PALLIATIVE CARE FOR AN AGEING POPULATION:

A RURAL BASED MODEL?

Or,

"For whom the bell tolls"

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Abstract

Statistics show that Australia has an ageing population which will experience radical changes over the next 50 years due to the progression into retirement of generations born in the 'baby boom' years (1945-1965). Statistics also show that the proportion of Australian people over 65 is increasing and, as the majority of deaths occur in this age group the demand for palliative care, or care of the dying, is also likely to increase. Many retiring baby boomers looking for a sea change, gravitate towards coastal and rural areas may well be contributing to Foskey's (1998) notion of 'Aged Care Ghettos' where these areas may not have the desired infrastructure to deal with an increased demand for health services including palliative care services.

An increasing focus on, and public interest in palliative care research will likely emerge in keeping with the changing needs of an ageing population. It will become particularly important that relevant research undertakings are initiated to establish a clearer understanding of the issues and problems surrounding palliative care. At the present time there exists a limited research base in relation to palliative care and related services in Australia. While there has been a concentration of palliative support services in urban settings this has not been the case in rural based settings. Palliative Care Australia (2000) reported that half of the people receiving palliative care in Victoria in 1997 died in rural and regional areas, which may be attributed to harsher living environments, poor access to health services, specialists, and health professionals, lower socio-economic status and employment levels, and exposure to occupational hazards.

This thesis is concerned with examining palliative care services and related needs in a selected rural area within the Australian state of Victoria. The overall aim of this research was to investigate the availability of palliative care services, trends in ageing and to examine the relationship between the two.

Methodology used in this research incorporated a sequential mixed methods approach of quantitative and then qualitative methodology to determine the relationship between the needs of an ageing population and rural palliative care service delivery in Australia. The data collection included demographic statistics from the Australian Bureau of Census and Statistics and Palliative Care Australia, and were used for descriptive purposes to inform and support this research. Other ordinal data were obtained using a questionnaire. These data were analysed in the context of the research. Qualitative data were obtained through interviews with focus groups. The Gippsland area provided an excellent area for this research and the findings of this research would appear to be consistent with the literature relating to access and equity issues faced in rural areas. Other rural areas may replicate the data gathering used in this research.

A number of conclusions are able to be drawn from this research based on the review of literature and examination of the emerging issues, results and findings. Statistical projections into ageing indicate that the health of all Australians will have significant consequences for our society as we generally live longer and healthier lives. Health and ageing predictions and projections should prompt key stakeholders including baby boomers, the aged cohorts of the future, to plan and prepare, perhaps redefining ageing in the attempt. Findings further show that

planning should include preparations for the expected rise of dementia related diseases and the implications of gender on health which will have ramifications for an ageing population, and in particular for women as carers in our society.

As a result of this research recommendations are made for a model for the delivery of palliative care services in rural areas, which is specific to the needs of an ageing population. These recommendations are made in acknowledgement and with respect and consideration for the concerns of the rural community where feedback from focus group participants suggests that rather than another 'model', a hospice is what is needed to meet the current and future needs of rural communities. "Another 'Model' is the last thing we need, it's not the how we are doing things, it's the where – we desperately need a hospice down here" and, "It's bricks and mortar we want down here, not more theories". Evidence collected from this research also suggests that a 'rural attitude' to death and dying may prevail. In its simplest form, this attitude emerges in statements such as: 'it's the country you expect to get less' and 'we just look after our own when we can'. It is also apparent that while people in rural areas have the same medical and palliative care needs as those in metropolitan areas, this research shows that they are differentially disadvantaged when it comes to accessing palliative care services. This research has found that *a negative relationship exists between ageing trends in a selected rural area of Australia chosen for this study and the availability of palliative care services.*

Student Declaration

"I, Kerry Ryan, declare that the PhD Thesis entitled For Whom the Bell Tolls is no more than 100,000 words in length, exclusive of tables, figures, appendices, references and footnotes. The thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work".

Signature: Date:

thirst for knowledge exceeded only by their genuine desire and joy in sharing that knowledge. I learnt from you all that age has no boundaries, that ageing can be fun, that the learning can go on and can be shared but most of all you have confirmed for me that it's not about 'how old we are' it will always be about 'who we are.'

Kerry Ryan

February, 2007

Dedication

To my husband John, and daughter Emily, who have allowed me to indulge in my philosophy 'if you can dream it you can have it'.

To Shirley, who will always stay with me, and,

To all those people without whom, this research would have no purpose - those who have gone before us and, for whom the bell has already tolled.

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Chapter 1: Introduction

"The fields of youth are filled with flowers,
The wine of youth is strong:
What need have we to count the hours?
The summer days are long.

But soon we find to our dismay
That we are drifting down
The barren slopes that fall away
Towards the foothills grim and grey
That lead to Old Man's Town

And marching with us on the track
Full many friends we find:
We see them looking sadly back
For those who've dropped behind.

But God forfend a fate so dread-
Alone to travel down
The dreary road we all must tread,
With faltering steps and whitening head,
the road to Old Man's Town."

(The Road To Old Man's Town, From: The Collected Verse of A.B. Patterson: Australia: 1923, p. 224, Angus & Robertson Ltd.)

This poem by "Banjo" Patterson offers reflections on ageing and death, and the inevitability of a "….road we all must tread". And, perhaps even though more grim, John Donne (1624) also alluded to the "road we all must tread" when he decreed "Never send to know for whom the bell tolls, it tolls for thee" (The Columbia World of Quotations, 1996, Devotions Upon Emergent Occasions, Meditation 17).

Australia has an ageing population with the proportion of people over 65 increasing. The Australian Institute of Health and Welfare (AIH&W) (1998) reports that in 1960 it was estimated that 5 percent of Australians were 65 or over. The 1996 census estimated an increase to 12 percent, a figure that is projected to

increase to 16 percent by 2016. The literature supports the notion that we are living longer than our predecessors, although there is an ongoing debate about whether living longer necessarily means living healthier. Fries (1980, 2002) postulated that over this century we have witnessed a compression of morbidity whereby we live healthier until we die. Others have questioned whether there has been a reduction in disability rates in old age (Myers and Manton, 1984). The 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers noted that, of all people aged 60 years and over, less than half (41%) reported needing assistance with a disability or old age. Those aged 85 years and over did report a much higher need for assistance.

Nevertheless, our journey will also end, and as the majority of deaths occur in the 65 and over age group the demand for services for an ageing population and/or palliative care or care of the dying can also be expected to increase. It is acknowledged that although Australia is an ageing population, not all persons who are aged will require palliative care. It is also acknowledged here that whilst this thesis investigates palliative care for an ageing population, recognition should not be denied for younger cohorts who may also be in need of this type of care and these services in a rural area.

In medieval times, people who were dying were cared for along with the sick and infirm. Institutions where caring and comfort took place were referred to as 'hospices', where the primary concern was not necessarily for the person who was dying. A more modern use of the word *hospice*, which is used to describe the place where people go to die, began to emerge in 1842.

The topic of death was seen as taboo well into the 1960's. Dr. Kubler-Ross in her studies on grief may have been largely responsible for developing a societal "awareness" toward death. Her first book titled On Death and Dying (1969) which was re-published in 1973 sought to break down the barriers of denial which had previously prevented patients from discussing their concerns. Simultaneously, with the development of technology and changing times, medical research turned to the investigation of the death process – a study known as 'thanatology'. This in turn has led to the development of *palliative care* or care of the dying.

The concept of *living until you die* is grounded in the philosophy of ensuring quality of life until death and is central to the inception of the modern hospice movement. Concepts about the physical, psychological, social and spiritual aspects of care provides the foundations for palliative care, or, care for those whose condition is no longer curative.

Contemporary philosophy and ensuing work in palliative care may be attributed to Dame Cicely Saunders who was a driving force in the formation of St. Christopher's Hospice (London) in 1967. The modern hospice movement began as a model of palliative care delivery in an inpatient environment. Since then, services have developed and expanded over the past 30 years to include other settings such as hospitals, home care, community settings and nursing homes. Development in the area of palliative care has continued to the day, philosophically, that the dying person is recognised as a unique person who is assisted to live fully by maintaining family and other significant relationships, and who can still hold on to hopes and expectations, and to those deep and personal

meanings that can assist in ending life with a sense of dignity and completion (Doyle, Hanks and MacDonald, 1993). Standards and principles of palliative care as determined by key stakeholders Palliative Care Australia in their Strategic Plan 2003 – 2006 reinforce this philosophy.

According to Maddocks (2003), Australia leads the rest of the world in developing this relatively new discipline of palliative care. He attributes this to the mutually supportive relationship among the diverse centres for delivery of palliative care and the high level of Government interest and support for palliative care initiatives (Maddocks, 2003). The provision of palliative care in Australia is at the centre of ongoing debate, perhaps in line with the heightened euthanasia debate. Palliative care has come under scrutiny by governments, so that funding and accountability have become central issues. The concept of unlimited growth of funding for palliative care in Victoria for example, may be seen as uncertain, especially at a time when governments are attempting to reduce health care budgets. It has therefore become necessary for palliative care providers to deliver hard empirical research to justify professional claims for additional resources and services. This is especially so in rural environments where the main provision and understanding of palliation rests with nursing staff. A shortfall in specialists and doctors in rural areas leads to a reliance on nursing and care staff to provide essential palliative care services. This in turn creates education and training ramifications for the up-skilling of nurses in rural, or more isolated areas where the infrastructure is limited and access to services is either distant or where strain is often put on resources and services in larger neighbouring towns. Although palliative care education is provided in rural areas, nurses and carers experience access difficulties due to

either the lack of staff to backfill their positions whilst they undertake the training or lack of funding or, simply the tyranny of distance.

Residents of nursing homes are more often than not nursed and cared for until their death, as it is the nursing home environment which is thought of as the home of the resident. In circumstances where the needs of the dying resident are considered too complex, they may be sent from the nursing home to die in hospital. The benefits of palliative care are not only restricted to the terminal or dying phase. Residents have the right to expect the delivery of high quality palliative care, where the principles and standards of palliation are known and practised. It is acknowledged that not all residents in nursing homes will require palliative care, however some may, and if this is the case nursing staff need to be able to provide such care. Palliative care nursing is identified as an area of skill shortage in every state of Australia (Cairns and Yates, 2003). An ageing population will place increasing demands on all health professionals including general practitioners, who already are required to be proficient in many areas as well as palliative care.

With extensive changes in the healthcare delivery in the Australian environment, focus has shifted to the *needs* of the client, especially in the area of palliative care as outlined by Palliative Care Australia in their Strategic Plan 2003-2006. Palliative Care Australia (PCA) is the national peak body for palliative care in this country. Their goal is to work toward the relief of pain and suffering of people who are dying and the provision of their care. However, the palliative care needs of elderly people who are not dying of cancer and who present with less clearly defined prognosies and care needs may not be adequately met. Recent changes

have seen a greater expansion of community services available to terminally ill people in recognition of the client's wishes to remain at home for as long as possible. Metropolitan community services include home hospice and the Royal District Nursing Service (RDNS) which is a community based nursing service in the State of Victoria. Rural service providers such as the RDNS and Home and Community Care programs experience some unique problems in meeting the needs of their community in assisting someone to die at home. Nursing staff, carers, doctors and volunteers can expect to travel long distances in often inhospitable conditions, where mobile phones are inaccessible. For these palliative care workers, there are issues resulting from 1) the reality of often having to work alone, and 2) being unable to debrief their experiences as they will travel long distances between clients. Grief and loss issues are therefore put on hold for several hours or, several hundred kilometres until they can return to the office and receive the support from other team members.

1.1 Background to the Research:

As part of the 1999 International Year of the Older Person, which was initiated by the United Nations, the Australian Council on the Ageing made 12 recommendations to the Federal Government for the 1999-2000 budget. One recommendation was that health care services include improved access to palliative care for ageing populations (Council on the Ageing: Valuing Older Australians: 1999-2000: Federal Budget submission: Strategic Ageing vol.7/99).

Access to palliative care services may be restricted for many reasons; the tyranny of distance representing an obvious obstacle. Rural life can almost be defined by the need to travel long distances, through sometimes inhospitable terrain. Based on definitions suggested by Wilkinson and Blue (2002) and for the purpose of this research, *rural and remote* refers to those areas which do not include capital cities and the major metropolitan centres of Australia.

Social, political and demographic differences occur between rural and metropolitan communities. The limited availability of health services and related infrastructure can also define rural lifestyle, and there are some remote areas (rural and regional such as, the Northern Territory and parts of Queensland) where palliative care services are either limited or non-existent.

Victoria is the second most populous State in Australia, with a population of 5,022,346. Of this figure, 13.5% is over the age of 65 years (ABS, 2005). Situated in rural Victoria is the rural electorate of Gippsland Province (population 249,614) which includes the districts of Gippsland East, Gippsland South, Morwell and Narracan which would provide for some, the ideal retirement environment, due to its many idyllic tourist attractions and coastal retreats. ABS (2005) showed that almost 17% of this population is over the age of 65 years. Social, political and demographic differences as well as specific environmental health related factors such as asbestos related illnesses found in this area provide strong arguments for an increase in the need for palliative care services if not now then in the near future. For these

reasons, Gippsland in rural Victoria was chosen as the designated area for the focus of this research.

The 'baby boomers' cohort has been used in this research as they are largely represented within our ageing population. This cohort will have an impact on the demand, growth and type of services, much as they have redefined other life stages.

> Look back at the baby clinics of the 50's, the proliferation of primary and secondary schools and the increase of university and other tertiary facilities in the sixties all are a direct result of the boomers. Boomers and their love of any new technology fueled the technology explosion. Remember this was the generation that cut their teeth on television. (Baron 2000, p.30).

The baby boomers may also be expected to redefine what it is to age. Dychtwald and Flower (1990) concurred stating that "the boomers redefine whatever stage of life they inhabit" (Dychtwald & Flower 1990, p.20). They will become the new grey-haired society and will approach retirement with a vengeance possibly changing the nature of the journey along "the dreary road we all must tread" as referred to by Patterson (1923: p.224). The baby boomers will almost certainly wish to travel *another* road. They will be sure to shun any idea of a 'use by date', will refuse to grow old, and will re-shape aged care as it is known today. There may also be a desire for a revision of existing palliative care 'models' and services, with specific regard to the

ageing phenomenon and, especially with the penchant of the baby boomers to do things differently. With this penchant to be different, baby boomers choosing to retire in rural areas or looking for a sea change will also have an impact on existing palliative care services and possibly the direction of future services. Areas which are experiencing high retirement and residential aged care growth need to be proactive in preparing for the demands that this growth will bring, such as the need for palliative care services or care for those who are dying. Foskey (1998) noted that, in particular, rural coastal areas are experiencing high population growth among older age groups who are now seeking these areas as retirement destinations. Foskey states that:

> "In retirement areas decisions made on housing style and location when people are in their 'third age' or early retirement can result in greater dependence on services for care and support." (p.5)

Greater dependence on care and support by an ageing population which is unaware of, or is lacking in knowledge of the benefits of palliative care in rural communities may also have an association with the lack of services. It may also not be unreasonable to argue that people's attitudes, including those of the baby boomers, about death and more particularly, ageing in rural areas will impact on the demand for palliative care services. Ageism and attitudes to ageing impact on both the care provided and the care received by older people. A sense of 'there's nothing else to be done', or, 'they shoot horses don't they' may well prevail within rural and regional cultures.

People who wish to die at home including those who are now living in nursing homes, may be disadvantaged in rural and regional areas where access to palliative care service is limited or distant. By analysing ageing population trends it will be possible to predict palliative care demands and needs in targeted areas. There is a need to determine the wishes and needs of an ageing population residing in, or migrating towards these rural and regional areas. In addition. there is a need to determine the 'ideal' mode of delivery required for palliative care service provision to these areas, that needs to be a proactive approach to future planning for the anticipated aged care boom which is expected.

1.2 Problem Statement:

At the present time there exists a limited research base in relation to palliative care and related services in Australia. With the ageing of the Australian population it will become particularly important that relevant research undertakings are initiated to establish a clearer understanding of the issues and problems surrounding palliative care. While there has been a concentration of palliative support services in urban settings this has not been the case in rural based settings. This thesis is concerned with examining palliative care services and related needs in a selected rural area within the Australian state of Victoria.

The purpose of this research was to investigate ageing trends and palliative care needs in rural and regional Australia. Essentially I have argued that any model of palliative care delivery should now incorporate the needs and the wishes of an ageing population, in keeping with our changing demographic trends. I propose that models of palliative care service delivery to rural areas throughout Australia should also encompass the needs of an ageing population, including the baby boomer cohort by virtue of their penchant to be different, and their increasing polarization to rural and coastal areas. The research focus underpinning this thesis is, *"To select a major rural area for the purpose of investigating the availability of palliative care services, trends in ageing and to examine the relationship between the two"*.

I have addressed the preceding research focus by describing ageing trends in Australia and in particular rural and regional Australia and the chosen designated area for this research which was Gippsland in rural Victoria. An overview of palliative care is provided incorporating predictions for the demand for palliative care. Parameters of good practice for palliative care service provision in a rural area are identified, and recommendations are proposed which incorporate the needs and wishes of an ageing population, and which may be adapted to other rural areas. The impact of baby boomers on the ageing phenomenon is addressed along with ageism and attitudes to ageing and death and dying. A major rural area was selected for investigation in support of the research focus.

1.3 Justification for the research:

The research aims to raise the awareness of palliative care service provision in rural Australian communities and to ultimately promote the principles of palliative care with specific regard to the rapidly increasing demands of an ageing population. In so doing,

- The profile of palliative care needs in rural areas will also be raised.

- The research will benefit Australia's ageing population by raising their awareness of palliative care options. This will include the needs of baby boomers, the aged cohorts of the future, who will potentially have input into the design of future rural palliative care services. This could have a significant impact on aged care policy as well as on the retirement industry.

- The research will provide recommendations for palliative care models to incorporate the needs of an ageing population in a specific rural area which could be adapted to other rural areas.

- The research emphasises the need for a collaborative approach between palliative care providers including doctors, and other health professionals.

It is also perceived that this research will provide information for future directions for the rural health industry in Australia, as well as policy development for an ageing population.

1.4   Methodology:

This section provides a brief overview of the methodology used in this research, and is discussed in more detail in Chapter 3 of this thesis. Basically, the research used a sequential mixed methods design by firstly conducting the quantitative phase followed by the quantitative phase to determine the relationship between the needs of an ageing population and rural palliative care service delivery in Australia. Tashakkori and Teddlie (1998) noted that by using a sequential mixed methods approach clearer assumptions may be made between two distinct paradigms.

The research questions driving this research were:

- *What are the health and ageing trends in Australia?*

- *What are the palliative care demands and needs of an ageing population in a rural area, and are they any different to those in a metropolitan area?*

- *Would an ageing rural population be disadvantaged if and when they need palliative care?*

- *Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?*

- *Who will impact on the design of palliative services and make decisions for an ageing population?*

- *What would an ageing rural population want included in a palliative care service? - and what do the service providers want/need?*

- *Is there a lack of knowledge and understanding of palliative care in rural areas?*

- *To select a major rural area for investigation in support of the research focus.*

The data collection includes demographic statistics from the Australian Bureau of Census and Statistics and Palliative Care Australia, and was used for descriptive purposes to inform and support this research. Other ordinal data were obtained using a questionnaire. These data were organised and analysed in the context of the research. Qualitative data were obtained through interviews with focus groups.

The research was conducted in 5 stages:

Stage 1: Demographic data were collected from The Australian Bureau of Census and Statistics to establish ageing trends in Australia and in particular rural and regional Australia. These data were contextualised with further data obtained from Palliative Care Australia. Predictions for the demand for palliative care are also presented. This stage provided the underpinning of the statistical data for this research.

Stage 2: A 'tool' was designed in the form of a questionnaire to investigate ageing attitudes to palliative care. This has provided ordinal data to determine the future needs and wishes of people from the targeted areas who may require palliative care. As the review of the literature did not produce an 'attitudinal' questionnaire suitable for this research, one was developed by the researcher. The questionnaire was developed using the expertise of palliative care service providers and focus group members. It was proposed that the

results of the questionnaire would establish a level of palliative care "awareness", and would basically elicit "attitudes" to palliative care. Specific questions relating to the place of birth were asked in order to establish any rural origins. The questionnaire also sought information on attitudes toward ageing. Likert-type scales were used and Cronbach's Alpha which is a tool for assessing the reliability of scales was used for testing the reliability of items. The questionnaire was piloted to determine the internal reliability of questions, the time needed to complete the questionnaire and the ease of its facilitation.

A survey was conducted by firstly applying the piloted questionnaire to a sample of ageing members from the University of the Third Age (metropolitan). In order to identify a 'rural attitude', the survey was then conducted in a designated rural area using a sample of ageing members from the University of the Third Aged (Gippsland). University of the Third Age (U3A a worldwide organization) is a learning co-operative of older people that encourages healthy ageing by enabling members to share many educational, creative and leisure activities.. The responses from both rural and urban participants were compared using the SPSS computer program (version 11) for analysis. Mann-Witney U (1-tailed) tests were applied to compare the two separate groups. Kruskal Wallis tests comparing ordinal data between variable groupings were further applied to determine differences between groups. Secondly, interviews with a total of five focus groups were conducted.

According to Patton (1990) focus group interviews are typically based on homogenous groups, and involve conducting open-ended interviews with groups of five to eight people on specifically targeted or focused issues for about one to two hours.

The point here is that sampling for focus groups typically involves bringing people together of similar backgrounds and experience to participate in a group interview about major program issues that affect them (p. 173).

Subjects for these focus groups were obtained from approaching local baby boomers, as well as key health informants, including palliative care nurses, community workers, and local council representatives. Welch, Power, Kamien & Waddell (1994) have established that by interviewing a small group of key health informants, 80% of the information on health issues in rural communities can be obtained. Data obtained from this stage of the study were analysed using a qualitative methodology.

Stage 3: In stage three of the research, information was obtained from the National Inquiry into the Social Impact of Caring for Terminally Ill People initiated by Palliative Care Australia and this has been contextualised for the purpose of this research and was used to inform stage 4. The Inquiry sought to gather policy, opinions, experience and research related to the social impact of unpaid caring for the terminally ill. Submissions and contributions came from individual carers and service providers.

Stage 4: - Proposes recommendations for the development of a 'model' for rural palliative care delivery which incorporates the wishes and needs of an ageing population.

Stage 5: - Information containing recommendations for a model of service delivery in a rural area will be presented in the form of a report. This report would be suitable for palliative care service deliverers, especially rural providers, and will have specific emphasis on the needs of an ageing population.

The Methodology used in this research is discussed in more depth in Chapter 3.

1.5   Outline of this thesis:

This section will outline a brief description of the Chapters used in this thesis.

Chapter 1: Introduction

The broader field of this research is outlined in this chapter and establishes the research problems and aims which have underpinned the direction that the research has taken. The chapter outlines the justification for this research and gives a brief summary of the methodology which was used. Definitions used throughout the thesis are offered and delimitations of the scope of the research are provided.

Chapter 2: Literature Review.

In this chapter, a literature review is provided that attempts to provide a theoretical framework upon which the research is based, and is guided by the stated aim and research problems. Health and ageing demographics including rural issues for ageing populations are presented as well as literature on attitudes toward death and dying. The impact of the baby boomers within the context of an ageing population is also presented. The chapter further outlines the discipline of palliative care, models of palliative care and the importance of this discipline within an ageing population phenomenon, and research issues are further developed and explored.

Chapter 3: Methodology

This chapter describes the major methodology used to collect data that is used to answer the research questions. A detailed description of the Pilot Study is also presented. Chapter 3 further provides an outline of ethical considerations used in this research.

Chapter 4: Analysis of data

Research findings are analysed and presented in this chapter.

Chapter 5: Conclusions and implications

In this chapter conclusions about the research questions are summarized and explained from chapter 4. The research implications are explored and the contribution of this research to the body of knowledge is examined.

Limitations to the research and implications for further research are also presented.

1.6 Definitions

The key and controversial terms used in this thesis are defined in this section to establish the positions taken in this research.

Ageism: refers to the stereotyping of people on the basis of age.

Baby Boomers: refers to Australian residents who were born in Australia or overseas during the years 1946 to 1965, and also includes immigrants to Australia from countries which did not experience a post-war baby boom.

Cancer: is a term given to several diseases which result when the process of cell division, by which tissues normally grow and renew themselves, becomes uncontrolled and this leads to the development of malignant cells (ABS: 1995).

Community health: According to Hertzman (2001), *community health* occurs when there is a commitment by the community to work towards assisting the health and well-being of individuals, families and groups.

Disease: may be defined as a disturbance in structure and/or function of any part of an individual. Diseases may be classified according to their cause, the way in which they are acquired, or according to the body system which is affected. (WHO, 1992)

Elderly: WHO defines those aged 60-74 years as 'elderly', and those older as 'aged'. In terms of demographic ageing, the statistical figure given to the population in older ages is conventionally taken as 65 years and older.

Health: The World Health Organisation (WHO) define *health* as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 1992)

Morbidity rate: is the proportion of sickness/illness of a given population.

Mortality rate: is the rate at which members of a given population die.

Palliate: as to lessen or alleviate pain and suffering

Palliative care: For the purposes of this research, the *definition of palliative care* used will be that given by Australian Palliative Care in their Strategic Plan 2003-2006. 'Palliative care is specialized health care of dying people which aims to maximize quality of life and assist families, carers and their communities during and after death' (Palliative Care Australia, Strategic Plan, p.1).

People requiring palliative care: are those with an incurable illness and limited life expectancy and include people of all ages. (Palliative Care in Victoria: June 1995) This also includes people suffering from a terminal illness such as Cancer, AIDS, or other such diseases. People requiring palliative care also include those requiring *terminal* or *end stage care* and

incorporates the frail elderly who enter a terminal phase due to the ageing process.

Population ageing: According to McCallum and Geiselhart (1996), Rowland (1991), and Pollard and Pollard (1981) when the proportion of people over 65 increases, the population is said to be ageing. Healey (2003) stated that population ageing occurs when there is an increase in median age (the age that divides the population into two equal halves).

Rural: will mean everything that does not include capital cities and major metropolitan centres in Australia.

Specialist palliative care services: These services may accept prime responsibility for care, or work indirectly through advising clients' and professional carers. They provide physical, psychological, social and spiritual support and comprise a broad range of disciplines, including medicine, nursing, social work, pastoral care, physiotherapy, occupational therapy, pharmacy and related specialties.

The palliative care approach: aims to improve the quality of life of individuals facing life-threatening illnesses and their families, by preventing and relieving suffering through early identification, assessment and treatment of pain and other problems – physical, psychosocial and spiritual (WHO: 2003). This approach facilitates identification of the wishes of clients and

their families about care throughout a period of declining health and especially during end-of-life care.

1.7 Delimitations of scope and key assumptions

The research focus was *"to select a major rural area for the purpose of investigating the availability of palliative care services, trends in ageing and to examine the relationship between the two".* The 'scope' of this research was to investigate the palliative care needs of an ageing population in a designated rural area.

Delimitations specific to this research were manifested in the area of 'sampling'. Ultimately, sustaining sample numbers and participants for this research has been problematic largely due to the implications of the 'tyranny of distance', and the related limited numbers of the chosen sample to be found within the rural population. Sampling for both the Pilot Phase and the actual study came from ageing members of the University of the Third Age (U3A) both in metropolitan Melbourne and from Gippsland in rural Victoria. The use of U3A members for the sample in the Pilot phase, led to a depletion in appropriate numbers for the ensuing stages of the research. Members do not always attend meetings for many reasons including transport availability on the day, health reasons, or perhaps the topic of discussion. Accessing a larger sampling population was therefore problematic.

Whilst the overall number of key health informants who made up the focus group interviews was more than satisfactory, it was the occupational profile

of the health informants or service providers which was difficult to control. It was hoped to include a good cross section of palliative care nurses, social workers, carers, Occupational Therapists and doctors. The work demands of doctors in the designated area meant that they were not represented in the focus group interviews. Largely, focus groups were made up of nurses, allied health workers and social workers. Although interviews were well planned ahead, work demands of these workers were also difficult to gauge, there was always 'the greater need', and the 'unexpected call out to a dying person' which had a direct impact on the overall numbers of participating interviewees.

1.8   Conclusion

Chapter 1 has outlined the introduction for the thesis. It has introduced the research problem and raised other research questions to support the overall research focus. Then the research was justified, definitions were presented, the methodology was briefly described and justified, the report was outlined, and the limitations were provided. Based on these foundations, the thesis will now proceed to present a detailed description of the research.

Chapter 2: Literature Review

"The research focus is to select a major rural area for the purpose of investigating the availability of palliative care services, trends in ageing and to examine the relationship between the two".

Chapter 2 presents a literature review and exploration of the research issues and serves to provide a theoretical framework that incorporates demographic data for an ageing population. This review also includes the baby boomer cohort within the context of health and ageing, as well as relating to rural health. A review of the palliative care literature is also provided. As one of the objectives of this research was to investigate attitudes toward death and dying, a review of this literature is also included. Health and ageing trends will be discussed using ageing demographics which also provide an outline of morbidity and mortality rates specific to Australia. Metropolitan demographic characteristics have been provided by the City of Melbourne. Rural characteristics are representative of the Gippsland region. Ageing demographics will also consider the role of the baby boomers and the impact of 'ageism' on our ageing society. Details will be provided on palliative care in Australia, and models of palliative care with specific regard to rural palliative care and issues facing Gippsland. Death and dying issues for an ageing population will include grief and loss issues and the role of the carer in palliative care. Finally, several conclusions will be drawn from this chapter.

This Chapter begins by outlining the framework for this research and the construction of the literature review by stating the research aim and research problems, and how they were addressed, and are further represented in a 'Mind Map' shown in Table 1.

Research Questions:

- *What are the health and ageing trends in Australia?*

- *What are the palliative care demands and needs of an ageing population in a rural area, and are they any different to those of a metropolitan area?*

- *Would an ageing rural population be disadvantaged if and when they need palliative care?*

- *Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?*

- *Who will impact on the design of palliative services and make decisions for an ageing population?*

- *What would an ageing rural population want included in a palliative care service?- and what do the service providers want/need?*

- *Is there a lack of knowledge and understanding of palliative care in rural areas?*

The following (Table 1) represents a 'Mind Map' of the Research Focus and research problems and how they were addressed.

Table 1 'Mind Map' of Research Focus:

"to select a major rural area for the purpose of investigating the availability of palliative care services, trends in ageing and to examine the relationship between the two".

Research Questions	Address
1. What are the health and ageing trends for Australia? 2. What are the palliative care demands and needs of an ageing population in a rural area, and are they any different to those of a metropolitan area? 3. Would an ageing rural population be disadvantaged if and when they need palliative care?	• Demographic health and ageing • Palliative Care overview • Palliative Care demographics and Models • Palliative Care in Gippsland • Indigenous needs
4. Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?	• Death and dying in Australia • Attitudes to ageing • Rural attitude (Questionnaire)
5. Who will impact on the design of services and make decisions for an ageing population? 6. What would an ageing rural population want included in a palliative care service? And, what do the service providers want/need? 7. Is there a lack of knowledge and understanding of palliative care in rural areas?	• Baby boomer Cohort • Who are the Carers? • *(survey* and *focus groups)* • 'Models' of palliative care • What do people know of palliative care *(Questionnaire)* • What palliative care knowledge and skills are to be found in rural areas? *Discussion.*

2.1 Health and Ageing Overview

'Nobody grows old merely by living a number of years. We grow old by deserting our ideals. Years may wrinkle the skin, but to give up our enthusiasm wrinkles the soul.'' – Samuel Ullman (1840-1924) cited in (Platt, S: 1989, No. 2099)

(What are the health and ageing trends in Australia?)

Health trends in Australia are largely underpinned by guidelines as set down in The Declaration of Alma-Ata (WHO, 1978) (health for all by the year 2000) which came about after the 1978 World Health Organisation (WHO) Conference and called for:

Equity

Community participation and maximum community self-reliance

Use of socially acceptable technology

Health promotion and disease prevention

Involvement of government departments other than health

Political action

Cooperation between countries

Reduction of money spent on armaments in order to increase funds for Primary Health Care

World Peace

The driving force behind current health and ageing trends in accordance with WHO was the emphasis on living longer and healthier lives. Funnell, Koutoukidis and Lawrence (2004) acknowledged that due to technological developments and medical and scientific achievements over the last century, the world's population is generally living longer and healthier lives. Fries

(1980, 2002) also postulated that over this century we have witnessed a compression of morbidity whereby we live healthier until we die. Whereas others have questioned whether there has been a reduction in disability rates in old age (Myers and Manton, 1984). The 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers noted that, of all people aged 60 years and over, less than half (41%) reported needing assistance with a disability or old age. Those aged 85 years and over did report a much higher need for assistance.

Major disparities in health still exist for some of the world's population, with some countries still experiencing high population morbidity and mortality rates. It was in recognition of these disparities in world health that the World Health Organization (WHO) began its work towards achieving good health for all the world's population. According to Duckett (2000) there are definitional problems when defining health and he notes that there are many ways that health can be conceptualized. Health is generally understood to be an absence of disease or illness, and is thought to be a 'medical' model. A 'wellness' model of health on the other hand is a health promotion model and progresses towards higher functioning, energy, comfort, and integration of mind, body and spirit. Whereas an 'environmental' model of health looks at an adaptation to the more physical and social surroundings and seeks a balance free from pain or disability Duckett (2000, p.2). WHO defined '*health*' as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO 1992). WHO's definition of health is holistic in that it considers physical, psychological, cultural and

social factors. Variables such as politics, economy, social, cultural, environmental, behavioural and biological can all have an impact on health. Health then may be defined according to circumstances, context and perceptions and experiences, which may vary between individuals and between communities. Duckett (2000) noted that:

> While the breadth of this definition serves a useful political end in drawing attention to the positive nature of health, that same breadth may handicap measurement and, in turn, accountability for moving towards improvement in health status (p. 2).

Disease may be defined as a disturbance in structure and/or function of any part of an individual. Diseases may be classified according to their cause, the way in which they are acquired, or according to the body system which is affected (Funnell, Koutoukidis, Lawrence, 2004).

According to Hertzman (2001), *community health* occurs when there is a commitment by the community to work towards achieving the health and well-being of individuals, families and groups. This does not necessarily mean the community needs a vast number of medical services or an array of healthy lifestyle gurus and experts. Rather, healthy communities are those that feel empowered to shape their own destiny. They enjoy broad participation in health policies and in decisions that affect daily life; members of healthy communities are able to feel they have some control over the design and sustainability of the community's current and future potential. Hertzman's theory on community health assumes a cohesion and

collaborativeness whereby people feel a sense of control. This might arguably be nebulous for most rural communities, and for areas which are more isolated and remote and where high unemployment rates, and the attraction to major towns of people dependant on social security due to low housing costs may not portend to this healthy community ideology.

Issues of access and equity ideologies would appear to be particularly challenging for rural areas. In 1998, rural and regional residents throughout the country told the Human Rights Commission about their frustrations:

> This country 40-50 years ago was building physical and social infrastructure with far less rural population and far less GDP and government funding. Yet now we're being told the nation can't afford it. It's not possible to provide equal services everywhere. But Geraldton is close to Perth and a big city. Yet the services here are inadequate. If that's acceptable, three-quarters of the State is written off in terms of improving anything (Sidoti, 2000 cited in Wilkinson and Blue, 2002, p. 7).

As a response to growing expectations for a 'new public health movement' around the world, the first International Conference on Health Promotion was held in Ottawa, Canada in November 1986. The outcome of this Conference presented a charter for action to achieve "Health for All" by the year 2000 and beyond. This charter is known as the Ottawa Charter for Health Promotion.

The Australian Government policy on health activity began in the mid 80's. The Better Health Commission in 1986 formulated Australia's response to the *Health for All* by 2000 charter. *The Better Health Outcomes for all Australians* report (1994) represented the beginning of Australia's commitment to health goals and targets, carried through in several subsequent documents, including *Health Goals and Targets for Australian Children and Youth (*Child Adolescent and Family Health Service, 1992); *Goals and Targets for Australia's Health in the Year 2000 and Beyond* (Nutbeam et al. 1993); and *Better Health Outcomes for Australians* (Commonwealth Department of Human Services and Health 1994).

The health and quality of life of most Australians compares well with the rest of the world – with some significant differences in population sub-groups. "Poor socioeconomic status is the single biggest determinant of ill-health and death in Australia" (National Health Strategy, 1992, p.10). This is reflected in statistics of: sudden infant death syndrome, accidental drowning, motor vehicle accidents, other accidents, suicide, cardiovascular disease, respiratory disease and cancers. Gender and ethnicity are also seen as significant determinants of health chances in Australia. Mortality rates for males are higher than those for females. Men are also less inclined to seek medical assistance. Life expectancy in 1996 for males was 75.4 years, and for females 81.1 years. (Funnell, Koutoukidis, Lawrence, 2004). Females who are born in 2000-2002 can expect to live to 82.6 years and males to 77.4 years (ABS, 2004).

While many migrants have better health on arrival than the average Australian because of the requirements of the immigration process, this advantage soon disappears the longer they have been in Australia because of the decline in job opportunities, different health habits of their country of origin, and a lack of social support (Funnell, Koutoukidis, Lawrence, 2004).

Campbell, Moore, and Small (2000) note that "With migration and settlement in new countries, complex cultural shifts may occur" (p 69). These writers allude to the notion that cultural patterns influence health beliefs and may be seen as an accumulation of inherited knowledge and traditions. McMurray (2003) agreed referring to culture as a complicated integrated system that includes knowledge, beliefs, skills, art, morals, law, customs and any other acquired habits of a group of people. She believes that cultural beliefs explain diet and eating habits, child-rearing practices, reactions to pain, stress and death. She also believes that cultural beliefs give people a sense of past, present and future, and can explain responses to health care services and practitioners (McMurray, 2003). Similarly, Campbell, Moore, and Small (2000) acknowledged that the need to consider culture in understanding health beliefs and client behaviour is not enough, rather culture needs to be seen in context and in conjunction with socio-economic status, education, length of residence and the impact of historical events.

Reid, and Trompf (1991) remind us that while Indigenous Australian culture is embedded within a spiritual connection with the land, it must also be understood that Aboriginal people have many subcultures, speak many

different languages, have varying religions and healing practices, diets, traditions and communities. At the 2001 census, Indigenous Australians comprised 2.4% of the total Australian population – double the proportion identifying themselves as Indigenous in the 1986 census. Some Indigenous Australians live in rural or remote communities, but many live in urban centres, primarily in Queensland and New South Wales (Hayman, 2003). Aboriginal and Torres Strait Islanders experience an increase in infant mortality 2-4 times higher than other Australians, and hospitalisation 50% higher than other Australians. In 1989, *A National Aboriginal Health Strategy* was produced which identified both key issues and potential solutions to some of the major Aboriginal health issues. The preceding strategy emphasises the structural basis of Aboriginal health, recognising the link between Aboriginal health, land rights and the domination of Aboriginal people by non-Aboriginal cultures. Further, the Strategy argued for Aboriginal community control of health services and research into issues related to Aboriginal people and their health. This Strategy although considered to be a valuable contribution was evaluated five years after its release and was deemed to have been ineffectively implemented, possibly due to under-funding (Wass, 2000).

The National Women's Health Policy launched in 1989 highlighted seven priority areas for women's health, including the health of ageing women, and the health needs of women as carers. In 1991, the *National Non-English Speaking Background Women's Health Strategy* was released and in 1992, the *National Mental Health Strategy* recognised the importance of promoting

the mental health of the Australian community. The *Draft National Men's Health Policy* was developed following the National Men's Health Conference, held in New Zealand in August 1995. This policy is being reassessed, partly in the context of the budgetary process. In 1994 the *National Rural Health Strategy* was released and updated in 1996 and again in 1999. In 1995 the *Health of Young Australians: A National Health Policy for Children and Young People* was endorsed. (Commonwealth Department of Human Services and Health, 1995, p 29)

The focus of the Australian Health Care System has been largely based on the provision of individual treatment for individual problems which is reflected in how Australia spends its health budget.

38.1% to hospitals

7.6% nursing homes

1.2% ambulance

5.0% Community and public health

6.1% dental

3.1% administration

1.6% research

2.0% Aids and appliances

12.2% pharmacy

3.4% other professional services

19.7% medical services

(Proportion of recurrent health services expenditure by area of expenditure 1996-97, Australian Institute of Health and Welfare 1999).

Noticeable in the above health expenditure outline is the absence of any reference to palliative care. This may be because as reported by the Australian Institute of Health and Welfare (AIHW, 1999), the focus for Australia's health in the year 2000 was targeted on preventable mortality and morbidity rates and included cardiovascular disease, preventable cancer, injury, communicable diseases, HIV/AIDS, sexually transmitted diseases, maternal health problems and disorders, physical impairment and disability, developmental disability and oral health. The focus was also on healthy lifestyles and risk factors such as, diet and nutrition, overweight and obesity, physical activity, high blood cholesterol, high blood pressure, smoking, alcohol misuse, illicit drug use, quality use of medicines, healthy sexuality, reproductive health, sun protection, oral hygiene, safety behaviours, immunisation and mental health. Other targeted areas included health literacy and health skills, such as life skills and coping, safety skills and first aid, self help and self care and social support; and, promoting healthy environments such as the physical environment, transport, housing, home and community infrastructure, work and the workplace, schools and health care settings (AIHW, 1999).

The earliest attempts at recording life expectancy were published in the 16th century in the form of 'the Bills of Mortality'. The Mortality rate is the rate at which members of a given population die, whereas morbidity rate is the

proportion of sickness/illness of a given population. The recording of deaths in these 'Bills':

> "… by cause were intended to provide a monitoring system for plague and pestilence; they were to warn the wealthier classes of the population in time for them to leave the city early in the outbreak" (Susser,1973, p.17, cited in Kelleher, 2000, p.18).

The World Health Organisation defined those aged 60-74 years as 'elderly', and those older as 'aged'. In terms of demographic ageing, the statistical figure given to the population of older ages is conventionally taken as 65 years and above. According to McCallum and Geiselhart (1996), Rowland (1991), and Pollard and Pollard (1981) when the proportion of people over 65 increases, the population is said to be ageing. Healey (2003) stated that population ageing occurs when there is an increase in median age (the age that divides the population into two equal halves). This is an indicator of the shift of the population age distribution towards older ages. Over the past half century, the median age for the world increased by 2.8 years, from 23.6 years in 1950 to 26.4 years in 2000. Over the next 50 years, the median age is expected to rise by 10.4 years, reaching 36.8 years in 2050. This means one out of every 10 persons is now 60 years or older, and by 2050 that figure will increase to one in 5 and at this rate, by 2150 one in 3.

The literature consistently reflects a worldwide phenomenon of ageing populations. The Australian population has experienced major improvements

to life expectancy since the turn of this century due to reduced fertility and falling age specific mortality. Advances in health care and improved living standards will have a long-term impact on the structure of our ageing population. (National Commission of Audit Report to the Commonwealth Government, June 1996).

Presently, 13% of our population is 65 years and over. This number is expected to grow to around 24% and 27% in 2051, with the number of people aged over 65 growing from 2.3 million in 1999 to between 6.2 million and 7.9 million by 2051 (Healey, 2003). Haberfield (2005) agreed with these figures and further reports that Australia's population is expected to rise to 33.4 million by 2051 with half older than 50. Victoria's population is expected to reach 7.4 million in 2051 – indicating an increase of 2.4 million from 2004.

Najman (2000) noted that at the beginning of the century, life expectancy for males was 55 years and 59 years for females, whereas by the end of the century it was 75 and 81 years respectively (p.20). The Australian Bureau of Statistics (1999) support this with demographic characteristics in 1997 indicating that 2.2 million Australians were aged 65 years and over. More than half these were aged 65-74 years (58%) while 10% were aged 85 years and over. A higher proportion of those aged 65 and over were women and this trend has increased with age. More than twice as many women as men were aged 85 years and over. The Australian Bureau of Statistics (2004) reported that in June 2003, the number of older persons aged 65 years and

over in Australia was 2.5 million people, or around 13% of the total population.

2.2   Attitudes to Death and Dying and Ageing

(Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?)

Stereotypes of ageing reflect negative attitudes to ageing as suggested by McMinn (1996). These stereotypes suggest that old age is synonymous with disease. He alludes to an attitude that nothing can be done anyway, it's just old age, and states that, "Older people may themselves accept negative stereotypes of ageing, seeking palliation rather than preventive or corrective treatment (p.18). A Report for the British Medical Association and the Royal College of Nursing (1995) has found that as people now live longer and fitter lives perceptions of 'old age' change, not necessarily for the better as attitudes of ageing that are perpetuated portray the increasing population of older people as a social problem rather than as a positive asset. The report further noted that older people are marginalised (in England), and a person's risk of receiving inadequate health care increases with his or her age, leading to allegations of rationing health care resources by age.

Leeder (2000) posited that people age in unique ways, depending on gender, biological characteristics, ethnic and cultural backgrounds, and whether they live in industrialized or developing countries, in urban or rural settings. He says: "Climate, geographical location, family size, life skills and experience are all factors that make people less and less alike as they advance in age"

(Leeder, 2000, Conference paper). Preparation for death may occur when personal experiences are related to the physiological and psychosocial processes of ageing (Raphael, 1984). Marshall (1986) refers to this as an adaptive process. These writers believe that the longer one lives, the more prepared they are for death, and fear of death therefore diminishes with age. These views are supported by studies by Rasmussen and Brem (1996), Marshall (1986) and Kalish and Johnson (1972).

Several models have been developed to provide health professionals with frameworks to understand people's health *beliefs* and *behaviour* which influence the way in which they view health. Funnell et al (2004) referred to the most common model which was developed in the 1940's by Abraham Maslow. He believed that attempting to meet one's basic needs, forms an individual's motivations and behaviour. Maslow defined basic human needs as physiological, safety and security, love and belongingness, esteem and self actualization. Funnell, Koutoukidis and Lawrence (2004) noted that health promotion and illness prevention have become an important focus of health care for several reasons, such as there are still no cures for many diseases, health care costs are rising rapidly, and the community is more aware of the value of health maintenance. Health care services therefore recognize the need to focus on health rather than illness, and the emphasis is on health promotion and disease prevention at an individual and community level. Advancements in technology and scientific and medical achievements have led to the development of advanced diagnostic equipment. Early detection and recognition of the contributing factors which influence health and illness

can prevent the spread of disease both at an individual and a community level. Funnell, et al (2004) also argued that the Health Belief Model (HBM) developed by Hochbaum, Kegels and Rosenstock in 1952 is one of the most widely used 'conceptual' health promotion models which was developed to assist in understanding health *behaviour*. The preceding model offered a serious challenge to established practice that primarily focused on prevention rather than the treatment of disease. The model was largely influenced by change theories, and the notion that it is the world of the perceiver which determines what an individual will do and not do (Becker, 1974). The model attempts to predict health-related behaviour in terms of certain belief patterns and is used in explaining and predicting preventative health behaviour, as well as the sick-role and illness behaviour.

Cultural patterns also influence health beliefs (McMurray, 2003) Other writers (Smaje and Field, 1997, Braun, 1997 and Culley, 1996) argued that considering culture in understanding health beliefs and client behaviour is not enough, rather culture needs to be seen in context and in conjunction with socio-economic status, education, length of residence and the impact of historical events (Kellehear, 2000). Campbell et al (2000) believed that communication and linguistics are the key elements in determining cultural patterns and influences, particularly in the area of palliative care when the word 'cancer' can mean different things and has different implications for several cultures. Campbell, Moore and Small (2000) stated:

The palliative care environment is a unique environment dealing with the most fundamental and final of life's events, within which people may use religious and cultural patterns, beliefs, and rituals to serve as an anchor in a frightening and strange environment (p.70).

This current research has investigated the way death is viewed by an ageing "rural" society, and sought to determine whether there is such a thing as a "rural attitude" to ageing and dying, which would have an impact on palliative care service delivery. Whilst Maslow's theory and the HBM Model may assist in determining behaviour and beliefs relating to health they do not assist in determining attitude. In defining *attitude*, Rokeach (1976) claims that:

"An attitude is a relatively enduring organization of beliefs around an object or situation predisposing one to respond in some preferential manner" (p. 112).

Whilst several earlier writers such as Asch (1952), Allport (1950), Sherif and Cantril (1946), and Chein (1948) argued that attitudes are formed largely by past experiences, Rokeach (1976) argued that the definition of attitude is altogether independent of how it is learned. He defines a *belief* as any simple proposition, conscious or unconscious, and inferred from what a person may say or do, and *behaviour* constitutes the action based on a person's belief. Even though his work was published nearly 30 years ago, the works of Rokeach remain pertinent and instructive to this research.

In a literature review in the area of attitudes to palliative care and death and dying, a study conducted in Israel by Carmel, Galinsky and Cwikel (1990) investigated behaviour, health and ageing. The study examined knowledge about the elderly and its relationship to attitudes and preferences for work with the elderly, among physicians at various stages of their medical education. The study found that students and practising physicians do not differ in their general knowledge about the elderly, nor in their negative attitudes toward the elderly. The study also found that those physicians who were actually working with the elderly expressed significantly more willingness to work with the aged. Carmel and Mutran (1997) conducted a study to investigate the wishes of elderly Israeli people regarding the use of life sustaining treatments. They found that significantly more elderly people wanted to prolong their life in mild illness conditions, including having cancer with a relatively good prognosis, than in severe illness conditions. There appears to be consensus according to Ainslie and Beisecker (1994), and Cohen-Mansfield, Dorge and Billig (1992) about restricting the use of life sustaining treatments when there is an expected low quality of life. Carmel and Mutran (1997) also reported significant differences in different subgroups. Life sustaining treatment was more desirable for the religious, men more than women, the less educated more than the educated, and the relatively healthy more than the severely ill. Caddel and Newton (1995), Cohen-Mansfield, Droge, and Billig (1992), Faunce and Fulton (1968), Jorgenson and Neubecker (1980-1981) and Preston and Williams (1971) reported 'religiosity' and a willingness to prolong life is a consistent finding

across three western religions, Protestant, Catholic and Jewish. (Carmel et al, 1997).

O'Gormon (1998) in an examination of the relevant literature highlights the emergence of a consensual theory put forward by (Wahl 1959, Elias 1985, Bertman 1991, Mellor 1993, Rinpoche 1995), whereby societal attitudes to death and dying over the second half of this century have become more open and inclusive, leading to a more holistic view of life cited in (O'Gormon, 1998). With the arrival of the Australian publication *Death & Dying in Australia* edited by Kellehear, (2000), and the fact that the baby boomers have now a marked influence on social change, it may be plausible to suggest that the baby boomer generation is more prepared to tackle sensitive issues and attitudes surrounding death and dying.

O'Gormon (1998) purports that societal changes have influenced 'attitudes' associated with death and dying, and this would appear to be in keeping with Rokeach's (1976) definition of attitude, that is: '…a relatively enduring organization of beliefs around an object or situation predisposing one to respond in some preferential manner' (p.112). O'Gormon (1998) was intending to help nurses and other health professionals in their understanding of contemporary views regarding death and dying and the associated issues of health and healing. The article refers to eight stages in the development of current attitudes to death and dying.

Stage 1: 15th century -'Dance of the Dead', where death becomes autonomous

Stage 2: 16-17th century – 'Dance of Death', death becomes independent

Stage 3: 17-18th century – 'Bourgeois Death', death avoidance by paying for health

Stage 4: 19th century - 'clinical death' – the emergence of the scientific doctor and thanatology

Stage 5: 20th century – 'Health as a commodity' – health is seen as a civil right

Stage 6: (20th century) 'Death in Intensive care' – contemporary society unable to cope with death and dying, (changes in attitudes)

Stage 7: (20th century) – 'Social Death' – professionalization of death rituals

Stage 8: Return to holistic concepts – contemporary education endorses understanding of death as 'right of passage' (O'Gormon, 1998, pp. 1127 – 1135).

O'Gormon (1998) contended that:

"…in the first half of the 20th century, society lost sight of the importance of rituals associated with death and dying and of the need for appropriate death education…During the second half of the century there has been a proliferation of thanatology research and literature…The holistic approach to health care has been recognized by many researchers as being essential to health and healing, and therefore death and dying have to be addressed" (p.1127).

Griffin (2000) has no disagreement with O'Gormon who argued that societal change impacts on our views of death and dying, causing confusion about what to do and what to believe about death. Kellehear also believes that as we move into the 21st century we will be "moulded" by contending revolutions such as the industrial revolution and the ecological revolution. On the one hand, change and progress is favoured by the industrial revolution which focuses on youth, devaluing ageing, and with death being an embarrassment. Whereas, the ecological revolution acknowledges death as a natural part of the rhythm of life, advocating an openness to death. Griffin (2000) argued further that:

It is not just that the contending revolutions create contradictory trends and movements in society, in the funeral industry, and in the churches and faith groups. The contradictions have become internalized within each of us, pulling us in different directions and making clear and purposive thought and action difficult (p.50).

Adams (2000) pontificates his own values on death and states that: "…death is okay. Not only does it make life possible but, of course, it defines it" (p.105). He goes on to state:

How well you live is pretty well defined by the way you view death – or ignore it. And after countless thousands of years human beings still avert their eyes from that most numinous of events, one's own death. If we were better at discussing it, at facing it, far

fewer people would be in therapy. Or in cinemas watching movies

about Hannibal Lecter (p.115).

Adams' philosophy on death challenges the 'gate keeper' theorists who would question 'should we even be talking to ageing people about their death and dying?' Kubler-Ross (2004) who has made many contributions to the study of death and dying and the mental state of the dying, stated in a report as far back as in 1969 that "When I wanted to know what it was like to be schizophrenic, I spent a lot of time with schizophrenics. Why not do the same thing? We will sit together with dying patients and ask them to be our teachers" (p.12*).

Ultimately, contributions to research into the field of thanatology and the discipline of palliative care can only increase if we were to get much better at discussing 'it', and that may mean learning to sit with ageing and dying people.

The Implications of Ageism and Attitudes to Ageing in Australia:

The essence of ageing well cannot be decontextualised and reduced to mere biological functioning. Rather its true essence is to be found in the meaning that men and women attribute to their life, it is reflected in their entire system of attitudes, values and level of life affirming responses to the complex and ever changing dimensions and circumstances surrounding older age (Seedsman and Feldman, 2002 p. 204).

As Australians living within an ageing society paradigm, we may need to reflect on how ageing is perceived. We may wish to rethink the defining characteristics of ageing, not merely the pathology of ageing but the common perceptions held, the stereotypes and the beliefs of old age that as a society

we have grown up with, and possibly have learnt or owned since childhood. Older Australians themselves may even hold these perceptions of ageing.

The Macquarie Dictionary (1991) describes ageism as an attitude which stereotypes an elderly person according to their age, rather than judging them on their individual abilities. Common perceptions of old age generate the stereotype of frail, dependent, infirm people who consume considerable welfare resources. More often than not old people are shouted at because it is often assumed that 'they' are hard of hearing or have dementia or Alzheimers disease. McMinn (1996) espouses that the most widely quoted explanation for ageist attitudes is the fear people have of getting old themselves. He notes some common stereotypes of ageing which include 'older people are sick', 'all old people live in institutions', 'older people behave like children', older people live alone and are lonely', 'old age is a time of helplessness', 'old age means losses, of hearing, of bladder control', 'old age means senility'. These stereotypes suggest that old age is synonymous with disease. McMinn (1996) further alludes to an attitude towards ageing which may be held by the elderly themselves, and states that "Older people may themselves accept negative stereotypes of ageing, seeking palliation rather than preventive or corrective treatment" (p.18). Sax (1993) reports that if their independence and autonomy have been jeopardized elderly people perceive their health to be poor. The 1995 National Health Survey (AIHW 1998) on the other hand reported that when asked, older people saw themselves as healthy despite a number of them presenting infirmities.

Ageism found within medical practice effects the care given to older people. Rowlands (1991) acknowledged that ageism leads to a loss of opportunities and low standards of care and Kane (1990) found in US nursing homes superficial care, shorter consultations as age increased, earlier discharge from acute wards and health problems likely to be undiagnosed but which were treatable. Welte (1987) also suggests that a direct relationship exists between advanced age and the risk for inadequate treatment (as cited in McMinn, 1996, p.19)

An ageing society is a 'burdensome' society according to Healey (2003) and Kerin (2002) who also believe that population ageing will have major consequences for economic growth, savings, investment and consumption, labour markets, pensions, taxation and transference of wealth. These writers argue that people will have to work beyond the retirement age to support themselves. In keeping with the ABS (1998) report, they also believe that a changing age structure for Australia will have major economic implications in terms of supporting a growing aged population. A far larger aged population compared with a potential decline in the labour force (population aged 15-64) may mean it will be difficult to generate the level of resources and public support needed to maintain that population will have acceptable standards of living and quality of life. Future trends in younger age groups will also influence the level and nature of competing demands for university funding, for employment programs, for unemployment benefits, and support for low-income families placing a strain on available resources. Changes in social values, attitudes and government policy will also influence the level of

support provided for older people (and, other groups such as children, unemployed people and people with disabilities) as well as the respective roles of government, private business, community groups, families and individuals in providing it.

Rosenman and Warburton (1997) believed that many baby boomers will be in a better position than the current older generation. By accumulating assets such as the family home, good superannuation, investment property, stock, and shares, and the consequence of two-income families during the favourable economic conditions of the seventies and eighties they will not rely on the age pension for most of their income. However not all baby boomers had these opportunities, and may never accumulate enough superannuation to replace the age pension. According to Rosenman and Warburton, (1997), Healy (2003) and Kerin (2002) the trend in early retirement will be offset as some baby boomers extend their working lives beyond the expected retirement ages. With the exception of Tasmania, compulsory retirement no longer exists in all Australian States and Territories.

Healy (2003) and Kerin (2002) further espouse that because people are living longer and healthier lives by the time they enter into care later in life their health needs will be more chronic. Block (1996) supports this claim, reporting that the health care cost of an 85 year old male is four times that of a 50 year old male. Goss (1994) noted that baby boomers are expected to live

longer and also to remain healthier for longer, making most use of intensive health care resources the two years preceding death.

The Federal Minister for Ageing The Hon. Kevin Andrews MP, in 2003 opposes the notion of a burdensome ageing society:

> Australia's older population is not expected to be a burden on the community. Our sound retirement incomes system, projected growth of superannuation assets and accumulation of private savings will ensure adequate retirement incomes and quality health and aged care services will continue to be affordable in the future (Healey, 2003, p.14).

Shanahan (2002) also supported the argument that an ageing Australian society is not a burdensome society. She refers to new evidence which shows that older people are not a drain on society and that they make substantial financial contributions to the economy that offset many aged care costs. Through non-pension income, childcare, caring for the sick and elderly, volunteer work, self-help and loans, those aged over 65 are contributing billions of dollars a year to the economy. The high rate of home ownership among the elderly also means that they contribute after death by passing on mortgage-free properties to their children. Leeder (2000) agrees and sees the value of older people as a great resource and a tremendous asset to families and the community. The following summarized ABS data would support Leeder's notion that older people provide a valuable asset and resource.

- Currently about 17% of people aged 65 years and over donate time to voluntary organisations. (ABS, 1998)

- The 1998 Survey of Disability, Ageing and Carers estimated that people aged 65 and over account for 21% of all people who are the primary providers of informal care to someone needing help with self-care, mobility or verbal communication. (ABS, 1999)

- The majority of older primary carers are providing care to another older person – 75% were caring for their partner and 10% are caring for a parent (ABS, 1999).

The specific needs of older people in terms of health services planning and provision should be met, and older people need proportionally more health services, according to McMinn (1996). Australia is an ageing population. Because of that, health services need to be in place to prepare for this increase and the baby boomers will have an impact on how we do things. Ageism and attitudes to ageing exist and may impact on quality of services. Attitudes to ageism may also explain the phenomenon that an ageing society is a burdensome society, although there seems to be disparity amongst writers in this thinking. This is a generation that fought our wars, and survived the hardships of the Depression years, and in many ways have paved the way for our future generations and it seems ironical that we as a nation should not be seen to value our older people. Although these debates appear to be politically and economically driven, the need for 'valuing' our older people does appear to be emerging as demonstrated by the Plan for the City of

Melbourne cited later in this chapter. As access and equity issues for health already exist in rural Australia, especially for Indigenous Australians, then it is also to be expected that rural 'ageing' populations will also be disadvantaged, when it comes to accessing health services, including palliative care services.

2.3 Health Chances for Australians in an Ageing Paradigm

Specific health and ageing related statistics have been recorded by the Australian Bureau of Statistics (1995). They predict that as the population ages, there is a greater likelihood that people will die from cancer and other age-related diseases. 'Cancer' is a term given to several diseases which result when the process of cell division, by which tissues normally grow and renew themselves, becomes uncontrolled and leads to the development of malignant cells (ABS, 1995). ABS, 2004 further reported that in 2002 leading causes of death for older persons were diseases of the circulatory system and malignant neoplasms (cancers).

The cancer death rate in Australia has increased by 4% over the past two decades. In 1993, 32,691 people died of cancer, 18,479 males and 14,212 females, and accounted for one in four deaths. Table 2. shows that four types of cancer caused 45% of all cancer deaths. Lung cancer was the most common cause of cancer among men whereas for women it was breast cancer.

Table 2. 1993 Aggregate Numbers of death by cancer: ABS 1995

Cancer Type	No. of deaths
Lung	6,380
Colon	3,308
Breast (female)	2,641
Prostate	2,544
Pancreas	1,476
Lymphoid	1,275
Stomach	1,238
Rectum	1,130
Brain	933
Melanoma	854
All cancers	**32,691**

Source: (adapted from ABS: Australian Social Trends 1995

Health – Causes of Death: Cancer trends, p.2)

Figure 1. provides a graph of death rates in Australia caused by cancer and shows the high incidence of mortality by cancer in rural and remote areas.
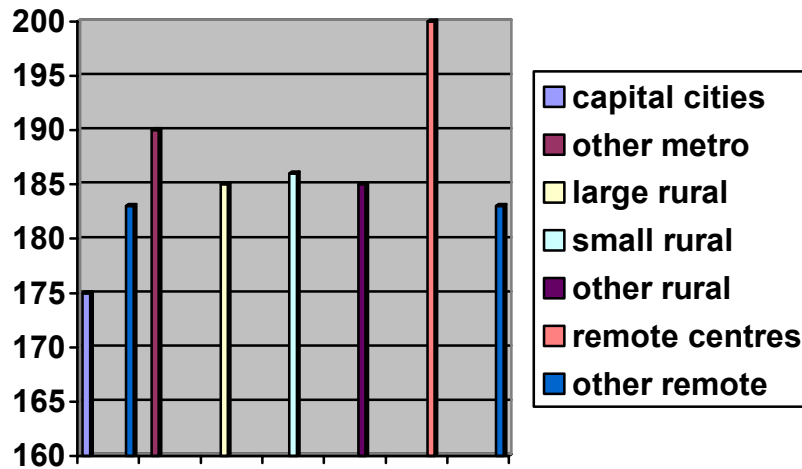
**Figure 1. Death rates in Australia by settlement type caused by cancer.
(deaths per 100,000 population)**

Source: (adapted from AIHW: 2000)

ABS (2001) reported that the most common and useful measure of a population's health is its death rate. Mortality and morbidity rates are therefore recorded to determine life expectancy. Mortality rate is the rate at which members of a given population die. Whereas morbidity rate is the proportion of sickness/illness of a given population. The 2001 ABS Report reflects other major causes of illness and death to include heart disease, stroke, cervical cancer, skin cancers, injury, communicable diseases, musculoskeletal, diabetes, disability, dental disease, mental illness, asthma (Australian State of the Environment Report 2001, ABS).

The most common causes of death 'recorded' on death certificates for older people in Australia according to the Australian Institute of Health and

Welfare (AIHW) (1998) are ischaemic heart disease, cerebral vascular accident (CVA) or stroke, lung cancer, chronic obstructive pulmonary disease and colorectal cancer (AIHW, 1998). There are around 127,000 deaths in Australia in each year. Deaths of persons aged 70 years and over accounted for 70%, 20% occurred at ages 50-69 years, 8% at ages 20-49 years, and 2% at ages less than 20 years (AIHW 2000).

The AIHW (1998) reflected that Australia has experienced a considerable reduction in death rates over the past century. They report that death rates are less than half what they were in the early 1900-s, particularly deaths from infectious diseases. This is attributed to improvements in social and environmental conditions, such as sanitation, health education, the quality of food and water supply and better housing. ABS (2004) reported that in 2002 the death rate for persons aged 65 years and over was 4,250 per 100,000 older persons, with the male death rate higher at 4,641 per 100,000 males compared with a rate of 3,939 per 100,000 females. In 2002 leading causes of death for older persons were diseases of the circulatory system and malignant neoplasms. ABS, 2004 reports that:

"For persons aged 65-74 years, all malignant neoplasms (cancers) were the leading cause of death at a rate of 740 per 100,000 persons. By 75 years and over, all circulatory conditions become the leading cause of death, peaking at a rate of 7,513 per 100,000 persons for those aged 85 years and over." (p. 7)

In terms of 'promoting health' for Australians, the current focus is on preventing mortality and morbidity rates in the areas of cardiovascular disease, preventable cancer, injury, communicable diseases, HIV/AIDS, sexually transmitted diseases, maternal health problems and disorders, physical impairment and disability, developmental disability and oral health. The focus is also on healthy lifestyles and risk factors such as diet and nutrition, overweight and obesity, physical activity, high blood cholesterol, high blood pressure, smoking, alcohol misuse, illicit drug use, quality use of medicines, healthy sexuality, reproductive health, sun protection, oral hygiene, safety behaviours, immunisation and mental health. Other targeted areas include health literacy and health skills, such as life skills and coping, safety skills and first aid, self help and self care and social support; and, promoting healthy environments such as the physical environment, transport, housing, home and community infrastructure, work and the workplace, schools and health care settings.

In terms of 'ageing', the statistical figures given to the population in older ages is conventionally taken as 65 years and above. Although the age of 65 has often been described as retirement age, it does not provide a good indication of old age (there is no statutory retirement age in Australia), as many people now opt to retire from age 50 onwards. The Bureau of Statistics surveys have shown that 20 per cent of men aged 65 to 69 remain in the workforce after reaching pension age, while 10 per cent of women aged 65 to 69 are also working. The following Table 3 shows percentages by age group of workers in the workforce.

Table 3 Percentage of Australians (Men and Women) in the workforce: 1990 and 2002

Age Group	Feb 1990	Feb 2002
70 plus	3.2	3.4
65-69	8.3	14.6
60-64	32.5	37.3
55-59	52.9	62.7
45-54	75.1	79.1
35-44	83.3	81.1
25-34	80.2	81.2
20-24	85.1	83.0
15-19	62.1	61.5
Total	**63.8**	**64.0**

Source: (Australian Bureau of Statistics: 2004)

The ABS report stated that in 1990, 92,000 Australians were working on or after their 65th birthday and in mid 2002 this figure had increased to 160,000. Old age or feeling old is more often than not a product of the environment and life circumstances. There is a common saying 'you are only as old as you feel' which does not seem to have much to do with chronology. The famous comedian George Burns when asked about ageing and immortality was known to have said: "Retirement at 65 is ridiculous. When I was 65 I still had pimples." He is also credited with having stated ,

"If you live to the age of 100 you have made it because very few people die past the age of 100" (George Burns).

It is those people aged 60 to 74 years who the World Health Organisation defines as 'elderly', and those older as 'aged'. I would apologize here to those people in, or approaching this age group who may read this thesis and who may take umbrage at this definition of 'elderly' and 'aged', as this is not a view held by this researcher, who is of the opinion that these 'terms' will mean whatever the individual believes them to mean. However, for statistical purposes and in keeping with demographic data available from the Australian Bureau of Census and Statistics on population ageing, 65 will be the most commonly used term of reference throughout this thesis.

Population ageing is a major focus of social and economic planners and policy makers. The ABS (1998) reported that concerns for key stakeholders included an anticipated increase in costs for aged care, potential increased income support for a rapidly growing aged population, and the propensity or desire of Australians to pay for these increased costs (Australian Bureau of Statistics 1998: Population Projections 1997 to 2051, Cat. no. 3222.0, ABS, Canberra)

Government policy has focused on cost reduction as well as shifting costs and responsibilities from the public sector to individuals, families, community groups and private businesses. An example of this is seen in recent reforms to retirement income support which include mandatory occupational

superannuation for all workers introduced in 1992, tightening of the means test on the age pension and a progressive increase in the pension age for women from 60 to 65 by 2012 (introduced in July 1995).

The Australian Bureau of Statistics (1998) has provided *population projections* for the period 1997 to 2051. The base population recorded in these statistics is the estimated resident population as at 30th June, 1997. Population projections, rather than providing predictions or forecasts, provide an indication of what could happen. The projections are estimates of future populations based on a combination of assumptions about future levels of births, deaths and migration. These ABS statistics cover three possible future outcomes – based on high, medium and low population growth. Series 11 (medium) is based on the following assumptions.

1. Total fertility rate will continue to fall during the next decade – to 1.75 births per woman by 2006 – then remain constant at 1.75 until 2051.

2. Age-specific death rates will continue to decline, resulting in life expectancy at birth increasing by 5-7 years by 2051; and

3. Net overseas migration of 78,000 in 1998 then 70,000 per year from 1999 to 2051.

Table 4 provides data for 2001 to 2051 (Series 11) projections.

Table 4: Age composition of the population, estimates and projections

	1946 %	1961 %	1971 %	1997 %	2001 %	2011 %	2031 %	2051 %
Prop'n aged under 15	24.5	30.3	28.7	21.2	20.3	18.3	16.5	15.6
15-64	67.6	61.2	63.0	66.7	67.3	67.7	62.2	60.2
65 +	8.0	8.5	8.3	12.1	12.4	14.0	21.3	24.2
Baby Boomer age cohort	..	30.3	36.5	30.0	29.0	26.3	18.7	4.5
Median Age	years 30.8	years 29.3	years 27.5	years 34.3	years 35.5	years 38.3	years 42.2	years 44.1
Total Population	million 7.5	million 10.5	million 13.1	million 18.5	million 19.3	million 21.0	million 23.7	million 24.9

Source: (Demography, 1961; Population by Age and Sex, Australian States Territories, June 1992 to June 1997: Cat.no. 3201.0; Population Projections, 1997 to 2051 (Cat. no. 3222.0). (ABS: 1998)

With regard to projected health 'chances', gender presents a significant determinant of health in Australia. Mortality rates for males are higher than those for females. Men are also less inclined to seek medical assistance. Life expectancy in 1996 for males was 75.4 years, and for females 81.1 years. Table 5 shows the gender breakdown of persons aged 65 years and over in 1997.

Table 5. Persons aged 65 years and over – 1997

		Men		Women		Persons
Category A	'000	%	'000	%	'000	%
Age **65-74**	616.5	6.7	769.3	7.3	1,295.8	7.0
75-84	298.8	3.2	434.3	4.7	733.2	4.0
85 and over	65.3	0.7	150.8	1.6	216.1	1.2
Total	980.6	10.6	1,264.4	13.6	2,245.1	12.2
All Ages	**9,218.0**	**100.0**	**9,314.2**	**100.0**	**18,532.2**	**100.0**

Source: ABS: Population by Age and Sex, Australian States and Territories (3201.0) Year Book Australia. 1999 Special Article – Older Australians.

While population estimates from 2002 showing an almost equal proportion of males to females in the total population (50.3%) females), females were over-represented in the 65 years and over population with 56% being female. In addition, 69% of the population aged 85 years and over were female (ABS, 2004)

The Australian Institute of Health and Welfare (AIH&W), (1998) reports that differences in mortality rates between sexes can be explained by the various causes of death. Stevens, McFarlane and Stirling (2000) noted that although the number of women in the aged population is greater than men, there is a steady decrease from 58 percent in 1976 to 56 percent in 1996, and it is projected to be 54 percent in 2016. They note that "In addition to women's

greater longevity is their tendency to marry older men" (p. 175). They suggest that this results in an increase in the number of widows and that many will be living alone. Nay (1992), Sax (1993) and Speedy (1991) have also predicted that older women are more likely to experience financial hardship due to having been born into a patriarchal society, and that the care of old people will consist of mainly women caring for old women, both at home and /or in institutions.

Gender implications on health chances for Australians will have specific significance for women and their pre-supposed role as carers within our ageing population.

The AIHW (1997) report confirms these views and shows that death rates for unmarried and widowed older men and women were 40 per cent higher than for those who were married and 55 per cent of all women over the age of 80 were living alone as opposed to 27 per cent of all men. McCallum and Gieslehart (1996) noted that many of those living alone were reported to be in the lower socio-economic groups and have all the associated problems and complications arising from loneliness and isolation.

Another health consequence of population ageing will be seen in the expected increase of dementia in the population, which according to Macklin (1991) is expected to increase by 77.9 per cent over the next 20 years. The AIH&W (1998) reported that currently in Australia there are 134,000 people with some form of dementia. AIH&W (1997) reported that dementia affects about

5 per cent of the population aged between 65 and 84, and estimated that 25 per cent of people who survive beyond 85 years will develop some form of disability due to dementia. The report acknowledges that people with high levels of loss and care needs who have dementia live in aged care facilities, whereas approximately half of those people with dementia live in the community. The incidence of dementia increases with age, and while dementia itself may not be the actual cause of death, the syndrome can progressively lead to other health complications which result in death.

An expectation of an increase in the incidence of dementia due to population ageing and a decrease in mortality rates will have an impact on all carers and particularly women as carers. This will also have ramifications for how that care is given and the level of knowledge and skill that is required to provide that care given the change in ageing demographics.

The following points have been extrapolated from ABS (1998) statistical data providing a summary of implications and predictions for Ageing in Australia.

- By the year 2031, 21-22% of Australia's population will be aged 65 and over. It was 12% in 1997.

- By 2031, over a quarter (27%) of all Australians of voting age (18 years and over) will be aged 65 or older.

- Age-specific death rates will continue to decline, resulting in life expectancy at birth increasing by 5-7 years by 2051.

- Total fertility rate will continue to fall during the next decade – to 1.75 births per woman by 2006 – then remain constant at 1.75 until 2051.

- In Australia the fertility rate peaked in 1961 and by 1965 had dropped back to just below the 1946 level.

- Between 2011 and 2031, Baby Boomers will make a significant contribution to the numbers of people aged 65 and over. During this period, the population aged 65 and over is projected to grow from 3 to 5 million.

- By 2031, all surviving Baby Boomers will be 65-84 years of age.

- Between 2031 and 2051, Baby Boomers are projected to swell the population aged 85 and over from 612,000 to 1.1million.

Although all states are projected to continue ageing Tasmania's population is projected to age the most rapidly, overtaking South Australia as the oldest State in about 20 years. By 2051 the proportion of population over 65 is projected to reach 32% in Tasmania and 29% in South Australia, well above the average of 24% for total Australia. Data summarized from (ABS,1998)

Ageing in Victoria: Metropolitan characteristics: the City of Melbourne

Older people represent a significant proportion of the residential, working, studying and visiting population of the City of Melbourne. In 1998 the City of Melbourne had a growing residential population of 39,000 and a visitor population of 400,000 per day including many older people (Forward Plan for Older People: Nov. 1998, City of Melbourne).

There is an expectation that the City of Melbourne's older population (aged 55+) will grow exponentially as the baby boomers begin to age over the next ten years. Figure 2. Projected Population Growth of Persons Aged 55+, 1997 –2006 City of Melbourne is adapted from the Forward Plan for 1998 and highlights the youngest of the 55+ age groups are projected to increase significantly between 1997 and 2006, while growth among the oldest age groups is projected to slow and eventually decline.
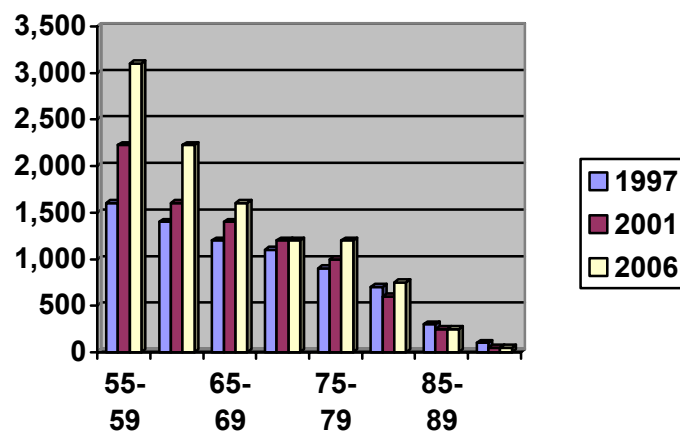
Figure 2. (adapted from Projected Population Growth of Persons Aged 55+, 1997 –2006 City of Melbourne)

Source: (Forward Plan for Older People: Nov. 1998, City of Melbourne).

People aged 55-59 are the largest of the 55+ aged groups in the City of Melbourne, and are projected to grow at the highest rate of all the groups, from 1,623 to 3,068 between 1997 and 2006. This group comprises people on low incomes, and early retirees with disposable incomes who have substantial leisure time, which the Council acknowledges as priority to emphasize participative, health promotion and prevention strategies. These strategies developed by the Council include valuing and encouraging the contribution of old people and investigating the initiation of supported learning through the University of the Third Age.

Health Chances for Rural Australians: Ageing in Rural Victoria: Gippsland Characteristics:

(Would an ageing rural population be disadvantaged if and when they need palliative care?)

Gippsland Province is a rural electorate which includes the districts of Gippsland East, Gippsland South, Morwell and Narracan. Gippsland has many idyllic tourist attractions and coastal retreats and would provide for some, the ideal retirement environment. Figures from the 1996 Census indicate that 17% of the population are aged 60 and over, compared to 15% of Victoria as a whole. Twenty four percent are in the 40-59 age group.

Table 6 provides the estimated population projections by age groups (ABS Census 1996 to 2016) and shows comparisons between Gippsland including East Gippsland and Victoria. Figures from Table 6 highlight the expected increase in the 65+ age group through to 2016.

Table 6: The estimated population projections by age groups.

Area	Age Group	1996 Census	2001	2006	2011	2016
East Gippsland Shire						
	0-14	8770	8594	8577	8733	8937
	15-29	6093	7354	7717	7882	7902
	30-44	7867	8263	8099	8071	8456
	45-59	7005	8201	8234	9552	9481
	60-74	5646	6783	7414	8776	10150
	75+	2394	3412	4161	4657	5191
TOTAL		37,775	42,609	45,184	47,671	50,117
Gippsland						
	0-14	54,515	49,643	48,298	48,277	48,547
	15-29	41,169	43,643	44,434	44,145	43,062
	30-44	49,680	45,475	43,049	42,155	43,360
	45-59	37,962	42,957	47,760	48,083	46,579
	60-74	26,656	29,225	31,697	37,962	43,964
	75+	12,012	14,641	17,288	18,628	20,243
TOTAL		221,994	225,584	232,526	239,250	245,755
Victoria						
	0-14	925,351	967,988	980,943	981,252	975,544
	15-29	977,252	997,987	988,943	1,013,002	1,035,236
	30-44	1,017,733	1,089,195	1,101,367	1,088,880	1,074,883
	45-59	741,140	888,246	986,066	1,025,703	1,066,592
	60-74	469,692	520,383	564,780	670,942	764,084
	75+	222,958	271,903	300,998	312,508	333,352
TOTAL		4,354,126	4,735,706	4,922,993	5,092,310	5,249,723

Source: (ABS Census 1996 to 2016)

Figure (3) looks at the comparison of selected population characteristics of youth and ageing by percentage for the same areas of East Gippsland, Gippsland and Victoria.

Figure 3: Selected Population Characteristics (%)
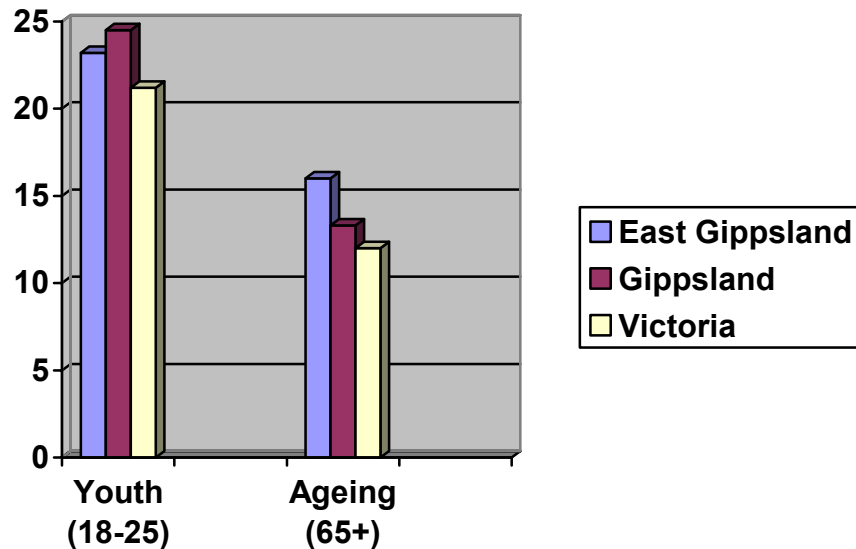
Source: 1996 Census (ABS)

This Figure shows that the percentage of ageing (those aged 65 and over) in the Gippsland area at the time of the 1996 Census is much higher than the Victorian percentages. (East Gippsland = 16.0%, Gippsland = 13.3%, Victoria =12.0%).

Several writers Foskey (1998), Wilkinson et al (2002) as well as the Australian Council on the Ageing in the Federal budget submission (2000) acknowledged the need to consider equity and universal access with attention being given to the needs of ageing populations. Particular attention needs to be given to rural needs and to how services can be effectively delivered to people in rural communities, (at least in the area of palliative care) where

recommendations given to the Government in the 1999-2000 budget, advised that health care services include improved access to palliative care for ageing populations.

For the purposes of this research the definition used to describe the term *rural,* will mean everything that does not include capital cities and major metropolitan centres in Australia.

The Australian Government held a National Rural Health Policy forum in 1999 and released *Healthy Horizons: A Framework for Improving the Health of Rural, Regional* and *Remote Australians.* which set seven key goals:

- improve health for areas of highest priority
- improve the health of Aboriginal and Torres Strait Islander people living in regional and remote Australia
- provide better information about the health of regional, rural and remote Australians
- ensure coordinated services are developed and maintained through collaboration
- develop a skilled and responsive health workforce
- that funding for regional, rural and remote communities be based on need

- recognise regional, rural and remote health as an important part of Australia's health system (National Rural Health Policy Forum, 1999, p.9).

A 'model' was proposed by McMurray (1999) in which health in ageing can be underpinned by health status, health resources, health service utilisation and health determinants and risk factors. She believed this model can be considered from a rural and remote perspective (Wilkinson and Blue, 2002).

Travelling long distances, to sometimes inhospitable and remote areas may be seen as unique to the Australian terrain. Historically, and since the landing of the first fleet in 1788 and throughout the convict and Gold Rush eras, through to the arrival of European settlers and would be farmers, Australia's rural population has been on the increase. Wilkinson and Blue (2002) described the factors influencing processes of population change in rural and regional areas. They include:

- fertility and the extent to which women living in the area have children
- mortality: the pattern of death in the sector
- internal migration the extent to which people move in the area from other parts of Australia and which residents move elsewhere in Australia
- International migration: the extent to which people move into the area from other parts of overseas and which residents leave for overseas (Wilkinson and Blue, 2002, p.19).

Larson (2002) reported that although seen to be booming during the 19th century, from 1880's onwards, Australia's rural population saw an increasing number of the population moving from the country to the capital cities.

> Land clearing, farming in unsuitable areas, or overstocking, in conjunction with huge rabbit populations, led to a very serious loss of vegetation cover and consequent serious soil erosion throughout Australia. Therefore, 1900 to 1950 was a period of consolidation, leading to a retreat by farmers and graziers from the drier margins of agricultural lands and a permanent reduction in livestock numbers (Wilkinson and Blue, 2002, p.4).

Change to the natural habitat of the Indigenous population would be seen to be inevitable. Rural population growth since 1986 has been confined to the east and south-west coasts and other areas with particular tourist retirement appeal (Wilkinson and Blue, 2002). More recently, 'sea-change retirement' is seen to be appealing to many retiring baby-boomers. Once removed from the metropolitan areas, travellers can experience many changes, not only to geography but also to social, political, demographic and infrastructure. Those who are 'less mobile, less healthy and less wealthy' will suffer more than those who have access to services in regional centres (McKenzie, 1994, cited in Wilkinson and Blue, 2002, p.7). Regional towns experiencing growth in population may already be feeling the burden of health services which are already lacking, high unemployment, increased social security payments due

to low housing costs, and the attraction of people relying on welfare assistance.

Foskey (1998) in a study on ageing in small rural communities argued that:

> Both the rate and type of change occurring in rural areas of Australia has implications for older people living in those areas which are often poorly understood (p.1).

Foskey has identified what could be termed a dangerous phenomenon – that is, the development of 'aged ghettos'. She believes that in areas of high concentrations of retired people and retirement villages where higher level services are sought but have not caught up with the population growth, people will be without many key services. Foskey sees the need "…to consider what equity and universal access means in these circumstances" (Foskey, 1998, p.1), and acknowledges that attention needs to be given to how services can be effectively delivered to people in rural communities. Foskey's Australian study used four case study communities from New South Wales based on Local Government areas – two coastal areas – Maclean and Nambucca; and two inland areas – Glen Innes and Severn. In comparison to the two coastal areas indicated that there was higher than State average population growth with the proportion of the population in the 65+ age group being well above the State average.

Jones (2003) agrees with the notions put forward by Foskey (1998) and reports that country councils will come under increasing financial burden and struggle to afford the health costs in supporting an ageing population. With more retirees choosing the country over the city, these writers reported a growing demand for human services and increased pressure to provide a more suitable age-related infrastructure.

The designated area for this study is Gippsland in rural Victoria. This choice was largely influenced by Foskey's concern for the development of 'aged ghettos' and retirement to coastal areas where infrastructure may be lacking or non − existent. ABS (2005) statistics show that 17% of the Gippsland population is over the age of 65 years, compared to 13.5% of Victoria as a whole. The Shire of Gippsland has many idyllic tourist attractions and coastal retreats and would provide for some, the ideal retirement environment.

The choice of Gippsland for the designated area for this research was also prompted by the question '*what are the health and ageing implications in this rural area?*' The Victorian Workcover Authority (2004) reported that:

> According to the Asbestos Diseases Foundation of Australia, it is estimated that between 2003 and 2020 more than 13,000 Australians will die from mesothelioma and a further 40,000 will develop asbestosis, with a 90% chance of developing full-blown mesothelioma over time (Victorian Workcover Authority, March 11, 2004).

One in four cases were reported in the state of Victoria in the late 1990's, while the area of Gippsland reports seven times the national average in asbestos deaths.

The Council on the Ageing (1999) also acknowledged the need to consider equity and universal access issues and to emphasise that attention needs to be given to how services can be delivered effectively to people in rural communities, (at least in the area of palliative care). In the recommendations to the Government in the 1999-2000 budget, they recommended that health care services include improved access to palliative care for ageing populations.

This current research was undertaken to determine the palliative care infrastructure and needs of an ageing population in a rural area, and the designated area for this research was Gippsland in Victoria.

"How one ages is determined by how one has lived, if one has lived well then one will age well; and if one has lived well, then ageing and dying will not seem so unacceptable."   *(from 'Jean' in Gippsland who is a 97 year old U3A member)*

The quote above by the U3A member signifies a very positive attitude to ageing, which hints at the notion that a healthy lifestyle may enhance ageing. 'Jean' goes on to say that she has never smoked, has a sherry on social and family occasions and grows her own vegetables, and by her own admission has lived a healthy lifestyle. Born in rural Victoria, where she still lives (alone), 'Jean' is self sufficient and independent.

Human health is influenced by factors including genetic inheritance, biomedical processes and environment, as well as economic, social and behavioural determinants (National Health Survey (NHS): ABS, 2001). The Australian Institute of Health and Welfare (AIHW, 1998) further acknowledged that socioeconomic disadvantages also tended to increase with increasing remoteness. The preceding AIHW report acknowledged that there are environmental impacts on health and that the differences between metropolitan and remote areas results in fewer services, long distances to travel, poorer road conditions, diminished public transport and environmental issues related to agricultural and mining occupations. In the Gippsland region, environmental and industry based issues related to the mining occupations have a special significance given the high incidence of asbestos related illness and in particular the high incidence of lung cancer.

2.4 Indigenous Health and Ageing in Australia:

"Things are not good in the' bush'. Depressed rural economies, high levels of unemployment, family breakdown, record levels of bank repossession on rural properties, issues of access and equity, and the list goes on." – (Blue, 1992)

The ABS (1996) Report indicates that across Australia, Indigenous persons represent 2% of the total population. This reflects the metropolitan and non-metropolitan percentages, of 0.9% and 3.7% respectively. According to the ABS Census (2001) there are 1,275 Indigenous people in Gippsland, of which 630 are aged 18 and over. Although identified as a minority group, Indigenous Australians form an integral part of the make up of Australian society and therefore our ageing demographics. Indigenous Australians,

however, do not enjoy the same health profiles as non-Indigenous Australians.

Global health statistics released by the World Health Organisation (WHO) in June 2000 confirm that the general population of Australia is one of the healthiest of any developed country and, in the event of illness, has ready access to a world class health care system. The same statistics verify that the Indigenous Australian population is one of the least healthy of all Indigenous populations within comparable developed countries, and does not have the same level of access to appropriate health care as the general population. Life expectancy at birth for Indigenous Australians is estimated to be around 20 years less than for other Australians (Commonwealth of Australia, Better Health Care, 2001). The major causes of their early deaths are injury, coronary heart disease, diabetes and homicide, with males in the rural and remote areas suffering higher rates of injury than females (McMurray, 2003).

Indigenous Australians who have a worse health status than non-Indigenous Australians have not enjoyed the same increase in health improvements for Australians generally. Indigenous Australians are more likely to be exposed to poor living conditions which can be attributed to a high rate of disease and injury. ABS (1997) reports that Indigenous people in rural areas are less likely to live within 25 kilometres of services and facilities.

According to the Commonwealth of Australia: Better Health Care report (2001), Indigenous people are not receiving timely, high quality diagnosis, treatment, rehabilitation and palliation with their level of illness; and the

system is failing to prevent poor health through the prevention of early intervention and population health mechanisms. This can result in the lack of early treatment for ear, eye or skin infections and the lack of detection and proper management of chronic disease leading to secondary complications, for example, poor management of diabetes can lead to renal failure and blindness and poor access to maternal and child health services can contribute to infant mortality rates.

Deaths amongst Aboriginal and Torres Strait Islander people are caused by diseases of the circulatory system, respiratory system, and endocrine system and also from injury. Substance misuse, in particular alcohol misuse, may contribute to harm and injury through motor vehicle accidents and interpersonal violence or intentional injury. The second largest contributor to Indigenous mortality according to AIHW (1998) data was motor vehicle accidents, fire, drowning, poisoning, violence and other causes of injury. Other common conditions are asthma, back problems, eye/sight and ear/hearing problems. Diabetes is a common cause of death and is a reported condition for 5% of Indigenous Australians. In 1998-1999 about 75% of Aboriginal and Torres Strait Islander people who received hospital treatment for diabetes had Type 2. Indigenous people with Type 2 diabetes often develop the disease earlier than other Australians and often die at younger ages (ABS, 2001). Kidney disease is associated with diabetes, high blood pressure, infections, low birth weight and obesity, all of which are conditions found more commonly in Indigenous populations. Kidney disease can also lead to sustained dialysis treatment regimes. In 1998-1999, 44% of principal

procedures in hospital recorded for Indigenous people were for haemodialysis (ABS, 2001). Rising rates of renal disease is seen as a serious public threat to Indigenous Australians.

Specific 'health goals' for Indigenous Australians were initiated in 1994 through the *National Rural Health Strategy* which was released and updated in 1996. Further to this in 1999 *Healthy Horizons: A Framework for Improving the Health of Rural, Regional and Remote Australians,* was released and identified a number of key goals including goals to improve 1) health for areas of highest priority, 2) the health of Aboriginal and Torres Strait Islander people living in regional and remote Australia, and 3) collection and availability of information about the health of regional, rural and remote Australians.

As a whole, Indigenous people are more likely to live outside urban areas than non-indigenous people and are therefore more likely to be disadvantaged in accessing appropriate health care. Palliative care services in particular, which are generally provided by 'mainstream' service providers do not necessarily have the knowledge of or understanding of Indigenous needs or 'Dreamtime' and Indigenous culture. 'Mainstream' and Indigenous health providers tend to work in 'parallel' and according to a National Indigenous Palliative Care Needs Study (Commonwealth Department of Health and Ageing, 2003) they often do not relate to each other. The study also reports a lack of understanding of palliative care and that there are insufficient resources for the provision of palliative care services to Indigenous people.

The study further identifies major gaps in the services that are provided, such as no home-based care for some rural regions.

2.5 The Impact of the 'Baby Boomers' on an Ageing Population: the Cohorts of the Future:

(Who will impact on the design of services and make decisions for an ageing population?)

"By the 100th anniversary of Woodstock, we'll be as scarce as Elvis. And there's no street demonstration, self-help book, guru, political ideology or religion that can do a thing about it. How we handle the next several decades will seal or confirm our destiny."   (Smead, 2001)

In 1961 baby boomers were the prominent end of the age distribution (all children under 15), as outlined in Table 4. Between 2011 and 2031, baby boomers will make a significant contribution to the number of people aged 65 and over, and will therefore be a predominant feature within population ageing statistics and dynamics.

Due to the sustained decline in fertility which followed the post-war baby boom, there has been a decline in the proportion of the population to be found in younger age groups and the consequent increase in the proportion found in older age groups. In 1961, at the height of the baby boom, the total fertility rate peaked at 3.6 babies per woman (ABS, 1998). By the late 1970's, it had fallen to around half that level and has continued to decline (at a much slower rate) throughout the eighties and nineties. Australia's population has aged steadily throughout this century, apart from a temporary reversal due to the post-war baby boom. During the 25 years after World War 11 the median age

declined, reaching a low of 27.5 years in 1971 as the first of the baby boomers began to have children of their own. Since then it has risen to 34.3 years in 1997 and is projected to reach between 42 and 43 years in 2031 (as the youngest of the baby boomers turn 65) (Australian Bureau of Statistics, 1998: Population Projections 1997 to 2051, Cat. no. 3222.0, ABS, Canberra).

According to the ABS (1998) and based on assumptions of continued low fertility, and small declines in mortality, Australia's population is projected to continue ageing into the next half century.

The period from the end of World War 11 until the 1960's – is often referred to as the 'The Baby Boom' and is known as such in several countries including Australia. Prosperity after the War led to industrial advancement, a rise in living standards and a decrease in serious labour shortages for countries such as Canada, the United States, New Zealand and Australia. These countries also welcomed high levels of immigration, and a rapidly growing population was seen as essential to continued economic progress (Statistics New Zealand 1995, New Zealand Now: Baby Boomers).

Australian residents qualifying for baby boomer status are those who were born in Australia or overseas during the years 1946 to 1965, and also includes those immigrants who came to Australia from countries which did not experience a post-war baby boom. Many social changes began to take place in the 1960's which may have heralded the onset of the Baby boomer era such as the introduction of oral contraceptives, the changing perceptions of the ideal family size, the growing acceptance of women's participation in

paid employment, and the decline in birth rates. Baby Boomers would have been influential in initiating these social changes due to the impact these issues had on their stage of life and their lifestyle, which would also be in keeping with the penchant of the Baby Boomers to do things differently.

As the literature on ageing grows, so too does the literature on baby boomers. The baby boomers are described throughout the literature as the cohorts of the future. Our population is ageing because the postwar baby boomers are now beginning to turn grey. By the year 2010 the children of the baby boom years will begin celebrating their 65th birthdays. A combination of advances in health care and improved living standards as well as a dominating culture of a more affluent, better educated, more widely travelled ageing population will impact on Australia's future retirement industry. This impact may already be evidenced with comments from the The Hon. Kevin Andrews MP, Federal Minister for Ageing such as in the future (with reference to employment) no Australians will have a 'use-by-date.'

Seedsman (1994) also noted:

> As the Baby Boomers become the aged cohorts of the future they will bring new demands for the realisation of health and achievement, not witnessed before in the history of modern societies (p.61).

Life's course is often described in the literature as a fourfold division. Lasslett (1991) in his book *A Fresh Map of Life* explains:

First comes an era of dependence, socialisation, immaturity and education; second an era of independence, maturity and responsibility, of earnings and of saving; third an era of personal fulfilment; and fourth an era of final dependence, decreptitude and death (p.4).

The baby boomers may well challenge Laslett's Life's Course definition, refusing to move into their *Third Age* graciously. They may not be so willing to give up their power of earning and independence to move into retirement at a predetermined age. They may wish to push the boundaries of ageing; wishing to extend rather than to relinquish, their *Second Age.* This can be seen by the increase every year of the number of women in their 50's in the workforce. Veronica Sheen, policy director at the Council on the Ageing agrees, and states:

"Baby boomers were on the cutting edge of social movements in their youth and now they will re-write old age"(cited in Healey, 2003, p.39).

Horin (2003) posits that baby boomers will be marked in history as those who fought wars, protested for free love, gay rights and women's liberation, and new educational opportunities – even though less than 10% went to university. Horin also highlights some negative milestones experienced by some baby boomers, in that they lived through two recessions, economic restructuring, and many lost out on job prospects to better educated

Generation Xers. Horin stated that several other experts such as Peter McDonald, Professor of Demography at the Australian National University; Veronica Sheen, policy director at the Council on the Ageing; and social policy researcher Julia Perry are of the shared opinion that the baby boomers will impact on our ageing society by reversing the trend into early retirement, and by claiming a greater part in the nation's affairs (Healey, 2003, p.39). McCallum (2005) sums it up well by saying:

"Baby boomers – born in the post-World War 2 years – are used to getting what they want and shaping a future that fits them. They want choice, flexibility, stimulation and above all, control. They won't want to be put away in hospitals or nursing homes" (p.30).

2.6 Palliative Care

(What are the palliative care demands and needs of an ageing population in a rural area, and are they different to those of a metropolitan area?)

A Census of Palliative Care Services in Australia has been undertaken (State of the Nation 1998: Report of National Census of Palliative Care Services: Palliative Care Australia). The Census provides data relating to palliative care services and program provision as well as demographic data for people receiving palliative care in metropolitan and rural Australia. Figures pertaining to rural service provision are collective for each state and are not regionally specific. The researcher approached Palliative Care Australia in an attempt to obtain more specific data. The Chief Executive Officer advised

that due to limited resources and the 'pioneer' nature of the Census (this Census was the first of its kind)[1] more specific data such as a breakdown of the data which would identify specific rural and regional areas is not available. A survey conducted in 1999 whereby data collection was carried out by volunteers again appeared to be hampered by a lack of resources. Other limitations to the Census data included:

- varied methods of record keeping across programs,

- difficulty in determining accuracy of numbers of patients receiving palliative care, and

- data were gathered on a self-reported basis, and no formal means of verification was in place.

Research suggested that defining palliative care is problematic. This appears to be true as the literature provides several definitions of palliative care. According to Doyle (1990) defining palliative care can be dependent on one's viewpoint and background. The guiding principles of palliative care have been identified by the World Health Organization (WHO), as:

1. affirms life and regards dying as a normal process and neither hastens nor postpones death,

2. provides relief from pain and other distressing symptoms

3. integrates the psychological and spiritual aspects of patient care,

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[1] Palliative care is still a relatively young discipline and therefore the methods for statistical data collection are currently under review.

4.   offers a support system to help patients live as actively as possible until

death,

5.   offers a support system to help the family cope during the patient's

illness and their own bereavement (Johnston and Abraham, 1995, p.

124).

According to these principles, palliative care should provide comfort and the alleviation of distressing symptoms. Doyle (1990) states that quality of life issues and the right to die with dignity are seen as central to palliative care and provide the focus for care of the terminally ill. Whilst Downing et al (1993) have defined palliative care as both a philosophy and a program, as palliative care can be seen as a combination of people, words, attitudes and education.

Buchanan et al (1990) claimed that palliative care was best described as a biopsychological approach. In this approach symptoms are still treated, however, central issues involve physical psychological, social and the spiritual. This approach is in contrast to a more biomedical approach, or one which has its focus on palliative medicine, the disease, symptoms and prognosis, such as Doyle's (1994) definition of palliative care as *palliative medicine.* This definition becomes problematic when palliative care is seen as a multidisciplinary approach. He defined palliative medicine as "The care and study of patients with active, progressive, far-advanced disease with a limited prognosis, and for whom the focus of care is the quality of life" (p. 291).

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For the purposes of this research, the *definition of palliative care* used will be that provided by Palliative Care Australia in their Strategic Plan 2003-2006.

'Palliative care is specialized health care of dying people which aims to maximize quality of life and assist families, carers and their communities during and after death' (Palliative Care Australia: Strategic Plan, 2003-2006, p. 1).

Palliative care grew out of the hospice movement, and may be seen as different from "hospice" care in that hospice patients are usually required to have a "terminal" illness, and a short prognosis. In its simplest form, palliative care is care of the dying, who may have a more indefinite time to live. The Oxford Dictionary refers to the term to *palliate* as to *lessen pain* or to *alleviate* pain and suffering. In its early days, the term palliative care was given to dying cancer patients in recognition of the need to alleviate the distressing symptoms associated with cancer, and a disease process that was not curative.

More recently, palliative care encompasses all other non-curative diseases/illnesses. As medical expertise and the study of "thanatology" have unfolded and combined with technological advances, so too has palliative care grown and become a recognised specialty for all who may require palliation. These may include those people dying of AIDS, coronary disease, motor neurone disease and may also include the frail elderly who are simply dying of non-curative old age or dementia which is recognised as an incurable

disease. The principles of palliative care can be applied to any person and in any setting. 'Any setting' in terms of this research has important ramifications given the tyranny of distance and imposed rural and regional boundaries. Palliative care takes place in hospitals, hospices, and nursing homes or at home, depending on the community and the wishes of the person who is dying. Palliative care is tailored to, and dependent on an individual's needs and wishes, and therefore does not fit well into a narrowly defined health system, especially in a rural environment where resources can be scant. Rural palliative care faces particular challenges in supporting a client and his or her family within the community where that person has chosen to die at home. Cairns and Yates (2003) argued that these challenges may also include a lack of education and a lack of palliative care expertise.

In general, palliative care may be defined as the provision of holistic care, and support by a multidisciplinary team for those approaching death. There is a recognition of the patient and their family or carers as to the unit of care. It is further seen as the coming together of philosophy and skills which seek to alleviate pain and suffering. Quality symptom control is believed to be fundamental to palliative care. The provision of psychosocial and spiritual care which upholds the values of quality of life is further seen as intrinsic to palliative care.

People requiring palliative care are those with an incurable illnesses and limited life expectancy and includes people of all ages including youth (Palliative Care in Victoria, June 1995). This also includes people suffering

from a terminal illness such as cancer, AIDS, or other such diseases. People requiring palliative care also include those requiring *terminal* or *end stage care* and incorporates the frail elderly who enter a terminal phase due to the ageing process. This group may or may not have complications or other chronic illnesses. For the purposes of this research 'dying people' will also include those dying of incurable 'old age'. Indeed some people may see old age as an affliction, infirmity – whatever the view, old age is definitely incurable. According to mortality statistics (1994 and 2000) which were collected by the General Registry Office for England and Wales, death by 'old age' is given as the only cause of death in an increasing (yearly) number of elderly patients.

A nursing home resident who requires palliative care will be one whose condition has progressed beyond the curative stage and where relief from pain and other symptoms that incur suffering will enhance quality of life. *Nursing homes* are defined as those facilities or residential care units which operate under the Commonwealth Department of Health and Ageing. They are accountable to the Commonwealth Government and must meet a range of Outcome Standards for Australian Nursing Homes. Nursing homes are required to provide continuous 24 hour nursing care which is developed to suit the needs of each individual resident and is directed towards maintaining their independence and skills. Nursing homes in general have developed their own vision statements which reflect an ideology pertaining to each environment. Nursing homes may be privately run for profit, they may be

charitable organisations (not for profit) or they may be State Government nursing homes, some of which may be partially Commonwealth funded.

People delivering palliative care are generally nurses who hold current registration with the Nurses Board of Victoria. Division 1 nurses, will have completed three years of a Bachelor of Nursing program, or have completed the Diploma of Nursing program under the previous nurse education system. Division 2 nurses, also known as State Enrolled Nurses or SRN as State Registered Nurses, have completed 1 year full time or two years part time training. An NA or Nursing Assistant is one who has had no formal nursing training, whilst a PCA or Personal Care Attendant (currently known as an Aged Care Worker) is one who performs non-nursing duties, and may or may not have completed a Certificate 111 in Aged Care Work, which constitutes approximately 470 hours of training.

Palliative Care Experience is defined as experiences when caring for any person whose condition is no longer curative, whose condition is terminal or who requires end stage care. In other words, any person who is at the end of their life for whatever reason, with the understanding that their condition is not able to be cured.

Caregiver/carer/caring. Carers are people who regularly provide the most assistance with one or more of the core activities of communication, mobility, transport, housework and self-care. A carer is also defined as someone who provides support without payment to a neighbour or family member who is

frail, ill or disabled.

Palliative Care Australia (PCA) is the national peak body for palliative care in this country. Their goal is to work toward the relief of pain and suffering of people who are dying and the provision of their care. They are the authors of Standards for Palliative Care Provision (October, 1999). This document outlines the Model of Quality Care for Palliative Care Services, which describes the components of quality specialist care for people who are dying, their families and the community, and is designed to reflect the standards for palliative care which are underpinned by core values and principles. Palliative Care Australia worked with the Australian Council on Healthcare Standards to develop these guidelines. A specialist palliative care 'model' of care incorporates expertise from doctors, palliative care nurses, social workers and pastoral care workers. Although community health groups, and the Royal District Nursing Service, as well as Hospitals offer palliative care services at varying levels and with varying modes of delivery, they generally sub-contract the specialist services to enhance their own program. The standards provide a benchmark for providers of specialist palliative care services. Applying these standards in a rural environment however may be problematic if even the most basic of the underlying principles cannot be met, such as supporting the dying person who wishes to stay at home. In June, 2003 Palliative Care Australia released a 'Planning Guide' which detailed the population-based resources necessary for palliative care service provision in Australia. However, Currow and Nightingale (2003) stated that "…there are still wide variations in equitable access to services" p. (23).

A review of the literature into 'rural palliative care programs' revealed that a number of programs which exist across Canada note their primary concerns, and the biggest challenge is in keeping the patient in their own community for as long as possible, ultimately to die the way they wish, surrounded by familiar faces. Expertise is often limited and is frequently sought from bases outside the rural community to support these programs.

Closer to home, a three-State (Tasmania, Victoria and South Australia) project which was conducted by Moorhouse, George and Young (2000) found that terminally ill Australians living in rural and remote areas should be enabled to die with dignity in their home community. The final report on this two year study entitled 'Promoting multidisciplinary collaboration in palliative care in rural Australian communities', basically recommended that community education be undertaken in rural and remote areas to promote the concept and support the reality of dying at home. The establishment of local palliative care teams in rural and remote areas was also recommended, as well as routine use of Telehealth videoconferencing to improve palliative care service provision and family support during end of life care (Moorhouse et al, 2000).

Palliative care is a relatively new specialty and one where much of the research tends to focus on pain management and symptom control. Doyle (1990) claims that many carers and physicians feel an antagonism towards research, deeming it invasive or incompatible with patient dignity. While this may have been so, current research such as those from the Melbourne Grief

Studies (Kissane, 2000) suggests that there may have been a shift in research. Participants in this study consist of family or carers experiencing grief and loss or bereavement in Australia. It may be now plausible to suggest that the baby boomer generation is more prepared to tackle sensitive issues surrounding death and dying. With the arrival of a new Australian publication edited by Kellehear (2000) we may be entering a new cultural awareness into death and dying. Palliative Care Australia has also published a report of a national inquiry into the social impact of dying, which details the experiences of those who care for the terminally and dying (Palliative Care Australia, 2004). This report has found that of the 20,000 yearly expected deaths in Australia, one third receive palliative care with support from a doctor and community services. The Report further found that most responsibility falls to 'carers'.

Palliative care is a new discipline, and as such continues to define itself. This is emphasised by the many definitions of palliative care found in the literature. Research into this area is often hampered by ethical boundaries due to the sensitive nature of data collection, and the fact that subjects are either dying or have recently died. Because of this, research into palliative care is limited. This current research outlined in this thesis aims to provide information pertinent to the discipline of palliative care and therefore to contribute to a developing knowledge base.

(Is there a lack of knowledge and understanding of palliative care in rural areas?)

The literature suggests there is a recognised need to improve education and training in palliative care (Doyle et al, 1993, Rutman et al, 1991 and Ross, McDonald and McGuiness, 1996). The literature identifies this need across all healthcare sectors. Sheldon (1995) acknowledged that there has been a rapid expansion in education for palliative care providers which has occurred in the past ten years. However, Maddocks and Donnell (1992) reported that this rapid expansion in Australia occurred without the advantage of established palliative care qualifications of teaching staff within the field. Ten years later, Cairns and Yates (2003) posit that although principles and practice of palliative care are now incorporated into undergraduate curricula, what little information is available indicates that there may still be gaps in this curricula. There is a need to improve education and training for palliative care providers, but until recently it has not been clearly identified what is needed to meet these improvements. The literature reveals very little pertaining specifically to nurses' knowledge of palliative care. A 1994 report on undergraduate nursing education in Australia noted a vast range in the total time spent on education about death and dying, that was between 5 and 192 hours (Cairns et al, 2003).

In Canada, Ross, McDonald and McGuiness (1996) developed and validated an instrument (the Palliative Care Quiz for Nursing) to measure nurses' knowledge of palliative care and concluded that this instrument was useful for

assessing knowledge, stimulating discussion and identifying misconceptions in palliative care. The Kuder Richardson formula 20 (KR-20) was used by Ross et al to assess the internal consistency of the PCQN. The PCQN is a 20-item true, false, *I don't know* test of knowledge, and is specific to palliative care. High internal consistency (0.78) was indicated. Analysis revealed that those who had received palliative care education scored significantly higher than those who had not. Ross, McDonald and McGuiness (1996) noted that "a desirable quality of a test of knowledge is that it distinguishes among respondents with specific characteristics relative to that knowledge" (p. 131).

In this Canadian study, an analysis of variance was computed that compared the mean number of correct items from registered nurses, and registered practical nurses who were currently employed in community and hospital settings and were experienced in palliative care and general nursing. It also included student nurse respondents who had little or no experience in palliative care, and had not been exposed to specific courses in palliative care during their training. Significant differences were identified: Registered nurses scored higher than students and registered practical nurses. Findings also confirmed that the more senior the student the higher their mean score. Ross, McDonald and McGuiness (1996) affirmed the validity of the PCQN as a measurement of knowledge and stated that "...it can be anticipated that as students progress through a 4-year baccalaureate program in nursing, they can be expected to be increasingly exposed to both content related to palliative care and to clinical experience with palliative care patients, and consequently to be increasingly knowledgeable about palliative care" (p.132).

In a 1998 study conducted by this researcher (Ryan, 1998) the Canadian study was adapted to suit the Australian environment in an attempt to determine the extent of nurses' knowledge in palliative care in nursing homes in Victoria. This study reflected the findings found in the Canadian study and has shown that there is an absence of formal palliative care qualifications within the nursing home sphere (at least). There were no post graduate qualified palliative care providers found within this study. This was an interesting finding when 60% of respondents reported having palliative care experience ranging from one to thirty-five years. The study highlighted the problem of defining palliative care as the term appeared to have many different meanings to different people, including end stage care and terminal care. A lack of formal palliative care qualifications among palliative care providers in *other settings, (i.e. non-hospice)* appears to be a consistent finding. Maddocks and Donnell (1992) asserted that:

"the discipline has expanded rapidly and its leading exponents in Australia have been forced to develop clinical programs, recruit staff and initiate training activities without the advantage of established qualifications in the field to support appropriate appointments, career paths or professional status" (p. 317).

A study by Uyeda, Farrell, Schneider and Millership (1997) determined the training and education needs of persons currently providing palliative care throughout Australia. Recommendations from this Report to the Department of Human Services and Health for future initiatives included:

- *Educate palliative care providers to utilise support services to enable the dying patient to die in their own home.*

- *Create the opportunity for palliative care providers to express their feelings through appropriate avenues.*

- *Include content on coping strategies in palliative care education and training programs.*

- *Develop further education and training for palliative care providers on skilled and sensitive communication.*

- *Include content on sources of stress and stress management in palliative care education and training programs.*

- *Maintain content on issues relating to religion, faith and spirituality in palliative care education and training programs.*

- *Include content on political and ethical issues and management strategies for these issues in palliative care education and training programs.*

- *Measure the effectiveness of all courses conducted in terms of enhanced patient care and improved social outcomes.*

- *Require that teachers in palliative care courses have appropriate educational qualifications and training.*

- *Include content on loss and grief in palliative care education and training programs.*

- *Teach basic principles of pain assessment and management of pain in palliative care education and training programs.*

- *Provide regular education updates in current issues in palliative care.*

- *Provide education and training courses, including loss and grief content, for unpaid palliative care providers.*

- *Encourage research into the identified education and training needs of the palliative care providers.*

- *Encourage palliative care providers to conduct research into the issues that concern them.*

- *Provide continuing education on teamwork in the workplace.*

(Uyeda et al, 1997, Summary p.1)

In May 2004, a project funded by the Australian Government Department of Health and Ageing released Guidelines for a Palliative Approach in Residential Aged Care. The National Palliative Care Program was prepared by Edith Cowan University, Western Australia. Whereas both the earlier Uyeda (1997) report and the current Australian Government Department of Health and Ageing: Edith Cowan University report (2004) basically concur, the Edith Cowan University Report also acknowledges Aboriginal and Torres Strait Islander issues as well as cultural issues in palliative care, as recommended education strategies now needed in palliative care settings. However. rural education needs do not appear to be specifically highlighted. A National Indigenous Palliative Care Needs Study (Commonwealth Department of Health and Ageing, 2003) found a lack of knowledge of palliative care and what it means among Indigenous people. The study also found a lack of palliative care training and recommended the urgent need for training for Aboriginal Health Workers.

According to Clare et al (1997) The Aged Care Monograph put out by the Australian Institute of Nursing Research asserts that:

> Nursing homes within Australia are providing palliative care to residents in a restricted way - limited by expertise, funding, educational programs, and time. According to currently available palliative care standards (AAH and PC 1994), nursing homes are lacking in almost all areas (p.55).

Palliative care is seen as burdensome in the nursing home environment because of the lack of funding, a poor skillmix of staff and a general lack of resources and education. In their report to the Australian Institute of Nursing Research, Clare et al (1997) recommended the need for on-going palliative care education specific to the nursing home environment. Maddocks et al (1996) in their study of palliative care in nursing homes in South Australia noted that given the resources available, palliative care is very well provided. However, they further recognise that funding and staffing of nursing homes is inadequate, and that time and education is required, they acknowledge that the needs of the elderly who are dying in nursing homes are unique and that there is a need for palliative care to be specific to the nursing home environment.

Hopefully, the Australian Government Department of Health and Ageing National Palliative Care Program (2004) prepared by Edith Cowan University should answer many of these criticisms. An 'evaluation' of the impact of these Guidelines, once implemented through training and education programs, will provide a valuable contribution to a discipline which is still considered to be 'new'.

The literature reports that there is a lack of support for nurses in aged care, and that aged care facilities are lacking in trained nurses with the majority of care provided by unregulated and unlicensed, pseudo nurses. Hare and Pratt (1989) concurred, finding that the number of persons dying in nursing homes is greater than in hospitals with para-professionals providing the major portion

of nursing care. They further found that 94% of para-professional nurses were not as comfortable with death and dying as were professional nurses. According to Clare et al (1997) "Nurses caring for a dying person must be comfortable with death in order to be able to care for dying residents in a positive and therapeutic way" (p. 57).

2.7 The Role of Palliative Care Within an Ageing Paradigm

"Our goal is to work toward the relief of pain and suffering of dying people in Australia and the provision of care they need." (Ellen Nightingale, President, Palliative Care Australia, 1998 State of the Nation Report, p.1).

The Victorian Government has allocated an additional $7 million over the next three years (2004-2007) for palliative care. Based on population needs in a geographic location and the mix of inpatient services and community care services available in the region, the Department of Human Services will review funding arrangements, allocating funds on an equitable basis (Department of Human Services, 2004).

Palliative Care Australia (2002) and the Department of Human Services (2004) reported that palliative care service provision in Australia is occurring across three settings:

- community settings
- designated palliative care beds or hospice settings
- acute hospital settings

Community settings include the person's private home or a community living environment such as an aged or supported care facility. Home is the setting in which many people choose to receive care, and in which a significant

proportion prefer to die. *Inpatient designated palliative care beds* include rural community hospitals. Palliative Care Australia (2002) estimated that in a population of 100,000, 295 patients will require an average of 7 inpatient palliative care bed days each year, and is based on an occupancy level of 85%. A significant proportion of anticipated deaths still occur in a*cute hospital settings.* Some patients will be identified as needing palliative care while in hospital and some will be admitted to receive treatment for acute medical or surgical conditions or for symptom control (PCA: 2002 Palliative Care Service Provision in Australia Planning Guide).

Palliative Care Australia conducted a Census of palliative care services in 1998 (State of the Nation, 1998: Report of National Census of Palliative Care Services). The Census called for voluntary participation of palliative care service providers and describes who receives palliative care, where they live, who provides it and how much is provided. The Census includes both metropolitan and rural data.

The 1998 Census indicates where palliative care is being provided and the type of programs being provided by palliative care services nationally. In Victoria, Community programs were reported to be N=33, Inpatient Programs N=13 Consultative Programs N=17, Outpatient programs N=6. *Regional and rura*l representation for palliative care service providers in this Report record only the 'major programs', noting Community programs N=23, Inpatient Programs N=7 and Consultancy N=12. adapted from (State of the Nation, 1998: Report of National Census of Palliative Care Services).

The Census also reports on accessing medical and palliative care nursing. Figure 4 reflects that most direct clinical services in rural areas are provided by nursing personnel, either Clinical Nurse Specialists or Registered Nurses, with very limited access to specialized medical support. This graph shows that palliative care services in regional and rural areas are less likely to provide access to specialist palliative care doctors than metropolitan areas.

Figure 4. Access to Medical and Nursing Palliative Care Services by Location

% of services providing access
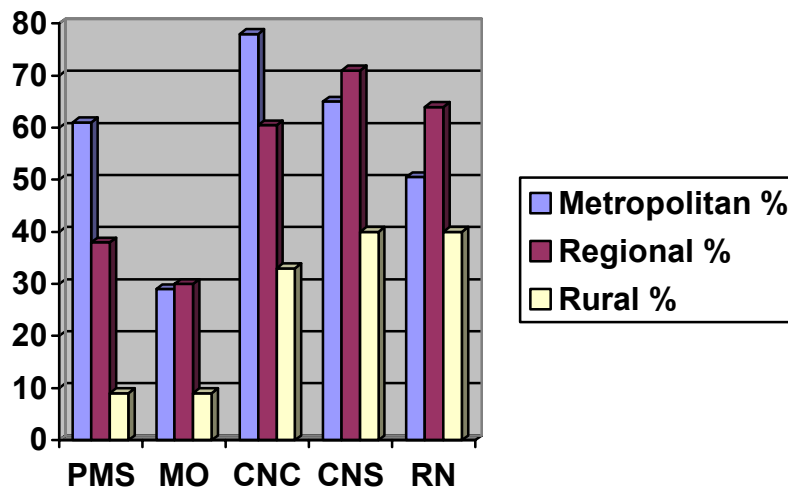
PMS: Palliative Medicine Specialist
MO: Medical Officer
CNC: Clinical Nurse Consultant
CNS: Clinical Nurse Specialist
RN: Registered Nurse

Source: (Palliative Care Australia – State of the Nation 98, p.15)

The following Tables (7, 8 and 9) show how many people might require palliative care. Palliative Care Australia (2002) report current and expected

deaths and referrals to palliative care services (annually) which are presented in Table 7.

Table 7. Current and expected deaths per 100,000 population and referrals to palliative care services annually.

Diagnosis Group	Actual Deaths	Current Referrals per 100,000	Recommended Referrals for assessment per 100,000	Ongoing consultancy per 100,000	Direct Care per 100,000
Cancer	187	94-168 (50-90%)	168	131	37
Non-Cancer	187	17-30 (9-16%)	94 (50%)	56 (30%)	19 (10%)
Total	**374**	**111-198**	**262**	**187**	**56**

Source: (PCA: 2002 Palliative Care Service Provision in Australia Planning Guide, p.17)

The clinical staffing guidelines are based on a number of assumptions and estimates. In relation to activity and appropriate use of resources it has been determined (based on best available empirical evidence) that palliative care services should be involved in:

Cancer patients:

- the assessment of 90% of patients within the area that die from cancer

- an ongoing consultative capacity for approximately 70% of cancer patients

- direct care for 20% of cancer patients

Non-cancer patients:

- referral for assessments of 50% of patients expected to die from non-malignant diseases

- an ongoing consultative capacity for 30% of these

- ongoing direct care for 10% of these.

Current data on cancer and non-cancer deaths indicates that there are approximately 187 deaths from cancer and 187 expected deaths from other causes per 100,000 population per year progressive predictable life limiting illness. (PCA: 2002 Palliative Care Service Provision in Australia Planning Guide, p.17)

Palliative Care Australia found that 85% of palliative care caseload is captured by the population of persons aged 55 years and over. Statistics collected on Census day show the relation to population aged 55 and over, which are presented in Table 8.

Table 8. Adjusted Registrations on Census Day: Relation to Population Aged 55+ Years

State	Metropolitan	R: 1000#	Regional/Rural	R: 1000
NSW/ACT	3530	4.2	2041	3.5
NT	63	8.3	13	1.5
QLD	807	2.8	864	2.2
SA	817	3.3	257	2.6
TAS	170	3.9	203	3.3
VIC	1511	2.2	697	2.2
WA	763	3.1	166	2.0
TOTALS	7661	3.26	4241	2.75

Registrations per 1000 of local population aged 55+

Source: (Palliative Care Australia – State of the Nation 98 p. 19)

Age distributions for males and females in three samples of the palliative care population were compared in the Census with the age profiles for Australians who died from cancer in 1996, these comparisons are represented in Table 9.

Table 9: Age Distribution of Palliative Care Patients: Comparison with Australian Cancer Deaths

Sample	N	Males				Females		
		◄55yrs	55-74	75+ yrs		◄55yrs	55-74	75+ yrs
ABS 96	34668	10.9*	49.8	39.3		15.3#	41.6	43.1
Inpatient 1998	1002	16.9	49.0	34.5		19.7	44.1	36.3
Community 1998	4590	14.4	52.9	32.7		22.5	45.4	32.2
Palliative Care deaths 1997-1998	2196	13.6	51.8	34.6		14.1	48.2	37.7

* % of all males in sample
# % of all females in sample

Source: (Palliative Care Australia – State of the Nation 98, p. 25)

Palliative Care Australia (1998) estimate that 12,456 annual deaths were reported by metropolitan services which represent 5.3 deaths per 1000 persons aged 55+ years. The 7,027 deaths which were reported by regional and rural palliative care services represened 4.6 deaths per 1000. More specifically in the State of Victoria (1997-1998) of the 4,065 people in the 55+ age group who died while receiving palliative care, 1,025 died in regional/rural areas. Victoria. Metropolitan deaths were N=2860. The Census further reveals that increasingly a greater percentage of deaths are occurring at home. In 1997-1998, 34.8% of deaths occurred at home whereas in 1996-97 the percentage was 27.5%. Population-based rates of admission to

palliative care services in regional and rural locations are 30-35% lower than in capital cities, attributable to the lack of access to specialist palliative care doctors. According to the Department of Human Services (2003) in 2002-03, 7,228 patients accessed community palliative care services including rural areas with 51% dying in a hospital. Of these, 52.9% were male and 76.4% were over the age of 60 years. Malignancy was the reported diagnosis in 87% of cases. Clinical consultancy or care was provided in 23.6% of contacts, and spiritual and/or emotional support and/or counseling was provided in 20%. Nurses were reported to have provided 74.4% of services (Department of Human Services, 2003).

Palliative Care Australia have drawn a number of conclusions based on their Census data, including:

- there is an increase from 56% in 1997 to 62% in 1998 in the number of people who die receiving palliative care;

- there are significant differences in access to any kind of palliative care services between people who live in metropolitan centres in Australia in comparison to regional and rural areas;

- more than one third of Australians who died receiving palliative care services die at home.

Models of Palliative Care

All Victorians with a progressive life threatening illness and their families and carers will have access to a high quality service system that fosters innovation and provides coordinated care and support that is responsive to their needs (Department of Human Services: 2004-09, Vision Statement p. 7.).

As one of the objectives of this research was to provide recommendations for a rural palliative care model with specific regard to an ageing population, this section will focus on models of palliative care with recognition and acknowledgement of the standards, principles and current policies and requirements of palliative care service delivery as determined by the key stakeholders.

Aranda (2000) notes that in the mid 1990's two community palliative care models were apparent in Australia. The first model emerged in South Australia and Western Australia and comprised small specialist teams which were linked to community nursing services. Palliative care was delivered in consultation with specialist nurse consultants (Kelleher, 2000). Yuen et al (2003) reported that currently in Perth Western Australia, the Silver Chain Hospice Care Service (the largest provider of palliative care services) provides a multidisciplinary care team comprising doctors, nurses, allied health professionals, volunteers and spiritual and counselling support; and that other programs or models would prefer to use doctors attached to palliative care teams from hospitals or hospices.

In Victoria the second model, a 'multi-disciplinary' model emerged and focused on small stand alone services. This model of care saw a predominance of nursing and an emphasis on the specialist nurse within the multi-disciplinary team (Aranda 2000). Aranda relates a personal communication with Hodder in 1999 where she reports on an antagonistic relationship which emerged between services and the Royal District Nursing

Service which "… prevented a close alliance between generalist and specialist nursing services in the provision of palliative care, only recently disrupted by Government initiatives to produce a more integrated service system (DHS, 1996) and highlights the dynamic tension between specialist and generalist conceptions of palliative nursing" (p. 258).

Palliative care teams nowadays may include nurses, doctors, social workers, volunteers, chaplains, allied health professionals and bereavement therapists, and even music therapists. Some teams also utilize massage therapists and complementary or alternate therapies. The multi-disciplinary team approach is an holistic model which embraces the physical, psychological, spiritual and social domains of palliative care. Crawford and Price (2003) noted that there are often challenges for the team working in this environment, resulting in role ambiguity, role overload, conflict and leadership challenges (p. 33).

Kellehear (1999) proposed what could be considered to be a controversial model– the health promotion model of palliative care. Subsequently, the philosophy of health promotion in palliative care is now included in recommended planning of service delivery in palliative care. In this model Kellehear proposes that whereas health promotion focuses on illness prevention, palliative care (conventionally) highlights illness management, and that the two should not be mutually exclusive. He argues: "Do health professionals need to learn all over again that dying does not, and should not, disqualify anyone from quality health and social care? Seriously ill people still qualify as members of the 'public', and so the offerings of public health,

including the promise and support of health promotion, are legitimately theirs also" (p. 15).

The Palliative Care Program of the Victorian Department of Human Services funds specialist care providers in 30 inpatient settings across Victoria and in the 8 departmental regions of the state. The Department of Human Services (DHS, 2004) have outlined several factors which they state need to be ensured in the planning of care for people with life threatening illness and their carers and families. Namely that :

- the health and residential care workforce practices the palliative care approach;

- there is equitable access to a level of specialist palliative care across the state;

- the mix of bed-based and community-based specialist palliative care services is appropriate;

- care and referral pathways are clearly defined and options are identified;

- communication strategies ensure general practitioners, community care providers and other health providers are fully informed of, and able to participate in, the care plan for patients under their care;

- effective and efficient links exist between hospitals and community-based services; and,

- sufficient numbers of appropriately trained specialist palliative care providers are available to provide care across a region (DHS, 2004, p.2).

Specialist palliative care services are services which may accept prime responsibility for care, or work indirectly by advising clients who have professional carers. They provide physical, psychological, social and spiritual support and comprise a broad range of disciplines, including medicine, nursing, social work, pastoral care, physiotherapy, occupational therapy, pharmacy and related trained specialists. The specialist approach therefore differs from a 'palliative care' approach, which is held as good medical and nursing practice in the absence of, or in conjunction with specialist palliative care services (DHS, 2004). A palliative care approach aims to improve the quality of life of individuals facing life-threatening illness and of their families, by preventing and relieving suffering through early identification, assessment and treatment of pain and other problems – physical, psychosocial and spiritual (WHO, 2003). This approach facilitates identification of the wishes of clients and their families about care throughout a period of declining health and especially during end-of-life care.

In determining appropriate 'models' of palliative care delivery and the future planning of services DHS as the major funding body, has identified practices and processes which are encapsulated by the following guiding principles:

Principle 1: People with a life threatening illness and their carers and families have information about options for their future care and are actively involved in those decisions.

Principle 2: Carers of people with a life threatening illness are supported by health and community care providers.

Principle 3: People with a life threatening illness and their carers and families have care that is underpinned by the palliative approach.

Principle 4: People with a life threatening illness and their carers and families have access to specialist palliative care services when required.

Principle 5: People with a life threatening illness and their carers and families have treatment and care that are coordinated and integrated across all settings.

Principle 6: People with a life threatening illness and their carers and families have access to quality services and skilled staff to meet their needs.

Principle 7: People with a life threatening illness and their carers and families are supported by their communities (DHS, 2004 pp. 13-33).

These principles are based on aspects of care which are consistent with findings of a number of working parties and consultation groups, such as, the Palliative Care Strategic Framework Working Party, the National palliative care strategy (Australian Department of Health and Ageing 2000) and other Department of Human Services policies, including A Cancer Services Framework for Victoria (Barton et al, 2003), Improving Care for older people (Department of Human Services, 2003) and Primary Care Partnerships-strategic Directions 2004-2006 (Department of Human Services, 2004).

Specialist palliative care services are required to demonstrate the quality elements that are fundamental to the palliative care approach, as set out in the Standards for Palliative Care Provision (Palliative Care Australia, 1999). The Self Assessment Services Audit (Palliative Care Australia, 2001) is recommended by DHS as a structural method for assessing services and can

be used as evidence of achievement and verification in the accreditation process of the Australian Council of Healthcare Standards.

In February 2005 Palliative Care Australia produced their national policy document, *A Guide to Palliative Care Service Development: A population based approach, which they describe as a 'needs based model'*. The document describes a service planning framework which can be used "...to provide assistance to health service planners, funding bodies and care providers to ensure that health care services are designed to meet the needs of the population" (Palliative Care Australia, 2005, p.18).

Approved funding of projects in the area of 'models' for palliative care delivery over the next two years include rural and remote projects such as a multidisciplinary study, a study to investigate and to support tele-medicine models, and a "pop-up" palliative care service model to deliver palliative care to individuals in rural and remote areas of Australia. The study titled *Development of a model for palliative care in rural remote communities: the 'pop-up model'* is being conducted in three sites: one in Western Australia, one in New South Wales and one in Queensland. The study did not include Victoria. Although pertinent to rural palliative care service delivery, these studies are not designed specifically to include the needs of an ageing population. Results from these studies were not available at the time of writing this thesis, including the 'pop-up model' study which is still in phase 2, and is still collecting data.

Palliative Care in Gippsland

Palliative care providers in Gippsland which are funded by the Palliative Care Program: DHS include:

Designated palliative care units at:

>   Gippsland Southern Health Service and,

>   West Gippsland Health Care Group.

Community-based palliative care services incorporating:

>   Gippsland Palliative Care;

>   Bass Coast Regional Health;

>   Central Gippsland Health;

>   Gippsland Southern Health Service;

>   Latrobe Regional Hospital;

>   West Gippsland Health Care and,

>   Bass Coast Regional Health.

Inpatient Palliative Care in Gippsland

Inpatient palliative care services provide services to patients who are in the terminal phase of illness, and generally this is when active treatment for the patient's diagnosed illness ceases. Eleven palliative care inpatient beds are designated to Gippsland and funding is on a per day basis at a daily rate of $413 (1 bed = 292 bed days @ $413 per day). Beds are allocated to one acute hospital in each Local Government Authority, although they are not equitably distributed across the region. It is not known how these bed numbers or their distribution are determined. Four smaller hospitals provide inpatient palliative care by conversion of funds. Unused bed day funds are recalled at the end of the financial year. Unassigned bed funds (funding equivalent to 1

inpatient bed for Gippsland) are to assist services in their ability to respond to the individual needs of a specific client. The funds may be utilised by services to acquire additional care for the client, to purchase equipment that is not readily available or to arrange for additional home care or respite care for the client.

Table 10 shows the designated bed allocation to local government authorities and the provider.

Table 10. Designated palliative care beds allocated to Gippsland

LGA	Bed Allocation	Provider
East Gippsland	1	Bairnsdale Regional Health Service
Wellington	2	Central Gippsland Health Service
Latrobe	4	Latrobe Regional Hospital
Baw Baw	2	West Gippsland Healthcare Group
South Gippsland	1	Gippsland Southern
Bass Coast	1	Bass Coast Regional Health

Source: Central Gippsland Health Service Palliative Care in Gippsland, 2004, p.2

Community Based Palliative Care in Gippsland

Community based palliative care services provide a range of services to clients in their home and may include nursing, liaison with medical practitioners, counselling for the client and their family, other allied health services, complementary therapies such as massage, and co-ordination with other services. Services are required to support the client and their family 24 hours a day, 7 days per week. This model of delivery ideally incorporates the

multi-disciplinary team approach, but with sometimes limited or non-existent access to specialist palliative care services or doctors.

Health issues specific to Gippsland

Arguably, health issues which would be found to be specific to the rural area of Gippsland encompass a range of variables which impact on health such as politics, economy, social, cultural, environmental, behavioural and biological. Selected characteristics from the 1996 Census for the area of (East) Gippsland only, total population (N=77,710) indicate that there are a number of people born overseas (N=4,100). ABS (1996) statistics also suggest it is an an area of low-socioeconomic status with a reported median individual weekly income of $232.00 and a median household weekly income of $469.00. Of those reporting to be 'not in the labour force', (N=32,889), a further (N=3,926) reported that they were employed. The 1996 Census also reported an Indigenous population of N=1,312. Environmental issues such as the impact on health of asbestos mining also impact on the area of Gippsland.

Australia mined and imported large amounts of asbestos throughout much of the 20th century. After the First World War, construction began on a series of power stations in the Latrobe Valley in Gippsland where there was a widespread use of asbestos. Although the import and use of asbestos was banned in 2003, large numbers of workers are still being diagnosed with asbestos related illnesses, years after they were exposed (OHS Reps, 2005).

A Victorian WorkCover Authority, 2004 report highlights that:

> According to the Asbestos Diseases Foundation of Australia, it is estimated that between 2003 and 2020 more than 13,000 Australians will die from mesothelioma and a further 40,000 will develop asbestosis, with a 90% chance of developing full-blown mesothelioma over time (p.1).

Asbestos is a silicate mineral, mined from the earth. Widespread use is due to its resistance to heat and chemicals. The ill health effects of exposure to asbestos arise from breathing in, and retention of, very small fibres of asbestos. Diseases caused are asbestosis, lung cancer and mesothelioma and some other cancers such as larynx and stomach. The International Confederation of Free Trade Unions estimates at least one case of lung cancer in 10 is caused by exposure to asbestos (OHS Reps, 2005).

Asbestosis is progressive scarring of the lung, leading to pain, breathlessness and eventually death. The first symptoms can appear 15 to 20 years after exposure. There is no known cure. *Mesothelioma* is a cancer of the lining of the chest (pleura) or of the abdomen (OHS Reps,2005).

In March 2004, WorkCover Minister Rob Hulls announced a $15,000 funding boost to the Gippsland Asbestos Related Diseases Support (GARDS). GARDS is a non-profit, non-government organisation dedicated to supporting the victims of asbestos and their families. GARDS also works

to raise the level of asbestos awareness in the community, industry and at all levels of government. In accepting funds, a GARDS representative acknowledged the number of asbestos victims is climbing in the Gippsland community and that local resources are crucial. The Gippsland area suffers seven times the national average in asbestos related deaths (Victorian WorkCover Authority, 2004).

An expected climb in the number of asbestos related death and illnesses in the community of Gippsland will have ramifications for all health service providers including grief and loss counsellors and palliative care service providers.

2.8 Issues surrounding death and dying in Australia

"Nothing is more inevitable than old age and death, yet nothing is more surprising to the majority of us. Also of surprise, considering we all end up doing it, is the lack of interest shown by researchers in the area of dying older. Such a lack of interest is possibly an indicator of both endemic ageism and denial of death within the community."

(Stevens, McFarlane and Stirling, 2000 p. 186)

An important issue relating to death and dying in Australia is not only what people are dying of and when, but also where they are dying. This has important ramifications for palliative care service delivery and in particular for community palliative care services who aim to assist people to die at home if that is their choice.

Where the aged cohort are dying

"...families and patients need to be able to make an informed choice about where death should take place and recognize that the best place for death to occur may change over time...A key point, however, is that family-centred palliative care is as relevant for inpatient settings as it is for home care" (Hudson, 2003, p.36).

The Australian Institute of Health and Welfare (1997) reported that approximately 11 per cent of the aged cohort live in an aged care facility at any one time, and that for the year 1995-1996 there were 1,470 facilities providing 75,008 nursing home beds and 1,497 facilities providing 62,645 hostel beds in Australia. This report shows that 72 per cent of nursing home residents are very old women. Stevens et al (2000) noted the high mortality rate in 'God's waiting room' or nursing homes, and that hospital use is greater among older people. In the year 1995-96, a total of 76,053 people died in hospitals, with more than 75 per cent being over the age of 65 years (estimated from AIHW 1998, National Hospital Morbidity Statistics 1995-96). In terms of community care where there is a drive to assist people to stay in their own homes for as long as possible, Stevens et al (2000) goes on to state that the majority of people who are wanting to die at home end up dying in hospitals or in nursing homes. They attribute this to the slowness of community palliative care teams to infiltrate some regions of the country.

Grief and Loss for the elderly

"With each passing year the older individual is progressively immersed in an expanding matrix of losses" (Seedsman and Feldman, 2002, p.207)

It was our older generation who fought our wars and lived through the depression years. We need to recognize the uniqueness of this generation and

acknowledge that they have seen a lot of death and dying and experienced associated grief and loss. Raphael (2000) upholds that the model for grief that evolved during these periods of war and the subsequent tragic losses which were experienced by our older generation was one of 'stoicism, privacy, and survival' (p.119). We need to value these experiences of our older generation and learn from their knowledge and the contributions that they can bring in meeting the needs of an ageing society.

Seedsman (2002) posits that loss is a normal part of the lifecycle, which occurs more frequently and compounds in old age. Bytheway (1995) and Seedsman (1999) believe that ageism and related issues provide 'fertile ground' for the investigation of grief and loss issues faced by the elderly.

Raphael (1984) believes the physiological and psychosocial processes of ageing largely prepares the older person for death, and that this preparation begins with a series of losses. Physical losses include bodily function, loss of vision, loss in hearing, sexual function and fertility, muscular strength and, ultimately mobility, and loss of brain function due to an increase in the incidence of dementia related increase in age. Raphael also refers to psychosocial losses such as loss of work and social roles and the loss of a spouse.

Haffner (1986) showed losses associated with the phenomenon of aged people living longer leads to lowered living standards, and grief and loss

issues which now have to be addressed over a longer period of time, and reports dementia and depression as frequent mental disorders or losses.

Maddocks (2003) recognises grieving as a normal response to loss. He acknowledges grief reactions can become complex and compromise health, and can last for years, and that major cultural factors will impact on how people grieve. Maddocks reports that palliative care workers experienced in bereavement work are concerned at the lack of bereavement support in major hospitals even though bereavement support is an integral part of palliative care.

The Role of Carers

"Who are you that comes to give care?" - Anonymous-

There are a range of issues which may be faced by palliative care workers in the care of the elderly or the terminally ill or dying person. Professional carers or health care workers provide physical assistance with daily living, discuss choices and options, manage symptoms and often become immersed in difficult and quite paradoxical family situations which can revolve around ethical dilemmas in care. Professional carers need knowledge and skills required to do their job and need the time to be able to improve and update that knowledge base. Caring can be physically demanding and an assumed level of fitness also requires professional carers to take care of themselves. Stressful events and moments in the life of the professional carer may be put on hold because of the commitment to the role, and may have implications for

the health of the carer. These issues would also apply to the family member or friend in the caring role. Challenges for these carers could include concurrent stress in the family environment such as not only dealing with the diagnosis and prognosis of the loved one who is ill or dying but the possible loss of income and an increased financial strain, or the problems faced by other members of the family, whose lives are going on. The incident such as the car breaking down or the cow needing milking when the caring routine is quite demanding can lead to tiredness and stress, ultimately challenging the respective coping abilities of family members.

Research for this thesis reveals that women are living longer and may expect to be thrown in to the role of carer either willingly or by default, at some time in their lives. Palliative Care Australia (2004) note that as women live longer, they are frequently carers for their partners, and children often care for their aged mothers. Certainly as mothers this role is somewhat assumed already. How prepared then will women be in a time when they can rightly assume that they will live longer? Kissane (2000) drawing on a range of studies revealed:

> "…a range of unmet needs in carers, including the provision of information (Schofield et al. 1998), psychological support (Northouse 1984; Stetz 1987), instrumental help with physical care (Kristjanson & Ashcroft 1994; Watson 1994), guidance about coping and adjustment (Klagsburn 1994; Given and Given 1996),

and recognition of altered roles and choice (Schofield et al. 1998) "(p.55).

A study by Schofield, et al (1998) surveyed Victorian carers and identified several predictors of a carer's sense of burden. They include resentment, family conflict, a depressed patient, close relationship and anger. Carer resentment was prompted by lack of social support, anger, acoping, and unclear medical diagnosis.

An English study conducted by Jones, Hansford and Fiske (1993) sought to collect information from carers of people who had died at home with cancer. This study found that 161 of the 207 patients were aged 60 and over, 110 were 60-80, and 9 were older than 80. One hundred and twenty-four carers were not given advice on financial help, 174 were not told of support available from charities. Although pain was well controlled, 25 per cent of patients had no relief from other symptoms. This study concludes that health professionals need to give carers more advice about available assistance other than health services (Jones et al, 1993).

Given and Given (1994) argue that less burden will be experienced by sharing caring tasks. The 'share the load theory' does not do much to help people in isolated or rural areas or for families where there are few members or where there is only one member left. Palliative care teams can lessen the burden and share the load, and offer respite, if and where these services are accessible or in existence.

2.9   Conclusion

Chapter 2 has covered the main topics of this research. An analysis of the literature that was available on 'health', indicates that there is an abundance of material available both in the form of medical publications written for health professionals, and general interest publications written to assist people attain a basic understanding of health issues and which fundamentally encourages health promotion and ownership of one's health. There is also an abundance of material available on ageing and ageing populations including the baby boomers. Research into ageing may well be prompted by the baby boomers who have a penchant to change and influence the way things are being done, especially when the way things are being done impacts on them and their particular stage of life. In contrast to the vast array of the demographic data that are available for ageing populations, literature on rural health and ageing could be seen as lacking in comparison.

More specifically, in conducting research for this thesis, literature on palliative care for an ageing population in rural Australia has found to be limited. The discipline of palliative care is relatively new to Australia, and has only been in existence for the past 30 years. Although, literature in this area is often hampered by the sensitive nature of the topic of death and dying, it is growing and becoming more and more prominent, with much of the available literature from Canada and the United Kingdom. Determining attitudes to death and dying has presented several challenges in terms of this literature review, in that prior studies and the analysis of attitudes specifically in the area of palliative care have been very limited or non-existent. A search

for a 'tool' such as a questionnaire, which addressed the ageing person's attitude to death and dying or palliative care was not successful. However, by exploring works on attitudes, values and beliefs such as Rokeach (1976), and based on his assumptions that all men (and supposedly women) everywhere possess the same values in differing degrees, a questionnaire was designed to provide the tool for this research.

A number of conclusions may be drawn based on the cited literature and an examination of the emerging issues. One of the most salient and challenging issues facing health service delivery in Australia is the demographic reality of population ageing. While Australians are generally living longer and have healthier lives, there is still a wide disparity across all age groups with respect to health related chances. This is particularly evident when considering the health chances of older Australians.

Health is influenced by genetic inheritance and culture, and by behavioural determinants, biomedical processes and the environment, as well as by economic and social factors. Socioeconomic disadvantages tend to increase with increasing remoteness, with people living in rural and remote areas of Australia tend to have higher death rates than those living in capital cities and other metropolitan areas. This may be attributed to harsher living environments, poorer access to health services, specialists, and health professionals, lower socio-economic status and employment levels, and exposure to occupational hazards. Access difficulties also relate to length of time, distance and cost of transport availability in rural areas. These issues are

indicative of the health chances and problems also faced by Indigenous Australians who do not have the same life expectancy as non-Indigenous Australians, and who do not receive timely, high quality diagnosis, treatment, rehabilitation and palliation with their illness.

Health and ageing predictions and projections should prompt key stakeholders including the baby boomers, the aged cohorts of the future, to plan and prepare, perhaps redefining the challenges of ageing in the attempt, and to be in readiness for the expected increase of dementia and the implications of gender on health which will have ramifications for a population ageing paradigm, particularly for women as carers in our society. There will be ramifications also for palliative care service providers, and an expected increase in demand of these services with the rise in cancer death rates in Australia, and the increase in numbers of people who die receiving palliative care. It is projected that as the population ages there is a greater likelihood that people will die from cancer and other age-related diseases. Models of palliative care delivery will need to reflect these projections and consider the specific needs of an ageing population, including rural needs, which may be unique to that community.

Healey (2003) provides an important and relevant message for current and future aged care providers:

> "Ageing is not a separate issue from social integration, gender advancement, economic stability or issues of poverty. It has

developed a connection with many global agendas and will play,

increasingly, a prominent role in the way society interacts with

economic and social welfare institutions, family and community life

and the roles of women" (p.11).

Chapter 3 describes the major methodology used to collect data to address the

research focus: *"to select a major rural area for the purpose of investigating*

the availability of palliative care services, trends in ageing and to examine

the relationship between the two".

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Chapter 3: Methodology

Chapter 3 describes the major methodology used to collect data used in this research to determine the relationship between the needs of an ageing population and rural palliative care service delivery in Australia. The research has incorporated sequential mixed methods designs by firstly conducting a quantitative followed by a qualitative phase. Sandelowski (2000) and Tashakkori and Teddlie (1998) noted by using mixed methodology two paradigms are able to be presented distinctly. In the case of this research the two paradigms investigated were the needs of an ageing population and rural palliative care service delivery. The designated rural area used in this research was Gippsland in rural Victoria.

3.1   Data collection

Data Collection included demographic statistics from the Australian Bureau of Census and Statistics and Palliative Care Australia, and other statistical reports and data collected from key authorative bodies. These were used for descriptive purposes to inform and support this research. This data has been mainly provided in Chapter 2, and will be further discussed in Chapter 4.

Other ordinal data were obtained using a questionnaire which was developed for the purpose of this research. These data have been organised and analysed within the context of the research and are presented in Chapter 4. Qualitative data were obtained through interviews with focus groups.

The methodology used to conduct this research was basically conducted in five stages. Demographic data were firstly collected in Stage One of this research from the Australian Bureau of Census and Statistics to establish health and ageing trends in Australia and in particular rural and regional Australia. These data were then contextualised with Census data and other major statistical reports largely obtained from Palliative Care Australia which provide predictions and projections for the demand for palliative care.

A 'tool' was designed in the form of a questionnaire in order to investigate attitudes of older persons to palliative care. These data provided descriptive data for the second stage of the research which sought to determine the future needs and wishes of people from the targeted area who may require palliative care. As a review of the literature did not produce an 'attitudinal' questionnaire suitable for this research, one was developed. The questionnaire was developed using the expertise of palliative care service providers. During the development of the research questionnaire twenty questions were formulated by the researcher who has formal qualifications in palliative care. Consultation was then sought from palliative care experts (N=6) who were senior members of their organizations, and who were 'deemed' well qualified in the area of palliative care. They were invited to review the draft questionnaire with the view of providing critical feedback in the interest of preparing a revised version for pilot testing. The 'draft' questionnaire was changed several times based on their suggestions and recommendations. The University Faculty Ethics Committee and research supervisors also offered recommendations that assisted in the final design and content of the research

questionnaire. It was proposed that the results of the questionnaire would provide ordinal data to establish any gaps in levels of palliative care "awareness", and would also elicit any specific attitudes to palliative care emerging from the sample of older people involved in this research. Specific questions were asked relating to place of birth in order to establish any rural origins. The questionnaire also sought information on attitudes to ageing. Likert-type scales were used and Cronbach's Alpha which is a tool for assessing the reliability of scales was used for testing the reliability of items. Respondents were asked to indicate their responses by circling one of the following: strongly agree, agree, undecided, disagree, or strongly disagree for each of the questions. Overall fifteen questions were finally developed. This questionnaire (Appendix 1: Aged Attitudes Towards Palliative Care Questionnaire (draft)) was then piloted to determine the internal reliability of questions, the time needed to complete the questionnaire and the ease of its facilitation. Of the fifty questionnaires distributed, thirty eight were completed and returned (N=38).

The Pilot: The sample for the pilot phase of the study consisted of thirty-eight participants (N=38) from groups of volunteers of:

- Eleven participants from a baby boomers cohort (N=11) – those people were born between 1945 and 1965. This sample was chosen as the aged cohort of the future. Volunteers were sought using a 'flyer' distributed at Victoria University which invited interested persons to participate.

- Seventeen members of the University of the Third Age (N=17). This is a group of people who come together to share their knowledge and skills, in the *third age* of their life (Melbourne metropolitan and Gippsland rural)

- Ten U3A members who were aged 55 to 65 (N=10) (Melbourne metropolitan and Gippsland rural)

University of the Third Age (U3A) is a learning co-operative of older people that encourages healthy ageing by enabling members to share many educational, creative and leisure activities. U3A is a worldwide organization. The Peak Body for U3A in Victoria is the U3A Network –Victoria, with over fifty U3A associations. The Third Age refers to the period of time after the First Age of childhood dependence and the Second Age of employment and parental responsibility, often called "the Age of active retirement". Ages of U3A members range from 55 to 97 years.

Letters which were addressed to The President (Appendix 2) were sent out to four U3A organisations (one metropolitan and three rural). The rural organizations were chosen from the Gippsland area as the designated area for this study. The letters outlined the study and invited interested persons/volunteers to participate in the pilot phase. The researcher also offered to attend any appropriate meetings which might be held by the respective U3A organizations in order to promote the research and to personally present the questionnaires. 'Flyers' (Appendix 6: Information to Participants) outlining the study and ethics considerations were also

developed which were distributed to interested members. All four groups responded positively and expressed an interest in the study. Initial contact with the individual presidents of the U3A organizations revealed that each group is autonomous and develops its own character. Programs vary from educational to recreational and are developed primarily from the interest of its members and the resources which are to be found within the community. Groups therefore vary in size and operation, and also in how often they meet. Some of the more isolated or rural U3A organisations have a much smaller membership and tend to meet less frequently than other metropolitan groups. For these reasons it was problematic to meet with one of the rural groups.

Of the remaining two (rural) organizations, the researcher was invited to attend group meetings and to speak about the research and to present the questionnaire to the attendees. Questionnaires, along with consent forms were distributed. The metro organization requested questionnaires and consent forms be sent to their president. The U3A president forwarded the questionnaires to interested members of the group for completion. The completed questionnaires were then forwarded on to the researcher for data analysis.

Factor Analysis using Cronbach's Alpha was applied (using SPSS computer software), to determine 'reliability' of the Questionnaire. In order to achieve satisfactory reliability results, 5 of the original 15 questions were removed leaving 10 stronger questions with Alpha = .7136. These Results are shown in Table 11.

Table 11. Reliability Analysis – Scale (Alpha)

No of Cases=38.0 Items Means	Mean	Minimum	Maximum	Range	Max/Min	Variance
	3.5605	2.1842	4.5526	2.3684	2.0843	.7550
Inter-Item Correlations	Mean	Minimum	Maximum	Range	Max/Min	Variance
	.2306	-.4743	.6191	1.0934	-1.3054	.0632

Analysis of Variance

Source of Variation	Sum of Sq.	DF	Mean Square	Q	Prob.
Between People	75.3079	37	2.0353		
Within People	452.3000	342	1.3225		
Between Measures	258.2132	9	28.6904	195.2441	.0000
Residual	194.0868	333	.5828		
Total	527.6079	379	1.3921		
Grand Mean	3.5605				

Reliability Coefficients   10 Items

Alpha = .7136   Standardised item alpha = .7498

Although the research questionnaire provided a stronger 'tool' with the changes, the 5 questions which were removed contained interesting anecdotal data which are discussed in the findings of this study.

A **Survey** was then conducted by firstly applying the revised piloted questionnaire (Appendix 7: Ageing and Care for the Dying Questionnaire) to a sample of two groups of ageing members of the University of the Third Age (metropolitan). Of the forty questionnaires distributed fourteen were

completed and returned. (N=14). In order to identify a 'rural attitude', the survey was then conducted in the designated rural area using a sample of thirty ageing members from the University of the Third Age (Gippsland). The response was (N=13). Letters (Appendix 3: Survey U3A) were again sent to the President of U3A groups, asking for participants. U3A participants for this Survey were different organizations to those used in the Pilot phase. Letters of appreciation were sent to all U3A organizations that participated in both the Pilot and Survey (Appendix. 4).

Twenty questionnaires were also distributed to volunteer baby boomers who responded to a 'flyer' requesting participation in the study which was distributed at Victoria University. Respondents were asked if they were born between 1945 and 1965. The response to these questionnaires was (N=17).

Questionnaire responses from rural and urban participants were compared using the SPSS (version 11) computer program for analysis. Mann-Witney U (1-tailed) tests were used to analyse the ordinal data. Kruskal Wallis tests were further applied to compare groupings to determine differences between groups. These results are discussed in Chapter 4.

The next phase of this research proposed to conduct focus group interviews, which are typically based on homogenous groups and involve conducting open-ended interviews with groups of five to eight people on specifically targeted or focused issues for about one to two hours (Patton, 1990). The point is made by Patton that sampling for focus groups typically involves

bringing people together of similar backgrounds and experience to participate in a group interview about major program issues that affect them. According to Denzin and Lincoln (1994) ensuring rigor, or "…commitment to the established rules for inquiry (p. 151)" is attained in qualitative research by sampling until repetition from multiple sources is obtained. Information obtained through focus group interviews therefore sought concurring and confirming data to ensure rigor throughout this phase of the research.

In order to conduct the focus group interviews, contact was initially made with the Regional Palliative Care Co-ordinator from the Department of Human Services in the designated area. The researcher was in this way able to alert the Department that the study was being conducted in their region and to outline the study and invite participation. The Regional Co-ordinator then tabled the information and introduced the study at the regional meeting attended by all Palliative Care Service providers. The outcome of this invitation was that the service providers requested that the researcher approach them personally. Letters were then sent to request their participation in this study (Appendix 5: Service Provider Letter).

It was felt that individual teams could then respond and participate through personal choice. In this way, the researcher made contact with four major service providers who chose to participate in the study and arrangements were made to conduct focus group interviews at suitable times, at four different locations. Samples for these focus groups were obtained from four groups of

Key Health Providers, including palliative care nurses, community workers and local council representatives. Welch, Power, Kamien & Waddell (1994) have established that by interviewing a small group of key health informants (providers) 80% of information on health issues in rural communities can be obtained. The make up of these groups varied in number. Participants were given Consent forms (Appendix 8: Consent Form) to sign. The meetings were all conducted with recordings being taped with the consensus of the group. A total of four focus group interviews were conducted in the Gippsland area with a total of thirty-two participants from the four groups (N=32).

In the main, representation consisted of Registered Nurses (Division 1 and 2), qualified Palliative Care Nurses, District Nurses, Occupational Therapists and Social Workers, and Allied Health representation from Home and Community Care. There were no doctors represented at any of the meetings, as there were none available at the time and all participants were female.

The following interview guide questions were used as the framework for all focus groups:

1. "What does palliative care mean to you?"

2. "How can people access palliative care services in this area?"

3. "Do people in your area know about palliative care?"

4. "What services do you think people want when they are dying?"

5. "What services do you think people need when they are dying?"

6. "What would you like to see included in any service for people who are terminally ill?"

7. "What sort of skills or knowledge would you expect from a person who looks after people who are dying?"

8. "Do you know of any difficulties experienced by people who are dying, which are made more difficult because they may live in rural areas?"

9. "What are some of the issues faced by carers in rural areas?"

10. "How can this research best help you?"

Transcripts of the focus interviews are provided in Appendix 9: Focus Group Interviews. Data obtained from this stage of the study were analysed using qualitative methodology, and these results are presented in Chapter 4.

Overall approximately one hundred and twenty people (N=120) have participated in this study.

Palliative Care experts consulted in the design of the Questionnaire during the Pilot phase (N=6)

Participants in the Pilot phase (N=38)

Participants in the Survey (Questionnaire) (N=44)

Participants in the focus group interviews (N=32)

TOTAL number of participants in this study **(N=120)**

Whilst the methodological design provided a firm framework for the conduct of the field studies, it was difficult to guarantee large numbers for the sample from the U3A cohort. In fact, the difficulty in obtaining strong research

numbers in rural areas would appear to be consistent with the distance and access issues particular to rural areas.

Membership in U3A varies considerably depending on the geographic location and attendance on the day. Also problematic was that by using the U3A sample for the Pilot Study, sample numbers that could be used for the actual study were diminished. It is argued that although the numbers are not as strong as first anticipated that the numbers obtained are sufficient, and that the findings of this research contribute to an expanding body of knowledge and provide information and directions for future research.

In stage three of the research information obtained from the National Inquiry into the Social Impact of Caring for Terminally Ill People (May 2004) initiated by Palliative Care Australia has been contextualised for the purpose of this research. The Inquiry sought to gather policy, opinion, experience and research related to the social impact of unpaid caring for the terminally ill. Submissions and contributions came from individual carers and service providers. These data and findings have been used to inform stage four of this research which sought to provide recommendations for the development of a palliative care delivery model in a rural area which incorporates the wishes and needs of an ageing population.

Recommendations for this model have been extrapolated based on the findings from stage three and were developed based on data collected and

obtained through an exploration of palliative care models, trajectories, predictions, as well as health and ageing demographics.

The final stage (5) of the methodology undertaken in this research was to provide information containing recommendations for a model of service delivery in a rural area which will ultimately be presented in the form of a report. This report would be suitable for palliative care service providers, especially rural providers, and would be aimed at addressing the needs of the elderly.

3.2 Ethical Considerations

It is acknowledged that in research involving human subjects there is always the possibility of minimal risk where people are asked to give something of themselves. In research of this nature where the subject content is ageing and death and dying, it is especially acknowledged that the content is sensitive and forewarns potential risk. In the hands of an inexperienced researcher the likelihood of this 'risk' is exacerbated. The researcher in this study into ageing and death and dying is a palliative care nurse and teacher of aged care and palliative care and therefore minimization and management of risk was given every consideration, and was based on the underpinning premise that individuals will experience grief uniquely. Ethical considerations were acknowledged in the event that:

- participants were to experience some sadness or re-surfacing of grief and loss issues brought about by the questionnaire,

- within the focus group environment disclosure and confidentiality issues may preclude some participants from talking freely,

- contentious issues such as euthanasia and suicide may pose a risk to participants who chose to disclose information which may implicate them legally or in some other way – perhaps personally.

Management of potential risks included the following strategies:

- all participants were advised of the background of the researcher,

- all participants were given a 'flyer' (Appendix 6: information to participants form) outlining research aims, methods and ethical considerations, and stipulating the volunteer nature for participation

- participants were advised that they could withdraw at any time and that provision for discussion and support was there,

- a list of local community health services outlining counseling services was provided,

- participants were advised that they may also choose to contact the researcher,

- participants were given consent forms to participate in the study

- participants were advised that any complaints or concerns may be referred to the principal research supervisor, and details were provided,

- in terms of breach of confidentiality, participants were advised that names and addresses would not be included in any reports and that for the process of analysis and identification a coding system would be used,

- during focus group interviews, should a participant break down or become upset – the process would be stopped, and a break suggested allowing time to talk with the distressed participant. Debriefing time would be included, the research supervisor informed and a documented report provided. Referral to counselling/bereavement services would be arranged and a follow up call would be made if and when appropriate.

3.3   Confidentiality

Participants (baby boomers and members of the U3A) were advised not to write their names or any identifying features on the questionnaire and they were informed in the information to participants that completion and return of the questionnaire constituted consent. Participants in the focus group interviews were not given questionnaires. Participants were advised that a coding system for analysis purposes would be used and that data would be kept by the researcher in a locked office for a period of five years. Confidentiality was assured for participants in focus group interviews. Interviews were recorded using a dictaphone, with the consent of the groups. The researcher introduced the session by asking all participants to give their first name only to indicate their participation, and that if they chose to speak after this they need not identify themselves again throughout the interview process. They were also asked not to divulge the service provider identity or the identity of their clients.

The need for confidentiality and the potential risk of breach in this process was of paramount importance in that the palliative care service providers in

the rural area were all aware of the study and knew of the other participating groups. Groups were therefore identified by code so as to maintain confidentiality and anonymity of the participating palliative care service providers. These strategies were developed under the rigor and guidance of the University Ethics Committee.

Chapter 3 has detailed the methodology used in this research and has also outlined the Pilot study and confidentiality and ethical considerations employed throughout the research. Results and findings are presented in Chapter 4 of the thesis.

Chapter 4: Analysis of data

"The focus underpinning this research was to select a major rural area for the purpose of investigating the availability of palliative care services, trends in ageing and to examine the relationship between the two."

An analysis of the data presented in Chapter 4 has been organized and is consistent with, the underpinning research issues and problems as defined by the research focus, as presented in Chapter 2. The data were collected as outlined according to the methodology in the preceding chapter. Section 4.1 will present the findings as derived from the data collected in Stage One, and will address the research questions

- *What are the health and ageing trends in Australia?*

- *What are the palliative care demands and needs of an ageing population in a rural area, and are they any different to those of a metropolitan area?*

- *Would an ageing rural population be disadvantaged if and when they need palliative care?*

- *Who will impact on the design of palliative care services and make decisions for an ageing population?*

Section 4.2 will present the findings of Stage Two and addresses the following research questions:

- *Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?*

- *Is there a lack of knowledge and understanding of the palliative care needs of older people in rural areas?*

Section 4.3 will contextualise relevant data and results extrapolated for Stage Three of this thesis. Data are taken from the Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People, initiated by Palliative Care Australia (2004), and from data obtained through the baby boomer cohort and focus group participants. These results address the following research questions:

- *What would an ageing rural population want included in a palliative care service?- and what do the service providers want/need?*

Section 4.4 will provide a summary of the research findings.

Summary tables and figures have been used throughout this chapter to demonstrate patterns and to organize the data. The concluding chapter (5) will provide a final discussion on the findings based on the analysis of data within the context of the literature. Stages four and five sought to provide recommendations for a 'model' and a 'report' of findings will also be presented and discussed in Chapter 5.

Mann-Witney **U** (1- tailed tests) were used for comparing ordinal data from the two separate groups, in this case urban and rural participants, who volunteered to complete the research questionnaire. Two major objectives of this research were to determine:

- *Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?*

- *Is there a lack of knowledge and understanding of palliative care in rural areas?*

Kruskal Wallis tests were further used to compare groupings and to determine any differences between variables, and Chi-Square tests were used to determine associations.

Subjects used in this research included males and females from the baby boomer cohort (those born between 1945 to 1965) (N=17). This cohort is described throughout the literature as the 'aged cohort of the future' and represents a very highly significant influence on population ageing overall. Subjects used in the sample from the University of the Third Age (U3A) (N=27) consisted of both males and females who ranged in ages from 55 to 97 years. Focus group subjects (N=32) consisted of key health informants from the designated area who were nurses, allied health workers, Occupational Therapists, Social Workers and Palliative Care Nurses. There were no doctors who participated in the focus groups, and all participants were female.

4.1 Analysis of Data collected in Stage One: Health and Ageing Demographics

The following data are presented in Table format and represent a summary of findings addressed by the research questions:

- *What are the health and ageing trends in Australia?*

- *What are the palliative care demands and needs of an ageing population in a rural area, and are they any different to those of a metropolitan area?*

- *Would an ageing rural population be disadvantaged if and when they need palliative care?*

- *Who will impact on the design of palliative care services and make decisions for an ageing population?*

These research questions have been outlined and discussed previously in Chapter 2 of this thesis. Table 12 presents a summary of selected findings from the research literature deemed pertinent to this research on health and ageing in Australia.

Table 12. Health and ageing trends in Australia.

Leading causes of death in Australia	Ischaemic heart disease, cerebral vascular accident (CVA) or Stroke, lung cancer, chronic obstructive pulmonary disease and colorectal cancer. **(ABS, 2001)**
There are around 127,000 deaths in Australia in each year.	Deaths of persons aged 70 years and over accounted for 70%, 20% occurred at ages 50-69 years, 8% at ages 20-49 years, and 2% at ages less than 20 years. **(AIHW, 2000)**
Life expectancy at birth for Indigenous Australians is estimated to be around 20 years less than for other Australians. (Commonwealth of Australia, 2001)	The major causes of their early deaths are injury, coronary heart disease, diabetes and homicide, with males in the rural and remote areas suffering higher rates of injury than females. **(McMurray, 2003)**
ABS (1995) predicts that as the population ages, there is a greater likelihood that people will die from cancer and other age-related diseases.	The cancer death rate in Australia has increased by 4% over the past two decades. **(ABS, 1995)**
In terms of 'ageing', the statistical figure given to the population in older ages is conventionally taken as 65 years and above. **By the year 2031, 21-22% of Australia's population will be aged 65 and over. It was 12% in 1997. (ABS 1997)**	Over the past half century, the median age for the world increased by 2.8 years. From 23.6 years In 1950 to 26.4 years in 2000. Over the next 50 years, the median age is expected to rise by 10.4 years, reaching 36.8 years in 2050. This means one out of every 10 persons is now 60 years or older, by 2050 that figure will increase to one in 5 and at this rate, by 2150 one in 3. **(Healey, 2003)**
Women are living longer than men	Life expectancy in 1996 for males was 75.4 years, and for females 81.1 years. **(ABS, 1997)** Females born in 2000-2002 are expected to live 82.6 years and males expected to live 77.4 years **(ABS 2004, ABS, 2003).**
Population ageing will see a rise in dementia	**AIHW (1997)** reported that dementia affects about 5 per cent of the population aged between 65 and 84, and estimate that 25 per cent of people who survive beyond 85 years will develop some form of disability due to dementia.

ABS (2004) reports that data obtained from the 2001 National Health Survey (NHS), that surveyed persons in private dwellings only, and excluded persons in aged care accommodation and nursing homes indicates that Australia has one of the highest life expectancy at birth rankings in the world at 80.4 years. Females born in 2000-2002 are expected to live 82.6 years and males expected to live 77.4 years (ABS 2004, ABS, 2003).

Table 13 presents a summary of relevant findings taken from the research literature relating to the impact of the baby boomers – the aged cohort of the future.

Table 13. The baby boomers – the aged cohort of the future.

By 2031, over a quarter (27%) of all Australians of voting age (18 years and over) will be aged 65 or older **(Healey, 2003)**.
Age-specific death rates will continue to decline, resulting in life expectancy at birth increasing by 5-7 years by 2051 **(ABS, 1998)**.
Total fertility rate will continue to fall during the next decade – to 1.75 births per woman by 2006 – then remain constant at 1.75 until 2051 **(ABS, 1998)**.
In Australia the fertility rate peaked in 1961 and by 1965 had dropped back to just below the 1946 level. **(ABS, 1999)**
Between 2011 and 2031, baby boomers will make a significant contribution to the numbers of people aged 65 and over. During this period, the population aged 65 and over is projected to grow from 3 to 5 million. **(ABS, 1999)**
By 2031, all surviving baby boomers will be 65-84 years of age. **(ABS, 1999)**
Between 2031 and 2051, baby boomers are projected to swell the population aged 85 and over from 612,000 to 1.1million. **(ABS, 1999)**

Table 14 presents a summary of selected findings from the research literature on rural health and ageing in Australia.

Table 14. Rural Health and Ageing in Australia

AIHW (1998) report that environmental impacts on health acknowledge the differences between metropolitan and remote areas, where there are fewer services, long distances to travel, poorer road conditions, diminished public transport and environmental issues related to agricultural and mining occupations.	In **Gippsland** environmental issues related to mining occupations has a special significance given the high incidence of asbestos related illness and in particular the high incidence of lung cancer. **(OHS Reps,2005)**
People aged 55-59 are the largest of the 55+ aged groups in the City of Melbourne, and are projected to grow at the highest rate of all the groups, from 1,623 to 3,068 between 1997 and 2006. (City of Melbourne: 1998)	Figures from the 1996 Census indicate that 17% of the population of **Gippsland** are aged 60 and over, compared to 15% of Victoria as a whole. Twenty four percent are in the 40-59 age group. **(ABS,1996)**

Table 15 provides a summary of findings of palliative care demands and needs of an ageing population as derived from the Palliative Care Australia Census (1998).

Table 15. Summarised Census Data (Palliative Care Australia: 2000)

There is an increase of 56% in 1997 to 62% in 1998 in the number of people who die receiving palliative care.	Palliative Care Australia report that 12, 456 annual deaths in **Australia** were reported by metropolitan services which represent 5.3 deaths per 1000 persons aged 55+ years. 7,027 deaths were reported by regional and rural palliative care services representing 4.6 deaths per 1000.
More than one third of Australians who die receiving palliative care services die at home.	In 1997-1998, 34.8% of deaths occurred at home whereas in 1996-97 the percentage was 27.5%.
Population-based rates of admission to palliative care services in regional and rural locations are 30-35% lower than in capital cities, possibly related to the lack of access to specialist palliative care doctors.	Of the 4,065 people in the 55+ age group who died while receiving palliative care in **Victoria** (1997-98), almost half died in regional/rural areas of Victoria (N=1205). Metropolitan deaths were N=2860.

Source: (adapted from Palliative Care Australia, 2000)

The Palliative Care Census has reflected that there are significant differences in access to any kind of palliative care service between people who live in metropolitan centers in Australia in comparison to regional and rural areas.

This section has contextualised and presented an analysis of data collected in Stage One: Health and Ageing Demographics. Section 4.2 will now present findings from Stage Two of this research.

4.2 Analysis of Data collected in Stage Two: The Questionnaire and Focus Group Interviews

- *Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?*

- *Is there a lack of knowledge and understanding of palliative care in rural areas?*

The Questionnaire

Of the 40 metropolitan questionnaires distributed during the actual field study, fourteen were completed and returned (N=14). In order to identify a 'rural attitude', the survey was then conducted in the designated rural area using a sample of 30 ageing members from the University of the Third Aged (Gippsland). The response was (N=13). Twenty questionnaires were also distributed to participants who responded to an invitation for volunteers from Victoria University who were born between 1945 and 1965. The response to these questionnaires was (N=17).

In total (N=44) questionnaire responses from both rural and urban participants were compared using the SPSS computer program (version 11) for analysis. Ten questions were listed to which respondents were asked to indicate their response using Likert-Scale ratings of *strongly agree, agree, undecided, disagree, strongly disagree*:

1) *People who are dying should go to a hospital*

2) *There's nothing that can be done for the aged and dying*

3) *Services for the aged are a luxury for aged people who live in rural areas*

4) *Aged people have limited access to health services in rural areas*

5) *People residing in a rural area cope well with death and dying*

6) *The aged dying person does not need access to health services*

7) *People who are dying because of old age do not suffer*

8) *People residing in a rural area support each other in times of need*

9) *Aged people who live in rural areas are more independent than aged people in city areas*

10) *Aged people who are dealing with death and dying do not see the need for health services.*

The following variables were further used to group data as provided by demographic data in the research questionnaire. Chi-Square tests were used to determine associations between:

a)   current location,

b)   location of birth,

c)   transition of birth place?

d)   Awareness of aged care services in your area?

e)   Awareness of services for people who are dying in your area?

f)   those above and below the age of 65

The results are presented and discussed according to each variable.

The following figures represent the overall percentage of questionnaire responses from all groups (N=44) for each question.

Question 1 – "people who are dying should go to a hospital".

Figure 5. Responses to Question 1 from rural and urban participants

People who are dying should go to a hospital
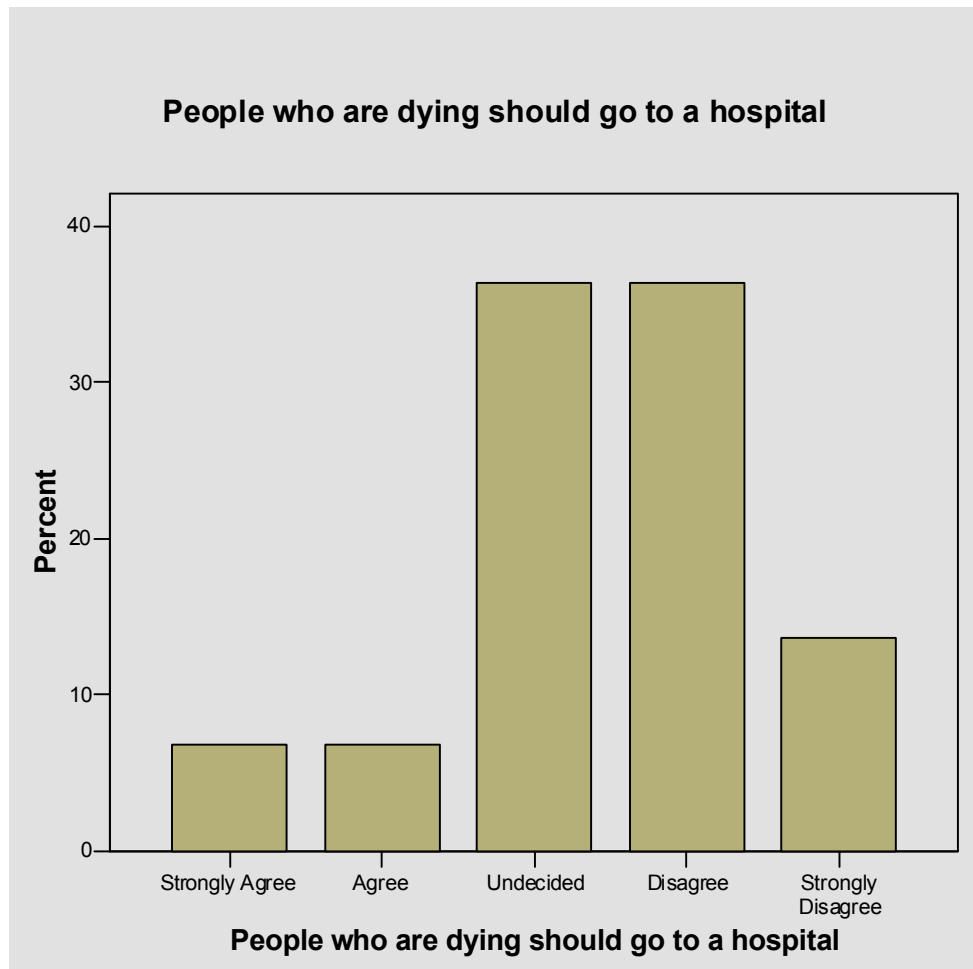
As shown in Figure 5, 72% of people were either undecided or disagreed with the statement. This was an expected response given the current propensity of people to choose to die at home.

Question 2 – "there is nothing that can be done for the aged and dying."

Figure 6. Question 2 responses from rural and urban participants
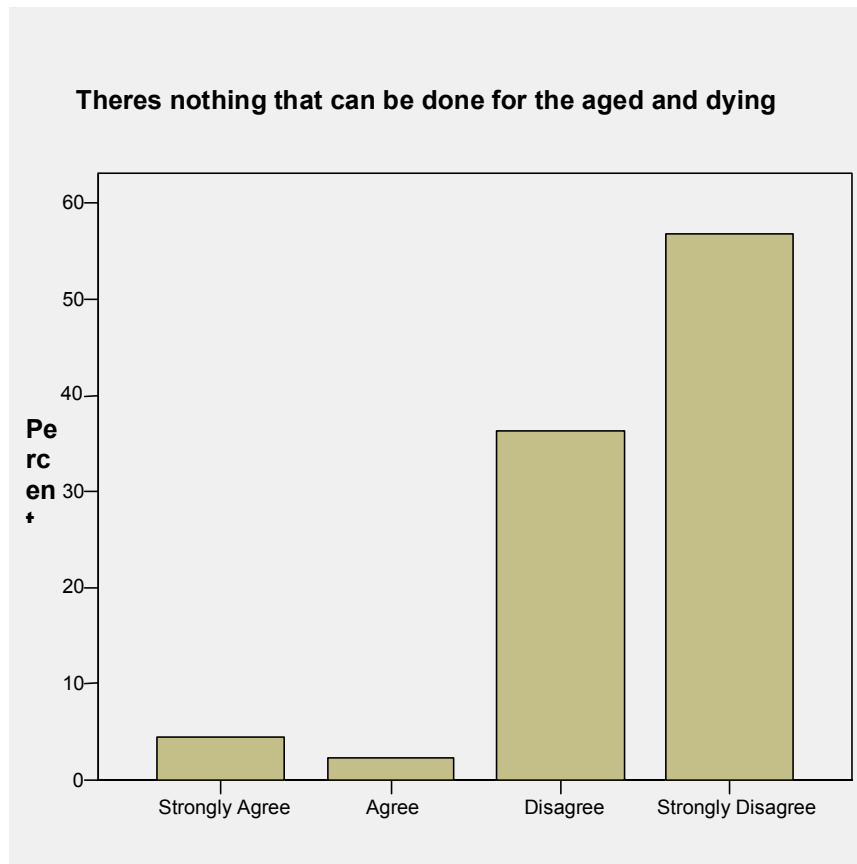
The majority of people (58%) strongly disagreed and (38%) disagreed with

the statement "there is nothing that can be done for the aged and dying".

Question 3 – "Services for the aged and dying are a luxury for aged people who live in rural areas."

Figure 7. Question 3 responses from rural and urban participants
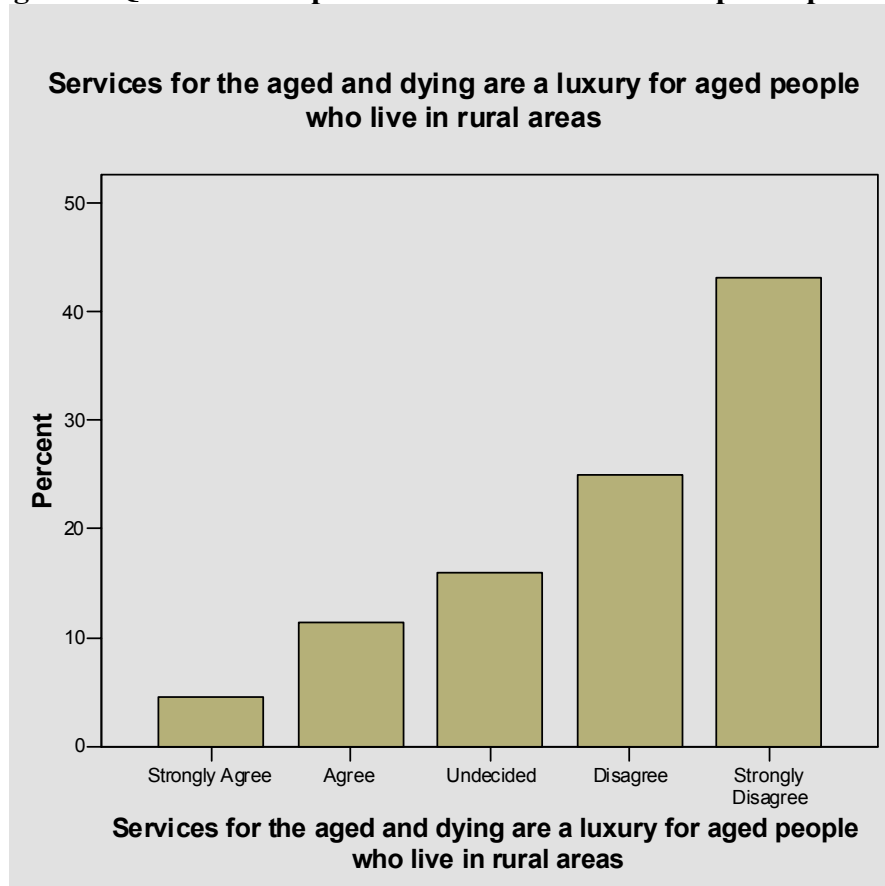
Most people (43%) strongly disagreed with this statement, and (25%) disagreed.

Question 4 – "Aged people have limited access to health services in rural areas." As shown in Figure 8, as many people were undecided as those who agreed. A more expected response to this question would have been that people tended to agree with an existing issue of access in rural areas.

Figure 8 Question 4 responses from rural and urban participants
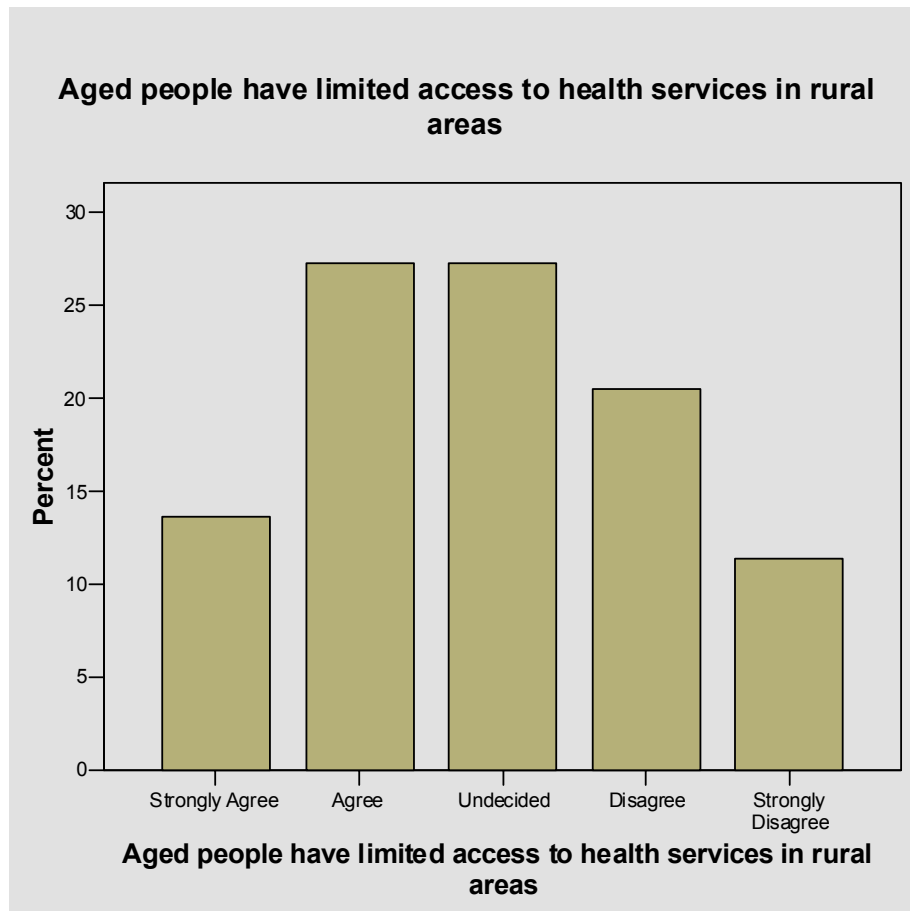
(39%) agreed with this statement, with (31%) disagreeing.

Question 5 – "People residing in a rural area cope well with death and dying."

Figure 9 Question 5 responses from rural and urban participants

People residing in a rural area cope well with death and dying
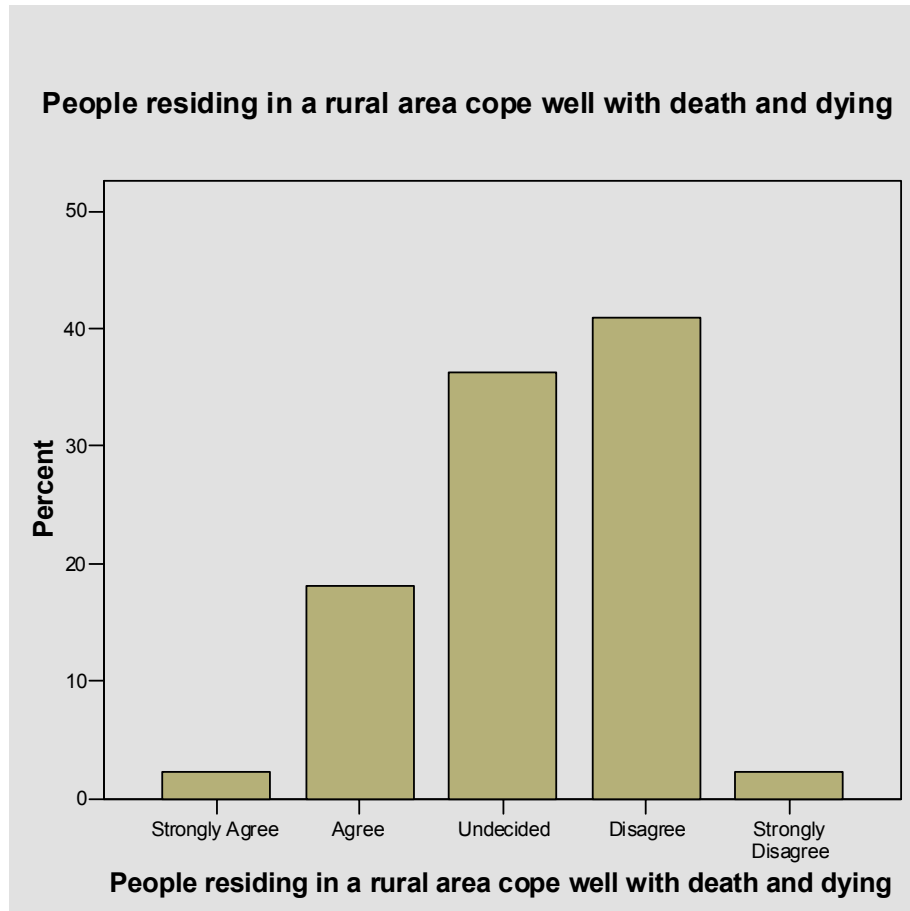
The majority (75%) of respondents were undecided or disagreed with this statement. An expected response to this question was that in determining a 'rural attitude' to death and dying respondents would have tended to agree with the statement.

Question 6 – "The aged dying person does not need access to health services."

Figure 10. Question 6 responses from rural and urban participants

The aged dying person does not need access to health services
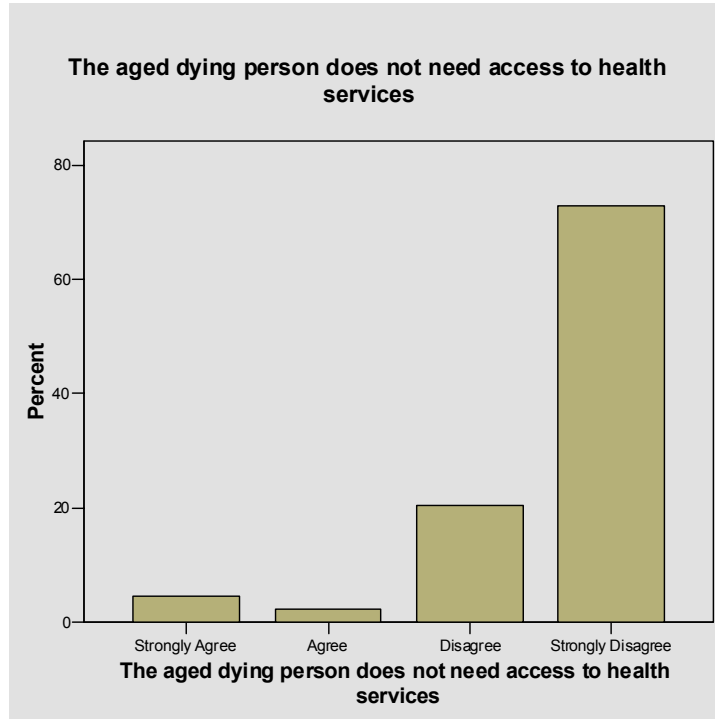
Figure 10 shows that 70% of respondents strongly disagree with this statement.

Question 7 – "People who are dying because of old age do not suffer." As

shown in Figure 11 most people tended to disagree with this statement.

Figure 11 Question 7 responses from urban and rural participants
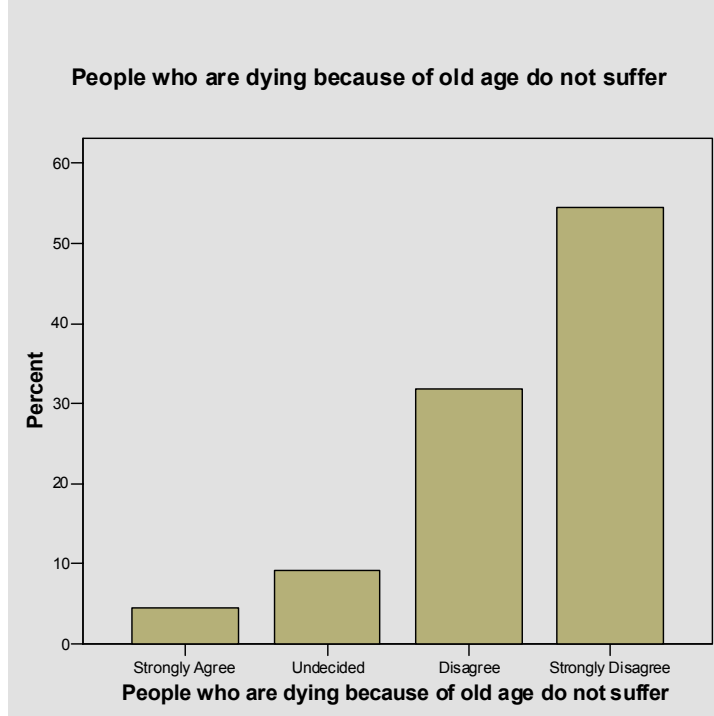
85% of people disagreed with this statement.

Question 8- "People residing in a rural area support each other in times of need."

Figure 12 Question 8 responses from urban and rural participants.
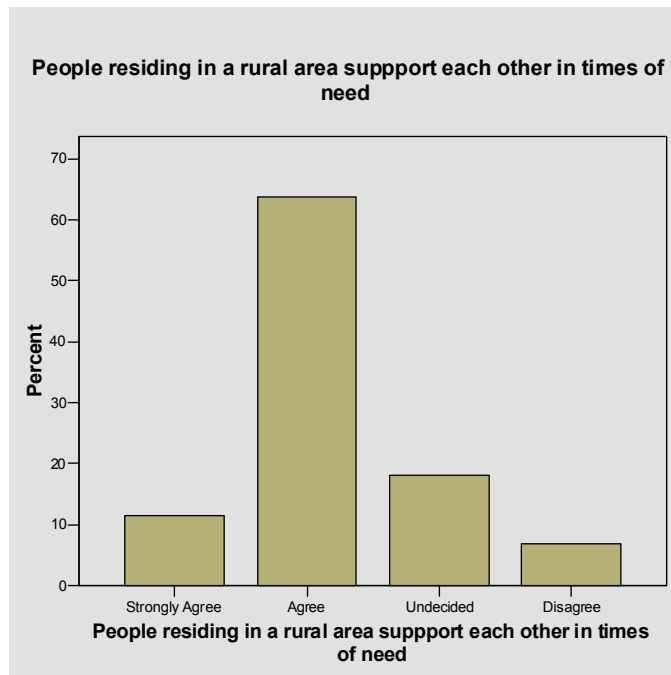
Figure 12 indicates that most people (62%) agreed with this statement. This was an expected response and would tend to support the notion of a 'rural attitude'.

Question 9 – "Aged people who live in rural areas are more independent than aged people in city areas."

Figure 13 Question 9 responses from urban and rural participants
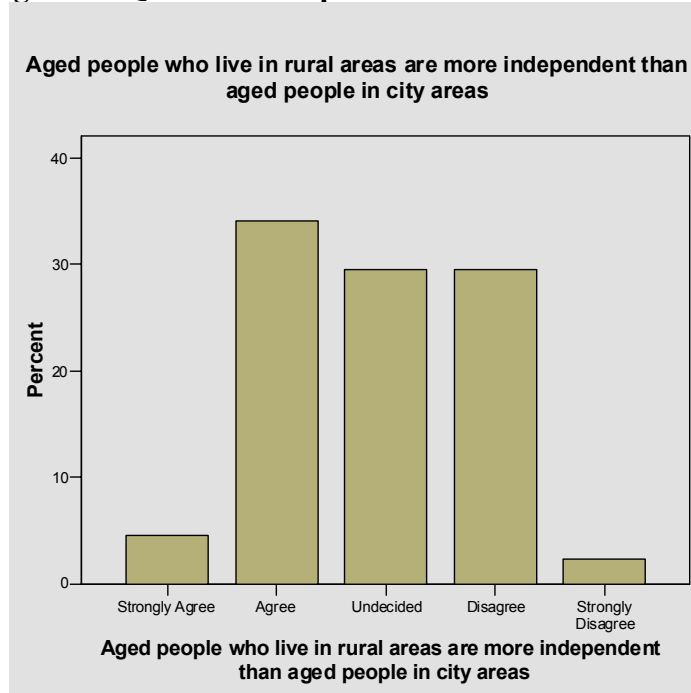
Figure 13 indicates that although 35% of people agreed with this statement (which would have been an expected response in determining a 'rural attitude'), while 52% were either undecided or disagreed with the statement.

Question 10 – "Aged people who are dealing with death and dying do not see the need for health services."

Figure 14 Question 10 responses from urban and rural participants.
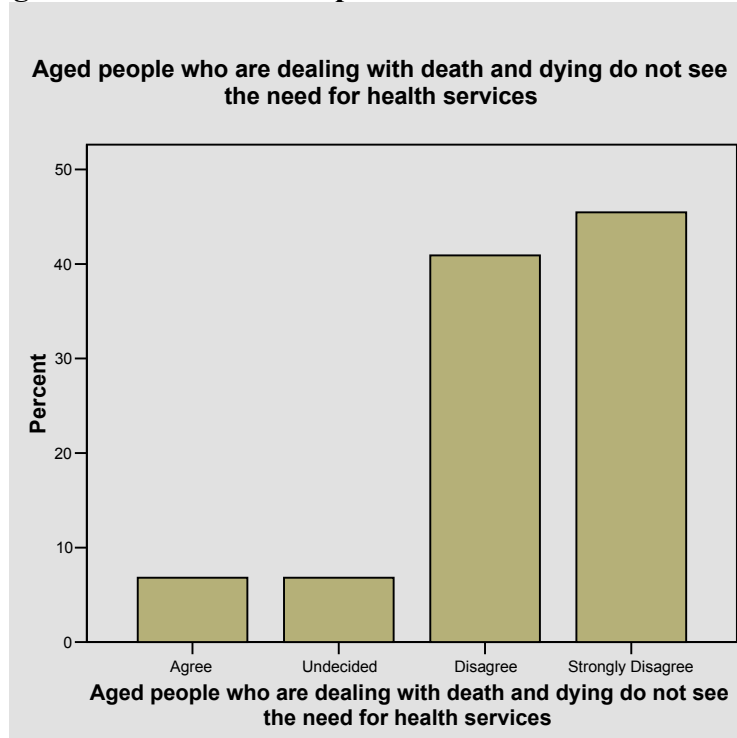
Figure 14 shows that most respondents disagree (40%) or strongly disagree (45%) with this statement. People who are ageing, who are dealing with death and dying need health services.

Statistical Associations:

The following Chi square analyses examined whether there were any associations between the demographic data. The Questionnaire was used to determine knowledge and awareness of services. No tests were found to be significant (there is no relationship between location and awareness of services) but because of the small sample size, some expected values were

less than 5, which means that the results cannot be interpreted with any certainty.

There were no associations with the following variables:

- Are you aware of any aged care services in your area and the person's birth location,

- Are you aware of any aged care services in your area and the person's current location,

- Are you aware of any aged care services in your area and has the person moved from their birthplace,

- Are you aware of any services for people who are dying in your area and the person's birth location,

- Are you aware of any services for people who are dying in your area and the person's current location,

- Are you aware of any services for people who are dying in your area and has the person moved from their birthplace.

Group Differences:

This section examines the differences between rural and urban areas and differences in the way in which participants responded to the questions. Mann Whitney U tests were used to compare the two groups (urban and rural) for any significant differences within the ordinal data.

a) **Current location of the participant (Urban v Rural):**

In comparisons of those currently living in rural areas and those living in the city, Mann Whitney U tests were conducted. Differences are noted in Q. 6 - *The aged dying person does not need access to health services.* Country people ranked this significantly higher, therefore disagreeing with the statement more than the urban group $U(44) = 148.000$, p=.0135 (1 tailed). In a comparison between people who live in the country and people who live in the city, people living in urban areas more strongly agreed with the statement that, *Aged people have limited access to health services in rural areas, than people in the country.* People in the country were more undecided $U(44)=141.000$, p=.026 (1 tailed).

b) **Location of birth (Urban v Rural):**

Comparisons between people born in the country and people born in the city found that with (Q.6) *"The aged dying person does not need access to health services",* people born in urban areas tended to agree more with the statement. People born in rural areas tended to be undecided about the statement $U(44)= 140.500$, p=0.025. (1 Tailed). With *Q. 4 Aged people have limited access to health services in rural areas,* country people tended to more strongly disagree with the statement than people born in urban areas who were more undecided, $U(44)=135.500$,p=0.012 (1 Tailed).

c) **Has the person moved from their birthplace? (Rural whole life, Urban whole life or Moved):**

Comparisons were drawn between people who have lived in the country their whole life, people who have moved between the city and the country, and people who have lived in the city all their life. The more that they have lived in the city, the more they were in agreement with the statement (Q: 4) *"Aged people have limited access to health services in rural areas"*. Whereas, the more that they lived in the country the more undecided they were. X^2 (2)=135.500,p=0.029.

Again, in (Q. *7*) *"People who are dying because of old age do not suffer"*, the more that they have lived in the city the more they were undecided about this statement, and the more that they have lived in the country, the more in disagreement with the statement. X^2 (2)=10.505,p=0.005.

d) **Are you aware of any aged care services in your area? and e) Are you aware of any services for people who are dying in your area?:**

A comparison was conducted about knowledge of services between rural and urban areas in this Gippsland study. A Chi square test of independence was run between whether participants had answered yes or no to the questions "are they aware of aged care services" and "are they aware of services for the dying", with their location. There was no significant association found between where they lived and if they knew about the services and where they were born and if they knew about the

services. Therefore, there were no significant differences if they answered yes or no.

A project conducted between 2003 and 2005 (Palliative Active Links (PALS) Project conducted in Queensland found that a number of previous situations in palliative care could have been more easily managed by patients, family and/or carers had information or access to information to assist them at their time of need had been available and accessible. They found that the best way to improve community awareness was to train volunteers as information links.

f) **those above and below the age of 65:**

People under 65 years disagreed more with the statement (Q*5) People residing in a rural area cope well with death and dying than* those people 65 and over.

The research questionnaire sought to determine a rural attitude. Again, the sampling size provides only tentative conclusions to be drawn. The challenge of obtaining strong sampling numbers for this research was found to be consistent with the challenges of distance and access issues particular to rural areas.

This next section will present the results from the focus group interviews.

Focus Group Interviews

Results derived from Focus Group Interviews are presented in matrices. The four focus groups have been coded: F1, F2, F3, F4. Each group contained on average of 6-10 participants. All groups were asked the same questions and transcripts have been provided in Appendix 9. Responses have been summarized and grouped according to each question.

Q1.: What does palliative care mean to you?

Question 1 Key Responses:

- Support and a positive experience
- Attitudinal approach to care
- Team work
- Passion
- Quality of life
- Support to family as well as patient
- Choices
- Dignity to dying
- Being a part of a journey

"It means different things sometimes, like end stage care, or terminal care, it depends what sort of training people have had, I mean whether they are specialists or just nurses who end up giving palliative care". (F4)

All the responses from the 4 groups incorporated key concepts of the overriding 'philosophies' of palliative care although in varying degrees, with little to no reference to symptom control and clinical care. Responses from one group in particular (F1) felt that palliative care from their team was a unanimous group response as *"the whole group feels the same way"*. Participants in F1 consisted of mainly nurses (generalists), and were not necessarily nurses who were qualified in palliative care, which may account for the 'attitudinal' type responses as opposed to responses indicating a knowledge based understanding of the role of specialist palliative care providers.

Q2.: How can people in this area access palliative care services?

Question 2 Key Responses:

- Doctor
- Family, neighbour, anyone, self
- They have to be aware they have been referred to a palliative care service
- Pamphlets in surgeries
- By referral from specialists
- Hospitals
- Social workers
- Community education and advertisements in the local paper

"The only pre-requisite is that the patient knows and understands that they have been referred to a palliative care service" (F3)

Responses to question 2 signified that people requiring palliative care in the designated rural area are referred to services largely by linking with general medical services such as the GP, or the hospital. Responses to the question highlight 'access' issues and the difficulty faced by people in rural areas to travel these medical services. It also highlighted that to access these medical services by referral or word of mouth or through neighbours and family members relies on people knowing what palliative care is, and also whether experiences were positive for these recipients.

Q3.: Do people in your area know about palliative care, is it something that is advertised?

Question 3 Key Responses:

- Word of mouth in the older group
- advertising and publicity
- education services were developed because people wanted to know more about it
- we are attached to a hospital – people know us

-attitude related responses:

- Palliative care strikes fear into the heart of most people
- They don't want to know
- 'they' don't want to confront the fact that they are dying
- until you need it, it doesn't stick in your mind
- its not understood
- people die from asbestos – (around here) they need to know
- we don't get told a lot of the time that they die from asbestosis

"Many people in this area die through asbestos and I reckon they need to know we are here, and understand what we do".(F3)

Q: (additional question) what is the major cause of death in this region?

A: *Cancer*

Q: What type?

A: *Lung   (F3)*

This question highlights the issues around 'attitudes' toward death and dying and also the high incidence of 'asbestos' related deaths in this area.

Q.4: (In your experience) what services do people want when they are dying, and is that different to what they need?

Question 4 Key Responses:

- their needs met, whether at home or in hospital
- to be independent and in charge
- most want to be cured
- some family members 'want' different things, which can be difficult
- it's about quality of life
- sometimes it's about 'things' like toilet seats
- it's about what they want and not what you think they need
- 'they' want to be heard
- 24 hour nursing care
- overnight nursing care
- what we offer is enough ie. Volunteers, meals on wheels
- what they want is usually what they need
- people around here are proud
- respite and appropriate accommodation
- people around here need a hospice
- what they want we can't give them it is not achievable

"I think that most people want to be cured, they want to live on, even though they may know that nothing more can be done to cure them. That's where the acute focus is totally inappropriate, at a hospital, any acute hospital you are supposed to get better and walk out. A person dying, well that doesn't happen and I don't think an Aged Care facility is appropriate either. People around here need a hospice, where…….even the receptionist knows how to be around dying people. And, they want to be around dying people more to the point". (F2)

Responses to question 4 highlight issues faced by service providers in terms of complex family situations and difficulties in supply and demand such as 24 hour nursing care. A consistent theme arising from this question was professional boundaries and although, *"...we think we know better we are only facilitators"*. This focus of care on the wishes of the patient and their families is consistent with standards as set down by Palliative Care Australia and underpinning palliative care philosophy. The question also brought out in participants both their passion and frustrations about working in the area of palliative care, and to some extent attitude of service providers in the provision of that service. A respondent from F2 states:

"I think that as professionals we have to be aware of boundaries…,I mean what is my view, and what it is that these people want. I think we are all influenced by our own personal views about death and dying, about our own experiences with palliative care and our own kinds of fears or hopes. I think that does impact on the way we see things".(F2)

Q.5: What sort of services would you like to see included in palliative care service delivery for an ageing population: are there things the elderly need that is different to the needs of other clients?

Question 5 Key Responses:

- support
- A hospice (consistent response)
- Good palliative care attitude and focus
- Nursing through the night is more likely to be required for older people
- Older people in this area are distant from people and services
- They end up in hospital
- Practical support
- Welfare funding to expand other levels of palliative care
- They have no family support
- Emotional support
- Transport help
- More funding
- Specialist palliative care nurses
- Some of us here think that dying because you are old is not enough reason to stretch our palliative care services.
- Dying is a part of life, if symptom control is needed that's different
- It would be different if we had staff and time

"I guess there are differences, sometimes just by virtue of the fact that they are at a distance, the older couples have moved down here from somewhere else, potentially they may be at a distance from people who can do that, so services can't be provided, and they end up in hospital". *(F2)*

Responses to question 5 clearly showed that there was a need for more funding and an increase in support specifically in palliative care service provision for older people. The need for a hospice or dedicated palliative care beds was seen as a high needs area. Participants from F3 offered responses that appeared to be different to the overall responses to this question. This may be attributed to the fact that participants from this area ranged in occupation and discipline, such as social workers, occupational therapists and home and community care workers as well as nurses. Palliative Care in essence is now seen to encompass all those who are dying from an incurable illness (including old age). This may be seen as specific (palliative care) knowledge which might not necessarily be seen as a shared philosophy or accepted by a larger team. Concerns from this group were embedded in funding issues which were possibly pertinent to their own local issues and specific to their region.

Q.6: Are there any specific difficulties faced by people who are dying in rural areas that you are aware of?

Responses to question 6 have highlighted access and equity issues for the elderly, mainly relating to transport and cost. Responses to this question also allude to the importance of volunteers and their role in supporting the elderly. Service providers are heavily reliant on the availability of volunteers in rural areas, and one respondent noted a 'difference' between metropolitan and rural communities: *"Since*

coming to the country from the city, community is very noticeable – the

volunteers are very supportive". (F4)

Q.7: What are some issues faced by the carer?

Question 7 Responses:

- Lack of services
- Volunteers doing more than their role –trying to pick up the pieces
- Stretching other services
- Distances to cover
- Driving at night long distances only to turn around and go back
- Getting equipment into houses
- Having enough equipment
- Our cars and tyres have to be in good condition
- Access to drugs
- Our mobile phones don't always work
- Going shopping (people know me)
- Kangaroos at night
- Expectations that you can fix it
- Accepting others 'death' choices
- Physical exhaustion
- No structured debriefing
- Family as Carers don't always want caring for their partners

"I've seen a number of elderly women who had terrible marriages and didn't feel cared for in any way by this man who is now dying and they are now in a position where they have to nurse this man. It's not all about the quality of life, there is a lot of anger, some people don't want to do it".(F2)

Respondents to this question spoke from their own perspective as professional carers and highlighted several safety aspects inherent in

their jobs, including travelling long distances, often in poor conditions incurring safety hazards. Carers in rural areas can travel sometimes from one person's death to another, without being able to debrief between clients. They were often feeling physically exhausted, and have had to deal with complex situations more often than not in isolation.

Q.8: Do you think we should be asking elderly people about death and dying?

Question 8 Key Responses:

- Yes, find out their expectations
- There are boundaries for some
- Most elderly are willing to talk about it
- Some cultures don't discuss it
- In the country, people are matter of fact, what is the fuss
- Who you are, not how old you are
- Older people want to talk about death because it is getting closer for them
- That's what we do - sensitively

"Well it's no good asking young people about it because they don't know anything about it, and, it's no good asking the dead, because they can't answer any questions".(F1)

And,

"If we don't ask how do we know if we are getting it right?"(F3)

Respondents consistently held the view that people who work in palliative care need to ask 'sensitive' questions so that the care they give is appropriate – asking older people about their death and dying is

simply what they need to do. There was also consistent reference to both the cultural and individual 'ways' of people, illustrated by the recurring sentiment. "S*ome people will wish to talk about 'it', some people can't – It's a matter of knowing the difference".(F1)*

Q.9: In that cultural group do you include Indigenous?

Question 9 Key Responses:

- We do
- They keep to themselves
- Not usually palliative care
- They look after their own
- We also have a large Maltese and Italian community
- The Maltese for instance don't want to talk about 'it'
- They have a special view about spirituality and other things

"They are inclined to keep to themselves a lot. In the 5 years I have been here, there has been a break, a transition, a change. Plus we had the Koori Co-Op used to do alot of care and now that doesn't happen. They are also now reliant on district nursing services and most of them on that part are pretty good and receptive." (F1)

Where respondents to this question were quick to identify cultural differences for clients and their care, very little was stated about Indigenous people. This may be due in part to the fact that when it comes to death and dying for Indigenous people, there is a conceptual belief that *"they look after their own"*.

Q.10: **How do you think the research could help your organization?**

| Question 10 Key Responses: | "I think the researching organization could be actually more than a research department and be a productive partner – we need hospice services." (F2) |

Question 10 Key Responses:

- New ideas we haven't thought of
- We do things very well – we do not need a new model
- We need bricks and mortar, staff, money, cars, transport
- Practical help
- We need a hospice
- Raises the awareness of palliative care
- New graduates who want to work in palliative care
- It's about education and getting feedback
- Physical infrastructure

Respondents in all groups expressed the need for more hospices and for more staff. Increased transport facilities was also seen as a priority. The need for a hospice in the designated area for this research was the single most dominant emerging theme throughout the interviewing process.

This research proposed to make recommendations for the development of a model for the delivery of palliative care services in a rural area. Comments from focus group participants strongly suggested that a 'model' for the delivery of palliative care in a rural area for an ageing population would not be considered a desirable outcome for them, as it would not meet their needs.

Participants were generally resistant and expressed negativity towards the notion of 'another model'. This may simply be interpreted as resistance to change. Investigating whether there may be a reluctance for change in rural areas or a rural 'attitude' towards change, was not an objective of this research however, further data collected in this area could assist in planning for population ageing. All participants in the focus group interviews displayed passion, strong community spirit and commitment to palliative care. Some comments:

"Another 'Model' is the last thing we need, it's not the how we are doing things, it's the where – we desperately need a hospice down here" (F2). and,

"It's bricks and mortar we want down here, not more theories"(F3).

Anecdotal evidence suggests that a 'rural attitude' to death and dying does prevail. In its simplest form, this attitude emerges in statements such as: *'it's the country you expect to get less' and 'we just look after our own when we can'.* Furthermore, *'In the country, people are matter of fact, what is the fuss?'(F3).* Most people (62%) agreed with the statement (Research questionnaire q. 8) "People residing in a rural area support each other in times of need" also supporting the notion of a 'rural attitude'.

Anecdotal evidence also suggested that talking to older people about death and dying provides valuable insights and contributes to our knowledge base

in providing palliative care. Participants were positive in their attitude to the topic of death and dying in the context of ageing. Comments included:

'… find out their expectations' (F1)

'There are boundaries for some but most elderly are willing to talk about it' (F1)

'Some cultures don't discuss it' (F1)

'Who you are, not how old you are' (F2)

'Older people want to talk about death because it is getting closer for them' (F3)

"Well it's no good asking young people about it because they don't know anything about it, and, It's no good asking the dead because they can't answer any questions". (F1)

And,

"If we don't ask how do we know if we are getting it right?"(F3)

It is also apparent that people in rural areas have the same medical and palliative care needs as those in metropolitan areas, such as access to regular support services. People in rural areas are more than likely to be disadvantaged when it comes to accessing palliative care services for the following reasons:

- Chemotherapy treatment requires regular trips to hospitals that provide this service. Whilst these services are available in the Gippsland area, patients find it difficult to travel between towns, let alone if they are

required to go to Peter McCallum Hospital in Melbourne for their treatment, or to see specialists.

- Transport is either limited or costly.

- Hazards such as inaccessible farm roads, kangaroos and the weather impact on the provision of timely care for the clients and their families.

- When the person who is requiring palliative care is the driver in the family unit other family members are disadvantaged.

- Technology and equipment failure including mobile telephones which are out of range.

- Nurses who attend the person who is dying may not necessarily be 'specialist' or palliative care trained nurses.

- Local hospitals are not equipped to take 'long term' patients.

- Young people who are dying are more often than not sent to the local nursing home, which is generally thought to be inappropriate for younger people and their families.

The need for community education in palliative care especially in areas where there is a high incidence of asbestos related illnesses appears to be a common thread among the groups interviewed. One of the major recommendations from a study titled "Promoting Multidisciplinary Collaboration in Palliative Care in Rural Australian Communities" conducted in 1999 recommended that community education be undertaken in rural and remote areas to promote the concept and support the reality of dying at home (Moorhouse, George and Young, 2000).

Dicks (1994) discussed the benefits of education and caring in general, stating that "To care is good, to educate is better." (p.1) Interestingly, the carers or service providers (nurses and auxillary staff) held varied perceptions about whether people providing palliative care require 'specialist' training and skills. Defensive statements such as *"...anyway, we provide good care here"* were made by individuals from organizations that did not prioritise their involvement and encouragement of staff to attend education sessions. People were often "too busy" or the education sessions were "inconvenient" either because of timing or distance. Participants often referred to, and spoke in terms of the 'philosophy' and 'attitude' of palliative care. On several occasions it was referred to an acknowledgement of the difference between specialist and generalist services. Members from one of the focus groups (F3) held a common belief that any generalist nurse or care provider from a discipline other than nursing could provide palliative care. This group did not recognise the need for 'specialist' training. Making do *'with what we have got'*. This same group was also almost unanimous in their belief that elderly people who are dying simply because of old age, should not be on a palliative care program unless there are issues with symptoms or pain control. This group had been together for a long time and several times expressed consensual opinions.

This section has presented findings derived from the research questionnaire and focus group interviews from Stage Two of the research. The following section (5.3) will now present findings from Stage Three.

4.3 **Analysis of Data collected in Stage Three: What is wanted/needed:**

Results are presented in two parts:

A) Data have been contextualised and extracted from (The Social Impact of Caring for Terminally Ill People in Australia, 2004, Palliative Care Australia).

B) Findings of a survey of baby boomer volunteers and focus group participants.

These results addressed the following two research questions:

- *What would an ageing rural population want included in a palliative care service? - and what do the service providers want/need?*

A) The Report on *Social Impact of Caring for Terminally Ill People in Australia, 2004, Palliative Care Australia* highlights that caring for a dying person differs significantly from care of other people in need, such as those with long term disabilities. The report acknowledged that end-of-life care can be intense and sometimes short in duration, and often manifests in grief and fear, bereavement and loss. The Report acknowledges the unique needs of carers, and identifies the impact of caring on which results in

- Stress;
- Disruptions and emotional strains;
- Health problems;
- Mental health issues;

- Reduced life opportunities;

- Financial strain;

- Increased reliance on health services;

- Workforce changes;

- Fractured community relationships.

Table 16 presents the main findings from the Report which indicates that the health conditions of care recipients. The figures presented here do not tally to 100% as some recipients had more than one condition.

Table 16. The ten most common health conditions of recipients of

palliative care in Australia - 2004

Health Conditions	Number	%
Alzheimers Disease/dementia/ memory loss	326	23%
Frailty in older age	326	23%
Intellectual disability	251	17%
Stroke	240	17%
Neurological disorder	228	16%
Heart condition/blood pressure	180	12%
Mental/emotional illness	164	11%
Respiratory	111	8%
Musculoskeletal	104	7%
Cancer	82	6%

Source: (PCA, 2004 Caring for a Dying Person in Australia, p.15)

Palliative Care Australia (2004) identified a number of issues for special groups of carers and reported that more than half of those who receive palliative care were over 75 years of age. As women are living longer than men, they are the main carers. These following issues reported by PCA (2004) are congruent with and support the overall research issues outlined throughout this dissertation.

Women provide more direct personal care and are likely to be disadvantaged by low income, unemployment, lifestyle restrictions, poor health, reduced career development and superannuation accumulation.

Rural and remote carers experience transport difficulties, privacy and confidentiality concerns, and a general lack of services and support.

Carers from culturally and linguistically diverse (CALD) backgrounds experience isolation and language difficulties, and a lack of understanding of the workings of the health system.

Indigenous carers experience unique issues with customary obligations, they also tend to experience poorer health and have less access to healthcare services.

Carers of children and children who are carers confront their own challenges.

"Parents caring for a child with a terminal illness can experience social isolation and marriage disruption, and report that they need strong practical assistance in order to cope during long and invasive treatment regimes. Young children who are carers can feel isolated and risk losing study and other opportunities. They can sometimes be hidden carers who bear responsibilities beyond their years" (PCA, 2004, p. 26).

Palliative Care Australia (2004) are committed to improving the outcomes for those who care for dying people by planning a wide–ranging campaign which aims to include:

- Generating awareness;

- Promoting services;

- Arguing for improved government policies and programs;

- Advocating for improved income support for carers;

- Encouraging palliative care services to provide better support to carers during and after death;

- Working with employers;

- Arguing for more research.

Gibson (2005) reported similar findings in studies completed in the United States, noting rural caregivers have special needs, concerns and barriers. Another study (Rural Caregivers Living in Shadowland) conducted in Canada highlights success with conducting small, in-home training sessions for groups of rural caregivers, either through teleconferencing or on-site instruction. Gibson reports further that positive changes occurred with these rural caregivers as they received information and education, providing support which also improved their quality of life.

B) Rural baby boomer volunteers and focus group participants: *what should be included in a palliative care service for an ageing rural population?*

Volunteers were asked about what they felt should be included in a palliative care service for an ageing rural population. Of most significance in this anecdotal evidence collected was the need for a centrally located hospice. Other identified (client) needs include:

- Twenty-four hour care and nursing through the night was seen as more likely to be required for older people, especially if they have no family support.

- Emphasis was also on the need for increasing family and carer support, including both practical and emotional support.

- Welfare funding to expand other levels of palliative care including the availability of specialist palliative care nurses was also seen as a priority.

- An increase in transport availability and volunteer supports was also emphasised.

- More 'choices' through counseling and support for family when carers may not want palliative care for their partners. This is because, they feel it needs to be them providing the care.

The needs of the rural palliative care service provider (as identified by focus group participants) included the need for:

- More staff and more time;

- Better equipment;

- Better access to drugs;

- Not driving alone at night for long distances;

- Well serviced cars;

- Structured de-briefing;

  - A better phone system and method of communication;

  - Privacy and confidentiality.

As found in the PCA (2004) Report, this research also found that rural and remote carers experienced transport difficulties, privacy and confidentiality concerns, and a general lack of services and support.

Section 4.3 has presented contextualised data obtained from the national study conducted by Palliative Care Australia (The Social Impact of Caring for Terminally Ill People in Australia, 2004) and the research responses from the baby boomer cohort and palliative care service providers.

4.4 Summary of Findings

The single most dominant finding to emerge from this research was the strongly expressed desire by palliative care service providers for a centrally located hospice in the Gippsland region. This research also shows that people who are dying in rural areas have the same needs as those dying in the city and that more and more people are choosing to die at home. While only tentative conclusions can be drawn from the analysis of questionnaire data with regard to determining a rural attitude, anecdotal evidence collected supports the notion that a rural attitude to death and dying exists. This will have an impact on the implementation of palliative care services in rural areas, highlighting the need to raise an awareness and understanding of

palliative care in areas which also have the additional challenges of cost, transport and access and availability of specialist care.

In terms of ageing, the statistical figures provided to the population in older ages is conventionally taken as 65 years and above. By the year 2031, 21-22% of Australia's population will be aged 65 and over. Women are living longer than men, and population ageing will see a rise in dementia related diseases. Baby boomers will make a significant contribution to our ageing population, and between 2031 and 2051 baby boomers are projected to swell the population aged 85 and over to almost double from 612,000 to1.1 million. The PCA (2000) Census shows that almost half of the people in the 55+ aged group who died while receiving palliative care, died in regional and rural areas of Victoria. Population-based rates of admission to palliative care services in regional and rural locations are 30-35% lower than in capital cities, no doubt related in part to the lack of access to specialist palliative care doctors. More than one-third of Australians who die receiving palliative care services die at home.

The Palliative Care Census 2000 reflect significant differences in access to any kind of palliative care services, between people who live in metropolitan centres in Australia in comparison to regional and rural areas. People in rural areas have the same medical and palliative care needs as those in metropolitan areas and more than likely are more disadvantaged when it comes to accessing those services. There are significant differences between remote and urban areas where there are fewer services, longer distances to travel, poorer road

conditions, diminished public transport and environmental issues related to agricultural and mining occupations, such as found in Gippsland and the high incidence of asbestos related deaths and illnesses.

Results from this research highlight the need for community education and awareness in palliative care, with specific attention being given to environmental and cultural health issues. Other implications for training and education will need to include the vast area of dementia. In particular there is an urgent need to develop rural based strategies which address the complexities of working with people who have dementia who are in pain, and who need assistance with symptom control in full recognition of the fact that they may be unable to articulate their pain or their needs.

Chapter 4 has presented the results of this research, and provided a summary of findings. The research has found that there is a negative relationship between ageing trends in rural Australia and the availability of palliative care services. The final chapter (5) will provide a discussion on these findings and will include recommendations and implications emerging from this research.

Chapter 5: Conclusions and Implications

Peace my heart……
Peace, my heart, let the time for the parting be sweet.
Let it not be a death but completeness.
Let love melt into memory and pain into songs.
Let the flight through the sky end in the folding of the wings over the nest.
Let the last touch of your hands be gentle like the flower of the night.
Stand still, O Beautiful End, for a moment, and say your last words in silence.
I bow to you and hold up my lamp to light you on your way.

(Tagore, 1915, *from* the Gardener, No.61)

In this final chapter, conclusions about research questions and the research findings are summarized and discussed in Section 5.1. Section 5.2 will provide recommendations for a 'model' of palliative care service delivery for an ageing population in a rural area. A final 'report' will be prepared, which will provide information containing recommendations for a model of service delivery in a rural area to palliative care service providers, especially rural providers which will include these recommendations for a model, having specific regard to the needs of an ageing population. Section 5.3 will discuss and present implications of this research and its contribution to the body of knowledge. Section 5.4 will examine research limitations and implications for further research.

5.1 Conclusions about research questions and the focus of the research to:

"Select a major rural area for the purpose investigating the availability of palliative care services, trends in ageing and to examine the relationship between the two."

Research questions:

- *What are the health and ageing trends in Australia?*

- *What are the palliative care demands and needs of an ageing population in a rural area, and are they any different to those of a metropolitan area?*

- *Would an ageing rural population be disadvantaged if and when they need palliative care?*

- *Is there a rural attitude to death and dying which would impact on the implementation of palliative care services in a rural area?*

- *Who will impact on the design of palliative care services and make decisions for an ageing population?*

- *What would an ageing rural population want included in a palliative care service?- and what do the service providers want/need?*

- *Is there a lack of knowledge and understanding of palliative care in rural areas?*

A number of conclusions have been drawn from this research based on the review of literature and examination of the emerging issues, results and findings. Australia is an ageing population and statistical projections into ageing indicate that the health of all Australians will have significant consequences for society as we generally live longer and healthier lives. Health and ageing predictions and projections should prompt key stakeholders including baby boomers, the aged cohorts of the future, to plan and prepare, perhaps redefining ageing in the attempt. Planning should include preparations for an expected rise of dementia related diseases and the

implications of gender on health will have ramifications for an ageing population, and in particular for women as carers in our society.

The Gippsland area provided an excellent area for this research and the findings of this study would appear to be consistent with the literature relating to access and equity issues faced in rural areas. Socioeconomic disadvantages tend to increase with remoteness, with people living in rural and remote areas of Australia tending to have higher death rates than those living in capital cities and other metropolitan areas.

PCA (2000) reported that half of the people receiving palliative care in Victoria in 1997 died in rural and regional areas, which may be attributed to harsher living environments, poor access to health services, specialists, and health professionals, lower socio-economic status and employment levels, and exposure to occupational hazards. Access difficulties also relate to length of time, distance and cost of transport availability in rural areas. Access issues were a significant issue referred to by a number of service delivery participants in this study. These issues are indicative of the health and well-being of Indigenous Australians who do not have the same life expectancy as non-Indigenous Australians, and who do not receive timely, high quality diagnosis treatment, rehabilitation and palliation with their illnesses and do not have the same life expectancies as non-Indigenous Australians. Health is influenced by genetic inheritance and culture, and by behavioural determinants, biomedical processes and the environment, as well as by economic and social factors.

PCA (2000) projected that as the population ages, there is a greater likelihood that people will die from cancer and other age-related diseases. This will create resourcing challenges for palliative care service providers of the future as the demand for service provision rises with increases in cancer death rates in Australia, resulting in an increase in the number of people who die receiving palliative care. Currently, access to palliative care services in rural areas is either limited or non-existent. In some rural areas palliative care services are less than optimal due to the absence of specialist or trained staff, including doctors.

The aim of this research was to investigate the availability of palliative care services, trends in ageing and to examine the relationship between the two. This research has found that *a negative relationship exists between ageing trends in a selected rural area of Australia chosen for this study and the availability of palliative care services.*

New models for palliative care delivery will need to incorporate the realities surrounding health and ageing projections and consider the specific needs of an ageing population, including the unique needs of rural communities. Palliative care service providers will need to be proactive in their preparation and planning for the future to make allowances for the projected increase in numbers of people retiring who are looking for the idyllic sea change and country change. Failing to plan for the health care needs of older people living in rural Australia may well result in 'aged ghettos', where there is

inadequate health services and unsustainable infrastructure available for people who are dying.

The following section provides a number of recommendations for consideration in respect of models of palliative care delivery for an ageing population in a rural area.

5.2 Recommendations for a 'model' of palliative care delivery for an ageing population in a rural area.

Palliative care for an ageing population- a rural based model?

One of the objectives of this research was to investigate models of palliative care and to provide recommendations for a palliative care model in rural areas which was inclusive of the needs of an ageing population. The following recommendations have been developed from the research and are outlined with recognition and acknowledgement of the standards, principles and current policies and requirements of palliative care service delivery as determined by the Department of Human Services and Palliative Care Australia. The Department of Human Services has identified a number of key elements that need to be built into the planning of care for people with life threatening illness and their carers and families. The key elements are that:

- the health and residential care workforce practises the palliative care approach;

- there is equitable access to a level of specialist palliative care across the state;

- the mix of bed-based and community-based specialist palliative care services meets the need;

- care and referral pathways are clearly defined and options are identified;

- communication strategies ensure general practitioners, community care providers and other health providers are fully informed of, and able to participate in, the care plan for patients under their care;

- effective and efficient links exist between hospitals and community-based services; and,

- sufficient numbers of appropriately trained specialist palliative care providers are available to provide care across a region (DHS, 2004, p.2).

These key elements provide ideal goals for service providers, and would support the research issues and findings which have been identified in this thesis.

'Specialist palliative care' service providers are expected to accept prime responsibility for care, or work indirectly by advising the professional carers who are looking after their clients. They provide physical, psychological, social and spiritual support and comprise a broad range of disciplines, including medicine, nursing, social work, pastoral care, physiotherapy, occupational therapy, pharmacy and related specialties. The 'palliative care approach' aims to improve the quality of life of individuals facing life-threatening illness and of their families, by preventing and relieving suffering

through early identification, assessment and treatment of pain and other problems – physical, psychosocial and spiritual (WHO, 2003). This approach facilitates identification of the wishes of clients and their families about care throughout a period of declining health and especially during end-of-life care, and is held as good medical and nursing practice in the absence of, or in conjunction with specialist palliative care services (DHS, 2004).

In determining appropriate 'models' of palliative care delivery and the future planning of services, DHS as the major funding body has identified practices and processes which are encapsulated by the following guiding principles:

Principle 1: People with a life threatening illness and their carers and families have information about options for their future care and are actively involved in those decisions.

Principle 2: Carers of people with a life threatening illness are supported by health and community care providers.

Principle 3: People with a life threatening illness and their carers and families have care that is underpinned by the palliative approach.

Principle 4: People with a life threatening illness and their carers and families have access to specialist palliative care services when required.

Principle 5: People with a life threatening illness and their carers and families have treatment and care that are coordinated and integrated across all settings.

Principle 6: People with a life threatening illness and their carers and families have access to quality services and skilled staff to meet their needs.

Principle 7: People with a life threatening illness and their carers and families are supported by their communities (DHS, 2004 pp.13-33).

These principles are based on aspects of care which are consistent with findings of a number of working parties and consultative groups, such as:

- The Palliative Care Strategic Framework Working Party;
- The National Palliative Care Strategy (Australian Department of Health and Ageing 2000);
- A Cancer Services Framework for Victoria (Barton et al. 2003);
- Improving Care for older people (Department of Human Services 2003) and
- Primary Care Partnerships-strategic Directions 2004-2006 (Department of Human Services, 2004).

Specialist palliative care service providers are required to demonstrate the quality elements fundamental to the palliative care approach, as set out in the Standards for palliative care provision (Palliative Care Australia, 1999). The Self Assessment Services Audit (Palliative Care Australia, 2001) is recommended by DHS as a structural method for assessing services and can be used as evidence of achievement and verification in the accreditation process of the Australian Council of Healthcare Standards.

In February, 2005 Palliative Care Australia produced their national policy document, *A Guide to Palliative Care Service Development: A population*

based approach, which they describe as a 'needs based model'. The document describes a service planning framework which can be used "…to provide assistance to health service planners, funding bodies and care providers to ensure that health care services are designed to meet the needs of the population" (Palliative Care Australia, 2005, p. 1).

Palliative care service personnel wishing to adopt best practice principles will need to frame their programs around the above principles and practices already set down and recommended by key stakeholders. As an addendum to this best practice framework recommendations are made which have been derived from the research findings of this thesis. These recommendations are offered with great respect and acknowledgement of the people who participated in this study who believe that another 'model' is the last thing they need. However, in the name of continuous improvement and with the knowledge that our society is ageing there may be a need to review our current models and practices, and to initiate change within our organizations or, to do 'some' things differently. Recommendations which have emerged from the research findings for this thesis can be incorporated into service delivery models which embrace the notion of 'palliative care for an ageing population – in a rural area'.

The single most dominant "wish" emerging from this research from the palliative care service providers and baby boomer survey was for a centrally located and fully functional hospice. The consensual opinion of the palliative care service providers within the designated area of this research was that *'it's*

bricks and mortar we want down here'. Baby boomer participants in this study described their need for a hospice which is staffed by trained people who have a positive attitude to ageing and death and dying and who are genuinely committed to total palliative care across all ages. As the population is ageing the need for a hospice will become more accentuated as people in isolated areas may not have families or carers who are either able or who want the responsibility of providing care. In planning the hospice of the future, the baby boomers will no doubt have much to contribute in keeping with their penchant to do things differently and to be proactive about change and initiation. Palliative care service providers will need to work collaboratively with one another as well as with key stakeholders, and as one participant stated, even with '*…Researchers and the research organizations,*' to cohesively and effectively lobby for a hospice for their community.

This research has found that the needs and wishes of an ageing population include:

- A country hospice ('*with lots of natural light and open spaces – like I was outside in the country'*)

- 24 hour nursing care when needed,

- More funding to be made available to strengthen current palliative care programs

- Increased transport facilities and more volunteers for transporting to chemotherapy appointments

- Improved communication and funding to access advanced technology

- Increased access to expensive medications

The following recommendations have been formulated as a consequence of the previously identified research issues and are derived from the results of this research:

Recommendation 1

That palliative care service providers in rural Victoria undertake a major review of current practices and models of delivery in order to prepare for the demographic realities presented by an ageing society.

Note 1.1: Kellehear (1999) proposed the health promotion model of palliative care. Subsequently, the philosophy of health promotion in palliative care is now included in recommended planning of service delivery in palliative care. The health promotion model espouses that dying does not, and should not, disqualify anyone from quality health and social care.

Recommendation 2

That future models of rural palliative care for an ageing population accept and include the philosophy of 'health promotion' as a working concept of palliative care, thereby embracing the true spirit of palliative care that aims to empower the aged person to live whilst they are dying.

Recommendation 3

That future formal and informal education and training in palliative care incorporate ageing and ageism and attitudes to ageing as compulsory units of study.

Recommendation 4

That education and training in 'dementia care for an ageing population' be included in palliative care training programs.

Recommendation 5

That support programs and networks be established and maintained for male and female carers in rural areas in order to ensure that they have ready access to both practical and emotional support.

Recommendation 6

That volunteer networks and associated recruitment programs in rural areas for palliative care be expanded to increase numbers across both genders and to include comprehensive training as well as support programs.

Recommendation 7

That structured de-briefing sessions be offered and encouraged for all palliative care staff including volunteers operating in rural areas. Time needs to be made available between traveling to more than one client.

Note 7.1: In theory most palliative care service provider programs make provision for counseling and debriefing sessions for staff, but in reality these sessions may be somewhat ad hoc and may not be structured as an inherent part of the job. It became evident through feedback from carers when conducting this research that these sessions are not utilized appropriately for several reasons. Either there is no-one available, or there is no time, or people are just too tired. Some people who acknowledged the importance of these sessions felt that they needed to talk to someone outside their own organization, for privacy and confidentiality reasons.

Note 7.2: Palliative care workers in rural areas often travel great distances alone, with little to no opportunity to debrief in between dying clients. Occupational health and safety questions could be raised in the event of any accident or incident.

Recommendation 8

That future provision of rural based palliative care services consider the impact of projected ageing trends and associated cultural issues with particular attention to Indigenous communities.

Recommendation 9

That palliative care service providers in rural areas work with the relevant community stakeholders to identify the health profile of their community with the intention of designing and providing counseling and support networks specific to those needs, either psychological or physical.

Recommendation 10

That compulsory professional development workshops be made available to all rural based palliative care providers on the contemporary and projected health issues specific to their community.

Recommendation 11

That strategically focused efforts be initiated to develop and sustain a rural based community awareness of palliative care.

Note 11.1: The argument *' most people know we are here – we've been here for years'* may require re-thinking in areas where there is high retirement and polarization of people to areas which are new to them. Anecdotal evidence gathered during this research indicates that most people think of palliative care as end stage care, or terminal care. Most people are unaware of the full attributes of palliative care programs, such as providing help with equipment, symptom control, medication management, counseling, and referral and respite.

Recommendation 12

Develop strong community partnerships and work collaboratively to review transport facilities, and develop strategies which could incorporate the sharing of costs associated with travel and transport with neighbouring councils.

Recommendation 13

That universities offering courses in nursing be encouraged to promote palliative care career opportunities especially in rural areas.

Recommendation 14

That appropriate levels of evaluation are designed, implemented, and disseminated for all key aspects of rural palliative care delivery.

This section has provided recommendations for a 'model' of palliative care service delivery for an ageing population in rural areas, which are based on the results and findings of this research.

5.3 Implications of this research and its contribution to the body of knowledge.

This research aimed to raise awareness of the need for well planned palliative care service provision within rural Australian communities including the application of key principles of palliative care arising from the expected increasing demands for related services arising from an ageing population. Palliative care is still considered a young discipline and is seen as a sensitive

research area because of the fact that subjects are either dying or have died. As such, Australian research in general in the field of palliative care in rural areas has been relatively slow. Through a literature review and analysis of studies in palliative care, as well as ageing demographics, this current research has provided data which is deemed to be relevant and which will hopefully enhance the practice of palliative care in rural areas for ageing populations and generally contribute to a steadily growing body of knowledge. While several studies have been conducted or are in the process of being conducted on palliative care delivery in rural areas, there is very little attention being given to the likely impact that an ageing population will have on service delivery. This research has provided recommendations for palliative care models to incorporate the needs of an ageing population in a specific rural area which could be applied to other rural areas. It is intended that a journal article and report will be prepared on completion of this thesis, in an attempt to share this information and to invite further discussion and open debate on the topic of preparing the field of palliative care for the new ageing paradigm, with particular reference to rural communities. The fields of education and nursing as well as other disciplines such as community workers, and local government authorities will perhaps also need to reflect on their current models of practice extending their thinking and planning to include issues for population ageing.

This research has attempted to raise the profile of palliative care needs for an ageing population in the rural area of Gippsland by including the Department of Human Services and key palliative care service providers within the focus

group interview process. Feedback from this research will be taken back to the participants. This research also raised awareness of palliative care options and benefits for our ageing population by including the members of the U3A in the field studies. The baby boomers, the aged cohorts of the future, who will potentially have input into the design of future rural palliative care services were also a part of this research. It is expected that this cohort will also have a significant impact on future aged care policy as well as on the retirement industry as a whole.

There is a need for a collaborative approach between palliative care providers including doctors and other health professionals. The implications of this type of research and its potential contribution to knowledge will rely on that collaborative approach working well, guided by the knowledge that rural areas experience access and equity issues and that the tyranny of distance complicates travel and communication. Future directions for the rural health industry in Australia, as well as policy development for an ageing population will be reliant on many areas of research with input from many different disciplines and bodies of knowledge. It is important therefore that research preparations for the future begin in earnest, and that funding be made available to researchers to advance our knowledge and understanding of health care with the context of an ageing population.

5.4 Limitations and implications for further research.

The scope of this research was intentionally delimited to the rural community of Gippsland in Victoria only, which as a community has specific needs in relation to asbestosis and other related illnesses. Concentrating on this one geographical location meant that the researcher was able to raise the awareness of the research which was being conducted in the area and also raise the awareness of palliative care as it appears to an ageing population. Challenges presented in obtaining large numbers of participants for this research due to both the pilot study and field studies being conducted within this geographic area.

Future research on the topic of palliative care for an ageing population utilizing a rural based model would need to include other rural areas, perhaps using a control area and doing a comparative study to determine the individual community needs. Raising the awareness of palliative care and asking questions about health beliefs and analyzing the health profile of the community will draw out any training needs specific to that rural community. Such studies should also explore the presence or otherwise of ageism and attitudes to ageing especially given our ageing population expectations. Specific studies on appropriate dementia training programs for care providers in rural areas would also support the expected rise in the incidence of dementia due to population ageing.

This current research attempted to investigate whether there is a rural attitude to death and dying which would impact on the delivery of palliative care. Questions were raised such as do country people know about palliative care, and if so, do they accept it, or are they self-reliant preferring to stick to themselves and to their communities? Research reveals that people in rural areas do have similar if not the same needs as people in the city and they have a high incidence of people choosing to die at home. Although the results of the Questionnaire have not been able to draw any firm conclusions due to the low sample size, overall evidence obtained in conjunction with the focus groups suggests that there is a rural attitude to death and dying which is likely compounded by a lack of awareness of palliative care, as well as the more 'rural' specific issues such as cost, transport and access and availability of specialist care. However, further research and investigation into determining the complex issues of ageing and rural attitudes and subsequent impact on the use of palliative care is highly recommended across other rural areas. Extending research into other rural communities to examine more closely attitudes as well as the effect of change and resistance to change, may further substantiate these findings. Having this knowledge will allow policy makers and planners to work more collaboratively within rural communities.

Of significance to this research was that palliative care service providers strongly expressed their need and desire for a hospice. It would be interesting to take this current research further and investigate whether 'country hospices' or 'bricks and mortar' are a unilateral need/desire for other rural communities.

Research into ageing may well be prompted by the baby boomers who have a penchant to change and influence the way things are being done especially, when the way things are being done impacts on them and their particular stage of life. In contrast to the vast array of data and in particular demographic data that is available for ageing populations, there currently exists in comparison a serious shortfall in contemporary literature on rural health and ageing. More specifically, in conducting research for this thesis, literature on palliative care for an ageing population in rural Australia has been found to be limited. We need to encourage research into palliative care so that we can continue to strive for excellence and ensure that we are doing the best we can.

In concluding this thesis I find myself thinking back to my early days in palliative care when as a novice I first heard the expression "a good death". I remember feeling outrage at this apparently common expression which is used quite frequently in palliative care circles, - of all places. I thought the expression was highly insensitive and failed to acknowledge the fact that there was someone at the end of that death who was sad and in pain irrespective of what age they happened to be, and – even if "he has had a good innings". As I gained experience working in palliative care I began to appreciate the value of a "good death" and, - it *is* worth striving for. A good death occurs when the dying person has all things in place which will ensure their dignity, it espouses good symptom control, so that the dying person dies pain free and is able to maximize his or her quality of life, with his or her wishes and needs being met.

People who work in palliative care experience what could be termed an excellent success rate of 100 percent. That is, every client on their program will die. Gauging how well you do your job therefore may look a little skewed. A good death is worth striving for, and provides a benchmark to gauge whether, as a team, 'we did the best we could' for the dying person. We need to encourage further research into palliative care so that we can continue to strive for excellence and ensure that we are doing the best we can for people who are dying, who are in our care, and who are packing for their final journey. Asking older people about their death and dying contributes to our knowledge base and enables us to get it right, to meet expectations and to improve our practice, and more specifically contributes to the ethos of a "good death" for our client group.

Palliative care is widely regarded as a sensitive, specialist area of care. Gate-keepers and key stakeholders in this palliative care environment are ever watchful and mindful and perhaps at times could be criticized as being over protective of the sensitive nature of their work. Research is often hampered by ethics committees, and for some, the topic of death and dying is still seen as taboo. Certainly for some cultures such as Japan and Italy for example, this may be true. Interviewing when research subjects have died or are in the process of dying and perhaps even because they are old raises the alarm; and it is largely because of this that the specialty area of palliative care has experienced a slow growth and is still considered a young discipline. Palliative care has been developing in Australia only over the past 30 years.

O'Connor (2005) notes that there is much work to be undertaken in palliative care and reports that:

"There are still people in our community who are not dying well and who, for many varied reasons, are not accessing the best care they could" (p. 1).

Changes in palliative care have presented some challenges in conventional thinking with the palliative client now being anyone who is dying of any disease, anywhere and of any age, including those dying of incurable old age. Community expectations are growing and more and more people are choosing to die at home. Baby boomers, the aged cohort of the future will present a range of significant challenges to the health care system. With increasing numbers of baby boomers likely to move to rural areas where health services and in particular palliative care services are limited or non existent, they will undoubtedly impact on the demand and need for new and improved health related services including modern palliative care.

Research of the type undertaken for this thesis can prepare the way and contribute to future planning so that our ageing population will not be disadvantaged when and if they may require palliative care in a rural area, and as 'Jean' says, "so people in the country receive the wonderful palliative care services found in the city".

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APPENDIX 1: AGED ATTITUDES TOWARDS PALLIATIVE CARE

**QUESTIONNAIRE (DRAFT)**

VICTORIA UNIVERSITY OF TECHNOLOGY

– This Questionnaire is a work in progress and will continue to be developed with Palliative Care expertise including input from Bethlehem Hospice.

This Questionnaire has been designed to determine the attitude towards palliative care for an ageing population. The Questionnaire will be used as part of a study which is investigating palliative care needs and wishes for an ageing population in rural areas of Victoria. There are 15 questions to respond to and it is anticipated that it may take 15 minutes of your time.

KEY:

When responding please circle to indicate your preference.

1	*2*	*3*	*4*	*5*
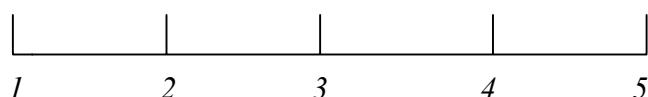
1.   *strongly agree*
2.   *agree*
3.   *undecided*
4.   *disagree*
5.   *strongly disagree*

What is your date of birth?:   *-----/----/----*
Please state the country and town of your birth………………………………………
What is your current postcode?:
Are you aware of any palliative care services in your area?:   *YES   NO* *Please circle*

Question 1   *Because old age cannot be cured there is a need for the provision of palliative care for our ageing population.*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
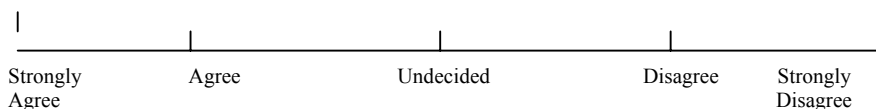
Question 2   *People who are dying should go to a hospital*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

Question 3   *Aged people who are dying should go to a hospital*

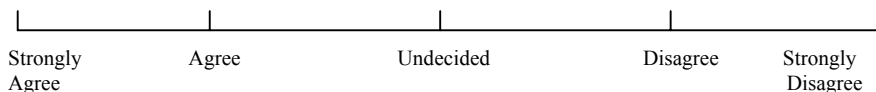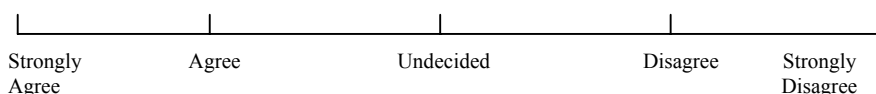|				
Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

Question 4   *There's nothing that can be done for the aged and dying*

.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
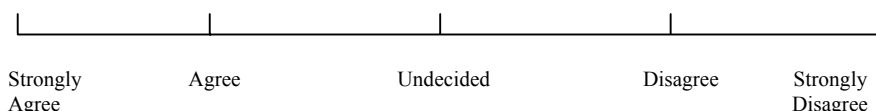
Question 5   *People should have choices about whether they die at home or in a hospital*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
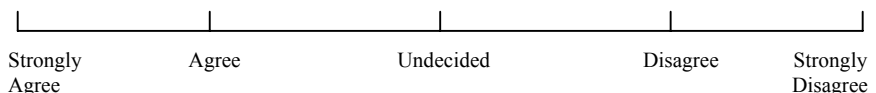
Question 6   *People who choose to live in rural areas are disadvantaged if they do not have access to palliative care*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
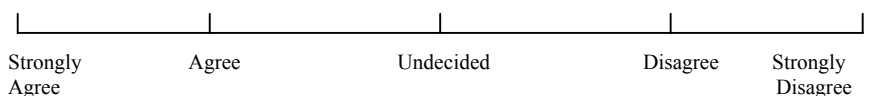
Question 7   *Palliative care is a luxury for aged people who live in rural areas*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
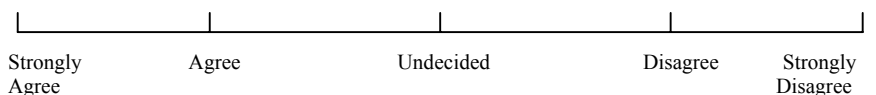
Question 8   *Aged people have limited access to health services in rural areas*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
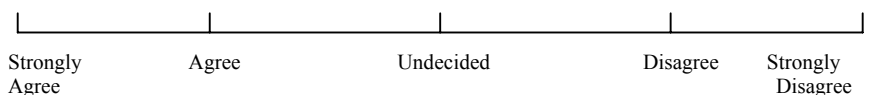
Question 9   *People residing in a rural area cope better with death and dying than those from the city.*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
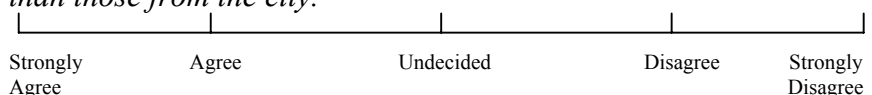
Question 10   *Palliative care alleviates pain and suffering*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
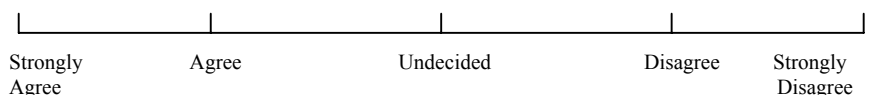
Question 11   *People just get old and die – there is no pain and suffering*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
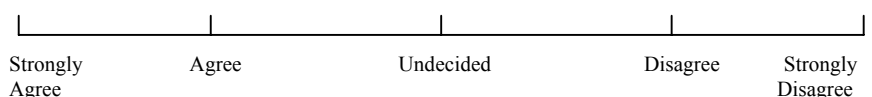
Question 12   *People residing in a rural area support each other in times of need*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
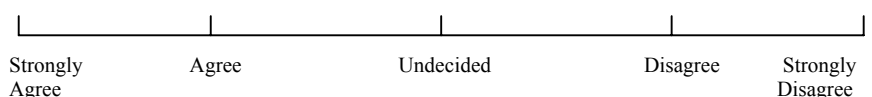
Question 13   *Aged people who live in rural areas are more independent than aged people in city areas*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
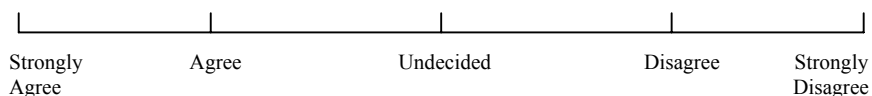
Question 14   *Aged people do not recognise the need for palliative care*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |
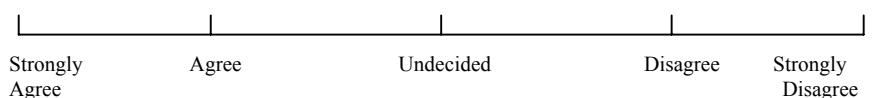
Question 15   *Aged and dying people living in rural areas feel powerless because there is nothing that can be done anyway*

| Strongly Agree | Agree | Undecided | Disagree | Strongly Disagree |

Thank you for your participation in this study.

237
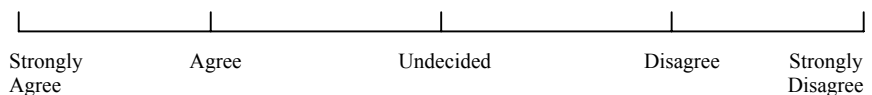
APPENDIX 2: U3A Pilot letter

P.O. Box 322
Laverton.
VICTORIA. 3028

Mr. K. Jackson
President,
U3A – Latrobe Valley,
P.O.Box 1114,
MORWELL. 3840.

Dear Mr. Jackson,

Re: Research Project: Palliative Care for an Ageing Population: A Rural Based Model

I am currently undertaking PhD studies within the Victoria University of Technology, and am investigating the palliative care wishes and needs of an ageing population in rural Victoria. Information obtained from this project will be based on a questionnaire and a series of interviews and surveys, and will be used to inform the development of a 'good practice model' for the provision of palliative care in rural Victoria. I have enclosed a flyer outlining this project, and write to you with a request that you might bring this project to the attention of your members.

Australia is an ageing population, and one that will experience radical change over the next 50 years due to the progression into retirement of generations born in the 'baby boom' years (1945-1965). The proportion of people over 65 is increasing, and as the majority of deaths occur in this age group the demand for palliative care services can also be expected to increase. This project may provide a proactive approach to future planning for the anticipated aged care boom

This study will involve the use of a questionnaire as well as a number of focus group interviews. At this stage I need to pilot the questionnaire and I would like to invite your members of U3A to participate in this area of the study. Ideally, this would involve 8- 10 of your members. I also anticipate collaborating with other branches of U3A in the region as the study will involve a further 60 – 90 participants.

I wish to assure you that any data obtained will be treated in strictest confidence and with anonymity. Names and addresses will not be included. For the purposes of identification and data analysis each questionnaire will be identified by code. Data will be kept in a locked office for 5 years according to VUT policy, after which it will be destroyed.

If appropriate, I would like an opportunity to meet with you for further discussion on this matter. I can be contacted at the above address, or e-mail address kerry.ryan@vu.edu.au or by phone: 9284 8956 (work), 0413 484 117 (mobile).

Yours sincerely,

Kerry Ryan

APPENDIX 3: Survey letter to U3A

VICTORIA UNIVERSITY OF TECHNOLOGY

P.O. Box 322
Laverton.
VICTORIA. 3028

President,
U3A – Morwell

Dear

Re: Research Project: Palliative Care for an Ageing Population: A Rural Based Model

I teach aged care and palliative care at Victoria University and am currently undertaking PhD studies also within Victoria University

I am investigating the palliative care wishes and needs of an ageing population in rural Victoria, and am at present undertaking the field study and data collection component of the project. Information obtained from this project will be based on a questionnaire and a series of interviews and surveys, and will be used to inform the development of a 'good practice model' for the provision of palliative care in rural Victoria. This study will involve the use of a questionnaire as well as a number of focus group interviews.

My interest in this subject is inspired by being a part of an ageing society. As Australia is an ageing population, we will experience radical change over the next 50 years due to the progression into retirement of generations born in the 'baby boom' years (1945-1965). The proportion of people over 65 is increasing, and as the majority of deaths occur in this age group the demand for palliative care services can also be expected to increase. This study may provide a proactive approach to future planning for the anticipated aged care boom.

I write to you in the hope that you and some of your members may be willing to participate in this project by responding to a questionnaire. I have enclosed an Information to Participants flyer outlining this project, and request that I might bring this project to the attention of your branch members. I would be more than happy to attend a meeting and provide an overview of this study. At this meeting I would leave questionnaires and reply paid envelopes for any interested volunteer participants to respond. Alternately, I can send questionnaires and reply paid envelopes and Information forms to you to distribute to any interested member. I can be contacted on 9284 8608 (business hours) or email: kerry.ryan@vu.edu.au if you would like to discuss this project and my request.

I wish to assure you that any data obtained will be treated in strictest confidence and with anonymity. Names and addresses will not be included. Participants do not need to supply names or any other identifying information when responding to the questionnaire. Completion and return of the Questionnaire constitutes consent. For the purposes of identification and data analysis each questionnaire will be identified by code. Data will be kept in a locked office for 5 years according to VUT policy, after which it will be destroyed.

I would be delighted to discuss any of these issues with you and thank you in anticipation,

Yours sincerely,

Kerry Ryan

APPENDIX 4: Letter of Appreciation

P.O.Box 322

LAVERTON. 3028

Carl Areskog
Secretary
U3A Werribee,
P.O. Box 1264
WERRIBEE.3030

RE: Research into Palliative Care for an Ageing Population: A Rural Based Model

Dear Mr. Areskog,

I am writing to thank you and your members for kindly participating in the abovenamed   research program. I appreciate both your assistance and your expediency. The Pilot is now complete and I will be proceeding onto the next phase.

I have also contacted members of U3A in both Morwell and Leongatha and have had the pleasure recently of meeting some of these members in person when I have delivered talks on my Research. I have learnt that the offices of U3A operate differently depending on the region,– some have guest speakers, some have more formal   education and learning activities. If you think your members may be interested I would be happy to attend one of your meetings and talk about my research or palliative care or aged care in general.

Could you please extend my sincere thanks to your members.

Yours sincerely,

Kerry Ryan

APPENDIX 5: Service Provider Letter

Kerry Ryan
P.O. Box 322,
Laverton. 3028

Dear   Palliative Care Service Provider, or
   Local Council Representative

Re: Research Project : Palliative Care for an Ageing population: A Rural Based Model.

I am currently undertaking PhD studies within the Victoria University of Technology, and am investigating the palliative care wishes and needs of an ageing population in rural Victoria. Information obtained from this project will be based on a questionnaire and a series of interviews and surveys, and will be used to inform the development of a 'good practice model' for the provision of palliative care in rural Victoria. I have enclosed a flyer outlining this project, and write to you with a request that you might bring this project to the attention of your team.

Australia is an ageing population, and one that will experience radical change over the next 50 years due to the progression into retirement of generations born in the 'baby boom' years (1945-1965). The proportion of people over 65 is increasing, and as the majority of deaths occur in this age group the demand for palliative care services can also be expected to increase. This project may provide a proactive approach to future planning for the anticipated aged care boom

I have enclosed a copy of the questionnaire in anticipation that you will be able to respond. I will be visiting your area on   and would like to arrange to collect the completed questionnaire and if possible meet with you for about 15 minutes for a brief discussion.

I wish to assure you that any data obtained will be treated in strictest confidence and with anonymity. Names and addresses will not be included. For the purposes of identification and data analysis each questionnaire will be identified by code. Data will be kept in a locked office for 5 years according to VUT policy, after which it will be destroyed.

Your participation in this research is greatly appreciated.

Yours sincerely,

Kerry Ryan

APPENDIX 6: Information Flyer

VICTORIA UNIVERSITY OF TECHNOLOGY

Research Project : **Information for Participants**

Palliative Care for an Ageing Population: A Rural Based Model R
   Researcher: *Kerry Ryan*

♦   RN, Dip. Applied Sc., Ba Nsg., Grad Cert Palliative Care, Ma Nsg. Clin. Mgt. & Prac., Grad Cert. Tertiary Ed. & Training. Workplace Assessor, Train the Trainer. PhD (Education) Candidate, School of Education, Victoria University.

♦   Recipient of Bethlehem Griffiths Research Foundation Award.

Supervisors:

Prof. Maureen Ryan (School of Education), VUT.

Prof. Terence Seedsman (Faculty of Human Development), *VUT.*

Ethical Considerations relating to this project:
♦
♦
♦   The Researcher, Kerry Ryan is an experienced Palliative Care Nurse and teacher of Aged Care and Palliative Care at Victoria University.
♦
♦   Interested parties are advised that participation is voluntary.
♦
♦   Participants can withdraw from the project at any time.
♦
♦   Provision for discussion and support is available.
♦
♦   Information provided is considered confidential, and as such names and addresses will not be used.
♦
♦   Queries or complaints regarding ethical issues may be referred to the Secretary, University Human Research Ethics Committee, Victoria University of Technology, P.O. Box 14428 MC Melbourne, 8001. tele: 03 9688 4710
♦
♦   For enquiries related to this research please contact Kerry Ryan on 9284 8608 (Business) or   e-mail kerry.ryan@vu.edu.au

♦ **Background:** Australia is an ageing population, and one that will experience radical change over the next 50 years due to the progression into retirement of generations born in the 'baby boom' years (1945-1965). The baby boomers may well re-define what it is to age.

♦ The proportion of people over 65 is increasing, and as the majority of deaths occur in this age group the demand for palliative care (care of the dying) will also increase.

♦ People who wish to die at home may be disadvantaged in rural and regional areas where access to palliative care service is limited or distant. By determining the wishes and needs of an ageing population residing in, or migrating towards these rural and regional areas, and then determining the 'ideal' mode of delivery required for palliative care service provision to these areas, a proactive approach to future planning for the anticipated aged care boom can be expected.

♦ **The purpose** of this research is to investigate ageing trends and palliative care needs in rural and regional Australia

♦ **Objectives:**

♦ To describe ageing trends in Australia and in particular rural and regional

Australia.

♦ To predict the demand for palliative care

♦ To identify the parameters of good practice for palliative care service provision in a rural area.

♦ To identify the palliative care wishes and needs of an ageing population in a rural area.

♦ To develop a 'model' of good practice for palliative care service provision in a targeted area which would incorporate the needs and wishes of an ageing population, and which may be adapted to other rural areas.

♦ To develop a 'kit' containing questionnaires, satisfaction surveys, recommendations for a good practice 'model' and a checklist 'tool' for assessing the extent to which needs are being met. The development of the 'kit' would be based on data gathered for the above objectives.

Location:

♦   This research will be based in Melbourne and conducted under the auspices of Victoria University. The designated area of focus for this research will be South East Gippsland in rural Victoria.

♦   Utilising quantitative data collection and incorporating qualitative data obtained through focus groups, the study will be conducted in stages.

Information for people participating in the Questionnaire:

Methodology: The researcher will provide volunteer participants with a brief questionnaire which will take approximately 10 minutes to complete.

Risks: Because participation in the survey will be anonymous participants may be left with unresolved feelings brought on by issues raised through the questionnaire.

Safeguards: Participants can withdraw at any time. A list of local community health services outlining counselling services will be provided.

Information for people participating in Focus Groups:

Methodology: The researcher will contact local providers by letter, requesting voluntary participation from interested persons. Questionnaires will be issued and discussion around set questions will form the basis of Focus Groups which should take about 1 hour. Consent forms will be given to participants.

Risks: Disclosure and confidentiality issues may arise as well as some grief and loss issues during the course of the discussion.

Safeguards: Participants can withdraw at any time. A list of local community health services outlining counselling services will be provided. Names and addresses will not be used in any reports A coding system will be used for analysis and identification purposes.

APPENDIX 7: AGEING AND CARE FOR THE DYING QUESTIONNAIRE

This Questionnaire has been designed to determine approaches towards palliative care for an ageing population. The Questionnaire will be used as part of a study which is investigating palliative care needs and wishes for an ageing population in rural areas of Victoria. There are 10 questions to respond to and it is anticipated that it may take 10 minutes of your time.

KEY:

When responding please circle to indicate your preference.

1   2   3   4   5

1.   *strongly agree*
2.   *agree*
6.   *undecided*
7.   *disagree*
8.   *strongly disagree*

What is your date of birth?:   -----/----/----

Please state the country and town of your birth………………………………………

What is your current postcode?:

Are you aware of any aged care services in your area?:   YES   NO

Are you aware of any services for people who are dying in your area   YES   NO

                                                   Please circle

---

Question 1   *People who are dying should go to a hospital*

|_____|_____|_____|_____|_____|
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 2   *There's nothing that can be done for the aged and dying*

.

|_____|_____|_____|_____|_____|
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 3   *Services for the aged and dying are a luxury for aged people who live in rural areas*

|_____|_____|_____|_____|_____| .
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 4   *Aged people have limited access to health services in rural areas*

|_____|_____|_____|_____|_____| .
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 5   *People residing in a rural area cope well with death and dying.*

|_____|_____|_____|_____|_____| .
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 6   *The aged dying person does not need access to health services.*

|_____|_____|_____|_____|_____| .
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 7   *People who are dying because of old age do not suffer*

|_____|_____|_____|_____|_____| .
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 8   *People residing in a rural area support each other in times of need*

|_____|_____|_____|_____|_____| .
Strongly   Agree   Undecided   Disagree   Strongly
Agree   Disagree

Question 9   *Aged people who live in rural areas are more independent than aged people in city areas*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

Question 10   *Aged people who are dealing with death and dying do not see the need for health services*

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
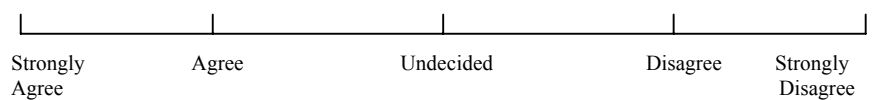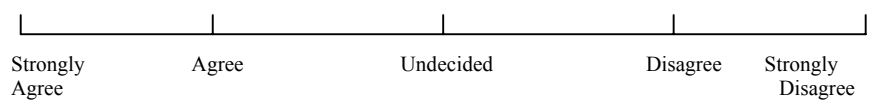
Thank you for your participation in this study.

APPENDIX 8: Consent Form for Subjects Involved in Research through Victoria University

INFORMATION TO PARTICIPANTS:

We would like to invite you to be a part of a study into Palliative Care for an Ageing Population: A Rural Based Model.. **(see attached flyer for project details)**

CERTIFICATION BY SUBJECT

I**,**

of

certify that I am at least 18 years old* and that I am voluntarily giving my consent to participate in the project entitled: Palliative Care for an Ageing Population: A Rural Based Model being conducted at Victoria University by: Kerry Ryan

I certify that the objectives of the project, together with any risks to me associated with the procedures listed hereunder to be carried out in the project, have been fully explained to me by: Kerry Ryan
and that I freely consent to participation in this project

Procedures:

You are being asked to participate in a **voluntary capacity** and to take part in Focus Group interviews. This requires you to respond to a questionnaire and your voluntary participation in discussions relating to ageing and palliative care. The questionnaire should take about 10 minutes of your time and discussions will be brief. Data collected will be kept confidential. If you find the nature of the discussions to be upsetting or troublesome you can refer to the contact names and details as outlined below.

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this project at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: ....   }

Witness other than the researcher: }   **Date: ....**
....}

Any queries about your participation in this project may be directed to the researcher (Kerry Ryan   ph. 9284 8608). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).

APPENDIX 9: Focus Groups Transcripts

Q1: What does palliative care mean to you (personally)?

F1
- *"Support to people in the last stage of their lives, not just the nursing part, but to make it worthwhile, as positive as you can be in that situation".*
- *"It is almost like an attitude, an approach to care".*
- *"We are lucky that the whole group feels the same way too. It is a very combined (palliative care service provider) group".*

F2
- *"Living with the quality of life we demand before we die"*
- *"Supporting the person who is dying as well as the family"*
- *"giving people some means to manage things in their life"*
- *"the choice, the ability factor and the acceptance factor".*
- *"I am passionate about palliative care and the work we do, I think you have to be to do this work"*

F3
- *"Dignified dying, giving people a choice/the truth"*

F4
- *"It means being part of a very privileged journey"*
- *"It means different things sometimes, like end stage care, or terminal care, it depends what sort of training people have had, I mean whether they are specialists or just nurses who end up giving palliative care"*

Q2: How can people in this area access palliative care services?

F1
- *"Usually through their doctor".*
- *"It can be family, they can ring up and say we need help, and it is not a problem, wherever the referral comes from, a neighbour, or anybody"*

F2
- *"At any point, by self referral, by GP referral, or in person or by telephone call".*
- *"They have to be aware that they have been referred to a palliative care service".*

F3

- *"Anyone can refer to the service, a family member or the person themselves"*
- *"The only pre-requisite is that the patient knows and understands that they are being referred for palliative care."*
- *"We have pamphlets in doctor's surgeries, we provide community education and advertise our service in the local paper."*

F4

- *" Through referrals and sometimes through GP's, hospitals and social workers."*

Q3: Do people in your area know about palliative care, is it something that is advertised ?

F1

- *"Generally people know what we do here".*
- *"In the older group it is getting more word of mouth, it is going around".*
- *"We have a nice day center, people come and have their lunch and they are entertained here".*

F2

- *care strikes fear into the heart of most people, unless it is a family who have previously been involved in palliative care".*
- *"I don't know……., I think they kind of know the word palliative care but I don't think they know what the services are. Last week, Palliative Care week, I was at a stall and giving out pamphlets, and the people were like – I hope I never need this. They didn't want to take the pamphlets. Some people knew palliative care because they had been involved with a relative in their family. But beyond that, people don't want to confront the fact that they are dying".*
- *"If you are not there at the moment, why would you want to think about it? People don't make wills and organize power of attorney when they are well – why on earth would they want to think about palliative care services and what we do here".*
- *"You can have any amount of advertising and publicity but it is one of those things like a lot of other services, until you actually need it, it doesn't really stick in your mind, oh yes it is around".*

F3

- *"We developed education services because people in our area wanted to know more about it (palliative care)".*
- *"I think the education sessions were developed because people were uncertain, because most people don't really know about it, but they probably hear about us through other services."*
- *"Yeah, I don't think they understand it until they come on to the service themselves".*

- *"I had a comment today from one of the patients that I went to only coming to me because 'when you came to my father-in-law, it was only within days of him dying' – so a lot of people see it as just those last days, like end stage. That's how he saw it. He wanted to know why we were there. Why palliative care? I mean, he knew we were coming because he had been admitted."*
- *"Many people in this area die through asbestos and I reckon they need to know we are here, and understand what we do."*
- *"yes, but we don't always know that they die through asbestosis because we don't get told a lot of the time".*

"what is the major cause of death in this region?"
- *"cancer"*

"what type of cancer?"
- *"lung"*

F4
- *"I have been here for 11 years and I just think people around here are very familiar with us and what we do because we are attached to the hospital".*

Q4: (In your experience) what services do people want when they are dying, and is that different to what they need?

F1

- *"They want their needs met – whether that is at home or palliative in the hospital. They want to know they can call us day or night, any time".*
- *"They want to be independent until the last - in charge!".*
- *"Because we are down to earth, people are realistic in their expectations of us."*

F2
- *"I think that most people want to be cured, they want to live on, even though they may know that nothing more can be done to cure them. That's where the acute focus is totally inappropriate, at a hospital, any acute hospital you are supposed to get better and walk out. A person dying, well that doesn't happen and I don't think a Aged Care facility is appropriate either. People around here need a hospice, where you have the staff from the cleaners, to the CEO, to the nurses, to the social workers, everybody, even the receptionist knows how to be around dying people. And, they want to be around dying people more to the point."*
- *"Sometimes it is tricky in families. Some members want to be in hospital. ' …because he doesn't want to be a burden to his wife (and her saying) 'I'm not really coping well, but I don't want him to go into hospital and I want him to stay at home'. Often you struggle with what different members of the same family want and/or need. It comes back to the family, we are the facilitators, they can be in charge".*

- *"doing it right… there is a long way to go, and it is about quality of life. One fellow wanted a softer toilet seat. He said ..'get me a top toilet seat… I know it sounds trivial..'. For a sick man at this point in time, that's what he wanted".*
- *"I think that as professionals we have to be aware of boundaries,….. I mean, what is my view, and what is that these people want. I think we are all influenced by our own personal views about death and dying, about our own experiences with palliative care and our own kind of fears or hopes. I think that does impact on the way we see things".*
- *"I think in palliative care there is an enormous amount of energy that is generated around a dying person. Lots of people want to do things for this person, and I think that it is important to be clear and focus on what the family wants as opposed to what you think they might need.*
- *".... and you have to be really aware of this to be able to hear what they want".*
- *"The thing that comes up in conversation with people, families or individuals, is that they want 24 hour nursing available".*
- *"In order to actually facilitate their choice what some people really need is to have a nurse there overnight".*
- *"Well they want that, we want to give it to them, but it not achievable."*

F3

- *"I might be wrong but I think what we offer is usually enough for them. We have things like volunteers and the usual meals-on-wheels and all those type of things."*
- *I don't think what they want and what they need are different, not initially anyway."*
- *"We quite often think they need things (because we think we know better), but they don't accept it. People around here are proud. What can we do? We can only suggest."*

F4

- *"they need respite and appropriate accommodation."*

Q5: What sort of services would you like to see included in palliative care service delivery for an ageing population:- are there things the elderly need that is different to the needs of other clients?

F1

- *"A few weeks ago we had a bereavement ceremony – we got very positive feedback. The person who ran the ceremony did not know anybody there – he moved into the area because of the support that we were giving people. They need support."*

- *"Hospice dedicated beds in a hospital environment, with hospital staff and medical facilities – but not in a hospital."*
- *"Good palliative care attitude and focus."*

F2

- *"Take that for example (nursing throughout the night), I mean, it would be more likely that would come from an older couple, where the older spouse hasn't got the capacity to be up all hours of the night with someone – and their anxieties. Whereas if you have got a younger family group it may be that they can rotate through sleeping hours so that they can share."*
- *"I guess there are differences, sometimes just by virtue of that fact that they are at a distance, the older couple have moved down here from somewhere else, potentially they may be at a distance from people who can do that, so services can't be provided, and they end up in hospital."*
- *"My experience of the younger people who have been dying is that their family and friends need more; in that, there seems to be a greater level of anger than there is with elderly people. Often with a younger person dying, what they require is different, my role is different – with elderly people it seems to be about practical support."*

F3

- **"welfare** *funding to do what we are doing. We would need to expand and take on other levels in palliative care."*
- *"Yes, we have a bit of polarization going on here, but then there are some of us here who think that ageing, or dying because you are old in itself isn't a sufficient reason to stretch our palliative care services."*
- *"Dying is nature, dying is a part of life. If there is some sort of symptom control needed or some other factor is presented that is different."*
- *"It would be different if we had a lot of staff and lots of time."*
- *"I think there are challenges in an older person because sometimes they have no family support – like their families have left the district and live along way away." "They need our emotional support and help with transport."*
- *"We need more funding, or something because how are we supposed to meet those kind of needs.?"*

F4

- *I would like to see a hospice.*
- *we need designated beds which are appropriately staffed*
- *I would like my own team. I find with district nurses if they have a diabetic run and they get a call in the middle it is hard for them. She has no time and I think we need in the philosophy of palliative care to give time. It is too hard for the generalists.*
- *Yes, I'd like to see the "specialist" palliative care nurse*
- *We have palliative care beds in acute but they are not allowed to stay. At times I have been able to get them to stay – but then, I have been here a long time.*

Q6: Are there any specific difficulties faced by people who are dying in rural areas that you are aware of?

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F1

- *"Yes, specialists and travel. They make appointments for them at 0700 or 0800 in the morning. They need to change the time. Especially for the elderly. They can't afford to stay overnight somewhere. We are lucky we have a good volunteer service to drive people in our area. They leave hospital here and if they live in Omeo well, we have volunteers who will drive them if they are well enough to sit in the car. And that's a two hour trip.*
- *"To go to Melbourne elderly people are sometimes restricted in sitting a couple of hours in the car. They then have to come back in a couple of weeks. They are not used to the city and finding their way around, and they can barely afford it."*

F2

- *"Distance, travel, facilities."*
- *"Yes, transport is the big one!"*
- *"When cars are available, there are not enough of them nor are there enough volunteers to drive them. Most hospitals have cars attached to them. The car is usually owned by the facility or shire, but it is made available for this service – to take them to medical appointments, and sometimes there is a nominal fee."*
- *"Volunteers take them to the most incredible and fantastic of places – without lifting an eye. They take them all over the city, but there are never enough and you have to book weeks ahead."*
- *"Yes, when you have an emergency situation or even if someone needed to go somewhere tomorrow – it is almost impossible to get the car>'*
- *"Often you find the neighbours chip in. That is not documented anywhere. There a lot of people out of the goodness of their heart that do it."*
- *"It (travel) is exhausting, dying people and sick people have no energy."*
- *"Metropolitan people have no idea, it is not even considered that we have to travel."*
- *"Can I just raise the issue of income because that is all on costs to an older couple. Travel costs and increased doctors costs because they haven't the options to visit bulk-billing. Older people don't have choices."*
- *I think there are some positives in a rural area. There a perhaps more community services to be found in this rural area."*
- *"I disagree – it has all been cut back."*
- *"But even so, people can come into hospital here and not expect to wait in corridors – you don't come through casualty - you go right in. If we refer someone down there (Melbourne) you can expect them to be seen after 2-3 weeks."*

F3

- *"Travel to Melbourne"*

- *"Some people don't drive or they are the only who does in the family"*
- *"If people don't have cars or it is broken down they have to rely on the community for help. Some of the over 80's are a hazard on the road and should have their licenses removed".*
- *"It's not just the over 80's - sometimes people in their 60's don't drive. I know of one situation from this area – the husband did all the driving. When he died she hadn't driven for 25 years and the public transport system here is not that good!"*
- *"Then there are the outlying areas, when you think about it, a lot of people retire in areas like Traralgon South where the public transport bus is so infrequent. It's hard to get from town to town let alone to Melbourne for treatment."*

F4

- *"Areas of isolation (people on farms) – access is an issue because sometimes our cars can't get through – they get bogged."*
- *"we have been short of OT's and we use OT's and physio's quite a lot"*
- *"There are plusses and minuses. Symptom management and going to Melbourne is difficult for families"*
- *"Confidentiality is a problem – everyone knows everyone's business"*
- *"We had a case of AIDS and in a small country town that is difficult to keep quiet – but we managed".*
- *"Since coming to the country from the city community is very noticeable – the volunteers are very supportive".*
- *"If the person who is sick or dying is the only one who can drive a car this causes huge problems for the rest".*

Q7: What are some of the issues faced by the carer?

F1

- *"A lack of services that we are getting. We have had the brakes put on health. They have overspent – over budgeted – there is a lack of rural funding across the board."*
- *"It puts more on the other services, for example, volunteers are doing more than their role, they are sort of trying to pick up the pieces."*
- *"There is no structured debriefing for us. Everybody finds a different way of coping – you just deal with it the best way you can. Quite often you come back to the office and there is nobody here."*
- *"I found the hardest when you lose a few, you come back, there is no-one here. I am a teary person, I want to come back and cry – everyone knows what I am like. But, I don't want to cry in front of them, I'm going home to cry. We have cuddles, my husband looks at me and goes you are a sook."*
- *"Generally, like this morning, with our palliative at the moment, it is good just to hear everybody talking about it, because basically, nobody knows what everybody else is thinking. We know she is going to die, but we are all having trouble with the path she is choosing to take – we are all having trouble accepting her choice. ……….. is really feeling it. Some days you*

have 2 or 3 palliative and all of them can really drain you, you find yourself mentally and physically exhausted by it."

- *"If someone gets behind we divide the list and we all pick up. But in Melbourne you have the palliative care team – we are everything to all people. We are not specialized palliative care nurses, its just everything all together here. These guys here are specialist wound care, personal care, general nursing and then they have to change hats because it is a completely different thing and become the palliative care team. That's very hard. I don't go on the road any more, but I watch what they have to do."*
- *"People think I've got that special magic – that quick fix."*

F2

- *"The biggest understanding we need to reach with the carer and with the patient is that because they are older they are still .....'doctor says, sister says – therefore I must', and they don't question. You really have to get back past that before you can start to get ideas of what they really need to make their quality of life and talking about what they need and what they want. What they really want is to get better and that is not going to happen. Maybe wants and needs should be the same thing. I mean, if they want to have somewhere where the partner can sleep in the same bed – what is so unreasonable about that? I think their wants should always be considered as legitimate needs. "*
- *"I see a number of carers who actually don't want caring for their partner. And, I've seen a number of elderly women who had terrible marriages and didn't feel cared for in any way by this man who is dying and they are now in a position where they have to nurse this man. It's not all about the quality of life, there is a lot of anger, some people don't want to do it."*
- *"The lady that died during the night, the family were very loving and cared for her...but could not come here…. I feel personally that nobody should die on their own, and this lady, though her family have been coming and going, when it got to the end, it was too hard for them.."*

F3

- *"I suppose the geography of it – I mean the more remote country areas particularly driving at night. If it is 40 minutes when you get called out, you respond, get home and have to go again. It's the job!."*
- *"It is a safety problem for us night driving especially if we break down and are out of phone range."*
- *"But we have been lucky here, when you compare with other areas. We don't have the distances to travel – there are major roads between the three major towns."*
- *"We have to make sure our cars are in good condition and our tyres are good."*
- *"We have a back up plan if we are called out at night and there are a couple of deaths and we are rostered on the next morning."*
- *"We try to do as much as we can here, we carry minimum drugs including valium".*

F4

- *" Access to drugs –we may have to put it back on to Peter Mac, accessing cetamine (anaesthetic for wind up pain)* **what do you mean by that?**
- *"It is hard to get and it is expensive"*
- *"Kangaroos at night are a hazard"*
- *"Our mobile phones don't work in all areas". "Nurses have to let people know where they are – they are putting in more radio towers"*
- *"For me, going shopping is a nightmare – (people know me)"*
- *"Having enough equipment".*
- *"Getting equipment into places"*

Q8:   Do you think we should be asking elderly people about death and dying?

F1.

- *"I think we should!" If they are willing to talk, ask them what their expectations are."*
- *"Well, it's no good asking young people about it because they don't know anything about it, and, it's no good asking the dead because they can't answer any questions."*
- *"For some people there are boundaries, but I find most of the elderly these days are willing to tell. They'll say I'm going to get buried at 'Joe Blow' because that's where I came from, most of them don't hold back what their plans are – they want to talk about it. My own parents are the same.*
- *"But in some cultures, I know it is something they don't discuss with partners or siblings."*

F3

- *"if we don't ask how do we know if we are getting it right?"*
- *"I think in the country, some people are pretty matter of fact – like, what is the fuss sort of thing."*
- *"Surely, it is who you are and not how old you are – some people want to talk and others don't".*
- *"I think old people want to talk about death because it's getting closer for them but a lot of the time they won't talk in front of others, especially if there are young ones around, or their own children."*

F4

- **"***That's what we do! It's about being sensitive and appropriate and it's about being honest. Sometimes there are times when you just need to go gently. I hate the clichés that go with the elderly – like 'they've had a good innings' when sometimes they have not."*
- *"It's about looking at the individual"*

Q9:   In that cultural group do you include indigenous?

F1

- *"We do. It is not usually palliative. They are inclined to keep to themselves a lot. In the 5 years I have been here, there has been a break, a transition, a change. Plus we had the Koori Co-Op used to do a lot of Koori care and now that doesn't happen. They are also now reliant on district nursing services and most of them on that part are pretty good and receptive."*

F2

- *"I think we should do research. Age just happens to be a number attached to a person. They are people the same as everybody else in the community, there is nothing about the date they were born that makes them more or less any different. They are human beings, everyone is individual, everyone is different. They are not the only ones in the community that are dying, but they are possibly more aware of the possibility."*
- *"I think we should be talking to people who are still alive – that is where the future planning comes from. Not by asking people in their 80's, nor people like John Howard who has very old fashioned views of what the world is about. What we really need is to be asking the younger people about what their life's view is going to be and what they would like to see in their future."*

F3

- *"well around here, they look after their own"*
- *"we have a large Maltese and Italian community here who have a special view about spirituality and other things like the Maltese for instance, they don't wont to talk about "it". It's hard because you can't say anything and the family hover around you to make sure you don't."*

Q10:   How do you think the research could help your organisation?

F2

- *"You might come up with a whole range of ideas we haven't even contemplated….."*
- *"I think the researching organization could be actually more than a research department and be a productive partner – we need hospice services."*
- *"We need real things not more models – not another way of doing things – I actually think we do things very well."*
- *"We need physical buildings – bricks and mortar, good staff, money, cars and transport. '*
- *"We've got good quality staff and we work particularly well as a team and I think people get excellent service and the results of the survey will prove the   same   things.   "*

"We don't need better practice…. We need physical infrastructure and staff…. Practical help."

- *"We need a hospice."*
- *"I think it would be good if some how out of this that there was specific input into mainstream courses say for the doctors, the nurses and social workers in relation to palliative care. Because not everyone wants to work in palliative care. I don't think it is something that sits easy– you either want to do it or you don't. I don't think you can be half hearted. But new graduates who actually want to work in palliative care bring new energy.*
- *"In occupational therapy we are expected to work across the board. If you choose to work in this community you are likely to come across palliative care anyway. It's the same in Aged Care, I mean, the number of new graduates who told me they don't want to work in nursing homes."*

F3

- *"We need a hospice".*

F4

- **"Keep raising the profile of palliative care"**
- *"I think we are still seen as the soft touch of medicine"*
- *"You hear nurses say we have been nursing the dying for years – whereas I think this is really a specialty"*
- *"We must keep getting patient feedback – it's about education"*