Exploring Psychosocial Care Provision for Palliative
Clients Living in a Rural and Remote Context

Lise Johns

Bachelor of Social Work (Honours)

School of Human Services and Social Work
Griffith Health Group
Griffith University

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degree of Doctor of Philosophy

JUNE 2014
Student Declaration

I hereby declare that the PhD thesis titled “Exploring Psychosocial Care Provision for Palliative Clients Living in a Rural and Remote Context” is no more than 100,000 words in length, exclusive of tables, figures, appendices, references and footnotes. This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made to the thesis itself.

Signature…………………………………… Date……………………
“There are four kinds of people in the world - those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who will need caregivers.”

Acknowledgements

To my wonderful husband, who could not understand my passion for working with the dying, or even less still why I would pursue it as a PhD topic for many years. But he supported me anyway with great love and made enormous sacrifices so I could fulfil a dream. I am eternally grateful and will not forget your commitment to me throughout the length of time this project took to complete. I owe you so much.

Towards the end of writing this thesis, my father-in-law came under palliative care and I was fortunate enough to be able to nurse him and provide the required emotional support to him and the family as he faced death and afterwards. From this experience, my husband now has more understanding as to why I do what I do.

To my children, who like my husband, did not understand my interest, but listened politely to my prattle about the PhD and how it was progressing. Their patience whilst I studied, researched or was “off in another headspace” was unwavering. Thank you for grounding me, keeping me balanced and indirectly reminding me I am always a mum first.

To my supervisors, Donna McAuliffe and Lesley Chenoweth, who are the cream of social work; thank you. You have made this experience possible; my gratitude runs to depths you will not know. You guided me every inch of the way so I never felt like I was floundering or lost. I always knew what the next step was with purposeful structure and direction. When I was on my five week road trip, you were accessible at every point, willing to listen and offer your advice when I called or emailed. This was invaluable to me; not once did I feel alone. To Margaret Shapiro, who joined our trio, thank you for coming in on the eleventh hour and generously offering your respected expertise. This has been greatly appreciated.
Last but not least, thank you to all of my participants. You made the study. Without you all there would be no thesis. You gave me your time, your insight and wisdom to which I hope I can do justice. I have taken this as a serious responsibility and sincerely hope positive change will evolve from the information you selflessly offered to me. And to those amongst you who have passed on, a special thank you. May you rest in peace.

A final, final thank you to Griffith University for awarding me with the 2013 Continuing Scholarship so I could see this project through to its completion. The funds made a difference when the family income went from two wages to one. Thank you.
DEDICATION

To my mother, who implanted caring and empathy in my psyche forever; your role modelling will never be forgotten. You are the reason I am what I am. You are a true social worker in essence; only missing a piece of paper with the words “bachelor” printed on it.
Abstract

Despite being one of the most avoided topics of all time, death is a guaranteed eventuality for us all. However, good psychosocial care as death approaches is not. Where people reside is likely to impact their accessibility to quality psychological, emotional, social, spiritual and cultural support. This thesis will explore this issue, seeking to ascertain how psychosocial care provision is being undertaken in rural and remote areas of Queensland, Australia as well as illuminating social work’s role within this context.

Thirty-eight rural participants were interviewed comprised of health practitioners, community workers, palliative care clients and carers. A five week research expedition was undertaken visiting twenty-four rural towns across Queensland, resulting in rich, qualitative data from which pertinent themes were derived. The results revealed that psychosocial needs for palliative clients in these country towns are currently being met in an ad-hoc, inconsistent manner, pending largely on the availability and perceived proficiency of health professionals.

Compelling evidence emerged to emphasise the need for a plan to address issues such as the lack of a skilled psychosocial workforce, limited resources, the restrictive eligibility criteria for palliative care funding, difficulties around equipment and travel, along with a need for public education on what palliative care can offer. The data also revealed that attention is required to review and explore bereavement further; a psychosocial concern that is currently being undertaken in a haphazard and unacceptable manner. A disparity also exists between the psychosocial needs identified by clients and those focussed on by health professionals.

The Bronfenbrenner ecological/systems model was a major theoretical influence for this study as it provided a focus for how persons living in rural and remote areas exist within different systems. A critical theoretical lens was also implemented to analyse the social and political nature of service delivery. By utilising a systems and
critical framework to drive this research, socially constructed influences and their impact on the terminally ill are exposed and challenged.

The study emphasised that psychosocial care, in most cases was the province of the social worker, if one was accessible, but this was not always a given. The perceived skill and competency of the rural social worker was revealed from the data, especially when decisions about referrals were being made by other practitioners. The data shows that the psychosocial sphere is indeed an ambiguous, shared and contested domain in many Queensland country communities as the literature indicates. However, other important factors such as, rural attitudes, the strength of social and community supports, funding and policy, vast geographical distances and the calibre of inter-professional relationships also impact the referral process.

These findings will inform specific implications and recommendations for health policy, education and training for health practitioners and the social work profession. It is anticipated that national standards and competencies will be written for the generalist social worker, providing a framework for practice when working with the terminally ill. Limitations to the research will be reiterated along with recommendations for future research.
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<tr>
<td>AASW</td>
<td>Australian Association of Social Workers</td>
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<tr>
<td>ABF</td>
<td>Activity Based Funding</td>
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<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<td>ACAT</td>
<td>Aged Care Assessment Team</td>
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<td>ACP</td>
<td>Advance Care Planning</td>
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<td>AHRC</td>
<td>Australian Human Rights Commission</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>CACPS</td>
<td>Community Aged Care Packages</td>
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<td>CHIP</td>
<td>Community Hospital Interface Program</td>
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<tr>
<td>COAG</td>
<td>Council of Australian Governments</td>
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<td>DSQ</td>
<td>Disability Services Queensland</td>
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<tr>
<td>DVA</td>
<td>Department of Veteran Affairs</td>
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<tr>
<td>EACH</td>
<td>Extended Aged Care at Home</td>
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<td>EACH-D</td>
<td>Extended Aged Care at Home for Dementia clients</td>
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<td>HACC</td>
<td>Home and Community Care</td>
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<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>ICCPR</td>
<td>International Covenant on Civil and Political Rights</td>
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<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<tr>
<td>IHPA</td>
<td>Independent Hospital Pricing Authority</td>
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<tr>
<td>MASS</td>
<td>Medical Aids Subsidy Scheme</td>
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<td>NASW</td>
<td>National Association of Social Workers (United States)</td>
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<td>NPCP</td>
<td>National Palliative Care Program</td>
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<tr>
<td>NEP</td>
<td>National Efficient Price</td>
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<td>NGO</td>
<td>Non-Government Organization</td>
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<td>NHMRC</td>
<td>National Health Medical Research Council</td>
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<td>NRCP</td>
<td>National Respite for Carers Program</td>
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<td>PCA</td>
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<td>PCP</td>
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<td>PCQ</td>
<td>Palliative Care Queensland</td>
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<td>PCP</td>
<td>Palliative Care Program</td>
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<td>Acronym</td>
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<td>PCRAM</td>
<td>Palliative Care Resource Allocation Model</td>
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<td>PEPA</td>
<td>Program of Experience in the Palliative Approach</td>
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<td>PoCoG</td>
<td>Psycho-Oncology Co-Operative Research Group</td>
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<td>PTSS</td>
<td>Patient Travel Subsidy Scheme</td>
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<td>RDNS</td>
<td>Royal District Nursing Service</td>
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<td>RRMA</td>
<td>Rural, Remote and Metropolitan Areas</td>
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<tr>
<td>SARRAH</td>
<td>Services for Australian Rural and Remote Allied Health</td>
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<tr>
<td>TAHPC</td>
<td>Tasmanian Association for Hospice and Palliative Care</td>
</tr>
<tr>
<td>TDHHS</td>
<td>Tasmanian Department of Health and Human Services</td>
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<tr>
<td>WACHS</td>
<td>Western Australian Country Health Service</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Chapter One

Introduction

My soul is being summoned
But hope yearns me to stay
A grandchild’s tear is falling
My hand wills to wipe it away
The whisper is gentle but luring
Like a moth
I long to become its prey

Oh the enigma and the quandary
Is this event that we call death
It is frightening but then again not
Is it just about that last breath?
My body is tired and weak
I have battle wounds and scars
Show me the way and let me go
Is there refuge in the stars?

LJ

I wrote this poem one evening in reflection after spending a long day with a palliative client and her family as she faced her final hours in a small rural hospital. I tried to put to paper her perspective according to the many conversations we had engaged in over the last six months in my outpatient clinic. Many discussions ensued
around psychosocial issues such as her emotional reaction to her illness, how she felt about the progression of her disease trajectory; her concerns for her husband, son and grandchildren; what she should tell them; and who she felt would struggle the most and why. Her spiritual beliefs and thoughts on dying were also talked about. Her husband came to some of our appointments and disclosed just how “angry” he was with cancer and its intrusion into their lives. Throughout the entire time, this client displayed a gamut of emotions and reactions, some of which were contradictory, like wanting to give up, yet at the same time remaining hopeful. There were moments she was frightened whilst at other times she was calm and accepting.

Although my experience with this lady only provides a minute glimpse of the up-and-down journey a person with a terminal illness may encounter, not all will experience their passage in the same way. The route is so unique to the individual with factors such as, the strength of their networks, the calibre of their medical team and the availability of other professionals, all influencing the person’s pathway. This thesis seeks to understand the experiences of the health practitioners that deliver care to this vulnerable group as well as give voice to the palliative clients themselves, along with their carers, who have opinions on how psychosocial needs are currently being met in rural communities of Queensland, Australia. A critical and ecological framework will be utilised to illuminate and query the funding and policy systems that have created the current state of affairs.

Placing psychosocial care for palliative clients living in country regions within a human rights paradigm offers a moral reference point for those who aim to reaffirm the values of humanity in a context of economic globalisation and postmodern relativism (Ife, 2012). Positioning palliative care within a human rights framework is supported by prominent institutions advancing guidelines for those working with the terminally ill,
based on human rights and ethical principles (Australian Human Rights Commission [AHRC], 2012; National Health and Medical Research Council [NHMRC], 2011). By also combining Bronfenbrenner’s (1979) ecological/systems as a second conceptual lens, a large, diverse and complex issue can become more explicit. Bronfenbrenner’s ecological/systems theory directs attention to person-in-environment processes and how broader social institutions influence functioning over time (Greenfield, 2012). At the same time, the ecological model can be utilised to organize and plan research across social, health and behavioural sciences (Onwuegbuzie, Collins, & Frels, 2013). These two frameworks are linked to the research aim and have influenced the collection and analysis of data.

Essentially, there are two aims to this research. The first aim is to explore how psychosocial care provision is addressed in rural and remote communities of Queensland from the perspective of health workers and palliative clients themselves, so insight may be gained into their experiences of how psychosocial care is administered in their community. The second aim is to understand the role of social work within the rural and remote context, as this discipline does stake a claim over the psychosocial domain, yet their activities are notably absent in the literature. The results contribute to palliative care health policy and have further implications for social work competencies and education.

To address the aims, the following questions were formulated:

**Primary question:** How is psychosocial care provision being undertaken for palliative clients living in rural and remote areas of Queensland?

**Secondary questions:**

a. How do rural and remote service providers perceive their role in providing psychosocial care to palliative clients?
b. What are the perceived barriers and enablers to social work referrals?

c. How do contextual factors impact on provision of psychosocial care?

d. What have been the experiences for rural and remote palliative clients and their carers of psychosocial care?

**Background to the Research**

The desire to understand palliative care on a wider scale began when I took up a position as a sole practitioner in 2009 at a small rural hospital with twenty-two beds; two of which are palliative care beds. This is a diverse, generalist position, ranging from assisting the elderly transition into nursing home care, dealing with all social work issues with in-patients, addressing situations of crisis in the Emergency Department and seeing persons in my outpatient clinic for various crisis-related matters. Although I love all areas of my work, it was my dealings with the terminally ill patients that ignited a spark of desire to look more closely at this sector of care.

As a social worker, I was not only deeply concerned with the individual before me and their immediate psychosocial issues, but also with matters on a larger political scale. Health reform was underway with the palliative care sector being implicated. Costs were being cut in many departments with multiple healthcare positions becoming redundant or reduced. The patient appeared to be the victim within this economic modification as new ways of hospital funding were introduced along with an accelerated push to move the patient on to nursing homes and out of the hospital system. I thus found myself thrust into the individual/structural dichotomy that is one of the inherent tensions for social work. From the first days of its profession, social work has been divided between those who emphasize the treatment and cure of individual problems, and those who prefer to illuminate structural inequities and the importance of social reform (Mendes, 2009). I related to both. I strongly believed all terminally ill persons,
no matter where they lived, had a right to quality psychosocial care with skilled staff, who could offer undivided attention, either in hospital or at home. But was this actually the case? How was psychosocial care being addressed? Were social workers meeting these? If not, who was? The rally shout “the personal is political” now became my own catchcry (Hanisch, 1969).

Kramer, Christ, Bern-Klug, and Francoeur (2005) state social workers share an ethical duty to develop, test professional knowledge and determine, through research, shrewd use of resources in the delivery of services. Due to their varied role in practice settings across the lifespan and a strong commitment to humane care, particularly to those most vulnerable, social workers have the potential to make meaningful contributions to research (Kramer et al., 2005). Inspired by these words, I made my own commitment to explore an issue close to my heart and be a voice for the terminally ill in rural communities. Thus, the idea for a PhD was born.

The Current Context

Palliative Care Queensland (PCQ) (2012b) reported that in 2010, 27,289 Queenslanders died; with 90% of these people dying from a period following a chronic illness such as heart disease, cancer, stroke or a neurological condition. Of noteworthy interest, 47.5% of Queenslanders live in areas classified by the Australian Bureau of Statistics as rural and remote (Queensland Council of Social Services Inc., 2009). It is well documented that people living with cancer in regional and rural areas have poorer survival rates than those in capital cities, with the incidence of all cancers being higher in regional areas, possibly attributed to lifestyle factors (National Rural and Health Alliance Inc., 2012; Strong, Trickett, Titulaer, & Bhatia, 1998).

Amplified costs related to healthcare delivery, diminished numbers of rural health professionals and a growing trend towards centralization of services have
negatively impacted on access to quality healthcare services in rural communities, affecting what can be offered to the palliative client (White, 2007). Challenges such as distance, the need to travel, after hours care, reduced healthcare provider input, practical support, economic issues and limited psychosocial support are but a few issues faced by patients, their families and the health professionals who work tirelessly to address needs with the limited resources they have (Hardy, Maresco-Pennisis, Gilshenan, & Yates, 2008; White, 2007). Queensland has a unique terrain, which cannot be undermined, covering an area of 1,727,000 square kilometres, with a landscape of waterless deserts, rugged mountains, subtropical rainforests and vast, endless featureless plains (Department of Natural Resources and Mines, 2014; Queensland Government, 2014). Persons living within these remote areas are at significant risk of an inferior treatment outcome (National Rural and Health Alliance Inc., 2012).

Interestingly, endorsed government policy stipulates all Australians have a right to equitable access to quality palliative care when and where needed but disparity still exists (Commonwealth of Australia, 2010; Community Affairs Committee, 2012). Palliative care services are not freely available to all Queenslanders largely due to geography, resourcing, workforce constraints and poor co-ordination (PCQ, 2012b). Some experts state Queensland has the potential to be a world leader in the provision of specialist palliative care and to offer world class treatment to those facing a life-limiting illness (Maddocks, 2003). However, a more dismal scenario exists. In Queensland palliative care has not been a political priority resulting in the State being one of the worst performing in this area with no state-wide plan, nor does it have equitable funding or a service delivery framework to ensure support and service provision across all of Queensland (PCQ, 2012b, 2012c). In June 2012, The Health and Community Services Committee was asked by the Legislative Committee to inquire and report on palliative
care services in Queensland against the back drop of national health reforms (Health and Community Services Committee, 2013). The outcome of this is yet to be seen. Dying people in rural Queensland are clearly disadvantaged when it comes to palliative care services.

Simultaneously, on a wider scale, the international palliative care community has proposed that palliative care be established as a basic human right for all. Both palliative care and human rights are based on principles of dignity of the individual and the principles of universality and non-discrimination (Gwyther, Brennan, & Harding, 2009). The United Nations General Assembly (1948) proclaimed the Universal Declaration of Human Rights as common standards, with Article 25.1 stating “Everyone has the right to a standard of living adequate for the health of himself and his family including food, clothing, housing and medical care and necessary social services” (p.76).

In palliative care, there can be ambiguity around interpretation on exactly what palliative care involves in its holistic entirety (Brennan, 2007). However, if there is obscurity around the interpretation of “social services” as set out in Article 25.1, The Open Society Foundations (OSF) Fact Sheet on Palliative Care as a Human Right could be referred to. OSF promotes palliative care as a human right, stating that “psychosocial, legal and spiritual problems associated with life threatening illnesses must be considered along with physical care” (OSF, 2014, p. 1). Additionally, Dr Catherine Le Gales-Camus, World Health Organization (WHO) Director-General for Non-communicable Diseases and Mental Health also states: “The relief of pain – physical, emotional, spiritual is a human right” (WHO, 2007b, p. 1). Access to psychosocial services should therefore be considered from a human rights perspective.
This raises intriguing questions around availability of skilled psychosocial staff to deliver the social services.

**Locating Social Work Activities in Rural Queensland**

An extensive search in the databases over three years – CINAHL, MEDLINE, PROQUEST, Web of Science and PubMed revealed no literature on social work activities regarding psychosocial care for palliative clients in rural Queensland. A few articles were located on psychosocial care in rural areas for cancer patients in other Australian states with one article on end-of-life issues in an Alice Springs Hospital involving social workers; however this was all that could be identified (Gunn, Turnbull, McWha, Davies, & Olver, 2013; Nadimi & Currow, 2011; Shepherd, Goldstein, Olver, & Parle, 2008). Interestingly, this paucity of research is not acknowledged even within existing social work literature and research.

Social workers are indeed well positioned to meet the psychosocial needs of palliative clients due to the perspectives they work within and the theoretical base they draw upon (Monroe, 2010). Gwyther et al. (2005) state social workers are most qualified and well placed to work in palliative care and bereavement. A core component of the social work profession is its value base, person-in-environment perspective and particularly the approach to problem solving which not only incorporates the individual, but the family and/or societal structures as well.

A consistent bio-psychosocial-spiritual perspective combined with practical and clinical skills set social workers up to offer quality interventions (New York State Society for Clinical Social Work, 2013). Yet as mentioned, their activities in rural and remote Queensland are not visible in the literature despite social work’s claim for dominion over the psychosocial sphere. There is also acknowledgement that the experience for the social worker in a specialist palliative care team will be different than
the experience of the rural generalist social worker which will be discussed later in this thesis.

Evidence from the literature indicates that in many communities nurses have to meet psychosocial needs despite this not being part of their original training (Hegney, McCarthy, Rogers-Clark, & Gorman, 2002; Kenny & Allenby, 2013). Access to ongoing bereavement support, another psychosocial issue, is also limited in rural communities leaving nurses to do the best they can with virtually no resources (White, 2007). Nurses are the front-line workers who have to provide services that normally other disciplines would offer.

**Justification for the Research**

The literature repeatedly purports that emotional and psychological needs of palliative clients living in remote and rural areas in Queensland are not adequately met mostly due to lack of access to skilled staff. (Hegney et al., 2002; PCQ, 2012b; White, 2007). Social workers are employed in many rural communities so the question can be raised about how psychosocial care provision is being undertaken. This was the gap I identified and sought to investigate.

The results of this study are pertinent in that they will not only add to current literature regarding the challenges for health practitioners administering care in a vast terrain, but will also provide implications for health policy in relation to existing inequities pertaining to psychosocial care provision in rural communities. The second significance of this research is that it illuminates the role of the generalist rural social worker working with palliative care clients, which has not yet been a prominent aim of research in Queensland prior to this time. The results will provide implications for the social work profession and education for future development.
A third and final factor that deems this study distinguishable is the capture of the voices of the palliative client and their carers. No other study in Queensland that could be located has gained the perspective of the rural palliative client on the psychosocial issues they wanted to discuss and issues they felt were of concern. Although family members and other social networks often fulfil many psychosocial needs, the palliative clients and their carers’ viewpoints around access to psychosocial support from a health professional will provide an all-round précis to a contentious issue in the literature.

**Theoretical Framework and Methodology**

There are many theories that fall under critical perspective umbrella. In a research context, theory can assist to devise questions and strategies to explore an issue in the social sphere (Kincheloe & McLaren, 2002). A human rights based practice is a critical perspective along with anti-oppressive practice, anti-discriminatory practice and postmodern critical social work (Allen, 2009); all of which can be conceptual frameworks. This thesis will focus on human rights approaches that sit comfortably under critical theory; a fitting means to investigate systemic issues and state responsibility (Cohen & Ezer, 2013). This critical view can be adopted to illuminate how structural forces such as government health policy marginalize and negatively impact minority groups (Briskman, Pease & Allen, 2009; Nipperess & Briskman, 2009).

As with all critical perspectives, a human rights framework places social structures as the culprit for individual problems, as well as giving social workers the tools to analyse the world around them (Nipperess & Briskman, 2009). Payne (2014) states critical theory complains of the limited utilisation of systems and ecological ideas in social work. This thesis will integrate both theories, which will serve to drive and conceptualize the project. If change is made to one part of the system, there is likely a ripple effect that spreads throughout, thus achieving significant movement across
systems (Payne, 2014). A critical human rights perspective, together with an ecological systems paradigm, critically highlights the nature of powerful systems, the interactions between them and the potential impacts on the individuals within them. Access to quality palliative care, in particular psychosocial care, is a human right that should be addressed within structural macro spheres. The effects can thus filter down through exosystems and impact the palliative client, their family and others living within a microsystem in either negative or positive ways.

Some writers state that ecological theories make an assumption that improving fit into an environment is desirable, which critical theory can reject (Payne, 2014). There can therefore be a disparity between critical theory and ecological/systems theory. However, by also implementing Bronfenbrenner’s ecological model as a way of conceptualising the various systems and how they impact the palliative client living in rural and remote areas of Queensland, while maintaining a human rights perspective that highlights how change needs to occur at structural levels, the inequity that caused the disparity in the first place can be exposed.

Healy (2005) states many social work commentators use Bronfenbrenner’s approach in which a series of concentric rings are used to illustrate a series of varying system levels. Although Bronfenbrenner’s (1979) model essentially is a theory for human development, the paradigm is often utilised as a conceptual basis for research, serving as organizing as a metatheory for understanding (Sontag, 1996). It provides a taxonomy consisting of a hierarchy of systems, a) microsystem, b) mesosystem c) exosystem and d) macrosystem which promote the concept of multi-person systems, their interactions and the impacts of these collaborations on the individual (Sontag, 1996). This is how the model will be utilised within this qualitative research study.

This is how the model will be utilised within this qualitative research study.
Denzin and Lincoln (2000) state qualitative researchers turn the world into a series of representations, including interviews, field notes and conversations. Qualitative research involves an interpretative naturalistic approach. This is the strength of this thesis. The data were collected through qualitative methodology; a means to hear the voices of a minority group that has not yet been heard before in Queensland along with the voices of health practitioners and community workers. By capturing the lived experience, my objective was to explore how the participants make sense of their experience and transform it into meaning. This required me to intricately confine how the individual experiences the psychosocial aspects of dying without assumption or bias.

Outline of the Thesis

This thesis begins by articulating the aims of this study - how psychosocial care provision is addressed in rural and remote communities of Queensland and to understand the role of social work within the rural and remote context. The research questions are also expressed. The background that led to this study is provided along with a justification for the research. A brief summary of the overarching theoretical framework and chosen methodology is also provided. With a continued focus on the contextual overview of palliative care, Chapter Two begins by defining what palliative care is and its purpose; it explains its history and origins along with its current context on a world-wide scale, showing no universal model exists.

The chapter then provides comprehensive details on how palliative care is delivered in the UK, USA and Canada and how rural communities in these countries are serviced. A discussion follows on how palliative care is being advanced from a human rights perspective, and the push for psychosocial care to be incorporated within this framework. An overview of palliative care in Australia is highlighted, with a particular focus on the complexities around Commonwealth policy and the funding arrangements
that ultimately impact our rural dwellers. This is illustrated by means of a flow chart.

An analysis of palliative care service delivery in all Australian states is presented, emphasising the significant differences between them. The pertinent issues and gaps for palliative care for indigenous Australians are also featured and how palliative care in general is situated in rural Australia.

A thorough explanation of what psychosocial care is in accordance to the literature is presented in a second literature review chapter. **Chapter Three** presents a comprehensive overview of psychological concerns, emotional issues, social situations, spiritual distresses, cultural norms, practical concerns and bereavement complexities. The chapter then highlights the importance and value of psychosocial care with a detailed table presenting illustrated examples. Further consideration is presented regarding the blurred domain of psychosocial care with disparity around which professional discipline is actually responsible for it. The role of social work and what this discipline contributes to palliative care is discussed; however it warrants mentioning that this information is based on social workers in specialist palliative care teams only and not the rural generalist social worker. The contested sphere of psychosocial care will feature literature highlighting how not all social workers are viewed as responsible for addressing psychosocial issues for palliative clients.

The chosen methodology and justification to answer the research questions is outlined in **Chapter Four**. Details are offered regarding the theoretical framework that underpins the study and why it was selected. How and why the particular sample group was chosen and the recruitment process that ensued is discussed. Barriers that arose throughout the study are also mentioned. The research questions are detailed, followed by a discussion around the data analysis process. Ethical considerations and limitations to the study are also provided within this section. Strategies undertaken to establish a
truthful qualitative study is also articulated. The thesis will then move on the three findings chapters.

The focus then shifts to referrals. The results in Chapter Five identify which discipline are receiving referrals for psychosocial care. The result of who are meeting the psychosocial needs of palliative clients in rural and remote areas of Queensland is presented in tables and a graph. Some of the barriers and challenges for social workers are featured, along with a confirmation of what the literature states around the psychosocial sphere being a shared and contested domain.

Chapter Six emphasises how macro influences of policy and funding is a significant factor in how palliative care is delivered in rural and remote areas of Queensland. Palliative care funding models and the impacts of geographical distance are explored in this chapter. Chapter Seven is the last of three findings chapters, highlighting the psychosocial issues that are identified by the palliative clients themselves and their carers. A disparity occurs between what the health professionals articulated and what the palliative care participants deemed important to discuss.

Chapter Eight focusses on the implications for health policy and funding, highlighting the urgent need for systemic change. This is followed by implications for education and training for health practitioners and implications for the social work profession. Recommendations for future research will be also presented as well as limitations of the study.

Conclusion

This chapter has introduced the specific focal point of this research, exploring psychosocial needs of palliative clients living in rural and remote areas of Queensland. The significance of this research is that it is undertaken within a human rights framework to explore macro influences that impact a vulnerable group. Research
questions to address the aims of the study were articulated. Factors were introduced that led to why the study was undertaken, which was then followed by the current context of palliative care in Queensland. The location of social work activities in the rural setting was illuminated, followed by justification of the research and the chosen methodology. An overview of the chapters and what will be contained within was also detailed. Subsequently, the next two chapters will present the literature which forms the foundation of the study.
Chapter Two

Literature Review

Part One: Understanding Palliative Care in the Macro Context

This chapter will examine the existing literature on palliative care and how its varied modes of delivery are influenced by macro forces such as historical beginnings, funding and policy, which filter down through a range of systems and ultimately impact the palliative care client. Despite the sector becoming a specialized field of care linked to much empirical research, significant gaps relating to service delivery, specifically provision of psychosocial care, in rural communities still exist.

A decade ago, Maddocks (2003) was of the view that Australia was leading the rest of the world in developing the discipline of palliative care because 1) mutually supportive relationships existed between the diverse centres of palliative care and 2) there was a high level of government support for palliative care initiatives (Maddocks, 2003). Maddocks (2003) further contended that despite the advances, there was “still a long way to go” (p.6). This chapter will highlight the advances over time as well as “the long way to go” areas via the literature, along with the inconsistencies in the level of government support.

Defining Palliative Care

Whilst there are numerous definitions on what palliative care is, the most appropriate definition would be that articulated by the World Health Organization (WHO). It is the definition most recognised throughout the world and appears in a majority of the palliative care literature. It is also the definition currently being utilised as the foundation for the National Palliative Care Strategy (Commonwealth of Australia, 2010); a stand-alone document which sets objectives and strategies intended
to underpin palliative care service development in Australia. The WHO (2002, p.1) definition of palliative care follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patients illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
This comprehensive definition is particularly apt when considering the broad settings within which palliative care is administered. Its tenets can be encompassed in a variety of contexts and implemented universally. It is also be the chosen definition for the meaning of palliative care within this thesis, particularly because the psychosocial aspects of it are so eloquently incorporated. As stated by Sheldon (1997) dying is considered a normal part of life, but by encompassing psychosocial issues such as psychological, social and spiritual care, the emphasis is always on achieving the best quality of life possible for the palliative client.

Death is the inevitable result for every human being. In past generations, millions of people were eradicated by epidemics such as the Spanish Flu, Cholera, Yellow Fever, Small Pox and various plagues. In times gone by, death in infancy and childhood was frequent, with families being torn apart by grief as more often than not, one of their own, young in years, was taken from them by illness (L. Payne, 2014). But fortunately advances in medicine have altered this scenario considerably in recent decades.

Vaccinations have abolished multiple diseases and with the introduction of antibiotics, chemotherapy and surgical procedures, people are living longer with lower mortality and morbidity rates in children. Many diseases have been reduced or eliminated that one killed or harmed many infants, children and adults (Centre for Disease Control and Prevention, 2013). Older people, living well above 80 years are on the increase; this being a direct result of the baby boomer generation where six or seven children were commonplace (Australian Bureau of Statistics [ABS], 1999). So whilst these medical technological advancements have had drastically positive influences, referrals to palliative care services are also on the increase as diseases such as cancer,
neurogenerative disorders and some paediatric cancers and disorders still persist (PCQ, 2012b).

The purpose of modern palliative care is not to offer curative treatment for diseases but rather focus on offsetting physical symptoms so any pain is well managed, improve a person’s quality of life and to support them in a process of change, seeing them through a holistic lens. This is what is referred to as utilising a palliative approach (PCA, 2014a). The person’s physical, psychological, emotional, social, spiritual, cultural and practical issues are all considered and valued by the multi-disciplinary team or by predominant health care providers as the vital components that make up their whole being. In other words, the person is not viewed by their disease alone but all aspects of their life are considered (Sheldon, 1997). A palliative approach is about getting to know a person and their family early and putting all supports in place to ensure care is delivered to the highest quality possible. Late referrals to palliative care services can lead to frustration for service users so offering it at an appropriate time is crucial (Beresford, Croft, & Adshead, 2007). A contemporary perspective to dying has evolved to this standard over time; however an existing worldwide need for this service still remains greater than the current, available provision (Abu-Saad, 2001; Clark, 2007). It is noted nonetheless, tender nurture for the dying remains; just as it was from the sector’s beginnings (Abu-Saad, 2001).

In the first millennium the church was directly involved with setting up the original hospices to provide end-of-life care for dying travellers (McLeod, 2008a). Hospice is still a term that is often synonymous with “palliative care,” which since the early eras, was a place for the sick, wounded or dying to receive treatment or merely eat their last meal and breathe their last breath. It could well be likened to a modern day hospital (Beresford et al., 2007). Cohen (1979, cited in Abu-Saad, 2001) stated that the
original hospitals were an offshoot of religion rather than medicine. However, the
practice of medicine soon became elementary and integrated into the hospitals/hospice
systems, with patients being cared for in all ways, including religious services being
offered when recovery was not possible. Ultimately, in a time of increasing
technology, hospitals became centres of cure rather than holistic care, which had been
initially provided in earlier periods. In the twentieth century, more Christian-sponsored
medical centres were erected to align and cater for both spiritual and physical needs.
Simultaneously, medical developments kept on advancing, resulting in a general focus
on cure, which impacted terminally ill patients. With this infiltrated emphasis, the
opportunity to discuss fears, concerns or grieving was lost (Abu-Saad, 2001).

Palliative care, or the hospice movement, as we know it today, emerged in the
1960’s from the vision and arduous work of a British woman named Dame Cicely
Saunders. Saunders began her working life as a nurse, then trained to become a medical
social worker and finally a physician (Maddocks, 2000; Smith, 2000). Saunders, above
anyone else, established the culture of contemporary palliative care by introducing
effective pain and symptom management. She and others experimented with a wide
range of opioids to address pain, producing a comprehensive approach to addressing a
variety of sufferings experienced by the terminally ill (Fallon & O'Neil, 1998). Her
focus was not simply physical aspects of care. Saunders insisted dying patients were
treated with dignity, respect and empathy. She saw the person wholly, not as just their
disease, introducing the concept of “total pain,” which encompassed not just physical
pain but also their psychological, emotional, social and spiritual struggles (Sheldon,
1997). This is what is referred to as “psychosocial needs.” The National Council for
Hospice and Specialist Palliative Care Services (1997, cited in Jeffrey, 2003) has
defined psychosocial care as “being concerned with the psychological and emotional
well-being of the patient and family/carers, including issues of self-esteem, insight into an adaption to the illness and its consequences, communication, social functioning and relationships” (p. 3). It also considers a person’s culture, their spirituality and its impact on the situation (Reith & Payne, 2009). This holistic perspective has become the foundation for contemporary palliative care.

From 1963, Saunders took her philosophy out of the UK, embarking on a series of tours of the United States of America. Florence Wald, the Dean of Yale, attended one of Saunders’ speeches whilst on tour. She took a sabbatical from her position as Dean to work with Saunders in England, learning all she could about hospice care. Wald then returned to the United States and established Connecticut Hospice, the first hospice in America to open its doors in 1974 (Hospice Foundation of America, 2013). Wald also chose an inter-disciplinary team from Yale University to conduct research and learn more about the needs of terminally ill patients. Additionally, she organized a series of educational seminars to raise awareness in the community and improve palliative care (Adams, 2008b). This was the beginning of hospice and palliative care in the USA, where there are now more than 4,700 hospice programs, most of which are home-based, in operation (Hospice Foundation of America, 2013).

Around the time of Saunders bringing her philosophy to America (i.e., 1960s), a psychiatrist named Elisabeth Kubler-Ross emerged with her own research regarding the needs of the dying. She released a book in (1970) titled On Death and Dying, in which she described the process of dying in five stages – denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1970). The book achieved worldwide circulation, causing Elisabeth Kubler-Ross to become a household name when it came to the terminally ill and her ideas on how family/caregivers are affected by bereavement. Saunders and Kubler-Ross were pivotal in changing world views on death and dying.
In 1967, Saunders opened St Christopher’s Hospice in London (Abu-Saad, 2001; Clark, 2000; Maddocks, 2000; Smith, 2000). Here patients could be treated medically, as well take art lessons, work in the garden or become involved in music therapy (St Christopher's Hospice, 2013). With each passing year, St Christopher’s continued to expand, adding home care services, an education centre and advance research of pain management. Saunders served as the medical director of St Christopher’s for 18 years. She died peacefully there at 85 years of age. St Christopher’s Hospice is now a 48 bed inpatient facility, staffed with doctors, nurses, social workers, chaplains, psychiatrists, physiotherapists, occupational therapists, creative therapists and bereavement counsellors. It also serves over 2000 people each year in their own homes. It is one of the two hundred hospices running in the UK (Help the Hospices, 2014a; St Christopher's Hospice, 2014).

Along with Cicely Saunders and Elisabeth Kubler-Ross being instrumental in impacting societal view on death and dying, Canadian physician Balfour Mount was also a key player. Dr Mount became a pioneer in this emerging medical sector by bringing palliative care to Canada, instigating a model which focussed primarily on providing palliative care in a hospital. After studying the work of Kubler-Ross and spending a week with Cicely Saunders at St Christopher’s in London, Mount decided to adapt Saunders Model for Canada, but he believed a more affordable approach would be to provide care in hospitals. Although impressed by St Christopher’s Hospice, Dr. Mount believed the free-standing hospice model was too expensive to apply to Canada. Palliative care in Canada is mostly now delivered in a hospital setting, although hospices do exist (Ferguson, 2010).

All services at St Christopher’s are offered for free, with the hospice relying on private fundraising to cover most of its costs. Dr Mount did not consider this feasible
due to the Canadian system of publically funded health care (Ferguson, 2010). The term “palliative” is derived from the Latin word *pallium* or cloak, a metaphor utilised to cloak the symptoms of terminal illness whilst providing comfort. As early as the 16\textsuperscript{th} century, the term “palliation” was used by doctors to describe the relief of suffering. But it was Dr Balfour Mount who was considered the first person to institute the term “palliative care” when he took the concept back to Canada (Ferguson, 2010, p. 3). Mount (1973, cited in McLeod, 2008a) thought the term “hospice” would confuse the French-speaking population, who use this term for nursing homes. The term, “palliative” was thus adopted by many other countries resulting in a new medical speciality known as palliative medicine.

**International Modes of Service Delivery**

Despite significant advances to adopt an integrated model similar to St Christopher’s, there is no universal provision of palliative care. In many western countries, end-of-life care may include any or all of the following, as outlined by Reith and Payne (2009, p.14):

- In hospitals, a consultant and an integrated specialized team made up of doctors, nurses, social workers, occupational therapists, counsellors and other professionals who provide care
- Palliative care beds are allocated to certain hospital wards, which removes patients from the normally curative environment. Patients are seen by a multi-professional team, but predominantly doctors and nurses
- Palliative home care, where advice is given to a generalist, specialist nurse and other practitioners to a caregiver by specialist medical consultant
- Hospice at home services, offering nursing support at the home
• Community in-patient hospices, where patients stay until death and receive specialized care
• Palliative outpatient services, where persons can access to medical, nursing and multi-disciplinary assistance by visiting a clinic

In other less developed countries, some localized provision of palliative care can be found, whilst others have just hints of movements in this area. Unfortunately, there are still a significant number of countries where palliative care services are currently non-existent (Wright, Wood, Lynch, & Clark, 2008). Brennan, Gwyther, and Harding (2007) state the reason for the deficiencies and inequities is largely due to a paucity of resources and a lack of political will to prioritize health. The WHO (2007) released its first guide on planning palliative care services for all people living with advanced cancer, identifying highly effective low-cost public health models of care for advanced cancer patients, especially in developing countries. The document highlights “palliative care is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases. Palliative care is particularly needed in places where a high proportion of patients present in advanced stages and there is little chance of cure” (WHO, 2007a, p. 2).

In the UK there are 223 hospice and palliative care inpatient units, 3200 hospice and palliative care beds, 291 home care services, 197 Hospice at Home Services, 275 Day Care Centres and 344 hospital support services. For children, there are 43 hospice inpatient units and 338 hospice beds. 1.6 million pounds is spent on hospice care every day. The adult hospices in England gain approximately 34% of their funding from the government, whilst the children’s hospices receive less. More than 100,000 people volunteer in local hospices in the UK. Without them hospices could not continue the work that they do. Research undertaken by Help the Hospices in 2006 estimated the
financial value of volunteers to independent charitable hospices in the UK to be 112 million pounds (Help the Hospices, 2014b).

Interestingly, in other western countries the terms hospice and palliative care are used synonymously; however a distinction does exist within the Australian context. Both palliative and hospice care focus on management of pain (which also includes total pain such as psychological, emotional, social and spiritual), but hospice care is generally accessed when curative treatment has ceased and life expectancy is reduced. The National Association of Social Workers (NASW, 2004) illuminates the difference by stating, “Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. Palliative care may segue into hospice care as the disease progresses” (p. 12). Hence the difference is about time of access; additionally, a palliative client’s financial status may also impact, with some hospices preferring patients with private health insurance that can be bulk billed (Hopewell Hospice, 2013).

In the USA, there are currently more than 4,700 hospice programs with hospice programs caring for 965,000 people enrolled in Medicare in 2006, and nearly 1.4 million people in 2007 (Hospice Foundation of America, 2013). There are four primary levels of care; routine home care, continuous care, general inpatient and respite/respite inpatient, all of which should be met by the hospice (Smith, 2000). In America, there are non-profit hospices as well as for-profit organizations. Non-profit charitable hospices should provide services for persons who are not covered by Medicare, Medicaid or private insurance, whereas a for-profit organization can turn away a patient who does not have this coverage. The non-profit service will rely heavily on donations and charities, soliciting funds if they wish, whereas a for-profit can only receive donations (Hospice Patients Alliance, 2013).
Generally, for eligible Americans, hospice care is met by Medicare, Medicaid or private insurance, which is paid in accordance to the days the patient was enrolled in the program, not the actual service. This is referred to as the per-diem basis, meaning that hospices are not reimbursed on a fee for service basis; rather, hospices are paid on a basis of how many days the patient is enrolled in the program and received services (Hospice Patients Alliance, 2013). In order to receive payments for hospice patients under Medicare or Medicaid, a hospice must be certified by the Centres for Medicare and Medicaid Services (Hospice Patients Alliance, 2013; Smith, 2000). Hospices appear to be a significant mode of delivery of palliative care in the USA, with for-profit facilities implementing a business focus, causing concern for some stakeholders (Jena, 2012).

This raises the query as to why there are hundreds of hospices in the UK and thousands in the USA but hardly any in Australia? The answer appears to be they are considered too expensive, as articulated by Dr Balfour Mount in his reference to hospice care in Canada. There is a strong reliance on volunteers and a need for continual fundraising. Take for example the Ipswich Hospice, based in the south east corner of Queensland, Australia.

The Ipswich Hospice is a seven bed health care facility in Ipswich, which offers high quality palliative care for the people of this region. It is a not-for-profit organization which relies on State and Commonwealth grants, bequests, donations and payroll deductions, fundraising events, Hospice enterprise “Bargain Centre” and monies raised from their “Friends of Hospice” bookshop (The Ipswich Hospice Inc, 2013). Over 15 000 hours of volunteer time is contributed to patient care (Mitchell & Price, 2001). Hospice employees totalled 56 personnel, boasting 260 active volunteers throughout 2011/12 period, with 73 new volunteers recruited in most areas of the
organisation. Care is overseen by Registered Nurses, who along with other staff work in conjunction with the guest, their family, the guest’s own GP, a Palliative Care Specialist that visits weekly and a psychosocial co-ordinator (The Ipswich Hospice Inc, 2013). Ipswich Hospice is one of eight hospices in Queensland, along with other centres, Little Haven Hospice, Cittamani Hospice, Katie Rose Hospice, Hummingbird Hospice (Childrens’ Hospice), Karuna Hospice and Hopewell Hospice. Both Cittamani and Karuna are based on Buddhist philosophies; however clients of the service do not need to be connected to this faith to utilise their services. Emotional, social, welfare, practical and spiritual support is attended to by these eight organizations (The Ipswich Hospice Inc, 2013).

Similarly, in Canada, only 16% to 30% of persons with a life limiting illness currently have access to hospice palliative care. Depending on where they live in Canada, some will receive scant services. Although Canada scored in the top ten countries in terms of quality and availability of end-of-life care by the Quality of Death Index released in 2010, valuable hospice palliative services is still unavailable to over 70% of persons dying in Canada. Figures indicate that although most Canadians prefer to die at home, 70% of deaths occur in hospital (Canadian Hospice Palliative Care Association, 2012). Funding has been radically reduced. The Canadian Hospice Palliative Care Association (2012) states that hospice palliative care programs are still at least 50% funded by charitable donations, with families having to bear a brunt of the cost. Only a small number of provinces have designated hospice palliative care programs as a core service provision under their provincial health plans. In some areas hospice palliative care may be included in the service budget are always vulnerable to budget reductions.
By way of comparison, palliative care in the UK is delivered mostly by hospices which also rely on donations and charitable fund raising. Palliative care in the USA is also delivered largely by hospices, however the for-profit facilities often utilise a business focus, as Medicare, Medicaid and private insurance offer significant rebates. There are still many not-for-profit hospices in America that assist those who are not covered by Medicare, Medicaid or private insurance so therefore rely on charitable fund raising as in the UK and Australia. In Canada, however, most palliative care is delivered in the hospital setting with fewer persons being able to access adequate hospice care. Persons living in a rural or remote community are severely limited in what palliative care services they can access (Canadian Hospice Palliative Care Association, 2012).

Evans, Stone, and Elwyn (2003) conducted a systematic literature review to examine studies undertaken that have looked at the organization of palliative care and views of professionals in rural areas worldwide. Twenty-six studies were found, mostly from the UK and Australia. The following themes emerged across the literature: 1) health professionals lacked access to training and education; 2) reported problems in symptom control; 3) management of emotional issues such as bereavement counselling for nurses and carers were problematic; 4) difficulties in accessing specialist palliative care services such as hospices; 5) families having problems accessing information and; 6) communication problems between primary carers (General Practitioners) and specialists. Evans et al. (2003) concluded that very little research has been conducted in this area. Most of the literature that was found all identified significant concerns in delivering palliative care to rural areas.

O'Neil and Marconi (2001) add a further concern stating the lack of health insurance is possibly another complicating factor for those needing access to palliative
care in the USA. Persons living in rural and remote areas with generally poor healthcare availability will tend to fare unsatisfactorily regarding palliative care. Gibson (2001) states even if palliative care was availably universally, not all Americans could access it. Forty-two million Americans lack health insurance covers resulting in poor health outcomes. Racial and ethnic groups are more likely than others to lack insurance, possessing a traditional history of underutilization of palliative services and a lack of receptivity.

The Rural Assistance Centre (2013) state that hospice and palliative care is definitely an issue in rural areas of America. Not all areas of rural America have hospice programs available. Lynch (2013) agrees stating most counties across the United States did not have access to a Medicare-certified hospice, with only 36% of rural communities being served. The Rural Assistance Centre (2013) identified that those in areas that do have services, similar challenges were identified that have been presented in the rural Australian context. Challenges such as a lack of family caregivers, financial hardships as under the Medicare Benefit programs are obligated to offer an array of services under a per diem mechanism, lack of qualified staff and trained interdisciplinary professionals that can assist with 24/7 coverage, increased expenses due to greater travel, reimbursement for rural hospices, such as Medicare does not account for higher cost incurred in rural communities and a lack of grief and bereavement support (Hardy et al., 2008; White, 2007).

A further systematic literature review on rural palliative care was conducted by Robinson et al. (2009). Their purpose was to identify, evaluate and synthesize the published literature on rural palliative care. The researchers were able to retrieve 79 eligible studies on the topic. A large number of the studies came from Canada, Australia and the USA. The authors concluded that accessible palliative care in both urban and
rural communities is patchy. For example, it is estimated that approximately only 15% of Canadians have access to palliative care services, with inequities likely to rise as the ageing population increases. There is clearly a need to advance palliative care services in remote and rural areas (Robinson et al., 2009). The researchers found in many of the studies, psychosocial aspects of delivery of palliative care was most challenging for rural clinicians. The study found in Australia, attention must be particularly paid to the diversity of demographics through the development of cultural sensitive programs; specifically for Aboriginal people (Robinson et al., 2009). Other topics that were also identified as important were communication and stress management.

It is apparent research on palliative care in rural and remote communities in numerous countries is still in its infancy stage (Robinson et al., 2009). According to a Canadian study, rural specialised palliative care services are rare in many communities. Persons living with a terminal illness do not want to leave their homes or communities; nor do families want to be separated by distance at such a crucial time. Although local hospitals do provide much of the end of life care in some cases, rural families provide much of the care at home. However, these families do need more information and support. Formal nursing is a key factor but often falls short in many rural communities (Wilson et al., 2006). An additional Canadian study shows volunteers are invaluable in rural communities addressing practical, emotional, spiritual or social needs, mostly because they have the time (McKee, Kelley, Guirguis-Younger, MacLean, & Nadin, 2010). In summary, the literature reveals palliative care is administered in a varied method throughout the world, with no consistent universal execution of service delivery.
Palliative Care as a Human Right

Heard (1997) contends that the attraction with human rights is that it sets a universal standard that can judge a society, particularly on how it treats its citizens. Without human rights, one is left to assert one’s own thinking on an issue (Heard, 1997). Human rights belong to everyone, regardless of their race, sexuality, citizenship, gender, nationality, ethnicity, or abilities (Amnesty International, 2013). The Australian Human Rights Commission (AHRC) was established in 1986 by the Australian Federal Parliament; they are an independent statutory organization that report to the Commonwealth government via the Attorney-General (AHRC, 2014a). One of their key missions is keeping governments accountable to national and international human rights standards. The Commission is closely aligned with other national human rights institutions, as well as undertaking bilateral agreements as part of the Australian Government’s development program run by the Australian Agency for International Development (AusAid) (AHRC, 2014a). Gwyther et al. (2009) state that lack of political support and awareness, social and cultural issues, adequate teaching of doctors and nurses, entrenched attitudes, and the low prioritization of palliative care amongst policy makers is a barrier to overcome, hence the need to advance palliative care within a human rights framework.

Brennan et al. (2007) state three disciplines – palliative care, public health and human rights are now interacting with a growing reverberation. Advancements are being made to promote palliative care as human right, although complex and not without limitations, the concept serves to combine a broad medical, moral and legal imperative. The authors continue to purport the care of terminally ill patients is a basic and fundamental responsibility of all governments, societies and health professionals (Brennan et al., 2007). Additionally, the AHRC (2014d) state human rights recognise
the inherent value of each person, regardless of background, physical location, appearance and attitudes. A human rights approach is the application of a set of essential principles to policies and programs that provide a foundation for human rights protection. The perspective is an avenue in which norms, principles, standards and goals of national and international human rights law into all decision making processes, law and policy development can be integrated (AHRC, 2012). The AHRC (2014c) report Australia does not generally agree to be bound by a human rights treaty unless it is satisfied that its domestic laws comply with the terms of the treaty. However, Australia has agreed to be bound by the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) as well as other major human rights instruments (AHRC, 2012c) with ICESCR Article 12 stating all have a right to the enjoyment of the highest attainable standard of physical and mental health (Office of the High Commissioner for Human Rights, 2014).

Whilst much of the discourse on palliative care and human rights is steeped in medical equity, psychosocial issues for the terminally ill are much less mentioned. Brennan (2007) touches on it, when he states a human right to palliative care may be implied from the international right to health care, however if the overall goal is freedom from suffering, then other services to relieve suffering must be considered. This would include any services that could diminish distress. Breitbart (2008) continues that psychosocial matters such as psychological, emotional and spiritual concerns are also left unattended and excluded, despite being a strong component of palliative care philosophy.

Heard (1997) does state that rights can cover a large and very expensive, variety of social-welfare programs, which may seem too enormous to even consider. However,
an important issue here is that dialogue is beginning on the incorporation of the psychosocial aspect of palliative care and human rights, despite having a long way to go. The human rights lens does provide a conduit to view a systemic issue and highlight government responsibility (Cohen & Ezer, 2013). Yet human rights are not static and continue to evolve (Ife, 2012).

As articulated in Chapter One, The Universal Declaration of Human Rights, Article 25.1 state “everybody has the right to a state of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services” (United Nations General Assembly, 1948, p. 76). This human rights approach to palliative care clearly highlights the care of terminally ill patients is a core responsibility of governments to ensure equitable access to services based on a non-discriminatory premise, including necessary social services and needs to be promoted as such. Australia was also one of eight nations involved in drafting the Universal Declaration and has remained a supporter of human rights throughout international treaty negotiations (AHRC, 2014b). Yet psychosocial services for palliative clients still remain an unmet need in many rural communities of Australia.

Hanks et al. (2011) also confer palliative care is derived from a rights ethos. There may be practical, economic, geopolitical or social reasons that make it difficult to provide palliative care, yet duty of care is obligatory despite the barriers. Clearly, there is still much work to be done on a worldwide scale to ensure palliative care, in its full philosophy, becomes available to all people despite limitations and challenges.

**Overview of Palliative Care in Australia**

Fortunately, advancements in palliative care provision have found their way to Australia. In metropolitan and large regional areas, specialist palliative care teams provide an integrated high quality service (White, 2007). Whilst pain and symptom
control are a dominant component, social workers, occupational therapists, physiotherapists and chaplains are vital members of the team. All members work together to address the physical, psychological, emotional and spiritual aspects of care.

In Australia, palliative care is delivered in a variety of health care settings, which include community settings such as home and aged care residential facilities, hospices and hospitals (PCA, 2003). Besides specialist palliative care physicians, there are also generalists whose usual roles are as local General Practitioners or hospital doctors who also offer palliative care services. When necessary, these generalists often seek direction from a palliative care specialist but do their utmost to meet the needs within the limits of their knowledge, skills and competence in palliative care medicine.

Palliative Care Australia (PCA) is the peak national organization that represents the interests and aspirations of all who promote the ideal of quality care and end-of-life. Their mission is to influence, foster and promote high quality end-of-life care for all Australians (PCA, 2012a). PCA originally was called the Australian Association for Hospice and Palliative Care Incorporated (1990). In its early days (mid 1980’s), it was made up from some committed individuals from different Australian states who had travelled overseas and identified what was occurring in other countries regarding palliative care. The role then of the association broadened, with its name being changed to Palliative Care Australia (PCA) in 1998. PCA supports its nine members who share the vision, mission and aims of PCA and operate through a federated governance structure (PCA, 2012b). Its membership is illustrated in Figure 1.
Figure 1. Palliative Care Australia membership (Source: PCA, 2014b)
All of these individual organizations come under the PCA which serves as the national organization addresses national palliative issues, represents the area to the commonwealth government and media, and acts for the sector when dealing with other peak bodies and organizations. PCA works closely with the Department of Health and Ageing to implement the National Palliative Care Strategy, raise awareness of palliative care issues and improve the understanding and availability of services across Australia (PCA, 2012b). Each state member aims to carry out the vision and mission of PCA in their own state or territory. For example, Palliative Care Queensland’s (2012a) principle role is to:

- To improve awareness and understanding of palliative care in the general community
- To influence the development of public policy in relation to death, dying and end of life
- To support the professionals and volunteers who provide palliative care
- To improve health professional education
- To develop and distribute palliative care educational resources
- To provide information, support and advocacy to people affected by terminal illness, and
- To provide support and professional representation to Palliative Care Queensland members

Each of the state members is made up of individuals from the palliative care community, who deliver care to dying persons. This includes coordinated medical, nursing and allied health professionals, who address not just pain and symptom control but also psychological, emotional and spiritual support similar to Dame’s Cicely
Saunders’ first model. The purpose of each palliative care service in Australia is to assist towards fulfilling the WHO’s definition of palliative care as articulated in the first few paragraphs of this chapter. To gain an understanding of the provision of palliative care it is necessary to consider macro influences.

**Macro Influences on Service Provision**

The outer circle in Bronfenbrenner’s (1979) model depicts macrosystems that include laws, policy, beliefs and customs that impact a developing human being. This will be discussed in more detail in Chapter Four. However, in this study, as mentioned, a major underpinning macro influence is the belief that palliative care is a basic human right (Breitbart, 2008). The discourse and structure of human rights has become well established on the world scene; a concept that serves to unite medical, moral and legal obligations and place responsibility of the care of terminally ill persons as the responsibility of governments, societies and health professionals (Gwyther et al., 2009). Human rights have at their core base that all human beings have an equal moral worth and they are beneficiaries of human rights simply on the fact that they are human (Brennan et al., 2007). According to data collected from WHO and the International Narcotics Control Board, only a minority of the more than one million people who die each week receive palliative care to alleviate their suffering. Developing countries, which accommodate approximately 80% of the world’s population account for only 6% of global consumption of morphine (Breitbart, 2008). This situation is both alarming and disturbing; it is hoped the work of human rights activists will not give up the crucial fight to continue to bring this to the attention of policy makers and funders alike.

Stjernswärd, Foley, and Ferris (2007) state the WHO pioneered a Public Health Strategy for integrating palliative care into a country’s health care system. The strategy incorporates advice and guidelines to governments on how to prioritise and implement
national palliative care programs. This approach is deemed effective for integrating and establishing palliative care into a country (Stjernswärd et al., 2007). Advancements are to be acknowledged when considered in palliative care’s relatively short history, but governments have a responsibility to continue the progress.

As articulated previously, along with a critical human rights perspective, a second overarching framework for this study is Bronfenbrenner’s (1979) ecological/systems theory, which emphasises how macro systems such as government policy and funding arrangements filter down through the exosystems and ultimately impact the individual in some way. It is essential to this study to comprehend the policies that underpin how palliative care is funded nationally, how these monies are distributed to the states/territories; then dispersed down to a district level for services to be ultimately delivered to the client. With this understanding one can grasp what a palliative client living in a rural community in Queensland can receive in regards to service delivery, and in particular, psychosocial care. It is only when it is understood, it can then be challenged. Due to the fact that funding and policy has a major impact on what services can be offered to palliative care clients, it is imperative to include a section in this thesis that draws attention to the relationship between macro systems and the palliative client living in rural and remote areas of Queensland.

A significant stakeholder that should first be introduced when it comes to health care funding in Australia is the Council of Australian Government (COAG). COAG is a peak intergovernmental forum whose members comprise of the Prime Minister, State and Territory Premiers and Chief Ministers and the President of the Local Government Association. COAG meets generally once or twice a year or when needed with the Prime Minister acting as chair for the forum. The role of COAG is to initiate, develop and then promote policy reforms of vital national importance, ie; funding for health
care, which in turn needs to be cooperatively managed by all Australian state/territory governments (COAG Reform Council, 2013).

Formal agreements are reached which are released after each meeting and termed as National Agreements and/or National Partnership Agreements. Health reforms and funding for the Australian health care system is therefore governed by particular agreements stipulated by COAG at these meetings or in out-of-session collaborations. The objectives, outcomes, outputs, reporting and financial arrangements are thus filtered out to the states/territories who become system managers of the changes (COAG, 2011; Health Policy Solutions, 2012).

In 2006, COAG established the COAG Reform Council to assist COAG drive its reform agenda. It is independent of individual governments with its members being made up of a Chairman, a Deputy Chairman, four Councillors and a Deputy Councillor who also serves as the head secretariat. The COAG Reform Council reports to COAG directly on reforms of national significance. They report on how states/territories are performing under the National Agreements and their progress regarding how initiatives are being delivered. The Council ensure states/territories are utilising funding in an economical way, performance benchmarks and targets are being achieved and relevant sectors are actively engaged in service delivery as per stipulations within the Agreements (COAG Reform Council, 2013). It would be fair to say the Council becomes the overseer of the reforms.

Within these Agreements, funding for palliative care comes under the “subacute” banner. Four subacute categories are formally recognised within the agreements under this domain – 1) rehabilitation 2) palliative care 3) geriatric evaluation and management and 4) psycho geriatric care.
The two agreements that discuss subacute reforms are – 1) The National Partnership Agreement on Hospital and Health Workforce Reform and 2) The National Health Reform Agreement – National Partnership Agreement on Improving Public Hospital Services (COAG, 2008, 2011; Community Affairs Reference Committee, 2012). The National Partnership Agreement on Hospital and Health Workforce Reform was agreed upon on November 29th, 2008, with COAG committing $3.042 billion to improve efficiency and capacity in public hospitals through the following four components:

a) Introducing a nationally consistent Activity Based Funding Approach
b) Improving health workforce capability and supply
c) Enhancing the provision of sub-acute services; and
d) Taking the pressure off public hospitals

COAG pursued reforms against a milieu of increasing demand due to an ageing population, rising chronic disease, advancing technology and pressures related to shortfall in the workforce (COAG, 2008). The Agreement outlines objectives, outcomes and outputs, roles and responsibilities, performance benchmarks, reporting and financial commitments – ie; payment schedules. It is an explicit document with the expectation that the reforms are imposed by the states/territories, who are now accountable and need to pursue the articulated benchmarks then answer to the COAG Reform Council.

These changes have been gradually implemented from 2008 onwards, with some states advancing the directives ahead of others. But a new reform was deemed necessary as trends indicated that over five years to 2010, states and local governments had experienced growth in health spending of around 9% per year. State and local government tax revenues in the same time frame were around 6 %, which meant
projections showed that by the year 2045-46, health spending alone would be more than all revenue collected by state and local governments. Essential action was taken by the Commonwealth to address these challenges by working with the states/territories to secure an agreement referred to as National Health Reform. It was agreed that these reforms would provide better access to services, enhance transparency, increase responsiveness to local communities and provide a firm financial foundation for health in the future (Department of Health and Ageing, 2011c).

On August 2nd 2011, COAG finalised the National Health Reform Agreement, which is often termed as the “The Agreement.” This new agreement additionally is supplemented by two further agreements: The National Partnership Agreement on Improving Public Hospital Services and the National Healthcare Agreement (Australian Medical Association, 2011; COAG, 2011). The National Partnership Agreement on Improving Public Hospital Services is the other Agreement that incorporates subacute reforms, which is relevant to all stakeholders in palliative care and will be referred to throughout this paper.

Although there are numerous National Agreements and National Partnerships, this thesis will focus on the two Agreements pertinent to subacute care. As mentioned, Activity Based Funding (ABF) was initially introduced in the Agreement regarding Hospital and Health Workforce Reform back in 2008. It is important to understand this new funding approach as it has relevance to palliative care and how it is delivered.

Activity based funding is exactly what its title implies. Hospitals are funded according to the activities that they undertake (Department of Health and Ageing, 2011a). A vital aspect of ABF is that each health service needs to be able to define, classify, count, cost and pay for each activity in a consistent way (Eagar, 2010). COAG
articulates the different categories in which ABF will provide funding (Eagar, 2011; Medical Technology Association of Australia, 2013):

- Acute inpatient admissions such as surgery, medical admissions, maternity and paediatrics
- Emergency Department services
- Subacute care (both in-patient and outpatient) such as rehabilitation and palliative care
- Outpatient services
- Hospital-auspiced community health services such as home nursing and post-acute care
- Mental Health

Of these five activities, only acute inpatient care has nationally adopted a classification that can be currently used to define the “activity” to be incorporated in the ABF model (Eagar 2011). This classification is the Australian-Refined Diagnosis Related Group (AR-DRG). When it comes to acute care, the treatment and its costs can readily be predicted according to the patients’ principal medical diagnosis. Acute care patients represent about 97% of patients treated in public hospitals with a typical stay of a few days (Eagar, 2010).

However, in regards to subacute care, the treatment is determined by their functionality rather than their primary medical diagnosis. For this reason the DRG classification is not appropriate. Patients receiving subacute care generally require longer hospital admissions and their care involves numerous clinicians – i.e.; doctors, nurses, physiotherapists, occupational therapists, social workers, speech pathologists, dieticians and pastoral care workers. The services required by subacute patients is therefore different to the mix of services consumed by acute patients. Subacute patients
are more likely to require more allied health input, often for several hours per day. The patient’s families are often also involved. Furthermore, once a subacute patient is discharged, follow-up care is often continued in the home (Eagar, 2010). So the difference between acute and subacute is significant. Some palliative care stakeholders have raised concerns on how ABF will play out, particularly in a multidisciplinary setting (Community Affairs Reference Committee, 2012). The initial classifications that will be used as the basis of the ABF payments has also been agreed will commence from 1st July 2012, with the sub-acute and mental health categories to commence 1st July, 2013 (Department of Health and Ageing, 2011a). A clear picture may take several years.

Under the National Health Reform Agreement, the Independent Hospital Pricing Authority (IHPA) was established authority to thus progress ABF. The IHPA is an independent agency established to contribute to significant reforms to improve Australia public hospitals. The IHPA’s primary function is to calculate and deliver an annual National Efficient Price (NEP). The NEP is a major factor when addressing the level of Australian Government funding for public hospital services (IHPA, 2013b). The NEP is a set amount that is utilised to work out funding for public hospital activity. It also provides a price signal or benchmark for the efficient cost of providing public hospital services. The IHPA will also develop the criteria for those services that will still receive block funding rather than ABF. It has already been established that rural and regional communities will continue to be block funded rather that activity based funded (Department of Health and Ageing, 2011b; IHPA, 2013c). The IHPA will also determine if some services should be eligible for a mixture of both ABF and block funding. COAG will make the final decisions to any criteria and recommendations that the IHPA puts forth (IHPA, 2013a).
It is interesting to note, that in residential aged care, ABF has been implemented for some time on a national level, however there is a difference. In residential care, the activity is calculated per day, whereas in hospitals, the activity is calculated by episode of care. In ABF the financial incentive would be to minimize the episode of care, meaning a reward if the hospital stays is reduced. However, the risk in doing so could be the patient is discharged too soon or returns to hospital within a short time after discharge counteracting the financial reward. These concerns could be addressed if patient outcomes are measured at discharge and there is a continuum of care at home for the patient (Eagar, 2011). A major rationale behind ABF is that it will empower health care workers to strive for improvement and produce more value for money outcomes in hospital service delivery.

As mentioned, how ABF will impact palliative care is yet to be determined. PCQ (2012b) postulate that purchasing agreements, based on ABF for community and consultancy liaison palliative care service provisions, need to include an array of components. These components are outlined in PCQ’s (2012b) submission to the Queensland Parliament’s Health and Committee Services Inquiry into Palliative Care and Home and Community Care Services (p. 34). The IHPA has called for public submissions to see how ABF is best structured to meet the needs in subacute care because it is recognized ABF for acute care is much simpler than it is for subacute care, largely because of the variety of settings subacute care can be provided. These complexities are not covered in the National Health Reform Agreement (Community Affairs Reference Committee, 2012).

In November, 2011, the Senate proposed the service provision of palliative care in Australia be referred to the Senate Community Affairs References Committee for inquiry. The Committee found in its investigation that there is much inconsistency in
the standard of palliative care delivered across Australia. This has been largely attributed to complexities in the funding allocations, with palliative care being incorporated in the subacute funding category. A significant stakeholder, Palliative Care Australia, holds the opinion that palliative care should be ring fenced and not included with subacute funding for fairer distribution (Community Affairs Reference Committee, 2012).

**Impacts on Exosystems**

Once again, keeping within Bronfenbrenner’s ecological model, exosystems depict the agencies or influences that indirectly impact the client despite the fact they are external, such as local policy and funding constraints (Tissington, 2008). Because palliative care is provided in an array of settings - hospitals, home with community support, hospices and aged care facilities, difficulties can arise because of the varying funding models for each of these settings. There is a complicated arrangement of state/territory money, federal government funding and grants along with bequests and community donations. There are many sources of funding and the allocation of funding is different from one district to another. It is the same with the eligibility criteria which also varies from district to district and often from service to service, all indirectly affecting the palliative client in some way (Community Affairs References Committee, 2012).

PCQ state that remoteness and distance also impact on the allocation of funding. Because palliative care is bundled in with subacute funding, the money is not getting to certain areas (as cited in Community Affairs Reference Committee, 2012). PCQ are of the firm belief that extracting palliative care from the “sub-acute” grouping is necessary to prevent palliative patients from ending up in the acute care setting and not in palliative care allocated beds. The Committee has put forth the recommendation to the
Senate that palliative care be removed from the subacute category and a new funding category of “palliative care” as an initiative to address this issue (Community Affairs Reference Committee, 2012). The outcome of this recommendation is yet to be seen.

As highlighted, palliative care arrangements are funded from many sources. The Home and Community Care Program (HACC) services are funded by the Commonwealth government with persons over 65 years being able to access this service (Australian Government Department of Health, 2014). HACC services can provide general in-home nursing, allied health support, domestic assistance, assistance with home modifications and meals on wheels. However, HACC is not meant to be used for palliative care as per Commonwealth guidelines; it is generally the first line of funding used to support people with a terminal illness in a community (PCQ, 2012b).

There have been recent reforms of the HACC program which came into effect on 1 July, 2012. The most significant change is that the Australian Government has taken full funding, policy and operational responsibility for HACC services for older persons over 65 years in all states/territories, except Victoria and Western Australia. However the state/territory government will have to fund HACC services for those under 65 years of age or under 50 for Aboriginal and Torres Strait Islander people. Prior to this the HACC program was jointly funded by the Commonwealth and the state/territory governments, with the state/territory governments being responsible for managing the service. The Commonwealth had a broader, strategic role until now (Australian Government Department of Health, 2014).

Other government aged care packages are Community Aged Care Packages (CACPS), Extended Aged Care at Home (EACH) and Extended Aged Care at Home – Dementia (EACH-D) for persons with dementia. These packages are designed to provide more hours than HACC services and can be more flexible (PCQ, 2012b). These
packages are allocated to different service providers such as Blue Care, OzCare, Anglicare etc. These packages can assist terminally ill clients until Palliative Care Funding (PCP) becomes available (to be discussed later in the chapter) (PCQ, 2012b).

For the average person who is not a health professional, understanding and negotiating these different packages from different providers can be confusing and difficult to make sense of.

Additionally, there are also Community Health services, which can be accessed by palliative clients for allied health support, such as physiotherapy, dieticians and social work. These are state funded and again a contribution towards the service is sometimes required. Although this service offers access to more holistic support which is central to palliative care, the wait times can be long and poor staffing often limits access to the appropriate staff member, particularly those in rural areas (PCQ, 2012b).

Disability Services Queensland (DSQ) is another state funded service that can provide care packages for persons younger than 65 years. However, the person requires a thorough assessment for eligibility with wait times being lengthy and the process for access can be drawn out. This raises all sorts of complexities when the person is in hospital and unable to move forward until such processes occur. For persons under 65 requiring nursing home care, a DSQ assessment is required before the necessary Aged Care Assessment Team (ACAT) can assess them for residential care. The policies between DSQ and ACAT seem to be a source of debate with practitioners often caught in the middle spending time trying to negotiate a complicated system (PCQ, 2012b).

The Department of Veteran Affairs (DVA) has funding available for a small number of patients that have served time in the defence forces (oversees service). DVA packages are funded by the Commonwealth. Applying for DVA funding can be yet
another lengthy and drawn out process. Many staffing hours are utilised on assisting families with the DVA paperwork (PCQ, 2012b).

In regards to equipment, there is a rather complex system in place. Each state has a different way of accessing equipment for palliative care clients. There is money provided by the Commonwealth to support palliative care equipment but it is a separate pool of equipment, which is managed by the states or the disability sector and not easy to access (Community Affairs Reference Committee, 2012). Palliative clients are not generally eligible for the Medical Aids Subsidy Scheme (MASS) for equipment as the money for this group is expected to come from elsewhere (Queensland Health, 2013a).

When it comes to respite for carers, the Commonwealth funds the National Respite for Carers Program (NRCP). It is designed for emergency carer support as it is well recognised that supporting the carer is an effective way to reduce hospital admissions. The program can be utilised if the carer becomes sick or extremely fatigued and requires immediate respite. Overnight support can be organized in a short amount of time. If the carer is requiring longer reprieve, NRCP can assist with seeking out respite beds in residential aged care facilities (PCQ, 2012b).

Every year Queensland Health receives $8.1million from The National Palliative Care Program (NPCP) in addition to the subacute funding outlined in the National Agreements. This money is utilised for palliative care services in the community, such as nursing care, respite services, medical supplies and dressings. This initiative was established by the Commonwealth (PCQ, 2012b) to achieve the following through their funding:

- Supporting patients, families and carers in the community
- Increase access to palliative care medicines in the community
- Education, training and support for the workforce; and

- Research and quality improvement

There are 17 Hospital and Health Service Districts in Queensland (including Child Health) all of which support palliative clients in their community who are allocated a division of this NPCP funding or in some documentation it is referred to as PCP funding. Strict criteria or classifications is often placed on client access with most regions in Queensland stipulating that access to this money is only available for persons in the last three months of life. This makes it difficult for service providers who are caring for persons with diseases that have a longer trajectory of decline as these clients are often not eligible for the NPCP funding yet still have a terminal illness. Some examples would be persons suffering with neurodegenerative illnesses or end stage organ failure (PCQ, 2012b).

As mentioned, the IHPA is required to develop Block Funded Criteria for hospitals where ABF is not practical. Rural and remote areas fall under the criteria of receiving block funded (Department of Health and Ageing, 2011b; IHPA, 2013a). Block funding is a system where public hospitals receive a fixed amount of money based on population and previous funding. The National Health Reform Agreement states that ABF funding should be implemented “wherever practical” but does recognize that some hospitals, in particular, rural and regional communities, would be better funded through block grants. The Agreement does acknowledge that there are costs over and above those able to be addressed using the ABF model, that are related to the capacity to deliver services to the local community (as cited in Health Policy Solutions, 2012, p.5). Therefore throughout Queensland most hospitals will be funded in accordance with the ABF model, however exceptions, such as some regional and rural hospitals will be block funded.
The future impacts of the reforms and the outcome of the recommendations forwarded to parliament by the Senate, and how that will impact service delivery, remain to be seen. However, at present, the flow chart of the current funding system for palliative care can be illustrated as follows in Figure 2:
**Figure 2. Flow of funding for palliative care services in Queensland**

(Queensland Health, 2013b; PCQ, 2012b).
In Queensland, one of the largest hurdles to palliative care service delivery is the lack of access to the PCP funding, which has not been increased to meet the dramatic increase in referral rates. There is a strict criterion a palliative client must meet in many districts in order for services like Blue Care to access the funding from Queensland Health. In most regions in Queensland, PCP funding is only available for persons who have less than three months to live. This becomes difficult for community nursing services who are seeking to support a person with terminal illness that may have a longer trajectory of decline (PCQ, 2012b).

PCQ (2012b) state contract funding from Queensland Health usually represents 40-60% of the annual income for such providers like Karuna, Cittamani (hospices) with the rest is made up from donations, bequests or community fund raising activities. Many of these non-government organizations (NGOs) struggle to meet the increasing demand as they try to balance this with increasing operational costs – (i.e.; insurance, accreditation, etc). Some NGOs were successful in obtaining funding via the 2010-14 National Partnership Agreement subacute funding round, however to obtain this money, certain key performance indicators have to be reached (PCQ, 2012b). Both macro and exosystems inevitably impact on the microsystem.

**Identifying and Engaging Microsystems**

Blue Care is one of Australia’s largest providers when it comes to delivering in-home palliative care (Blue Care, 2014). This domiciliary nursing service will apply to Queensland Health for funding when they determine one of their clients may be entering the terminal stage of their illness and will pass away within three months. As mentioned, the way the PCP funding is set up, the person should be in the last three months of life to be eligible (PCQ, 2012b). To determine when someone will die is difficult so often palliative clients live past the projected three months and their funding
runs out. This means that Blue Care often find themselves in the position of trying to locate new ways to continue providing care as they do not feel they can reduce the care when the person now needs it the most (Blue Care, 2014). Funding is usually limited to around one hour per day but in the last phase of life, when the person’s condition has significantly deteriorated, a palliative client could need more hours. It often works out that some of the required services cannot be funded under the palliative care funding so service providers such as Blue Care may need to draw on HACC funding, with patients paying a co-payment for care (Blue Care, 2014).

Testimonies on the Blue Care website highlight the benefits of allowing Blue Care nurses into an individual’s microsystem and providing support (Blue Care, 2014). The General Practitioner is a significant member when someone is terminally ill. Their involvement is likely to increase in a milieu of an ageing population and the number of patients choosing to die at home (Troller, 1995). Other organizations and individuals such as country organizations, church groups or volunteers can assist. Family and friends are invaluable and a major component of the microsystem, helping with meals and social support. It is well known that terminally ill persons who perceive they have inadequate support are more likely to experience psychosocial distress (CareSearch Palliative Care Knowledge Network, 2014). However, the strength of the microsystem will vary from family to family. On a larger scale, exosystems will also vary from state to state.

A Comparative Analysis of the States and Territories:

**Queensland.** As articulated in the introduction of this thesis, there are 17 hospital and health service districts in Queensland (one district belongs to Child Health) that receive a portion of commonwealth funding. Twelve of these districts provide limited specialist in-patient and community palliative care services with the remaining
five districts accessing specialist palliative care assistance in an informal, patchy, poorly funded ad hoc manner (PCQ, 2012b). Additionally, there are only seven hospices and one paediatric hospice that offer in-patient and home support, but are all situated in south east Queensland (PCQ, 2012b). Queensland is experiencing significant growth regarding referrals for palliative care but the funding is not congruent with the demand. In fact, Kristensen (cited in PCQ, 2012c, p. 3), then Chief Executive of Palliative Care Queensland, describes the situation as “dire” for the following reasons:

- There is no state-wide plan for palliative care service delivery
- Access to palliative care is inequitable
- Services are poorly funded and inadequately resourced
- There are severe shortages of specialist doctors, nurses and allied health staff
- There are significant gaps in education and research at a local level and
- No Queensland specific awareness raising/community education initiatives exist

These matters above along with other issues, such as paediatric palliative care and issues with palliative care in residential aged care facilities in Queensland have been submitted to the Community Affairs Reference Committee to be included in their inquiry. Remoteness and distance in Queensland were also mentioned in the investigation as matters of concern when it comes to funding allocation. This final report was finalised in October 2012 and was submitted to the Senate for review (Community Affairs Reference Committee, 2012). They were also submitted to the Health and Community Services Committee, a separate committee, which was set up by the Legislative Assembly in 2012 to investigate and report on palliative care services as
well as chronic and frail services in Queensland (Health and Community Services Committee, 2013). The Health and Community Services Committee (2013) responded in Report No. 22 with 63 recommendations being offered to improve palliative care service delivery in Queensland (Health and Community Services Committee, 2013). Outcomes of such recommendations are yet to be seen. However, inequities and discrepancies in palliative care service delivery in Queensland will be discussed throughout this thesis however palliative care service delivery for other Australian states needs to be reviewed to highlight the variances.

**Victoria.** Victoria’s model of palliative care has been named as the “gold standard” of palliative care, being considered one of the most comprehensive models in the country. The Palliative Care Resource Allocation Model (PCRAM) is based on a model developed by PCA that provides a formula for a more equitable allocation based on the needs of the population within defined geographical catchment areas (Community Affairs Reference Committee, 2012, p.48). PCRAM takes into consideration the following:

- Changes in the population
- Age structure
- Rurality
- Socio-economic status

There are 264 designated palliative care beds located across 30 health services in Victoria. Within the state, there are eight Regional Palliative Care Associations or Consortia as referred to in the Palliative Care Victoria (PCV) literature. The consortia facilitate regional palliative care planning and co-ordination in each of the eight health regions (three metropolitan and five rural regions) (PCV, 2012; State Government Victoria, 2011).
Victoria has 16 specialist palliative care consultancy service providers who offer expert advice and education to community, hospital and aged care providers (PCV, 2012). The Victorian Healthcare Association stated to the Community Affairs Reference Committee (2012) that a major reason for the state’s strength is not just to do with the amount of funding they receive but because of its distinct PCRAM delivery model (Community Affairs Reference Committee, 2012).

**Western Australia.** Like the state of Victoria, palliative care in Western Australia is a priority and well-funded by their state government. A prominent service provider in this state is Silver Chain, an organization that began as a small nursing provider 100 years ago and is now one of the largest palliative care nursing providers in the state. Approximately 95% of Silver Chain’s funding is provided by the Western Australian Government (Community Affairs Reference Committee, 2012; Silver Chain Western Australia, 2013). Additionally, the Western Australian Country Health Service (WACHS) is a country division of the Western Australian Health Department. It has seven regions in country Western Australia, with established palliative care teams in each of the regions. WACHS delivers acute and primary health services to regional districts, providing an integrated service delivery system which has a primary health care focus on small towns and isolated communities. Services are managed and adapted to address local needs with consultation with a wide range of key stakeholders (WACHS, 2011).

Besides Silver Chain and WACHS, the Western Australian Department of Health also funds the Palliative Ambulatory Services North; a service that can provide consultancy advisory support, patient reviews and consultations in complex cases, plus staff education services, particularly those working in aged care facilities (Bethesda Hospital, 2010; Community Affairs Reference Committee, 2012). In light of the recent
inquiry and literature, Queensland’s service delivery appears reduced when compared to palliative care service delivery in states like Victoria and Western Australia.

**South Australia.** The South Australia Government funds palliative care utilising a case mix approach. The South Australian Health Department believe they have adopted a sound framework for palliative care on two fronts – 1) the launch of the state-wide Palliative Care Services Plan from 2009 – 2016 and 2) the development and endorsement of the clinical network for palliative care which came into effect in February 2010 to support the plan. It provides strategies around how to move palliative care forward with consideration being given to the ageing population. The health department plan to move attention away from local palliative care services towards regional palliative care services, forming stronger partnerships with country services. This will reduce inequities for persons living in rural areas that wish to die at home and to ensure they are provided adequate support (Community Affairs Reference Committee, 2012; South Australia Health, 2009).

The Palliative Care Services Plan 2007-2016 utilises a delineation framework which is their own adaption of the national palliative care service delineation profile articulated in PCA’s (2005) Standards for Providing Quality Palliative Care document. The criteria for the Standards have been developed according to the four levels of care defined within a matrix model, almost identical to the one formulated by PCA. According to the plan, Adelaide will have three Level 6 palliative care services which will be based at three general hospitals. These three Level 6 services will serve as a tertiary level resource to a designated number of Level 4 and Level 2 services based in country South Australia with the aim of ensuring equitable access and consistent specialist coverage across the whole state (South Australia Health, 2009).
In September 2011, the Royal District Nursing Service (RDNS), South Australia’s dominant nursing service merged with Silver Chain, which is fast becoming recognised as an exemplary provider of palliative care on a national level. RDNS boasts over 500 nurses, expanded allied health staff and care workers, making over 15,000 home visits a week across Adelaide alone (RDNS, 2013). Now that the organization has become part of the Silver Chain group, they would be considered one of the largest in-home care providers in Australia.

Silver Chain was complimentary in its observations of the South Australia’s system as was Professor Vora, President of Palliative Care Australia in his response to Senate Inquiry who considered elements of the South Australian system “admirable” (Community Affairs References Committee, 2012, p.55). However, information provided by RestHaven, an aged care service provider, to the Senate Inquiry, indicated still more had to be done to regarding the linkage between aged care and specialist palliative care as the funding for any specialist palliative care is still retained within the public system. The concern was that there are insufficient numbers of general medical practitioners who have a specialised interest in palliative medicine. The knowledge of the General Practitioner regarding this sphere of medicine makes a difference to how easy it is for aged-care staff to manage an individual with high palliative care needs (Community Affairs References Committee, 2012). This is indeed evidence of South Australia’s moving forward in regards to palliative care service delivery and progressing towards reducing inequities.

**New South Wales.** As with nearly all states, palliative care in New South Wales (NSW) is provided at 1) primary, 2) specialist and 3) paediatric care levels, with the implementation of both metropolitan and rural models (Community Affairs Reference Committee, 2012). Within this state, there are 300 specialist palliative care
beds located in NSW public hospitals, affiliated hospitals and other facilities with care also being provided frequently in non-designated palliative care beds (NSW Ministry of Health, 2012). Of the 13,000 persons who die of cancer each year in NSW, about two thirds will receive specialist palliative care. There are significant gaps regarding access that still require addressing. Like Queensland, palliative care service delivery is not uniform, with persons living in rural areas being particularly affected (NSW Ministry of Health, 2012). In response, the NSW Government has pledged to develop new models of care, initiate new partnerships and establish better linkages across services to enhance and develop a more co-ordinated network of primary care, specialised care and community services. The government has committed an additional $35 million over the next four years to improve palliative care service provision in this state (NSW Ministry of Health, 2012).

However, reports provided to the Community Affairs References Committee (2012) by service providers, found that funding from the state government were lacking. As with Queensland, the referrals for palliative care support have increased but the funding is not congruent with the demand. New South Wales Health informed the Community Affairs References Committee (2012) that it is in the process of mapping palliative care services in accordance to population needs and investigating what other states are doing to ensure adequate services are provided across the state. However, according to HammondCare, a service provider specialising in palliative care, dementia care, rehabilitation, older adults’ mental health and other services, activity targets for sub-acute hospitals have “remained unchanged for too long, despite an increase in the number and acuity of palliative care patients as the population ages, and there is no mechanism for adjusting ongoing funding to meet these challenges” (Community
The future of palliative care service delivery in New South Wales remains to be seen.

**Tasmania.** From the 1980s onwards palliative care has gradually been evolving in Tasmania mostly due to the efforts of community activism, dedicated volunteers, the establishment of community-based teams in three regions, resulting in an in-patient palliative care unit in Hobart (established 1987). In the private sector, there are currently 19 oncology/palliative care beds Hobart. There was a six bed hospice in Launceston, but its doors closed when the three public beds were transferred to another healthcare provider in 2007. There are now three private beds and four public beds in Launceston (Tasmanian Association for Hospice and Palliative Care [TAHPC], 2013). However, there are still huge gaps in service delivery with TAHPC (2013) seeking urgent funding to improve resources, equity and accessibility across the state.

In 2004, the Tasmanian government commissioned a review of the provision of palliative care in that state and have been working on the recommendations that the review made. As a result, the Model for Palliative Care service delivery was developed and is now in use in three Tasmanian Area Health Services (Community Affairs Reference Committee, 2012; Eagar, Gordon, Quinsey, & Fildes, 2004). The TAHPC informed the Senate Inquiry committee that although progress has been made, more needs to be done in terms of “designated palliative care beds across the state” and there is a shortfall in the palliative care workforce (as cited in Community Affairs Reference Committee, 2012, p.59). On a positive note, the Tasmanian Department of Health and Human Services (TDHHS) added to the Senate Inquiry (2012) that although the three Area Health Services operate independent palliative care services, they have a consistent approach and meet monthly to network and discuss issues (Community Affairs References Committee, 2012, p.57).
Affairs Reference Committee, 2012). It is clear palliative care in Tasmania has improved but more funding is urgently required to improve quality and equity.

**Northern Territory.** The Northern Territory is fundamentally covered by two palliative care services, The Top End Palliative Care Service (40% Aboriginal/Torres Strait Islander clients) which operates out of Darwin and the Territory Palliative Care Service which operates from Alice Springs (50% Aboriginal clients) (Sullivan et al., 2003). There is a 12 bed hospice located on the grounds of Royal Darwin Hospital as well as a suburban home recently fitted-out and refurbished in Alice Springs through a Territory-Commonwealth Partnership Agreement to provide day care for palliative patients (Lambley, 2013; Northern Territory Government, 2013). The most significant difference between the Top End Palliative Care Service and Territory Palliative Care Service appears to be staffing (Northern Territory Government, 2009).

The Top End Palliative Care Service is a consultancy service which provides education and support to health practitioners in hospital and community settings as well as clients and families in urban Darwin and some rural and remote areas. Outreach services are limited for cost reasons, for instance, getting staff into remote communities and the lack of accommodation (Sullivan et al., 2003). The Territory Palliative Care Service also provides a specialised consultancy and education service throughout the Northern Territory, offering 24 hours a day telephone advice and support service (Northern Territory Government, 2009). The substantial challenge for Northern Territory palliative care service providers relate to accessibility to remote regions. Some remote regions are cut for six months at a time due to seasonal weather conditions raising concerns for palliative clients living in these areas (Sullivan et al., 2003).

There are no indigenous-specific palliative care services in the Territory; however, there are practice principles and implementation strategies that are culturally
appropriate for providing palliative care to Aboriginal and Torres Strait Islander persons (Department of Health and Ageing, 2007; Sullivan et al., 2003). These Practice Principles were formulated after extensive consultation with palliative care providers and Aboriginal and Torres Strait Islander peoples and their communities, with acknowledgement that no assumptions can be made and each palliative care client will have unique cultural needs (Department of Health and Ageing, 2007).

On May 24th, 2013, the Northern Territory Minister for Health praised the work of the Northern Territory palliative care teams for their commitment to patients with a terminal illness and their families in a media release. Lambley (2013) committed the Government to providing high quality palliative care for all persons in the territory. The Government currently provides approximately $8.5 million for palliative care services (Lambley, 2013). Maddocks and Rayner (2003) state in the Northern Territory great diversity exists with weather issues, such as the “wet season” being a major factor when providing palliative care (p.19). Additionally, even though some Aboriginal communities do have their own planes, and services and supplies may be maintained by this mode, road access, even in the dry, is still very difficult.

**Palliative Care in Rural and Remote Australia**

In Australia, and as discussed, hospices are much fewer in comparison to our American and UK counterparts. The service delivery of palliative care in Australia, particularly in metropolitan areas, is carried out by an interdisciplinary team of coordinated medical, nursing, allied health and social services who aim to integrate physical, psychological, social and spiritual care (PCA, 2003). However, it is clear from the research that persons living in rural areas are disadvantaged when it comes to the provision of palliative care and do not have the same access to service as their urban equivalents (McGrath, Holewa, & McGrath, 2007; Reymond, Charles, Israel, Read, &
Treston, 2005; Thomas, Hudson, Oldham, Kelly, & Trauer, 2010). In rural and remote areas, palliative care services are carried out by the local General Practitioner and community nurses. There is thus a requirement for the General Practitioner to possess certain skills and expertise, particularly when working with indigenous populations (Community Affairs Reference Committee, 2012; Yates, 2007).

The Rural, Remote and Metropolitan Areas (RRMA) classification was developed in 1994 by the Department of Primary Industries and Energy, and the Department of Health and Ageing (which was then called The Department of Human Services and Health). The classification puts rural and remote areas of Australia into categories in accordance to population size and an index of remoteness. The Services for Australian Rural and Remote Allied Health (SARRAH; 2013) state the RRMA uses population size and direct distance from the nearest service centre to determine seven categories – capital cities, other metropolitan areas, large rural centres, small rural centres, other rural centres and other remote areas. There are implications regarding access to resources and the way services are delivered in accordance to classifications such as the RRMA (SARRAH, 2013). Once one steps away from the metropolitan area and enters into a rural or remote categorised community, the palliative care scenario changes completely.

Humphreys and Wakerman (2008) state geographic location, which impacts accessibility to and availability of health services, and remote environments with encompassing factors such as socioeconomic status, lifestyles and indigenous issues are hallmark characteristics that shape practice and service delivery in rural Australia. The need to tailor policy responses to the context of rural and remote populations is crucial. Inequity and access are predominant issues that are consistent within the literature.
Additionally, Dade Smith (2007) states there are three major factors that impact a person’s health – their age, their culture and their geographical location. Living conditions, social isolation and socioeconomic disadvantage and distance from health services all contribute to the huge inequalities that currently exist. Those who live in rural areas die four years younger than other Australians, with the chance of an early death increasing with further remoteness (Strong et al., 1998). McGrath et al. (2007) state lack of equipment, lack of funds for equipment, lack of awareness about equipment, time delays, power problems, wet season, strain of travel for the ill person, lack of telephone service, lack of trained staff to meet palliative care needs, to name but a few, are all barriers to the delivery of effective palliative care to remote communities.

As stated earlier, once a traveller leaves metropolitan Australia, not only does the physical landscape change but so does the social and political environment along with the demographics and infrastructure (Wilkinson & Blue, 2002). It is important to remember the ecological systems that our rural dwellers exist within are different to the metropolitan regions. Health services to remotes areas are grossly underfunded, adding further disadvantage for those with a terminal illness. Economic and physical barriers such as geographical distance, lack of transport, poor quality roads and more expensive fuel as well as reduced services will impact rural families (White, Wall, & Kristjanson, 2004). Lack of psychosocial support and counselling services, particularly around bereavement is also a huge gap (Kenny & Allenby, 2013; White, Wilkes, Yates, & Cairns, 2005). According to Wakerman and Lenthal (2002) The Australian Institute of Health and Welfare (AIHW, 1998, p. 132) found that:

- The supply of GPs and pharmacists are dramatically reduced in remote areas
- Nurses provide the majority of the health care
• The number of medical specialists per capita of population is incredibly lower
• The more remote the area, the less supply there is of nursing home care
• Data reveals people living in remote areas use fewer services than those living in metropolitan areas
• Overall hospital rates are highest for those living in the remote zone

The Community Affairs Reference Committee (2012) received feedback from palliative care health professionals that getting appropriate staff to work in rural communities is and will continue to be a challenge. Whilst it is acknowledged it would be unrealistic to have specialist hospices and clinicians in every rural and remote pocket across Australia due to vastness and sparseness of the population, the need for hubs of palliative care specialists was recommended by Catholic Health Australia (Community Affairs Reference Committee, 2012). Formalised agreements between different parts of Australia, and an assurance that the hub is “up-skilled and adequate enough to provide support that does not become burdensome to that unit, so all Australians can be promised care if they require it” (Committee Affairs Reference Committee, 2012, p. 90).

The Inquiry also found there were also concerns about the roles of General Practitioners in palliative care and the expectations on them. An observation was made within the report that a proportion of doctors are overseas born and trained, having no specific knowledge of palliative care. Sometimes there is reluctance from them to take advice from a palliative care nurse. In rural communities, reliance on the General Practitioners’ competence is a significant factor in end-of-life cares and management for quality care to be achieved (Community Affairs References Committee, 2012).
In Australia, approximately one third of Australians live in rural areas, and another half a million live in remote areas of the country. Although the overall incidence of cancer is similar for rural dwellers as well as those living in metropolitan areas, the journey to end-of-life is likely to be more problematic when it comes to access for those living in rural and remote regions of Australia (White, 2007; White et al., 2005). In rural communities, the majority of the care is undertaken by the local doctor. Research indicates that General Practitioners see relatively low numbers of palliative care patients each year, limiting their opportunity to gain experience and expertise. Due to the context in which they work, education for rural doctors to up-skill is limited in comparison to General Practitioners in urban areas (Reymond et al., 2005; Trollor, 1995; White, 2007). Providing after-hours access, staff shortages, limited access to specialist services and allied health professionals and lack of financial reward for conducting home visits, including aged care facilities, have been identified as challenges for quality palliative care service provision in rural communities (Phillips et al., 2006; White, 2007).

Furthermore, McGrath (2010) states there is a lack of knowledge about hospice and palliative care service provision to Aboriginal persons in remote and rural areas. The issues are predominantly associated with transport, equipment, power, distance and telephone access. According to McGrath (2010) there is a serious lack of local, culturally appropriate palliative resources needed for quality end of life care. The absence of publicly funded health services is exacerbated by the material poverty of Aboriginals, who do not have the home resources needed for end of life care. Due to the scarcity of assistance, Aboriginals have to rely on acute care services such as the emergency department in hospitals, health clinics, General Practitioners, local nurses and nursing homes. Cultural preferences to die at home, connected to land and family
cannot be met. Indigenous Australians have the worst health status in Australia, and on some health indicators, they are categorised as the worst in the world (Dade Smith, 2007). To even evoke conversations around death and dying with indigenous persons can be a challenge within itself (House, 2013).

Additionally, the ABS (2011) report the average life expectancy for Aboriginal Australian men is 67.2 years of age and 72.9 years for Aboriginal women at a national level from 2005-2007. In comparison to their Caucasian counterparts whose men live to an average of 78.7 years and the women live to 82.6 years. The gap widens pending on which state one lives in. For example, the gap between indigenous and non-indigenous males is 14 years in the Northern Territory and Western Australia. Elston and Dade Smith (2007) state there are 1216 discrete Aboriginal and Torres Strait Islander communities in Australia, which are defined by geographic locations, bounded by physical boundaries and made up mostly of Aboriginal and Torres Strait Islander people. The health status of this clientele who live within these confines is poor, becoming more significant with remoteness.

Maddocks and Rayner (2003) highlight numerous issues when dealing with persons requiring palliative care in Aboriginal communities – 1) All Indigenous communities in Australia have a common heritage of loss 2) Death rates for are among the highest in the world, particularly so in the 25-45 year age group, which is 5-8 times higher than non-aboriginal Australians 3) Cultural considerations need to be understood and respected. This requires education on Aboriginal and Torres Strait Islander understandings of cause of disease, attributions of blame for sickness, the performance of ceremonies after death and the importance of dying on traditional lands and 4) Aboriginal and Torres Strait Islander Health workers in clinical care increases confidence in the healthcare system as a whole.
Cultural identity can become more profound at time of death – health professionals need to understand the pressure on patients as they face dying in a hospital setting. They will often resume their cultural identity at a time of crisis or chronic illness evoking a need for a cultural approach to be utilised to understand what is at stake and what really matters to the patient and their families (Ow, 2014). It can help identify how or to what extent why palliative care is not engaged with or is not being accommodated within the hospital setting (Chan, MacDonald, & Cohen, 2009). As stated by Chan et al. (2009), “patients are cultural beings, bringing to care contexts differing values, beliefs, customs, and varying perspectives about illness causation, preferred methods of treatment, fears about illness, and expected outcomes of healthcare” (p.117).

As mentioned in the introduction, Maddocks (2003) states Australia leads the rest of the world in developing contemporary palliative care. Maddocks (2003) purports our advancement is due to “the mutually supportive relationship among the diverse centres for the delivery of palliative care” (p.4) and “the high level of government support for palliative care initiatives over the past two decades” (p. 4). However, Maddocks (2003) does agree that palliative care has a long way to go for persons living with a terminal illness in rural, particularly Aboriginal and Torres Strait Islander communities.

The Senate Inquiry (2012) found that the Aboriginal population does not utilise the term palliative care and are of the belief they should look after their own. They do not necessarily know that assistance is available to them. There can be a disparity between what the Government thinks should be provided and what aboriginal families think should be offered. PCA (2012) purports that “all policies, procedures and processes of health care must respect and reflect different cultural and ethnic values,
beliefs and practices that surround death, dying and end-of-life” (as cited in Community Affairs Reference Committee, 2012, p. 155). PCA (2012) continues to state that the numbers of Aboriginal and Torres Strait Islander health workers need to be increased, appropriate training and education about cultural perspectives in end-of-life care is paramount along with the inclusion of palliative and end-of-life related topics in the core curricula for Aboriginal Health Worker Certificate three and four, with the continuation of the Program of Experience in the Palliative Approach (PEPA), to build on or further develop culturally appropriate education for indigenous workers (as cited in Community Affairs Reference Committee, 2012). The PEPA program enhances the skills and expertise of all health care providers in providing care for people who are living with a life limiting illness and their families, assisting with back fill and can travel to some communities and provide education.

As previously stated, statistics and research show that Australians are more likely to die in a hospital, despite home being the preferred option for 73% of Australians to die (PCQ, 2012b). This is problematic for Indigenous Australians where home is their traditional land and this is where many want to be when they die; a cultural factor that must be understood and considered by all health workers (Nadimi & Currow, 2011). In Australia there are poignant cultural differences in the way disease, death and dying are understood by Anglo-Australian society and Aboriginal and Torres Strait Islander people (McGrath & Holewa, 2006). McGrath (2010) states that research in the area of palliative care service delivery to Aboriginal peoples is still in its infancy, there many gaps to address as verified by the literature presented within this chapter. This is an area of research that requires further exploration and investigation to improve the lives of our indigenous population whose life expectancy is much less than their Caucasian counterparts (Strong et al., 1998). One is reminded of Fred Hollows’
standpoint of seeing the world as the “haves” and the “have nots” and decided something needed to be done to address the disparity, particularly for Aboriginal and Torres Strait Islander peoples in rural communities (The Fred Hollows Foundation, 1993).

Conclusion

This chapter has examined the literature on what palliative care actually is in its contemporary form, with due consideration to its evolvement over time in the UK, USA, Canada and Australia. Historical factors have contributed largely to its development and how services are delivered. Comparisons were made between the varying modes of service delivery to emphasise the differences. Hospice care is relatively minimal in Australia when compared to the UK and the USA. Research indicates much of palliative care is carried out in hospitals in Canada and that access to hospice care is unlikely for many. In Australia however, care is mostly administered in hospitals or at home through a specialist palliative multi-disciplinary team; but this is mostly for persons living in metropolitan areas or large regional communities. General practitioners and community nurses will take responsibility for care in rural communities; however dying at home is less likely with increased remoteness.

Human rights advancements and the need to continue to put forth the importance of psychosocial care as part of the palliative care approach within this framework, was highlighted. Macro influences such as policy and funding were also examined, with a break-down of complex processes and how they trickle down through exosystems, such as community nursing organizations that are the frontline workers delivering care to those living in rural and remote areas of Queensland (microsystem). After all, what policies are in place and what monies can be accessed will predominantly impact what services can be offered to a terminally ill client.
The states within Australia vary significantly in their funding and service models. The literature revealed this matter basically boiled down to how each state prioritises palliative care. Queensland appears to be lacking in comparison to other states. The issue has been repeatedly been put forth in political forums by means of numerous submissions, filled with recommendations with outcomes yet to be seen. Finally the chapter was completed by putting the spotlight on Aboriginal and Torres Strait Islander palliative care and how this issue is in need of further exploration and review.

Now that the milieu in which palliative care operates within has been established, Chapter Three will review the delivery of psychosocial care, a major component of effective palliative care. Considering a terminally ill person as a whole person with pain other than physical is pivotal to palliative care philosophy and entrenched within the literature.
Chapter Three

Literature Review

Part Two: The Psychosocial Domain of Palliative Care

Good quality psychosocial care will assist persons and their families living with a terminal illness to adjust to physical, psychological, emotional, social, spiritual and cultural changes as death draws close. It can effectively reduce anxiety and depression; improve adaption to a stressful situation, not just for the patient, but for both patients and families; as well as enhance peace of mind. Distress, fears and concerns are all normal reactions when a prognosis is poor, however the brunt of impact can be minimised with the support of skilled health professionals who provide genuine, empathic care at a vulnerable time. The purpose of this chapter is to explore such issues in relation to the literature with a focus on a social workers’ role in delivering psychosocial care.

The previous chapter presented the journey of palliative and hospice care on an international scale, featuring how historical developments and macro influences have strongly impacted the way palliative care is administered in its current contemporary context. The information provided clarity and insight into how palliative care is delivered, not only on the world scene, but in Australia and its states. This background knowledge provides the backdrop as the focus shifts to exploration of psychosocial care provision to palliative clients living in rural and remote areas of Queensland. The important role of health practitioners, including social workers, is examined within this context.

This section will begin by providing a definition of what psychosocial care is, highlighting its significance and its benefit. This will be followed with a detailed explanation of each psychosocial concern – psychological issues, emotional issues,
social issues, spiritual issues, cultural issues, practical issues and bereavement complexities. The team approach to palliative care service delivery will also be presented and why this is considered the optimum mode of care.

The focus will then transfer to what the literature states regarding the psychosocial domain becoming a blurred and ambiguous sphere of care. As highlighted in the previous chapter, in countries like the UK, social workers have been entrenched in the history of palliative care. However, in Australia, social workers do not have such a strong, proud historical claim, particularly in rural communities. Traditionally, nurses have taken on the role of psychosocial care in this domain.

Christ and Blacker (2006) state social work perspectives, skills, views and expert knowledge set them apart to offer high quality assessments and interventions. They are trained to practice from a “person-in-situation” standpoint, which is invaluable when dealing with patients and their families as they approach the end of their life. However, it cannot be ignored that almost all of the palliative care literature on social work activity is written within the context of specialised palliative care teams and not for the generalist social worker. This paucity in the literature will be acknowledged, with an illumination on some of the challenges faced by the rural generalist social worker, working with palliative clients on an intermittent basis.

The chapter concludes with an examination of nursing literature which highlights the stresses nurses experience in trying to access skilled health professionals, to address psychosocial care needs. They have to take on this role themselves, often with reluctance and a lack of confidence. This very literature evokes confusion, as social workers work in many rural communities and claim dominance over the psychosocial sphere, yet nurses state they cannot access them. This discrepancy also became a point of interest for this study.
Defining the psychosocial domain of palliative care

The term “psychosocial” can be linked to psychologist Erik Erikson (1959) when he first formulated his theory that a developing human being will pass through eight psychosocial developmental stages, each with conflict and challenges that require mastery. Each stage is said to build upon the success of the previous stage (White, Hayes, & Livesey, 2005; Erikson 1959). Although the theory is not without its critics, particularly around its lack of universal application to resolve each developmental crisis, the theory does bring attention to significant psychosocial events across the lifespan (McLeod, 2008b). In keeping within Erikson’s meaning, psychosocial issues clearly relate to one’s psychological development in accordance to one’s interaction with their social surroundings.

Since this time, a variety of definitions can be found, but most refer to Erikson’s (1959) original concept of a person’s psychological development in accordance to one’s interaction with their social environment. The Mirriam-Webster Dictionary (2014) [On-line] defines psychosocial as “relating social conditions to mental health.” The Oxford Dictionary (2013) [on-line] defines psychosocial as: “relating to the interrelation of social factors and individual thought and behaviour”. The Free Dictionary (2014) [on-line] defines it as being, “the mind’s ability to, consciously or unconsciously, adjust and relate the body to its social environment.” These meanings define the concept as predominantly relating to psychological and social factors. In palliative care literature the term psychosocial is utilised more extensively and is more encompassing than this.

The National Council for Hospice and Specialist Palliative Care Services (1997, cited in Jeffrey, 2003) defined psychosocial care as “concerned with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into an adaptation to the illness and its consequences, communication,
social functioning and relationships” (p.3). Spirituality and culture are not mentioned here although it could be argued that spiritual beliefs and cultural matters are closely aligned with psychological schemas and social relationships (Ow, 2014). An example of this may be a palliative client who believes in Buddhism. He or she may closely attribute their diagnosis with the debt of past karma that needs to be paid and move into coping and acceptance as their belief system impacts the way they think about their disease. In regards to culture, a Muslim woman with a terminal illness may still be seen as serving her husband without complaint despite being chronically unwell. This may be totally acceptable to her and provide a sense of normality. Much of the literature discusses psychosocial issues at length but does not provide a universal, succinct definition of it, leaving it open for add-ons and omissions. There appears to be an assumption that the reader knows what it entails, thus proving a need for the term to be clarified to thwart obscurity.

Bendelow and Williams (1995) state pain should be not merely reduced to a physiological symptom, but rather pain must be seen as culturally shaped by a person’s worldview, needing an approach that incorporates “physical, emotional, biological and cultural, even spiritual and existential” (p.99). Sheldon (1997) provides the example of persistent vomiting or diarrhoea and how this may impact the person’s view of their God or their relationship with their partner. In other words, Sheldon (1997) purports that psychosocial aspects of care must also be concerned with how physical symptoms interact with these psychosocial domains. Most palliative care literature defines psychosocial care as directly correlating to psychological, social and spiritual concerns (Fallon & O’Neil, 1998; WHO, 2002). Dix and Glickman (1995, cited in Reith & Payne, 2009) incorporate the emotional and cultural aspects as well. This is closely aligned to the conceptualisation of Saunders who, as mentioned, attributed the concept
of “total pain” as not just physiological suffering but also incorporating a person’s psychological, social, spiritual and practical concerns (Clark, 2000; Ong, 2005; Reith & Payne, 2009). Jeffrey (2003) and Dix and Glickman (1995, cited in Reith & Payne, 2009) also adds practical matters such as housing and finances, in his concept of psychosocial care, whereas other literature does not include the practical component. Dix and Glickman (1995, cited in Reith & Payne, 2009) is a comprehensive definition that encompasses all aspects of the psychosocial domain as follows:

Patient:

- To maintain identity
- To maintain control and independence
- To receive psychological, emotional, and spiritual support

Family members and caregivers:

- To acknowledge individuality
- To recognize the part they play
- To receive psychological, emotional and spiritual support

Common needs of patients, caregivers and family members:

- Recognition of ethnic, cultural, and spiritual needs
- Information about and access to state, private, third sector help and self-help organizations
- Advice and information to specialized legal advice – ie; making a will
- Advice on post-bereavement practical problems
In accordance with the definitions articulated above, the psychosocial domain is therefore described as involving the psychological, emotional, social, spiritual and cultural aspects of a person with practical issues playing a role. This thesis will thus refer to all of these domains as belonging to the psychosocial sphere as demonstrated by Dix and Glickman’s (1995) definition (as cited in Reith & Payne, 2009). Although bereavement is closely associated with the psychological, emotional realms and even the spiritual domain for some, it will be mentioned separately within this context, because of its uniqueness and implications. All of these psychosocial issues are likely to interplay with each other and will impact coping in either a positive or negative way (Sheldon, 1997). As mentioned, practical matters will also influence a situation, as pragmatics, such as an inability to pay a bill due to loss of income, may exacerbate a palliative client’s anxiety. Although not usually incorporated in the literature as part of the psychosocial category, it warrants a place as purported by Jeffrey (2003). Each psychosocial issue therefore deserves a thorough explanation in relation with the literature and will be presented as follows:

**Psychological Issues**

Studies indicate psychiatric co-morbidity or psychological distress is prevalent in cancer patients, which will demonstrate itself in the form of adjustment issues, depressed mood, anxiety, impoverished life satisfaction and loss of self-esteem (Passik & Kirsh, 2003). Psychological distress has been defined as a “unique, discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent, to the person” (Kelly, McClement, & Chochinov, 2006, p. 779). Patients in psychological distress can feel a sense of hopelessness, thoughts of worthlessness, existential or spiritual crisis and overall suffering which can result in a reduced capacity for pleasure, no sense of
meaning, a lack of ability to connect with others and an overall feeling of negativity (Kelly et al., 2006).

Furthermore, Pessin, Rosenfeld, and Breitbart (2002) state sometimes both patients and clinicians avoid discussing psychological despair because of fears that open conversation of this nature may aggravate distress or distract the doctor from pertinent medical issues. Tools have hence been developed to detect psychological distress in terminally ill patients so effective interventions can ensue (Psycho-Oncology Co-Operative Research Group [PoCoG], 2014). However, such measures can be time consuming and cumbersome, hence their use in routine clinical palliative care teams are often limited (Pessin et al., 2002).

Peterson (2004) states the way a terminally ill person copes with their impending death may depend upon their age, gender, culture, temperament, the nature of the illness and social support. Coping mechanisms will psychologically protect individuals by reducing the level of anxiety, helping them adjust to the situation they are in. Some persons may use intellectualization as a means to reduce anxiety, by learning all they can about the disease in order to avoid distress and remain distant from the reality of the situation (Cherry, 2014). In contrast, others may use denial as a coping mechanism, which is a form of disbelief or avoidance; a coping strategy used when reality is too painful to tolerate (Kennedy & Charles, 2001).

Health professionals can sometimes struggle with denial or what they may refer to as unrealistic hope. However, to make a judgement that unrealistic hope has phased into denial is extremely difficult and a highly sensitive issue that needs to be handled with care (Sheldon, 1997). Denial is seen as satisfactory in the early stages of when a person is told their prognosis; however it is viewed as an obstacle to palliative care if a person does not progress into what is termed as “acceptance.” Denial can be viewed by
many health workers as a hindrance as it can stand in the way of open discussion around dying and care planning. Acceptance is deemed to be integral to palliative care and an ultimate psychological goal (Zimmermann, 2012). However, as the literature highlights, denial is not necessarily negative, and although it may be hard for health professionals to work with, it protects a person from overwhelming psychological pain and confusion (Lazarus, 1998; Kennedy & Charles, 2001). The person often has an awareness of the reality of the situation but it is just too painful to “go there.”

An individual with capacity can choose to view their illness how they like; needing to be responsible for their own actions and beliefs once they have been informed of their prognosis (Sheldon, 1997). There are two schools of thought when it comes to denial, 1) the Freudian view that denial distorts reality and is pathological and 2) the view of psychologist, Richard Lazarus, that denial is a coping mechanism and a method of avoiding stress regarding the illness (Sheldon, 1997; Zimmermann, 2012). Hope, denial and coping are integral to palliative care and fall under the psychosocial umbrella and should be addressed with respect and unconditional positive regard for the patient.

Sometimes persons use cognitive restructuring techniques as a means of dealing with stressors in their lives (Baron, 2001). One does not have control over critical events that occur but one does have control over how they react to them. Controlling thoughts as a method of replacing a negative appraisal or belief about an event to a more beneficial one is to think about it differently (McLeod, 1998). This technique of introducing more helpful self-talk is implemented at times of stress, resulting in modified adaptive thoughts (Baron, 2001). Cognitive restructuring is a part of Cognitive Therapy and Rational Emotive Behavioural Therapy where an individual can be assisted by a counsellor to challenge and change unhelpful beliefs (Payne, 2005).
Studies indicate altering irrational beliefs have been highly effective in treating depression (Baron, 2001). However, Payne (2005) states the technique has had limited use in specialised settings with particular client groups. One European study states it is less recognized that persons with terminal cancer are able to cognitively restructure their life situations and create meaning. The study identified a gap in the literature on this topic (Van Der Lee, Swarte, Van Der Bom, Van Den Bout, & Heintz, 2006).

Other techniques such as externalising a stressor, such as physiological symptoms of cancer, by giving it a name, such as “it’ or “the thing” can help to separate the issue from the person, allowing them to see it as if from afar and deal with it as if it is a disconnected identity. This coping strategy has proved helpful providing the individual with a sense of mastery over the situation (Dallos, 2006; Geldard & Geldard, 2001). This method, when introduced by a counsellor, is linked to narrative therapy, a post-modern approach that contends narratives shape a person’s identity and can become focal points for intervention (Healy, 2005). Morgan, (2000) states when people are separated from their problem, their competencies and abilities become more visible. Although the end result for the palliative client will ultimately be loss of life, such techniques can be beneficial to enhance quality of life throughout their journey.

Health professionals have to be careful about trying to remove any coping strategies that may be working for the patient (MacDonald & Hobbs, 2008). If the patient has been given correct information about their disease status and they are not making detrimental, negative decisions for themselves or their families; then it is not actually harmful for patients to have an optimistic outlook (MacDonald & Hobbs, 2008). Of noteworthy interest, there can be differences between genders regarding how a terminally ill client will receive and consider their prognosis. Female clients are more likely to be vocal and active in their discussions, whereas men tend to be more passive
and less communicative (Fletcher et al., 2013). Despite this, coping mechanisms should be seen for what they are; and treated with utmost sensitivity and respect. This only amplifies the need for health professionals to possess specific skills and expertise when working with the dying.

Additionally, Kubler-Ross (1970) purports an individual’s personality may also influence the way they cope with a life-limiting illness. This is in congruence with Peterson (2004) who also contends temperament is a factor when assessing how a terminally ill person deals with their situation. A prominent personality theory states the human personality is made up of five core elements – openness, conscientiousness, extraversion, agreeableness and neuroticism (Baron, 2001). Although the theory has its critics, these dimensions of the human personality, also known as the “Five Factor Model” has formed the basis to measure what a person is like and how an individual copes with stressors (Block, 1995). Baron (2001) states the dimensions are indeed basic; however, conclusions can be made where an individual stands along these dimensions and how they are likely to respond or behave. An example is Carver and Connor-Smith’s (2010) study which found low neuroticism plus high extraversion or high conscientiousness predicts lower stress exposure and threat appraisals.

Furthermore, Chochinov et al. (2006) state that although the influence of personality and coping with end-of-issues has not been extensively studied, however a strong correlation exists between the personality characteristic, neuroticism and end of life sources of distress. This would include depression, anxiety, a sense of dignity, quality of life, hopelessness, concentration and outlook for the future. Although under researched, it appears certain personality traits may come into play into how well they cope and adjust with is happening to them.
Research continues to purport that recovery rates from cancer, are not higher among patients who take a positive attitude about battling their illness (Payne, 2004). A study by O’Baugh, Wilkes, Luke and George (2008) found their patients did not state a positive attitude increased their survival or cured them; however it had a strong influence in getting through every day events of the journey. Although there are studies that highlight the reverse to be true, researchers and critics, state these cases are in the minority and flawed in serious ways (Chopra, 2011). There are countless anecdotes of people who are adamant they have lived longer because they possess a positive attitude. Whilst this remains a contentious issue; it can be argued there is a strong correlation between body and mind. In this modern age, breakthroughs in the mind-body connection have led to therapies such as yoga, meditation and stress management techniques being incorporated into the treatment regime which have increased coping (Komarnicki, 2013).

**Emotional Issues**

As mentioned in Chapter Two, Elisabeth Kubler-Ross (1970) was the first person to record and analyse the experiences of dying people and how they moved through a series of emotional responses, such as denial, anger, bargaining, depression and acceptance prior to facing their inevitable death (Kubler-Ross, 1970; Sheldon, 1997; Peterson, 2004). These responses are not sequential and not everyone will experience them. Additionally, many will die without ever reaching acceptance, however, Kubler-Ross’s theory undeniably brought the taboo topic of death out of the closet and onto the world stage, opening it up for discussion and review. Although her critics remain, many health professionals continue to use some of these tenets in their work with the dying today (Peterson, 2004).
Since this time, a plethora of literature exists regarding the emotional responses of the dying. This has provided the evidence needed for skilled counsellors to assist the dying with some of the emotional responses that may cause distress. Two such studies will be highlighted subsequently.

A research project undertaken in a Japanese hospice (Morita, Tsunoda, Inoue, & Chihara, 2000) involving 162 terminally ill patients found persons experienced the following emotional responses:

- A sense of dependency (39%)
- Meaningless in present life (37%)
- A sense of hopelessness (37%)
- Feeling a burden to others (34%)
- Loss of social functioning (29%)
- Feeling emotionally irrelevant (28%)

An American study that considered the existential needs of an ethnically diverse population, reported that 51% of cancer outpatients experienced difficulties with overcoming fears, finding hope (42%) and meaning in life (40%), finding spiritual resources (39%) or someone to talk about finding peace of mind (43%), the meaning of life (28%) death and dying (25%) (Moadel et al., 1999). It is clear opportunities need to be provided for persons experiencing emotional pain to have the chance to talk to someone they feel comfortable with about their feelings. Skilled counsellors can assist with words of comfort and reassurance and appropriate therapeutic responses to ease the turmoil one may feel as they approach death. Finding ways to assist coping and evoke peace of mind are paramount.
Folkman and Moskowitz (2004) define coping as a series of thoughts and behaviours that are drawn upon in situations of emotional distress. Coping is a process that emerges when circumstances are perceived as significantly stressful or highly taxing (Folkman & Moskowitz, 2004). The individual is said to appraise that certain goals, ambitions, plans have been harmed or lost, leaving the person feeling threatened and vulnerable. One of the first tasks of coping is to down-regulate the negative emotions that are hindering the coping process. The emotions continue as an integral component to coping as new information emerges and reappraisals of the situation occur. The context in which the stressful event is occurring is of utmost importance (Folkman & Moskowitz, 2004).

Lingren (2013) adds that emotional responses co-exist with coping mechanisms but they do not always protect the person from the trauma of loss. Emotional reactions are a way for the individual to release emotions and feelings associated with their situation. Some reactions are anger, guilt, fear and anxiety, loneliness and depression. Unfortunately, according to Hodgkinson (2008), health professionals are not always skilled at identifying distress, have never received training on how to communicate with an emotional individual and lack confidence to do so. Given this is the skill set of social workers; it could be argued that social workers or counsellors should be an integral part of the multi-disciplinary team.

Social Issues

Aristotle conceded that, human beings are social animals. Our lives depend upon other people from the moment we are born and so it is when we are close to death (Aristotle, 350 BCE, cited in Tardy, 2013). As death comes closer, palliative clients are usually more confined to their homes and a social withdrawal will occur either from themselves or from others (Lawnton, 2000). Much of the time is spent around pain
management and resting. Social engagement proves harder due to physical symptoms (Canadian Virtual Hospice, 2014). Withdrawal is likely to come from within the person who is living with a life limiting illness, however stigmatisation of the effects of the illness and the knowledge that the person is going to die, can cause family and friends to gradually remove themselves from the situation (Lawnton, 2000).

Withdrawal is a natural part of the process of dying as a person begins to separate from the outside world (Canadian Virtual Hospice, 2014). This will begin with friends and other social institutions and progressively incorporate close family members. It is often related to profound weakness and reduced capacity to communicate with others. It can also have an emotional or spiritual motivation in that they prepare for their impending death, turning their attention increasingly inward (Canadian Virtual Hospice, 2014). This is a gradual process and becomes more overt as death becomes closer. Family members may draw on support from the community or close social contacts as they journey with their loved ones towards end of life. The palliative client may also partake of this support until the natural withdrawal begins to occur.

A study by Horsfall, Noonan, and Leonard (2012) re-focuses the medical approach to death towards a communal and social perspective, considering social and community networks as potential contributors to assisting persons die at home. Caring can contribute to social capital with carers and the cared for being part of a network of relationships (Horsfall et al., 2012). The medicalization of death can be reconsidered and seen through a more social lens. Informal social networks can be mobilised to assist families keep their loved one at home for as long as possible. One recently proposed palliative care model identifies the terminally ill client at the centre of a network which incorporates inner and outer networks, communities and service
organizations, all of which are fortified by policy development (Abel et al., 2013). Health professionals should always consider, along with the patient, families as the primary unit of care (Phillips, Bernard, Phillipson, & Ogg, 2000; Schuler, Zaider, & Kissane, 2013). However, families need support and there is a growing body of research considering the community as assisting in providing this (Freeman, Ramanathan, Aitken, Dunn, & Aird, 1998; Horsfall et al., 2012; Abel et al., 2013). Other research purports attending social support groups can enhance coping and positively impact emotional states and adjustment to illness (Zabalegui, Sanchez, & Sanchez, 2005).

Additionally, Sheldon (2003) states for a number of advanced cancer sufferers and their carers, social isolation can be a source of pain in some instances. Particularly for carers, expected support from some persons may not be forthcoming, causing one to feel rejected and confused. Isolation can have a negative impact in that it may contribute to feelings of loneliness, a sense of alienation, decreased feelings of self-esteem and control (Cohen, 2004).

An experienced health professional will assess who the primary supports are by utilising genograms and asking questions to ascertain who can be mobilised to assist if needed (Reith & Payne, 2009). Although caring for someone at end-of-life is a highly rewarding experience, it can be tiring, overwhelming and stressful. To link into supports a patient and carer are comfortable with, to share the responsibility or provide emotional or practical support can be invaluable.

Furthermore, it should also be acknowledged, that for many persons who live alone and do not have a primary caregiver, it will be unlikely they will be able to die at home, even if this is their desire (Aoun, Kristjanson, Currow, Oldham & Yates, 2007).
The absence of a caregiver will significantly impact a terminally ill person’s journey towards end-of-life.

**Spiritual Issues**

When reference is made to spirituality, it does not necessarily mean the person must have a religious affiliation or belief system (Rumbold, 2003). It can also incorporate existential issues such as one's personal search for the meaning of life and death, and hope (Moadel et al., 1999; Carroll, 2001). It can encompass unfulfilled ambitions, past regrets and the maintenance of dignity (Pessin, Potash, & Breitbart, 2003). Cobb (2003) states when people have to contemplate their own death, it essentially means contemplating their impending non-existence in the world as they know it. Questions may be asked such as, “why me?” to further questions about life after death. Spiritual beliefs can come to the forefront at a time of transition or change, for example, when trying to make sense of a prognosis regarding a condition that is no longer curable. Some persons may choose not to disclose these quandaries whereas others may openly seek to resolve them. In palliative care, spirituality, whether abstract or overtly religious, may impact on how the person copes with their journey towards end-of-life.

Adams (2008a) states re-evaluating ones purpose in life can be positive within the framework of one’s religious or spiritual beliefs. Responses will often vary from patient to patient and much may depend on where the person is within the disease trajectory or their physical symptoms at the time. However, for others, particularly those suffering a recurrence of a second cancer, this can trigger a more profound existential crisis, resulting in a sudden awareness of their own mortality and the real threat that their existence as they know it will end (Adams, 2008a). A powerful threat to the emotional equilibrium of the patient and their families are therefore evoked.
Health professionals need to be alert to such matters, ready to support and assist by offering a safe space for the person to express their concerns. It should be noted, sometimes just actively listening, without jumping in with commonplace reassurances, can alleviate distress (MacDonald & Hobbs, 2008).

Furthermore, patients may feel a need to undertake a life review, reflecting on their identity, family relationships and past experiences. However, this could leave them at risk of dissatisfaction and a sense their life holds no meaning at all (Adams, 2008). Studies indicate that beneath the banners of social support and communication, existential concerns are prominent in the minds of cancer patients (Rosenbaum et al., 2006). Some health professionals feel inadequately prepared to offer spiritual care or to initiate conversations around existential or spiritual distress, leaving this particular psychosocial issue neglected or overlooked (Adams, 2008a; Penman, Oliver, & Harrington, 2009). The importance of raising the matter was also emphasised by another study that found religious beliefs do influence a person’s end-of-life decisions despite not always being accepted blankly by physicians (Cohen et al., 2008).

On the other hand, Sheldon (1997) also describes hope as a dimension of spirituality. The Australian Pocket Oxford Dictionary (1996) defines hope as being, “an expectation and desire for a thing” (p.525) and “to cling to a mere possibility” (p. 525). McGee (1984) refers to hope as being a “fragile blanket” (p.34) that covers an array of emotions for persons encountering illness. Hope is one factor that can make life meaningful, provide a reason to keep moving forward in times of stress and anguish. With hope, physiological and psychological defences can be fortified, with its absence having been correlated with an early demise (McGee, 1984). Hope is a topic that arises in palliative care that is not only an aspect of the spiritual dimension but also is influenced by a person’s culture or living environment (Sheldon, 1997). Smith (2000)
states health professionals need to be aware that there are different types of hope, despite a person being told that there is nothing that can be done to alter the disease. Patients may sometimes need to redefine hope and could need guidance to do so. Smith (2000, p. 81) offers insight into five different ways hope can be thought of:

- True hope is always based in reality
- Hope can and does change as one’s reality changes
- Finding areas of hope in a threatening situation enhances hope
- Each person’s hope is personal and unique
- Hope seems to follow a progressive path of development

Another study found relationships and love were closely entwined with spiritual engagement (Penman et al., 2009). When a person has a terminal illness and requires a level of care, there are experiences of complete selflessness, a demonstration of unconditional caring from one human being to another, the show of concern, long-suffering, kindness without expectation of reward, remaining totally present and rendering service to a loved one that is more vulnerable, are manifestations of spirituality along with the more overt religious practices or existential discussions (Penman et al., 2009). There is often very little reciprocated back to the caregiver when a person is approaching death. The patient may sleep for extended periods of time and is often not always wholly present when awake. But a gentle smile, a soft squeeze of a hand can evoke feelings of immense love as the caregiver continues to offer his or her service unconditionally and wholeheartedly.

However, in contrast one’s spirituality can be negatively impacted by the actions of a church (Robbins, 1995) or a terminally person may reject their religion all together,
turning away from their previously held beliefs due to an inability to make religious

sense of the current situation (McGrath, 2003).

Cultural Issues

Chan et al. (2009) state culture is an “elusive concept that is both complex and
continually evolving” (p.117). It has been narrowly defined as strongly connected to
ethnicity, particularly in palliative care, especially around reasons why some cultural
groups do not engage with palliative care services. For example, there is much
discussion regarding Aboriginal culture and their reluctance to openly discuss death and
thus engage with palliative care services (House, 2013). However, equating culture
with ethnicity can be a narrow view and should be expanded to other areas such as
family culture, workplace culture, peer culture, rural culture etc. Seeing the bigger
scope of culture will promote best practice when it comes to palliative care.

Furthermore, the literature states every culture forms attitudes, rituals or
particular ways of handling life cycle events such as death; all of which needs to be
respected by health professionals (Edwards, Dade-Smith, Smith, & Elston, 2007;
Sheldon, 1997). In Australian society, cultures can dwell collectively in certain
communities infiltrating that particular town with their array of foods, rituals and rich
festivities. Most cultures hold certain attitudes when it comes to caring for the sick,
elderly or dying impacting the extent of how much outside professional support is
accessed. Whilst this can be a positive aspect to any culture, the down side can be that
expectations may be beyond what a caregiver can cope with if holding down a full-time
job and having numerous other responsibilities.

In rural areas, pertinent cultures also exist. Rural attitudes, connected to country
culture such as “we can cope; we don’t need help” belief systems, all impact whether or
not access to outside professional help is sought out. Country persons are generally
guarded about health professionals who tend to stay relatively short-term so trust and rapport will often take more time to establish (Edwards et al., 2007). Besides having to earn the trust of locals, health professionals generally have to prove they are going to stay for a while before referrals to their service will be accepted. Hyatt (2012) states trust can take months or even years to build. The rural attitude of being tough; stoic, and seen as coping is the norm rather than the exception. Rural culture and environmental factors do interact with rural dwellers lives and their subjective experience with cancer (Bettencourt, Talley, Molix, Schlegel & Westgate, 2008). Rural culture can have significant influence regarding seeking professional support.

Health practitioners can never make assumptions around culture as there are cultures within cultures. Cultural viewpoints can be abandoned throughout the lifespan but then returned to in times of crisis (Sheldon, 1997). Chan et al. (2009) state that by adopting a broader view of culture instead of narrowing it down to ethnicity, will provide a useful means for better understanding what is meaningful to the patient and their families and what is important to them at the end of their lives. This is particularly pertinent when it comes to dying in a hospital setting as cultural views on this place of death should be considered. Cultures are a set of guidelines which tells a dying person how to view the world, right from preferred place of death down to favourable food to eat, rituals and symbols of comfort (Sheldon, 1997). Health professionals need to take time to explore a patient’s cultural views but not solely through the narrow lens of ethnicity.

**Practical Issues**

As mentioned in existing research, practical issues that arise when living with advanced cancer can evoke anxiety and concern (Jeffrey, 2003). As part of psychosocial assessments, pragmatics is a crucial factor to explore. A person with
terminal illness may have heightened anxiety around how the rent is going to be paid now that they are no longer working, can the surviving spouse afford to keep living in the house they are in once they are gone, will there be enough money for a funeral. Questions of who will look after the children and how will whoever is caring for them afford their schooling, clothing and other needs, will all impact on their experience of pain and their journey with their illness (Sheldon, 1997).

Other issues that need to be considered are related to Advance Care Planning (ACP). Issues such as Wills, Enduring Powers of Attorney and Advance Health Directives all need to be discussed and organized. ACP allows persons, with decision-making capacity, to record their wishes for what treatment they would want or would not want in the future if they were to lose competency (Cartwright, 2006). This is advisable for every Australian. What arrangements one would like for their funeral may need to talked about so wishes may be respected and the cause for dispute at a time of grief and sadness can be avoided. Social workers can assist with such matters as family members often find these issues hard to raise. Monroe (2010) states social workers can also assist with facilitating packages of care in the community, such as Meals on Wheels or linking into community or government agencies. This can involve assisting with paperwork for Carers payments, disability parking permits or food parcels if necessary.

In light of the above, the term psychosocial, is thus referred to in this thesis as relating to the holistic philosophy on which palliative care is based, pertaining to a person’s psychological, emotional, social, spiritual and cultural needs as defined by Sheldon (1997). This is considered within the milieu of how physical symptoms interact with these aspects of a person living with a life limiting illness and their
experiences. Practical matters contributing to a person’s well-being and psychological functioning should always be considered within this context.

**Bereavement**

To lose someone we love is to be deprived of an endeared presence that may have even been taken for granted. Loss creates an unpredictable world where attachment, reliability and dependability on a presence, and the associated emotional investment, leaves a deep void (Martin & Weston, 1998).

There are numerous models and theories that attempt to explain the complexities around loss and grief and how best to deal with bereavement. The focus has shifted from theories of attachment and loss to concepts of acute grief, to tasks that need to be undertaken, to stages, to psychological processes and phases (Humphrey & Zimpfer, 2008). Several of these have been found to be useful to counsellors who assist the bereaved after the loss of a loved one. However, many counsellors are wary around the dangers of turning grief into pathology or medicalizing this process after loss, treating it as an illness. It is common knowledge that some persons will require psychological support after a death of a loved one, whilst others will draw on their own strengths and resources and will not seek this assistance (Parkes, 2001; The Australian Centre for Grief and Bereavement, 2013a).

Complicated or unresolved grief is an issue that arises in a small group of bereaved persons that will usually require some kind of psychiatric assistance (Parkes, 2001). Complicated grief is a long-lasting form of grief that completely takes over the person’s life. It is different to normal grief in that it consumes a person’s every thought and is pervasive, leaving them unable to move forward (The Center for Complicated Grief, 2013). The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines persistent complex grief in a series of symptoms that is differentiated from
normal grief. Complicated grief may develop if certain symptoms are still persistent 12 months after the death. According to the American Psychiatric Association (2013, p. 577), symptoms include:

- Persistent yearning for the deceased/marked difficulty accepting the death
- Feeling that life is meaningless or empty without the deceased
- A desire to die in order to be with the deceased
- Persistent bitterness or anger related to the loss
- Excessive avoidance of reminders of the loss
- Difficulty with positive with positive reminiscing about the deceased

Assessing for complicated grief takes skill and expertise. Certain tools are developed to help with the assessment process. Careful therapeutic interventions are often required and referrals for psychiatric care should ensue (Parkes, 2001). In rural communities the likelihood of such support or any bereavement support for that matter is non-existent and an identified gap in the literature, leaving people at psychiatric risk. A research project undertaken in 1995 with the aim of assessing palliative care training of 134 General Practitioners in country New South Wales found that 20.2% of the General Practitioners stated they found bereavement counselling and support very difficult (Trollor, 1995). A 1993 South Australian study found that 60% of general practitioners treating terminally ill patients found it difficult to deal with distressed families and over one third (37%) did not feel adequate to address the social problems of the families (Freeman et al., 1998). Additional studies from nurses indicate providing bereavement support and other psychosocial support is an on-going gap and major concern in rural communities (White, 2007; Kenny & Allenby, 2013).
Giljohann et al. (2008) states finding appropriately trained staff in rural areas can provide challenges for organizations. So when there are health professionals undertaking this task, they need to be supported in every possible way, which means adequate funding. Supervision and support for sole rural practitioners mean provision of cost of communication – ie; telephone and internet. Staff travelling for supervision or debriefing is also another cost as overnight accommodation may need to be considered. There is also the cost of finding space to undertake a bereavement counselling session to occur. Due to the limited resources, rural people have to go on long waiting lists for support, while the capacity to even locate a skilled professional to assist is a significant challenge (Giljohann et al., 2008). It is usually for these fiscal and resource reasons that bereavement follow-up and support for those offering it is not undertaken adequately and consistently. For those who develop bereavement complexities in rural communities, the likelihood of good bereavement follow-up and support will be improbable.

The Importance and Value of Psychosocial Care in Rural Areas

A study conducted by Gunn et al. (2013) aimed to identify key issues associated with the provision of psychosocial care from the perspective of 17 rural Australian cancer patients. The results revealed that psychosocial care is highly valued by those who access it. Rural cancer patients want to be recognised as unique and different to their metropolitan counterparts, therefore highlighting a need for more targeted information and rurally relevant information regarding psychosocial services (Gunn et al., 2013). There is a general lack of understanding of how psychosocial needs can benefit rural dwellers, an education focal point for future funding and policy, also indicating a need to make it a standardised part of care.
Furthermore, Hodgkinson (2008) states that psychosocial interventions can assist the patient and their families with physical, psychological, social and spiritual adaption by reducing isolation and alienation, increasing coping, addressing information needs, facilitating hope and realistic optimism. However, when curative treatment is no longer working and it is now time to prepare a client and family for end-of-life care, psychosocial support can be beneficial with the assistance of quality interventions. The table attached as Appendix K can illustrate how health workers can support persons with their most common concerns in a kind, professional manner. The table by MacDonald and Hobbs (2008) illustrates how valuable skilled interventions by trained health professionals can make a significant difference when one is faced with the end of their life and their families are with them.

When skilled health professionals can assist with psychosocial issues, the benefits for the person and their family can be significant as highlighted by Gunn et al. (2013). However, as indicated in the previous chapter, it is accessing the skilled staff to meet these needs in remote communities that is the barrier (Reymond et al., 2005). By way of interest though, an examination of what disciplines form a specialist multidisciplinary team in metropolitan areas can be compared to the teams that exist in country Queensland.

**The Inter-Disciplinary Approaches to Service Delivery**

Teamwork is considered pivotal to palliative care with an inter-disciplinary approach being the fundamental philosophy on which the sector is based (Crawford & Price, 2003; Jünger, Pestinger, Elsner, Krumm, & Radbruch, 2007; O'Connor, Fisher, & Guilfoyle, 2006). A specialist palliative care team in a metropolitan area may be comprised completely differently to a group of practitioners working with palliative clients in a rural community. A typical specialist team may consist of doctors,
palliative care nurses, social workers, volunteers, allied health practitioners, chaplains and other therapists (Crawford & Price, 2003). Jünger et al. (2007) state the palliative care team members’ conception for successful inter-professional co-operation is:

- Communication
- Team philosophy
- Work climate
- Team commitment

Communication is considered of utmost importance with close information exchange occurring regularly so team members could be kept up to date. Team dynamics have to be considered from a systematic perspective, with the idea there are constant reciprocal interrelations between different variables. Changing one variable such as a new staff member with different role clarity will affect the whole system and impact all other variables (Jünger et al., 2007). This makes team cohesion somewhat fragile and the need for constant maintenance is obvious.

However, in rural communities the gold standard of an interdisciplinary specialist team does not exist, but the need for effective communication still prevails more so than ever amongst the existing health professionals (Robinson et al., 2009). Because the team may not be co-located, there is a need to keep in close contact, particularly if there is a change in the disease status or evidence the family is not coping, so referrals can ensue. There has to be a common vision of what the aims of palliative care are for all involved (Crawford & Price, 2003; Jünger et al., 2007).

In rural and remote communities, those working with the terminally ill will usually comprise of a general practitioner, community nurses and whatever allied health staff happen to be available or working within that community. It is clear team structures vary widely in palliative care, particularly due to geographical constraints,
which needs to be acknowledged. Teams evolve in accordance to what funding and opportunity will permit (Crawford & Price, 2003).

Each health professional in palliative care will have a specific role, possess a distinct identity and will bring to the community strengths that enhance client care and team cohesion. Crawford and Price (2003) states for teams to function effectively, all must possess an understanding of each other’s role and have an ability to pool resources. However, team conflict, role ambiguity, role overload, interpersonal conflict, leadership dilemmas and breakdown of communication can be major challenges in palliative care. Communication has been identified as being the major factor in success or deterioration of team cohesion (Crawford & Price, 2003).

The inter-disciplinary team has proven effective in mental health, rehabilitation, aged care but less well in acute care because timeframes are short, costs are pertinent with the hierarchical structures determining the process (Crawford & Price, 2003). When health professionals do not work well together, referrals will be slow and burdensome; it becomes easier not to refer (Crawford & Price, 2003). For social workers and nurses working in rural communities, the referrals from General Practitioners’ or hospital doctors is integral to their service, highlighting the importance of team cohesion based on open and continuous communication. When it comes to psychosocial care, the boundaries can become obscure with no set guidelines on who does what. This role ambiguity can be a significant challenge to good teamwork (Crawford & Price, 2003; O’Connor et al., 2006). This can be a particular issue in rural communities where access to appropriate staff for psychosocial care is challenging.

The Blurred Role of Psychosocial Care

Unfortunately, the sphere of psychosocial care can be a blurred role and a topic of disputation within some palliative care inter-disciplinary teams. Numerous members
of the team claim ownership of it, with no real clarity around whom this realm of care actually belongs to. Assumptions are made as to who has and who does not have the appropriate competencies and skills. There is limited awareness regarding the professional backgrounds of health workers claiming responsibility for it, how standards are monitored and what strategies are put in place to prevent burn-out (Walker, Walker, & Sharp, 2003). McAuliffe (2014) argues that tensions are often heightened in interdisciplinary teams where there is a lack of clarity about professional values.

Hodgkinson (2008) states in cancer care, all health professionals can provide some level of psychosocial support, such as facilitating access to resources and showing empathic interest in the individual. However, the level of care will be influenced by the availability of psychosocial support staff and services and the care model being worked within. Furthermore, O’Connor et al. (2006) state that responsibilities and expectations can become indistinct when what one team member “is supposed to do” (p. 134) may overlap with the expectations of another health professional.

Although, psychosocial care is the concern of all health professionals, social workers, psychologists and community nurses can all see it as central to their own practice which can create disharmony within the team as mentioned in the preceding paragraph (O’Connor et al., 2006). Generally, the whole team would be expected to have some knowledge of this area, with social workers, psychologists and some community nurses having a head start over the doctors (Sheldon, 1997). The literature provides no real clarity either, as social work literature will claim this domain as their own, psychology literature views psychological care in palliative care as a psychologist’s territory and nursing literature sees psychosocial issues as integral to their practice (Christ & Blacker, 2005; Payne & Haines, 2002; Weber & Grohmann, 2004). O’Connor and Fisher (2011) state this issue results in a “struggle” (p.192) where
different team members are trying to differentiate themselves from other disciplines and promote their professional status.

O’Connor et al. (2006) states the psychosocial realm is more than a “shared” realm; it is a “contested” realm (p.135). Lee (2007) further claims it is not clear to other professions that social workers actually do claim responsibility for it. In fact, rather than being viewed as an equal team member, the social worker is often considered “a resource” guide to the physician, and are generally not accepted as having the competence to provide counselling, assist patients with adjustment to illness issues or other psychosocial concerns (Abramson & Mizrahi, 1987, p. 3). This mindset is still prevalent in many inter-disciplinary teams today; however, it appears to be more on a case by case basis. One psychiatrist stated in regards to social workers addressing psychological concerns: “Now I’m not saying a social worker couldn’t provide such input, they can. Some of them can. Not all of them can. It depends on their training and their interest” (O’Connor & Fisher, 2011, p. 193).

A social workers’ competence in addressing psychosocial issues is not taken as a given, as a dietician, without question, has authority over a patients oral intake. A social worker’s competence regarding addressing psychosocial must be demonstrated and their training in the area be proven, as stated by the above-mentioned psychiatrist. Furthermore, one study highlighted social workers themselves state they require additional training when it comes to end-of-life palliative care and ethical dilemmas (McCormick, Randall Curtis, Stowell-Weiss, Toms & Engelberg, 2010). They want to feel equipped and confident to adequately address all issues, particularly the ethical dilemmas and complex cases they come across. This matter is now being addressed in a few curricula in some schools of social work in the United States (McCormick et al., 2010). In Australia, educational accreditation standards for social work do not list
bereavement, loss and grief as core areas for inclusion in the curriculum although it is expected that ethics would be covered well (Australian Association of Social Workers [AASW], 2012).

Social workers may have their critics and a perceived limited status, but it cannot go unnoticed that social workers have been involved from the beginning in the development of palliative care with the domain’s founder Cicely Saunders, being a trained social worker as well as a nurse and physician (Beresford et al., 2007; Saunders, 2001). It would therefore be beneficial to highlight the role of social work in palliative care in a general sense before considering the activities of social workers in rural areas of Australia and the challenges that they face as generalist practitioners dealing with palliative clients on a sporadic basis.

The Role of Social Work in Palliative Care

Social work in palliative care is gradually becoming recognized as a specialist area of practice, with workforce numbers growing steadily in the UK, Europe and USA. The essence and skill of the social worker is slowly being explored within the literature with new contributions emerging assisting to expand understanding of the role of social work within palliative care. However, overall, the quality and depth of what the social worker can bring requires further exposure and publication (Sheldon, 2000). In Australia, the social worker profile is slowly catching up to their British and American counterparts, however their activities are not as prevalent in the literature, possibly contributing to the blurring of roles and uncertainty that is still evident in Australian interdisciplinary teams regarding the psychosocial domain.

An American study undertaken by McCormick et al. (2010) involved mailing out questionnaires to families who had been involved with the social worker in an intensive care palliative care unit to ascertain the social work contribution to the inter-
disciplinary team. The results revealed the increased level of social work experience and decreased case load were independently associated with higher ratings from families. The findings evoked the need to further examine training social workers receive at undergraduate level to deal with end-of-life issues (McCormick et al., 2010).

Monroe (2010) states that all disciplines will do some social work but the actual social work profession does bring its own perspectives and approaches that are distinctive and unique. However, social workers operate within their own perspectives and approaches, being defined by three major perspectives – 1) the intervention starting point is always defined by the patient and/or the family/carer 2) The patient is viewed by the social worker as belonging to a family, friends and a community, with social and cultural values within that context and 3) The social worker will have knowledge on how a patient may be impacted by law and other social institutions. They are trained to draw upon an ecological approach to problem solving which incorporates the multi-dimensional impact of individual, family and socio-cultural influence, all of which fits well with palliative care (Bosma et al., 2010).

Raveis, Gardner, Berkman, and Harootyan (2009) agree with this adding social workers are primary providers of psychosocial interventions; with their unique value-based perspective which emphasises person-in-situation, assessment and intervention on multiple levels of analysis, a commitment to meeting the needs of vulnerable populations and the integration of research into policy and practice. The profession’s strong ethical foundations provide an emphasis on respect for the dignity and self-determination of every client, which promotes accountability and attention to family dynamics (Raveis et al., 2009). Social workers aim to take into account the place, the time and the circumstances, as well as their own experience and self-knowledge when making decisions (Chu & Tsui, 2008). They can offer valuable contributions to the
palliative care client and their families as well as complementing the multi-disciplinary team.

**Critique of the Social Work Profession**

Despite the above, Ferguson (2012) states the criticism and humiliation that can be placed upon on social workers is limitless. This was written in the context of child protection and adoption, which has received endless bad press over decades. Social workers have been viewed as the culprit for many child protection cases that have gone wrong. Specht and Courtney (1994) contend social workers have been proclaiming unwelcome messages to society, uncovering distasteful and unpleasant problems, so society has treated them accordingly – with ambivalence.

As mentioned earlier, according to Abramsom and Mizrahi (1987), social workers in medical settings are often merely considered as a resource to the doctor and not utilised to their full capacity. Although an older study, recent research indicates the role of social work is still contentious. In palliative care teams, there can be an overlap between the social worker and other team members with social workers sometimes getting into role conflict (Wittenberg-Lyles, Oliver, Demiris, Baldwin, & Regehr, 2008). Payne and Haines (2002) states there can be concerns regarding psychological care and who owns this domain in palliative care teams. Health professionals can contend that “nurses, doctors, social workers, counsellors, chaplains and liaison psychiatrists regard psychological input as falling into their roles” (Payne & Haines, p. 401). The authors put forth that whilst psychological care is the responsibility of all caregivers, Psychologists have unique skills that differentiate them from other disciplines. Payne and Haynes (2002) continue to state all healthcare professionals must practice in a way that is not psychologically harmful to the patient. Meier and Beresford (2008) state social workers are integral to the team but it can be a challenge
for physicians to let go of the psycho-social aspects of the work and refer appropriately. Although some authors highlight the expertise of social work in palliative care teams (Monroe, 2010; Christ & Blacker, 2005), social workers can find their roles a source of contention and conflict.

**The Generalist Social Worker in the Rural Context**

Social workers working in rural communities often fall under the generalist banner, meaning they have to address whatever issues come their way, working with “client systems at all levels and connecting clients to available resources” (Miley, O'Melia, & DuBois, 2007, p. 10). For rural social workers to be effective they require a wide variety of specialised social work skills and interventions. Their practice requires them to have multiple abilities to address issues including child safety concerns, assisting the elderly with the transition from hospital to nursing home and mental health issues. Advocacy to ensure equitable distribution of resources and research are also core social work business in generalist practice, with a highly tuned understanding of the Code of Ethics to guide their interventions (Hickman, 2004; Miley et al., 2005).

However, to be fair, it is unlikely for a social worker to have extensive knowledge and experience on every single issue that arises in a rural community. As palliative care is considered a specialist area of practice, the rural generalist health worker may not have received adequate training in this one particular area or has had little exposure to this clientele so may not have the confidence to deal with all areas of psychosocial care, in particular cultural issues, communication and stress management (Robinson et al., 2009). This could result in palliative clients and their family members possibly falling through the gaps with their psychosocial needs not adequately addressed.
It has been debated that there is very little difference between rural and urban social work, however it cannot be ignored that those who live in rural areas die four years younger than other Australians, with the chance of an early death increasing with further remoteness evoking the likelihood of a need for psychosocial support (Olaveson, Conway, & Shaver, 2004; Strong et al., 1998). White (2007) states that economic and physical barriers such as distance, lack of transport and the need to travel, as well as reduced services from which to choose significantly impact those living in rural areas. White (2007) continues to say that access to counselling for psychosocial issues such as loss and grief counselling is a challenge for those living in these regions.

A further study found that geographic isolation, delayed diagnosis, inadequate transport, health workforce shortages and higher indigenous populations with a lower socio-economic status are contributing factors to poorer cancer survival rates in rural and remote areas. Limited access to allied health services, particularly for psychological support were also identified areas for improvement (Underhill et al., 2009). In accordance to the literature, psychosocial support in rural communities in general is a significant challenge for healthcare workers.

Despite the scarcity of publications on social work activity in palliative care in Queensland within the literature, it should be noted there is an organization called Amaranth on the border of New South Wales and Victoria, which was established in 2009 to specifically respond to the social, emotional, psychological and existential needs of palliative persons living in remote and rural areas. The founder and CEO, Julianne Whyte, is a social worker who was able to obtain funding that enabled the trial and development of a new model of primary health care delivery that would address the gaps and challenges, reduce the inequalities in service provision in remote and rural regions, prove that the service is affordable and accessible and ensure care is delivered
within the framework and standards set out by PCA. The foundation provides a range of services such as provision of information and support, intake services, psychosocial assessments, counselling and support, brokerage of equipment and services, resources to support patients/families/carers and targeted therapeutic interventions for patients/families/carers (Amaranth Foundation, 2013).

Amaranth appears to be the only model of its kind in rural Australia highlighting the competencies of social workers to effectively address the psychosocial needs of palliative clients living in rural and remote areas if given access to funding and resources. It is clear social workers do have a place in end-of-life care. Their skills in advocacy, listening, helping people adjust to illness, working with the whole family and their theoretical base are satisfactory components to achieving effective outcomes.

Social workers are also skilled at identifying strengths and assets within their rural communities and do not always see their working context as a series of deficits. It cannot be ignored that there are positive aspects to rural communities. Country values of hard work, independence, strong familial roots, a firm sense of community and institutions like church based organizations are recognized and drawn upon as additional supports (Daly & Avant, 2004). Social workers become familiar with these existing strengths and structures and utilise these networks in their daily practice, supporting them as well.

Furthermore, of noteworthy interest, in Australia, social workers are not required to be members of the AASW if they choose not to; hence there are currently 7,500 voluntary members nation-wide. The actual number of qualified social workers is much higher (AASW, 2013). Membership of the AASW remains a voluntary choice for social workers, having not yet achieved the status of a registered profession (Chenoweth & McAuliffe, 2014). The AASW has attempted for many years to pursue statutory
regulation for social workers but all attempts to bring this matter into the political agenda have ended in unsatisfactory action. The main reason for bringing in mandatory registration is for public protection as there have been cases involving a small number of practitioners who engage in exploitative, predatory and illegal behaviour. If such persons were registered, they could have their registration removed and no longer have the right to practice, strongly removing the potential risk of further harm (Australian Health Ministers' Advisory Council, 2013).

On March 26th, 2008, COAG signed the Intergovernmental Agreement for a National Registration and Accreditation Scheme for Health Professionals, so a single national system of registration and accreditation of health professionals could be established within a specific framework. Social work is excluded from the fourteen health professionals regulated under the scheme (Australian Health Ministers’ Advisory Council, 2013). Much lobbying has been undertaken since to have social work included in this structure. The AASW (2013) believes the only effective means of protecting the public from harm is to hold all social workers accountable through National Registration and Accreditation.

In 2011, The Australian Health Minister’s Advisory Council instigated a national consultation to examine the need to strengthen regulatory protection for those who access the services of unregistered health professionals (AASW, 2013). The government’s response to this consultation was the introduction of the National Code of Conduct, a regulation that means action can occur after harm has occurred but nothing can be done prior to prevent malpractice (AASW, 2013). The AASW therefore opposes the National Code of Conduct and purports it is an inadequate response to such a serious issue and ever more supports the introduction of external regulation to ensure professional standards and protection for vulnerable service users of social work.
(AASW, 2013). Due to the fact that social workers are not mandated to register with a regulating body, they could therefore not be mandated to uptake skills and competencies regarding psychosocial needs in palliative care. This could be an organizational expectation at best.

**The Role of Nursing in Psychosocial Care**

A recent Australian study by Kenny and Allenby (2013) state nurses in oncology have to address psychosocial needs but are confronted with significant barriers such as, 1) workload pressures 2) feelings of inadequacy related to lack of knowledge and skill 3) ineffective communication, including avoidance of difficult conversations 4) organizational factors, including lack of supportive management, 5) emotional exhaustion, stress and burnout 6) stigma associated with the psychological field and 7) poorly integrated and coordinated services. Furthermore, access to ongoing bereavement support, another psychosocial issue, is also limited in rural communities leaving nurses to do the best they can with virtually no resources (White, 2007). Nurses have to provide services that normally other disciplines would offer.

Rosenberg and Canning (2004) also discuss some of the significant challenges nurses face when addressing the needs of palliative patients in remote and rural areas. As mentioned, the main issues relate directly to scarcity of resources and increasing demand on nurses to provide services that other medical or allied health team members would provide. Rosenberg and Canning (2004) continue to state that not only do nurses working in remote districts have to carry out their professional duties; they also live in these communities, having relationships with palliative care clients and their families, which can have an emotional impact (Rosenberg & Canning 2004). The demands of the job, remuneration issues, workplace communication and geographical location are a further feature of nursing in remote areas, causing nurses to leave
Queensland Health Facilities (Hegney et al., 2002). Nurses in rural Australia are highly skilled generalists who provide care to palliative patients without specialist knowledge or skill. They have limited access to other health professionals to assist their practice, meaning they assume additional roles for which they are not vocationally prepared (Hegney et al., 2002; Kenny, Endacott, Botti, & Watts, 2007). Gaining access to social work support to address psychosocial issues for palliative patients would clearly reduce some of the stress placed on nurses working in rural communities.

Kenny et al. (2007) echoed Rosenberg and Canning’s (2004) study stating providing psychosocial care to cancer patients in rural communities came at their own emotional expense. Having to provide care to patients in areas they do not have skill or knowledge about was a cause for emotional exhaustion and fatigue, majorly impacting their own well-being. The dual relationship of being a nurse as well as a community resident only added to the complexity. Lack of health resources, such as skilled staff, geographic isolation, poor quality roads, expensive fuel only add to the pressures (White et al., 2004). Research undertaken by Hardy et al. (2008) to identify the barriers to dying in Queensland revealed the following results:

- Inadequate funding for palliative care
- Lack of after-hours care (community)
- Insufficient after-hours medical care (community)
- Not enough health professionals in palliative care
- Limited after-hours medical support
- Not enough palliative care specialists
- Not enough trained staff in aged care facilities
- Limited residential aged care facility support from specialist palliative care
- Services
• Insufficient GP support
• Insufficient community care

Community nurses are doing what they can to address these gaps to the best of their ability, however, it is clearly to the detriment of their own well-being. An additional study found that “a lack of counselling skills was the most prominent source of frustration as nurses experienced inadequacy to respond effectively to the emotional needs of clients and their families. One nurse stated – “sometimes I don’t know what to say and sometimes I am crying as much as they are” (Rose & Glass, 2010, p. 1411).

People living in rural and remote areas of Australia are obviously disadvantaged when it comes to palliative care service delivery with enormous challenges identified (Reymond et al., 2005). As stated by White (2007) a challenging area that remains unmet is access to bereavement support and quality psychological support. More skilled social workers in rural communities could alleviate some of these significant stressors.

On a final note in regards to psychosocial care in rural communities, a review of existing research was undertaken by Shepherd et al. (2008) to consider the use of the telephone, videoconferencing and the internet as possible modes of communication for psychological support for persons with cancer. Whilst the use of the telephone was found to be most favourable, with videoconferencing and the internet being promising, there is still yet to be further research to establish its effectiveness for counselling. There is not the evidence base to prove technology alone is optimum for psychological care.

Additionally, a Queensland pilot study investigated the effectiveness of a home telehealth service for paediatric patients living in rural areas. Although successful to some point and a most feasible option of communication, there has been a lack of
evidence in its effectiveness with the adoption of telehealth being considered very “slow” regarding palliative care. Whilst considered a feasible mode of communication to palliative clients living in rural and remote areas of Queensland, further research needs to be undertaken as the evidence base for its success at present is not significant. There is still a heavy reliance on telephone contact (Bradford et al., 2012; Thomas et al., 2010).

Conclusion

This chapter has presented the definition of psychosocial care and its variations. A decision on what the psychosocial domains are in relation to the literature, was detailed with clear explanation of what comprises psychological concerns, emotional concerns, social issues, spiritual concerns, cultural issues, the practical component and the complexities that can occur around bereavement. The incongruence of what is included in the definition of “psychosocial” was clear when the literature was examined.

The literature revealed psychosocial care for palliative clients can be an antagonistic area; often considered a shared and contested realm. Nurses and psychologists can see the domain as integral to their role and not necessarily belonging to the social worker (O’Connor et al., 2006). This has resulted in the social worker often being reduced to a mere resource guide to the physician (Abramson et al., 1987) rather than working to their potential and capacity. It should be noted, this is not the case in all teams as continued inconsistencies were illuminated. Other research found that in regards to psychological care for palliative clients, “some social workers can and some can’t” (O’Connor & Fisher, 2011, p. 193). The literature also revealed that all professionals will undertake some form of psychosocial care; however social workers are adequately equipped to undertake their contribution due to their training and the
person-in-situation perspective in which they operate (Monroe, 2010). This was discussed to some depth.

It was noted that almost all located research on social work activities in palliative care is aimed at social workers in specialised teams and not the generalist rural social worker. Addressing the needs for a client group only reviewed intermittently and not on a daily basis can be challenging. The literature revealed that the generalist social worker requires an extensive array of knowledge on a large variety of issues, making it difficult to develop specialised skills in one specific area. Because palliative care is not core day-to-day business, this could contribute to a lack of confidence as undoubtedly their needs are unique and different compared to other client groups.

With the exception of Amaranth, an organization staffed with social workers whose primary focus is to address psychosocial needs for terminally ill persons living in rural districts, no other literature regarding social work activity administering psychosocial care in rural communities could be located. The chapter then highlighted how nurses are required to be highly skilled generalists, having to assume roles they are not vocationally trained for as access to skilled staff to address psychosocial care is too problematic. The literature also revealed telehealth has been slow to be taken up in rural communities, with strong reliance on the telephone still existing.

The following chapter will set out the methodology adopted for this research, establish the theoretical and conceptual framework and outline the steps taken to obtain data to explore the identified research questions.
Chapter Four
Methodology

This chapter will present the methodology and the rationale for this particular design. The study is exploratory with qualitative methods applied. In this way, the interviewer can obtain insight into how the participants make sense of their experience and transform it into meaning (Patton, 2002). How a person thinks and feels about a topic within their own context is the basis of interviews for the study. Qualitative semi-structured interviews were the chosen data collection mode however unexpectedly one group interview was undertaken and incorporated within the methodology. This will be explained later within this chapter.

The methodology process can be likened to making a patchwork quilt as undertaken by many country women in rural communities. Taking little snippets of information and piecing them together one thread at a time (data analysis procedure) in order to create an overall object of both uniqueness and practicality (conclusive results). Sometimes the quilter can become enmeshed in the little pieces (data from each interview) and loses sight of the overall product; however, once all the pieces are stitched together bit by bit, the eye is drawn to certain squares of the quilt (distinct themes) than perhaps over others. However, all the squares sit side by side and become a complete creation. The 38 participants within this study provided insightful, thought provoking information that when put together, specific themes were consistent forming a blanket foundation for future policy and funding implications for practice, plus material for additional research.

On a wider scale, the metaphor can also symbolise the overall scenario of how psychosocial needs are met in rural and remote areas of Queensland. The State is like a patchwork quilt, with some squares of the quilt being vibrant and strong (certain
communities) and other squares faded and dull needing reinforcing and attention. It is hoped evidence derived from the study can be utilised to enhance a more uniform consistent scenario when it comes to the delivery of psychosocial care for palliative clients living in rural and remote areas of Queensland. The process of how these conclusions were drawn will be thus deliberated within this methodology section of the thesis.

The chapter begins by outlining the conceptual framework underpinning this research. A justification is provided for why critical theory, which is positioned within the major transformative paradigm and an ecological approach, attached to the interpretivist/constructivist major paradigm, was chosen. Critical theory and its consideration of problems stemming from structural levels and how human rights sit within this critical canopy, is then conferred. Qualitative interviewing is reasoned to be an appropriate and congruent method for both the transformative and interpretivist/constructivist paradigms to collect data (Mackenzie & Knipe, 2006).

Subsequently, Bronfenbrenner’s (1979) ecological/systems model and how macrosystems, mesosystems, exosystems and microsystems impact the palliative client living in rural and remote areas of Queensland is articulated and its role as a conceptual lens. This will be followed by an explanation of the recruitment process and final sample group, along with the method utilised to recruit participants. Details regarding the eligibility criteria for the inclusion of participants will also be discussed.

A major barrier that required addressing in the ethical clearance and data collection process is highlighted as it resulted in an amendment to the study and impacted the commencement time of data collection. The research questions will then be articulated in accordance to the framework within which they were formulated. A rationale is thus provided regarding the chosen exploratory data collection method and
why a research expedition to conduct semi-structured interviews was deemed most fitting.

Data analysis and thematic analysis development will be outlined in accordance to King and Horrock’s model (2010). The process was undertaken with reference to the literature, with an illustrated step by step summary provided for clarity. Ethical considerations are referred to in the following paragraphs, with issues such as confidentiality, the risks and benefits of the study followed by reflections of the researcher. Finally, the chapter will finish with an articulation of the limitations to the study and strategies implemented to establish trustworthy qualitative research.

**Conceptual Framework**

Silverman (2000) states theoretical models provide an overall framework for how we look at reality. Theories arrange concepts to define and explain a particular phenomenon, providing a footing to consider the world and so what is unknown can be organized. Without theory, a phenomenon cannot be understood (Silverman, 2000). A paradigm, also referred to as a model (Silverman, 2000) is composed of a basic set of human constructed beliefs that guide and direct thinking into action (Denzin & Lincoln, 2000). The paradigm’s role is to assess and refine goals, select appropriate methods and help develop research questions (Maxwell, 2013). A conceptual framework is the system of concepts, assumptions, expectations, beliefs and theories (paradigms) that underpin the research; a key component of the design (Kumar, 1996; Maxwell, 2013).

To explore the issue of psychosocial care for palliative clients in a rural context, two theoretical approaches were selected so the topic could be understood, organized and research questions could be formulated within this framework. The following table (Table 1) by Mackenzie and Knipe (2006) highlight the numerous paradigms that can be
drawn upon by researchers, with each category having matching data collection methods.

Table 1
Paradigms (Mackenzie & Knipe, 2006).

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<td>Normative</td>
<td>Social and Historical</td>
<td>Advocacy</td>
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<td>construction</td>
<td>Grand Narrative</td>
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<td>Interaction</td>
<td>Race Specific</td>
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<td></td>
<td></td>
<td>Political</td>
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Transformative paradigm. Mertens (2005) state this group of researchers from the traditions of Marxism and feminism; utilize critical theory as frameworks for research. The transformative paradigm is different to the constructivist paradigm in that it directly addresses the politics in research by confronting social oppression at whatever level it occurs (Mertens, 2005). The transformative researcher examines marginalized, vulnerable groups, analysing how results of social inquiry on inequities are linked to political and social action (Mertens, 2005). Mackenzie and Knipe (2006) state a transformative paradigm contains an action agenda for reform that may change the lives of the individuals. This is why human rights fall within this paradigm as it analyses how and why inequities occur based on gender, race, ethnicity, disability, sexual orientation or socio economic class and seeks to challenge it (Mertens, 2005).

Critical theory. Kincheloe and McLaren (2002) state critical social theory is concerned predominantly with power and justice and the ways that the economy, race issues, class and gender, ideologies, discourses, education, religion and other social institutions and cultural dynamics interact to construct a social system. A critical perspective can assist to analyse and negotiate a change of power relations and structures in ways that can empower everyone (Costello, 2009). A palliative client living in a rural and remote community in Queensland may feel powerless, at the mercy of the limited resources available, without thought that these systems can be questioned or challenged. However, health practitioners who work within these socially constructed systems can reflect upon how dominant ideologies as well as societal institutions impact the client they are seeking to assist, being a voice to who have died, or are too overcome by their loss to speak (Briskman et al., 2009; Chochinov, 2000). Challenging such influences evoke a critical paradigm.
Briskman et al. (2009) state critical theory also queries the place of existing institutions, such as the family, educational establishments and governance with an aim to constructing a more just society. Critical theory therefore provides an appropriate lens to illuminate the systems that will be explored in the thesis, focusing closely on structures and the social and the political contexts of peoples’ lives (Briskman et al., 2009). Human rights falls under the critical theory umbrella highlighting if change is to occur, then adopting such a perspective can go far to challenge social, political and economic power relations, as well as avoiding the snare of becoming encompassed by a prevailing discourse that privileges individual rights and responsibilities (Briskman et al., 2009; Nipperess & Briskman, 2009). The use of critical theory together with ecological theory will assist a critical exploration of the relevant systems that operate within a socio-political context.

Payne (2014) states a main aim of ecological theory is an individual’s adaptation to the environment with, the assumption behind the theory that improving the fit is desirable. However, critical theory can be used to challenge these assumptions. This thesis will take the stance that undertaking a critical approach places the spotlight on the structural forces that impact the palliative client living in rural and remote areas of Queensland; adaptation to the current systems in place are not acceptable. Identifying macro structures is vital in order to expose and challenge them.

**Constructivist.** Mackenzie & Knipe (2006) state interpretivist/constructivist approaches to research have the intention of understanding the world of human experience. It is suggesting that reality is socially constructed. The researcher tends to rely upon the participants perceptions of the situation being studied, through qualitative methods (Mackenzie & Knipe, 2006). Yet as stated by Mackenzie and Knipe (2006) transformative researchers contend the interpretative/constructivist approach to research
does not satisfactorily address issues of social justice and marginalized persons, believing that inquiry needs to be intertwined with politics. Within this research, the interpretative/constructivist paradigm shines the light on an issue by use of qualitative methods, yet the transformative paradigm can possibly take it one step further and utilise the data to challenge political systems. Hence, in this particular study the two frameworks are congruent.

A specific goal of this research was to capture how each respondent perceived, described, felt, judged, remembered their experiences and opinions around how psychosocial needs are met for palliative clients living in their area. Hence qualitative interviews provided the most logical and effective method for data collection. The literature suggests that participants’ experiences are significantly influenced by where they live geographically and as a result often by the inequitable distribution of funding in rural remote areas (Community Affairs Reference Committee, 2012; PCQ, 2012c). Funding is a consequence of macro forces. Macro influences in the delivery of palliative care will be discussed in more detail in Chapter Six; however it is a major component to explore this study. Furthermore, as psychosocial care is often addressed by micro systems and others Bronfenbrenner’s approach is used as an overarching theoretical framework for the study.

Tudge, Mokrova, Hatfield, and Karnik (2009) evaluated the application of Bronfenbrenner’s ecological theory in their empirical work with families and found only four papers out of twenty-five had applied it in accordance to its true entirety. Tudge et al. (2009) continue to state researchers tend to draw on specific concepts from the theory or on an older version. This research is not seeking to utilize Bronfenbrenner’s ecological theory as a means of testing human development. Rather, this study has utilised Bronfenbrenner’s model as a conceptual means to explore the
various societal structures that may potentially impact the palliative client living in rural and remote areas of Queensland. Many researchers are said to use the model as a conceptual framework for research purposes (Sontag, 1996). The circles so aptly illustrate the various systems and the interactions between the systems and can provide a conceptual link between research, practice and policy (Sontag, 1996). The model is illustrated as follows:
Figure 3. Bronfenbrenner’s Ecological/Systems Model (Hchokr, 2012)
The theory defines four major systems that contain responsibilities, norms and guidelines that impact on an individual’s development. These are referred to as the micro system, the mesosystem, the exosystem and the macrosystem. The micro system is the family, the nursing team that visit the home, friends, church, etc. In other words, the micro system is the immediate environment in which a person lives and impacts the individual directly in their everyday life. How a person develops and adjusts will depend upon the content and structure of the microsystem. Regarded as significantly important are the connections between other persons within the setting, the nature of these links and how they influence the individual (Bronfenbrenner, 1979, 1994). The mesosystem is thus the interaction between two or more components of the micro systems in which the individual participates (Bronfenbrenner, 1979, 1994; Tissington, 2008). For example, the palliative client’s spouse/carer and the health care services may discuss how the carer is coping and may make plans for respite, which in turn will impact the palliative care client. The exosystems are agencies or influences that the client is indirectly involved with but these systems are external to the client’s day-to-day affairs (Tissington, 2008). This could be the carer’s workplace if a spouse has had to leave work for a short time to care for a terminally ill client or it could be Centrelink or another social service that is indirectly impacting the situation. It can also incorporate local politics and their influence on an individual’s life.

The final system in Bronfenbrenner’s theory is the macro system. This system is not a specific context but refers to values, laws and customs of a particular culture or environment in which a person lives. The priority a macro system attributes to a particular need, or a change in law or health reform, affects the support that is received at lower levels of the environment (Tissington, 2008; Victor Valley College, 2013).
An example of this is how policies for health impact the way palliative care is delivered in rural and remote communities as discussed in Chapter Two of this thesis.

In order to understand a person’s experience effectively, consideration must be given to the relationship between the individual and their environment. This includes a variety of settings, such as the person and their home, their community, their state or territory and finally how macro systems such as widely shared cultural values, commonwealth laws, and funding set-ups influence a person’s life and their thinking (Baron, 2001). By continuing on with a systems framework; and viewing families and rural communities as a system, I was able to ask myself throughout the entire data collection phase, “How and why does this system operate as it does?”

Holistic thinking is pertinent in both general and ecological systems theory, because systems are an array of interrelated components that depend upon what is happening to other parts (Payne, 2005; Patton, 2002). There is such an integration and interconnectedness that any change in one part can alter or even eliminate another, impacting on the system as a whole (Patton, 2002). This research explored how policies, funding, staffing, resources and equipment plus vast distances impact the experience of the palliative client and their psychosocial needs. The Bronfenbrenner model was the major theoretical influence of this study providing an ever-present focus as to how persons living in rural and remote areas exist within different systems. A systems orientation was also most useful in exploring the qualitative data as consideration was given to the system within which the participant operated, providing insights as to why they responded the way that they did. A critical theoretical lens was used to interrogate the social and political nature of service delivery. Therefore, the chosen theoretical framework for this research project is illustrated in Figure 4:
The purpose of this research is to explore psychosocial care provision to palliative clients living in rural and remote areas of Queensland and to better understand the role of social work within this context. The study involved a five week rural Queensland expedition with brief stopovers in various rural and remote towns for interviews for selected participants in each locality.
The study was designed to capture the “lived experiences’ of rural and remote people within the prevailing context of end of life decisions and psychosocial care provision. Morse and Richards (2002) posit that people are considered to be tied to their worlds and are only understandable in their contexts. The interviewer must bracket their former understanding about an issue and attempt to process the point of view of the participant (Kellehear, 1993). The qualitative research method of bracketing (Gearing, 2004), was applied to assist objectivity and empowered the researcher to explore and describe the issues and ideas that arose from the respondents themselves, rather than those based on possible preconceived theories. The result is a gained understanding of the experience from those who have actually lived and encountered the prevailing context with all its challenges and opportunities. Travelling the distances meant I could place myself in the position of understanding how far a practitioner must travel in their outreach work as well as gaining insight regarding the distances a person with a life limiting illness must tolerate to reach appropriate services or appointments.

DiCocco-Bloom and Crabtree (2006) state qualitative interviews can be conveyed in unstructured, semi-structured and structured formats. I chose to utilise a semi-structured approach as it can be a sole data source and a set of pre-determined questions can be organized with opportunity for dialogue to occur between researcher and interviewee (DiCocco-Bloom & Crabtree, 2006). Di-Cocco-Bloom and Crabtree (2006) also contend interviews can be scheduled in advance at a designated time and location, which is what needed to occur to undertake the task at hand.

Five weeks leave from my social work position was granted and an itinerary was proposed. To systematize a co-ordinated research expedition to interview a sizeable number of people from all over Queensland involved intricate planning. Once ethical
clearance was authorized (process will be explained later in this chapter), phone calls and emails could take place. It was a substantial feat to calculate travel times in conjunction with the most appropriate time to interview a participant. However, this was organized and recorded within a diary and highlighted on a map. Flexibility had to be factored in as the adopting a snowball method meant most Community Workers were not factored in until the trip was well under way. Over a period of thirty-two days, I travelled throughout rural and remote Queensland and interviewed thirty-eight participants as depicted below in Figure 5.

![Figure 5. Map of towns visited](image)

**Recruitment Methods**

Participants were recruited using purposeful sampling and then with snowball sampling. Patton (2002) states the logic and power of this type of purposeful sampling and its emphasis on in-depth, understanding. A selection of information rich cases
result in more detailed learning about a central issue of significant importance to the research. In purposeful sampling, a site or cases may be chosen because there is good reason to believe that “what goes on there” is crucial to understanding an issue. The researcher is directed to persons who have significant information and are willing to share it. It was via this method I was able to locate my first two participant groups – Queensland Health Social Workers and Blue Care nurses (Kumar, 1996; Schwandt, 1997).

By then utilising snowball sampling, I was able to locate other potential subjects. This process begins by asking “well situated people” questions such as “who can I talk to?” or “who would know a lot about” (Patton, 2002; Taylor & Bogdan, 1999). As a result, snowball sampling was used to formulate a sample by using pertinent networks. Within this research, purposeful sampling located which organization and individuals within were primarily addressing the psychosocial needs of palliative clients living in rural and remote areas of Queensland. Furthermore, once pertinent sites and persons were identified, snowball sampling assisted in locating additional individuals, such as my third group – Community Workers, that added to accumulating information rich cases. My last group were palliative clients themselves and their spouses, who were provided with information and consent forms through the process of a health professional. The use of gatekeepers to obtain samples has long been found to impact on access to the desired participants (Wanat, 2008). Gaining admittance to palliative clients was a problem for the research, highlighting the reason why limited thesis data was obtained from this particular sample group. Hence, my participants were as follows:

1. Queensland Health Social Workers working in rural communities (mostly in small hospitals or state government community health centres)
2. Blue Care Nurses

3. Community Workers— this group was made up of individuals who were identified throughout the data collection phase that were not Queensland Health Social Workers or Blue Care Nurses but were primarily addressing the psychosocial needs of palliative clients living in their district

4. Palliative Clients/Spouse

Social workers were selected as a potential sample group as the literature purports that social workers claim special proficiency regarding psychosocial needs in palliative patients and aim to strengthen this role (O'Connor & Fisher, 2011). Additionally, Christ & Blacker (2005) state social workers possess expert knowledge about navigating medical and social systems that are often barriers to palliative patients. Their perspective was paramount to the purpose of the study.

Blue Care nurses were chosen as a second sample group as research also highlights that nurses do the best they can to provide emotional support to patients and families to assist in alleviating stress (White, 2007). Their contribution was vital to this research as it appeared from the literature addressing psychosocial needs was a task that often had to be taken on by nurses as they visit clients in their homes and relationships ensue.

The third sample group entitled “Community Workers” was a group that became apparent as important during the research. By utilising the snowballing technique, members of this participant group came to light when discussing psychosocial needs with other relevant stakeholders during the five week exploration. Only three participants from this group were identified prior to the research expedition. Ethical clearance was obtained beforehand to contact and access this group as they were discovered during or just before data collection. For a rich and more meaningful study,
it was important to have been granted permission to access these individuals to reduce rigidity and add flexibility as addressing psychosocial needs should not be pigeon-holed as belonging solely to social workers or Blue Care nurses.

To explore psychosocial needs and how they were being met, it seemed logical to interview palliative client themselves and/or their family member/carer. I wanted to understand the psychosocial issues that were important to them and whether or not they felt satisfied that such needs were addressed within their community.

Sample

**Sample Group 1) Queensland Health social workers.** Recruitment of Queensland Health Social Workers was initially identified via the Director of Social Work for that particular Health District. Queensland Health is divided up into 16 Hospital and Health Service Districts (not including Children’s Health Services). There is a Director of Social Work who governs the social workers of each individual health service district. In order to recruit potential participants, the first step was to make contact with the Director of Social Work of each hospital and health service district and make enquiries regarding the social workers in that area. It was pertinent to only seek out the social workers who were likely to work with palliative care clients.

Once ethical clearance was obtained from the Darling Downs Human Research Ethical Committee to access Queensland Health staff (HREC/12/QTDD/7), the Directors of Social Work from the Darling Downs, West Moreton, South West and North West Health Service Districts were contacted and sent a Site Specific Assessment (SSA) Form. This document is a component of research governance. Its purpose involves assessing the suitability of a “site” where the research is potentially going to be conducted. It is basically a method to ensure transparency and financial accountability regarding the contribution of resources from Queensland Health (Office of Health and
Medical Research Queensland Health, 2010). In this case, the resource compromised the social worker’s time away from their clinical work to be involved in the study. This is a cost to Queensland Health that needed to be approved. All four SSA forms were signed by appropriate Queensland Health staff members and, approval granted to contact social workers.

Twelve social workers were contacted from four Hospital and Health Service Districts and sent information/consent packs via email. All twelve social workers consented to being involved in the study. However, just prior to leaving for the research journey, one social worker withdrew her consent as she was leaving the position. There was no replacement social worker. Since the site had already been approved via the signed SSA form, the Queensland Health community nurse who took over the psychosocial care for this town was interviewed instead. So in total, eleven social workers were interviewed for this sample group. The nurse became part of the community workers group.

The Queensland Map below (Figure 6) illustrates the Queensland Hospital and Health Service Districts. As mentioned, SSA approval was sought from four Hospital and Health Service Districts. Please note the small green area to the right of the Darling Downs Health Service District is the West Moreton Health Service District.
Sample Group 2) Blue Care nurses. Investigative enquiries indicated that Blue Care nurses were dominant in delivering domiciliary nursing care in much of rural Queensland. It was determined that to gain the perspectives from the health professionals that went almost daily into the homes of palliative clients, Blue Care nurses should be recruited as potential participants for the study.

Once ethical clearance was granted from UnitingCare Ethical Committee, recruitment for nurses was achieved by sending the information/consent pack to each Blue Care Domiciliary Nursing Service Manager in seven rural communities. The service manager then forwarded the package onto the nurses whom she/he determined worked most closely with palliative clients. Ten nurses signed the consent forms and in total ten nurses were ultimately interviewed. In three towns, two nurses were interviewed from the same agency.
Sample Group 3) Community workers. Some forward planning meant that ethical clearance should be sought prior to the data collection phase for a specific sample group which would be identified along the way as addressing psychosocial needs of palliative clients living in their area. These persons would not be Queensland Health Social Workers or Blue Care Nurses. Ethical clearance was granted by the Darling Downs Human Research Ethical Committee for this group. In total, twelve participants made up the “Community Workers’ sample group. The group consisted of two nursing home nurses, six HACC support workers, one HACC nurse, two Queensland Health nurses working in a town where a social workers was either not available or not deemed as having appropriate skills (approval sought), and one hospice social worker. These persons were identified just prior to the road trip or during the five week data collection phase.

Sample Group 4) Palliative clients and carer. Ethical approval was granted by three ethical committees – The Griffith University Human Research Ethical Committee, UnitingCare Human Research Ethical Committee and The Darling Downs-Toowoomba Human Research Ethical Committee (HREC/12/QTDD/7). In the initial application, palliative clients/family members were to be recruited via their General Practitioners. However, after contacting scores of General Practitioners all over Queensland with no response or very little interest in the study, it became apparent that seeking access to palliative clients had to be altered to other avenues. A request for an amendment was re-submitted to all three ethical committees to recruit this sample group either via a Palliative Care Consultant, a Blue Care Nurse or another health professional. The amendment was granted and General Practitioners were no longer sought to pass on the information/consent packages to their clients as this did not turn out to be an effective conduit to reach the potential sample group.
Once ethical clearance was granted by all three committees, the appropriate paperwork was completed (SSA forms included) and consent was granted by Directors of Social Work or Blue Care Service Managers, many emails and telephone discussions ensued to various health professionals to organize an interview day and time. The following table illustrates the final sample group that responded to the study. Eleven Queensland Health social workers, ten Blue Care nurses, twelve Community Workers and five palliative care clients/spouses were interviewed. The palliative care client/spouse group were identified through health professionals once the amendment to the study was granted. All the participants consented to the interview after a health professional passed on the information/consent pack. The participants then contacted me direct and an interview date and time was thus organized. All participants were aware the interviews would be audio taped and consent could be withdrawn at any time. Summary of participants is provided in Table 2:
Table 2

Sample Characteristics

<table>
<thead>
<tr>
<th>Sample</th>
<th>Total Participants</th>
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<tr>
<td><strong>Queensland Health Social Workers</strong></td>
<td>n = 11</td>
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<tr>
<td>• 10 female social workers</td>
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<tr>
<td>• 1 male social worker</td>
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<td>Only one female social worker was a new graduate. The rest of the group ranged from 3 – 20 years’ experience. Ten participants were generalist social workers with one social worker working in a palliative care team in a regional community that outreached to rural areas.</td>
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<td><strong>Blue Care Nurses</strong></td>
<td>n = 10</td>
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<td>All the nurses were female – ranging from to 7 – 36 years’ nursing experience In three instances 2 nurses were interviewed together</td>
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<td><strong>Community Workers</strong></td>
<td>n = 12</td>
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<tr>
<td>• 2 Qld Health Nurses (female)</td>
<td></td>
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<tr>
<td>• 2 Residential Aged Care Nurses (female)</td>
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<tr>
<td>• 1 HACC Nurse (female)</td>
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<tr>
<td>• 6 HACC Support Workers (females) all interviewed as one group</td>
<td></td>
</tr>
<tr>
<td>• 1 Hospice Social Worker (female)</td>
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</tr>
<tr>
<td><strong>Palliative Care Clients and/or Family Member</strong></td>
<td>n = 5</td>
</tr>
<tr>
<td>• 3 Palliative Care Clients (males)</td>
<td></td>
</tr>
<tr>
<td>• 2 Spouses/Carers (females)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>38 participants</td>
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Nine Queensland Health social workers were interviewed in a Queensland Health facility, with one social worker requesting to be interviewed at home. This was due to the fact that she only worked part-time hours and had a young child and felt more comfortable to have me in her home on one of the days that she was not working. An eleventh social worker was interviewed via videoconference at his Queensland Health workplace as he was not available on the day I was visiting the town in which he was employed. However, I did still drive to the town in which he worked as I interviewed his co-worker, a second social worker, who also received numerous referrals for palliative care clients, at their Queensland Health site.

All Blue Care nurses were interviewed in their workplace. My aim was to time the interviews when they had returned from their home visits and were in the office undertaking paperwork etc. I was always conscious of all the practitioners’ busy work schedule. Regarding the community workers, ten workers were interviewed in their workplace, with one community worker wanting to meet me in a coffee shop during her lunch break. She had a stretched workload and felt this was more optimal for her. She felt freer to speak within this environment. A final community worker also conducted her interview via videoconference from her workplace when I returned from the research expedition as she had forgotten about the interview the day I arrived at her agency. Although this may have seemed disappointing to the reader as I had travelled seven hours to see her, the visit to this town was not a lost one, it was rich with history and culture and it gave some time to actually sight see for a little while to break up the endless driving.

All palliative clients/spouses were interviewed in their homes. Patrick’s interview took some intricate planning as where he lived involved a 20 minute ferry ride. The ferry ran on an hourly basis. This had to be timed explicitly around his pain
medication for optimal conversation. Some discussion had to take place with the palliative care nurse who drove 1 ½ hours each week to see him to check optimal times and functionality. Patrick was aware of these conversations as I gained his permission from him prior to discuss with the nurse. He consented for these interactions to take place. Fortunately the ferry was on time, Patrick was feeling quite bright by the time of my arrival and the interview continued without an issue.

The pseudo names of all participants are detailed as appendix B, however, for simplicity initials will be placed in brackets after the participants’ comments, for example - SW for social worker, BCN for Blue Care nurse, CW for community worker, PC for palliative client and C for carer and will be referred to throughout the findings chapters.

**Eligibility Criteria**

All participants had to be over eighteen years of age and able to offer informed consent. If a patient was deemed not to have capacity to provide consent, a family member would have been invited to be interviewed. However, this was not the case with any of the palliative care participants. All participants were deemed competent to make their own decisions. Capacity, although a legal construct; is determined by a medical professional (The Law Society of New South Wales, 2009). If there had been an uncertainty, a discussion with the local General Practitioner who has been treating the client would have needed to occur prior to determine capacity. In palliative care you are often dealing with two clients – 1) the palliative care patient and 2) the carer or family member. It is for this reason I have collated the palliative client and/or their carer/spouse as one sample group.

I was prepared to interview Aboriginal and Torres Strait Islander persons in my study and include them had they consented to the research. I have undertaken cultural
sensitivity training and work closely with the indigenous community in my own practice. However, due to the fact that Indigenous persons often view cancer, dying and the main stream health system from a different perspective, I did not target this group in particular as I believe their experience deserves a study in its own right. In summary, the eligibility criteria can be listed as follows:

- All participants had to be over eighteen years of age and have capacity to offer informed consent
- All health professionals had to work with palliative clients and/or their families/carers.

**Barriers**

Throughout the data collection phase, gaining access to palliative care clients and/or family members/carers was one of the most challenging aspects to the study. Even with the amendment, the gatekeepers were difficult to engage regarding passing on the information/consent forms to their palliative clients. Jupp (2006) states a gatekeeper is the person within a group or community who makes a final decision as to whether or not access to undertake research is granted. I quickly learnt gaining access to potential participants via a gatekeeper, to undertake research could be problematic. When ethical clearance was first sought, the application stated that the palliative clients should be identified through a rural General Practitioner. Multiple phone calls and emails to the practice managers were initiated, as the General Practitioners could not be contacted directly. It became apparent that an amendment to the original application needed to take place as not one General Practitioner would assist in forwarding the information/consent package onto their palliative clients. To overcome this, I had a Palliative Care consultant who I have worked closely with for many years write a letter on my behalf which ended up becoming a key component in allowing an amendment to
take place. However, this meant clearance for the amendment had to be obtained by all three ethical committees a second time to seek another avenue to reach the palliative clients. Clearance was thus ultimately granted to contact a health professional to obtain access to palliative care clients. Five participants for this sample group were obtained after much difficulty.

**Research Questions and Rationale**

As mentioned previously, the conceptual framework should, among other tasks, develop realistic and relevant research questions (Maxwell, 2013). By utilising a human rights and ecological lens, my questions were formulated. All questions reviewed by three ethical committees who awarded consent.

My overall prominent research question for this study was *how is psychosocial care provision being undertaken for palliative clients living in rural and remote areas of Queensland?*

The secondary research questions that were formulated are as follows:

a) How do rural and remote service providers perceive their role in providing psychosocial care to palliative clients?

b) What are the perceived barriers and enablers to social work referrals?

c) How do contextual factors impact on provision of psychosocial care?

d) What have been the experiences for rural and remote palliative clients and their carers of psychosocial care?

At the time of the interview, the definition of psychosocial issues was presented to every participant and discussed if further clarification was requested. A slightly adapted version was provided to the palliative client/spouse group and as articulated in Appendix J. The definitions were as follows:
**Definition of Psychosocial Needs:** Psychological, emotional, social, spiritual and cultural issues/concerns that a client may experience in their journey with a life limiting illness.

**Psychological:** What a client *thinks* about his/her illness/prognosis. Beliefs the client may have about their illness/prognosis.

**Emotional:** How a client *feels* about their illness/prognosis. There may be fears and concerns.

**Social:** Identifying the client’s social network, how well the client is supported and how do they cope within this environment.

**Spiritual:** What spiritual/religious needs/concerns would a client like addressed to assist with comfort or support.

**Cultural:** What cultural aspects a client would like considered/respected that will assist with comfort or support.

**Data Collection**

*Social workers, Blue Care nurses and community workers.* The data were obtained via in-depth semi-structured interviews. The open-ended questions assisted exploration of the perceptions of participants within their own context. Rosenberg and Canning (2004) state that nurses not only work in these communities, but live there as well and often have dual relationships with the palliative client. Awareness of this issue was constantly in the forefront of my mind. The interviews began with a brief introduction to the study and its purpose. Participants had received this information previously through channels mentioned; however the participants were reminded and were provided an overview. An acknowledgement was given regarding the sensitivity of the topic and a guarantee that the interview would be terminated at any time should the participant not feel comfortable. Consent for audio taping was re-discussed.
As mentioned, the data were collected over a five week period as a rural research expedition was planned to conduct the interviews in a successive time frame. I utilised my accrued annual leave to undertake the task. Two interviews were conducted after the five week time block so some travelling was still necessary after the initial data collection phase. The interviews were conducted from south west Queensland to Central Queensland to remote Queensland and to north Queensland. A total of 24 towns were visited with a distance of 7,500 kilometres travelled. Thirty-eight participants were interviewed; in some instances two Blue Care nurses were interviewed from the same office, however generally it was only one participant per community. On one particular day, I was able to interview four participants from four different communities as there was approximately 1 ½ hours driving between towns, with one participant being able to travel to meet me in the last town and be interviewed after the third participant of that day.

**Palliative care clients and carers.** The questions were designed with a high level of sensitivity, with utmost consideration given to the emotional experience of the participant. At the time of discussion, a clear, succinct explanation of what psychosocial needs are, psychological, emotional, social, spiritual and/or cultural was offered. Questions such as – “tell me about your own experience with any of these issues in your journey with your illness?” or “what was it like to go through this experience with your loved one?” was asked. Open-ended prompts were offered throughout the interview such as “What happened?” “What did that feel like?” or “What did that mean for you?” The interview was completed with a summary of the main points, confirming accuracy of the data/or seeking clarification. The participants were thanked for their time and informed about the purpose of the study and the aim for the results. The time frames for the interviews ranged from thirty minutes to fifty
minutes as consideration was given to impending pain medication times and need for rest.

With this type of method, challenges can arise that create anxiety and problem solving needs to occur in rapid time. On one occasion, I visited a town to interview a Community Health Worker (a HACC support worker) as there was no nursing service or social worker employed in this particular community. This had been pre-arranged for some weeks. When I arrived at the office, I noticed numerous workers were pulling into the car park at the time of my arrival. I assumed that this was a staff hand-over time and mentally made a note that I would tell the interviewee I was happy to wait until the meeting was over and there was no need to hurry. To my astonishment, there was no hand-over meeting scheduled; all of these workers were waiting for me to interview them. I assumed there had been a misunderstanding; that it had somehow been interpreted that I was coming to conduct staff training or professional development. I explained to the service manager that I was there to interview one employee and that I had not come for any teaching purposes. To which she responded, “I know, but all the staff wanted to be interviewed” and thus presented me with five additional signed copies of consent forms.

I become worried and wondered what I would do as I could not possibly interview six staff members separately. They were all very interested in the topic and wanted to offer their viewpoints and I did not want to let them miss out. My next interview was scheduled for early the next morning in which I needed to travel almost five hours so could not stay in this town for that long. I had no choice but to conduct a group interview. I had to make sure everyone was clear about stating who they were for transcription purposes later on. The discussion went smoothly, with all participants offering rich data from which themes could be derived. The result was positive in that I
was able to gain six perspectives in one instance, providing me with a clear snapshot of psychosocial care provision in this community. As posited by DiCocco-Bloom et al. (2006), an individual interview allows for deeper delving into a matter, whereas a group interview evokes a wider range on a topic. There are clear positive and negative aspects to both types of interviews. All interviewees within this group held an opinion on psychosocial care in their community and considered this as an opportunity to express it. However, this incident is an example of the unexpected challenges that can arise when choosing this type of data collection methodology, with swift judgements sometimes having to be made.

By utilising the Rural, Remote, Metropolitan Areas (RRMA) Classification (2004), sites were identified as “rural” or “remote.” The RRMA classification measures remoteness in accordance to the direct distance between goods and services to the nearest urban centre. This is then combined with measures of personal distance resulting from population density. Three zones are established - Metropolitan, Rural and Remote, which are sub-divided into seven categories that are built on the Index of Remoteness (Australian Institute of Health and Welfare, 2004; Department of Health, 2001; Kelly & Dade Smith, 2007). The RRMA classifications are featured subsequently, followed by Table 3 which outlines the classifications of the towns visited for this study.
RRMA Classification

**Metropolitan**

Capital cities and large metropolitan areas **M1**

Other metropolitan areas with urban populations greater than 100,000 **M2**

**Rural**

Large Rural Centres: urban centre population 25,000-99,999 **R1**

Small Rural Centres: urban centre population 10,000-24,999 **R2**

Other Rural Areas: urban centre population less than 10,000 **R3**

Remote Zone: urban centre population more than 5,000 **Rem1**

Other Remote Areas: urban centre population less than 5,000 **Rem2**

Table 3

RRMA Classifications of towns visited

<table>
<thead>
<tr>
<th>RRMA Classification</th>
<th>Number of towns visited</th>
</tr>
</thead>
<tbody>
<tr>
<td>R1</td>
<td>2</td>
</tr>
<tr>
<td>R2</td>
<td>3</td>
</tr>
<tr>
<td>R3</td>
<td>9</td>
</tr>
<tr>
<td>Rem1</td>
<td>2</td>
</tr>
<tr>
<td>Rem2</td>
<td>8</td>
</tr>
</tbody>
</table>

As the research question was centred on “how is psychosocial care provision being undertaken for palliative clients living in rural and remote areas,” sites were chosen where persons living with a terminal illness could gain access to both a social worker and a nurse. The information was derived from the Queensland Health Intranet. As depicted in Figure 7, a campervan was hired to travel to the identified rural and remote areas so data could be collected through the interview process.
Data Analysis Methods

All interviews were transcribed by me, so I could become familiar with the content, be able to connect with the data and mentally observe any emerging patterns or repeated responses. Once all the interviews were transcribed, they were imported into the QSR NVivo 10 computer program and placed into “nodes.” Under each node was a series of sub-nodes or themes that related to the overarching node. The NVivo 10 program does not sort and code the data for the researcher, it must be done with a great deal of thought manually, however, by utilising the capabilities of the program, the complexity was reduced and process was simplified.

Thematic analysis is a series of stages that is undertaken for final definitive emerging themes can occur. I utilised the stages as outlined by King and Horrocks (2010) for its simplicity and comprehension. The interviews allowed the participants to freely express their thoughts; views, opinions and experiences of how they felt psychosocial needs for palliative clients were met in their town. Additionally, the palliative care clients and/or spouse/carer were also asked to express their experience in
the same way. Key themes could ultimately be extracted from this form of interview. The steps taken to analyse the data as per King and Horrock’s model (2010) are illustrated in Figure 8 as follows:
STAGE ONE: DESCRIPTIVE CODING

1) Transcribe interviews, transfer to NVivo, placing all the interviews in the participant groups
2) Read and re-read through the transcript
3) Highlight relevant material (anything in the transcript that might assist to understand the participants views and experience – make comment)
4) Repeat for each transcript and articulate descriptive codes or categories (this can be just one word or two words ensuring they are self-explanatory –ie; “Attitudes”)

STAGE TWO: INTERPRETIVE CODING

1) Cluster descriptive codes (group together descriptive codes that share a common meaning – ie; under the “Attitudes” Code, cut and paste any data that relates to this – ie; stoicism, “we look after our own,’etc.)
2) Consider and interpret the meaning of clusters, in relation to the research question and overarching theoretical framework
3) Move from descriptive coding and apply interpretive coding to full set of codes – ie; Descriptive Code: “Attitude” – an Interpretive code could be: “rural attitudes such as stoicism impacts psychosocial care referrals.”

STAGE THREE: OVERARCHING THEMES

1) Derive key themes for data set as a whole by considering the theoretical perspective in which study has been undertaken
2) Construct a diagram to represent the relationships between levels of coding in the analysis

Figure 8. Adapted from King and Horrocks Analysis Model (2010)

Table 4 highlights the original codes or categories that were derived from the data. Within each of these codes (or nodes as per NVivo), a cluster of sub-categories
were formed (not highlighted here as there were 65 of these). From these data, key themes could be interpreted in alignment with the research questions and aims of the study.

Table 4

<table>
<thead>
<tr>
<th>Codes from data collected from Qld Health social workers, Blue Care nurses and Community Workers</th>
<th>Codes from data collected from Palliative Care Clients and/or Spouse/Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitudes (Rural)</td>
<td>Education (about palliative care)</td>
</tr>
<tr>
<td>Bereavement</td>
<td>Emotional</td>
</tr>
<tr>
<td>Distance and Isolation</td>
<td>Psychological</td>
</tr>
<tr>
<td>Experience (of Health Professionals)</td>
<td>Social</td>
</tr>
<tr>
<td>Funding and Resources (how it impacts service delivery)</td>
<td>Spiritual</td>
</tr>
<tr>
<td>Improvement or Change (for palliative care service delivery in the future)</td>
<td>Distance and Transport</td>
</tr>
<tr>
<td>Indigenous Clients</td>
<td>Psychosocial General</td>
</tr>
<tr>
<td>Person in the Role</td>
<td></td>
</tr>
<tr>
<td>Policy</td>
<td></td>
</tr>
<tr>
<td>Referrals (Timeliness)</td>
<td></td>
</tr>
<tr>
<td>Regular Meetings (ie; case conferences)</td>
<td></td>
</tr>
<tr>
<td>Relationships (Inter-professional)</td>
<td></td>
</tr>
<tr>
<td>Social Work Referrals</td>
<td></td>
</tr>
<tr>
<td>Support (Social)</td>
<td></td>
</tr>
<tr>
<td>Trust and Respect (Both inter-professional and from client to practitioner)</td>
<td></td>
</tr>
<tr>
<td>Workload</td>
<td></td>
</tr>
</tbody>
</table>
The findings that emerged will be explored in depth in the subsequent three chapters. The themes in this instance will inform policy and practice. They will potentially be utilised for influencing future policy and funding as well as becoming indirectly possible material for future research purposes. With every step of King and Horrocks’ model (2010), my thinking transferred from descriptive, concrete codes towards a deeper, abstract content from which key themes could be interpreted. As articulated by Grinnell and Unrae (2011) the need for flexibility and a willingness to move back and forth between and among the steps is pertinent in order to produce meaningful results that can be disseminated for higher purposes.

**Ethical Considerations**

Interviewing persons with a life limiting illness can be emotive as persons disclose their experience regarding met/unmet psychosocial needs. To cause harm to a vulnerable person would be a violation of social work values and principles. Ethical clearance was obtained via three Human Research Ethics Committees, with a detailed rationale regarding the proposed methodology. Graziano and Raulin (2004) state it is the responsibility of the researcher to ensure their proposals are submitted and approved by ethical committees before gathering data. Once clearance was obtained, I forwarded the information/consent packages to potential participants as per purposeful sampling. Straightforward language was utilised when gaining consent, rather than formal structured processes; otherwise it may not have been clear or understandable to the participant. This was also consistent throughout the interview process.

Capacity to offer consent was another noteworthy point for consideration. Although it did not eventuate to be necessary, if at any time the participant’s capacity was questionable, the General Practitioner would have been contacted for clarification. However, this did not turn out to be an issue as the palliative clients were all deemed to
have capacity as clarified by the health professionals who invited them to participate in the study.

Careful consideration was also given to identification issues. For example, if there is only one social worker in a town (which generally was the case), then information given by the nurse could easily have identified the social worker resulting in a potential confidentiality breach. To address this problem, I needed to select towns or sites where a client could access both a social worker and a nurse. I then only interviewed the social worker in that town. In another selected town, the researcher only interviewed the nurse. Two of the palliative clients and their carer/spouses were identified by an interviewed health professional; the other was identified by health professionals that were not interviewed.

Due to the fact that the nature of this study was centred on death and dying, it was specifically acknowledged throughout the interviewing process that this was a sensitive topic and reassurance was provided that the interview could be terminated at any time. As an experienced social worker, dealing daily with palliative care clients and addressing their psychosocial needs, the risk of harm was potentially minimised due to a certain level of skill in this area. This was not a guarantee but reduced the likelihood of the interview being a negative experience for the participant.

The following strategies were considered to manage potential risks should they occur:

- In the information/consent pack the participants were informed of who to contact should there be any concerns or complaints about the ethical conduct of this research.

- The aims of the research, what was expected from participants, the selection criteria, the expected benefits of the research, risks, confidentiality and
contact information was all provided to the participants in the
information/consent packs to read prior to the interview.

- All participants were informed that the researcher was a social worker who
dealt with these psychosocial issues regularly.
- Participants were informed that they could contact the researcher directly
and arrange the interview or this could be facilitated via a health
professional.
- Participants were aware the interview could be terminated at any time.
- Participants also knew they could withdraw their consent, even after
interview was conducted.
- All participants were informed that names and addresses would not be
included in the data and that in the analysis phase consistent themes would
be derived with no identifying information being included.
- In regards to the palliative clients, feedback was provided to the health
professionals who had invited the participants to participate, about the
emotional response to the study so that follow-up could be organized if
deemed necessary.

**Anonymity and Confidentiality.** Participants were informed they could state
their name in the interview; however this would not be used in the data analysis process
or in any final reports. Additionally, participants were not given a questionnaire where
their names and addresses could be written. The participants did sign a consent form
with their names on it, which in turn, would be kept in a locked office for a period of up
to five years before being shredded or destroyed.
Confidentiality was assured in all interviews. Unless directed to a community worker during the data collection phase, I took precautionary measures to the best of my ability to ensure none of the health professionals or community health workers knew each other when organizing the data collection road trip. All the health professionals were interviewed in separate towns with no information being provided about the other. When health professionals were discussing their clients, no names were divulged regarding their identity.

Additionally, I was travelling all over Queensland with another adult who was not involved in the study project in any way. Travelling with another adult was pertinent and recommended for my safety. None of the interviews were discussed with the other adult with all consent forms, lap top and taping devices being locked in a safe in the campervan with the key held only by the researcher. All phone calls were made away from the other adult. Any debriefing that needed to occur after the interviews took place with university supervisors who were available throughout the entire data collection phase. The other adult merely travelled with me to ensure physical safety as discussed with all three ethical committees.

**Risks and Benefits**

The results of this study have indicated that psychosocial needs are not being met in a consistent manner for palliative clients living in rural and remote areas of Queensland. Policy and funding bodies could now be influenced to inject capital and other resources – ie; skilled psychosocial staff to address this gap in service delivery. A human rights perspective will be embedded in the implications in Chapter Eight with the aim to ultimately inform stakeholders on a macro level.

Additionally, the study has provided palliative clients an opportunity to make a contribution prior to their death. Research conducted by Steinhauser et al. (2000) stated
that making a contribution or passing something on is a major component to a “good
death.” Participation in the research may bring a sense of giving back and satisfaction
prior to death. It also provided the opportunity for the client to have their experience
heard by a competent practitioner who was non-judging and held unconditional positive
regard for them.

The risks to the palliative clients was minimal, however, discussion of the
emotional aspects of facing the end of one’s life could have caused some discomfort.
As an experienced social worker who works daily with palliative care patients, I felt
competent to manage any distress throughout the interview. The client was aware that
the interview can be terminated at any time and that this included after the interview
was completed. I could be contacted and all information would be deleted from the
study. Feedback from the referring health professional after the interviews was
completed indicated the client was happy they participated in research and no distress
ensued.

Additionally, social workers and nurses not only work in these communities, but
live in them too. They often know the palliative clients personally, which could have
caused some discomfort when discussing the topic. However, due to my experience in
dealing with emotional issues, I believe I would have been able to manage this, and this
was not necessary in any instance.

**Researcher Reflections on the Process**

As a practitioner working daily with palliative care clients, I was not
significantly emotionally impacted by the content of the interviews. Palliative care is
an area I have been exposed to for some years now, so I am familiar with end of life
psychosocial concerns and am comfortable with normal emotional responses. I was
also able to regularly debrief with my supervisors on a frequent basis, which was
beneficial throughout the data collection phase. However, this is not to say other tensions did not arise.

One challenge I did face was the difficulty around shifting from the familiar social work role to a more unfamiliar researcher role. It was perplexing at times, when interviewing palliative clients, to not launch into full therapeutic responses and to remember I was there as a researcher and not as a social worker. To keep myself on track, I continually reminded myself I only had a small window frame of time as the person before me was gravely ill and the interview was taking place in between a rigid pain medication regime. I did not want to lose sight of this. A principle set out in the Research Section in the AASW (2010) Code of Ethics states “social workers will place the interests of research participants above the social worker’s personal interests or the interests of the research project,”(p.36) a thought that was foremost in my mind.

Furthermore, in the communities where access to a social worker was difficult or unlikely, the palliative client and their spouse were unaware of the psychosocial service they were missing out on. Now that they had met a social worker and understood what a social worker could offer, it appeared to leave them with a sense of being deprived of something helpful, a feeling that had not been there prior to my visit. After I finished the interview I managed these tensions by journaling them in a diary and by debriefing these concerns with my supervisors.

Finally, as a sole researcher on a five week research expedition, I did feel an enormous sense of responsibility and some anxiety around potential unforeseen circumstances that would have impacted the itinerary, ie; vehicle breakdown, damaged roads etc. However, the entire data collection phase went smoothly with all participants ready and waiting to be interviewed with not one major problem arising to speak of; an issue of which I am most appreciative.
Limitations of the Study

Due to identification issues I could not interview two different health professionals from the same town. This meant I was interviewing one Blue Care nurse in one town and then travelling to the next town to interview a Queensland Health social worker. As most social workers are sole practitioners they are easily identified. If I had interviewed a nurse who questioned the competence of the social worker to address psychosocial needs of palliative care clients and then I interviewed her next, a preconceived idea would already be formulated creating bias in the study. This is a limitation in that I was only able to gain the perspective from one person from one organization in that particular town. A clear overall picture could not be ascertained.

Another limitation to the study was the sample size of the palliative care clients. If a sample size is too small, it will be difficult to find relationships from the data and have the findings considered representative of groups of people to whom the results will be generalized or transferred (University of Southern California, 2014). The palliative client sample is small and could be considered a limitation, however, it should also be noted that generalizability was not an intended goal. As identified, it was problematic to gain access to this clientele via the medical professionals. Much time and effort was put into just getting the five respondents who agreed to be interviewed. This limitation is openly acknowledged and articulated throughout the thesis.

Furthermore, Maxwell (2013) states it is impossible to eliminate a researchers’ own beliefs and perceptions, however understanding how one’s own values may influence the study is important. This is often referred to as bias. I was the principal researcher and collected the data alone, meaning other input and perspectives were not obtained, as is likely to occur when working on a project with other team members. I am also a social worker, addressing psychosocial needs for palliative clients in a rural
community. Although the research was overseen by two experienced supervisors, and a rigid data analysis structure was adhered to, my own management of the project could be considered a limitation to the study because of my position. However, to maintain integrity and truthfulness, certain techniques were adopted, which will be discussed further in the subsequent section.

**Strategies to Achieve Trustworthy Qualitative Research**

Shenton (2004) states the trustworthiness of qualitative research is often queried, perhaps because concepts of validity and reliability cannot be addressed in the same way in naturalistic work. Terms such as credibility, transferability, dependability and confirmability are the criteria utilised by qualitative researchers replacing the usual criteria of internal and external validity reliability and objectivity (Denzin & Lincoln, 2000). Silverman (2000) states validity is another word for truth, thus certain procedures should be undertaken to establish truthfulness. In summary, rigor can be incorporated to establish trustworthiness by means of certain strategies (Lietz, Langer, & Furman, 2006).

A strategy articulated by Lietz et al. (2006) states the use of reflexivity, a means that involves deconstructing who we are and the ways in which our beliefs, experiences and identity intersect with that of the participant. I cannot make an assumption that all other social workers in rural Queensland are undertaking the same tasks in palliative care as I do. I believe social workers are well equipped for this role, but I had to be honest, aware and reflective that this may not be the case in every community. Lietz et al. (2006) states to establish trustworthiness the research should not hide behind a false sense of objectivity but be upfront about who we are and what is our position. All participants were made aware that I was a Queensland Health Social worker with an interest in palliative care. Throughout the entire data collection and data analysis phase
it was important for me to reflect upon how my position constructed meanings and whether or not this was an asset or a hindrance to the project. As an example, on one occasion, I wrote in the journal that I penned in each day:

[Nurses name] is an amazing nurse, who goes above and beyond for her clients. She addresses all psychosocial needs because of her experience, age and personality. She has lived in this community all of her life. She states the social worker is young, unmarried, has never travelled and does not seem competent in palliative care. I am wondering if it really always has to be a social worker.

Here I start off a little descriptive but then move into pondering and reflection, trying to construct meaning from the interview by challenging my beliefs. Reflection was a constant process that I sought to apply and record in my research journal.

As mentioned above, a journal was utilised each day to write down my experiences for guidance and reflection as I could not discuss the research with my travelling companion. I also wanted to keep a record of all that happened on my journey. This strategy could also be referred to as an “audit trail”, another strategy mentioned by Lietz et al. (2006). By means of the journal, a map and a diary with a clear record of scheduled appointments, all that occurred on the trip could be identified and critiqued. It also allowed me to follow my own research pathway and keep a transparent account that could be referred back to or shown to my supervisors.

A third strategy is referred to by Bowen (2008) is called “negative case” analysis. This is when contradictions occur in research and narratives arise that do not fit in with other consistent themes. Silverman (2000) states the criticism of qualitative interviews involves anecdotalism. Anecdotalism is revealed in a way that reports telling examples of a phenomenon, without any attempt to analyse less clear data. This complaint of anecdotalism questions the validity of much qualitative research. I have
addressed this issue to the best of my ability by exposing contradictory data within the findings not just detailing reports that “fit” the existing data. There could be a temptation to omit them. However, to ensure trustworthiness, I have added such contradictions into my findings and discussed them. I present the case of Ellen, a social worker who was young and had only graduated from university eighteen months prior. She was essentially not an experienced social worker, yet was receiving regular referrals for psychosocial care. I could have failed to include her comments as “they did not fit” with the theme that years of experience is correlated with referrals. This is discussed further in the subsequent findings chapter. A major goal in the research I consistently sought was to find ways to challenge my ideas and to think critically on the findings.

Conclusion

This chapter has highlighted the conceptual framework that underpinned and drove the study. A rationale was provided as to why a qualitative interviewing method was selected. The recruitment and sample section identified the four participant groups and a justification as to why this group was selected. Characteristics were detailed with pseudo names utilised to protect the participant’s identity and are attached as appendix B.

The eligibility criteria for participation of the study was then provided, which was by no means rigid. The chapter then discussed the research questions and their formulation. The questions became the basis for the interviews and the catalyst in deriving prominent themes. Attempting to gain access to the palliative clients by inviting General Practitioners to forward the information/consent package on to their terminally ill clients proved ineffective, becoming a barrier to the study. It was thus determined an amendment should occur, which was detailed.
The data analysis process was thus featured in length, with a step by step illustration of how it was undertaken utilising King and Horrock’s model (2010). Ethical considerations such as confidentiality, risks and benefits of the study and the impacts on myself as the researcher was also put forth. The tension of swapping hats from social worker to researcher and having to moderate therapeutic responses was identified as having some effect.

Finally, the chapter finished with a discussion on the limitations of the study which should be considered. Besides the identification factor as discussed, the small sample group of palliative clients and their carers make it difficult to generalise to the wider palliative care community, nevertheless, the depth of data makes up for this limitation. The qualitative findings inspire additional future research that may be of a more quantitative kind. The fact that there was only one main researcher collecting data and undertaking an analysis, the benefit of input from other team members was not a component of the study. This also mean reflective practice needed to occur throughout the data collection and data analysis phase. Lastly, the strategies employed to establish truthfulness in the study were articulated. Like a patchwork quilt, the methodology was a combination of multiple factors that, when put together, resulted in the collection and analysis of rich data that provided an overall picture of psychosocial care provision in rural and remote Queensland.

The next three chapters will consider the findings derived from the data analysis for the four participant groups. The subsequent chapter - Chapter Five, will highlight the results around how psychosocial care provision is perceived by health professionals, with the issues that can surround social work referrals being illuminated.
Chapter Five

Findings and Discussion

Referrals and Engagement with Psychosocial Care in a Rural Context

This and the following two chapters present findings and discussion from the research. This section will consider the findings to the research questions, how do rural and remote service providers perceive their role in providing psychosocial care and what are the perceived barriers and enablers to social work referrals. This chapter begins by exploring referral pathways for psychosocial care, from which pertinent themes were derived. The next section considered barriers and enablers to social work intervention highlighting how the experience, skills and competency of the social workers impact referrals. Service sustainability was vulnerable in that there was a considerable reliance on particular individuals, resulting in concerns around lack of structure. The findings then revealed how engagement with psychosocial care was also influenced by rural culture and context as well as the strengths of community and social supports. The chapter closes with a detailed discussion of these results.

The questions were asked against the backdrop of existing literature that purports social workers claim expertise over the psychosocial domain for this clientele, possessing pertinent skills to undertake this role. Results from this study reveal mixed views about this. In some communities, the nurses saw the psychosocial domain as pivotal to their role as some had undertaken additional study in this area. It was of noteworthy interest, that not all non-social work participants thought social workers actually possessed the required skills to deal with palliative care clients in their community. However, in many other cases, social workers were actively engaged in this care.
Exploring Referral Pathways for Psychosocial Care

Referrals for psychosocial care are often made by medical or nursing staff, usually a community nurse who visits the palliative client and their family in their home. When signs of emotional or psychological distress are exhibited, the visiting practitioner will consider how best to address this psychosocial concern. It may even be a practical matter, such as applying for a carer allowance or assistance with how to organize an Enduring Power of Attorney. All health practitioners should have a sense of the level of psychosocial support that is available in their community. As it is generally community health nurses who are at the frontline of care, it was imperative to gain the perspectives of this group regarding psychosocial needs. As indicated in the previous chapter, Blue Care nurses were one of the primary target groups.

Perspectives of Blue Care nurses. Ten Blue Care nurses were interviewed about how psychosocial needs of the palliative clients in their particular communities were addressed. Three primary themes emerged from the data, which related specifically to why nurses often found themselves in a position of addressing psychosocial needs of palliative clients. The first theme related to training and education in end-of-life communication and palliative that two nurses had undertaken in previous study. These nurses clearly perceived themselves to be experienced in this area and well able to take on this aspect of the work themselves without need for a referral elsewhere:

I don’t do a lot of referring because I’ve done counselling as part of a degree. I have worked in oncology overseas where we did a lot of counselling. So my response would be different to other nurses because of my background and experience. (Erica, BCN)

Additionally, Yasmin similarly stated:
I have a Masters in Palliative Care so have done all the end-of-life communication, and do not have a problem regarding addressing psychosocial needs as with the other girls. (Yasmin, BCN)

The second theme from the data related to the perceptions of three other Blue Care nurses, from two different communities, who reported the social workers were difficult to access and their response to a referral often came too late. None of these nurses had undertaken specific training in the area of psychosocial care, but all reported they had learned through experience as they had been nurses for many years.

The truth of these perceptions correlated with the comments made by social workers Ellen, Christopher, Lesley and Donna who expressed concerns about travel, stretched workloads and in some cases, part-time hours. The Blue Care nurses recognised this and undertook the task of psychosocial care themselves; however, it was more out of necessity, unlike Erica and Yasmin who saw it as part of their practice.

Palliative care clients do not have the luxury of extensive time, so when issues arise, it is expected they be addressed in a rapid manner.

They are very busy and often the palliative client needs it, like tomorrow or today. It can be a couple of weeks before we can get anything in. So we have to fill the gap which is stressful. (Candice, BCN)

Marlena agreed with Candice stating:

In the country the social worker tends only to flit in and out once a week or once a fortnight. They’re not here long enough. And she has to cover every situation, not just palliative care, so you learn to be a bit of a social worker yourself because of the situation we are in. We are so far away and there aren’t the resources past the dotted line. (Marlena, BCN)
The third theme that emerged related to the perception that some nurses expresses that the social workers in their communities may lack skill and competency in palliative care. Three nurses also did not believe the social workers could adequately address psychosocial issues of palliative clients so they addressed the needs themselves. As Nellie states:

Well it’s not good enough for me to say, “I’ll just refer to a social worker.” For me, it has be a social worker that is versed in palliative care. To me it makes no sense to refer someone to a social worker who has never dealt with palliative clients. And we get protective because we have done it all along; it’s hard to separate that out. I will stand by the fact that social workers who work in palliative care should have special experience in palliative care. (Nellie, BCN)

As outlined in the literature review, some nurses will see psychosocial care as integral to their role and a core nursing activity and will not consider putting in a referral to a social worker for psychosocial support. This supports the sentiments of O’Connor et al. (2006) who states nurses do see this domain as pivotal to their practice. Furthermore, the results also revealed other nurses take on this sphere of care due to the difficulties in accessing psychosocial support or unavailability of this resource, which is congruent with existing research that succinctly highlights this gap in service delivery. Many nurses do take on the role; however do not feel vocationally prepared for it (Kenny & Allenby, 2013; White, 2007; Rosenberg & Canning, 2004; Hegney et al., 2002).

Additional themes were derived from the data relating to Blue Care nurses’ perspectives, which will be addressed later within the chapter. The following section will provide perspectives from social workers raised by nurses.

**Perspectives of Queensland Health social workers.** The research revealed that in the 22 towns where health professionals were interviewed, eleven social workers in
total were receiving regular referrals for psychosocial care. Seven of these social workers were based in Queensland Health Hospitals which is where they spent most of their time, undertaking some outreach work when necessary. For these seven practitioners, there was a very clear understanding of their expertise in the psychosocial domain.

In four other communities, social workers were also receiving referrals to address psychosocial needs for palliative clients but certain factors impacted the extent of services that could be delivered. Four distinct themes emerged relating to factors that impacted the extent and quality of psychosocial care that could be offered. The first theme pertained to the employment status of the social worker; the second theme related to the vast geographical distances that needed to be travelled; the third theme had to do with the positioning of the social worker whilst the last theme related to workload pressures.

The first theme acknowledged was the employment status of the social worker. It is not uncommon for fractional appointments to be made in healthcare service provision depending on funding sources and competing priorities. Two social workers worked part-time. One social worker, Donna, was particularly conscious of the fact that her part-time status limited what she could provide, particularly to towns that were part of their outreach work and potentially inhibited the depth of interventions that could be offered. She was receiving referrals for palliative clients but had to work closely in conjunction with the community nurse as she physically could not address all the needs herself:

Well I don’t do enough of the satellite towns. I am very conscious of the fact that I am not servicing these towns adequately at all with my part-time hours.

But that will change when I increase my hours. (Donna, SW)
Antoinette, also worked part-time hours and left the psychosocial needs up to the nurses stating her reduced hours were part of the reason:

I haven’t had much to do with them really [palliative clients]. Because I’m part-time as well. Some nurses just do it naturally. And some have had training, you know training in palliative care and they would know how to be with people, what to tell them and what to leave up to the doctor. (Antoinette, SW)

It is of noteworthy interest that Donna felt a sense of culpability that persons in outlying communities were receiving a sub-quality service because of her hours, whereas Antoinette did not feel this way, believing the nurses had more skill than her anyway, therefore did not possess the same qualms. This will be discussed in more detail a little further on.

A second theme that impacted the extent of what social workers could offer was the vast, geographical distances that had to be travelled to outreach communities. This limited face-to-face time and thorough interventions. This was an issue for four social workers in particular, working as rural generalists. Social workers reported feeling pressure in trying to meet the psychosocial needs for palliative clients living hundreds of kilometres away from their hospital or community base. Ellen admitted reduced face-to-face time with the client raised concerns around the quality of the intervention:

I outreach to two towns on one day, so it’s basically three hours on that Wednesday. But the third town I do on another day, it’s actually two and a half hours each way. So it’s a huge amount of travel and not much in terms of actual face to face client time. (Ellen, SW)

Christopher also identified he travelled up to 400 kilometres at times to get to smaller outlying communities. Christopher spoke of the importance of having good rapport and
communication with these outlying communities, especially when issues arose. He needed to be able to call on health professionals he had a rapport with to assess the need and see if a trip out was warranted:

It is very difficult building trust and rapport, especially in the smaller communities and within the Indigenous communities, it does take time. When new rotational doctors came through, the rapport process had to start over again. (Christopher, SW)

However, Christopher stated he needed to have these relationships in place in order to gain collateral to determine justification of travel.

Lesley, who also had large distances to cover in her outreach work, admitted the distance put clients requiring support at possible risk of being missed. She stated:

It is stretched and that’s only because of the distance you will find in rural areas, you just can’t be in all places at all times. Outpatients sometimes fall through the cracks a bit. (Lesley, SW)

It became apparent that the crux of the work had to be crisis oriented or focussed on practical concerns that compromised the depth of quality interventions. These findings support research about barriers such as distance, lack of transport and the need to travel, as well as reduced services from which to choose and how they significantly impact those living in rural areas (Hardy et al., 2008; White, 2007). Access to bereavement support for psychosocial issues such as loss and grief counselling is a huge challenge for those living in these regions. Limited access to allied health staff impacted by geographical distance, particularly for psychosocial support, is problematic and requires improvement (White, 2007; Underhill et al., 2009).

A third theme that impacted referrals and caused concern was the positioning of social work services. For example, in one community concerns were raised that some
palliative clients could potentially be missed in the referral process. In this district, it was ascertained that the social workers should no longer be positioned in the hospital but should be placed in the community health setting. Whilst this offered certain advantages regarding the community clients, Christopher expressed concerns regarding the potential gaps for palliative care clients in hospital:

Because we are no longer on hospital grounds and are now seated at the community health centre, which is down town, and it’s only been a recent change but I think it’s going to be more difficult in receiving those referrals as we don’t have daily contact with the hospital, whereas previously we’d do ward rounds at the hospital every morning. That doesn’t occur anymore, now that we’ve been removed from the hospital, so I think there will be some problems with the referring of palliative care patients to social work. (Christopher, SW)

Exosystems, such as local policies dictating where social workers should be positioned can impact on practice immensely and often the social worker will have no direct role in the decision making process. Not only does it influence the social worker, it ultimately trickles down and affects the palliative patient who has absolutely no control over such issues. New laws, government health reform, environmental regulation, financial re-organizing and industry can all indirectly have a profound effect on the micro and mesosystem (Victor Valley College, 2013). This local policy change concerned Christopher who was removed from the hospital setting where he attended ward rounds every morning with doctors and received constant referrals for palliative care clients to now being situated in the community. The potential for palliative clients in hospital and in need of psychosocial review being missed concerned Christopher who was uncertain how the change in his location would impact service delivery.
The fourth and final theme that impeded social work interventions for psychosocial care was workload pressure and not inclusive of the reasons noted above. In one community in particular, there was only one social worker to service the needs of all patients of a regional 50 bed hospital, with a nursing home attached. The social worker was so stretched in her workload that she had to be stringent regarding her outpatient criteria as it was too difficult to support palliative clients at home to a satisfactory degree. There were limited services the social worker could link the client with for additional support:

I am it. There are no other social workers. In terms of outpatients, my role is predominantly to provide information referral consultancy. I really stress [to the client] that I am not going to be able to provide that ongoing support. (Sally, SW)

There is no pre-existing literature that highlights the activities of social workers working in rural communities in Queensland and their interventions with palliative clients. However, these barriers to effective psychosocial care resonate with the literature that highlights the extensive travel nurses have to undertake to care for their patients and the complexities of having to stretch ones’ services beyond capacity. Nurses experience similar obstacles of workload pressures, organizational factors, emotional exhaustion, stress and burnout and poorly integrated and coordinated services (White et al., 2004; Kenny & Allenby, 2013).

**Perspectives of community workers.** In numerous communities, it became apparent that needs were not being addressed by social workers or community nurses. A third group were identified in this research and were referred to as “Community Workers.” In some instances, community workers were identified just prior to the data collection phase through preliminary enquiries or during the data collection stage from
utilising the snowball method highlighted in the preceding methodology chapter. The community workers sample group was made up of six HACC support workers, one HACC nurse, two Queensland Health nurses, two aged care nurses and one non-government social worker. The themes identified by workers in this group were not dissimilar by those previously mentioned.

One participant, Janelle, stated she was meeting the psychosocial needs out of necessity because there was no social worker currently in her community, but she preferred a social worker to address such issues when they had one on staff:

> When we’ve got a social worker, I would much prefer them to, but you know, they’re the ones who are trained in the counselling role. We do it together, it’s a bit collaborative. But we haven’t had a permanent social worker for some time now. (Janelle, CW)

Another worker was addressing all psychosocial needs and appeared to be doing so in an effective manner, stating she had received positive feedback from her interventions and her clients preferred to speak with her over the social worker:

> I feel I’ve had a lot to offer people, that’s just on a personal level and I’ve had feedback that they are more than content with the way that I approach. Some of my patients have been in hospital and I’ve arranged for them to see a social worker but they’ve come back to me and said – ‘we prefer to talk to you in the future.’ Not a worldly girl, hasn’t travelled, very quiet so I think there’s some issues there; that’s the feedback from my client. (Carla, CW)

In communities with few facilities, psychosocial needs were being addressed by HACC support workers who had not had any significant training in the area of psychosocial support, but were doing so out of necessity as nurses and social workers were difficult to access.
We have to link up with the hospital to get and attract a nurse and have a nurse on our team just isn’t happening at the moment so I think that’s the bit we really need help with at the moment, especially for palliative care.......I believe there is one [a social worker] that comes out on a regular basis through the hospital [health centre] so we don’t see her, but I’m not sure if she comes fortnightly or monthly. (Sonya, CW)

Helen stated she touched on palliative care in a Certificate Three in Aged Care course, but really couldn’t do much more than sit with her palliative clients and “listen to them, but it’d just be comfort” (Helen, CW).

In another community, a HACC nurse echoed the same sentiments as Candice (BCN) and Marlena (BCN) as well as Christopher (SW), identifying problems with access to the social worker in a timely manner and how they are positioned in the community as a challenge. Anne-Louise purported:

The social workers are great but we do have a little trouble accessing the social worker because of the way they are situated. They are half with the health department and half with the education department and they travel west.

Sometimes you have to wait a week and a half even longer. (Anne-Louise, CW)

Finally, the last community worker, Christina, who was identified as meeting all psychosocial areas for palliative clients, worked in a non-government hospice as a social worker so end-of-life psychosocial care was her core daily business. The local General Practitioner in this town stated he sent referrals to this particular social worker as he felt she adequately met all psychosocial needs of palliative clients in this particular community. Christina worked part-time, so therefore job shared with another social worker. They ran numerous bereavement groups and undertook home visits on a daily basis. If a palliative client was fortunate enough to live in the catchment area of this
hospice, their psychosocial needs appeared to be addressed well. This will be verified by one of the palliative clients in Chapter Seven. The following tables (Table 5 and Table 6) will provide an overview of who was receiving referrals to address psychosocial needs, highlighting the inconsistencies across the state.

Table 5

Communities Where Blue Care Nurses and Queensland Health Social Workers were Addressing Psychosocial Needs

<table>
<thead>
<tr>
<th>Health Practitioners</th>
<th>2 communities</th>
<th>2 communities</th>
<th>7 communities</th>
<th>4 communities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blue Care nurse identified as</td>
<td>3 communities</td>
<td>Social worker identified as</td>
<td>Social worker identified as</td>
<td>Social worker identified as</td>
</tr>
<tr>
<td>effectively addressing all psychosocial needs as they were experienced or had undertaken training</td>
<td>3 Blue Care nurses identified as addressing psychosocial needs</td>
<td>Social worker identified as addressing all psychosocial needs with no significant issues reported</td>
<td>Social worker identified as receiving referrals but certain factors impacted effectiveness or extent of what could be provided</td>
<td>Social worker identified as receiving referrals but certain factors impacted effectiveness or extent of what could be provided</td>
</tr>
</tbody>
</table>

* BCN in Town 16 also believed the social worker was not skilled
Table 6
Community Workers Addressing Psychosocial Needs

<table>
<thead>
<tr>
<th>Community Workers</th>
<th>4 communities</th>
<th>1 community</th>
<th>1 community</th>
<th>1 community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qld Health Nurse</td>
<td>2 workers (6 workers)</td>
<td>(Town 7, 9, 13 &amp; 20)</td>
<td>(Town 14)</td>
<td>(Town 12)</td>
</tr>
<tr>
<td>HACC support workers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HACC Nurse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-government social</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>worker</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The results to the research question around who was meeting the psychosocial needs in a particular community revealed a patchwork, inconsistent scenario. Clearly, the person meeting the psychosocial needs of palliative clients is the person who was deemed to have the appropriate skills and/or is most accessible and this was not attributed to any particular profession. It was usually the social worker, but this was not a given. These findings revealed the psychosocial sphere is definitely a shared realm with no real clarity as to who it belongs to (O’Connor et al., 2006; Lee, 2007). Social workers claim sovereignty over it but so do some community nurses (Christ & Blacker, 2005; Weber & Grohmann, 2004). It appears social workers have not been particularly adept at promoting their profile and marketing their competencies. Additionally, some social workers did not appear to have the appropriate skills to address psychosocial needs of palliative care clients. This is consistent with the literature that shows an absence of educational opportunities for social workers in end-of-life care (AASW, 2012).
Queensland Health does not apportion social workers in rural communities in accordance to a set ratio per population. Consideration is given to what services the clients require in a specific geographical area and who can best deliver it. It will largely depend on the identified model of care implemented in that community and the evidence base for services required. In regards to psychosocial care for palliative clients, Queensland Health will not necessarily see the social worker as being the only discipline specifically skilled to provide this service. The need can be met by a nurse, community counsellor or a community worker, if deemed skilful, as proven by these results. Basically, it is apparent that whoever is available and competent will be attributed the task of addressing psychosocial care. The chapter now turns to the findings about experience, skills and competencies of social workers.

**Barriers and Enablers to Social Work Intervention**

The data revealed that the years of practice experience, the social workers’ perceived competency and skill along with personal attributes also influenced referrals for psychosocial intervention.

Eleven social workers were identified as regularly receiving referrals for psychosocial care. As articulated, it was imperative to some of the community nurses that the social worker had to have experience with palliative care clients or they would meet the psychosocial needs themselves. The findings therefore revealed there was a strong connection between the experience of the social worker and referrals. Table 7 identifies the years of experience of each social worker interviewed.
### Years of Experience of Queensland Health Social Workers

<table>
<thead>
<tr>
<th>Town</th>
<th>Years in practice as a social worker with exposure to palliative clients within this time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Town 3 (hospital social worker)</td>
<td>20 years</td>
</tr>
<tr>
<td>Town 4 (hospital social worker)</td>
<td>12 years</td>
</tr>
<tr>
<td>Town 5 (hospital social worker)</td>
<td>26 years</td>
</tr>
<tr>
<td>Town 6 (hospital social worker)</td>
<td>3 years (had worked as a community nurse for 12 years prior)</td>
</tr>
<tr>
<td>Town 8 (hospital social worker)</td>
<td>12 years</td>
</tr>
<tr>
<td>Town 10 (hospital social worker)</td>
<td>18 years</td>
</tr>
<tr>
<td>Town 11 (was hospital based but recently became community based)</td>
<td>6 years</td>
</tr>
<tr>
<td>Town 11 (was hospital based but recently became community based)</td>
<td>1½ years (see 3rd paragraph below)</td>
</tr>
<tr>
<td>Town 15 (hospital social worker)</td>
<td>identified by Blue Care nurse years of experience not available</td>
</tr>
<tr>
<td>Town 18 (hospital social worker)</td>
<td>30 years as identified by Blue Care nurse</td>
</tr>
<tr>
<td>Town 19 (hospital social worker)</td>
<td>identified by Blue Care nurse years of experience not available</td>
</tr>
<tr>
<td>Town 21 (hospital social worker)</td>
<td>8 years</td>
</tr>
</tbody>
</table>

Total 12 social workers

(With the exception of town 6 and 11, all of these towns had one social worker employed in that community)
An interesting factor that came out of the study was illustrated by Carissa (Town 13 and not receiving referrals), who had been a practicing social worker for two years. She had not long arrived in the rural community where she worked and was having trouble gaining access to palliative clients. Carissa felt strongly that hospital nurses had taken ownership of the psychosocial sphere, purposefully withholding referrals from her despite the fact she was keen to work closely with this clientele. She stated she had little to do and was readily available and waiting for referrals. Carissa was frustrated because she could not get the nurses to refer to her service. She felt she had to side-step the nurses and educate the hospital doctors on what she could offer, but this created a huge tension between herself and some of the nursing staff. She reported there had not been a social worker in this community for a very long time and so therefore nurses were not used to referring to a social worker for this domain of care. This concurs to some degree with Blue Care nurse, Nellie’s earlier comments when she stated – “We get protective because we have done it all along; it’s hard to separate that out.” Carissa explains:

The nurses control the referrals so I don’t get a lot of referrals. We don’t have that opportunity because we are blocked. Our intervention has already been blocked by the nursing staff. Social work in palliative care is not well established. They are not utilising us. People, patients and relatives are not aware that social worker should work hand-in-hand with the oncology team and I am part of the oncology team and I should be there on the initial interview. I should be getting the referrals. This is because there has been no social worker who has worked here for a long time. It is very political as far as referrals are concerned. Referrals are controlled by nurses. (Carissa, SW)
However, in contrast, one newly graduated social worker in Town 11 was receiving referrals for palliative clients. Although she worked side-by-side with another more experienced social worker, she also appeared to be the exception rather than the rule. This is where characteristics of the social worker came into play and how networking with other disciplines and co-workers contribute to receiving referrals for psychosocial care of palliative clients. Although a fairly new graduate, Ellen presented as mature and as older than her years. Her co-worker described her as different and exceptionally quick to pick things up. She worked hard at building networks and establishing rapport both within the hospital and the community. She was visibly present at community meetings advocating what social workers can assist with. Here is what Ellen had to say:

I think it took that first three months to really start to establish rapport and connections within the community and also getting my head around the role. I built a good rapport with the treating doctors at the hospital and within the community. There was one doctors’ surgery in the community and their nursing staff, which I felt was really important; then also establishing myself in the outreach centres. It really took three months to get my foot in the door and from there it’s been a process of building on that. So for twelve months or so now I really feel a part of the community. (Ellen, SW)

It appeared this was more of an issue about history in regards to palliative care as well as experience. The town which Carissa worked in had not had a social worker for a very long time so nurses were well entrenched in taking on this role and used to doing this. Ellen, although a new practitioner worked in a community that always had a social worker addressing psychosocial needs.
Lesley too, had been a social worker for three years and did receive regular referrals for palliative care clients. However, she did identify with some of the struggles Carissa relating to the profession being valued and utilised to its full potential:

I really feel that social work isn’t as valued as it should be. I think social work has been undermined. They [nursing staff] refer to somebody else. So what they have done is eroded what social workers have the capacity to do and are trained to do. They farm out the referrals to somebody else. Social workers have lost their profile. (Lesley, SW)

Although Lesley was receiving some referrals for palliative clients, she felt it was a fight to obtain them and she really had to work hard to promote the social work profession. It is interesting to note that both Carissa and Lesley were relatively new social workers to health and had not had excessive experience in working with palliative care clients as well as inter-professional collaboration with nurses, although both were very enthusiastic and keen to do so. These findings suggest that nurses need to feel confident in the social workers’ skills and experience before they will refer. Historical issues around the presence of a social worker also can play a role as illustrated by Carissa’s situation.

An exception to the rule on the other end of the spectrum was demonstrated by Antoinette’s case. Antoinette had been a social worker for approximately ten years but chose not to see palliative clients as she only worked part-time hours and felt nurses “did it more naturally” than she did. She believed the nursing staff was better equipped than herself to work with this clientele, despite her 10 years of experience as a social worker.
They [the nurses] have training in palliative care and they would know how to be with the people, know what to tell them and what to leave up to the doctor and stuff like that. (Antoinette, SW)

This was contradictory to the association between experience and referrals for palliative care, however, a stand-alone case. Antoinette did not see addressing palliative clients needs as pivotal to her role, feeling the domain belonged to the nursing staff.

In contrast, some of the nurses themselves articulated how they appreciated the social worker’s experience in palliative care. Marta expressed it like this:

I think we are really lucky here because we do have a really good social worker who’s had a lot of experience in palliative care. (Marta, BCN)

Nancy similarly stated:

We would probably refer to the social worker. The social worker up at the hospital; she’s been around as long as I have. [30 years] (Nancy, BCN)

Sally, was not hesitant about stating her years of experience in regards to palliative care and knew she had a lot to offer:

I’ve also got a wealth of experience. I’ve worked not only within palliative care, but I’ve also worked with AIDs sufferers many years ago. (Sally, SW)

Chu & Tsui (2008) state experienced front line practitioners are repositories that are often highly personal and often unarticulated. Sally did not let her front line experience go “unarticulated” as many social workers tend to do, and expressed it openly in the interview. Practice wisdom is acquired through the application of social work values in practice, derived from reflection and deliberation; knowledge that is attained through direct patient experience (Chu & Tsui, 2008). The results of this study demonstrated how social workers that have acquired such experience with palliative care clients are highly valued in their communities. Additionally, the findings would also support the
study by McCormick et al. (2010) that found family satisfaction was higher for those who had intervention with a social worker with years of experience.

Social workers themselves stated it was pertinent to have relevant skills and competencies when it comes to dealing with palliative care clients as indicated by Christopher:

I think it’s a skill that I guess hospital social workers quickly hone when you work with palliative clients. I think it’s a skill that takes a bit of time, working with the understanding of the loss and grief process that people go through and having to deal with an immediate end. I think it’s definitely a big skill.

(Christopher, SW)

As demonstrated if the social worker was perceived to be lacking experience and skill in palliative care, then the nurses would address the psychosocial issues themselves.

Yasmin was forthright about this issue:

The current social worker that comes probably isn’t as au fait with palliative care and you know, you’ve got to be very careful you don’t send someone to someone who does more damage. (Yasmin, BCN)

This raises a new dimension on the pre-existing literature that continually state nurses have to address psychosocial needs of palliative care clients because it is too difficult to gain access to staff to meet these needs (Kenny & Allenby, 2013; White, 2007; Rosenberg and Canning, 2004; Hegney et al., 2002). The emphasis here perhaps should be on gaining access to skilled staff as in some communities’ staff is available but they are not deemed to have the appropriate competencies in palliative care.

Overall, from an analysis of the data, the experience, skills and competency do play a role in whether or not a social worker will receive referrals from community nurses for palliative care clients. In particular, Carissa’s situation highlights how
nurses need to feel confident in the social worker’s skill and ability before they will refer. They can also become territorial as stated by Nellie. It is clear new social workers need to up-skill in end-of-life issues after their undergraduate degree and prove their competence otherwise referrals will not be forthcoming. Carissa’s experience only reiterates what some of the nurses articulated throughout their interview. The psychosocial domain does not automatically belong to the social worker. It is clear that social workers need to earn the trust of their colleagues and demonstrate their skill and experience in what is a very complex area of practice.

Monroe (2010) states that all disciplines will do some social work, however it cannot be disputed the social work profession does bring its own perspectives and approaches that are distinctive, unique and of benefit to the palliative care client. This skill base can be refined and built upon with specialised training to assist those facing the end of their lives and their families. Social workers do have the theoretical background, values, principles and perspectives to undertake effective psychosocial care for this clientele (Christ & Blacker, 2005). Social workers working with palliative clients need to develop and demonstrate additional skills and competencies, which will be discussed in more detail Chapter Eight.

**Service Sustainability**

Following on from the above theme around barriers and enablers there is a notably undue reliance on the person in the role, rather than the role itself. As the data have revealed, whoever was receiving referrals in a particular community was the person with experience, skills, competencies and accessibility. This could be the social worker, community nurse or a community worker. Often these persons were going above and beyond their call of duty and offering an optimal service to a vulnerable
clientele. In many instances, because rural community services are so small, the one person is the actual service. Christopher, had an opinion on this:

Palliative care works pretty well out here because of a particular nurse. Like I said she is so pro-active when it comes to palliative care.

Because services are so small out here, often it’s the one person who makes the service and so the service will remain but that person will leave and whoever come into the service following; it will depend upon them to provide and their level of skill. (Christopher, SW)

Yasmin echoed a similar viewpoint:

We do a very good job but if there’s a change in staff, there no structure in place to ensure that that’s what happens, so we’ve fluked it here. But really it could all fall in a hole and you’d be left with it just to be in the lap of the gods again.

(Yasmin, BCN)

Yasmin then added:

A psychosocial approach for the future is not really very good, because it is so dependent on the individuals. It’s not through any wonderful government initiative or Blue Care initiative, or anything like that, it’s because you’ve got decent people. (Yasmin, BCN)

Blue Care nurse, Erica had been doing after hour’s on-call service for sixteen years from her own good will. She stated there was a lack of funding to pay for this service but she couldn’t bear the thought of a palliative client queuing up in an emergency department at midnight when some simple advice could be provided over the phone.

This is what she had to say:
We have never been paid to do on call. I’ve done it for sixteen years for nothing. And I’m doing less and less of it because I’m getting too old for it.

(Erica, BCN)

If Erica left the service, then this after hours contact would likely fall down completely. It was due to Erica going above and beyond her call of duty that the service existed in the first place. This is because morally Erica felt obligated to offer this as there was nothing in place for families in despair in the middle of the night. Hegney et al. (2002) states nurses are leaving their positions in rural communities due to the “emotional demands of the work” (p.35), and having to deal with issues that are outside what they were trained for. Erica presented as tired from many years of going above and beyond her role description and one would hope she will not become another statistic as articulated in Hegney’s (2002) study.

A skilled and experienced social worker is also a community asset and beneficial to terminally ill clients. If a social worker was addressing psychosocial needs for palliative care clients in a particular community because she had the confidence and competence to do so, there was no guarantee the next social worker would have the same skill set or interest. This irregularity leaves a lasting negative impression of the social work profession in general as medical staff have to wait and see if the new social worker is a “good one” or not when it comes to referring for psychosocial support for palliative clients.

The above findings are congruent with the study undertaken by Jünger et al. (2007) on team cohesion and cooperation. Team dynamics are based on reciprocal interrelations between the different variables. If there is a change to one variable, for example, one person leaves or a new staff member has different views on role clarity; the whole team system is affected. Working with palliative care clients can be a highly
emotional task, therefore there is a strong reliance on all members of the persons working with a palliative care client to be attuned to the nature of the work and able to cope with the emotional burden (Jünger et al., 2007). A new staff member may not be so willing and avoid this clientele altogether, allowing others with more experience and confidence to take on the referrals. As the results have concluded, Queensland has no clear structure in place for psychosocial care. It is an ad-hoc affair with much pending on the person in the role rather than the role itself. The subsequent section will now consider rural attitudes and its impact on the referral process.

**Rural Culture and Context**

Most participants offered comments regarding the prevalent attitudes that exist among rural dwellers. Many felt that the client’s attitude played a large role as to whether or not they accepted psychosocial support from a health professional. Throughout the study, certain attitudes were identified by health professionals that determined the acceptance of a referral for psychosocial support. The main themes evidenced in the data were 1) Attributes of rural dwellers 2) Knowledge of available supports and resources and 3) Acceptance of prognosis impacts (not limited to rural dwellers).

The first theme identifies many of the attributes that accompany rural culture. There is a culture that exists amongst rural dwellers that one must be stoic, resilient and tough. Media images of masculine stockmen in dusty attire handling large herds of cattle or ill-tempered horses whilst on the back of a motorbike are not conducive to discussions around feelings and thoughts on death and dying. There is a strong connection between how one thinks about their illness as to how they cope and what support they will access when faced with a life limiting illness. Many of the health professionals interviewed stated that dealing with that “need to be strong” and resistance
to help was a challenge. Marlena stated the following about persons in her rural community:

Some of them you will never get to accept a referral because that means “they do need help” and it means they are not strong enough. A lot of them are doing the palliative care at home because that is what the person wants but not what the carer can manage. This plays a big emotional strain. (Marlena, BCN)

Another Blue Care nurse, Coralyn, stated in her community there wasn’t a lot of emphasis on accessing psychological support because of the attitude of rural persons:

People in the bush tend to think they have to be a little tough, more resilient than anywhere else. As I was saying before, they are: “we can cope, we can do this, we don’t need help.” (Coralyn, BCN)

It is not the aim of this study to assert that all persons will need psychosocial support when faced with a terminal illness. Not all persons will require support of this nature. It mostly became a challenge for health care professionals when the carer was not coping well and was seeking additional support. Charmaine came across this issue in her work with palliative clients:

Well we’re working with two groups – patients and carers. And whilst patients might be as stoic as hell, they can only exist at home as long as their carers are fine and dandy. I went to visit an elderly man this morning that is now incontinent of faeces. The son is saying, “I can’t do this anymore” and then there’s his father saying to him, “so all you want is to get rid of me?”

(Charmaine, SW)

This “stoic” attitude meant that referrals for psychosocial support were not often accepted by the client until the disease was well advanced and numerous members of the family were not coping. Social workers will always go with “where the client is at”
and not enforce their presence. Nurses too will respect the client’s right to make
decisions around whether or not they can refer for psychosocial support and can only do
their best to support the client and their family emotionally and psychologically
throughout the disease trajectory, providing information on what can be accessed if and
when the client and/or family members are ready.

It is well recognized in the domain of health and law that persons with capacity
can make their own decisions as to what services they wish or do not wish to engage.
But as Charmaine said, “we are working with two groups here – patients and carers.”
So whilst psychosocial support was not always accepted by the client, the main carer or
other family members may need and seek the additional support. The matter becomes
delicate when a carer states they can no longer cope, but the palliative client, who is
deemed to have capacity, is saying he or she refuses to go anywhere or accept anyone
into the house. This matter is usually handled by the doctor with nursing and social
work staff in attendance or in the background, ready to support. It highlights some of
the complexities that can arise in palliative care. It is unlikely the patient can stay at
home unless there is a willing carer to support and assist them with most care needs.
The carer’s needs are also of utmost importance, an issue well documented in palliative
care literature and philosophy (Reith & Payne, 2009).

Throughout the study, some of the participants mentioned that country people
are generally private people who do not like “strangers in their house” and do not like
others to know their business. They preferred to deal with issues utilising their own
networks and supports. Whilst this is usually commendable and preferable in most
situations, it only became a challenge when family members or the carer was no longer
coping, as mentioned by Coralyn:
They don’t like strangers around but sometimes it’s the family that need the support so you can get around it by saying: “well you may not want it but what about your family?” and then they can, they often use it themselves anyway.

(Coralyn, BCN)

Donna also stipulated that when she was aware that a crisis had occurred or perhaps social work could assist with loss and grief support, the rural attitude around privacy often mean a referral would not be accepted:

Being a rural community, what happens is normally the walls go up with the family very very quickly for privacy because they don’t want the rest of the community to know, to see their grief. You don’t ask for help, it’s private business. “I can cope with it.” I was dealing with a lady who has now died. I knew she wanted me to engage with him [her husband] and that was the reason for my visit. He thought I was visiting her. And that’s the way it’s got to work.

(Donna, SW)

This sentiment was once again echoed by Blue Care nurse, Alison with this comment:

The persons who’ve been out in the world and mixed a lot, they’re usually okay, but it’s usually the loner ones or that come in from the bush or something that really just want to keep it in-house. The nurse is allowed but “we don’t want anyone else.”(Alison, BCN)

Sometimes rapport had to be built before help and acceptance for support would be accepted. Two social workers mentioned in the study that rural people like “stayers” and want trust to be established with the social worker before they will engage. Sometimes a community has to have time to see if they will trust this particular social worker or not. This is particularly in the case of social workers, as historically they have often only stayed a short while and then left. If a person has had a previous
negative experience with a social worker, it will take a long time to trust the present one that is now working in their community. Donna had this to say on this topic:

When I first came here most people asked how long I was staying. I said, “don’t worry, I’m staying.” And I didn’t do the right thing in saying as I didn’t imagine I would be going on maternity leave. It’s been two and a half years since I’ve been back. People say, “ah we remember you and we know you’re not going to go.” But it’s taken a long time for the community to trust again. They don’t want to go and share with someone who isn’t local. (Donna, SW)

Trust was also mentioned by some Blue Care nurses. Psychosocial issues were often not raised or discussed until trust was built and established. Blue Care nurse, Amie, had this to say:

We sit down and you get to know these people quite intimately so you can feel when something is wrong. And you know by then you have built rapport. And then it [the psychosocial stressor] usually just tends to come out. And yeah we do feel very comfortable in that. (Amie, BCN)

A second Blue Care nurse, Candice had this to say regarding the connection between trust and raising psychosocial issues:

I think it’s about trust; there’s a point when they trust you, if you’re in early enough. I’m thinking of a person who has been palliative for some time, which is very unusual that they’ve outlived what the doctors expected and so it took us six months to find out that that wife had a mental health issue. It took us that long to put things in place because of the trust. (Candice, BCN)

The study raised questions around the concept of trust and health professionals. Trust is about confidence in an individual which is usually determined by that person’s style of communication and overall demeanour (Hyatt, 2012). Effective skills and overt
competence also enhance trust as identified earlier between nursing staff and social workers. It is clearly the same with the palliative clients and the health professionals involved in their care. The interpersonal skills and competence of the worker will play a role as to whether they can be trusted or not. It appeared this trust issue was more about the social worker and psychosocial support rather than the local General Practitioner or community nurse.

In rural areas, this study asserts that trusting a health professional is closely married with rural culture. As stated by Edwards et al. (2007), specific cultures do exist in rural communities. Rural attitudes, connected to country culture such as “we can cope; we don’t need help” belief system all impact whether or not access to outside professional help is sought. As highlighted in the literature and confirmed by the comments made in this study, country persons are generally guarded about health professionals who tend to stay relatively short-term so trust and rapport will often take more time to establish (Edwards et al., 2007).

Trust is not as forthcoming as it might be in metropolitan areas where access and assistance is available for almost every conceivable issue. The comments from the health professionals highlight how trust is integral and a most vital component to the client-worker relationship, particularly as clients are expected to offer sensitive, personal information and discuss emotive issues that are generally contrary to rural culture. Hence the data only further solidifies the need for social workers to possess the appropriate skills and competence to evoke trust. Once it has been established, it can provide immense comfort, security and support for those facing the end of their lives. However, it may take some significant rapport building and effort on the part of the social worker. This also reiterates the importance of receiving referrals in a judicious manner as time for palliative clients is limited and trust takes time to build.
The second theme derived from the data related to knowledge around access to available resources and support. Rural dwellers are not used to having access to a lot of services, so they do not think to ask or enquire about what is available. The General Practitioner will often be the only health professional a person sees, so if he/she is not well educated in local services then a person with a life limiting illness or their family will not have any knowledge on what support is available to them. Country people often do not like to trouble others so will not ask. Blue Care nurse, Nellie, said the following on this topic:

The other issue we face around here is, that being a rural area, is that people don’t know how to access stuff if it is available. There are also a lot of people that just won’t trouble other people. (Nellie, BCN)

It is well documented in the literature that rural people do not have the same resources as their metropolitan counterparts (Thomas et al., 2009). But there are some services still available in their small community that they may not know about or do not look for as articulated by Eloise:

I think when you are working with country people; I think they are very different, by and large. I have to give them that. Stoic is a word in my mind but it’s more about resources. They’re not looking for support from health professionals. (Eloise, SW)

A third theme was connected to acceptance of prognosis. Another aspect regarding willingness to engage with a social worker or a significant other for psychosocial support often involved whether or not the person had accepted their palliative prognosis. This attitude is not confined to rural dwellers but did emerge in the study. World-renowned psychiatrist, Elisabeth Kubler Ross, put death and dying on the world stage by writing extensively about her research on emotional responses to death
and dying. Kubler-Ross (1970) theorised people will often feel a strong array of emotions ranging from denial, anger, bargaining and depression before acceptance will occur. Whilst not everyone will experience all of these emotional reactions and many will die without ever reaching acceptance, it was interesting to note that how a person viewed their prognosis impacted whether one would accept a referral. Nellie put it this way:

I never forget one of my patients saying to me after being asked questions around Enduring Power of Attorney, Advanced Health Directives and that kind of stuff – “you just talk doom and gloom.” So it depends on where people are in the disease process and their acceptance or non-acceptance as far as that goes.

(Nellie, BCN)

The psychological state of a person with cancer will change continually throughout the disease trajectory. There will be days of hope for a cure, days of despair, irritation and anger, then back to hope again, all of which can be emotionally challenging and felt every step of the way by the family/carer who will also experience similar emotions as theorised by Kubler-Ross (1970). The road towards end of life can be contradictory and ambiguous, highlighting the need for health professionals to always be aware of “where the client is at” psychologically.

Acceptance of one’s prognosis will always be a determining factor as to whether psychosocial support is agreed to or not. Denial can be a coping mechanism that persons utilise as a method of dealing with their prognosis as articulated in the literature review (Sheldon, 1997; Kennedy & Charles, 2001; Lazarus, 1998; Zimmerman, 2012). The acceptance or the non-acceptance of a terminal illness for which treatment has ceased, will impact whether or not one will consent to a referral for psychosocial support. If a palliative client is unwilling to discuss their prognosis in any depth, they
are unlikely to engage with a social worker for emotional and psychological support. In many instances, people do not always die in full acceptance of their situation. Acceptance and its influence regarding psychosocial support are not limited to rural dwellers, but an issue worthy of consideration.

So whilst numerous aspects come under the theme of “attitude of the rural client,” it would be suffice to state that no matter whether it is a “stoic” manner, a need for privacy or an unwillingness to bother anyone, or where a person is regarding their acceptance of the prognosis, these factors will influence whether or not a referral for psychosocial care is consented to or not.

**Community and Social Supports**

A key finding that emerged from the research identified how the strength of community and social supports will influence the need for referrals. There are many positive aspects to rural and remote communities that cannot be underestimated. These towns should never be considered only as a series of deficits but also as a possible repertoire of valuable assets. Country values of hard work, independence, strong familial roots, social networks, a firm sense of community and institutions like church based organizations are recognized (Daly & Avant, 2004) and can play a significant supportive role when “one of their own” is living with a terminal illness. Christopher had this to say about the community he worked in. He viewed social work and the community as often having a complementing function in assisting palliative clients:

> Sometimes it’s a dual role. We do get referrals from the hospital for palliative clients and predominantly it’s a short intervention because of the nature of the community. Friends, relatives, community members, church members, community groups, specific groups; everybody knows everybody. You still have your cliques out here where certain groups won’t interact with other
groups but very few people are isolated because normally people are fitting into one of these groups.

I guess being a small community, social supports for most people are fairly strong, so for the psychosocial aspect of palliative care clients are strongly met by the community and those social supports that people build in a small community. (Christopher, SW)

Christopher’s comments are in sync with the study undertaken by Horsfall et al. (2002) and Abel et al. (2013) which highlight the role of social and community networks as a potential resource to assist and support families keep their loved one at home. The role can strengthen social capital and develop compassionate communities. Christopher’s observations about his community indicate this does indeed occur and appear to work well.

Social worker, Eloise, also stated the church and social networks was a significant support to palliative clients in her community. She mentioned the following:

There are quite a number of churches and they are a good support. I think the Catholic Church is very large here and we work very closely with them with clients that need spiritual support from them. So the church is quite good with the clients. I think it very much depends on the strength of those social networks. If they’ve got people who are really supportive, then they’re probably not going to need us in the same way. Sometimes they need both.

(Eloise, SW)

Social workers are trained to view an individual through a “person-in-environment” lens. Clients of social workers will always be considered as possessing significant strengths, living in a community with established assets that can be drawn upon and utilised. Church organizations or voluntary agencies can be tapped into by our rural
social workers to assist with psychosocial support if consented to and play a “dual role” in caring for the client.

However, it cannot be ignored there will always be some persons who have a life limiting illness that are more socially isolated and have not made those connections within the community or do not wish to access this as a support avenue. This presented concerns for health professionals when such a person, who may be married, becomes palliative and is heading towards end-of-life. Blue Care nurse, Nancy, raised this scenario based on what she was seeing in her area:

Like the single married couple with one of them dying … like if it’s the husband, who is caring for his wife, and he is now the palliative person, well that raises all sorts of concerns because they don’t know what’s going to happen afterwards. Who’s going to look after her? You know that’s certainly an issue we are seeing more of. (Nancy, BCN)

Eloise added this to her earlier comments about the clients in her area that were socially and geographically isolated:

You know I think it is part of the culture of the whole area because being rural people, they are very spread out so tend to go one way or the other. In general, they develop really good social networks or they become really isolated. The more isolated geographically and socially they are; they would probably need that help a lot earlier and lot more consistently. I think it’s a major problem the distances people live from each other and services and of course public transport is non-existent. So providing psychosocial supports I suppose can be quite challenging. (Eloise, SW)

Christopher made similar comments regarding the impact of social networks on psychosocial support for palliative clients. As mentioned earlier, he felt regarding
providing psychosocial support was a dual role between social work and the community. He also believed that if a patient was fairly new to the community and had not built up sufficient networks then they would possibly experience more difficulties; but did acknowledge that for some country dwellers, being socially isolated was a conscious life choice they had made and that becoming palliative didn’t change that. He had this to say:

We do have some people that are isolated that come through and become palliative but what I find with those people is that it’s sort of a life choice and when they become palliative, it’s a brief intervention because I guess these people are in the mindset they they’ve got through life on their own, they’ve built strategies on their own so end-of-life issues are the same. (Christopher, SW)

Regardless as to whether or not it is a life style choice to be socially isolated or whether it is circumstances, for example, being new to a particular area or family have moved away, the journey with a life limiting illness will be challenging and potentially difficult. Isolation can have a negative impact in that it may contribute to feelings of loneliness, a sense of alienation, decreased feelings of self-esteem and control (Cohen, 2004). This may be accelerated if an isolated person is now faced with a life-limiting disease and qualms arise. If it is a couple that are isolated and one partner becomes terminally ill, stress and anxiety will be heightened as fears arise for the well-being of the one that will be left behind with no significant social supports in place.

In numerous country towns, many migrant families came for farming purposes and established strong familial roots. One town in particular had a strong Italian culture, visible by the homes in the community which have stayed true to the typical Italian architecture. Their strong sense of family impacted how much input was
required for psychosocial care for their relatives with a life-limiting illness. Nancy had this comment to say about this:

    I think it depends on the cultural background of some people as well. You know like some of the people have close family ties, they don’t seem to reach out as much. We do have close knit families because we have a high Italian culture up here. They’re strong. (Nancy, BCN)

Although this is a community strength and asset, a negative aspect to this was highlighted by Blue Care nurse, Coralyn:

    It can be very confronting, conflicting, you know, because you’ve got the older Italian people who have different views to the younger ones and that can sometimes be a bit of a problem. There’s a lot of guilt if they feel they are not coping and they don’t always feel they can say, because it’s an expectation.

    (Coralyn, BCN)

Antoinette commented in her community there were a lot of Korean and Brazilian people that worked in the local abattoir. Antoinette stated they had strong connections to their church, so there was a lot of sharing when someone was sick with family and friend addressing a lot of the needs. She also mentioned the strength of the Country Women’s Association in her community as having a significant presence who visited people and supported where they could.

    Many of the social workers interviewed worked closely with the Aboriginal and Torres Strait Islander Liaison Officer to address the needs for Aboriginal clients. Social worker, Kerry-Ann, stated that the liaison officer often asks her to assist because she is related to many of the families. There are strong family connections within the Aboriginal culture who often have an aversion to the mainstream health care system. Kerry-Ann stated, “As for Aboriginal people, they want to look after their elders at
home, within the family; rather than have them in here [hospital]” (Kerry-Ann, SW).

When the medical team offered the Indigenous patient to stay, Kerry-Ann stated, “they will usually say – ‘No, I want to go home.’ They need to have their own Aboriginal health workers in the community with good access to palliative care” (Kerry-Ann, SW).

Donna, stated she also worked closely with the Aboriginal and Torres Strait Islander Liaison Office, who referred to her often. Donna stated the following when mentioning a recent case:

I believe there was that underlying cultural fear of being in the hospital. The patient didn’t culturally feel comfortable in the hospital bed and being in the hospital setting and I as a social worker, felt quite powerless. I felt another option should have been offered. (Donna, SW)

Both workers identified that there are significant cultural differences between Aboriginal Australians and Anglo Australians when it comes to death and dying, particularly place of death. Social workers try to utilise what supports are in place but believe more could be offered for this clientele. Both workers acknowledged the support of the family and their determination to take care of their own. This topic is a research matter in its own right and not the focus of this study as there are distinct issues around death for this clientele that health professionals need to be well aware of.

However the support of the family and the Aboriginal and Torres Strait Islander Liaison worker in the community is acknowledged and firmly recognised as invaluable within this study.

In regards to aboriginal culture, their desire to die at home and not be in a hospital was mentioned numerous times in the interviews. This raised cultural issues around preferred place to die and fears around the general health system. As Donna stated “she felt quite powerless” as she tried to advocate on her indigenous clients’
behalf regarding being able to leave hospital. As the literature states, indigenous palliative care is in its infancy, with still a way to go (McGrath, 2010). This research only touched on this topic, but does reiterate the value of employing Aboriginal Health workers to assist with palliative care needs. This sentiment was echoed by one social worker in particular, who worked in a community with a high aboriginal population. She stated, “they need to have their own Aboriginal health workers in the community with good access to palliative care.”

As highlighted in the literature, every culture forms attitudes, rituals or particular ways of handling life cycle events such as death, all of which needs to be respected and understood by health professionals (Ow, 2014; Edwards et al., 2007; Sheldon, 1997). As mentioned, in some of the communities where interviews took place, prominent cultures existed. The study revealed that culture is an influencing factor regarding accessing psychosocial support, whether that be in the form of ethnic culture as illustrated above, or rural cultural attitude of “we can cope; we don’t need help” belief system as highlighted.

Choosing to engage with outside psychosocial support and bringing them into their microsystem is also a dominant feature of Bronfenbrenner’s ecological/systems model. Within the model, a microsystem is a pattern of activities, social roles and interpersonal relations that an individual experiences in a face-to-face manner with persons such as their family, close friends, church group or others. How well a person adjusts to situations, such as facing the end of their lives, will very much depend upon the content and the structure of the microsystem (Bronfenbrenner, 1994). In relation to palliative care, the strength of an individual’s immediate microsystem may be sufficient to sustain a client as they adjust and journey towards end-of-life. A person with an
incurable illness may not always feel a need to access the support from outside professionals and invite them into their space.

In contrast, despite the content and structure of the microsystem, many will seek outside psychosocial support henceforth, referrals for social work and community nursing are initiated. This will possibly depend upon where a person is within their disease trajectory. Conversations with persons further away from death can be quite different to conversations held when death is much closer.

**Discussion**

The relief of pain, whether it be physical, emotional, spiritual and social is a human right (WHO, 2007b). Not all will take up the support, but this important service should be readily available for those that do. However, services are impacted by funding. In keeping with Bronfenbrenner’s ecological model, macro influences filter down through exosystems and eventually impact what services are funded for and exist in rural communities. Skilled staff who are adequately trained for dealing with loss and grief, assessing for psychological distress, existential and spiritual concerns, bereavement complexities are limited in rural communities of Queensland. The data revealed there is no structured system when it comes to psychosocial care in rural areas of Queensland. It is usually the social worker that is assigned the task, but could also be a Blue Care nurse or a community worker, pending on perceived competency and availability. These results support current literature that report the psychosocial sphere is an ambiguous, shared and contested domain (O’Connor et al., 2006).

The study is unique in that it highlights the activities of social workers working with palliative clients in rural and remote areas of Queensland, which currently does not exist in literature. Social workers are employed in country Queensland working as generalist rural social workers; however barriers such as part-time hours, vast
geographical distances to travel, position in the community and workload pressures impact referrals and quality interventions. Response time for referrals can also be problematic because of these factors, evoking other disciplines to meet the needs despite not feeling vocationally prepared for the task.

The strength of a person’s microsystem can be influenced by whether or not outside professional assistance is sought. Social and community supports play a significant role in assisting palliative clients and in particular, their family members, which will impact the need for referrals for psychosocial support. This study is not arguing that all palliative clients will and must require psychosocial care; however the opportunity for access for this support should exist throughout the entire state of Queensland despite where one resides.

Rural attitudes such as stoicism will also determine consent for psychosocial support. Country people also tend not to trust the social worker unless he or she is either a local or proven to be trustworthy as indicated within literature (Edwards et al., 2007). Rural dwellers are used to dealing with problems themselves, like to keep matters private and are not always quick to involve others in their affairs. This does not necessarily change because someone in the family has a terminal illness. However, there are two client groups in palliative care, the individual with the life limiting illness and their carer. Problems can arise when the palliative client, who is “tough,” refuses additional support, but the carer is not coping and thus seeking that assistance, highlighting some of the complexities that can arise in palliative care. If a terminally ill person is presenting as being in “denial” and not willing to discuss at any depth what is happening to them, this will naturally influence whether or not consent for a referral to a social worker will be accepted or not. As articulated in the literature, “denial” is a
coping mechanism that can minimise anxiety and distress and should be treated with respect and expertise from skilled health professionals (Sheldon, 1997).

Finally, rural communities should not always be considered as an amalgamation of deficits. Social and community supports such as church groups, voluntary organizations, neighbours, close friends and family can also impact whether there is a need for outside psychosocial support. Many persons die without professional psychosocial care as those within their microsystem have undertaken specific roles. Cultural norms for some groups can also play a part as expectations and rituals are adhered to around the life cycle issue of death and dying. Such practices too will impact whether or not outside professional assistance is sought out or the matter is dealt with within their group. This study would purport that Aboriginal palliative care requires further exploration and more concentrated research, which will be discussed further in Chapter Eight.

The subsequent chapter will illuminate on what takes place once a palliative client and/or their caregiver consents to a referral for psychosocial care and they are now in the healthcare system. Macro influences and exosystems will influence what services a palliative client living in a rural or remote community in Queensland can receive, identifying factors that contribute to the quality of care.
Chapter Six

Findings and Discussion

Contextual Factors that Impact Psychosocial Care Provision

Important issues and challenges relating to the referral processes for psychosocial care for palliative clients in rural and remote areas of Queensland were highlighted in the previous chapter. The data show that referrals in these rural settings were made or withheld on the basis of personal judgements about competency, skills, accessibility and workload pressures. Inadequate resources, together with geographical challenges and the lack of available expertise for palliative care provision demonstrate the great challenges that exist for practitioners in rural and remote Queensland, with subsequent implications for palliative clients and their families.

As has been argued throughout the thesis, macro systems are likely to impact other important parts of the system in which palliative care is provided. The focus of this chapter is on the provision of palliative care to patients and families. This chapter is the second of three findings chapters, where the research question relating to contextual factors impacting psychosocial care provision will be addressed. Within this chapter, three key findings will be identified and discussed. The first finding relates to policy and funding allocation. Macrosystems such as fiscal distributions in accordance with Commonwealth and State policy will ultimately influence the microsystem of the palliative care client, their carer and family living in rural settings. The second finding relates again to vast geographical distances that impact on access to services, particularly at times of crisis. Once a palliative client is involved with a health practitioner, much work needs to take place via the telephone. Lack of transport or the patient being too unwell to travel can create barriers for persons living in rural and remote communities accessing quality psychosocial care. The third key finding pertains
to mesosystems, the strength of inter-professional relationships that exist within community. As seen in the previous chapter, inter-professional relationships are important. Cohesive professional relationships and continuous communication between General Practitioners, community nurses, the social worker or in other cases, community workers, must be based on trust and respect for each other’s discipline in order to achieve successful conclusions. Timeliness of referrals from General Practitioners is a major issue that relates directly to both funding and inter-professional relationships.

**Policy and Funding**

Funding is always at the core of service provision. Funding issues were a problem raised repeatedly by the majority of health practitioners interviewed. From the 38 persons interviewed, 22 health practitioners made 70 references to funding and how the lack of funding impacted everyday service delivery. It was interesting to note which health practitioners made the comments and the nature of the comments. As highlighted in Chapter Two in most regions in Queensland, PCP funding is only available for persons who have less than three months to live (PCQ, 2012b). A stringent policy such as this creates significant tensions and challenges for the health professionals trying to offer optimum care.

The three month funding restriction for care of the dying clearly was of great concern to the Blue Care nurses in these rural settings. As highlighted in Figure 9, all ten Blue Care nurses interviewed spoke extensively about funding in their interviews and how it impacted on services to palliative care patients. Many of their comments related to the numerous sources of funding, their accountability to those sources and the complexities of meeting the needs of palliative clients within these constraints. Four of the eleven social workers mentioned funding in their interviews but their comments
related more to improving the service for the palliative clients in their area such as improving palliative care for Aboriginal and Torres Strait Islander persons, more money for patient travel, pragmatics such as financial assistance and training to up-skill. There was less concern by Queensland health social workers than Blue Care nurses as to where money was going to come from to fund equipment and how services could be offered when funding was withdrawn. A number of community workers mentioned funding but their comments were a mixture of funding constraints and what could be offered along with improving the service. Two participants from the palliative carer group mentioned more attention was needed to assist with travel and community education about what palliative care can offer. Bereavement follow-up was also of concern as a significant funding gap. The issues surrounding funding are discussed below.
Figure 9. Findings regarding funding

- **Blue Care nurses** who mentioned funding relating to what could best assist the palliative client within their budget constraints. Respite, nursing hours, bereavement, equipment, supplies came from various funding sources and needed to be accounted for (n=10)

- **Community workers** who mentioned funding both in relation to service constraints due to funding and how services could be improved in their community (n=6)

- **Social workers** who mentioned funding for (n=4):
  - Patient travel
  - Indigenous palliative care
  - Pragmatics
  - Up-skilling

- **P/c spouse** who mentioned community education, pt travel and accommodation needed attention (n=2)
As illustrated, all Blue Care nurses interviewed mentioned the complex funding criteria and the vital impact it had for them to care adequately for their clients. Not all Blue Care services receive the same funding, being dependent on how applications are constructed and the foresight considered for future planning. One of the issues raised was that the funding received was not congruent with the increase in palliative care clients. It is difficult to identify the exact amount of Commonwealth funding received by the Queensland government for PCP funding over the past ten years, but according to documents from 1998-2011 it was $5m annually and more recent documents indicate from 2008-2012 it was $8.1M (PCQ, 2012,b).

The data show that increases in funding have not been seen by practitioners in the field. Significant increases in referrals have not been met with a significant increase in PCP funding. Additionally, changes in HACC and the complexities of various funding pools have been problematic for some service providers. A Blue Care nurse, Nancy, made a number of comments on the funding issue through her interview. The quotes explain her perception of the issue and its impact:

The funding has remained the same for the last ten years, so the funding hasn’t gone up. But certainly the number of clients has gone up.

We get a set amount for the year to provide everything, not just nursing, we provide nursing, in-home respite, social support, home improvements because a lot of these people need rails put in, we provide all the equipment – hospital beds, hoists, everything. It goes in no time and then we have to pick up extra costs because well you can’t….well you can …. You’re supposed to say “no” but I can’t. (Nancy, BCN)
The HACC program give us 75% and we find 25%, either by fund raising or by pinching from Peter to pay Paul. So I think I’ve got around eight different budgets, you see. (Nancy, BCN)

Blue Care services are based on funding from different sources requiring a high level of accountability and transparency with funding bodies. Each funding body has expectations around finance, cost effectiveness and measurable outcomes as noted by one Blue Care nurse:

Our whole service is based on funding. It’s not Blue Care that funds it so much; it’s the people that fund us. So we get funding from HACC, DVA and the Palliative; and yeah they’re the ones that put the provisos. (Coralyn, BCN)

Service providers have to juggle resources in order to source funding to best meet the needs of palliative clients when they fail to meet set criteria. Amie reported, “We play volleyball with trying to get funding to meet the needs” (Amie, BCN). Another Blue Care nurse voiced frustration about categorising clients in order to fit funding requirements:

The government doesn’t care about the patient. The patient’s got to fit in the box – does it fit into the palliative care box, can we stick it back in the acute funding box, can we put it in the HACC funding box? Everyone’s got to fit into a category. God forbid the patient who is actually palliative and has a disability and a mental health issue. Who the hell is going to fund it? (Erica, BCN)

One of the six HACC workers interviewed, Sonya, made reference to how persons who are under 65 years of age are often difficult to find funding for. Under the HACC funding, a person must be over 65 years of age or if they are under 65 years of age, they must have a disability. If they are to fall under the palliative care funding, they must be within the last three months of life, which is often hard to determine and not likely if the
person suffers from a slower degenerative disorder. Sonya works in a community where there is no domiciliary nursing service, only a HACC service that only employs support workers. The health centre that had recently been down-graded from being referred to as a hospital had nine beds. The lack of finances for service provision was an on-going problem that appears to have no ready solutions, especially if clients fell outside the strict criteria.

I think one of the biggest issues with palliative care is if there’s any young people; like our client base is elderly. Predominantly there’s been a couple of young ones that haven’t been clients of ours that have had a terminal illness and I think that that’s one of the biggest gaps because I know when the hospital ring us and say “now what can you do? And funding wise there is nothing we can do.

(Sonya, CW)

Despite the inadequacies identified, service providers work hard to offer the best service possible to their palliative clients within their funding parameters. They often had to be creative and Nancy aptly described, “Pinching from Peter to pay Paul” to ensure the client did not miss out.

**The three month eligibility criteria.** Concerns were repeatedly expressed about the three month eligibility criteria for funding. Under the PCP funding through the local hospital, funding criteria requires clients to be in the last three months of life. This caused a great concern for some Blue Care Nurses who sought creative ways to support patients when PCP funding stopped when the person did not die within the three month time frame.

The hospital funds for three months and then it’s up to us to organize with doctors to get from other funding. So there is a lot of stuff that is led into grey
areas. If that could be a better transition then that could be a lot less emotional and financial strain on the family. (Marlena, BCN)

Another Blue Care nurse, Erica, also perceived tensions around the three month funding criteria. For Erica, the definitions for funding for palliative care needs rethinking:

Funding under palliative care under the state government appears to be diagnosis related as opposed to palliation means when you are no longer actively treating a disease and looking at end of life. Whereas here you are funded for - if they don’t die within three months, you risk losing the palliative care funding. They’re not getting their definitions right cause they’re using palliative as that last three months and that’s not the definition, the true definition of palliation. (Erica, BCN)

Other Blue Care nurses referred to the definitions and how they impact hospital funding:

I think the funding and the classifications make a big difference because our funding comes from the hospital. (Amie, BCN)

Blue Care nurse, Yasmin, also expressed concerns:

I think it’s a very narrow criteria and I think that they’re excluding a lot of people. Yes, so I just find that palliative, the actual formal palliative program, probably misses a lot of palliative care clients, particularly the chronic disease ones. (Yasmin, BCN)

Palliative Care Queensland expressed concern that three month eligibility criteria excluded persons with a longer trajectory of decline and has advocated strongly for it be reconsidered. In the Submission to the Queensland Parliament Health Inquiry into
Palliative Care and Home and Community Care Services (2012), PCQ put this matter forth for parliamentary attention. PCQ (2012, p. 32) stated:

In most regions of Queensland, PCP funding is now only available to those who have less than 3 months to live. This is a direct response to a shortage in PCP funding at a local service level, the consequences of which can be devastating. Many non-malignant patients are therefore ineligible to access PCP funding due to their longer trajectory of decline.

However, the comments made from nurses in this echoed this sentiment clearly.

**After hours.** Nurses also raised issues concerning the 24 hour on call service. The services were inconsistent and erratic across the state. Some reported 24 hour on call in place, or at least access to it if the community was geographically close enough to a specialist palliative care service that offered the service. Some nurses, it seems, were not financed to provide the service but provided it for free from good will and care for the client above all else. Calls for 24 hour community care with access to specialist care services have been sought as a basic standard no matter where one lives (PCQ, 2012b). Service shortfalls in rural and remote Queensland are often met by concerned professionals, rather than appropriate funding at the state level. The following comment from a Blue Care nurse highlights some of the issues:

Then it comes back to the dollar because governments want something cheap so they’d rather send an unregulated worker in than send in one of us on a regular basis as we cost too much. And in this centre we have never been paid to do on-call. (Erica, BCN)

As stated in the literature, The Health and Community Services Committee (2013) released its report after an inquiry into palliative care services in Queensland. The committee recommended that the Minister for Health provide resources as soon as
possible for a 24-hour state-wide palliative care information, referral and support
service. This has not yet been introduced and capacity is only being assessed at this
point in time. However, if deemed viable, the pressure would be taken off invaluable
staff members like Erica, who are becoming tired and are at risk of burnout because
they are trying to fill a gap for the good of the client.

**Equipment.** Access to equipment was a further issue that was raised by care
providers. The Health and Community Services Committee, Report No. 22, (2013),
states that palliative clients often need to access equipment promptly. The data from
this study shows that access to equipment in rural Queensland settings is difficult as
equipment often is in short supply, with difficulties accessing at short notice and
expensive to hire. In urban settings these issues can also be problematic but arise
frequently in rural settings where distances are greater and services are fewer. In some
cases the MASS can be accessed to subsidise equipment, but it seems their paperwork is
lengthy and complex, often draining staff time and resources (PCQ, 2012b). Some of
the nurses expressed their frustration:

They need to restructure. We can’t get equipment for clients. (Erica, BCN)

And this from Candice:

I think that it needs to be a clear protocol that needs to be written as to what
equipment needs to be provided for each person at what stages. So it’s not up to
somebody who holds the funding to say to personally decide who can have what.

(Candice, BCN)

Another Blue Care nurse further emphasised the connection between equipment and
how lack of it raises anxiety in turn affecting the psychosocial domain. Palliative
clients cannot be cared for at home without adequate equipment and support. There is
also a cost factor to clients, many of whom have no funds to spare, causing psychological and emotional despair to an already stressful situation.

Once someone has had a palliative diagnosis then MASS won’t help. And that’s our only funding body for equipment. So if we are talking about resources for palliative and not only the psychosocial that impact on them because they can’t afford to hire a bed or they can’t afford a commode or whatever. So that just adds to angst in the family. But if we could afford this, then we could keep them at home. (Nellie, BCN)

**Hospice care and bequests.** These findings amplify the tensions that Blue Care nurses have to assist a client and their family within their budgets. In sharp contrast, one Community Worker was employed in a hospice that provided nursing care had more positive experiences about funding through donations to the organization she worked for:

We apply for grants from Queensland Health and that covers about 50 - 55% of our funding. The rest is donations…so…we get a little bit of Commonwealth funding like from DVA if there’s certain people that can apply for that money. And… yeah…but we don’t get really any other federal money and the rest is donations. We’re really fortunate we can support people at the end of their road and we can get a claim from wills and stuff like that at the end. And in the past two years we’ve had some generous big…one off donations that we weren’t expecting so that’s been really nice and that’s allowed us to increase the number of people that we see. So we’re actually, we’re okay financially, which is really nice. (Christina, CW)

This bequest funding allowed them to offer this service:

So we have...there's six nurses and we operate 24 hours a day, seven days a
week. So in saying the nurses are on call 24 hours. So ah (pause) the nurses will have (pause) might have (pause) on most days there's three nurses on and one will be sitting in the office and they will go and see people in the home. They come back and have hand-over and then one of them is on call overnight and then you'll have one person on the weekend. (Christina, CW)

Although bequests are not a funding source that can be relied upon in any way, it had, with this particular hospice allowed an adequate nursing and social work service with an extensive bereavement program. The funding contrast compared to others, reinforces the inconsistencies that exist in the state. The report by this community worker contradicts existing literature that highlights the fiscal difficulties and the expense of hospice care, featuring the luck of donations, although duly noted, this is not a funding source that can be guaranteed for ongoing future assurance.

**Funding for improved services.** Only four out of the eleven Queensland Health social workers interviewed, mentioned funding in their interviews. Funding was discussed in the context of improving palliative care services in their community. Stressors around budgets and eligibility criterion was not reported, rather their concerns about finance were around the following:

- Not enough money for patients to travel to larger hospitals to see consultants. As Sally stated, “whilst there are patient travel schemes, it doesn’t meet the needs. To get to the PA Hospital from here, it’s $80.00 - $90.00. That’s a phenomenal amount of money” [2 hour drive with community transport] (Sally, SW).

- More money for indigenous palliative care as highlighted by Kerry-Ann who stated: “They need to have their own aboriginal health workers in the
community, with access to good palliative care. Needs more funding” (Kerry-Ann, SW).

- Access to more funding for up-skilling and training. Rural health workers have higher travel costs and back-fill issues when trying to attend workshops. Christopher stated: “It’s okay to get training, but the budget is so tight, it’s really difficult to get professional development allowed. I just pay a lot of it myself” (Christopher, SW).

- More funding for financial support for palliative clients or persons living with cancer. Clara stated: “The Queensland Cancer Council would provide some financial support but now their funds are going low. Before they used pay telephone, electricity, gas, transport, accommodation, but now they are limited to what they can provide. We need financial support for people in palliative care, especially those with cancer” (Clara, SW).

Community Worker, Yolanda, agreed that the lack of financial support for patients having to travel long distances created problems. She felt there should be funds for a staff member to travel with an elderly or terminally ill patient if no family member was available to go with them. Yolanda worked in a community where the nearest treating hospital was over five hours by train. She reported that the patient often had to find their own accommodation once they arrived at their destination; a difficult task to manage when you are unwell, in unfamiliar surroundings, not used to the city and alone. She stated she sometimes went to the train station with them at night to ensure they got on, if they were frail. She felt nervous about disclosing this as it was in her own time, but she felt morally obliged to help. As noted by White (2007), the experience of travel
for a terminally ill patient required to travel is under-researched and warrants further exploration.

It appears service providers could effectively disguise these “behind the scenes” funding issues with none or minimum disclosure or disruption to the client. However, the issue of bereavement follow-up was a different issue altogether.

**Bereavement follow-up.** A prominent psychosocial issue related to palliative care and funding that was repeatedly expressed throughout the study was bereavement follow-up. Although not all persons will be receptive to bereavement follow-up depending on their resources and networks, the service should be offered and accessible for all those who have had a family member die, particularly if they are experiencing significant emotional, psychological and even physical responses. Funding had a significant impact on how bereavement follow-up was addressed. There were 36 references made regarding this issue from 21 participants. Like the issue of funding, it was interesting to note that bereavement follow-up was perceived in different ways depending on the health practitioners. Four Blue Care nurses had a tendency to state that one follow-up visit was adequate whilst five nurses felt this was insufficient but really more about collecting equipment. Four social workers indicated bereavement follow-up was undertaken in an ad-hoc manner and three Community Workers indicated follow-up was non-existent, unsystematic or restricted to two visits alone. Others felt just letting the family know they were there if they needed anything was sufficient. This psychosocial issue lacked systematic structure or a uniform procedure, with a lack of funding a contributing factor as described by Nancy, “Now we could do that much better but there’s no funding for bereavement visits, so we do one visit” (Nancy, BCN).

Amie stated their Blue Care service also funded one visit but admitted, “this was really more about picking equipment up”. Queensland Health social worker, Sally,
agreed with the comments made by the Blue Care nurses, stating the Blue Care nurses “provide support under the guise of bereavement support, but it’s more about retrieving equipment.” Sally added that she was so stretched in her workload; she couldn’t offer much more herself.

Carla spoke about being instructed to limit bereavement support to two visits maximum. “If any more is needed, then I’m to refer to the community social worker” (Carla, CW).

It was clear many Blue Care nursing services only funded one visit after a death. Whilst five nurses felt the one post visit was not adequate, four other Blue Care nurse felt it was sufficient. This meant it became a matter of interpretation. Marta felt the one post visit was a “system in place” stating, “We sort of follow-up, regardless of whether the social worker follows-up or not. We go in. There is a system in place and we do follow-up. And they know to ring us.” Similar sentiments were repeated by three other nurses.

However, in another community, Yasmin, detailed a more specific system, stating:

We try and attend the funeral and we usually follow-up with a bereavement visit between about 2 – 6 weeks with the primary carer. We might ring them the next day and talk to them about how to return the equipment. If someone is experiencing complicated grief, we will admit them as a client and do ongoing bereavement stuff with them. (Yasmin, BCN)

Yasmin has undertaken a Masters in Palliative Care with a component on end-of-life communication. She felt confident to do this because of her additional study and the fact that her particular Blue Care agency allowed this level of follow-up. Remembering, Yasmin had also stated earlier there was no structure in place it was just
there were “decent people” who went above and beyond in her agency, that they were able to provide this service. The data consistently revealed that these rural workers sought to fill the funding gaps that the State and other service providers failed to provide.

The data brings to light the inconsistencies that exist in palliative care in rural communities. Overall bereavement follow-up was undertaken in an unsystematic ad hoc manner, with much reliance on the resources (ie, qualified staff) and funding available. A social worker respondent reports below:

It’s a bit ad hoc, the whole process is a bit ad hoc. Obviously those who go to the six bed hospice and die have a whole series of volunteers sort of following up and ringing. There’s a counsellor that visits there on a weekly basis that they can tap into there. There are ones who die in hospital that I may never see.

(Charmaine, SW)

Blue Care nurse, Nellie, perceived that bereavement follow-up in her community was “kind of bizarre.” She stated it was about which health professional had rapport with the family.

It’s kind of bizarre. If we’ve developed a rapport and know them and all that kind of stuff…so it’s very much personality led rather than needs (Nellie, BCN).

In another community, which did not currently have a social worker, it was reported that the “General Practitioner likes to do the follow-up bereavement. I don’t think we have a very good system in place” (Janelle, CW).

Other participants stated bereavement follow-up was virtually non-existent in their communities, raising concerns for those who may struggle in their grief and require additional support. These comments are congruent with the literature that states
bereavement follow-up is a significant gap in rural areas (White, 2007; Kenny et al., 2013). Giljohann et al. (2008) found that due to limited welfare services, there are long waiting periods with the ability to locate qualified staff being a major challenge. Furthermore, the cost of staff travel, accommodation, suitable space to undertake the counselling, telephone and technological costs are all considered and impact what can be provided. As the Blue Cares nurses highlighted they have funding for one visit only and it is really under the guise of collecting equipment.

PCQ (2012b) have long recognized bereavement follow-up as an issue and have recommended changes to funding support. It remains to be seen the outcome of this recommendation which is so evidently a significant gap in service delivery that needs attention in rural areas. The findings from this study confirm this along with other existing literature.

A major geographical difference in rural Queensland is related to access to hospice care. If a palliative client was fortunate to live in a rural setting that was in the catchment area of a hospice, bereavement was undertaken in an extensive and systematic manner. For example, Community Worker, Christina, worked in a well-resourced area.

We run two bereavement support groups a week. So when somebody dies we have a handover, so …we might have 15 deaths a month and so those 15 deaths get passed over to the bereavement team. We continue phone support for as long as people want it. So it can go for 18 months. (Christina, CW)

These data indicate the inconsistencies of bereavement follow-up in rural areas. Again it appears to depend very much on funding. Not all rural areas get the benefit of services hospices can offer. This was also the case with some specialist palliative care services
that had a bereavement counsellor or experienced social worker on staff. To access services one had to be living in close proximity to the eastern Queensland coastline.

**Vast Geographical Distances**

Chapter Five highlighted the plight of Queensland Health social workers and how vast distances that needed to be travelled to service outlying communities was a factor in quality face-to-face interventions and response times to referrals. Social workers generally outreach to outlying communities once a week or once a fortnight, some on a needs basis only, meaning the telephone became a most valuable resource as highlighted by a social worker:

> Now if I was “Johnny On-The-Spot” we could get together and have a meeting with the client and the family. But you know, we have to do it by phone and a lot of it is by phone. The phone is the best resource I’ve got. I’ll take time to answer them because I’m physically not there. (Lesley, SW)

Communication by phone, rather than in person raises its own complexities. Assessing what the client themselves actually wants is difficult when often a family member may take the call. Privacy and the client’s thoughts on an issue cannot be easily gauged on the phone. The client’s decision making capacity also needs to be determined, which generally requires face-to-face contact with a health professional. Many factors need to be taken into account, all of which can be difficult via a telephone conversation.

To highlight the tyranny of distance experienced by social workers working in remote contexts in order to provide quality interventions, the following account was offered by HACC Support Worker, Helen. The extremity of the case is acknowledged, however it does illuminate some of the distinct challenges faced by rural health practitioners.
I had a fellow who wanted to know what happens because he didn’t have a will and he had no family here. They tried to get a social worker from [named the town]. Well this young fellow committed suicide before they got to him.

(Helen, CW)

Nurses too had to grapple with distance. Anna-Louise reported:

If we took on a palliative patient further out than that [over 60 kilometres away], we would have to do a full assessment and just see what their actual nursing needs required. Because we couldn’t justify unfortunately, we’d like to be able to, but financially I’ve got to be very mindful of the fact that there’s only a short pool of money there. I would have to do a full assessment and make it very clear to the family that we couldn’t continue this every other day. We would determine how often we would need to visit, whether it’s practical or not to continue. (Anna-Louise, CW)

The further one drives from the eastern coastline and away from the metropolitan areas, both the physical landscape changes and also the infrastructure and resources (Wilkinson & Blue, 2002). The supply of social workers, community nurses and General Practitioners per capita are lower. Persons who are palliative and living in rural and remote areas have access to fewer resources than those living in metropolitan areas. Where a person resides in Australia has a major impact on the services they will receive at end of life, particularly psychosocial care services.

The data strongly supports existing literature which states physical barriers such as geographical distance, lack of transport, the need to travel as well as reduced services impact what can be provided for rural families living with a life limiting illness. Access to quality counselling and psychosocial services in rural settings presents a huge challenge (White, Wilkes et al., 2005; Thomas et al., 2010). Phillips et al. (2006) state
that geographical location strongly implies inequality when it comes to palliative care service delivery. Furthermore, afterhours access, staff shortages, limited access to specialist services and allied health professionals and lack of financial reward for conducting home visits, including aged care facilities, have been identified as challenges for quality palliative care service provision in rural communities (White, 2007).

The evidence in these findings support current literature indicating that nurses have to take on the majority of care due to limited access to qualified staff who can travel the distances and provide timely interventions (Kenny & Allenby, 2013; Kenny et al., 2007; Rosenberg & Canning, 2004; White, 2007; White et al., 2004). As a result nurses fill the necessary gaps that arise generally and more particularly in the psychosocial domain.

**The Significance of Inter-Professional Relationships**

A prominent theme throughout the data was that of the significance of inter-professional relationships among the health professionals in a particular community. Almost every health professional interviewed mentioned the importance of inter-professional relationships. As the literature states, inter-disciplinary team work is pivotal in the practice of palliative care, with its focus on addressing a person’s needs through a holistic lens in order to offer support with psychological, emotional, social, spiritual and cultural issues (O’Connor & Fisher, 2011). In fact, there is a plethora of literature that emphasises the importance of an interdisciplinary team as being fundamental to the delivery of holistic care (McAuliffe, 2014; O’Connor et al., 2006; Junger et al., 2007; Crawford & Price, 2003). As this research has highlighted, access to a full interdisciplinary team was not a reality in rural and remote areas of Queensland due to geographical distance, workload issues and availability of appropriate staff.
members to name but a few. The palliative care “team” as such, will likely consist of the General Practitioner, community nurses and whatever allied health professionals happen to be accessible in that community, making psychosocial care a vulnerable sphere within this context.

Blue Care nurse, Nancy valued the existing harmonious and available social worker:

We’re lucky because we have such good relationship [referring to the social worker]. I think they realise that if we are sending a referral, we really need it.

(Nancy, BCN)

Marta also respected the social worker in her community, valuing her experience in palliative care. This was evident by her comment:

I think we are really lucky here because we do have a really good social worker here who has had a lot of experience in palliative. (Marta, BCN)

The same respect was reciprocated from the social worker to the community nurse in her particular region:

I see a lot of stuff that the community nurse does I should be doing. But she’s been in town for 15 years; she’s got the patient trust. Its taken time, but our community nurse is amazing. (Donna, SW)

Queensland Health social worker, Kerry-Ann, perceived the effectiveness of psychosocial care in her community was due to the strength of inter-professional relationships.

The service providers, the community health nurse, Blue Care, the nursing home have all been here a long time. I suppose it’s just because of all the people involved. (Kerry-Ann, SW)

Hospice social worker, Christina, had similar perceptions.
We work closely with all the GPs in the community. It’s like a string of GP’s that often refer to us because they like working with us. We’ve got a nice reputation so we’re pretty lucky. It’s been going on for 17 years. We are very much part of a team here. The nurses may say: “I admitted a guy whose wife was really anxious, so I offered social work.” (Christina, CW)

As mentioned, in some communities, social workers were not accessed and nurses were addressing needs. In these communities, a good relationship generally still existed between the nurses and the local GPs with constant communication regarding progress of a palliative client. Here is what Anna-Louise, HACC nurse, had to say:

We’re very fortunate that we can deliver the care that we do because of the doctors that we have in this town. I think that we’ve just worked together for so long that we’ve got to know each other and respect each other’s point of views. If I’m out of town, I will ring the doctor and say, “look I think that this patient really needs to be transferred to hospital because of XYZ,” and they will say, “Okay I shall organize it. I’ll ring the hospital and notify that you’ll bring them in.” That’s the sort of respect we have. (Anna-Louise, SO)

Blue Care nurse, Yasmin, had similar to say about the relationship with the local GPs in her community, where the social worker was not addressing the psychosocial needs:

Well we’ve all been working together for years. We all get on well with the doctors; we don’t have fights with the doctors. You know, there’s no power struggles, they know us all. Like I said, I think we are doing a good job just because of the people we’ve got. (Yasmin, BCN)

Additionally, even in communities where the social worker had large geographical boundaries and numerous outreach towns to service, strong networks with the local
General Practitioners, Aboriginal and Torres Strait Islander Health workers and nurses existed. It just meant more work was undertaken via the telephone.

Furthermore, concentrated effort was also required to maintain these links. Some of these relationships took years to establish as reported by Christopher:

I keep in contact with all the clinics out there and if a need arises then I travel out. It’s very difficult building that trust and rapport especially in the smaller outreach communities and within the indigenous communities. It takes a long time to build trust and rapport. We’ve built it up over the years. I work from the health centres there; I touch base with the hospital, the outreach as well, but primarily work from the non-government indigenous service when I go out. And with the palliative care patients, the outlying hospitals and clinics are very good at referring. (Christopher, SW)

Clearly the data suggests that there was regular communication and a trust and respect for each other’s discipline. This is congruent with existing research which states for palliative teams to be effective, the members must have a common purpose and an understanding of each other’s role (Crawford & Price, 2003).

As identified in the literature, the gold standard of palliative care is an interdisciplinary specialist team (Robinson et al., 2009). However, the data shows, there are fewer workers available in the rural community, with health professionals not necessarily working under the same roof. Ideally, for a cohesive team approach, existing health professionals must be “in continuous interaction and have close links to the other professionals” (Junger et al., 2007 p. 349). This “continuous” communication is crucial to effective outcomes for palliative clients regarding psychosocial needs and as the results have indicated, can be realised.
Data show that where there was a cohesive relationship between the General Practitioner, nurses and a skilled and available social worker, based on trust and respect, psychosocial needs for palliative clients in that community were perceived by professionals to be met very well. If there was a unified relationship between the GP and the community nurse and not the social worker, psychosocial needs were adequately met but this was mostly due to a nurse having undertaken extra study or had extensive experience in the area. If she left, the whole system was impacted (Junger et al., 2007). There was also potential for patients to fall through the gaps. In the communities where there were no community nurses or social workers and only HACC support workers, psychosocial needs appeared not to be as well met.

**Importance of interprofessional contact.** Another theme that emerged from this study regarding factors that contribute to psychosocial needs being well met for palliative clients was the regular meeting together of pertinent stakeholders. Throughout the study, in communities where social workers (and other allied health if available) and community nurses were meeting together then referrals were more frequent to the appropriate staff and professional relationships were established. Within this forum, mesosystems were enhanced due to trust and respect between the health professionals being established.

Due to the fact that many of these health professionals working in rural and remote areas are not working within the same building, a need for team members to a set aside time to interact to discuss clients and their care proved highly beneficial. This is echoed by Crawford and Price’s (2003) statement “interdisciplinary teamwork requires the interaction of the team to produce the final product.” There are the domiciliary nurses working in their agency, social workers working in Queensland Health facilities, (other allied health staff if available), Indigenous Health workers and
in some cases residential aged care facility nursing staff. It was generally accepted that General Practitioners did not attend these meetings. These weekly conferences were held either at the hospital or in a community agency. In the towns where social workers were receiving regular referrals for psychosocial care for palliative clients, these inter-professional meetings were fundamental and well established:

It’s a culture of this community; we meet together and always have. I’ve been in this position for 22 years and you know we’ve all been together forming when we didn’t have anything and you know, all of us kept hanging together and we sort of didn’t worry about who gets what in town.

We go to the ACAT [Aged Care Assessment Team] meetings every week; we also have a HACC meeting right after our case conference where we discuss our clients. (Nancy, BCN)

In some communities the local aged care residential facility Director of Nursing (DON) would attend these discharge meetings. Here is what Blue Care nurse, Marta reported:

We have a discharge planning meeting at the hospital so you have all the disciplines involved and even the D.O.N from the nursing home comes as well.

(Marta, BCN)

Ellen commented on all the agencies that met together regularly in her town to discuss discharge planning and continuing care. She also mentioned the Nursing Unit Manager (NUM) of the nursing home usually attending as well:

Well who goes to those meetings? Significant community services such as Aboriginal Health Service, their registered nurse comes along to that. Then we have Blue Care, there’s two nurses that attend and we Qld Health and the HACC Co-ordinator and myself. We did have an Occupational Therapist and a Physiotherapist but now that the meeting has been moved from the hospital to
the community, it’s more difficult for them because it’s off campus. Of course, the community nurses from Qld Health who does the CHIP [Community Hospital Interface Program] the interface role, they come along. They are a great link. We used to have the NUM [Nursing Unit Manager] from the nursing home but she’s currently on leave. A lot of my referrals are generated from that meeting. (Ellen, SW)

For the health practitioners who worked in communities that were located closer to the eastern coastline had access to a local palliative care specialist team, so community agencies would link in with them. Hospice social worker, Christina, stated, “we have case conference with the palliative care team once a week on the phone, so it’s pretty open.” (Christina, CW)

Meeting together on a regular basis is a fundamental component to establishing an effective interprofessional team made up of various available disciplines in the community. However, it should be noted that even in communities where the social worker was not overly involved with the palliative care clients, regular meetings with pertinent staff members were still taking place with the outcome for the palliative client being the key focus. Earlier data shows that psychosocial needs were met by a nurse rather than the social worker.

It should be noted a contradiction arises here. Not one of the health professionals interviewed mentioned that the doctors should attend these regular discharge planning meetings. It was generally accepted that they were too busy with patients to attend. Overall, there were many comments made regarding the positive relationship between themselves and the General Practitioners with many feeling generally respected by the doctors in their community. However, when the question was asked to the health professionals about the timeliness of referrals there were many
negative comments made regarding how late the referrals came from General Practitioners in the disease trajectory. Nurses felt doctors failed to understand the assistance that could be offered at the end of life. If doctors were attending these meetings, perhaps this problem could be reduced.

Timeliness of referrals. Participants were asked to discuss the timeliness of referrals. Responses from thirteen participants indicated they were receiving referrals too late in the disease trajectory. There were occasions where there was insufficient time to build rapport and to organize Enduring Powers of Attorneys or Advance Health Directives because the person no longer had capacity or was too overwhelmed to discuss. Additionally, some Blue Care nurses perceived that the General Practitioners were bringing their nursing service in too late, with the person’s disease being well advanced and families not coping well. The setting in which a health professional worked also impacted. For example, one participant worked in a hospice, one worked in a palliative care outreach team in a regional community and a third participant worked in a regional specialist palliative care team. This meant they were aware of palliative clients early on and had time to establish rapport and work closely with them. Other participants stated the timeliness of their referrals was an issue that could be improved upon. Nancy had this to say about referrals from doctors in her community:

I think the referrals we get are far too late. We had a referral just recently for a young man with motor neurone disease. He had got to the stage where his wife wanted to commit suicide because she couldn’t cope anymore. (Nancy, BCN)

Nellie, had similar to say:

I think it gets to be a lot of piecemeal stuff at the end of a journey. When, with a bit of forethought and forward planning and available resources, if you could put into place, probably not the day of diagnosis, but around an earlier time, the
support mechanisms to access. It would be a heck of a lot better than scrambling at the end to try to get things to work. (Nellie, BCN)

I think a classic example is that of the introduction of the CHIP scheme in the public hospitals where it is recognised that discharge planning should occur on the day of admission rather than leave it until the day they go home. I believe that same approach needs to be taken on any disease process on the scale of psychosocial needs. If someone knew early on that you access this and that, then you can gear things to a better experience. (Nellie, BCN)

Yasmin felt similar to Nellie and Nancy regarding the timelines of referrals. Although Yasmin stated the Blue Care service in which she worked generally had a good working relationship with the General Practitioners, she still felt much improvement could occur regarding when in the disease trajectory the doctors were referring:

The other issue I have is late referrals from General Practitioners. There’s not acknowledgement of “oh my goodness this person has been diagnosed with cancer and I should bring them in to meet the Blue Care nurses because two years down the track they’re going to need them.” You know, we’ve gone in and the person’s died the next day. I guess it goes back to there’s a poor understanding between palliative care and end-of-life, and that’s why the referrals are often inappropriate and late. (Yasmin, BCN)

Some social workers perceived that that their services should have been introduced earlier in the process so practical matters such as Enduring Powers of Attorneys, wills and Advance Health Directives could be discussed and organized. Lesley commented on this regarding the practical and legal issues:

I am thinking if we got them earlier; when you have somebody that they have diagnosed, I would like to see us involved a lot earlier, to get to know them, to
get along side. You know, get those things like Enduring Powers of Attorney on board and the Advance Health Directive. If we could actually get staff and doctors to get us involved a little bit earlier because it’s not good when it hits the fan. (Lesley, SW)

Donna also echoed similar sentiments by stating:

I think the earlier we are introduced the better, when the patient is first diagnosed and it’s going to end up being a terminal illness. Social workers should be involved further up to validate that person’s experience and normalise it. (Donna, SW)

It is evident, social workers, nurses and the clients strongly felt they were receiving referrals too late in the disease trajectory. There was not enough time to establish sound rapport to effectively discuss and organize what was necessary. As Nellie stated, “it’s often a scrambling at the end to get things to work.” All health professionals and Sherri felt the doctors were accountable for this.

The results demonstrate the pertinent need for continuous interaction to occur where possible between existing health professionals (Gunn et al., 2007). However, there was a general feeling from the nurses that the doctors were not referring because they believed the community nurses could not assist unless the person was in the last three months of life due to the PCP funding eligibility criteria. Whilst this is true, community nurses could still assist utilising other funding sources.

It was clear from the number of responses regarding the timeliness of referrals in the disease trajectory that this was problematic for reasons pertaining to misconceptions around funding; a more pressing issue for Blue Care nurses, which will be discussed later. However, social workers also found it more difficult to build rapport and assist with practical matters because they were brought in too late in the disease trajectory.
Crawford & Price (2003) stated that referrals processes between professionals who do not truly work well together can be slow and burdensome; therefore it may become easier not to refer. The data from this rural Queensland study suggests that many factors worked together to impede referrals, not the least being clarity around funding and eligibility.

In Queensland, PCP funding is allocated to each Health Service District. Palliative care funding comes under the “sub-acute” category alongside rehabilitation, geriatric evaluation and management and psychogeriatric care. As mentioned in the literature review, PCQ (2012) state that remoteness and distance also impact on the allocation of funding. Because palliative care is bundled in with subacute funding, the money fails to reach certain areas (as cited in Community Affairs Reference Committee, 2012, p.51). However, what funds are delegated can be accessed via a Qld Health Palliative Care service or hospital in that region. There can be strict eligibility criteria. For example, the client “must be in the last three months of life” to access these funds. It appears that some GPs believe that community nurses cannot support and assist patients until the last three months of life so hence do not refer. Blue Care nurse, Candice, refutes this, stating this is a misconception:

I sort of think that sometimes they (the General Practitioners) are not understanding that they can refer them earlier even if they don’t fit into the palliative funding; to refer them earlier, we can support them from an early stage. (Candice, BCN)

Candice also added:

Another thing about palliative that does bother me is, an example is somebody, maybe if they have a fungating breast cancer and they can no longer function at home and they do need nurses every day for huge big fungating dressings, but
they don’t fit into the palliative funding category, so what does this person do?
They can no longer work, how do they afford these dressings, how do they afford nursing care because they don’t fit into the three month category.

(Candice, BCN)

Other health professionals also felt it was the GPs lack of understanding regarding the three month eligibility criteria for the PCP funding. The data shows the difficulties that arise when the PCP funding is only available to those with less than three months to live. Perhaps it could be worth exploring Erica’s suggestion who stated, “There needs to be another phase in palliative care that isn’t in the three month bit, some other funding.” The criteria are clearly a concern for nursing staff trying to accommodate a palliative client who has lived past the three months within their funding arrangements or has a condition with a longer trajectory of decline. The tension this creates for frontline nurses when a person lives past the three months cannot go unmentioned. Nellie’s comment highlights the awkward situation nurses can be put into because of the three month criteria:

I know we have a limited budget and the only three months and all that kinda stuff, and I understand all that kind of stuff needs to be in place. But they got to hand it back. “Sorry you didn’t die, hand it back.” (Nellie, BCN)

The literature review highlighted that there are many sources of funding and the allocation of funding differs from one district to another. It is the same with the eligibility criteria which also varies from district to district and often from service to service (Community Affairs References Committee, 2012). However in this study, many of the participants interviewed mentioned the three month eligibility for PCP funding was the policy in their community. This is a direct indication that there is not
enough money in the PCP funding pool otherwise there would be no need for such a strict criterion.

It seems however that Blue Care nursing services are still able to offer some assistance for persons with an incurable illness prior to accessing the PCP funding, by utilising HACC or DVA funds. This suggests that rapport could be established and the nursing, respite services and psychosocial support can be underway before the person with the life-limiting illness became closer to requiring more involved end-of-life care. One social worker suggested that GPs need more support about when to refer for palliative care services and a clearer understanding of the three month eligibility criteria. She stated the following:

Doctors need more support I think in feeling more comfortable about understanding palliative, but the dilemma seems to be around the three months because of the funding. I think the difficulty is around having these conversations and the ability to have the hard talk. (Sally, SW)

To determine the length of time one has to live is a very difficult call for any doctor to make, especially as GPs may not see many palliative clients in their average workload. The comments derived from health professionals interviewed make it clear that more education needs to be provided to both General Practitioners and hospital doctors in regards to when to refer to a community nurse for palliative care and a social worker for psychosocial support.

**Offering social work services.** Data further revealed that some palliative clients were offered psychosocial support when they were attending outpatient appointments in larger hospitals amongst an array of other services mentioned at the relatively short consult with their palliative care specialist. The clients did not really know what a
social worker could offer so declined the referral. This will be discussed further in the subsequent chapter.

Queensland Health social worker, Donna, was able to empathise and really appreciate how it must feel for a patient only being told about a service in amongst a plethora of other information and not really understand what they can offer. She valued what her profession could bring to the client and felt it was not being utilised to its full potential. She believed if she had been introduced from the client’s initial contact with the medical service, there would be more readiness to accept psychosocial support:

There may be a different level of acceptance. Instead of doctors just saying to clients- “would you like to see the social worker?” I feel like if I was there in the room and introduced – “this is Donna.” But they very often don’t think “let’s bring the social worker in,” they think – “let’s offer social work.” (Donna, SW)

This is in alignment with the study conducted by Gunn et al. (2013) which found rural cancer patients would appreciate relevant, targeted information both to inform them of, and change their attitudes towards psychosocial services. The study by Gunn and colleagues (2013) revealed psychosocial care is highly valued by those who access it. Rural cancer patients want to be recognised as unique and different to their metropolitan counterparts. They clearly want the same information targeted to their context as many people generally do not really understand what psychosocial support actually is.

Discussion

The data have revealed that macrosystems such as government policy and funding arrangement filter down through the exosystems and ultimately determine what the palliative client can receive. As identified within this study, there has been an increase in palliative care clients across the state, but the funding has not increased to
meet the demand. PCQ (2012) state delegating palliative care under the *sub-acute* banner ultimately can mean an unfair allocation to rural areas (as cited in Community Affairs Reference Committee, 2012). This was emphasised by the lack of PCP funding available for local nursing services to access through Queensland Health to assist palliative care clients in their communities. The money allocated to the PCP needs to increase to support the rise of persons with a terminal illness accessing palliative care support.

Furthermore, the criterion to access the PCP funding distributed to Queensland for palliative care services needs review. The current eligibility criterion states that a person must be in the last three months of life in order to access the funding. This system excludes persons with certain illnesses that have a slower rate of decline. It also creates significant tensions for community nurses when the person lives beyond the three months and the funding runs out.

To consider this fiscal situation from a human rights perspective, social services are indeed necessary in many of these rural and remote communities as per Article 25.1 in the Universal Declaration of Human Rights, although funding arrangements will need to occur. Psychosocial care is a dominant component of palliative care and access to it should be considered as a human right for all (United Nations General Assembly, 1948; OSF, 2013). This was particularly highlighted in the case of bereavement, a significant service delivery gap and a major concern in rural communities as indicated in the literature (White, 2007; Kenny & Allenby, 2013).

The results indicated most Blue Care nursing services were generally funded to provide one bereavement follow-up visit to a family after a death had occurred. This provides an example of how one system influences another within the meso system. The palliative client has now passed away therefore equipment needs to be retrieved
from the community nursing service as per funding guidelines. Additionally, the bereaved family is also a part of that system with the possible need for on-going support but is impacted by the policy guidelines of the nursing service.

The issue became contentious as some nurses purported one follow-up visit was not an adequate service as it was really about retrieving equipment more than anything else. Bereavement follow-up is clearly an area that requires pressing attention relating to funding. It is currently delivered in an unsystematic fashion. Health professionals were setting their own rules around this psychosocial issue despite the funding constraints. In sharp contrast, if a palliative client was fortunate enough to live in the catchment area of a hospice, they appeared well serviced with thorough bereavement follow-up, highlighting once again Queensland’s inconsistent palliative care service delivery. The eligibility for access was not as stringent.

General practitioners need to have more education around the three month eligibility as they were not referring to Blue Care nurses in a timely manner. Blue Care nurses can still assist even whilst a person is still receiving treatment; they just access funding from another source. Social workers also need to be referred to earlier in the disease trajectory, as time is needed to build rapport, assist with pragmatics and address psychosocial issues as they arise. Furthermore, social workers could also provide an educative role to General Practitioners in regards to appropriate and timely referrals for psychosocial support and input. Furthermore, some social workers and palliative clients felt psychosocial services were offered an array of services, leaving the palliative client with no real understanding of what social work could offer. The physical presence of social workers at consults in the larger hospital would also be helpful or an initiated introduction from the social worker herself, stating how she could assist.
Social workers are not a plentiful resource in rural and remote Queensland. The ones that do exist are stretched in their workload and have vast distances to cover. Much work was undertaken via the telephone. This raises complexities when crisis occurs or only one perspective is being received. Nurses too found the distances difficult as funding has to considered if travel to a client was too exhaustive. It would be likely that palliative clients would be encouraged to come into town and be admitted into residential care or have lengthier hospital admissions, if nursing care could not be justified. For those able to be cared for at home by a willing caregiver, a 24 hour telephone support to assist would be optimum at times of stress and uncertainty. To be able to speak with a medical staff member or allied health professional to clarify or ask a question may be all that is required, instead of taking the client to the Emergency Department of a rural hospital in the middle of the night.

When the interprofessional relationship between the General Practitioner (and hospital doctors), community nurses and social worker (plus other staff) was based on trust and respect for each other’s role and communication was frequent and open, psychosocial needs of that particular community appeared to be addressed very well. When one of those components was missing, for example, the social worker was not deemed competent to address psychosocial care so therefore not involved in palliative care meetings, psychosocial needs appeared to still be met but there was an undue reliance on the skills of certain nurses. This is one matter that highlights why Queensland requires a state-wide plan for palliative care service delivery. There is no structure in place for psychosocial needs to be addressed on a state level, reiterating why the results revealed an inconsistent scenario. There is too much reliance on the interest and skill of individuals rather set expectations for within the role itself.
The following chapter moves into the experiences of the palliative clients themselves and their carer. The psychosocial issues they considered significant and the ways they addressed them will be presented. This will be considered within their rural and remote context.
Chapter Seven

Findings and Discussion

Palliative Clients and Carer Experiences of Psychosocial Care

The diverse landscape of Queensland is symbolic of the broad range of settings in which palliative care is delivered. As highlighted in the previous two chapters the availability of psychosocial support from a skilled health professional is highly variable with multiple factors impacting whether and how psychosocial care is delivered. Issues such as perceived competencies, geographical location, funding and policy and the strength of inter-professional relationships all impact the provision of psychosocial care. The needs of the palliative client and their family should take priority, as they journey towards end-of-life. Unfortunately, this is not a reality for a number of rural dwellers, with significant psychosocial concerns failing to be given required attention.

This study is unique in that it incorporates the perspectives of the palliative client and their family of their experiences of the psychosocial care they received. In addition to interviewing health professionals, three palliative clients and two carers were also interviewed. The data were integrated into the analysis to provide a more comprehensive exploration of the issues that have been previously discussed.

This chapter will discuss the findings relevant to the research question “what have been the experiences for rural and remote palliative clients and their carers of psychosocial care?” Within the interviews, the participants were first invited to discuss the psychosocial issues that were pertinent to them and were then asked to discuss their perception on how such matters were addressed within the context of their community.

Before commencing the interview there was acknowledgement given to all the participants that the topic being discussed may be sensitive and the interview could be
terminated at any time. The participants were then provided with a description of what psychosocial needs were, which reads as follows:

**Psychological Issues:** your thoughts and beliefs about your illness and prognosis

**Emotional Issues:** how you feel about your situation

**Social matters:** who supports you and helps you cope (social network)

**Spiritual issues:** any religious or spiritual issues that need addressing or provide comfort

**Cultural issues:** Any matters regarding your culture that require addressing or need to be respected

The participants were asked to talk about any of these issues or any other issues they felt were important to them. The two carers were also asked about their experiences as carers for their loved one. They too spoke about certain psychosocial issues they deemed relevant and how these were addressed in their community.

Due to the fact that this particular sample group only contained five persons, they will be introduced with changed names to safeguard their anonymity in Table 8. All three palliative clients were males, aged between 60 – 70 years of age, with advanced cancers. All three participants were within the last weeks and months of life, meaning their functionality had been greatly reduced; they were on high levels of pain medication and at the time of interview were rarely leaving the house. Interviews were timed in accordance with their medication regime.
Table 8

Characteristics of Palliative Clients and their Spouses/Carers

<table>
<thead>
<tr>
<th>Participant</th>
<th>Illness</th>
<th>Distance from Major Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edward</td>
<td>Germ Cell</td>
<td>115 kilometres</td>
</tr>
<tr>
<td></td>
<td>Carcinoma</td>
<td>(1 hour 20 minutes’ drive)</td>
</tr>
<tr>
<td>Sherri</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(married to Edward and is his carer)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Robert</td>
<td>Prostate Cancer</td>
<td>90 kilometres</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1 hour 10 minutes’ drive)</td>
</tr>
<tr>
<td>Myra</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(married to Robert and is his carer)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patrick</td>
<td>Lung Cancer</td>
<td>1 ½ hours travel</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(no kilometres due to a part of the distance being water)</td>
</tr>
</tbody>
</table>
This third findings chapter will begin by presenting the psychosocial issues identified by the participant as significant. Psychological, emotional, social, spiritual and practical matters such as travel and education were all raised within the interviews. Cultural issues were not raised as this was not a psychosocial issue discussed by this particular sample group. The chapter will be structured around these five primary themes and how the participants dealt with these issues within the context of their community.

The chapter will be structured around these five primary themes and how participants dealt with the milieu of the psychosocial support that was available to them. The issue of geographical location will be significant, as seen in earlier chapters, as where one resides will impact the calibre of psychosocial support an individual will receive. Other factors will play a role such as individual coping styles and the strength of one’s social networks. In accordance with an ecological conceptual framework, the impact of macro and exosystems will be illuminated as impacting the individual and their families and their families.

**Psychological Issues**

An analysis of the data indicated the way in which the respondents thought about their illness contributed to how they coped. All three palliative clients identified that they had certain thought patterns about their cancer that assisted them in their journey. At the time of interview, there appeared to be some resilience with Robert and Patrick who identified how their thought patterns assisted them to cope with their illness. Robert, in particular, had a lot to say on this issue. He commented that he met some other men with prostate cancer and noted that they had allowed the cancer to become the focal point of their lives. He did not agree with the way they did this. His
thinking strongly impacted how he handled his own cancer. He externalised his cancer throughout the interview, referring to it as “it.”

It [the cancer] just drove them. I’ll drive it rather than it drive me. I’m going to control it rather than succumbing to it to control me. I believe I will die with it, rather than because of it. I know we’re all going to die, but I’ll die with it, rather than it be driving me, if you know what I mean. (Robert, PC)

Robert strongly believed his thinking and his religious beliefs (to be discussed later in this chapter) gave him ten extra years. Robert continued to say, “it is starting to win now but I’ve still had ten years long.”

Patrick also commented on how his psychological thinking impacted how he coped. Like Robert, he believed the way he thought about his cancer had added to his length of time. Patrick stated the way he had psychologically handled stressful situations in the past was how he was handling his cancer now. “Yeah, you’ve got it and that’s it. I think that’s why I have lasted so long because I face things pretty well head on.”

For many years it was thought having a positive attitude can impact the length of survival, however many medical professionals state this is a myth. What a positive attitude can do is improve quality of life during the journey with cancer and increase feelings of well-being, perhaps evoking inner strength to keep going (Chopra, 2011; O’Baugh et al., 2008). Robert and Patrick both stated their beliefs around their psychological response to their disease increased their longevity.

Edward stated psychologically he struggled with negative thoughts, particularly in certain stages throughout the disease when a new issue had arisen or a particular treatment did not work. He described his journey as “phases,” stating he coped better in some phases than in others. Edward had this to say:
There was a phase there where you think, “I’m useless” and you do think about euthanasia or like suicide. And you got to cut it out and just… But I’ve gone past that, but it does come in. (Edward, PC)

Edward presented as lower in mood than Robert or Patrick, openly acknowledging he struggled with negative thinking. However, he did state he recognised his negative thought patterns and readjusted them to the best of his ability. His comments also indicated some psychological distress which will be discussed further.

Edward’s wife, Sherri, commented how her own psychological thinking impacted how she coped with her husband’s end stage of life. Sherri changed her focus from what they did not have to what they still did have:

You can see this is not going to get any better. It’s probably the hardest time but what can you do but live day-by-day. We find something good in the day and something that you can do. (Sherri, C)

Myra, Robert’s wife, stated she used a similar day-by-day approach to her thinking. Myra identified that taking “a day at a time” was how she coped psychologically with what was occurring in her life. Both women had identified a long and tumultuous journey with their husband’s cancer and found this “taking one day at a time” and “finding something good in the day,” was the best approach. It should also be noted that both Myra and Sherri were not only wives; they were carers and their husbands main support person, which was difficult for them and will be discussed later within this chapter.

The data revealed that a psychological process, such as how the palliative clients thought about their disease, was associated with coping. As mentioned, Robert continually referred to his cancer as “it.” He externalised the disease, considering it as something he would control rather than “it” control him. Robert’s comments therefore
support the literature in that externalisation can be a beneficial technique to assist coping (Geldard & Geldard, 2001). Although unlikely deliberate, the participant had instinctively adopted the technique, attributing the way he thought about his illness assisted with his capacity to manage disease progression.

Coping with a stressor such as caring for your loved one who is dying can often be related to the uniqueness of one’s personality as mentioned by Myra who stated:

I think a lot of it depends on the personality of the person too. Because other people draw on everything and everybody and I tend not to. (Myra, C)

As stated by Carver and Connor-Smith (2010) personality and coping both play independent and interactive roles in influencing mental health. Myra believed personality types impacted how much help was sought from others. She stated her own personality was not this type. The stoic, rural attitude of “I don’t need help” as highlighted by the health professionals in a previous chapter, could also be a contributing factor.

As mentioned, Edward was clearly distressed at certain times in his journey with cancer to the point where he felt “useless” and contemplated euthanasia. This is congruent with studies that highlight psychiatric co-morbidity or psychological distress-prevalent in cancer patients, which will be manifested in the form of a depressed mood, anxiety, impoverished life satisfaction and loss of self-esteem (Passik & Kirsh, 2003). Patients in psychological distress can feel a sense of hopelessness, thoughts of worthlessness, existential or spiritual crisis and overall suffering which can result in a reduced capacity for pleasure, no sense of meaning, a lack of ability to connect with others and an overall feeling of negativity (Kelly et al., 2006). This is exactly the experience Edward described. How these issues were addressed within the context of their community will be discussed later in this chapter.
Emotional Issues

Out of three palliative clients, Edward stated he felt emotional at certain stages of his illness, in particular when a new issue arose. Robert stated he did feel angry at the time of diagnosis and felt “the rug had been pulled out from beneath my little world.” He perceived that the doctor presented his diagnosis to him in a callous manner so he switched doctors and was happier with the second consultant’s approach and communication style, despite the diagnosis remaining the same. However, Robert did not report feeling too emotional after this initial period attributing this to his thinking and religious beliefs that provided him with strength throughout his ten year battle with the disease. Patrick stated he did not feel particularly emotional or need to discuss his prognosis at all throughout the entire disease trajectory. Patrick’s comments would support a study by Fletcher et al. (2013) which states men are more passive about understanding and discussing their illness than females, who were more communicative about their prognosis and end-of-life issues.

From the three palliative clients, it was mostly Edward who spoke about needing emotional support at certain times. He was honest in his statements, openly admitting to emotionally struggling throughout his journey with cancer. This is what he had to say:

Generally I cope with it good, but at different phases, at different times, you feel a bit low and you need a bit of support. (Edward, PC)

As stated, Edward admitted he had become so low at points where he contemplated ending his life, but attempted to change these thought patterns when he focussed on his wife and friends. In some ways he presented as grieving himself: “certain little things get you down, stupid things. There’s always outside worries, like your family and your
friends.” Sherri responded to this by saying to Edward: “I guess you are grieving too.”
To which Edward responded with: “Yeah.”
Edward was clearly grieving his own losses and allowed himself to sit in that
grief for a while. Grief reactions are experienced in the cancer progression right from
the point of diagnosis through to death. Loss of good health, independence, bodily
functions and hope for the future are associated with distress, sadness and despair
(MacDonald & Hobbs, 2008). Edward’s appearance of sadness presented as a grief
reaction to a concurrent series of losses. Edward also spoke about some friends who
had recently died, which he found confronting. He mentioned the sadness he felt and
became emotional when discussing the events. Although he did not elaborate, Edward
was reminded of his own imminent loss of life as he attended funerals of close friends.

Myra stated that at the time of Robert’s diagnosis, their daughter had died of
cancer. She stated that at that time she not only had to deal with her daughter’s death
but then had to deal with the prospect of potentially losing her husband to the same
disease. She perceived that this impeded her grieving process over her daughter as she
was so distracted by her husband’s prognosis. Myra stated she felt increasingly
emotional, particularly in light of the fact that her husband’s health was significantly
declining. She had recently linked into a hospice service that assisted with nursing care
and was keeping in touch with her previous work colleagues but did not appear to be
drawing on anyone in particular for emotional support. As she mentioned earlier, her
personality tended not to draw too much on outside assistance. She was also a qualified
nurse which meant she could confidently manage Robert’s care needs herself at home.

Myra said:
There is [named the hospice service] when I need back-up support pain management and with aides. But the rest of the time it’s just us. Some people draw on everyone and everything and I tend not be like that. (Myra, C)

Myra made a significant point here. It should not be assumed that everyone will require emotional support throughout their journey. Sometimes just knowing a service is available is the only safety net required. Some individuals may display minimal emotional responses, whilst others will be openly sad or distressed, displaying their emotions in a more overt manner. There are no formulae on how to face death. It should be noted that whilst both Robert and Patrick did not feel overly emotional throughout their journey, they did both talk about the interruption cancer had caused to their retirement plans:

I’ve been a bit annoyed because I worked hard all my life and just when I’m about to retire, this drops on me, you know. I could’ve done with a few years of playing around, like going bush for a couple of years or whatever. (Patrick, PC)

Robert was a little more casual in his response:

We were at that stage where we thought retirement was going to be a whole lot different to this. But anyway. (Robert, PC)

As mentioned, throughout the disease process, the person will undergo a series of losses. These losses include a loss of health, income, independence, future plans. All of these losses are grieved in some way. A loss of retirement plans can be significant for those facing death in this particular age bracket with a sense of being “annoyed” at the intrusion of cancer as mentioned by Robert and Patrick. This is congruent with the literature which states loss and grief reactions such as anger or depression are normal for those facing the loss of their lives (MacDonald & Hobbs, 2008). Facing death can
also bring up past losses and memories of others who have died. Myra also spoke about this when she mentioned how the current situation was bringing up the loss of their daughter ten years before. She said:

I struggled with the ability to be able to grieve after she died because we had a house full of people. We had the funeral and by then it was time to go back to work. We knew were going down this road again and so I don’t think I ever did grieve properly. (Myra, C)

Furthermore, feeling angry can also be a normal reaction for anyone facing a life-limiting illness and those closest to the person can share those responses. Anger is often a biological response to hurt, frustration or feelings of helplessness. Myra talked about feeling hurt over people in church questioning their faith because Robert had cancer. Her comments would support the words of Robbins (1995) who writes that the church can be a place of hurt rather than healing. This turned out to be an additional loss the couple faced. Myra said:

My biggest difficulty is as the support person and as the wife are people of the same faith judging you. “How come you’ve got cancer when you believe in God?” Things like that, pointing the bone at you and saying “Where’s your faith? Why isn’t Robert healed?” That sort of thing I found really hurtful. (Myra, C)

In all, out of all of the participants, Edward spoke more about feeling emotional at certain times, whereas Robert and Patrick did not disclose any particular emotional responses. Myra was emotional, which she openly displayed and discussed within our interview. Edward mentioned emotional issues, whereas Robert and Patrick hardly raised this as a chief concern, other than mentioning some agitation because of interrupted retirement plans. As highlighted, Edward spoke of low points where he felt
“useless” which supports literature that thoughts of worthlessness, no sense of meaning and an overall feeling of negativity can occur for persons with a life limiting illness (Kelly et al., 2006).

Social and Community Support

Social support can be immensely helpful for persons facing the end of their lives, but particularly so for their spouses who are also carers. All five participants spoke about their social situation and where they drew support. Edward, Robert and Patrick spoke of their recent social withdrawal as their disease had progressed. However, when the two wives were interviewed, Sherri was still seeing friends and having friends come to the house, whereas Myra was still seeing a few people but was mostly spending all of her time with Robert.

Robert spoke about his friends withdrawing from him rather than he withdrawing from them. He spoke of this in a matter of fact manner and in more of a bemused tone rather than in a critical way:

Initially it was very noticeable that a lot of friends and associates didn’t know how to handle you, so they withdrew. I looked normal, was acting normal and was getting on with life, I guess that dormant stage if you like. It was then very noticeable that people just, “oh he’s got cancer, it’s like leprosy, don’t touch him,” so that was very noticeable. I didn’t find it hurtful; I found it sort of almost amusing, if you like. That was a funny period because before I got secondaries, was the period they were withdrawing. So by the time I’d got secondaries they’d withdrawn and life had taken on a different role. (Robert, PC)

In keeping within Bronfenbrenner’s ecological perspective, participants moved from interactions of work and extended family and became more house bound and adjusted to
new micro systems. Meso systems strengthened as interactions increased between the
carer and community nursing services. The exosystem, such as welfare systems were
resourced but not extensively.

In Robert’s case, he noticed his social circle was reducing, with friends from the
church engaging less and less. Myra added this comment: “We needed to sort of re-
focus. So we’ve really been each other’s support. There’s not a lot of outside people
that we lean on” (Myra, C).

On the other hand, Edward was withdrawing himself, finding it difficult to
socially interact when friends telephoned or called in. Edward was spending significant
times alone, retreating into himself more and more. This is what he had to say:

There’s one thing, like I’ve really sort of withdrawn into myself a lot. If the
phone rings I won’t answer it because I don’t want to talk to people and things
like that. This has been in the last six months. I think it’s a protective thing;
you don’t have to explain who you are and where you’re at. You just want to
be in your little box. (Edward, PC)

However, Edward did state in another section of the interview that he appreciated
people calling because it helped with his “self-esteem that people were thinking about
him.” But overall, Edward’s mood was low; he was introspective and appeared
defeated. He drew most of his support from his wife, Sherri, who appeared glad that
Edward was talking about his feelings, stating she believed this to be a positive thing.
She had been concerned about his withdrawal and was pleased he had consented to be
interviewed for the study. Edward did talk about having some close friends but did not
go into a lot of detail and did not mention any person in particular. Sherri intentionally
invited friends over and talked about Edward’s illness in an honest way:
I make a point of inviting people over quite a bit. Sometimes Edward doesn’t really want to do it but he enjoys it when they’re here. But I’m at the point now where when people ask me about Edward, I have to tell them he is very unwell. (Sherri, C)

Sherri appeared to prioritise social contact, for her and for Edward. She was aware that Edward would prefer not to socialise but she felt this was important. The couple did not have any children. She appeared to be undertaking specific self-care strategies recognising the importance of looking after herself as well as Edward.

Patrick also spoke of spending a lot of time in his house as he was experiencing regular coughing fits and needed to arrange his activities around his pain medication. Patrick lived alone but did have a partner who spent a lot of time with him. Patrick had a son and daughter who came regularly and assisted with practical issues such as mowing the yard and helping out with household chores. When Patrick was asked if at any time he had felt the need to draw upon his social networks for support, he said:

No, it’s all been volunteered really. I haven’t asked for anything and you know, my partner would have been here now for this interview but she had to go to the doctors herself. If I needed support I would have to turn to my partner, but I’m usually propping her up most of the time. I don’t feel a need for any outside help, but I know it’s there if I need it. (Patrick, PC)

Patrick presented as robust and resilient regarding his disease. He had a firm sense of self and just looked at the situation as another thing to deal with head on. He did not require emotional or social support to any significant degree. He was happy with just being with his partner when she visited and the weekend visits from his children. Patrick lived in a small community with a population of approximately 2,400 persons where most people knew each other, so social support was readily available but
he chose not to access it to any noteworthy extent. Patrick was logical about the fact that when the end came closer he would have to “go to hospital for a while and then to a hospice.” He lived 1 ½ hours away from mainstream services, with the trip including a 20 minute ferry ride across a waterway so did not see dying at home as an option. He appeared to take a rational and realistic approach to this issue. Perhaps Patrick’s intellectualization of his situation was a coping mechanism as outlined by Cherry (2014) who states individuals will attempt to master their situation by thinking about their prognosis in a compartmentalised manner. This was evident in Patrick’s rationalising comment, “you’ve got it and that’s it.” This allows the individual to remain emotionally detached.

Furthermore, Sheldon (2003) states for some advanced cancer sufferers and their carers social isolation is a source of pain. This was notable within this study. Robert stated he had noted others had withdrawn as his disease progressed. Myra said she had found this particularly hurtful as there was perceived judgement that this was the participant’s fault for not having enough faith to be healed by God as mentioned earlier.

It seemed they would have welcomed the support from the church, however since it was not forthcoming, they had “to refocus.” Robert adjusted to the withdrawal by instinctively utilising cognitive restructuring techniques, still keeping his faith to his God, despite the actions of his fellow church associates. Social pain can occur for some, resulting in feelings of confusion and rejection. The carer may then become protective of the palliative client developing a more wary and cautious attitude to outside social support.

Furthermore, withdrawal is likely to come from within the person who is living with a progressive life limiting illness. Withdrawal is a natural part of the dying process as a person begins to separate from the outside world. This will begin with friends and
other social institutions and progressively incorporate close family members. It is often related to profound weakness and reduced capacity to communicate with others. It can also have an emotional or spiritual motivation in that they are preparing for their impending death, turning their attention increasingly inward (Canadian Virtual Hospice, 2013). Family members may draw on support from the community or close social contacts as they journey with their loved one towards end of life. The palliative client may also partake of this support until the natural withdrawal begins to occur.

The role of community and social supports cannot be underestimated in rural communities where professional services for palliative clients are not abundant. Community church organizations or similar groups can be invaluable. This resonates with literature that describes rural communities not always as a series of deficits, but also full of assets and strengths that are often overlooked (Daley & Avant, 2004). Depending on how entrenched and connected an individual is within their community will influence the level of social contact they will accept.

**Spousal relationships.** The data collected and observations made throughout the interviews highlighted how close spousal relationships were intimate and very close. There appeared to be immense selflessness from both Sherri and Myra towards their husbands as they cared for them at the end stage of their lives. The love displayed between Edward and Sherri and Myra and Robert appeared deep and unconditional. They appeared to treasure every moment together. Sherri spoke about the time they had left and what they were doing. She said:

Well now we really won’t be going anywhere. Just go to the beach and watch whales, hey darl? [smiling at Edward]. That’s our therapy. (Sherri, C)

Edward responded to this with:
We just go for a drive and do what we can, when we can. That’s the best we can hope for. (Edward, PC)

Being together, going for a drive when it could be managed and looking for whales in the water was an example of two people utilising time left partaking in quality activities.

Whether I live or die I’m in a win, win situation because you know I’ve got to spend my life here with the woman that I have loved for 46 years. (Robert, PC)

Myra stated there were not a lot of people in their world; it was mostly just them at this time. It seemed they had built a cocoon around themselves as they spent their last time together as a couple on their large property. They looked at each other with great love and devotion, which was humbling to observe.

Patrick was obviously cared for and loved by his family but he was interviewed alone so observations could not be made around relationship dynamics. Patrick was still reasonably functional and had not reached the point of full-time care in his disease trajectory, whereas Edward and Robert needed more intensive attention.

The results of this research support findings by Penman et al. (2009) that spirituality was associated with “God” “coping” “religion” and “relationships with others”, whilst spiritual engagement was associated with “maintaining relationships” “love” and “participating in religious practices.” In discussion with the palliative client’s carers, they were fully devoted to their husbands’ needs; available around the clock to meet their every care, ensuring their husbands’ last phase of life had quality and meaning. They had put their own lives on hold and were completely dedicated to the caring role.

Who is in a palliative client’s microsystem and the extent of their social networks will strongly influence place of death and how the last phase of life will be spent. The study found that this could be as minimal as a caring spouse, a trusted
General Practitioner and a community nurse. Not only does where a person live become a deciding factor in end of life care, but also the availability of a devoted, able-bodied caregiver who can offer around the clock assistance, particularly as the terminally ill patient becomes more confined to bed. This person must be supported in every way possible, including access to 24/7 telephone support if required. Not all families will have such a person within their social context, meaning a transition to hospital, hospice or a nursing home may become inevitable.

**Spirituality/Religiosity**

Spirituality was a strong theme with the three palliative participants and a matter they all spoke about in varying lengths. It is important to differentiate between spirituality and religion as they are often referred to synonymously but this is not the case. Religion is an organized system of beliefs and worship, whereas spirituality has a broader scope. Spirituality goes beyond a religious affiliation; it is about the meaning of life, one’s purpose, an aspiration to be in harmony with the universe and it can come into focus when one is undergoing times of duress (Caroll, 2001). In this study, Robert was connected to a church, whereas Edward and Patrick had spiritual beliefs that were not affiliated with any religion. All three stated their belief system helped them to cope, provided comfort and reduced fears after death. Myra also had a strong Christian faith; whereas Sherri did not disclose her belief system in the interview, allowing her husband, Edward, discuss his beliefs on this topic:

I’m not a religious person, like I’ve got friends that are going to church and praying for me and things like that. I understand and appreciate that. I have a little corner here [pointing to a small table next to his bed] with Buddhas and things like that. I have some cards with some sayings and whenever I stress out I just go through them. They help when you’re really stressing. But I don’t
like to go to church to pray. I suppose I do sort of meditate and sort have my own praying, not like a formal church thing. A lot of times you’ve got to do that to get through the hard times and things. (Edward, PC)

It is clear from Edwards’s comments that when he was going through times of despair and moments of crisis, his spiritual beliefs were able to provide a measure of comfort. As mentioned, Edward presented as one experiencing anticipatory grief, aware of the loss ahead and was preoccupied with this. There was a quiet sadness about him but it was reassuring to know that his spiritual views provided him with some comfort.

Robert stated that “right from day one I had a different slant on the disease.” He was not only talking about how his psychological responses to the disease helped him to cope but was also referring to his religious beliefs. From the moment Robert was diagnosed, he referred to his spiritual beliefs. This is what he had to say to his urologist at that time:

I forget how the story went but I asked her what chance I had because the other guy [the doctor who initially diagnosed the cancer] said I had little chance. I said to her, “the God I believe in gives me a far better chance than that. He tells me if I read his good book, he tells me he’s [God] taken my sin and without a breath, he’s taken my disease and I said I know he’s [God] taken my sin because you know, 30 years ago I used to be a real mongrel and I said that took a lot of changing so disease works the same way. I’ll walk out of this. And I remember this person saying, “You are an unusual man.” (Robert, PC)

Robert belonged to a Christian church that had strong views on the connection between disease and faith. It appears initially, he believed that he would be cured by his faith. Robert lived with the disease for ten years before he started to lose the battle. Robert’s
faith did not waver. He was accused of having a lack of faith by the churchgoers, who believed this was evident because he was not cured of his cancer. He stated he was “amused” by their comments but still did not lose devotion to his God:

I had this fellow in the church we go to, just a few weeks ago, come up to me and asked how I was going. I said, “Oh yeah, doing okay, mate.” Then he said to me, “I’ve got a question for you that I want you to think about.” I said, “Yeah, okay.” And he said, “what do you think it would take to exercise a little bit of faith?” I looked at him as if he had two heads. We’re both Christian people, go to the same church. “What do you think got me through this journey in the last ten years? If you don’t think I’ve got faith, I don’t know where you’ve been. I believe it’s my faith that’s got me this far.”

The thing that helped myself and us the most was that we are Christians and have a faith. We simply believe that, you know, exercising in that faith that all things work together for good. That’s very much part of our belief system. I couldn’t see how it was going to but that’s where faith comes in. I don’t know how people without a faith would end it. But anyway, that’s where we come from. (Robert, PC)

Robert believed he was going to “a better life” once he had died. This is why he described his situation as a “win/win” because he got to be with his wife whom he had loved for 46 years and then he was going to his God in the afterlife. His beliefs appeared to come from deep within him and went beyond the confines of his church. As mentioned in the preceding section, Robert had noticed a withdrawal from his church associates over the last few years; he spent most of his time with Myra and not with too many other people. But his faith was strong and intact despite the lack of regular contact with fellow churchgoers.
Like Edward and unlike Robert, Patrick had strong spiritual rather than religious views that provided him with a sense of meaning and comfort regarding the afterlife. Patrick was very clear about his ideas about where he would like to be born in his next life:

I do believe in life after death. I believe there is life after death and I believe in reincarnation. Next time I want to be born on [names an island] Island. I want to be brought up there. It looks like a beautiful place. I love snorkelling and fishing so that’s where I’d like to be next time. (Patrick, PC)

All three participants were close to the end of their lives, therefore their spirituality or religion became a poignant issue for them. Spirituality is a significant issue that is often in the forefront of a palliative client’s mind when facing the end of their life. Whether a palliative client holds beliefs that are affiliated with an organized religion or holds more abstract spiritual views, this domain has proven to be a source of comfort and a contributing factor to coping. Spirituality is closely connected with psychological processes in that it gives palliative clients a way to think about their illness. It also provides comfort for beliefs about what happens after death as revealed by the study. Robert and Patrick spoke extensively about their hopes for a better life in the hereafter and how thinking about this made their situation tolerable. Edward also drew on Buddhist’s sayings and his own style of meditation to help him through the “hard times.”

Rumbold (2003) states spiritual issues can arise at different times within the course of the illness. In palliative care, spirituality, whether abstract or overtly religious, may impact how the person copes with their journey towards end-of-life. Literature supports hope as one factor that can make life meaningful, provide a reason to keep
moving forward in times of stress and anguish. With hope, physiological and psychological defences can be fortified (McGee, 1984).

**Practical Matters**

**Impact of excessive travel.** It was of noteworthy interest that both Edward and Patrick spoke about the travel involved when they were receiving treatment or were visiting the palliative care team as outpatients. Edward had a more unusual form of cancer, so during his treatment phase had travelled to Brisbane and Melbourne for assessment and treatment. He regularly had to drive 1 ½ hours one way to see specialists. He said:

> That’s the hard part and being away from your family. I think it’s probably the most difficult part of it because you’re away from your own surroundings. But the hardest part is the travelling and as you get really sick, you find it more difficult to actually go on these trips because it’s so taxing. And you get so tired. Sometimes you prefer to ignore it instead of having to travel. (Edward, PC)

Sherri noted that Edward would get very anxious just prior to travelling. Edward added to this, saying:

> I mean that’s the thing. I’ve been lucky that we’ve been up to this stage, been able to cope with the travelling. But as you go deeper into the thing, you get tireder and weaker and you find it harder to do the travelling and that sort of thing. There is a lot of stress and worry. (Edward, PC)

Sherri also highlighted the expense of travelling and accommodation. Patrick too commented on the expense of travelling backwards and forwards when receiving treatment. These sentiments are in congruence with the statement made by White et al. (2004) who stated, “the roads are poorer, fuel is more expensive and subsidised
transport is poor” (p. 29), all adding to the anxiety of the patient. Patrick had to travel
two hours each way, stating he was exhausted by the time he got home. When it was
determined that he should come under palliative care and no longer receive treatment,
Patrick stated, “I was glad when all of that was finished with.”

It is evident the issue of travel can be a huge stressor for someone undergoing
treatment for a terminal illness or needing to see palliative care consultants. Travel is
not only expensive but also provokes physical and emotional anxiety. If the palliative
care service undertook more outreach work, instead of the patient having to physically
travel to see them, the stress for some individuals could be lessened. Sherri made
reference to this:

The palliative care team ring us; we’ve got access to them on the phone
anytime. But to actually let them physically see Edward, we have to go down.

We did that a couple of weeks ago, which was very difficult. (Sherri, C)

As mentioned, Sherri lamented over the amount of money they had to pay for travel:

And the expense. Although we have been in the Patient Travel Scheme….but
really. (Sherri, C)

Sherri also mentioned that she had to find her own accommodation whilst Edward was
receiving treatment in a larger hospital. Regarding the accommodation fees Sherri said:

For twelve months that Edward was in hospital, I had to find my own
accommodation. It was not easy at all. (Sherri, C)

As mentioned in the literature review, practical issues that arise when living with
advanced cancer can evoke significant anxiety and concern (Jeffrey, 2003). Both
Edward and Patrick found travel for specialist appointments particularly challenging.
Robert was fortunate enough to live in a community that was within the catchment area
of a hospice that that could offer extensive support in his home. The issue of the impact
of travel on an individual with a terminal illness is under researched and warrants further exploration. This will be discussed in the following chapter.

**Education.** Edward appeared accepting of his prognosis, stating that education about his disease and what was likely to occur next, was helpful. But as indicated by the health professionals, not all are willing to hear the details of their disease. Although sad, Edward was clearly not utilising denial as a means of coping with his illness and prognosis. He felt having knowledge and education about his cancer assisted him to cope better. He said:

It’s sort of the unknown, you don’t know when the next phase is and things happen a little bit and then [pauses] the Blue Care nurse, for example, she will, she’s really good, she’ll explain it to you, what could happen, what will happen and what they will do and you know, things like that helps a lot. (Edward, PC)

However, the literature states an individual with capacity can choose to view their illness how they like; needing to be responsible for their own actions and beliefs once they have been informed of their prognosis (Sheldon, 1997). Some palliative clients and their family members will be open for more intricate details about their disease, like Edward, whilst others will not want to discuss these details. This may give the impression of denial or avoidance. All coping mechanisms should be seen for what they are, treated with utmost sensitivity and respect. This only amplifies the need for health professionals to possess specific skills and expertise in working with the dying.

Palliative care has come a long way over the last twenty years, however, a lack of knowledge regarding its benefits persists. Edward stated:

I don’t think a lot of people appreciate how big their role is – palliative care.

And probably that needs to be expanded a bit more and how their role can help people. I thought of palliative care as you know, like, you went to the doctor
and he said, “You’ve got a couple of weeks to go.” But when you go there, they’ve got other services that expand further and do more than that. (Edward, PC)

As identified in the previous chapter, not only were the health professionals acknowledging they were receiving the referrals too late, palliative clients also acknowledged that referrals may have been made too late. Sherri wanted to know why Edward and herself were not referred to the specialist palliative care team earlier when they went to see oncology services in the larger hospital 1 ½ hours’ drive away. She felt they were offered this assistance only when their situation was in crisis. She said:

Why wasn’t it [palliative care] offered sooner? It wasn’t until things were very, very bad that suddenly we knew about palliative care, then somebody referred them to us. But we did not know about them. (Sherri, C)

Evidently, more work needs to be done to enhance public knowledge and education on what palliative care can offer. Edward and Sherri would have accessed this support, particularly psychosocial support, when accessing the specialist services in the larger hospital they had been connected until recently. They were only referred to a specialist palliative care team when Edward’s condition had significantly deteriorated. It was not long after; Edward could not manage the travel so they were left back in the care of their General Practitioner and community nurse. This is congruent with a South Australian study which also found a lack of information about services is a barrier for cancer patients living in rural communities (Gunn et al., 2013).

**Addressing Psychosocial Issues in a Rural and Remote Context**

Health professionals trained in palliative care issues, will assess for psychological or emotional distress and other psychosocial concerns, and offer interventions accordingly. The matter becomes problematic when such health
professionals cannot be accessed and a terminally ill person is struggling. As stated by Edward and Sherri, there was not a skilled counsellor that they knew about in the community in which they lived. This couple believed their input would have been beneficial:

I don’t think there are any counsellors here. We have never been offered counselling here. (Sherri, C)

If there were good counsellors and people available, they would be invaluable now. If someone was allocated to you, you know, like once a week or once a month, they could say ring you and say “how ya going?” (Edward, PC)

On a different note, as identified by Patrick, not all persons with a terminal illness will wish to access outside help: “I don’t feel a need for any outside help, but I know it’s there if I need it” (Patrick, PC).

Patrick lived in a community that did not even have a nursing service. A nurse practitioner from a specialist palliative care team would outreach to his community once a fortnight. She had to travel almost two hours to see him. She kept very regular contact by telephone. The nurse practitioner had told Patrick about psychosocial support that could be accessed but he did not wish to be referred. This was Patrick’s perspective at the time of the interview, which may have changed in time. Whether a palliative client takes up the offer of support is up to them, but psychosocial support should be available for all to access, no matter where in Queensland one resides.

In sharp contrast, Robert and Myra lived in a community that was in the catchment area of small hospice. This meant they had access to 24/7 medical support, with nurses visiting the home regularly along with an experienced social worker. Myra spoke of somebody she knew in a similar situation who lived only 11 kilometres away.
but was not in the hospice catchment area so could not access the support Myra and Robert were receiving.

I have a contact who has terminal lung cancer who lives in [named the community] and she doesn’t have a lot of support. You know, recently diagnosed…out of control pain wise. I told her to ring the hospice but she was told she was out of range. (Myra, C)

Myra had utilised the hospice ten years prior when her daughter was terminally ill with advanced cancer. The same social worker who supported her at that time was still on staff. She was calling on Myra and Robert regularly and providing psychosocial support. Myra and Robert did not draw on other informal social supports because they felt let down by their church community. If Robert and Myra lived in the community 11 kilometres away from their home, their experience would have been completely different.

**Discussion**

These stories from palliative clients and their carers demonstrate the complexity of issues that signify end-of-life transitions. It is clear that many of the themes in the previous chapters are repeated here, however there were other important areas of psychosocial need that were not really mentioned by the health professionals interviewed for this study. The importance of attention to the spiritual and religious domain was one of these areas.

The findings reveal that palliative clients have unique, identifiable psychosocial issues that were significant to them and their family. It was revealed that how a person thinks about their illness impacts how they cope. Psychological thinking was closely entwined with the spiritual framework the participant identified with. Spiritual or religious beliefs were drawn upon for comfort, particularly as the disease progressed.
Its value is often neglected by health professionals who generally do not initiate conversations on this topic. Yet it was the one of the most prominent psychosocial issues mentioned by the palliative care participants within this study.

In keeping within the theoretical framework of this study, the international human rights covenants and the discipline of palliative care, have common themes, incorporating the inherent dignity of the individual and the principles of universality and non-discrimination (Brennan et al., 2007). Where one lives should not be a discriminatory factor regarding what services one can receive when it comes to palliative care.

Furthermore, in alignment with Bronfenbrenner’s ecological/systems model, and in recognition of the skills that social workers have in working within the psychosocial domain, adding a social worker into the microsystem, the journey towards end of life can be beneficial as a social worker can discuss psychological, emotional, spiritual needs as well as offer practical support not only to the client but family members. By drawing on family systems knowledge and their understanding of coping mechanisms, the social worker can examine the uniqueness of a family and offer effective and therapeutic interventions to highly stressed individuals (Christ & Blacker, 2005; MacDonald & Hobbs, 2008). Furthermore, social workers can assist with pragmatics such as helping with Centrelink forms for carers payments, organizing an Aged Care Assessment Team assessment, Enduring Powers of Attorney and Advance Care Planning, liaising with other existing community organizations to assist with meals and finances at a most emotionally taxing time. Following up and supporting the family through their bereavement after the death can lighten the heavy toll of grief.

The strength of the microsystem is the catalyst as to whether or not one will require additional psychosocial support. If that microsystem only comprises of the
palliative client and a spouse, the General Practitioner and perhaps a nurse that visits once a week or fortnight, it is possible stressors will become significant when the palliative client becomes closer towards death. If the microsystem comprises of church members visiting, family and friends calling in regularly and offering meals and respite, or just a listening ear, the General Practitioner and the community nurse, the need for outside professional psychosocial support may diminish somewhat. However if the microsystem also incorporates a skilled social worker who can assist with psychological and emotional support, practical issues and bereavement follow-up, the strength of the microsystem could be enhanced. Appendices M and N will illustrate the difference psychosocial support could make by means of a skilled social worker when they become a part of the microsystem.

Emotional responses will vary from person to person, with some palliative clients showing remarkable resilience. But in other instances, emotional responses will be more significant when there is a change or a decline in the disease trajectory or a new “phase” emerges to contend with. The chance to talk to someone like a skilled social worker would be beneficial at these times as indicated by the findings.

Social factors were found to be a significant psychosocial factor with the strength of the participants’ social networks impacting how the participant got through each day. This was particular when the marital relationship was close and devotion to the terminally ill clients’ cares was paramount.

However, social matters were also identified as a source of pain, particularly when expected support from some social circles did not materialize. Rural dwellers are said to be more religious, independent, have a non-materialistic lifestyle, familial and conservative (Bettencourt et al., 2008). The participants in this sample group certainly
presented this way, with outside social interactions appearing to be confined mostly to family and close friends.

The findings regarding travel and distance from the perspectives of the palliative clients related to difficulties with finances, management of pain, anxiety and exhaustion. Interestingly, the discussions about geographic distance highlighted by the health professionals were more focused on impacts for them of extensive travel and the impacts of their workloads and budgets. Only one of the community workers discussed her concerns about a palliative needing to travel long distances alone by train.

A final matter was that of community awareness that also arose, highlighting a lack of public knowledge on what palliative care can offer. This was a gap noted by Edward when he mentioned that palliative care’s role needed to be expanded so it can be more widely known how they can help people. Most people think “you only have a couple of weeks” to go if the term palliative care is mentioned. In accordance to the WHO’s definition “Palliative care 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.1). The study highlighted that palliative care is not viewed this way and considered as a service to be brought in at the very end of life and not earlier on. The findings illuminated the three month eligibility criteria is a significant contributing factor to this situation.

A follow-up phone call many months after the interview, either to the health professional that introduced the study to the participants or to the surviving spouse, revealed the subsequent outcomes (Figure 10):
A phone call to Sherri, one year after the interview revealed Edward died peacefully at home three weeks after our discussion. Friends moved in two weeks prior to his death and assisted Sherri with his cares, being directed by the General Practitioner and the Blue Care nurse. Sherri described this time as a “beautiful, wonderful experience.” Sherri did state however, she would like to see more assistance for persons living in small communities in the future, particularly in regards to psychosocial care. She stated Edward had been glad he had the opportunity to contribute to research before he died.

A phone call eight months after his interview revealed that Robert is still at home, being care for by his wife, Myra, who is a nurse. He has not had a hospital admission throughout this time. Myra is assisted by a hospice nursing service and a social worker. There is some family involvement but this is not extensive. Robert is quite unwell now as the cancer has invaded many parts of his body. It is expected he will die at home within a short time under the care of his devoted wife, Myra.

A follow-up call to Patrick’s nurse eight months after his interview revealed Patrick died five months after our discussion. He lived longer than the palliative care team had anticipated he may have. He went to live with family just prior to his death as they resided closer to services, but was soon transferred to a large hospital where he stayed until he died.

Figure 10. Outcome

The final chapter of this thesis will provide a critical discussion of the implications for health policy, health professional education and the social work
professions. Recommendations for future research and a coverage of the limitations of the study will be also be presented.
Chapter Eight
Conclusions and Recommendations

This thesis has explored psychosocial care provision for palliative clients living in rural and remote Queensland. A major focus has been on the importance of human rights as a starting point for understanding policy and practice. Contextual factors such as macro influences that filter down through exosystems and ultimately impact clients and service providers at a micro level have been identified and explored. This final chapter highlights the results, draws implications and conclusions, makes recommendations for further research and identifies possible limitations of the thesis.

A critical human rights perspective and an ecological/systems model provided the lens for the research and its exploration. A human rights perspective offers a universal standard or a benchmark to critically explore the treatment of people by society and government, and as has been proposed in literature, governments need to prioritize health and welfare as essential human rights (Heard, 1997). By applying this perspective to the issue of psychosocial care provision, the thesis firstly identified a key policy gap in government services to terminally ill clients in rural and remote communities. Secondly, it identified essential practice issues and service delivery difficulties. Finally, the thesis highlighted the importance of well trained, competent and skilled practitioners and in particular the vital service role that social workers can play and the relevance of high standards for social work practice and future education.

Overall Goal of the Research and Thematic Analysis

The overall goal of the research was to investigate how psychosocial care provision is being undertaken for palliative clients living in rural and remote areas of Queensland. It further sought to uncover the barriers and enablers to social work interventions within this context. With the adoption of Bronfenbrenner’s (1979)
ecological framework, macro influences such as how palliative care is funded and in particular, how current systems impact on the phase of end of life for the terminally ill living in rural or remote areas of Queensland were explored. The psychosocial spheres, including definitions and relevance have been established. Challenges derived from literature, such as the blurred role of psychosocial care and the position of social work within this context provided a primary focus.

Thirty-eight participants from four sample groups were interviewed from 24 towns throughout rural and remote areas of Queensland, resulting in rich, qualitative data allowing analysis of distinct themes.

The thematic analysis of the data was provided in the three findings chapters. Many factors emerged from the interviews with health professionals and from the interviews with a small sample of palliative clients and carers. Conclusions from these are discussed throughout the chapter. A human rights and ecological systems framework introduces the importance of systemic influences and interconnected systems in rural and remote settings and the significance of these to policy formulation.

**The Interconnectedness of Systems**

A rationale to apply the two chosen frameworks was to conceptualize how the palliative care client living in a rural or remote community in Queensland is influenced by micro, meso, exo and macro systems. The palliative client in a country area has a faint voice amongst strong forces that formulate policies and funding allocations. The concept of human rights in patient care thus broadens from the individual patient-provider relationship to examine systemic factors and State responsibility in the provision of patient care (Cohen & Ezer, 2013); and for this study in particular, the provision of psychosocial care in rural and remote Queensland (see Appendix L for an illustration of the varying systems and how this
type of analysis can provide a basis to inform new policy and funding). The importance of understanding systemic influences and the context in which the provision of care is provided cannot be understated for policy implications.

**Implications for Health Policy**

**Resources, training and equity of access.** The findings revealed that psychosocial care was undertaken well in some areas and was simply inadequate in others. A patchwork, inconsistent situation was revealed throughout rural and remote Queensland, with a significant dependency on available staff members and their calibre of skills, competency, interest and experience. The data clearly shows that up-skilling in psychosocial care for palliative clients is an important factor to consider in rural and remote settings, particularly for social workers whose skills were scrutinised and often disregarded by referring practitioners. Negative perceptions of social work skills impacted on whether or not palliative clients were referred to them for psychosocial support. Generally terminally ill patients had their psychosocial concerns addressed by nurses or other community workers who filled this important gap. However, some nurses professed a lack of skills and training, which caused them discomfort in providing psychosocial care. Other nurses reported low or negative perceptions of the skills of the social worker, so hence declined to refer and tended to these issues themselves. The social workers who were available to do this work, and were skilled and confident to do so, were regarded highly by their colleagues.

Government policy in rural and remote Queensland should seek to address general understaffing in rural and remote health services, and lack of training for health practitioners in end-of-life care and psychosocial service provision. The standard of quality care should not be about competent staffing and variations in competency depending on one’s geographical location. Inequities of this kind in
Queensland rural and remote settings are unacceptable and clearly fail to meet both local and world standards (Lynch, 2012; Gwyther et al., 2009). Current policies hardly reflect values such as clinical integrity, respect for persons, justice and beneficence as outlined by the NHMRC ethical framework document (2011). For psychosocial care to be universal for all communities, access to such support systems need to be in place, and funding should be allocated for the assured availability of skilled staff to address such issues. It may not be feasible to have a qualified palliative care trained social worker in every rural and remote district of Queensland; however, access to sufficiently trained staff should be available.

As mentioned throughout this thesis, where an individual lives geographically impacts the services received. The availability of a competent caregiver will also impact on the situation, particularly when it comes to place of death. In Queensland, home, hospital, a hospice or residential aged care will ultimately be the place of death as was revealed by the data and literature on which the study was based. Over 70% of Australians state their wish is to die at home but in Queensland only 28% actually do, while 56% die in hospital, 15% die in aged residential facilities and only 1% die in hospices (PCQ, 2012b). In Queensland, the cost of an inpatient palliative care bed is approximately $950 per day, while the average daily cost of keeping a palliative client at home in the community is $63 per day. This raises the prospect of future consideration of a community development program where members of the community, with appropriate training, could be mobilised to offer support such as meals, transport, overnight stays and some emotional support. Assistance of this kind is necessary to consider in the community context as governments are failing to provide appropriate and on-going services.
A number of nurses highlighted the precariousness of end-of-life care in government policy suggesting that suitable structures for sustainability had never been in place and were unlikely to be put in place in the near future. Meaningful palliative care service planning cannot occur to address such important issues as sustainability unless a comprehensive needs assessment is conducted, which takes into account Queensland’s geography and demographics and other factors that would ensure planning is feasible and future funding is equitable (PCQ, 2012b). Such an assessment should include the allocation of appropriately skilled health professional staff in accordance to the needs of the population. This should not be based on historical data as is the current situation, but rather a projection in the context of the aging population. Palliative Care Queensland has lobbied for the development of a state-wide service plan for palliative care in Queensland, however no document has been ratified to date. The need to put policies in place to address these issues is long overdue. The finding that a social worker is required to cover distances up to 400 kilometres and that the closest social worker may be a five hour drive away is not appropriate, nor feasible. Situations of this kind for rural and remote families living in Queensland show that terminally ill clients often fail to receive the services they require. As a consequence of government policies and poor resourcing, persons with a life limiting illness and their families often revert to their own resources. This in itself could be considered a desirable outcome; however the opportunity for access to psychosocial support should be available to anyone who may require it.

Accessing services over long distances when one is weak and at the end-of-life can prove most difficult for rural and remote Queenslanders both financially and physically. In rural and remote Queensland, the extensive distances and
associated travel required to access treatment and other services was often met with relief by some when treatment was over. Financial costs can be substantial, even with assistance through the Patient Travel Subsidy Scheme (PTSS). There has been a recent commitment made by the Queensland Government to double the funds currently allotted to PTSS to assist Queenslanders living in rural and remote areas. Accommodations subsidies have also been increased, the first increase since 1987 (Queensland Government, 2012). Funding of this kind is important and should be further supported in order to assist the additional financial burden that rural and remote individuals and families endure.

To further address the equity of access issue, video conferencing may provide a mode of communication that could assist with consultations occurring at home, but as highlighted in literature, more research and further exploration may need to be undertaken to establish an evidence base for this type of intervention (Bradford et al., 2012; Thomas et al., 2010). For example, the technology relies on persons having a computer, with reliable internet connectivity, and possessing the knowledge to use it, which is not always the case in every household, particularly among the elderly. Video conferencing remains an under-researched area and warrants further exploration in terms of the provision of appropriate services to those at end-of-life. A lack of services is a major issue, together with access to after-hours services.

Access to after-hours care was mentioned throughout the study as often being undertaken by goodwill. Although not always renumerated, nurses took on the role because of empathy, compassion and concern for the client. While it is recognised that specialist palliative care cannot physically be available in every rural and remote pocket of the state, a 24 hours state-wide telephone service that either the palliative client themselves/ their carer or health professionals can call at any time could address issues
that arise (Health and Community Services Committee, 2013). A trained social worker could also be available for psychosocial telephone support to address psychological and emotional issues, particularly at the time of death. It is recommended that provision of a 24 hour palliative care telephone service to rural and remote Queensland should be on the government policy agenda.

**The three month eligibility policy.** Queensland Health has a three month eligibility criteria ruling for end-of-life care provision. If the person lives longer than three months, as many do, the issue of service withdrawal is raised. This eligibility criterion is of great concern to those working within the policy guidelines. It creates enormous tension and angst for nurses behind the scenes struggling with funding. Some reported taking considerable measures to ensure that the client or family were unaware of the funding struggles behind the scenes.

Such a narrow criterion places significant distress on the nursing staff who seek to keep palliative clients at home, and with their families, for as long as possible. Sourcing funds and doing it in a way that did not impact the client was reported as most difficult and took long hours of work. Nurses came up with innovative ways in their budgets to allocate money from other sources to stretch the strict criteria for ailing clients, while hiding this fact from families. Such was the practitioner commitment to their work and their clients.

The amount of palliative care funding accessed from Queensland Health has not increased for many years yet the number of referrals are said to be continually increasing (PCQ, 2012b). The policy emphasis is placed on persons with conditions with a short trajectory rather than illnesses that have a longer trajectory of decline. More money needs to be placed in the PCP funding pool for each Health District so more resources can be provided and persons with illnesses that have a longer trajectory
of decline are not excluded. The criterion is unacceptable and exclusive. Alternatively, an extended time frame of at least six months (preferably last 12 months of life) would mean inclusion for persons with illnesses with a longer disease trajectory of decline, such as neurodegenerative disorders or dementia (PCQ, 2012b). This would also address the difficult situation faced by nurses who reported significant discomfort with requirements to retrieve equipment or reduce input to a terminally ill client because they did not die within the specified timeframe.

Rurality and remoteness impact on the allocation of funding, with PCQ (2012b) suggesting the fact that palliative care funding is bundled in the sub-acute category results in the money ending up with rehabilitation patients as “everybody wants everybody to get better” (p.51). The reality is some people do not.

The three month eligibility criterion conflicts with evidence from the palliative care literature, which promotes early access, with the transition to palliative care and other forms of care being a gradual process (NHMRC, 2011; WHO, 2002). The results of this study reveal that a gradual process of care in rural and remote Queensland does not necessarily occur, with terminally ill clients being referred late in their trajectory and often when they are in crisis. The criterion is a direct indication that there is a shortage of PCP funding at a local level (PCQ, 2012b), an issue that requires urgent attention for both policy and practice considerations.

Gaining access to equipment was also deemed problematic in some rural areas and played a role in how long a terminally ill patient could be kept at home. The results found gaining access to funds for equipment was yet another stress nurses faced on the front line. There also appears to be some confusion around whether or not MASS can be accessed as a resource for equipment for persons with a palliative diagnosis (Queensland Health, 2013a). Equipment needs to be sourced
through the PCP funding, which again was difficult due to the three month eligibility criteria. The Health and Community Services Committee (2013) recommends that all Hospital and Health Services operate an accessible equipment loan service to provide equipment for terminally ill patients with the aim of keeping them at home longer. This initiative, if implemented could be cost effective, however the criteria around eligibility needs attention.

Bereavement follow-up services as a policy concern. Most participants reported that bereavement follow-up was undertaken poorly in their community, being delivered in an inconsistent manner with no structured system in place. The results indicate bereavement follow-up was, at best, an ad hoc process, often being the result of a particular health professional who had rapport with a patient and their family following up with services after death. Overall, throughout rural Queensland there were no policies or formal structures regarding ongoing bereavement follow-up. Blue Care nursing services were funded for one bereavement follow-up visit, which was reported to be more ostensibly about collecting equipment than providing bereavement support. If a hospice was established in a community, bereavement services were reported to be more than adequate. It should be noted, however, that there are only eight hospices within Queensland, with the majority being in the more populated areas. Bereavement is an area of care that requires specific expertise, skill and training. The results of this study complement the literature that identifies bereavement and access to skilled staff as a service delivery gap for those living in rural and remote communities of Queensland (Giljohann et al., 2008: White, 2007).

End-of-life considerations for practice. A document produced by the National Health and Medical Research Council (NHMRC, 2011) provides an
ethical framework for health practitioners working with terminally ill patients. The document outlines a number of pertinent questions that should be asked by health professionals. One of these relates to the sensitive topic of euthanasia: “What resources do I have for discussions about euthanasia if this is raised? Am I able to have an open and honest discussion?” Practitioners who work with palliative care clients need to have some knowledge of this topic as it is possible a query around this will be encountered. Palliative Care Queensland (2013) hosts regular forums on euthanasia in an attempt to increase knowledge and open up dialogue on the topic.

An issue of importance for end-of-life consideration was that of spirituality, which was dominant on the minds of the palliative clients’ interviewed as they journeyed closer to death. Many health practitioners feel uncomfortable asking terminally ill clients about their spirituality and whether or not it could be a source of comfort and as a result often leave the topic alone (Penman et al., 2009). In this study, palliative clients and their carers made it very clear that this was an issue of importance, yet the health professionals interviewed failed to mention this as something they focused on in their practice. The NHMRC (2011) framework states that all health practitioners should enquire about a person’s emotional, physical, spiritual, social and cultural well-being as part of their interactions with clients. The results from this thesis suggest that despite a few exceptions, generally these enquiries were not made either because the practitioner did not feel comfortable to do so or there were not the resources in the particular community to refer. As a result it was concluded best not to raise the issue of spirituality in the first place.

As reiterated throughout this thesis, governments have a responsibility to ensure basic human rights are embedded into their healthcare policies (Brennan et al., 2007).
The medical aspect of care is of utmost priority as is other sources of pain. However, it is important for governments to include policies which relate to the psychosocial aspects of care. If the approach is addressed in accordance with its true holistic philosophy, psychological, emotional and spiritual distress should also be a priority (OSF, 2014). Strategies are needed to eliminate barriers to high quality psychosocial care as articulated in the Universal Declaration of Human Rights (1948) as follows, “Everyone has the right to a standard of living adequate for the health of himself and his family including food, clothing, housing and medical care and necessary social services” (United Nations General Assembly, 1948). The palliative clients’ voices need to be heard within the context of human rights and within macro policy circles.

**Implications and Recommendations for Education and Training for Health Practitioners**

The study revealed that palliative care and end-of-life issues are specialised areas of care that require specific training but the provision of such training was not adequate. There is a national training program for practitioners working with palliative care clients’ such as the Program of Experience in the Palliative Approach (PEPA). PEPA is targeted at all primary health care workers who work with palliative care clients. The specific aims of PEPA (Queensland Health, 2014), are to:

- Enhance the skills and expertise of health care providers in providing care for people who are living with a life-limiting illness and their families
- Support and enhance the skills of groups working collaboratively across the professional boundaries
- Develop and explore opportunities for health care providers from a range of areas of practice to gain professional exposure to, and experience in, palliative care
Develop opportunities for increasing the skills and knowledge of health care providers in the care of people who are living with a life-limiting illness.

PEPA provide training in Queensland workplaces or financial assistance to backfill positions to enable practitioners to access their workshops in specific locations. The workshops focus on enhancing confidence to engage with a terminally ill patient and feel more assured to raise sometimes difficult issues such as psychological, emotional or spiritual issues which were identified by the palliative care participants in this study. All healthcare workers who interact with palliative clients would benefit considerably from the content of the workshops.

A trained psychosocial workforce could reduce the amount of burnout and resignations from nurses who often have to undertake tasks out of their scope of practice. An interdisciplinary team approach is integral to palliative care philosophy, with each team member offering a vital contribution. However, an all-inclusive team does not exist in country districts, challenging that philosophy to some extent. Therefore available disciplines should be utilised to their full potential in a context of trust, respect and open communication.

The study also found that in the communities where the existing health professionals had a healthy respect and understanding for each other’s roles and regularly met together to discuss clients, psychosocial needs were met reasonably well. A well trained psychosocial workforce will likely adopt mechanisms for understanding the specialized nature of palliative care and psychosocial care.

As previously highlighted in literature, the frameworks and value base taught within the discipline of social work provide a solid foundation for undertaking the provision of psychosocial care (Monroe, 2010). However, once an undergraduate degree is completed, for those social workers working with palliative care clients, this
foundation would be need to be built upon, with further training and education in this
specialized area being recommended. The results of this study indicate that the skills
of individual social workers were not always perceived as adequate and in one instance,
the social worker herself claimed a lack of skill. For confidence to exist when referring
to social work for psychosocial care, competency and skill must be evident before trust
will ensue. Otherwise nurses and other health professionals can readily lay claim over
the psychosocial domain. Henceforth, further education and training is necessary for
social workers to claim expertise in this area.

Social workers are not mandated to register with a regulating body; they are
therefore not obligated to uptake skills and competencies regarding psychosocial needs
in palliative care. This sphere of care could be an organizational expectation for all
social workers in healthcare. Directors of Social Work could stipulate that the PEPA
workshop be attended by their staff prior to commencing or early in employment. This
could be a basic requirement for social work. As with all new staff members working in
the health sector, certain mandatory training is required. Addressing psychosocial
needs when working with the terminally ill could be added to this training, however,
only for those social workers that would interact with this clientele. It would not be
feasible for those social workers working in mental health or the Child Health sector.
As an outcome, future social workers will have greater confidence to address end-of-life
issues with terminally ill clients and other healthcare workers will also have confidence
in the abilities of social work.

There are 26 universities in Australia offering a combination of Bachelor of
Social Work and Master of Social Work degree and three additional universities only
offering the Master of Social Work qualification (AASW, 2013). The social work
curriculum is quite broad and cannot be expected to cover every area of practice.
However, specialized learning modules are available via the Palliative Care Curriculum for Undergraduates (PCC4U) program, which provides resources for palliative care education in universities (PCC4U Webpage, 2014). Because the social work curriculum is already condensed with palliative care not considered as an essential and core subject, only three social work schools to date are actively incorporating the PCC4U learning resources to complement their palliative care content in their courses (A. Farrington, personal communication, October 24, 2013). Schools of social work need to consider the modules and incorporate them into their curriculum.

A further issue of importance to social work practitioners is that of loss and grief. All social workers should have additional specific training on this topic. Loss and grief education should be included in university curriculums as it has significance across all fields of social work, not only for those working with the bereaved. The Australian Centre for Grief and Bereavement is the largest provider of grief education in Australia. The organization is based in Victoria but has a yearly planner, which articulates what workshops will be conducted in all other Australian states. The Centre offers a range of customised training and consultancy services to meet the specialist training needs of organizations, groups and individuals. They can also provide training in universities and hospitals in venues throughout Australia (The Australian Centre for Grief and Bereavement, 2013b). Furthermore, the Centre for Palliative Care Research and Education also provides a yearly calendar of events all over Queensland on a vast array of topics. If feasible, all social workers working with palliative care clients should undertake this psychosocial training. It would be recommended all universities offering social work courses include this vital teaching component into their curricula. Once confident, social workers can provide education sessions to other health
professionals in their community on how a social worker can contribute to the care of palliative clients and their families.

Confidence is an important factor for practitioners in their ability to raise sensitive end-of-life issues (McCormick et al., 2010). As mentioned previously, the study revealed a disparity between the psychosocial issues the palliative care clients wanted to discuss and those social workers and health professionals explored. For the terminally ill clients, psychological processes, emotional responses and spirituality were the dominant issues. The results, once again highlight the need for programs such as the PEPA program to be attended along with other professional development and training.

The importance of a cohesive professional relationship between health practitioners in the rural setting cannot be overstated. Interdisciplinary teams are integral to palliative care with all aspects of care being met by an array of health professionals (Junger et al., 2007; Crawford et al., 2003; O’Connor et al., 2006). Communication across professions is of utmost importance for effective team collaboration and outcomes. Team dynamics have to be considered from a systematic perspective, with the idea there are constant reciprocal interrelations between different variables (Junger et al., 2007; McAuliffe, 2014). Universities need to incorporate into their curriculum how the range of different health professionals can best work within an interdisciplinary context, whether that is in small teams common to rural communities, or larger teams.

Simulated role plays within university courses could assist with preparation because, as the results of this study have suggested, social workers are not utilised to their full potential with their roles being defined by other members of the team. Social workers have to be accountable for the part they have played in this outcome but now need to take positive action to improve the situation. As reiterated, this could be
addressed at a curriculum level. A major task for the professional association is to facilitate and endorse a framework that clearly articulates parameters of social work practice with palliative care clients. A discussion follows concerning the implications and recommendations from the thesis with regards to social work and the profession.

**Implications and Recommendations for Social Work and the Profession**

A National Standards and Competencies document for social workers in specialist palliative care teams, with an accompanying stand-alone document specifically for rural generalist social workers, needs to be developed to ensure high quality assessments and interventions take place. An endorsed document by the AASW would provide generalist rural social workers with a framework articulating the scope of social work practice and guidelines when working with persons approaching the end of their life and their families.

National competencies and standards are in place for social workers working in palliative care in the USA and Canada, but not in Australia. There was some discussion circulated by the NSW Palliative Care Practice Group seeking endorsement of the Canadian Hospice Palliative Care Competencies as an interim measure until an Australian document could be written. However, it was decided the Canadian framework was not relevant for the Australian context so the matter is at a standstill. Hence there are no national competencies in implementation at this time of writing. A set of competencies should be developed and accompany the National Standards document relevant to the generalist rural social worker working with palliative clients in their communities on a regular basis.

There is one existing organization that has developed a model of care in Australia designed specifically to provide psychosocial care to terminally ill clients living in rural and remote areas. The organization called Amaranth is located in
Corowa, a small rural community situated on the banks of the Murray River on the border of Victoria and New South Wales. The model was founded by a social worker and is based on social work principles. Recognition of the gap in psychosocial care to outlying rural communities formed the basis of the service (Amaranth, 2013).

Amaranth provides an important example of a social worker who identified the lack of psychosocial care in the rural community in which she lived and as a result developed a model in the context of equitable access regardless of geography. Ife (2012) states human rights are important for all health practitioners in general, however, particularly so for social workers. By adopting a human rights framework in every-day practice social workers are equipped with a moral and ethical base that can guide them to advocate for those whom they serve. Human rights policies exist because injustices were identified and action taken. This has led to vulnerable people getting the help and services they deserve, purely because they are human. However, there is a link between rights and obligations on individuals and governments to ensure those rights are protected (Ife, 2012). This is where social workers play a role. Instead of human rights being viewed as a theoretical concept, human rights can be incorporated into day to day practice. This can be undertaken by dialogue with others, respectfully highlighting inequities in appropriate forums, linking the local to the global by conducting research or writing letters to appropriate stakeholders.

**Recommendations for Future Research**

As highlighted in the literature review, interdisciplinary teams are pivotal to palliative care philosophy. While a team of medical staff and numerous allied health staff members form a specialist team in metropolitan areas, the rural palliative care “team” is unlikely to be extensive. The rural and remote “team” will probably comprise of a General Practitioner, community nurses and whatever allied health staff members
are on hand, if available at all. They do not operate out of the same facility as their metropolitan counterparts. Further research could be undertaken to explore team dynamics, as such, within this context. Capturing viewpoints on issues such as overlapping of boundaries, blurred roles and communication factors could be investigated further with the aim of gathering ideas for change.

Bereavement follow-up was a major issue identified as a service delivery gap. Although there are recommendations articulated that such a service should be accessible to all, should it be required, the question around receptivity and engagement could be explored further. To what extent do most rural dwellers wish a health practitioner to follow them up after the loss of their loved one? This question is asked in light of the findings that rural attitudes of stoicism and privacy can form a barrier to acceptance of referrals.

The impact of travel from the palliative client’s perspective is under explored in the literature and warrants further investigation. Anxiety around physical pain induced by travel, timing within pain medication regimes and the practical matter of finance can be sources of anxiety.

Finally, the use of volunteers to assist families caring for a terminally patient or patients that live alone should be considered for further exploration. An Australian study conducted by Freeman et al. (1998) proposed the establishment, education and coordination of a network of palliative care volunteers to assist with non-medical support in rural communities. A training package was formulated, trialled and evaluated. The results were positive. Additionally, the study by Horsfall et al (2012) highlights the benefits of mobilising the community to assist with keeping terminally ill persons at home as long as possible. Although this concept is not new, models and initiatives
based on community development concepts warrant further investigation and evaluation.

**Limitations of the Research**

As with all studies there are issues that arise that evoke the need to consider the research with caution. Although it was not the intention to generalize the findings derived from the three palliative clients and two spouses, the small sample size is acknowledged. Furthermore, all of the palliative participants were male; aged between 60 – 70 years, all lived approximately 1 and ½ hours’ drive from main services, with two of the participants having a spouse/carer living in the home administering 24 hour care. The lack of diversity within this group is therefore recognized. The similarity between the participants is coincidental and a direct result of who ultimately consented to participate in the study.

Additionally, in almost all of the towns, only one person or persons from one agency was interviewed. This meant that only one perspective was gained from a community. This limited the capture of a broad picture regarding psychosocial care provision in a particular district. This precaution was due to identification issues as many health practitioners are sole practitioners and known to most persons in their communities. Confidentiality and avoidance of potential bias was paramount.

A rigid data analysis structure was adhered to with themes extracted from the data with transparency by means of the NVivo program. Some critics of qualitative research state that there is a potential for a researcher to only present anecdotal evidence that is consistent and congruent with the overall findings and evidence that “does not fit” are not put forth (Silverman, 2000). To address this issue, conflicting data were highlighted.
Conclusions

This study has explored how psychosocial care provision was undertaken in rural and remote areas of Queensland. The study further considered social work practices in the provision of rural and remote psychosocial care. Social workers claim expertise over this sphere of care, yet very little literature could be located regarding their involvement with terminally ill clients. This thesis provides one of the first available bodies of research to highlight the generalist social work role in country Queensland regions and the challenges social workers encounter when delivering care across a geographically vast landscape.

Implications for health policy and health practitioners were derived from the study, some of which were in alignment with current recommendations recently articulated by the Health and Community Services Committee Report No. 22 (2013) (see Postscript below). Other implications were derived which seek to influence future planning and policy. Recommendations have been made to address social work skills and competencies in psychosocial care for terminally ill clients. The aim is for future social workers to feel more confident in their capabilities to address psychological, emotional, social, spiritual and cultural issues as they arise. However support is required from a University curriculum level as well as an endorsed National Standards and Competencies document to serve as fundamental foundations.

By utilising a combined theoretical approach, the phenomena herein could be explicitly exposed; highlighting the immense influence that interconnecting systems can have on each other and ultimately affecting the palliative care patient, at the centre. Bronfenbrenner’s ecological/systems model provided the means to explore four systems closely so deeper understanding could be gained of the complexities around these issues of practice and highlight how health policy impacts on practice and those people
needing palliative care and support in rural areas. By adding the critical component of human rights, the problem was conceptualized as socially constructed from macro realms; forces that the palliative client had little power over, but those which a social worker could indeed challenge.

Article 25.1 in the Universal Declaration of Human Rights states access to necessary ‘social services’ is a human right (United Nations General Assembly, 1948). While this can be a source of contentious interpretation, from my perspective as a social work practitioner I believe that psychological, emotional, social, spiritual and cultural issues are concerns that a dying person may want to address with a skilled health practitioner and it is their human right to expect these services. It is not assumed that all will take up this support, however, as a basic human right; a service should be available if needed. While death will ultimately be an inevitable outcome for us all, the government needs to take responsibility and ensure good psychosocial care can be a likely outcome too, before and after the event. Advocating for those who are vulnerable is a must for health professionals. A lone voice is not enough.

**Postscript**

Of significant consideration is the fact that during the course of undertaking this research project the Health and Community Services Committee in June 2012 was asked by the Legislative Assembly to inquire into palliative care services in Queensland. Furthermore, the Senate Community Affairs References Committee for inquiry into palliative care service provision in Australia was also commissioned and results were revealed on October, 2012. These initiatives were undertaken against the backdrop of national health reforms and the establishment in Queensland of Hospital and Health Services as statutory bodies (Health and Community Services Committee,
2013). The initiatives provided support for the need for the thesis. The results and recommendations herein echo some of those argued by state and federal committees. In addition, it will be of noteworthy interest to see how the 2014 Federal budget will impact funding for the palliative care sector, and whether or not rural communities will continue to be casualties of the inequitable funding allocations.
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Appendices

Appendix A: Definitions

The terms that appear within this thesis are defined in this section for clarity regarding the position taken in this study:

**Advance care planning:** Preparing for possible scenarios at end-of-life, involving a discussion and paperwork about a person’s wishes regarding their understanding of their medical condition and prognosis, values, preferences, family resources, cultural issues. Their wishes are talked about, written down and respected (Palliative Care Australia [PCA], 2008).

**End of life:** The international definition is “the last two years of life.” However the term is generally used in Australia to relate to the final days. The average time people are receiving end of life care is 37 hours (Commonwealth of Australia, 2010, p.19).

**Generalist social worker:** refers to a social worker that works within a practice setting that requires him or her to assist all client systems within that context, basing all interventions on a Code of Social Work Ethics, pertinent theory and an appreciation of human diversity, and a commitment to social and economic justice (Bloomsburg University of Pennsylvania, 2013).

**Home and Community Care program (HACC):** This is a service funded by the Commonwealth government for persons aged over 65 years or aged 50 years and over for Aboriginal and Torres Strait Islander persons, with the aim of keeping them at home for longer with support. HACC can provide general nursing in the home,

**Hospice care:** a service generally accessed when people have a life expectancy of less than six months and patients are no longer seeking curative treatment. Hospice care can be undertaken at home or sometimes in a specialised facility (National Caregivers Library, 2013).

**Palliative Care:** this research will utilise the World Health Organization definition of palliative care which is as follows:

> “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2002, p. 1).

**Program of Experience in the Palliative Approach (PEPA).** PEPA is an education program that targets all primary health care workers, including Aboriginal and Torres Strait Islander health workers. PEPA can offer assistance with financial support for backfill and can travel to some communities and provide education. Its aims are:

- Enhance the skills and expertise of health care providers in providing care for people who are living with a life limiting illness and their families
- Support and enhance skills of groups working collaboratively across the professionals boundaries
- Develop and explore opportunities for health care providers from a range of areas of practice to gain professional exposure to, and experience in, palliative care
• Develop opportunities for increasing the skills and knowledge of health care providers in the care of people who are living with a life-limiting illness (Queensland Health, 2014).

**Psychosocial needs:** Dix and Glickman (1997, cited in Reith & Payne, 2009, p. 90) refer to psychosocial needs as follows:

**Patient:**

• To maintain identity
• To maintain control and independence
• To receive psychological, emotional, and spiritual support

**Family members and caregivers:**

• To acknowledge individuality
• To recognize the part they play
• To receive psychological, emotional and spiritual support

**Common needs of patients, caregivers and family members:**

• Recognition of ethnic, cultural, and spiritual needs
• Information about and access to state, private, third sector help and self-help organizations
• Advice and information to specialized legal advice – ie; making a will
• Advice on post-bereavement practical problems

**Rural and remote:** refers to communities that are not Australian capital cities or major metropolitan centres. Within this thesis “rural and remote” are defined as per the RRMA classifications which measure remoteness in accordance to the direct distance between goods and services to the nearest urban centre. This is then combined with measures of personal distance resulting from population density. Three zones are established - Metropolitan, Rural and Remote distinctions. This
thesis is mostly concerned with rural and remote classifications (Australian Institute of Health and Welfare, 2004).

**Specialist palliative care services:** is a specific team of specialist palliative care professionals whose core activities are working with persons who have an incurable condition. Specialist palliative care services are provided in the home, the community, hospitals, aged care residential facilities and palliative care units. Service is delivered in accordance to Palliative Care Australia’s (PCA, 2008, p. 16) service provision model which:

- Provides direct care to patients with complex needs
- Provides consultation based services to patients being cared for by primary care providers
- Provides support and education to services providing end-of-life care

**Spirituality:** refers to organized religious beliefs with established rituals as well as a set of beliefs or philosophies that one purports to be true but not associated with a religion. This can include the meaning of life, connectedness to humanity and being in harmony with the universe. It can also include relationships with others, ourselves, places and things, all of which contribute to a feeling of wholeness, defining who we are and how we fit in the grand scheme of things (Penman, Oliver, & Harrington 2009; Rumbold, 2003).

**Total pain:** was a term first penned by Cicely Saunders, the founder of the palliative care hospice movement, who described “total pain” as incorporating physical, psychological, social, spiritual and practical struggles (Ong, 2005).
Appendix B: Pseudo Names of Participants

Pseudo Name: **Queensland Health Social Workers**
- Lesley
- Christopher
- Clara
- Antoinette
- Charmaine
- Eloise
- Ellen
- Kerry-Ann
- Sally
- Carissa
- Donna

Pseudo Name: **Blue Care Nurses**
- Coralyn
- Yasmin
- Erica
- Candice
- Amie
- Nancy
- Marta
- Alison
- Marlena
- Nellie

Pseudo Name: **Community Workers**
- Anna-Louise
- Janelle
- Christina
- Kylie
- Dayna
- Carla
- Karen
- Yolanda
- Julie
- Helen
- Robyn
- Sonya

Pseudo Name: **Palliative Care Clients / Spouses**
- Edward
- Sherri
- Robert
- Myra
- Patrick
Appendix C: Information/Consent Form for Rural Social Workers

PSYCHOSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND

INFORMATION SHEET for Rural Social Workers

<table>
<thead>
<tr>
<th>Student Investigator</th>
<th>Supervisor One:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs Lise Johns</td>
<td>Associate Professor Donna McAuliffe</td>
</tr>
<tr>
<td>Griffith University Higher Research PhD Student</td>
<td>School of Human Services and Social Work</td>
</tr>
<tr>
<td>PH: w: 5541 9222</td>
<td>PH: 3382 1070 ext: 21070</td>
</tr>
<tr>
<td>Mob: 0409 611449</td>
<td>Email: <a href="mailto:d.mcauliffe@griffith.edu.au">d.mcauliffe@griffith.edu.au</a></td>
</tr>
<tr>
<td>Email: <a href="mailto:lise.johns@griffithuni.edu.au">lise.johns@griffithuni.edu.au</a></td>
<td></td>
</tr>
<tr>
<td>Or <a href="mailto:gfjohns@optusnet.com.au">gfjohns@optusnet.com.au</a></td>
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</table>

Why is the research being conducted?

The study aims to investigate how psychosocial (psychological, emotional, social, spiritual, cultural) needs are currently being met for palliative clients living in rural and remote areas of Queensland. There is limited research on what these needs are, who are meeting these needs for this client group and how effectively these needs are being met in rural Queensland. It is hoped this study will put this issue in the
spotlight, highlighting any gaps in service delivery, which could influence future policy and funding. The research is being conducted as a PhD study at Griffith University, Logan Campus.

What you will be asked to do

You will be asked to participate in a face-to-face interview with one researcher lasting up to one hour. This will be scheduled at your workplace at a time that suits you. In the interview you will be asked a series of questions to elicit your opinions, thoughts, ideas and experiences in regards to how you feel psychosocial needs are currently being met for palliative clients living in rural and remote areas of Queensland. The interview will be recorded and transcribed in order to correctly capture main points. Your consent will also be sought to re-contact you should clarification on any point be required.

The basis by which participants will be selected or screened

The Director of Social Work that oversees the particular site the researcher aims to visit will be initially sent the information/consent pack. The Director will provide the social workers working with palliative care clients with the information/consent package and then inform the researcher of willingness of participants.

The expected benefits of the research

It is acknowledged that this study will have no direct benefit to the participants. However, overall it is hoped the results will ultimately impact future policy and funding. A summary of the results of the research will be available to any participants who wish to receive this. They can contact the researcher and this will be forwarded to them in the form of a letter.
Risks to you

Participation in the interview involves minimal risk. The questions have been designed to be sensitive and non-invasive. You can choose whether or not to discuss any particular issues and can terminate the interview at any time. If you should become distressed after the researcher has left, the following process is recommended:

- Contact the researcher, Lise Johns – 0409 611 449 and inform
- The researcher will in turn either address over telephone or organize follow-up support either by your workplace superior or other depending on the resources in your community.

Your confidentiality

The data collected is confidential. No identifying material will be contained within any written material. Identifying details of individuals will not be kept with the audio recordings or the transcripts. Once the research is completed, the tapes and any personal details will be eliminated. Until the destruction, the audio recordings and personal details will only be available to the recorder.

Your participation is voluntary

Participation is voluntary and participants are free to discontinue at any stage. If afterwards, the decision is made to withdraw, the researcher can be contacted and information will be withdrawn.

Questions / further information

If participants require additional information regarding the study, the researcher, Lise Johns, can be contacted on 0409 611 449 or lise.johns@griffith.edu.au or gfjohns@optusnet.com.au. The supervisors overseeing the project are Associate
Professor Donna McAuliffe and Professor Lesley Chenoweth at Griffith University – Logan Campus.

The ethical conduct of this research

Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Griffith Research Ethics on 3735 5585, email: research-ethics@griffith.edu.au or The Darling Downs Toowoomba Health Service District Human Research Ethics Committee Co-ordinator on 46 16492, email: Kate_Norman@health.qld.gov.au or UnitingCare Qld HREC Chair on 3025 2118.

Privacy statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.
PSYCHOSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND

CONSENT FORM

Researcher
Mrs Lise Johns
Griffith University PhD Student
Contact Phone:  0409 611449
Contact Email:  lise.johns@griffithuni.edu.au
gfjohns@optusnet.com.au

Supervisors:
Associate Professor Donna McAuliffe
School of Human Services and Social Work
Griffith University
PH:  3382 1070 ext: 21080

Professor Lesley Chenoweth
School of Human Services and Social Work
Griffith University
PH:  3382 1005 ext: 21005

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will include a face to face interview for up to one hour;
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
• I understand that there will be no direct benefit to me from my participation in this research;

• I understand that my participation in this research is voluntary;

• I understand that if I have any additional questions I can contact the research team;

• I understand that I am free to withdraw at any time, without comment or penalty;

I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; or The Darling Downs Toowoomba Health Service District Human Research Ethics Committee Co-ordinator on 46 16492, email: Kate_Norman@health.qld.gov.au or UnitingCare Qld HREC Chair on 3025 2118.

• I agree to participate in the project.

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Appendix D: Information/Consent Form for Rural Nurses

**PSYCHOSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND**

**INFORMATION SHEET for Rural Nurses**

| **Student Investigator** | **Supervisor One:** Associate Professor Donna McAuliffe  
Griffith University Higher Research  
PhD Student  
PH: w: 5541 9222  
Mob: 0409 611449  
Email: l.johns@health.qld.gov.au  
Or gfjohns@optusnet.com.au |
|--------------------------|-------------------------------------------------------------------------------------------------------------|
| **Supervisor Two:**      | Professor Lesley Chenoweth  
School of Human Services and Social Work  
PH: 3382 1005 ext: 21005  
Email: l.chenoweth@griffith.edu.au |
Why is the research being conducted?

The study aims to investigate how psychosocial (psychological, emotional, social, spiritual and cultural) needs are currently being met for palliative clients living in rural and remote areas of Queensland. There is limited research on what these needs are, who are meeting these needs for this client group and how effectively they are being met in rural Queensland. It is hoped this study will put this issue in the spotlight, highlighting any gaps in service delivery, which could influence future policy and funding. The research is being conducted as a PhD study at Griffith University, Logan Campus.

What you will be asked to do

You will be asked to participate in a face-to-face interview with one researcher lasting up to one hour. This will be scheduled at your workplace at a time that suits you. In the interview you will be asked a series of questions to elicit your opinions, thoughts, ideas and experiences in regards to how you feel psychosocial needs are currently being met for palliative clients living in rural and remote areas of Queensland. The interview will be recorded and transcribed in order to correctly capture main points. Your consent will also be sought to re-contact you should clarification on any point be required.

The basis by which participants will be selected or screened

The researcher will send the information/consent pack to the Service Manager of the Blue Care Nursing Service. This pack will then be forwarded to the nurses who work with palliative care clients/families. Willing participants will then contact the researcher.

The expected benefits of the research

The results of the research could influence future policy and funding if it is determined there is a gap in service delivery and psychosocial needs are not being
adequately met in remote and rural areas in Queensland.

**Risks to you**

Participation in the interview involves minimal risk. The questions have been designed to be sensitive and non-invasive. You can choose whether or not to discuss any particular issues and can terminate the interview at any time.

**Your confidentiality**

The data collected is confidential. No identifying material will be contained within any written material. Identifying details of individuals will not be kept with the audio recordings or the transcripts. Once the research is completed, the tapes and any personal details will be eliminated. Until the destruction, the audio recordings and personal details will only be available to the recorder.

**Your participation is voluntary**

Participation is voluntary and participants are free to discontinue at any stage. If afterwards, the decision is made to withdraw, the researcher can be contacted and information will be withdrawn.

**Questions / further information**

If participants require additional information regarding the study, the researcher, Lise Johns, can be contacted on 0409 611 449 or Lise_Johns@health.qld.gov.au or gfjohns@optusnet.com.au. The supervisors overseeing the project are Professor Lesley Chenoweth and Associate Professor Donna McAuliffe at Griffith University – Logan Campus.

**The ethical conduct of this research**

The information sheet should indicate that Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If
potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Research Ethics on 3735 5585 or research-ethics@griffith.edu.au.

**Privacy Statement**

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.
PSYCHOSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND

CONSENT FORM

Researcher
Mrs Lise Johns
Griffith University PhD Student
Contact Phone: 0409 611449
Contact Email: ljohns@griffith.edu.au
gfjohns@optusnet.com.au

Supervisors:
Associate Professor Donna McAuliffe
School of Human Services and Social Work
Griffith University
PH: 3382 1070 ext: 21080

Professor Lesley Chenoweth
School of Human Services and Social Work
Griffith University
PH: 3382 1005 ext: 21005

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will include a face to face interview for approximately one hour;
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time, without comment or penalty;
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and
- I agree to participate in the project.

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Appendix E: Information/Consent Form for Community Workers

PSYCHOSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND

INFORMATION SHEET for Community Workers

<table>
<thead>
<tr>
<th>Student Investigator</th>
<th>Supervisor One:</th>
</tr>
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<tbody>
<tr>
<td>Mrs Lise Johns</td>
<td>Associate Professor Donna McAuliffe</td>
</tr>
<tr>
<td>Griffith University Higher Research PhD Student</td>
<td>School of Human Services and Social Work</td>
</tr>
<tr>
<td>PH: w: 5541 9222 Mob: 0409 611449</td>
<td>PH: 3382 1070 ext: 21070 Email: <a href="mailto:d.mcauliffe@griffith.edu.au">d.mcauliffe@griffith.edu.au</a></td>
</tr>
<tr>
<td>Email: <a href="mailto:lise.johns@griffithuni.edu.au">lise.johns@griffithuni.edu.au</a> Or <a href="mailto:gfjohns@optusnet.com.au">gfjohns@optusnet.com.au</a></td>
<td>Email: <a href="mailto:l.chenoweth@griffith.edu.au">l.chenoweth@griffith.edu.au</a></td>
</tr>
</tbody>
</table>

Why is the research being conducted?

The study aims to investigate how psychosocial needs (psychological, emotional, social, spiritual and cultural) are currently being met for palliative clients living in rural and remote areas of Queensland. There is limited research on what these needs are, who are meeting these needs for this client group and how effectively they are being met in rural Queensland. It is hoped this study will put this issue in the spotlight, highlighting any gaps in service delivery, which could influence future
policy and funding. The research is being conducted as a PhD study at Griffith University, Logan Campus.

**What you will be asked to do**

You will be asked to participate in a face-to-face interview with one researcher lasting up to one hour. This will be scheduled at your workplace at a time that suits you. In the interview you will be asked a series of questions to elicit your opinions, thoughts, ideas and experiences in regards to how you feel psychosocial needs are currently being met for palliative clients living in rural and remote areas of Queensland. The interview will be recorded and transcribed in order to correctly capture main points. Your consent will also be sought to re-contact you should clarification on any point be required.

**The basis by which participants will be selected or screened**

Significant persons will be indentified in the data collection phase as being the ones who are providing psychosocial support to palliative clients/family members. Once determined who these persons are, the researcher will initiate contact herself, provide information/consent package and await a response regarding willingness to participate.

**The expected benefits of the research**

It is acknowledged that this study will have no direct benefit to the participants. However, overall it is hoped the results will ultimately impact future policy and funding. A summary of the results of the research will be available to any participants who wish to receive this. They can contact the researcher and this will be forwarded to them in the form of a letter.
Your confidentiality

The data collected is confidential. No identifying material will be contained within any written material. Identifying details of individuals will not be kept with the audio recordings or the transcripts. Once the research is completed, the tapes and any personal details will be eliminated. Until the destruction, the audio recordings and personal details will only be available to the recorder.

Your participation is voluntary

Participation is voluntary and participants are free to discontinue at any stage. If afterwards, the decision is made to withdraw, the researcher can be contacted and information will be withdrawn.

Questions / further information

If participants require additional information regarding the study, the researcher, Lise Johns, can be contacted on 0409 611 449 or lise.johns@griffithuni.edu.au or gfjohns@optusnet.com.au. The supervisors overseeing the project are Associate Professor Donna McAuliffé and Professor Lesley Chenoweth at Griffith University - Logan Campus.

The ethical conduct of this research

Griffith University conducts research in accordance with the National Statement on Ethical Conduct in Human Research. If potential participants have any concerns or complaints about the ethical conduct of the research project they should contact the Manager, Griffith University Research Ethics on 3735 5585, email: research-ethics@griffith.edu.au or The Darling Downs Toowoomba Health Service District
Human Research Ethics Committee Co-ordinator on 46 164924, email: 
Kate_Norman@health.qld.gov.au or Uniting Care HREC Chair on 3025 2118.

Privacy statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.
By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will include a face to face interview for approximately one hour.
- I have had any questions answered to my satisfaction;
- I understand the risks involved;
• I understand that there will be no direct benefit to me from my participation in this research;

• I understand that my participation in this research is voluntary;

• I understand that if I have any additional questions I can contact the research team;

• I understand that I am free to withdraw at any time, without comment or penalty;

I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; or The Darling Downs Toowoomba Health Service District Human Research Ethics Committee Co-ordinator on 46 164924, email: Kate_Norman@health.qld.gov.au or Uniting Care HREC Chair on 3025 2118.

• I agree to participate in the project.

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Appendix F: Information/Consent Form for Palliative Clients and/or Family Members

PSYCHSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND

INFORMATION SHEET for Palliative Clients and/or Family Members

<table>
<thead>
<tr>
<th>Student Investigator</th>
<th>Supervisor One:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs Lise Johns</td>
<td>Associate Professor Donna McAuliffe</td>
</tr>
<tr>
<td>Griffith University Higher Research</td>
<td>School of Human Services and Social Work</td>
</tr>
<tr>
<td>PhD Student</td>
<td>PH: 3382 1070 ext: 21070</td>
</tr>
<tr>
<td>PH: w: 5541 9222</td>
<td>Email: <a href="mailto:d.mcauliffe@griffith.edu.au">d.mcauliffe@griffith.edu.au</a></td>
</tr>
<tr>
<td>Mob: 0409 611449</td>
<td>Supervisor Two:</td>
</tr>
<tr>
<td>Email: <a href="mailto:lise.johns@griffithuni.edu.au">lise.johns@griffithuni.edu.au</a></td>
<td>Professor Lesley Chenoweth</td>
</tr>
<tr>
<td>Or <a href="mailto:gfjohns@optusnet.com.au">gfjohns@optusnet.com.au</a></td>
<td>School of Human Services and Social Work</td>
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<td>PH: 3382 1005 ext: 21005</td>
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<td></td>
<td>Email: <a href="mailto:l.chenoweth@griffith.edu.au">l.chenoweth@griffith.edu.au</a></td>
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Why is the research being conducted?

The study aims to investigate how psychosocial (psychological, emotional, social, spiritual and cultural) needs are currently being met for palliative clients living in rural and remote areas of Queensland. There is limited research on what these needs are, who are meeting these needs for this client group and how effectively these needs
are being met in rural Queensland. It is hoped this study will put this issue in the spotlight, highlighting any gaps in service delivery, which could influence future policy and funding. The research is being conducted as a PhD study at Griffith University, Logan Campus.

**What you will be asked to do**

You will be asked to participate in a face-to-face interview with one researcher lasting up to one hour, maximum 1.5 hours. This will be scheduled in a time a place that suits you. It may be in your home or in a room at the GP’s medical office. In the interview you will be asked a series of questions to gain an understanding of your experience when it comes to what your psychosocial needs are/were and how they were addressed. This will include the needs of family members or caregivers. The interview will be recorded and transcribed in order to capture the main points.

**The basis by which participants will be selected or screened**

The local GP will act as a source of referral and will select clients whom they consider may be willing and able to be involved in the study. They will provide the client/family member with the information package/consent forms. The researcher will then follow-up with GP and then carry out the formal consent process with the client and their family member.

**The expected benefits of the research**

It is acknowledged that this study will have no direct benefit to the participants. However, overall it is hoped the results will ultimately impact future policy and funding. A summary of the results of the research will be available to any participants who wish to receive this. They can contact the researcher and this will be forwarded to them in the form of a letter.
**Risks to you**

Participation in the interview involves minimal risk. It may be that when emotional needs are discussed, some distress could ensue. The researcher is experienced in working with palliative care clients and will address accordingly. The questions have been designed to be sensitive and non-invasive. You can choose whether or not to discuss any particular issues and can terminate the interview at any time. If you should become distressed after the researcher has left, the following process is recommended:

- Contact the researcher, Lise Johns – 0409 611 449 and inform
- The researcher will inturn either address over telephone or organize follow-up support either by either the GP, a social worker (if available) or other depending in resources in that community

**Your confidentiality**

The data collected is confidential. No identifying material will be contained within any written material. Identifying details of individuals will not be kept with the audio recordings or the transcripts. Once the research is completed, the tapes will be destroyed and any written documentation will be shredded. Until the destruction, the audio recordings and personal details will only be available to the researcher.

**Your participation is voluntary**

Participation is voluntary and participants are free to discontinue at any stage. If afterwards, the decision is made to withdraw, the researcher can be contacted and information will be withdrawn.
Questions / further information

If participants require additional information regarding the study, the researcher, Lise Johns, can be contacted on 0409 611 449 l.johns@griffithuni.edu.au or gfjohns@optusnet.com.au. The supervisors overseeing the project are Associate Professor Donna McAuliffe and Professor Lesley Chenoweth at Griffith University – Logan Campus.

The ethical conduct of this research

Griffith University conducts research within the guidelines of the National Statement on Ethical Conduct in Human Research. If potential participants have any concerns or complaints about the ethical conduct of the project they should contact the Manager, Griffith Research Ethics on 3735 5585, email: research-ethics@griffith.edu.au or The Darling Downs Toowoomba Health Service District Human Research Ethics Committee Co-ordinator on 46 16492, email: Kate_Norman@health.qld.gov.au or UnitingCare Qld HREC Chair on 3025 2118.

Privacy Statement

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purposes. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at http://www.griffith.edu.au/about-griffith/plans-publications/griffith-university-privacy-plan or telephone (07) 3735 5585.
PSYCHSOCIAL NEEDS OF PALLIATIVE CLIENTS LIVING IN RURAL AND REMOTE AREAS OF QUEENSLAND

CONSENT FORM

Researcher
Mrs Lise Johns
Griffith University PhD Student
Contact Phone: 0409 611449
Contact Email: lise.johns@griffithuni.edu.au
               gfjohns@optusnet.com.au

Supervisors:
Associate Professor Donna McAuliffe
School of Human Services and Social Work
Griffith University
PH: 3382 1070 ext: 21080
Professor Lesley Chenoweth
School of Human Services and Social Work
Griffith University
PH: 3382 1005 ext: 21005

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this research will include a face to face interview for approximately 1 hour;

- I have had any questions answered to my satisfaction;

- I understand the risks involved;
• I understand that there will be no direct benefit to me from my participation in this research;

• I understand that my participation in this research is voluntary;

• I understand that if I have any additional questions I can contact the research team;

• I understand that I am free to withdraw at any time, without comment or penalty;

I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; or The Darling Downs Toowoomba Health Service District Human Research Ethics Committee Co-ordinator on 46 16492, email: Kate_Norman@health.qld.gov.au or UnitingCare Qld HREC Chair on 3025 2118.

• I agree to participate in the project.

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Appendix G: Research Questions for Rural Social Workers

RESEARCH QUESTIONS FOR RURAL SOCIAL WORKERS WORKING WITH PALLIATIVE CLIENTS IN RURAL AND REMOTE AREAS OF QUEENSLAND

Can you tell me how long you have been a social worker and how long have you been working in a rural area?

Can you please tell me about your work with palliative care clients – is this a clientele that you receive many referrals to address psychosocial issues for?

(If “yes”) How do the referrals come to you?

Do you feel the referrals are appropriate? Any comments?

Do you feel the referrals are given to you at an appropriate time in the client’s disease trajectory? Any comments?

(If “no”) Who do you feel is receiving referrals to address client’s psychosocial needs?

Overall, what are your opinions, views and experiences in regards to how palliative clients’ psychosocial needs are met in your rural area?

Would you like to see any changes in regards to how psychosocial care is delivered? Please explain.

Summarise main points and seek clarification on any issues if necessary.
Definition of Psychosocial Needs: Psychological, emotional, social, spiritual and cultural issues/concerns that a client may experience in their journey with a life limiting illness.

**Psychological:** What a client *thinks* about his/her illness/prognosis. Beliefs the client may have about their illness/prognosis.

**Emotional:** How a client *feels* about their illness/prognosis. There may be fears and concerns.

**Social:** Identifying the client’s social network, how well the client is supported and how do they cope within this environment.

**Spiritual:** What spiritual/religious needs/concerns would a client like addressed to assist with comfort or support.

**Cultural:** What cultural aspects a client would like considered/respected that will assist with comfort or support.
Appendix H: Research Questions for Rural Nurses

RESEARCH QUESTIONS FOR RURAL NURSES WORKING WITH
PALLIATIVE CLIENTS IN RURAL AND REMOTE AREAS

Can you tell me how long you have been a nurse and how long have you been working in a rural area?

Can you please tell me about your work with palliative care clients – is this a group that you deal with regularly in your nursing?

In your work with palliative clients’, do they (or their families) raise with you certain psychosocial issues that they would like addressed?

(If “yes”) Would you deal with these matters yourself or would refer to another discipline or person? Any comments?

(If “no”) Would you be comfortable to ask the client/family member about any psychosocial issues or would you refer to another discipline or person to raise the issue with them.

Overall, what are your opinions, views and experiences in regards to how palliative clients’ psychosocial needs are met in this rural area?

Would you like to see any changes in regards to how psychosocial care is delivered? Please explain.

Summarise main points and seek clarification on any issues if necessary.
Definition of Psychosocial Needs: Psychological, emotional, social, spiritual and cultural issues/concerns that a client may experience in their journey with a life limiting illness.

**Psychological:** What a client *thinks* about his/her illness/prognosis. Beliefs the client may have about their illness/prognosis.

**Emotional:** How a client *feels* about their illness/prognosis. There may be fears and concerns.

**Social:** Identifying the client’s social network, how well the client is supported and how do they cope within this environment.

**Spiritual:** What spiritual/religious needs/concerns would a client like addressed to assist with comfort or support.

**Cultural:** What cultural aspects a client would like considered/respected that will assist with comfort or support.
Appendix I: Research Questions for Community Workers

RESEARCH QUESTIONS FOR COMMUNITY WORKERS (that have been identified in data collection) WORKING WITH PALLIATIVE CLIENTS IN RURAL AND REMOTE AREAS

May I ask what is the nature of your work?

I believe that you support palliative clients by assisting them with any psychosocial concerns that they may have. Is this correct?

Where do your referrals usually come from?

What are some of the psychosocial needs that you assist with? Can you please explain?

Overall, what are your opinions, views and experiences in regards to how palliative clients’ psychosocial needs are met in this rural area?

Would you like to see any changes in regards to how psychosocial care is delivered? Please explain.

Summarise main points and seek clarification on any issues if necessary.
Definition of Psychosocial Needs: Psychological, emotional, social, spiritual and cultural issues/concerns that a client may experience in their journey with a life limiting illness.

**Psychological:** What a client *thinks* about his/her illness/prognosis. Beliefs the client may have about their illness/prognosis.

**Emotional:** How a client *feels* about their illness/prognosis. There may be fears and concerns.

**Social:** Identifying the client’s social network, how well the client is supported and how do they cope within this environment.

**Spiritual:** What spiritual/religious needs/concerns would a client like addressed to assist with comfort or support.

**Cultural:** What cultural aspects a client would like considered/respected that will assist with comfort or support.
Appendix J: Research Questions for Palliative Clients/Family Members

RESEARCH QUESTIONS FOR PALLIATIVE CLIENTS/FAMILY MEMBERS

I’d like to start off by acknowledging that I am aware that the topic we are discussing today can be sensitive, so if at any time you feel uncomfortable and do not wish to continue, this is quite okay. (allow for a response).

As set out in the information package, the term “psychosocial needs” include any needs besides physical issues that you (or your loved one) may have wanted addressed or wanted to talk about in your journey with your illness, particularly since all curative treatment was ceased.

This can be anything from

1) psychological issues, for example - your thoughts and beliefs about your illness and prognosis

2) emotional issues, for example – how do you feel about your situation

3) social matters, for example - who supports you and helps you to cope

4) spiritual issues, for example – has there been any religious or spiritual issues that have come up for you that you would like/or would have liked addressed

5) and what about Cultural matters – have there been any cultural issues you would have like to talk about or address

Can you please tell me if this was the case and what these needs actually were?

If certain needs were articulated... then ask...

What was it like to go through this experience?
If talking to a family member – What was it like to go through this experience with your loved one?

May I ask about your own experience with any psychosocial needs?

Could you please talk to me about what you did to address these issues?

Was there anyone in particular that you felt could assist you with this matter?

Do you feel these needs were adequately met or are they still an issue for you?

Then depending on responses, prompts will then be offered such as:

And then what happened?

What did that mean for you?
Appendix K: Benefits of Psychosocial Care

**Illustrated value of psychosocial care**

<table>
<thead>
<tr>
<th>Psychosocial Concern</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical And Cognitive Functioning</strong></td>
<td><strong>Concerns at the End of Life and Intervention Strategies</strong></td>
</tr>
<tr>
<td>Loss of independence – may include a fear of being a burden and the loss of dignity associated with relying more and more on others for self-care needs.</td>
<td>Negotiate with carers to include the patient in care needs as much as possible. Some well-meaning carers may tend to “take over” and add to feelings of loss of independence.</td>
</tr>
<tr>
<td>Reduced mobility and activity levels – this is often a difficult adjustment to make, particularly if the patient was previously fit and active</td>
<td>Assist the patient to be involved in activity in some way by “pacing” themselves or to develop alternative ways to spend time meaningfully. Consult an Occupational Therapist to provide information and equipment to assist in energy conservation, which may maintain some degree of independence.</td>
</tr>
<tr>
<td>Decline in cognitive functioning – i.e., frustration at word-finding difficulty and forgetfulness</td>
<td>Provide support to carers who may be grieving the loss of their loved one’s cognitive capacity and subsequent personality changes. Referral to extra support services to ease carer burden and support the patient.</td>
</tr>
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</table>
## Emotional Issues

<table>
<thead>
<tr>
<th>Grief about leaving the family and missing out on a future together - a lot of emotional distress experienced by a dying patient concerns leaving others behind and not being around to involved in their lives</th>
<th>Provide an environment that allows for the expression of feelings and grief that the patient may or may not wish to share with their loved ones. Actively listen and acknowledge concerns. Encourage patients to write card of letters, make audio or video tapes and create memories to leave for when they are no longer here. If a patient seems emotionally “stuck” and unable to move forward, specialised intervention may be needed.</th>
</tr>
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<tbody>
<tr>
<td>Concerns for loved ones – being a burden to family during the process of dying</td>
<td>Explore how families are coping. Are more resources need to assist them. Encourage the patient to allow others to care for them and to understand this is a way for them to give to others rather than being a burden. Ask the patient, “What would you do if the roles were reversed?” to illustrate that others want to help and be involved. Reinforce to parents of young children that they have given their children many valuable building blocks in life (trust, unconditional love, sound morals and...</td>
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<td>Section</td>
<td>Information</td>
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<tr>
<td>How to support children</td>
<td>Assist the patient to explore other ways in which they can “continue” their relationship; for example, being present as a star in the child’s heart. Patients and carers can consider a life album, letters, cards for significant future events, or videos they can leave as a permanent record for others.</td>
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<tr>
<td>How will loved ones cope when the patient is gone?</td>
<td>Encourage patients to discuss what future they would like to see for their family and what words of guidance would they offer. Ensure they have spoken with partners/carers about how they would like their children to be cared for. Some patients may wish to encourage loved ones to take on tasks that were previously theirs so that they can see how others will cope, although other patients may prefer to maintain involvement and control as long as possible.</td>
</tr>
<tr>
<td>Sexuality and body image</td>
<td>Physical affection, comfort and security is important. Patients can feel sensitive about how they appear to others and observe their reactions. They may feel</td>
</tr>
<tr>
<td>Fear of pain and the process of death</td>
<td>Regular review of pain management is essential. Patients need to feel confident that their pain will be managed well. It is important to consider the balance between effective pain management and the patient’s level of awareness; some patients may opt for less pain relief so that they can stay more alert. If there is an opportunity to “say goodbye to loved ones who have gathered together, it may be possible to plan and coordinate that at a time when the balance between adequate symptom control and clarity of thought and communication is optimised.</td>
</tr>
<tr>
<td>Existential and spiritual concerns – life meaning and unfinished business</td>
<td>Ask: “Tell me about your life?” Which parts stand out to you as being important? What has been your greatest accomplishment? How would you like to be remembered?</td>
</tr>
</tbody>
</table>
Actively listen and encourage reflection. Explore unfinished business. Ask: 
“Are there things that you felt you left unfinished?” Maybe we can write a list and work out which to prioritise?” Facilitate contact with religious ministers, pastoral care workers or spiritual leaders if desired.

<table>
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<tr>
<th>Practical Concerns</th>
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<tbody>
<tr>
<td><strong>Medical care</strong></td>
</tr>
<tr>
<td><strong>Financial/legal matters</strong></td>
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<tr>
<td><strong>Funeral arrangements</strong></td>
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</tbody>
</table>
funeral director, how to manage financial matters and the availability of community-based support services, can be provided verbally or via printed materials. Information can be given to a key contact person such as a family member who is a little more detached from the intense grief of the immediate family.

<table>
<thead>
<tr>
<th>Bereavement</th>
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<tr>
<td><strong>Common Responses following the death of a loved one and strategies to help</strong></td>
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<table>
<thead>
<tr>
<th>Comment</th>
<th>Response</th>
</tr>
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<tbody>
<tr>
<td>“I shouldn’t feel sad, she’s not suffering anymore.”</td>
<td>Whilst it is valid to express relief that the patient’s suffering is at an end, the very raw emotions of the loved ones need to be acknowledged. For example: “I know her suffering is over but it is not surprising you feel so terrible. Feeling so distressed and lost is normal – you were so close,” or “Yes, she may now be in a better place, but you are not. For her the suffering is at an end, but for you, the pain is intense.”</td>
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</table>
| “I didn’t do enough for him before he died.” | Don’t be dismissive of comments and be quick to respond with, “of course you
| "I feel bad that in the last few months I secretly hoped it would all be over." | were a good daughter’’ or ‘’no-one could have done more than you did.’’ |
| I wish I had been a better wife/husband/daughter/son/parent’’ | It is more helpful to draw out specific instance of what makes them feel that they weren’t good enough or didn’t do enough. Encourage them to reflect upon the aspects of their relationship in which they were “good enough” and fulfilled their caring responsibilities, acknowledging the enormity of the caregiving load and limits on individuals. |
| “I don’t know how I’ll cope – we’ve been together for thirty years. We did everything together.” | If feelings of remorse or self-doubt appear to be entrenched, strategies such as suggesting that the loved one write to the deceased may be a useful therapeutic tool in permitting self-forgivingness and giving permission to move forward. |

(MacDonald & Hobbs, 2008, p. 166 & 170).
Appendix L: Illustration of Ecological/Systems and Human Rights in Palliative Care

**Bronfenbrenner’s ecological/systems model including a human rights perspective**

<table>
<thead>
<tr>
<th>Microsystem</th>
<th>Mesosystem</th>
<th>Exosystem</th>
<th>Macrosystem</th>
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</thead>
<tbody>
<tr>
<td><strong>The Palliative Client</strong></td>
<td>The individual’s personality, coping mechanisms will impact the situation, combined with the strength of the microsystem. Immediate family – meet daily care needs. Certain family members will require psychological, emotional, Interactions between spouse and nurse about patients progress. Different family members try to support each other away from the palliative client. For example – a daughter takes mother (carer) to lunch and a movie. Interactions</td>
<td>The existing social workers have stretched workloads and not particularly trained in palliative care. The amount of social workers are based on historical issues and existing policies.</td>
<td><strong>Access to Psychosocial Support is a Human Right</strong> On Dec 10th, 1948 the General Assembly of the United Nations adopted and proclaimed the Universal Declaration of Human Rights. Article 25.1 states access to necessary social services is a human right – this is currently not embedded in federal health.</td>
</tr>
</tbody>
</table>
social, spiritual and cultural support as they become fatigued.

Friends and neighbours – meals, assistance with travel, respite, emotional support, social support

The General Practitioner provides
 * Medical care
 * Deems capacity status
 * Referrals to other disciplines
 * Seeks advice from Specialist team in regional area

Blue Care nurse who comes daily and provides
 * Medical support
 * Respite
 * Addresses some psychosocial needs to the best of her ability

The local church provides
 spiritual and practical support (this is not a guarantee)

Local volunteers assist with yard

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<tr>
<th>Spouse</th>
<th>Social worker</th>
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<tr>
<td>and</td>
<td>about</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>issues and practical concerns</td>
</tr>
<tr>
<td>Nurse, social worker and other stakeholders attend case conference to develop care plan and support family</td>
<td></td>
</tr>
<tr>
<td>Blue Care discuss patient at own case conference and develop care plan</td>
<td></td>
</tr>
<tr>
<td>Blue Care nurse liaises regularly with GP regarding medications, progress and family coping.</td>
<td></td>
</tr>
<tr>
<td>Both Blue Care nurse and social worker liaise with GP when necessary</td>
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<tr>
<td>Spouse liaises with her work and arranges time off from work to take on carer role</td>
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<tr>
<td>Social worker assists spouse with a carer allowance</td>
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PEPA programs are implemented to train medical and allied health staff in end-of-life issues and can come to local area and train medical staff

Funding is delegated to 16 health districts (not including Child Health). Palliative care falls under the sub-acute category and funds do not always end up for palliative care in the local area

There is a three month criteria to access palliative care funds which causes angst to front line workers and is exclusive

In 2012 an inquiry was requested by the Legislative Committee to report on palliative care services in QLD –

Policy.

Australia does not generally agree to be bound by a human rights treaty unless it is satisfied that its domestic laws comply with the terms of the treaty. Australia has agreed to be bound by the International Covenant on Civil & Political Rights and the International Covenant on Economic, Social, & Cultural Rights (Aust. Human Rights Commission 2014).

Commonwealth funding for palliative care is part of two health agreements with the Australian states/territories.

Funding for palliative care falls under the “sub-acute” category, along with rehabilitation, sub-acute mental health, psychogeriatric services and geriatric...
work, maintenance, meals etc.

Skilled social worker who is in regular contact and offers psychosocial support when she can. Social worker has a vast distance to travel so interactions are fortnightly or over telephone.

Palliative client has strong feelings of loss and deeply questions the meaning of this life. Nobody asks about this and so he/she keeps these concerns to themselves. Family are struggling to cope – the palliative client can sense he/she may not be able to die at home as hoped.

Nurse feels stressed as the palliative client has lived past the “three months” and the PCP funding has run out – this is discussed at case conference and other avenues of funding are explored.

Nurse and social worker both do not enquire about spiritual/existential or psychological concerns to any depth.

Conversations begin to take place with client, family, GP, Blue Care nurse and social worker about where patient will die.

GP does not see many palliative clients and is unsure about his decisions. His training in this area is minimal – he relies on the nurse and needs to call the specialist service situated hundreds of kilometres away for advice.

Significant gaps were identified which are currently being reviewed.

Qld does not have a state-wide strategy to ensure equitable funding. Funding for palliative care does not often end up in rural districts.

Before effective palliative care service provision planning can take place a needs assessment should happen first on local levels. This has not occurred to date.

More monies need to be provided to increase funds to the Patient Travel Subsidy Scheme.

There is minimal public transport in evaluation and management.

In the Inquiry on both state and federal levels, there have been recommendations to ring fence palliative care out of the sub-acute category as the funds often end up in other areas and not palliative care. No progress to date on this recommendation.

The Independent Hospital’s Pricing Authority (IHPA) primary function is to establish the National Efficient Price. The IHPA will also develop the criteria for those services that will still receive block funding rather than Activity Based Funding.

The National Palliative Care Program funding provides $8.1 million per annum along with sub-acute funds.
<table>
<thead>
<tr>
<th>area the client lives</th>
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<tr>
<td>No universal 24/7 afterhours support staffed with medical and allied health professionals in the local district</td>
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<tr>
<td>No universal structured bereavement strategy in the community to assist bereaved family members</td>
</tr>
<tr>
<td>Blue Care Nursing service is a dominant in-home healthcare provided but are governed by funding constraints</td>
</tr>
<tr>
<td>Palliative care is provided in the following settings: Hospitals Residential Aged Care Facilities Home Hospice - all with varying funding arrangements – ie: HACC, DSQ etc. The</td>
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<tr>
<td>Death and dying are not openly talked about in political forums highlighting the fact that Australia essentially is a death denying culture</td>
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<tr>
<td>The need to be “tough” and “stoic” are part of rural culture</td>
</tr>
<tr>
<td>No significant public education schemes on what palliative care can offer.</td>
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<tr>
<td>criteria for funding varies from district to district</td>
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</table>
Appendix M: Illustration of Service without Social Work Input

**Without social work input**

Sub-Acute funding does not always get fairly distributed to rural and remote areas.

Nurse organizes ACAT for respite/services and tells family to get affairs in order - spouse becomes full time carer.

GP, nurse and spouse regularly discuss progress.

Nurse emotionally supports family to the best of her ability – does not tell family about social worker as she is perceived as not skilled in palliative care or is too difficult to access.

Nurses utilise available local PCP funding, may need to use HACC or DVA funds.
Appendix N: Illustration of Service with Social Work Input

**With social work input**

Sub-Acute funding does not always get fairly distributed to rural and remote areas.

Nurse organizes an ACAT assessment for respite and services.

Nurses utilise available local PCP funding, may need to use HACC or DVA funds.

GP, Nurse, Social Worker and spouse discuss progress.

Social worker undertakes thorough psychosocial assessment and orchestrates interventions accordingly. She provides psychological, emotional, spiritual and existential support (or may refer for this). She partakes in regular family meetings and discusses coping mechanisms and checks on how different family members are managing as well as supporting the client. She also assists with paperwork for Centrelink regarding carers payments etc. and other pragmatics. She follows up with the family after the death and continues with bereavement support.