receiving palliative home care and their families and to develop a substantive theory of transitions in this population Rural study 6 older patients; 10 bereaved FCGs Recruitment: purposive sample, identified by PC co-ordinator Diagnosis: advanced cancer	3 rural health regions in a western Canadian province classified as one of the most 'rural' Canadian provinces	Grounded theory, open-ended individual audio-taped ITVs (patients – face-to-face; FCG – telephone) Interviewer: researcher	'Navigating Unknown Waters' describes transitions faced by older rural palliative patients and their families due to rural isolation, lack of information, limited accessibility to services, individual values and community connectedness FCGs experienced multiple significant transitions including significant changes in their own physical and mental health	Small sample, cross-sectional survey so point in time data, variable geographic location, cancer only	High
Duggleby et al. ²⁴ Canada	To determine factors influencing the hope of rural women caregivers Rural study 122 FCG (active) Recruitment: survey and invitation mailed to cancer patients (to forward to primary female carer) Identified by cancer registry with 60% not receiving services Diagnosis: cancer RR: 15.6%	Home address with a rural post code, Saskatchewan $\approx$ 9999 residents, Alberta <55,000	A cross-sectional prospective correlational design, written survey, quantitative analysis (SPSS)	Mental health, well-being and self-efficacy were predictors of hope; physical health was not significant Guilt lessens hope and increases burden, depression and family distress Higher hope scores associated with higher mental health scores, lower perceptions of loss and grief scores and higher scores in their ability to deal with difficult situations Rural women caregivers had low physical and mental health scores compared to US population norms (<25th percentile)	No measure of hope over time, small sample, small response rate, bias in recruitment – self-accepted invitation, cancer	Medium

(Continued)

Table 1. (Continued)

	Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Grant et al. ²⁵ Uganda, Kenya, Malawi	To describe patient, family (and local community) perspectives on the impact of three community-based PC interventions in sub-Saharan Africa Rural study	33 patients; 27 FCGs (17 active, 10 bereaved); also 29 leaders + 61 staff Recruitment: identified by PC team Diagnosis: advanced illness	Uganda: mobile PC service 120 km from Kampala includes fishing communities on Lake Victoria Kenya: rural, 240 km from Nairobi Malawi: peri-urban districts of Blantyre	Rapid assessment evaluation, qualitative, photographic ethnography, rapid evaluation field studies, ITVs with key informants, direct observations of clinical encounters, (review of local PC information), data triangulation, thematic analysis Interviewer: researcher, interpreter, PC worker present	Patients valued being treated with respect, maintaining dignity, integration of symptom control with practical, emotional, financial and spiritual care assisted patients to remain home, mobile phones enabled rapid access to clinical and social support networks, PC service (nurses and volunteers) important	Service evaluation, selection bias, small samples Palliative care worker present → may inhibit honest responses	Medium
Hansen et al. ²⁶ USA	To describe the experiences of FCGs with formal and informal care at the end-of-life for dying older adults Rural study	23 FCG (bereaved) Recruitment: purposive sample, identified by funeral director and hospice staff. Invitation mailed 2–12 months after the death Diagnosis: cancer and chronic illness	Rural, agricultural Pacific Northwest county; average of 11.2 people per square mile	Generic, qualitative, exploratory design; semi-structured, open-ended ITVs; purposive sampling; thematic analysis Interviewer: researcher	Rural setting: Benefits Neighbours, friends, volunteers offered household help and respite care Formal care providers often known personally Flexibility in organisational support, more creative Support from church members Challenges Limited resources for continuity of care Geographical service boundaries → limited availability, greater travel distances Lack of knowledge about EoLC by paid caregivers FCG stress	Small sample	High
Hatcher et al. ²⁷ Australia	To document carer perceptions of patients' transitions from community to hospital-based palliative care Rural study	6 FCGs (active) Recruitment: on admission to PC service Diagnosis: cancer	Rural community: not described	Qualitative, semi-structured ITVs, first ITV at time patient transferred to hospital, second ITV 3 months later, coding, thematic analysis Interviewer: non-treating PC service staff	Transfer to hospital occurred at a crisis point and not dissatisfaction with home-care service, experiences mostly positive Decision to transfer initiated and led by FCG – inability to provide optimal care; physical difficulties, patient pain and anxiety Smooth transition to community hospital due to good communication and continuity of care by PC nurse Hospital care – mostly satisfied; personal, treated as individuals, compassionate, safe and convenient to visit Negative aspects related to pain, interventions, communication and sense that hospital inferred impending death	Small sample, single PC service, self-selection, cancer, distance to hospital not reported	Medium

Table 1. (Continued)

	Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Herce et al. ²⁸ Malawi	To evaluate PC programme outcomes, to understand PC needs, knowledge and preferences with the aim of service improvement Rural study	36 patients (included 9 dyads), 11 FCGs (active) Recruitment: on admission to PC programme treatment clinics Diagnosis: Kaposi sarcoma, HIV, cancer	Neno district, (population 130,612) isolated rural area	Rapid evaluation method (REM); chart review Structured and open-ended ITVs, thematic analysis 9 joint ITVs Interviewer: Study investigators, interpreter and HW present	Greatest needs were financial (income and food), high prevalence of pain (64% moderate to severe), 75% of patients received psychosocial support from family Patients' preferred place of care home 46%, community facility 30%, hospital 24%, FCG: 46% FCG: felt obligated, some volunteered. Time commitment – ADLs, medication, emotional support, symptom care, transport Patient self-care coping strategies included Maintaining normality (goal setting, taking a break, independence, remain home) Preparing for death (what to expect, funeral planning, saying goodbye) Support from family and friends (physical and emotional), support for family often lacking Physical (symptoms, financial, aids to house) Emotional (acceptance, being positive, control, choice, hope, religion, peers) Support from HCP (home help, out of hours care)	Small study, specific cultural issues (while this study is generalisable to sub-Saharan Africa, it is not necessarily generalisable in the context of this review)	Medium
Johnston et al. ²⁹ Scotland	To understand patient and carer experiences of EoLC, to explore self-care coping strategies Rural and remote study	20 patients, their main carer (and their HCP) Recruitment: purposive sample, PC community nurse Diagnosis: advanced cancer	Rural and remote areas in Highlands and West of Scotland	Qualitative: 53 in-depth, unstructured serial ITVs (2 weeks apart), triangulation, thematic analysis 4 joint ITVs Interviewer: not specified		Small sample, recruitment bias, cancer only	Medium
Kelly et al. ³⁰ Canada	To understand cross-cultural hospital-based end-of-life care from the perspective of bereaved First Nations family members Rural study	10 recently bereaved aboriginal family members Recruitment: convenience sample, lived near health centre where family member died Diagnosis: not specified	A rural town in Northern Ontario with a catchment of 23,000 Ojibway and Cree aboriginal patients	Phenomenological semi-structured ITVs, crystallisation and immersion techniques; triangulation and member-checking methods Interviewer: nurses + research assistant, not involved in care	Cross-cultural care at the time of death is challenging Service delivery and communication strategies must meet cultural and family needs Respect (respectful directness), communication, appropriate environments (e.g. space to accommodate a larger number of visitors) and caregiving were important to participants for culturally appropriate palliative care First Nations family members described palliative care as a community and extended family experience Generally, relationships with nurses and the care the nurses provided were positive experiences	Small sample, single service, specific culture, only English-speaking families recruited	Medium

(Continued)

Table 1. (Continued)

Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Lockie et al. ³¹ Pesut et al. ³² To investigate the experiences of rural cancer patients and their FCGs, who commute to an urban cancer centre for palliative care Rural study	15 patients and their FCGs Recruitment: attending regional cancer centre, identified by researcher, approached by volunteer Diagnosis: advanced cancer	South central region of British Columbia, rural and remote communities, outside a major urban centre, population <10,000, mountains with winter snow and ice Population density 3.4 people/km ² , average length of commute 177 km (one way)	Mixed methods: semi-structured ITVs and written questionnaire, coding, iterative process, themes and subthemes Interviewer: research assistant	Benefits of rural living: environment, privacy, community support, friends, fundraisers. Intangibles of good health-happiness, contentment, peace Challenges of commuting long distances (weather, road conditions, break downs, access to mobile phone coverage), costs of fuel and accommodation, travel was added financial burden (costs) and time lost (work, family and community responsibilities) Positives of attending cancer centre – compassionate care, encouragement Commuting: 'making it work' Planning and preparation, well organised, sufficient pain medication, routine, timing of appointments Dealing with unfamiliar territory The toll of commuting – financial, time, FCGs' own health Making the best of it – utilising time well (errands, shopping, visit friends)	Small sample size, cancer patients	High
Mixer et al. ³³ USA To describe generic (folk) factors that healthcare workers can apply to provide culturally congruent end of life care Rural study	6 key informants (patients with life-limiting illness and/or their FCG (active + bereaved)) = 11 participants in total (9 general informants (HCP/pastor)) Recruitment: hospice workers and pastors Diagnosis: Life-limiting illness	Rural setting – East Tennessee region of rural Appalachia – a region medically underserved, with 19% living below the poverty line	Qualitative ethnographic methodology, semi-structured open-ended ITVs, thematic analysis Interviewer: principal investigator and/or trained students	Dignity through respect of folk custom, beliefs and faith and integration of folk care (e.g. folk remedies) into EoLC Spiritual care highly valued, faith fundamental to transition through EoLC Diversity in support provided by church members Family care at EoLC essential for culturally congruent care – at home, quality family time, however, burden of care → family cohesion or conflict Expect HCP to demonstrate trusting and caring behaviour No paediatric palliative care service Palliative care often misunderstood Symptom management accepted, however, service often declined due to belief PC is contrary to continuing curative care or associated with stigma of death Some patients preferred to stay in hospital than return home	Small sample size, specific cultural group within specified region, self-reported as Christian, selection bias	Medium

Table 1. (Continued)

Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Ostertag and Foreman ⁴ USA	To describe baseline community demographics and resources, to start a community inquiry into concerns at EoL by exploring the opinions and experiences of community members and HCPs Rural study	19 family members of patients who had died with (13) or without (6) hospice services. (53 HCPs, 9 hospice volunteers) Disease: > 50% cancer or heart disease	Hancock county, rural community	Focus groups, transcribed, thematic analysis	Family member's pain, physical symptoms and anxieties well-managed regardless of hospice or non-hospice status Poor physician communication common Many non-hospice FCG expressed the wish that hospice-type services had been offered to them, for example, assistance to facilitate a home death Those not enrolled were mainly chronic non-cancer patients; families were unprepared for terminal phase and death Appreciated primary care physicians who maintained a presence until the end, some were 'invisible' once cure no longer possible Those who had used hospice were appreciative and would recommend it to others	Small sample, single county Medium
Payne et al. ¹¹ UK	To describe the experiences of patients and carers of EoLC in community hospitals Mixed geographical study	18 elderly patients (≥65 years) and their FCGs (n=11) Recruitment: hospital nurses Diagnosis: cancer or advanced condition	4/6 sites were rural 3 small GP-led and 1 medium shared – care hospitals in small towns or rural areas	Semi-structured ITVs (8 joint ITVs), grounded theory, open coding, thematic analysis 8 joint ITVs (5 at home after respite, 3 in hospital) Interviewer: researcher, relationship to participants not specified	Rural community hospitals Flexibility Local (easy visiting) Personal care Community hospitals are acceptable for EoLC	Small sample, recruitment bias, 8 joint ITVs, 2/3 were retirees not 'rural locals' High
Pesut et al. ^{35,36} Canada	To gain understanding of the values informing and responsibilities that support good palliative care from rural participants' perspectives Rural study	95 rural residents including 25 FCGs identified by 'champions' Recruitment: purposive /snowballing, identified by community PC champions Diagnosis: not specified	4 rural communities in Western Canada population <10,000, located at least 3h by car from specialist palliative care treatment centre	Ethnography 51 days of field work, over 2 years, 95 semi-structured ITVs and 74h of direct participant observation. Thematic analysis Interviewer: university students	Core values of Families experienced meaning in caring with satisfaction outweighing the burden; responsibilities include providing, managing and co-ordinating care and advocacy Pain and symptom management a priority with expectation professional support available. The degree of symptom control shaped perception of quality of dying Knowing and being known – advantages and disadvantages as illness trajectory and grief were public events with loss of anonymity Being present and available – FCG needed on-site support not just a phone call Community and mutuality especially tangible support such as fundraising, home renovations, meals. Often those participants who were 'givers' to the community received the highest amount of support Families, HCP and administrators need to work together Remote healthcare decisions can severely undermine local capacity causing fragmentation in already underserved communities	Single region, snowballing recruitment bias, no indication if FCGs are active or length of bereavement High

(Continued)

Table 1. (Continued)

Purpose	Informants/recruitment	Rural definition	Methodology	Findings	Limitations/bias	Quality
Revier et al. ³⁷ USA	To explore the meaning of hope for the FCG in the context of end-of-life care, identify which nursing actions influence hope Rural study	FCG (n = 6); currently caring or had cared within previous 6 weeks Recruitment: identified by hospice programme nurses return consent by mail to researcher Diagnosis: not specified	Rural, Midwest USA	Phenomenological; two time-point dialogical engagement (hospice enrolment and 4–6 weeks bereavement); data analysis: extraction-synthesis, heuristic interpretation Interviewer: researcher	Four interconnecting themes as follows: Engaging, strengthening and maintaining connections Easing of self Finding meaning in the situation Acceptance Hope for FCG assists navigation through the caregiving experience, finding positive meaning within the situation and moving towards acceptance of the situation and healing Hope supported through relationship with nurses and information	Small sample, gatekeeping, recruited by nurses Medium
Tamannai et al. ³⁸ Cameroon	To understand the needs of patients and their families visited by a children's PC nurse in Cameroon and to identify aspects of the service that can be improved Rural study	3 patients (14, 9 and 10 years); 7 FCGs (3 mothers, 2 fathers, 1 grandmother, 1 grandfather) Recruitment: not reported Diagnosis: paediatric Burkitt lymphoma	FGC occupation – 'farmer'	Qualitative, semi-structured ITVs with open-ended Q, predesigned topic guide, thematically analysed Interviewer: not specified	Needs identified: financial aid, general disease improvement and prayers Carers did not know what to expect at home and how to manage preventable problems Incongruence in FCGs' and patients' views on clinical status and needs Open communication between FCGs and patients was challenging Failure to cure → acceptance outcome was in God's hands The disease greatly influenced QoL of patients and FCGs	Small sample, single service recruitment, programme evaluation, RR not provided, bias as all receiving free PC (interviewee courtesy bias), limited to lymphoma High
Williams et al. ³⁹ Canada	To share, in the form of a story, the experiences of rural female FCGs focusing on what fosters their hope (Living with Hope Program) Rural study	23 female FCGs (active) Recruitment: convenience sample, initial contact by PC service via mail Diagnosis: advanced cancer	Living outside major population areas in Saskatchewan and Alberta, rural areas designated by provincial postal codes	Daily 5-min journal entry on challenges and hopes faced and what fosters hope; 2-week period. Narrative enquiry approach – journal entries transcribed into narrative, thematic analysis, reported as a narrative story 'Hope against hope'	342 journal entries, 4 themes: Hope 'I hope tomorrow is better' 'Hoping against hope' → tension between hoping for and recognising there is no cure Hope is a choice and a mindset Hope influenced by temporal circumstances (travelling, finances mood and health of patient), social support; faith and spirituality Practical and emotional challenges (fear, worry, sadness, guilt, helplessness, anger, loneliness, empathy, love and gratitude) Multiple self-care strategies The emotional journey	Programme evaluation, small sample size, no randomisation or control group; cancer only Descriptive stories from only female FCGs Medium

FCG: family caregiver; PC(S): palliative care (service); RR: response rate; CBS-EoL: Caregiver's Burden Scale in End-of-Life Care; MSPSS: Multidimensional Scale of Perceived Social Support; ECOG: Eastern Collaborative Oncology Group performance scale; NOK: next of kin; QoDD: quality of death and dying; GAD-7: general anxiety disorder 7-item scale; PHQ-8: patient health questionnaire 8-item depression scale; EoL(C): end of life (care); HCP: healthcare professional; ESRD: end-stage renal disease; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease; ITV: interview; HNC: home nursing care; ADLs: activities of daily living; HW: health worker; QoL: quality of life; SD: standard deviation; CI: confidence interval.

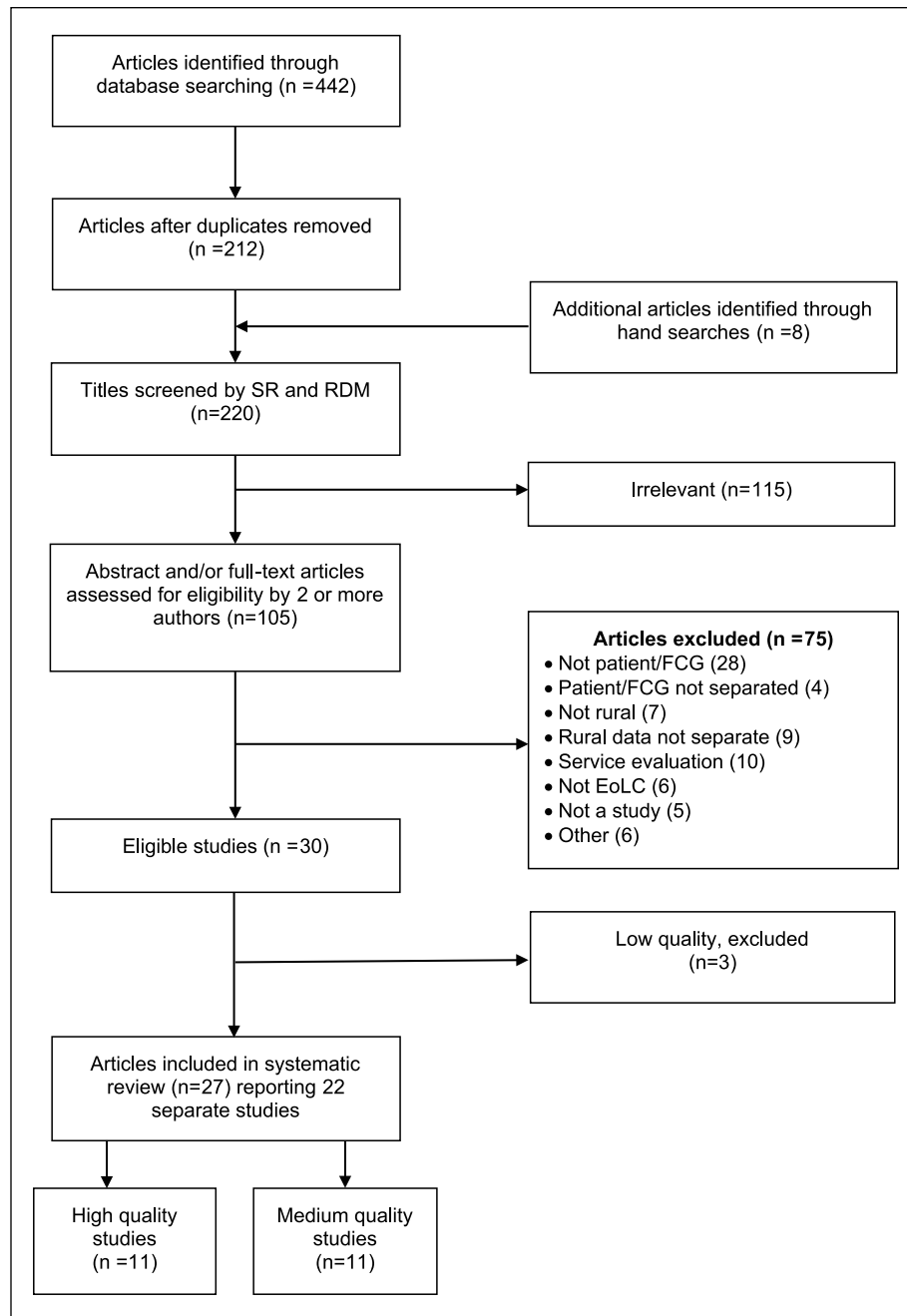


Figure 1. PRISMA flowchart.

Source: Modified flow chart as described by Moher et al.⁴⁰

FCG: family caregiver; EoLC: end-of-life care.

and one study included family caregivers of patients receiving or not receiving hospice care.³⁴ Length of end-of-life care by family caregivers ranged from 2 weeks to 120 months;^{26,28} 11 studies did not report length of care.

Patient experiences and perspectives

In total, 11 studies described the end-of-life care experiences and perspectives of rural patients and emphasised

the importance of not giving up,^{16,19–21} finding meaning in life,²¹ ‘steadfastly living life’,¹⁶ maintaining dignity,^{16,19,25,29} independence,^{16,19,21–24,29} and normality.^{16,19,29} This required patients to redefine normal,^{16,19,20,23,29} come to terms with change,^{21,23,29} (with resignation¹⁶ or struggle¹⁹) and make the most of everyday.¹⁶ Patients lived with exhaustion and stress,^{19,20,22,23} ‘in conflicting states of hope and despair (p. 783)’,¹⁹ and balanced independence with an awareness of their deterioration and

Table 2. Characteristics of patients.

Patient (n=)	167
Studies including patients (n=)	12
Gender	
Female	81
Male	53
Not specified	33
Age (n studies; range)	
Range	9–93 years
Paediatrics	1 (9–14 years)
Adults	5 (30–93 years)
All >65 years	4
Age not reported	2
Diagnosis (n studies)	
Cancer only	8
Non-cancer only	0
Cancer + non-cancer	3
Not specified	1
Receiving PC (n studies)	
Yes	10
Interviewed at time of enrolment into PC service	1
Not specified; attending oncology outpatients	1

PC: palliative/hospice care.

Table 3. Characteristics of FCGs.

Studies including FCG (n=)	19
FCG (n=)	1086
Active	280 (26%)
Bereaved	770 (71%)
Not specified	36 (3%)
Gender	
Female	762 (70%)
Male	227 (21%)
Not specified	97 (9%)
Age	
Range	27–90 years
Mean age >60 years	4 studies
Age not reported	9 studies
Relationship to patient	
Spouse/partner	422 (39%)
Parent	12 (1%)
Adult child	402 (37%)
Sibling	5 (0.4%)
Other family	237 (22%)
Friend	8 (0.6%)
Recipient enrolled in PC	
Yes	17 studies
Not specified	1 study
Interview at time of enrolment in PC service	1 study

FCG: family caregiver; PC: palliative/hospice care.

increasing dependence on others;^{22,29} talked about impending death while holding onto hopes and dreams for

the future;^{19,20,29} and endured life bravely while having no energy left to enjoy life.^{19,20}

Dignity was maintained by refusing to be defined by illness^{16,19,22,23,29} and finding hope^{19,21,23,25,29} as ‘hope is the key to enduring distress (p. 785)’.¹⁹ Awareness of increasing dependence on family and friends was associated with fear of becoming a burden^{16,19,22,23,29} and/or losing independence, so often they did not ask for help.^{19,22} One Norwegian patient found hope in pursuing life-prolonging chemotherapy despite losing dignity through side effects,¹⁹ while others refused chemotherapy in order to maintain their quality of life.²⁹

Preparing for death, ‘without loss of hope or the desire to keep living (p. 1622)’²⁹ was important for many patients. Patients engaged in funeral planning,²⁹ completing wills,^{16,29} preparing self and family for impending separation,^{16,29} and setting affairs in order.^{16,18}

In sub-Saharan Africa, pain dominated the lives of patients^{25,28} with 31 (86% of patients) in Malawi reporting pain to be moderate to severe.²⁸ Pain issues were reported in four studies from developed countries,^{20,21,29,32} with participating patients describing pain management as important,²¹ essential for self-care,²⁹ and the importance of anticipating medication requirements when commuting long distances.^{31,32}

Support of family, friends, community,^{22,28} and HCPs²³ was seen as essential and valued; however, despite this connection, the message from two studies was that patients felt isolated as their disease progressed, ‘I’m part of the community but I feel alone (p. 2)’²² and having to ‘walk the palliative path alone (p. 12)’.²⁰

Family caregiver experiences and perspectives

Rural family caregivers spoke of taking on the responsibility of providing ‘direct care, managing and coordinating care, and advocacy (p. 127)’³⁶ for their family member; however, the care provided was ‘not only about the dying person, but also about the living relatives (p. 392)’.¹⁸ Some family caregivers reported lacking knowledge²⁹ and with ‘few [being] physically, emotionally, or educationally prepared for the tasks and responsibilities of caregiving (p. 5)’³⁷ especially as the illness progressed.²² Family caregivers experienced a broad spectrum of negative emotions.³⁹ ‘Participants were very concerned with ensuring the dignity and comfort of their loved ones during their final days and experienced distress, guilt, and anger if they were unable to fulfil these self-designated responsibilities (p. 6)’.³⁷ If family caregivers could find meaning in the situation by focusing hope on the day-to-day moments,³⁷ redefining normal,^{23,39} connecting and separating,³⁷ they were better positioned to cope with the responsibilities, burden of care and transitions in roles.²³ Self-care and maintaining their own quality of life were important; however, Williams reported that family caregivers often lacked

the 'time and energy to do everything they needed and to care for themselves (p. 6)'.³⁹

To fulfil their caregiver responsibilities, family caregivers required support^{14,15,22,28,35,36} from family, friends, neighbours and HCPs and they 'identified the need of having someone to talk to and being appreciated by the care recipient (p. 15)'.¹⁴ Some family caregivers accepted the role out of 'familial obligation';²⁸ however, many found meaning in caring for their loved ones^{36,37} with the burden of care 'outweighed by ... the satisfaction they derived from having made a meaningful contribution (p. 130)'.³⁶

Facilitators and barriers to receiving end-of-life care in rural/remote settings

Communication; accurate and timely information. The greatest support need of participating rural patients and family caregivers in developed countries was informational; however, the need for accurate information was stated or implied in all included studies from both developed and developing countries. Effective communication between HCPs and patients/family caregivers and within families³⁸ reduced pain and distress,²⁵ empowered carers to fulfil their responsibilities,³⁷ facilitated smooth transitions of care,²⁷ and allowed patients and families to prepare for death.^{18,29} Most, but not all¹⁹ participants were satisfied with the standard of communication by rural HCPs. Participants in nine studies^{11,14,15,17,19,20,22,23,27,29,34,38} reported one or more communication difficulties such as receiving conflicting or untimely information,^{34,36} uncertainty as to 'which physician was in charge',¹⁷ and not receiving information from the person they considered to be the expert.^{23,36} While some patients accepted medical advice without questioning,¹⁶ others considered false hope³⁰ or poor communication a lack of respect for the patient and their family^{22,23,30} and that 'not knowing was worse than knowing (p. 1623)'.²⁹ One study revealed that primary care physicians were highly praised for honesty and presence at the time of death.³⁴

Formal services. Brazil et al.¹⁴ reported 82.6% of participating rural family caregivers indicated that formal palliative care services were readily available, with 68.6% having access to services after hours. While another study³⁵ reported a HCP was always available, these results were not universal with four qualitative studies reporting inadequate accessibility to care and continuity of care^{19,20,22,26,29} especially after hours.^{22,23,26,29} Access to HCPs with palliative care training,^{23,26} paid qualified in-home carers,²⁶ after-hours pharmacies or morphine,^{25,26} respite care^{14,15} and paediatric hospice³³ was limited or unavailable.

Features of care that facilitated quality end-of-life care included personalised care;^{23,26} knowing and being known by the HCPs;³⁵ and a willingness of HCPs to go beyond

their professional care.³⁵ However, loss of privacy and anonymity³⁵ and an expectation that friends will always be available³⁵ were perceived as barriers. Five studies^{19–23,26,32} reported that the quality of care provided was dependent on the personality of the HCP with difficulties arising if personality conflicts arose as often no alternative provider was available.¹⁹

In three studies, when care at home was not possible, the local community hospital was an acceptable alternative^{26,28,33} and were considered safe,²⁶ small, convenient, personal, welcoming and the nursing staff described as caring and compassionate. However, rural hospitals were not viewed positively by Indigenous participants in Australia¹⁸ and Canada,³⁰ mainly due to cultural insensitivity.

Informal social support – family, friends and neighbours. A total of 19 studies reported on the informal support provided by family, friends, neighbours and the community with some participants stating that family is the 'most important' factor^{19,21} and essential for 'culturally congruent care'.³³ Brazil et al.^{14,15} reported that the greatest unmet needs identified by rural family caregivers were the tangible or practical needs. Community support was reported to have a positive influence on rural end-of-life care with one participant describing a sense of solidarity as '[we] take care of each other ... That's just the way it is! (p. 5)'.²¹ It was acknowledged in two studies that not all patients have happy family relationships^{33,39} and in another that community support could not be taken for granted and was highly reciprocal in that those participants who had been involved in giving to their rural community also received the highest amount of support from that community.³⁵ Despite the strong sense of community, studies reported that as disease progressed and patients lost mobility and independence, there was a sense of isolation as quoted from a study participant: 'I am part of my community but I feel alone. Family and friends come to visit me, but I feel isolated as they are unable to understand what is happening to me and my wife (p. 2)'.²²

Emotional support. Strong emotional support was identified as a facilitator of quality rural end-of-life care and was dependent on good communication, information, the presence of HCPs, support of other patients,²⁹ faith and hope. Hope was maintained through connection with family,¹⁹ friends and being linked to something outside the illness.³⁷

Spiritual support. Spiritual connection and faith fostered hope,^{30,33,37,39} with faith seen as an enabler to persevering in life as death drew near. Faith was reported to be fundamental to rural Appalachians and their transition through end-of-life care.³³ In many rural communities, church support was not limited to spiritual issues as congregations also provided physical and financial support.³⁸

Sub-Saharan Africa. Support needs across the studies were similar; however, contexts varied and the experiences of patients and family caregivers were dependent on where they lived. Three studies^{25,28,38} were conducted in four developing countries in sub-Saharan Africa where 'poverty shaped how people died (p. 5)'.²⁵ The greatest needs of patients and family caregivers in sub-Saharan Africa were pain relief and access to basic medications,²⁸ practical support, funds to purchase even the basics of life (food, clothing),^{25,28,38} information regarding the diagnosis and what to expect,^{25,38} and access to trained HCPs. These three studies were all programme evaluations, and they described how the implementation of palliative care services improved the quality of life of both patients and family caregivers by restoring dignity through 'transforming a life of pain and hopelessness'.²⁵

Influence of rural place and culture

The rural location of participants was important as a cultural dimension and 'participants spoke eloquently of the benefits of their rural lifestyle including physical beauty, privacy and accessibility of recreational activities. The level of support provided by community members was an important factor in why individuals valued rural life (p. 190)'.³²

Despite diversity in rural settings each was seen as having positive and negative influences on rural end-of-life care for both patients and family caregivers with distance identified as the greatest negative influence. One study^{31,32} focused on the issues surrounding commuting for treatment, with another seven studies^{18-23,25,26,35,36} reporting the experiences relating to travel distances, not only to access outpatient care but also for HCPs in providing home care. Commuting for treatment was mostly seen as stressful and exhausting;^{19,22,31} inconvenient¹⁹ and expensive;^{25,26,31,32} impacting negatively on the health of family caregivers³¹ and resulting in fragmented care.²² Some accepted commuting²¹ as 'one of the compromises they have to make for living at home, that is, to live in a place that contributed to their overall health (p. 12)'.²⁰

Geographical distance or 'living off the beaten track'²¹ limited accessibility to home-based services as some patients lived outside the boundary for home visits,²⁶ visits were less frequent especially in bad weather^{18,31,32} and were often not available at short notice or after hours.^{22,23,26} However, opinions regarding the effect of distance on the quality of care were divided with some seeing it as a 'major obstacle in providing adequate home-based palliative care (p. 391)'.¹⁸ and others not viewing rural living as a disadvantage.²¹ However, with advanced illness, the participants' sense of solitude became one of isolation.²² Geographic isolation also explained the greater unmet emotional needs of rural caregivers as they lacked 'having the support of a group of people who are experiencing the same thing (p. 16)'.¹⁴

Three studies reported that mobile phones,²⁵ computers and Internet access^{21,32} helped reduce the sense of rural isolation by maintaining contact with distant family and improving access to HCPs; however, these technologies are not available everywhere^{31,32} and for some patients a phone call was not sufficient, as there was a preference for the physical presence of HCPs.^{26,35}

Meaning of home or home country. In one study, 46% of patients and family caregivers reported their preferred place of care to be 'home',²⁸ as 'being at home is like a brick being in the right place: this is my land and these are my people (p. 7)'.²¹ Many of the rural participants were entrenched in their community and had 'memories of the landscape, environment, and people they once knew (p. 5)'.²¹ resulting in a strong place attachment (physical, social and autobiographical). It was suggested,

that the rural context may provide an advantageous healthcare environment. Its potential to be a source of comfort, security, and identity concurs with cancer patients' strong desire for being seen as unique persons ... [and a] confidence 'this place and these people will be there for me'.²¹ (p. 8)

For indigenous rural residents, 'home' or 'country' had special cultural significance.¹⁸ The biggest barrier to using hospital-based palliative care services for these participants was not being able to die 'in country'.¹⁸ The lack of cultural awareness by HCPs and misperceptions of the concept of palliative care were barriers to accepting palliative care.^{18,25}

Discussion

This systematic literature review describes rural end-of-life care through the experiences and perspectives of rural patients and their family caregivers and illustrates the importance of listening 'to those experiencing terminal illness and [to] hear what they emphasise as they reflect on their lives (p. 782)'.¹⁹ Rural residents clearly hold 'distinct views'⁴¹ on the realities of rural life and rural dying, including benefits and challenges. The voice of rural patients and family caregivers helps ensure services are 'relevant to [and] embraced by community members (p. 462)'.³ Consistent with previous reports⁹ rural participants in this literature review were mostly satisfied with the end-of-life care provided to them; however, most were realistic and openly acknowledged their unmet needs which were often 'related to context ... and shaped by reduced access and availability of services'.⁴² While palliative care was available in all the countries included in this systematic review, the development and integration of palliative care into mainstream health service provision within each location were variable. A global mapping study by Lynch et al.⁴³ reported that the provision of palliative care in 2011 remained localised in Cameroon while becoming increasingly integrated in Kenya and Malawi.

On a country level, palliative care was at an advanced stage of integration in Uganda and the developed world; however, participants in this systematic review indicated that access remained limited especially in remote areas.

The over-riding themes for most patients and family caregivers in all locations were 'living life'; holding onto hope, dignity and meaning; receiving personalised care; being known; and for HCPs to demonstrate 'presence, reassurance and honouring choices'.⁴⁴ In sub-Saharan Africa, this was possible once pain was managed. The importance of family and dying within one's community was expressed by most participants; however, this was more significant for indigenous participants who considered cultural sensitivity and respect for their rituals¹⁸ and 'folk culture'³³ to be essential for end-of-life care. The end of life issues faced in general by all patients and family caregivers, regardless of where they live,⁴⁵⁻⁴⁷ were raised by the rural participants in this review; however, there are differences, facilitators and barriers, unique to rural settings that significantly impact rural end of life care.

Barriers to providing rural end of life care, such as the hardship of distance and isolation, are not only just the concerns of rural patients and family caregivers but also acknowledged in the literature by rural palliative and community nurses.^{48,49} While there is no expectation that resources in rural areas should be equivalent to those available in urban settings,⁵⁰ some rural HCPs lament their lack of palliative skills, training and mentoring.^{51,52} This insufficiency is especially significant in the hospital setting as end-of-life services need to be integrated into rural hospitals⁵³ as they often act as substitute inpatient hospices.^{54,55}

It was frequently reported in the literature that effective communication between the patient/family caregiver and HCPs and within multidisciplinary teams is essential but often lacking.^{9,56} Patients and family caregivers expressed poor communication as a barrier to receiving quality end-of-life care especially when care was fragmented due to distance and the need to commute between different locations and HCPs. Few studies in the literature reported on information and communication technologies for end-of-life care⁵⁷ and while mobile phones and the Internet^{21,25,32} enabled some participants to stay connected, no rural studies were identified reporting on the use of communication technology in rural settings or if terminally ill patients would accept this as an alternative to physical contact.^{3,26,35}

An additional challenge faced by rural communities is the ageing population^{4,58} with many rural elderly living on their own²⁰ as families disperse. While the elderly are less likely to complain and demand little, they bear significant stress.²⁰ Participants in this review were reliant on support from neighbours and the community with informal networks being an untapped resource⁵⁹ and the focus for future research. Rural communities are endowed with an 'incredible volunteer base' and many 'very generous

people ... who are really genuinely concerned about the community'.⁴⁸

In contrast to the literature which places a high priority on pain and symptom control,^{50,53} very few participants in developed countries indicated that this was a high priority. This is possibly due to the aims and specific focus of the included studies, and with most participants enrolled in palliative/hospice care, it is also possible these services were delivering satisfactory symptom management.⁵⁶ By comparison, in Kenya and Malawi, where palliative care is becoming more integrated into mainstream health services,⁴³ pain management remains a high priority. Effective palliative/hospice care also increases the chance of patients receiving care and dying in their preferred place, usually home,^{28,53} however, with the exception of Indigenous participants,^{18,30} and consistent with previous studies,⁵³ many participants in this review were accepting of the transition to the community hospital.^{11,27,33}

The results of this review show that while researchers continue to seek out the end-of-life care experiences and perspectives of rural patients and family caregivers, this research has mainly occurred in North America and mainly with elderly, Caucasian and cancer patients. More work is required on all aspects of end-of-life care from patient and family caregiver perspectives, especially those living in remote areas or indigenous communities within developed nations where formal HCP support is either very limited or absent; the experiences of patients with advanced chronic non-cancer disease; paediatric patients and their family caregivers; from other developing countries in Asia, the Pacific and South America; patients and family caregivers who have to relocate; the evaluation of technology in enhancing information and communication; and longitudinal studies examining changes in experiences and perspectives over time.

This review affirms that recruiting patients and their family caregivers at end-of-life is difficult,^{7,60} and even more so in rural regions, resulting in small sample sizes. However, it cannot be assumed that the findings from small sample studies are irrelevant and that the rural voice can be added in unison with urbanites. The risk here is that universal models of care may develop and ignore the specific attributes of the rural psyche ('stoicism, fatalism ... self-reliance and rugged independence, coupled with a lessened sense of confidentiality and increased pressure to conform due to the smaller, more intimate nature of smaller rural environments'⁴¹) or the specific rural challenges such as distance and isolation. Collaborative, multi-site or multi-national research may address this issue.

Limitations

This systematic literature review had limitations in relation to the quality of the identified studies and completeness of the review. Studies where titles, abstracts or

keywords omitted the selection criteria wording may have been overlooked; however, electronic searching was augmented by handsearching journals and reference lists. Some excluded studies included rural participants; however, rural data were not identified, and so, this exclusion meant that some potentially informative perspectives were not gained. Generalisability of results is limited by small sample size; heterogeneity and inconsistency in rural/remote definition meaning studies reported on a variety of rural locations, populations and proximity to health services; recruitment bias (single-service recruitment with most participants receiving formal end-of-life care); predominance of elderly participants who may be more accepting of their circumstances than young patients; high proportion of cancer patients; and North American bias.

Conclusion

It is necessary to explore end-of-life care experiences and perspectives of rural patients and their family caregivers, as valuable insights will be lost and rural patients/family caregivers' care may be compromised if their voices and needs are ignored. Common themes such as hardship of distance reduced access to palliative care, community support and importance of home and 'country' highlight the influence of rural location on end-of-life care. While the number of studies has increased since 2009,⁸ especially in North America, there still remains limited published rural studies reporting on patient and family caregivers' experiences and perspectives on rural end-of-life care and further research is encouraged. The development of national and international collaborative work using a universal definition of 'rural' may begin to more clearly articulate the 'rural' voice.

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