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August 2010
Quality of Life is Quality of Life is Quality of Life:

The Views of Older People Ageing in Place

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A thesis submitted for the degree of
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ABSTRACT

Quality of life is a concept that has been subject to considerable academic gaze from mainly a quantitative perspective. Qualitative descriptions have been limited to conceptualising quality of life from a health perspective. Little attention has been paid to understanding quality of life as it is experienced, perceived and interpreted by older people. Still missing in the great quality of life debate is the voice of older people. This is an interesting predicament considering the assumptions made about population ageing and ageing in place.

This phenomenological study breaks the silence on the quality of life experience of older recipients of home based services by exploring in particular the quality of life experience of nine older people who live at home and access low level home support services (between one and three hours of home support per week for six months or more) in a selected locale in New Zealand. It also sheds light on the role home support plays at the "lower" end of health resource allocation to elderly recipients’ quality of life. As well as providing valuable insights on elders’ perceptions of current national policy that advocates for ageing in place.

Through face to face interviews using a semi-structured format this study found that while quality of life as a notion remains evasive to academics and professionals its meaning is well understood and easily expressed by elders themselves. Giving meaning to quality of life for the elders in this study were six key features: the good people in their lives, taking care of day to day life, keeping healthy, living with loss, thinking of the future and being the age that they are. They confirmed that quality of life is a dynamic concept made up of multiple interconnected realities that are both positive and negative in nature but where the whole is greater than the sum of its parts. As an experience quality of life was influenced by events over the life course and viewed relative to other older people’s lives. Home helpers made a vital contribution to these elders’ quality of life experience but ageing in place as a policy construct extended no further than the current provision of low level home support they accessed.
The implications that can be drawn from the findings of this study are:

- That older people who access low level home support will do better when health professionals and others who are part of the formal support systems appreciate the meaning of quality of life as it is experienced and defined by elders themselves.

- That low level home support services are a vital service component for ageing in place which contributes to the quality of life experience elderly recipients.

- That elders receiving low level home support are not in need of a rehabilitative model of support.

- That older people be informed at the point of low level home support service entry or at any other point of the options available to remain ageing in place.
ACKNOWLEDGEMENTS

"The journey of a thousand miles must begin with a single step" – Lao Tzu

This Tibetan quotation has been propped on and by my keyboard as I have journeyed my a thousand academic miles. It represents both a personal level of courage to embark on a scholastic endeavour that I initially had no paper qualifications for and the people who have been ‘with’ me right from my single step and who without, this piece of work would not be possible. To be able to acknowledge these people in my thesis is a great honour and pleasure indeed.

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CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION

What is it like to be elderly and to receive home support? What is the experience of quality of life of older people in this situation? How do older people receiving home support conceptualise and express quality of life? What part does low-level home support play in the maintenance of quality of life for these older people? Within this thesis titled 'Quality of life is quality of life is quality of life' these questions form the basis from which I explore the quality of life of nine older people who access low level home support in a selected locale in New Zealand. It is a phenomenological study in which the seven women and two men aged over 75 years, who live at home and have been accessing between one and three hours of home support per week for six months or more, describe what quality of life means to them.

Quality of life is the centrepiece of this research study. As a research topic there is an extensive body of work on quality of life. A measure of its proportions is captured in Chapter Three which is the formal literature review for this thesis. However, in spite of how considered the term is, the concept remains complex and elusive at all levels and importantly relatively little attention has been paid to understanding quality of life as it is experienced, perceived and interpreted by older people in particular (Gabriel and Bowling, 2004, Hendry and McVittie 2004). The silence is overwhelming on the experience of the quality of life of older people who access home based support services. This is an interesting predicament for both western world and developing countries considering the assumptions made about population ageing and the worldwide prediction of an ‘age wave’ of almost tidal proportions. The policy commitment to keep older people in their communities (ageing in place) and the fact that quality of life has become a common outcome marker and driver for excellence in care and service in health is equally a universal predicament. These prevailing conditions mock the lack of research interest and action on understanding the quality of older peoples’ lives from their perspective at a time of seemingly great importance.
Within gerontology, the fundamental goal of nursing, medicine and the allied health fields is to enhance the quality of each person’s life. In my opinion this involves not only technical expertise from health professionals but also the need for a deep appreciation of the quality of life understandings that are born out of each older person’s life experiences. A key argument within this thesis is that the phenomenon of quality of life as experienced by older people who access home support can only be understood if these individual experiences are revealed. Phenomenology as an approach is well equipped to give older people a voice and shed light, in this instance, on the meaning of quality of life for older people receiving home based services.

1.2 PERSONAL INTEREST

My interest in a study of this kind is fuelled by a lifetime connection with older people. Personally and professionally my world has always been filled with elders. My personal interest in the lives of older people initially stemmed from my maternal and paternal grandparents with whom I regularly visited. My grandmothers though stand out. These two women in their own individual ways afforded me many hours of their time as an older girl and young woman. They freely shared their stories and knowledge whether it be working alongside each other as we ‘did’ things around their homes or just sitting with a ‘cuppa’ chatting. These two older women whom I loved fascinated me with their oldness, their personal histories and wisdom.

In these last few years it has been my own parents’ ageing that has continued to personally engage me in the worlds of older people. My father died recently. Not before needing in the last few months of his life the formal help of others and the continued informal support of his family as he chose to remain living and dying at his home. Now it is my mother who continues to enlighten me on the subtleties and shades of growing older. This teaching is almost silent on her part such is her natural grace and poise. I observe her using these and other gifts in great abundance as she negotiates her own ageing in her own terms but with help of home support 3 hours each week and the support of her family. We talk together each day and see each other most days. It’s
mutually satisfying. It feels normal and natural and human. My mother’s ageing experience makes me wonder about the lived experience of her brothers and sisters and her peers. It also sees me reflecting on my own ageing. In my fifth decade I can chronologically be described as well into my middle years. If I am lucky I will live to be an old woman so I will have my own lived experience within which to really understand ageing, being old and quality of life. In the meantime I bear in mind the words of this anonymous elder “I know it’s hard for you to understand, after all I have been your age but you yet have not been mine”

As well as these personal experiences fostering a deep interest in the lives of older people so too has my nursing career contributed. I am a registered nurse with thirty years’ nursing experience in clinical and non clinical settings both here in New Zealand and Australia. The last 12 years of my professional life has been focused on supporting the lives of older people needing long-term support. Even if these have been spent working for a large organisation in a leadership role created for the sole purpose of quality assurance that later became spoken of in the rhetoric of continuous quality improvement. It is over this time as the Quality Manager that I developed an increasing fascination and curiosity about the meaning of a ‘good life’ or the quality of life of older people. This interest comes from working intimately with quality assurance and continuous improvement programmes. I reached an understanding that these particular quality frameworks with their roots firmly embedded in manufacturing and industry did not necessarily translate into getting a ‘good life’ or even understanding its meaning. To me they were powerful constructs that enabled what I refer to as ‘systems’ quality but by their very design these frameworks were extremely limited at touching the real life situations of people. It seemed to me if I was to understand the meaning of a ‘good life’ then I would need to listen to the voices of older people themselves. Of particular interest to me were the voices of older people who access formal help into their own homes on the quality of their lives: by this time, the era of ageing in place had clearly reached New Zealand public policy and practice (Ministry of Social Development 2001).
This longstanding personal and professional interest in the lives of older people has been a strong catalyst in my desire to engage in my own research on matters of quality of life and ageing. This is not say that I didn’t experience a level of trepidation, nervousness and moments of hesitation at the thought of the learning journey I was about to undertake. The fear of the unknown is an uncanny sensation and I respect it for what it represents. It made me thoughtful about my motives. I came to understand the personal and professional importance of grasping an academic opportunity to think more deeply around the issues of ageing, being old and quality of life. I see this as reward in itself but I also see other profits. This is that this study has the ability to contribute to the gerontological work on quality of life in old age by adding to the conceptual framework and body of knowledge on quality of life in old age with particular regard to the views of older people who access low levels of home support.

1.3 STUDY OVERVIEW

The purpose of this phenomenological study is to explore, obtain insights and describe the quality of life of a small group of older people accessing low level home support in a selected locale in New Zealand. The broad research question to be answered is:

How does the provision and delivery of low levels of home support feature in the overall experience of quality of life of older people including the ability to remain 'ageing in place' (Ministry of Social Development 2001) in their community?

More specifically this research project seeks to answer:

• How do older people conceptualise and express quality of life?
• What part does low-level home support play in the maintenance of quality of life for these older people?
• What is understood as low level home support and what are the policy development implications?
1.4 OUTLINE OF THESIS

This thesis has commenced with an introduction to the phenomenon under study along with the articulation of the types of questions I have sought to answer. It also briefly outlines the research design and rationale. The chapter then proceeds to discuss my personal and professional interest in the phenomenon of quality of life as it relates to the lives of older people. This is immediately followed by an overview of the study which states the purpose of the study along with the broad and specific research questions.

Chapter 2 acknowledges the many dimensions of ageing but specifically discusses three macro-level aspects of later life in New Zealand that are most relevant to this study. These are: population ageing, ageing in place and home support. It also presents briefly the setting for this study.

Chapter 3 reviews the national and international literature on quality of life. To give some coherency to such a vast body of knowledge I have approached this review by firstly considering the terms historical context followed by definitions, measurement, meanings and concluding with an in depth discussion on the chosen methodology for this study.

Chapter 4, the methods section, explains the techniques and procedures used to undertake this phenomenological research project. The participants and setting, data collection, data analysis, ethical considerations and the study’s strengths and limitations are all discussed.

Chapter 5 represents the heart and soul of this thesis which is the presentation of the study’s findings. In keeping with the style of qualitative research these appear in a narrative fashion drawn from the nine interviews. Key themes are used as subheadings and these are organised in order of importance to the nine older people participating in the study.

Chapter 6 presents and discusses my interpretations and meanings based on the findings and answers the study’s research questions. My thesis concludes in Chapter 7 with an
explanation of the significance of this quality of life study along with some implications for the future enhancement of the quality of life of older people receiving low level home support.
CHAPTER 2: BACKGROUND

2.1 INTRODUCTION

Growing older and being old is not an event though it tends to be regarded as one with the age of 65 years used to signal the beginning of old age, when the reality is that ageing is a biological, psychological and social process of gains and losses that takes place over the life course. These processes are influenced by many factors. For example, health, gender, ethnicity, relationships, housing, employment, retirement, financial resources, recreation, community, religion, security and politics (see Whitbourne 2005, Atchely and Barasch 2004). These themes while contextually important to refer to will not be elaborated on directly. Instead the purpose of this background chapter is to bring into focus three macro-level aspects of later life that are closely related to each other and which provide the broader context for this study on ageing and quality of life. They are population ageing, ageing in place and home support. While these topics hold international significance they will in the main be discussed within the New Zealand context.

Population ageing, ageing in place and home support when discussed within a health care context tend to lend themselves to a discourse of disability and dependency. It is important to be clear that I have taken as read that while growing older involves physical ageing it in no way means that this process will be accompanied by disability and dependency. The truth of the matter is that most older people grow old and live independently in their communities without experiencing any form of specific disability (Jacobzone 2000).

2.2 POPULATION AGEING

Following a global trend New Zealand’s population is getting older. Demographically known as population ageing, the term refers to both an expansion in the older population and in the proportion of older people to younger people (Heenan 1993). Population ageing in New Zealand is a result of three demographic trends: declining fertility, the
ageing of the baby boom generation and an increase in the average life expectancy (Cornwall and Davey 2004). Statistically older people in New Zealand currently make up 12 percent of the total population but this proportion of the population is growing, peaking at around 25 percent in 2050 (Dwyer, Grey and Renwick 1999). The most rapid increase will be in the 85 plus age or “old-old” group who are expected by the middle of the century to account for 25 percent of the older population and 6 per cent of the total population (Davey and Gee 2002). The changing of New Zealand’s population structure is captured in Figure One below:

While claimed as an “unprecedented demographic transformation” (Ministry of Health 2004) population ageing is not a new demographic phenomenon in New Zealand. As Heenan (1993) points out the historical census records show that population ageing has been a demographic feature of New Zealand’s past dating back to the late 1860s. However, this current change in population structure poses some significant concerns to government in terms of future healthcare management in relation to a taxable workforce, labour shortages, increased service demands, new ethical debates and cultural sensitivity.

Unlike previous periods of population ageing this growth in the older population is going to be accompanied by a decrease in the number of younger people (Cornwall and Davey 2004, Davey and Gee 2002, MOH 2005, MOH 2004). The outcome of this demographic shift is the absence of a sufficiently sized taxable workforce to support the health and
welfare needs of the older age group. It also has serious labour market implications for the health and disability sector. Based on the sector maintaining its share of the working age population it is predicted by 2011 the demand for healthcare labour will exceed workforce supply (NZIER 2004). Cornwall and Davey (2004) in their work on “Ageing New Zealand and Health and Disability Services 2001-2021” for the Ministry of Health assert that “workforce issues may prove to be the greatest challenge facing health systems in the future”. The supply of healthcare workers both professional and non professional will be a major issue.

An increase in the numbers of old people and especially the ageing of the “old-old” will also affect the demand for health and welfare services (NZIER 2004). Levels of “need and dependency” tend to be greatest in the very old or 85 (McCracken and Phillips 2005, pg 47) and it will be necessary for the “continuum of care” health model to be able to respond to the accompanying increase in the incidence of chronic illness and diseases that are associated with this age group such as: cardiovascular and cerebrovascular diseases, cancers, diabetes, chronic airways disease, osteoporosis and the like (Cornwall and Davey 2004).

An increased demand for health and disability services creates a significant financial challenge for government. Currently as a proportion of the country’s gross domestic product (GDP) New Zealand spends 21% on health. This level of total health spending is in line with other developed countries (MOH 2005). In dollar terms for the 2004/05 financial year this equates to $8.81 billion. As of 2002 older people (over sixty five year olds) consumed 40% of the health budget. With New Zealand’s population expected to age and the increased demand for health and disability services it is projected that by 2051 that this share of health and disability expenditure for older people will increase to as much as 63% of GDP (MOH 2004). Based on these projections it is not difficult to understand in some way the government’s disquiet over just where the money will come from.
Population ageing and the pressure on government health expenditure will also raise ethical concerns. One predicted moral dilemma will be around the issue of “disability-reducing versus life-extending interventions” (MOH 2004, pg.viii). The literature review chapter (3) will attend more deeply to this moral aspect of health economics that already commands attention and rather vigorous debate within the domain of health-related quality of life.

According to Pool (2004), New Zealand unlike other western world countries has a unique but small opportunity to meet the fiscal challenges of population ageing through the “baby-blip” generation. Pool emphasises that it will require sagacious management from government if there is to be the best possible harnessing of this valuable resource in terms of a taxable workforce and a viable health and caring workforce. Some level of fiscal remedy may also be found in adopting a more preventative approach to disease and illness by targeting risk factors such as smoking, obesity and lack of physical exercise in the general population.

Population ageing in New Zealand is also an ethnic issue. Drawing again from the work of Cornwall and Davey (2004) who report that between now and 2021 that there will be an even greater percentage increase of older Māori, Asian and Pacific peoples, 185%, 400% and 178% respectively, even though they remain a smaller proportion of their respective ethnic group and of the total population aged 65 and over. With life expectancy expected to increase for both New Zealand’s older indigenous people and older Pacific and Asian people so too will the demand for culturally appropriate health and disability services for this group of elders.

Unquestionably, population ageing has New Zealand on demographic ‘alert’. In question though is the use of such alarmist language to describe the demography of ageing. Vincent (2003, pg 77 and 1999, pg 120) criticises “apocalyptic demographers” for the use of such rhetoric and others like it, for example “the demographic time bomb” to describe the global changes to the ageing population structure. In his mind taking such a rhetorical stance only serves to further construct the idea that population ageing is a “crisis” and
older people as a “burden” to society based on the negative perception that the increased numbers of older people will overwhelm all available health, social and environmental resources. Others too raise concern over the negative imagery that surrounds population ageing. Victor (2005, pg 79) explains eloquently how ageist attitudes once exclusive to individual older people have been effortlessly transferred to ageing populations. Negative attitudes such as older people lack “energy”, “enthusiasm”, “innovation”, and “artistic and intellectual achievement” are now translated to ageing populations in terms of this group being “unresponsive to change” and “traditional in approach”.

The widespread prejudice and discrimination towards older people and subsequent negative stereotyping and stigmatizing of them by many within western society is well documented (see for example Bevan and Jeeawody 1998, Lothian and Philip 2001, Nelson 2002, Redfern 1999, Shield and Aronson 2003, Victor 2005, Vincent 2002 and 1999). Within this wealth of literature two issues of ageism stand out for their particular relevance to this study. Firstly, the ageist attitudes just previously mentioned and other prevalent negative imagery of ageing such as illness, disease, powerlessness, hopelessness and death set up powerful expectations that older people take on themselves. Secondly, these very attitudes are also well embedded in the very environments in which older people seek care and support. Kite and Wagner (2002, pg. 130) illuminate the challenge. When speaking of the North American situation they say “ageist attitudes stem from cultural beliefs about older adults and the ageing process...messages conveying the cultural unease with aging are everywhere...messages so well learned that people respond to them below the conscious level”. This too could be said about New Zealand.

To diminish ageism would involve a conscious effort by society to reduce negative stereotypes, discrimination, prejudice and stigmatization towards the elderly. Braithwaite (2002) suggests that it would necessitate the dedication of time and space at all levels, that is from governments to families to individuals, to be reflective on the issues of ageism. With respect to research and social gerontology Vincent (1999, pg 146) puts forward the idea that the perfect anti-ageist strategy is to make age “insignificant and
treat people as stories in the context of their lifetime”. The phenomenological feel to this thought is not lost on me. As long as society continues to shirk the collective and individual responsibility towards eliminating ageism older people’s needs and preferences will continue to reflect a social image of old age that is based on incompetency.

A crucial element to the understanding of population ageing is that this particular issue of demography has major implications for social, health and economic policy development and implementation (Victor 2005). This situation is most evident here in New Zealand where the concept of ageing in place has been adopted as a national strategy for the ageing population, in recent years.

2.3 AGEING IN PLACE

The concept of ageing in place in New Zealand is embodied in two overarching policy documents framing a greater focus on the overall health, well-being and fitness for older New Zealanders. These are the Positive Ageing Strategy (MSD, 2001) and the Health of Older People Strategy (MOH, 2002). The Positive Ageing Strategy 2001 is regarded as the cornerstone of ageing policy in New Zealand. It articulates the Government’s vision for a society where people can age positively, where older people are highly valued and they have continuing opportunities to participate in the community in ways that they choose (Positive Ageing Strategy 2001).

Supporting the strategy’s vision are ten positive ageing principles along with ten priority goals. The Health of Older People Strategy 2002 is the ‘vehicle’ for implementing the health and independence goals of the Positive Ageing Strategy. One of the independence goals is ageing in place. Ageing in place as a social policy recognises the often deep attachment and familiarity older people have to their homes and responds to their desire to live out their lives in their own homes, neighbourhoods and communities (Dwyer et al 2000, Gallagher and Truglio-Londrigan 2004, Marek and Rantz 2000, Reed et al 2003, Rosel 2003). As an economic policy, ageing in place reflects a desire to keep older people in the least costly setting as possible (Hirdes, Brant, Morris, Ikegami,
Zimmerman, Dalby, Aliaga, Hamner and Jones 2004). Both of these perspectives are key influencers to ageing in place policy development here in New Zealand and it is argued that the financial implications of population ageing place economic concerns before the “humanitarian dimensions” of social policy (Victor 2005, pg 309).

The notion of ageing in place while appearing initially in the Positive Ageing Strategy 2001 is in fact not a new concept. The work of Rowles (1993) cited in Reed, Payton and Bend (2003) charted the development of the idea that people who are older should stay in one location as they age rather than move to specialised accommodation. Ashton (2000) commenting on long-term care in a decade of change over the 1990s in New Zealand informs readers that since the early 1990’s public policy in New Zealand has supported the philosophy of ‘ageing in place’. However, as a principle, ageing in place appears to have been made most explicit as a result of the work of the Prime Ministerial Task Force on Positive Ageing (1997). Other major platforms for the conceptual and philosophical development of ageing in place in New Zealand were the International Year of the Older Persons (1999), Senior Citizens Unit Post Election Briefing Papers (1999), Ministry of Social Policy Report (2000), National Health Committee Report – Health Care for Older People (2000) and the New Zealand Health Strategy (2000). Highly influenced by population ageing but working within the spirit of “positive ageing” and two other closely related contemporary concepts “active ageing” and “successful ageing” (McCracken and Phillips 2005, pg.59) these forums strengthened and cemented the Government’s emphasis and support for ageing in place. Ageing in place is defined in the Positive Ageing Strategy (2001, pg.10) as “to be able to make choices in later life about where to live, and receive the support needed to do so”.

Ageing in place ideology insists that the location of care for long-term support for older people is in their home and community. This is in vast contrast to the enduring and more usually funded institutional care model that has held service dominance for more than a century in New Zealand. Institutional care today continues to consume the largest single portion of the older person’s health budget (43%). The remaining 57% is spread amongst the services that support home health care such as assessment, treatment and
rehabilitation (3%), home support (9%), environmental support (10%), carer support (5%), respite care (2%), high and complex (7%) and other services like continence, stomal therapy, oxygen etc (21%) (MOH 2005). Clearly, if ageing in place is to be more than just a set of lofty health, social and economic goals it will require a significant shift in this current imbalance of care between institutional and community environments. This will be imperative to meet the potential issue of increasing numbers of older people who might previously have accessed residential care but who will in the future access support in their homes and as such age in place. Also pressing is the need to understand the meaning and experience of home as a place of care that up to this point is not well understood (Wiles 2005).

Ageing in place as a notion and a policy strategy is highly reliant on the capacity and capability of community care and support services to be able to respond to the long-term physical, psychological, social and cultural needs of older people in their own homes and communities. It is a ‘now’ as well as a prospective issue. Currently playing an instrumental service role in ageing in place in New Zealand is home support.

2.4 HOME SUPPORT

The growth from very sparse beginnings of home support as a small domestic assistance scheme in the early 1950’s (Richmond et al 1996, Wainwright 2003) to its dramatic expansion in the 1990’s (Wainwright 2003) clearly signals the importance of home support as a community service model in response to ageing in place, and in turn population ageing. There have been in New Zealand the recent implementation and trialling of so called ageing in place models such as Community FIRST, Coordination of Services for the Elderly and the Slow Stream Rehabilitation Project (ASPIRE 2006). It is argued in this thesis that home support is the service innovation that by and large translates the rhetoric of ageing in place into action. As such it is not only an important component of the health and disability service composition at this point in time but will continue to be a force in the future.
Home support in New Zealand is widely understood as domestic assistance and personal care (Wainwright 2003). It sits amongst a range of formal home care services such as district nursing, carer support, meals on wheels, continence services, stomal services, oxygen services and allied health services that are designed to allow older people and others to live in their own homes and familiar community. These support services along with institutional care for older people are just one component of health and disability support services provided to the people of New Zealand. Other elements include primary and community health care, hospital outpatient and inpatient services. Long thought of as the health system, the increasingly common parlance for this suite of health and disability services is a “continuum of care” (Otago District Health Board 2004). Twenty one District Health Boards (DHBs) act on behalf of government to plan and fund health and disability services in geographically defined areas (MOH 2005).

Long before ageing in place was a fashionable idea or explicit policy, a number of the formal homecare services just outlined have played a fundamental part in enabling older people to remain in their homes and communities. For example, the district nursing service has a long record of service dating back to first half of last century and the meals on wheels service has been around since the mid 1950s (Saville-Smith 1993).

Defining home support as a service model here in New Zealand is the Home Support Services National Service Specification. A joint document developed by the Ministry of Health (MOH) and the District Health Board of New Zealand (DHBNZ) on behalf of all the DHBs it is used to fund and contract services. In other words this document is the ‘scene setter’ for how home support is conceptualised, contracted and delivered in this country. It says:

The purpose of the Home Support Services is to promote and maintain independence of people who are experiencing difficulty caring for themselves because of an illness or chronic medical condition, or as a result of hospitalization. This service enables clients to remain in their own home or other private accommodation in the community or return to their home as soon as practical, by providing services that support and sustain activities necessary for daily living in a way which promotes the client’s independence and quality of life….. **Personal care** is defined as assistance with activities of daily living that
enables a person to maintain their functional ability at an optimal ability. These activities include but are not limited to: personal hygiene and grooming, toileting, dressing, transfers and mobility, and assistance with feeding. 

**Domestic assistance** is defined as services which enable a person to maintain, organise and control their household/home environment, including but not limited to: cleaning, laundry, meal preparation and shopping in exceptional circumstances (MOH and DHBNZ 2002, pg.2).

Quality of life along with ageing in place, independence, care and support are clear themes underpinning home support in the specification. Other prominent design features are an emphasis on maintenance and functional tasks. Considering whether home support can deliver on quality of life is an important dimension of this study on quality of life and older people who receive low level home support. Apart from a recent qualitative study commissioned by the MOH (Chal, Parsons, Dixon, Brandt, Hayward, and Nabobo-Baba 2004) that sought to gain the perspectives of “users” on service quality, there is little to no published research here in New Zealand on the quality of life, or any other experience of this population group (Wainwright 2003). The literature review chapter (3) will address this area (and its neglect) in much more depth and detail.

It is important to recognise that the evaluation of service quality does not necessarily equate to a specific interest in the quality of life of those being served. Often the emphasis is more risk and safety orientated. So it is within this context that I report on the MOH study (Chal et al 2004). While an overall research aim was to improve the quality of life of disability support “users” it was still clearly a study on service quality. Another limitation was that older people only represented 25% of the research sample. The rest were younger people with disabilities receiving home support. However, the results do provide some understanding on what the quality of older people’s lives might be like as recipients of home support. In this study using focus groups to interview 80 participants Chal et al (2004, pg.7) found that the overriding perception held by participants with regards to current home support service delivery was that it was “inadequate and made them feel devalued”. Reasons for these perceptions included: the lack of respect shown by care workers especially towards the person’s home as being their home, the lack of involvement in decision making, the lack of agency follow-up once care and support was put in place, the inability to have influence over changes to care and support and an
overall lack of choice and control over their individual lives for example when care and support took place.

Similarly, research overseas has also been directed at home care service quality rather than the quality of life of those using the services. But again this research does provide some insights into what their quality of life may be like. The research highlights older people’s preferences for familiar care workers, having care workers who care about them as people, who turn up as scheduled and are competent, and like the just mentioned New Zealand study older people value being kept informed about changes (Henwood, Lewis and Waddington 1998, Kane et al cited in Kane and Kane 2001). Quality of life however was more explicit in a qualitative study by Patmore (2004) that again explored the quality in home care for older people in Britain. This work questioned the goal of quality of life in home care where services are commissioned to meet the most basic of human needs such as eating, drinking, toileting, getting dressed and the cleaning of essential rooms in the house. Patmore (2004) stresses that these matters of physical survival are not the quality of life concerns of older people, instead he found it was assistance with activities such as changing light bulbs, shopping outings, finding reliable private tradesmen, leisure outings and helping with a pet that contributed to quality of life of older home care consumers.

Just as population ageing has created a significant level of economic nervousness for government, anxiety too has been created over the capability of home support as a service model to deliver financially. Moloney (2005) in a comprehensive evidence based report for a DHB argues that the current emphasis on maintenance and tasks works against any hope of managing the future cost implications of an ageing population. In order to contain costs Moloney recommends that the thrust of home support service design should be one that “prevents deterioration and promotes informal support”. The way forward according to Moloney is to move to a rehabilitative focused philosophy for home support. An emphasis on health recovery implies that the support approach is one that encourages people to get back to self-managing as quickly as possible. Certainly this is a laudable aim that is very much more in step with the principles of ‘positive ageing’ for older
people. However, less certainty must be felt around the promotion of informal support. It is already known that as much as two thirds of all care to older people is provided in the home by informal carers such as family and friends (Gundersen 1999, Jacobzone 2000, Victor 2005). Hence it is difficult to comprehend any further capacity building by policy makers, funders and providers around informal support.

Central to any discussion on ‘rehabilitation’ as a possible financial cure to population ageing is the fact that older people are the biggest recipients of home support (Chal et al 2004), and they need to do so because of the impact of living with chronic illness. It has already been noted earlier that an increase in the older population means that chronic conditions are increasing in prevalence along with increased disability rates and demand on health and disability services. This is largely due to medical advances in technology and cure rates which have made fatal diseases of the past now more chronic in nature. This is not to imply that all chronic illnesses are disabling. Quite the opposite is true with many chronic illnesses responding to prevention, treatment and rehabilitation. However, it is acknowledged that for about 40% of people over 70 years of age, living with a chronic illness does restrict their activity and cause need for help with either household tasks or personal care or in some cases, on a both long term basis (Atchely and Barusch 2004). While a rehabilitative approach may undoubtedly improve the life of this group of older people it is unlikely to remove totally their need for ongoing formal care and support. If anything it would perhaps increase the need for low-level home support.

Government funding pressure is already impacting on this level of home support service with evidence that the number of people receiving low-level home support is dropping (Chan et al cited in Wainwright 2003). Of concern is that this act of fiscal prudence takes place in spite of the fact that low level home support is effective in preventing entry to institutional care (Cohen cited in Wainwright 2003). Budget savings strategies are not only limited to the ‘getting’ of low-level home support. From recent personal experience both my parents had half an hour each trimmed off their existing low-level home support allocation with no other explanation given than that lots of people like themselves were being asked if they could manage with a bit less. Coming from the ‘make do’ generation
that they do, my parents naturally acquiesced. Most certainly this non alignment between the principles of ageing in place and budgetary constraints provided me with some strong rationale for limiting this quality of life study to those older people who receive low-level home support.

If the MOH and DHBNZ were to adopt Moloney’s (2005) rehabilitation recommendation it would also interestingly have the effect of legitimising home support’s position as an ‘ageing in place’ service model. As mentioned earlier three based home care service models that are philosophically driven by a rehabilitative approach are currently being trialled in New Zealand targeted towards hi-use older service users rather than of low level home support.

Irrespective of the philosophical underpinnings of home support, home support as a resource for responding to the impact of population ageing and the policy directive of ageing in place is heavily reliant on the calibre of the home support workforce. In the discussion on population ageing workforce issues have already been raised as a future challenge for home based care. However, workforce problems prove to be a substantive current issue. I draw on Moloney’s (2005) work again as she gives the most recent synopsis of the nature and extent of the problem though it is evident from other research that home support workforce issues have been an industry agenda item dating back to the late 1990s (Dwyer et al 2000, Wainwright 2003). At the heart of service delivery are care workers and it’s in this vital part of the industry’s structure that the issues lie. According to Moloney (2005) the problems include: extreme difficulty in the recruitment and retention of care workers with staff turnover as high as 50-80% in the first year of employment; a much casualised workforce with over half of the care workers working less than 10 hours per week; minimal orientation and ongoing training; poor wages; no reimbursement for travel and almost a total lack of monitoring and supervision of care workers. These issues affect the quality of home support services and from the little that is known of older New Zealander’s experience of quality of life and home support it could be said that these in turn have a negative impact on quality of life.
To receive home support older people must be needs assessed. This is undertaken by a Needs Assessment and Service Coordination Service (NASC) agency. Needs assessment is an essential access criterion. Home support is not an age related entitlement. NASC services are part of the DHB structure. Referrals for needs assessment are accepted from older people themselves, carers and family/whanau, general practitioners and hospital. The needs assessment while most valuable to be undertaken in the person’s home can be undertaken in any setting. This is managed by a NASC needs assessor who assesses a person using a standardised needs assessment tool to determine the level of service to be provided. It is from this assessment using another tool, the Support Package Allocation Tool (SPA Tool) that an older person is categorised as having low need to high needs based on cost. Low level home support is in the cost band of $0 to $30 per week (Moloney 2005, Service Contract 2002). NASC maintain an ongoing reassessment and management role. It has been suggested in these times of scarce health resources that structures like the NASC with the sole responsibility of needs assessment and service coordination play a pivotal role in the rationing of home support (Wiles 2005).

More older people and most of these are women aged over 75 years of European descent, are assessed as needing domestic assistance (Chal et al 2002). In the DHB region in which this study takes place, more than two thirds of home support usage is domestic assistance and a third of both domestic assistance and personal care is for less than 2 hours per week (personal conversation with Paul Martin, Contracts Manager, Otago District Health Board, 2005).

Home support to older people is provided by independent providers who hold funding contracts with the DHBs. Funding contracts can also be held with Accident Compensation Corporation (ACC) but the vast majority of older people needing home support are serviced through the DHB contracts. Service delivery is as outlined in the DHB service specification that has been spoken of earlier in this section. In the region which this study takes place there are 6 home support providers. Nationally there are approximately 110. Again Moloney’s (2005) report provides a current and up to date snapshot of the industry’s structure. She elaborates that providers are a mix of for-profit
and not-for-profit agencies and services operate a 7 day a week, 24 hr service. In light of
domestic assistance being the major component of home support it can be concluded that
most service delivery takes place between Monday and Friday during daytime hours.

2.5 SUMMARY OF THIS chapter

This background chapter has attempted to outline three domains of ageing and later life
that are contextually relevant to this study on quality of life and ageing in place. The first,
the demography of population ageing, the second, the concept and policy strategy of
“ageing in place” and the third, the service response of home support. They are all
important understandings both at an individual level and in a collective sense as well for
their dependency on and in relationship to one another. Without population ageing there
may have never been a policy and formal service response that openly supported the
keeping of older people out of institutions and in their own homes and communities. At
long last older people are being treated in similar fashion to younger people who need
long-term care. But more than this, population ageing, ageing in place and home support
bring into sharp focus the length of lives being lived and to be lived with chronic illness.
What becomes impossible to ignore is when the quantity of life is extended then the issue
of quality of life becomes paramount. Quality of life therefore is a very important concept
to be understood and considered as part of both policy and the practice of providing care
and support to older people living with chronic illness in their homes.
CHAPTER 3: LITERATURE REVIEW

3.1 INTRODUCTION TO QUALITY OF LIFE

Quality of life belongs to no particular domain. As a concept it traverses across many disciplines for example: philosophy, literature, geography, psychology, health, health economics, advertising and marketing, politics, and the medical and social sciences (Bowling 2001, Hunt 1997, Rapely 2003). Through these diverse lenses quality of life is viewed from macro, micro, global, national, objective, subjective, individual and health related perspectives. The notion has consistently evaded consensus as to its definition. As such it remains complex and elusive but this has not halted its common use as an outcome marker for economic, health and social policy (Bowling, Bannister, Sutton, Evans and Windsor 2002).

As a concept it is not age specific and it is argued that the multiple dimensions which are used to define quality of life for older people are indeed those which apply to people of all ages (Hughes 1990, Raphael 1996). Nor is it fixed as a notion, rather it is a dynamic concept that has the capacity to respond with great fluidity as people’s values and priorities change in response to life circumstances of which ageing is one such circumstance (Carr and Higginson 2001).

The purpose of this chapter is to review the literature on quality of life as it relates to older people and ageing. This will be undertaken by examining the concept of quality of life from a health, social science and gerontological perspective within which this particular study is located. However, my intention is to initially gaze backwards and provide some sense of the place quality of life has held over time and from this historical context proceed to discuss how quality of life for older people is defined, the measures and the meanings, concluding the chapter with a discussion of the chosen methodology for this research project.

3.2 HISTORICAL CONTEXT

The rise of quality of life is captured rather succinctly by Rapely (2004, pg.24) who states “quality of life as an idea has a short history, but a very long past”. As long ago as the very
early Greek philosophers in the sixth century BC there is evidence of interest in recording
the question of life and being (Wells 1938). Aristotle (384-322 BC) and others
after him continued to ponder the meaning of life in ancient Greek philosophy. It is not until
the fifteenth century that a shift in philosophical thinking is noted with scientists such as
Galileo, Newton and Harvey applying mathematics to explain the way of the world. A few
centuries later in the nineteenth century the first School of Positivism was established and
positivist thinking became the dominant approach that continues today to “defining and
measuring concepts in the human sciences” (Chung, Killingworth and Nolan 1997, Fayers and
Machin 2000, pg.5).

However, it is widely acknowledged quality of life as an idea can trace its origins to the ‘social
indicators movement’ and the emergence of social indicator research in the 1960s (Bowling
indicator’ is used to express a social statistic that is meant to have some significance for the
quality of life and can be expressed in both objective and subjective terms. Objective
indicators refer to things that are empirical, easily observable entities that one can count or
measure for example, employment, income, marital status, home ownership, educational level,
numbers of people admitted to hospital, numbers of people dying per year (Michalos 2002). In
the first half of the twentieth century it was these types of indicators that were essentially used
to measure how well a person was doing in society compared to others. A notion of quality of
life developed that was closely connected to what Veenhoven (1996) describes as the
“material level of living” or gross national product (GNP) related measures.

The social indicator movement as the positivist ‘grass roots’ of quality of life has been a
powerful mathematical mould in the shaping of the notion of quality of life. At the heart of
matters was the belief that the quality of people’s lives can be measured and compared
directly. This influence remains as powerful today as it has been over the course of the
conceptualisation of quality of life and it has been said that a vision of a “grand accounting
scheme” is what motivates most social indicators researchers (Michalos 2002).
A subjective approach on the other hand signals that people themselves were the best judges of the value or worth of their own lives. Mostly based on psychological responses, subjective indicators refer to personal feelings, attitudes, preferences, opinions, judgements or beliefs for example: life satisfaction, job satisfaction, personal happiness or the benefits of a particular programme, or treatment (Hagerty, Cummins, Ferris, Land, Michalos, Peterson, Sharpe, Sirgy and Vogel 2001, Michalos 2002, Rapely 2004).

The social and political climate of the 1960s and 1970s in America created a ripe environment for the rise of subjective social indicators bringing with it a substantial shift in opinion from the initial and somewhat myopic view of objective indicators. Two occasions of particular political significance were the inclusion of the term quality of life in a report of President Eisenhower’s Commission on National Goals in 1960, which referred to education, concern for the individual, economic growth, health and welfare (Farquhar 1995) and a 1964 speech by President Johnson that declared that progress on social goals “cannot be measured by the size of our bank accounts, they can only be measured by the quality of the lives our people lead” (cited in Cummins 1997). These two events strongly indicated that it was no longer acceptable to conceptualise quality of life based on economic growth alone. As a result a concept of quality of life was born in the USA and a term coined that while retaining objective indicators now included the importance of individuals’ subjective experiences.

From the 1970s interest in the idea of quality of life as an individual construct gathered considerable momentum. It was at this time that the term quality of life begins to emerge in the health, social science, and gerontological literature. These three disciplines are of particular interest and importance to this study. The way in which quality of life was conceptualised within these disciplines was highly influenced not only by social indicators research and the dominant approach of the positivist paradigm (Chung et al 1997) but also by a commanding conservative ideology that idealised competition, the market economy and the responsibility of individuals. These prominent ideas created an enormous paradigm shift. The result was a dramatic move, beginning in the early 1980s, away from health and healthcare being operationalised at physician led level to a business management culture (Bond and Corner 2004) or what became commonly known in New Zealand as a ‘corporate model’ of health.
Coinciding with these corporate developments was the virtual ‘melting’ of the term quality of life with other quality concepts borrowed from commerce and industry such as quality assurance, quality control, total quality management, continuous quality improvement and managing for quality (Rapely 2003). These were the business management ‘buzz’ words at an executive level in and outside of health over the 1980s and 1990s and continue today. They reflected the powerful discourse of “corporatism and managerialism” (Rapely 2003, pg 137) and as such were a vast contrast to the usual discourses of human services for example nursing, medicine, occupational therapy, social work and physical, mental and intellectual disability where the meeting of human need is cased in caring, curing and charitable or welfare paradigms.

It was over this time period that the term health-related quality of life emerges. Its conception was largely led by health research and medicine in response to mounting concerns over chronic illness, new technology, cost, medical outcomes and an interest in humanising healthcare (Albrecht and Devlieger 1999, Bowling 1996, Bullinger 1999, Farquhar 1995, Hunt 1999, Hyland 1999). In a postmodern health care environment, health-related quality of life becomes an important and powerful outcome marker to measure all of these concerns.

Health-related quality of life becomes the means to provide information about the extent to which disease and treatment of disease improve or diminish a person’s ability to function mentally, physically, or socially (Bond and Corner 2004). Also, it is a mechanism through which to inform health economic discussion, debate and decisions on the allocation of increasingly insufficient healthcare resources (Selai and Trimble 1999). Effectively, health-related quality of life as a notion under these conditions within healthcare became understood as the value given to a human life made different by impairments and disability as a result of disease, illness or accident (Hunt 1997). Health-related quality of life became a means to assess care and treatment in terms of a “life worth living” (Bowling 1996, pg 221). This assessment took and continues to take place predominantly in a positivist paradigm meaning that the valuation of care, treatment and life circumstances is undertaken with the idea that it is possible to quantify the quality of a human life.
To conclude, it is evident from this brief historical overview that quality of life in the new millennium is a vast evolving landscape. It continues to be of deep interest to a myriad of disciplines with a multitude of perspectives and this diverse range of interest ensures that there has been and continues to rage, a vigorous debate on what constitutes quality of life and its expression.

3.3 DEFINING QUALITY OF LIFE

It is perhaps not surprising with the multiple interests in quality of life that there is no universal definition of quality of life. Instead the literature reveals a wide range of conceptions matching the diverse disciplinary interest in the phenomenon, with little consensus as to what the term actually means (Hunt 1997, Victor and Scambler 2000). This is perhaps not too surprising when one considers the different perspectives, approaches and methodologies from which the notion is conceived. For example one finds contrasts between: sociology versus psychology perspectives, positivist versus realist approaches and quantitative versus qualitative methods (Raphael 1996). Add to this the simple fact that quality of life can mean different things to different people based on what is personally valued and their individual life circumstances makes quality of life a problematic and elusive concept (Albrecht 2006, Clarke 1995, Farquhar 1995).

Also problematic and creating confusion is what is described by some as the “popularization” of the term (Farquhar 1995, Haas 1999, Smith, Sim, Scharf and Phillipson 2004). The frequent use of the term in ordinary or everyday language from all types of media to general public parlance essentially sees the meaning being “proffered” resulting in many assumptions being made about what is understood as quality of life ensuring popular and lay meanings are plentiful (Seed and Lloyd 1997, pg.11).

Likewise at an academic level, scholars themselves have and continue to use the term with little more attempt to define what is meant by quality of life (Farquhar 1995, Hunt 1997). The work of Gill and Feistien cited in Smith, Avis and Assman (1999) and Hunt (1997) which reviewed 75 randomly chosen articles on quality of life found that very few researchers
attempted to define quality of life. Conceptual confusion is also the result of terms such as quality of life, health-related quality of life, health status and well-being all being used in an interchangeable fashion in the literature (Bond and Corner 2004). Rapely (2004, pg. 29) cites “definitional diversity” as one of the key problems of quality of life research along with the failure by researchers to relate to an explicit theory of quality of life. Other researchers concur, in particular Hagerty et al (2001) who as part of a review of 22 of the most-used quality of life indices from around the world found that most of those reviewed failed to specify any well-established theory supporting the index.

This oversight, if indeed it is one, takes place in spite of some established quality of life theory, such as the “good life” model, the human needs model, social/psychological models, happiness models and social expectation or gap models (Bowling 2005, pg. 8). With particular reference to gerontology, the field has used other key gerontological theories or perspectives as a way of exploring the quality of later life. For example activity theory, continuity theory, disengagement theory, successful ageing, structured dependency and most recently self in society or personal identity theories have all been associated with the idea of a good quality of life (Bond and Corner 2004).

However, it is not a complete definitional crisis or disaster. Some consensus does exist with agreement that quality of life is a multidimensional construct though the number and kind of dimensions remains controversial (Haas 1999, Hagerty et al 2001, Rapely 2004, pg 30, Smith et al 2004).

So it is within a rather chaotic and complex definitional environment that I now proceed to discuss how quality of life is defined in relationship to older people and ageing. Before tackling this task though, it is in my view, necessary to briefly define quality of life at a global, national and health-related level in order to contextualise the defining of older people’s quality of life within the larger scheme of things. Doing so acknowledges that older people’s lives are not conducted in a vacuum but to varying degrees remain connected to these other quality of life domains within which quality of life is thought about and acted upon. It may also prove helpful in lessening some of the confusion that haunts quality of life.
3.3.1 Global Quality of Life

The Millennium Development Goals (MDGs), (2000) developed by the United Nations are a good and very current example of social indicators identified by a major international organisation being used as a defining framework for quality of life at a global scale. Developed from a series of international conferences and summits over the 1990s eight goals have been set. These focus on the eradication of extreme poverty and hunger, achieving universal primary education, promoting gender equality and empowering women, reducing child mortality, improving maternal health, combating HIV/AIDS, malaria, and other diseases, ensuring environmental sustainability and developing a global partnership for development. (World Bank 2005). At the time of goal setting The United Nations claimed “these goals are worthwhile because they will improve the quality of human life” (United Nations 2000).

3.3.2 National Quality of Life

Just as the concept of quality of life is considered globally so too is the idea thought about nationally by most western nations. Quality of life in nations refers to how well the citizens of that country live and is commonly defined in terms of economic well-being, schooling, political freedom, social security, health and happiness (Veenhoven 2005). These very terms and others are reflected in New Zealand’s attempt to gauge the quality of life of its peoples. Social indicators of health, knowledge and skills, paid work, economic standard of living, civil and political rights, cultural identity, leisure and recreation, physical environment, safety, and social connectedness have been defined by the Ministry of Social Development (MSD) as 10 discrete components of well-being that are viewed as “signposts” to measure the wellbeing and quality of life of New Zealanders (The Social Report 2005).

Challenging the abstraction of national and global indices, Salavaris (2000) cited in Rapely (2003) suggests that authenticity lies in the act of local communities defining and developing for themselves social indicators that are genuinely meaningful to them. Communities around the globe have attempted to incorporate social, environmental and economic goals around some kind of vision of well-being/quality of life as it relates to that particular community.
Here in our own backyard the New Zealand Quality of Life Project is such an example of this type of community responsiveness. Now involving twelve New Zealand cities this urban project established in 1999 provides amongst other things: a framework for consistent monitoring of quality of life outcomes, raising quality of life and monitoring issues, and quality of life awareness across many other local authorities in the country (Big Cities Project 2003). While closely connected to the national social indicators, the Quality of Life Project indicators were developed from a wide stocktake through broad community consultation that elicited what people wanted as well as incorporating what the Project Team considered to be viewed as good measures of quality of life (personal discussion with Kath Jamieson, Project Coordinator, 11 July 2005).

While deliberately titled the Quality of Life Project and naming the indicators as quality of life ones, Ms Jamieson points out that there has been no attempt to define the term quality of life. Instead the term reflects the most agreed upon term by project team members. In addition, the team felt it was better understood and more encompassing than the term well-being which a lot of people tended to associate primarily with health. Quality of life in this Project is taken to include knowledge and skills, economic standard of living, economic development, housing, health, natural and built environment, safety, social connectedness and civil and political rights (Big Cities Project 2003).

### 3.3.3 Health-Related Quality of Life

As mentioned in the historical context quality of life since the 1980s has been regularly defined in terms of health and health-related quality of life. A derivative of the generalised notion of quality of life, health and health-related quality of life is plagued by the same ongoing debate as to what the term actually means. There is criticism that little or no attention is paid in the literature to defining the concept. Instead what is described is a range of measurement components such as functional ability, social and community interaction, psychological well-being, burden of symptoms, adjustment and life satisfaction (Albrecht 2006, Bowling and Brazier 1995, Lacasse et al 1999).
Disapproval is also voiced at the lack of distinction made between the terms health-related quality of life and quality of life. It is suggested that the term health-related quality of life should just be forsaken altogether, such are the contradictions and controversies that plague the term both from a definitional and measurement standpoint (Michalos 2004).

In the absence of conceptual clarity it seems that health-related quality of life often gets viewed and reported on as quality of life per se. Haas (1999) in a study employing “concept clarification comparison” as a method to distinguish quality of life from closely related concepts, found that researchers too often measure one component i.e. wellbeing or functional status, and report it as a measure of overall quality of life. In a similar fashion with specific reference to older people Lawton (1999) investigating the quality of life in chronic illness, cautions against the use of health-related quality of life as a sole measure of older people’s quality of life. He urges that non-health related areas of older people’s lives which may well override the negative aspects of poor health must be accounted for as well. In a conceptual climate that is driven by a belief that medical care and treatment now need to be evaluated in terms of whether they have resulted in a “life worth living” (Bowling 1996) these calls for caution are clearly not misdirected. To separate quality of life in terms of health and healthcare completely fails to recognise the other complex and dynamic constituents of human existence, and which indeed bear greatly on individuals’ experience of quality of life. As Seed et al (1997, pg. 4) state:

Quality of life is about the connections between all of the dimensions. It is about the connections between individual and global concerns. It is not about an individual’s condition in isolation – though many of its technical usages, especially in medicine, have tended to limit it in this way.

In spite of the degree of definitional difficulty there is evidence that attempts have been made at both a health and health care level to define what is meant by health-related quality of life. As explained earlier, driving the conceptualisation of quality of life within health and healthcare are economic, clinical and humanitarian reasons. It is for these precise reasons as well as cross-cultural ones that the World Health Quality of Life Group (WHOQOL) provides
a broad definition of quality of life and health that is widely accepted. Based on assumptions that a) quality of life is subjective, b) multi-dimensional and c) it includes both positive and negative dimensions, the WHOQOL (1995) defines quality of life and health as:

Individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way individuals’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment.

While not out of step with the WHOQOL definition on quality of life and health, health-related quality of life has largely been defined from a medical illness perspective. Usually from a psychological perspective, though there is increasing emphasis on rehabilitation and health promotion. Defining health-related quality of life at a health care level Bowling (2001, pg. 6) states:

Health-related quality of life is optimum levels of mental, physical, role and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include some assessment of the patient’s level of satisfaction with treatment, outcome and health status and with future prospects.

As part of conceptualising this definition of health-related quality of life Bowling (2001) does make a distinction between health-related quality of life and quality of life by adding that quality of life as a whole would also include adequacy of housing, income and perceptions of the immediate environment.

Still gazing at health-related quality of life from a health care perspective, Carr, Gibson and Robinson (2001) make the suggestion that health-related quality of life is in fact about the gap between individuals’ expectations of health and their actual experience of it.
Taking another perspective, Guyton et al cited in Yu, Lee and Woo (2004) claim health-related quality of life is a construct to understand the impact of chronic disease on patient well-being. This definition of health-related quality of life draws attention to why the term is both important to older people and to this study. As mentioned in the history of quality of life, the term health-related quality of life’s conception is closely associated with the shift in medicalised thinking from the management of acute illness to chronic disease. Chronic illnesses are the diseases of old age in Westernised populations, and a very likely reason why health-related quality of life is a dominant quality of life theme in older populations in the gerontological research (Bond and Corner 2004, Higgs, Hyde, Wiggins and Blane 2003).

3.3.4 Older People, Ageing and Quality of Life

Quality of life is also defined in terms of older people and ageing. Just like health-related quality of life, the concept of quality of life and older people is intertwined with the broader view of quality of life. This holds no strangeness or concern to some as has already been suggested in the introduction to this chapter, in that the concept is not age specific and it is argued that the elements which define quality of life for older people are indeed those which apply to people of all ages (Hughes 1990, Raphael 1996). What may be different are the reported levels of quality of life within the various dimensions. For example Sprangers, de Regt, Andires, van Agt, Bijl, de Boer, Foets, Hoeymans, Jacobs, Kempen, Miedema, Tijhuis and de Haes et al (2000) found that older people with chronic conditions reported a poorer quality of life compared to younger people with chronic illnesses with regard to physical functioning. For these reasons Bond and Corner (2004) view quality of life as a relative concept to the historical, economic and social context of each person and as being influenced by individual life experience.

Like other notions of quality of life, quality of life and ageing is dogged by the same definitional controversies but again this has not deterred attempts to define it. In an effort to create definitional order out of definitional chaos Farquhar (1995) coming from a gerontological perspective suggests a classification framework within which to assign all the available definitions and which is arranged in such a way as to reflect the origins of the
definition. That is, whether it is an expert or professionals' definition or a lay definition. She elaborates further that the 'expert' literature reveals definitions that can be further broken down into sub groups that classify definitions into global, component and focused definitions. I, like Bond and Corner (2004) find Fraquhar’s proposal provides a perfect scaffold within which to hang a review of the literature on definitions as it relates to quality of life and older people.

**Expert/Professional Definition**

By Farquhar's (1995) reckoning, global definitions of quality of life are generalised and as a rule include ideas of satisfaction/dissatisfaction and happiness/unhappiness. Happiness and satisfaction are a more recent focus and suggest a more positive emphasis on quality of life compared to earlier phases that focused on survival, freedom of disease and the ability to perform activities of daily living (McDowell and Newell 1996).

Happiness is recognised as more of an affective state as opposed to satisfaction that is viewed as a cognitive one (Hagerty et al 2001). Abrams cited in Carley (1981) early in the piece thought of quality of life as a cognitive state where he defined the concept as the level of satisfaction felt by individuals with different aspects of their lives. Calman cited in Haas (1999) defined quality of life as satisfaction, contentment, happiness, fulfillment and the ability to cope. Raphael (1996, pg.296) states that quality of life is “the degree to which the person enjoys the important possibilities of his or her life”. More recently Gilhooly, Gilhooly and Bowling (2004, pg 18) define quality of life as “the degree of satisfaction over all areas of life important for the individual concerned” and most recently Veenhoven (2005) defines quality of life as “how happy people live”.

While quality of life is a term that implies the quality of an older person’s whole life and not just some component part, it is commonly defined or broken down into a series of dimensions. Hughes (1990) identified eight dimensions as part of developing a conceptual model of quality of life in gerontological research. These are: personal autonomy, expressed satisfaction, physical and mental well-being, socio-economic status, quality of the environment, purposeful activity, social integration and cultural factors. It is argued that individual and cultural values
are critical dimensions (Clarke 1995) and Binstock and Spector (1997) describe quality of life as including such components as psychological functioning, social functioning and activities, enjoyment of living environment, a sense of dignity and autonomy, and religious functioning. Grundy and Bowling (1999) highlighted three major dimensions with sub components: perceived well-being and autonomy (life satisfaction, loneliness and control), health and activity (activities of daily living, general health and health problems), environment (likes the area, warmth and security).

Smith et al (2004) looking at the quality of life of 600 older people in deprived neighbourhoods also identified quality of life as multidimensional. These researchers claim health and well-being, social networks and supports, access to socially perceived necessities, finances, work and retirement, housing, neighbourhood, crime and local services as to constituting quality of life for this study group. Similarly yet different Bowling and Gabriel (2004) identify psychological characteristics and outlook, health and functional status and personal and neighbourhood social capital as the core components or “central planks” of quality of life when they compared the results from three quality of life projects in Britain. Higgs et al (2003) in another British study, on quality of life in early old age conceptualised four domains of quality of life: control, autonomy, self realisation and pleasure.

Outlined earlier in this chapter was the disagreement on the number and variety of dimensions that constitute quality of life. What these expert dimensions from the gerontological literature reveal is that while consensus may not be reached there certainly is a level of close alignment between the identified dimensions. Congruence can also be found outside of the gerontological literature, for example with Hagerty et al (2001) who recommend seven universal dimensions of quality of life: relationships with family and friends, emotional well-being, material well-being, health, work and productive activity, community and personal safety.

Finally in the line up of expert definitions are focused definitions which target only one or a very small number of quality of life dimensions. These are usually found in the health-related quality of life literature and have been outlined already in this chapter.
**Lay Definition**

It has predominantly been experts or professionals who impose meaning on the concept of quality of life though some experts would claim some level of lay legitimacy by having consulted usually small groups of older people as part of questionnaire design, for example Smith et al (2004). However, there is evidence over more recent times of a growing interest in seeking the views and individual perspectives of older people themselves on what constitutes quality of life.

Lay conceptions reveal the subjective dimensions of people's lives that tap into the very centre of a person's sense of meaning and self. Farquhar (1995) in a mixed method study sought to identify lay definitions of quality of life among older people living at home in two selected locales in Britain. From interviews with 210 older people using a small set of unprompted open questions about the quality of their lives, she found firstly that quality of life was not just a matter of the good things in older people's lives but also the bad or negative things as well. Secondly participants defined their quality of life as more than just health and reported that family relationships, social contacts, activities and material circumstances were valued elements.

This theme of lay perspectives is a dominant driver of the Growing Older Programme in Britain funded by the UK Economic and Social Research Council (ESRC). It claims to be the largest social science research project investigating older people and ageing and its sole interest is to understand growing older and quality of life, and how the quality of older people's lives can be extended (Walker 2005). Out of 24 research projects devoted to this endeavour, five projects have been dedicated to defining and measuring quality of life. Researchers working in these dedicated projects took pains to ensure that the methodological approaches used in the projects to define quality of life elicited older people's perspectives as to its nature and constituent parts. In one of these, Gabriel and Bowling (2004), interviewed in depth 80 purposively selected participants who all lived in their own homes, found that quality of life was built on a number of interconnected themes. These were: social relationships, home and neighbourhood, psychological well-being, social activities and hobbies that are both communal and solo, health, financial circumstances and independence. Similarly in another of
the defining projects within the Growing Older Programme, McKevitt (2001) found from interviews with 41 stroke survivors that they defined their quality of life in terms of: having the health needed to participate socially with family and friends; being able to get out and about; the ability to work, whether inside the home or in paid work; access to material resources; happiness or enjoyment of life; satisfying family and personal relationships; and attitude to life.

A very recent study undertaken in Sweden that also sought to gain older people’s perspectives on quality of life echoed similar findings to the studies undertaken in the Growing Older Programme. Wilhelmson, Andersson, Waern and Allebeck (2005) found from interviews with 141 older people that social relations, health, activities, functional ability, well-being, personal beliefs and attitudes, their own home and personal finances were considered as constituting quality of life. In addition to seeking what older people considered to constitute quality of life they also sought to understand what was important for older people’s quality of life. These researchers found that social relations, functional ability and activities may influence the quality of life of older people as much as health status.

Taking a rare phenomenological stance Hendry and McVittie (2004) examined individual understandings of the concept of quality of life with 10 older people. They also explored the relationship between these understandings and those that are commonly identified by the experts. These qualitative researchers found that quality of life did not fall into distinct domains. Instead quality of life was found to be inextricably linked to the whole experience of older people’s everyday lives, that it was regarded as relative to other people’s experiences, that it gave rise to both positive and negative experiences and that quality of life was a life experience that older people had control over. Expressed by the researchers as holism of experience, relativity to others, ambivalent views and the management of quality of life, (they make the point) these individual understandings of quality of life differ quite markedly from the conceptualisations found in many of the common use measures.

To conclude this section on how quality of life is defined, the reviewed literature of expert and lay conceptions finds the concept gazed upon and in some instances raged about, from many
diverse angles. In sum, quality of life has become known to be all of the constituent parts just outlined. In summary, it can be said that quality of life is: multidimensional in its construction, very subjective in nature, consistently complex and conceptually elusive in spite of how familiar the term seems.

3.4 MEASURES

Despite the complexity, the diversity and the lack of definitional agreement both quantitative and qualitative approaches are used to measure and assess quality of life. However, due to quality of life's long rise out of the social indicators movement it is perhaps not surprising that its conceptualisation has largely been a very measured affair from all perspectives. Most of the published quality of life research is quantitative as opposed to qualitative (Raphael 1996).

There is no "gold standard" for measuring quality of life (Hunt 1997), instead there is a vast range of methods such as instruments, questionnaires, surveys, self reports, scales, trials and evaluations producing a plethora of measures to statistically measure the quality of life of human beings globally, nationally, regionally or individually (Joyce, McGee and Boyle et al 1999, Rapely 2003, Veenhoven 2005). Crucial to the measurement effort are issues of validity, reliability, appropriateness, sensitivity and interpretability (Bond and Corner 2004, Selai and Trimble 1999).

The measurement of quality of life amongst older people, as with its defining, has largely been led by health care. The transition of the term into the medical field where it is at times used interchangeably with health status has seen the construction of many health-related measures which in the absence of definitional consensus have been based either on the particular researchers' best loved definitions (Chung et al 1997) or none at all. In a conceptually neglected state there are calls for measurement abandonment (Hunt 1997) based on the fact that it is impossible to measure what cannot be defined (Wade 1992). At the very least, the view is taken that these tools are not much more than demonstrations of methodological expertise (Bullinger 1999).
Gilhooly et al (2005) point out that there are other serious and difficult measurement issues that arise. For instance, people when they respond to questions on quality of life tend to respond in several ways: they use information that just comes to mind, recall what they feel to be adequate information on which to base the answer and this will be shaped by how recently and how often this particular information has been previously used, answer according to their current mood state and/or respond in a socially desirable fashion. Of concern to Eckermann (2000) is the issue of gender and the fact that few quality of life measures are responsive to the subtle effects of gendered socialisation on perceptions of quality of life.

Needless to say these issues have not stopped the development of a plethora of measures such is the clinical, economic and research interest in health-related quality of life, fuelled by a need to monitor the outcomes of care and the outputs of Western World health systems in these times of fiscal constraints. If chaos and confusion dominates the defining of quality of life so too does the sheer volume and choice of measures create a similarly bewildering measurement environment. Others have thought so too and to this end have sought some semblance of order by developing systems or frameworks within which to categorise or group measures. For example texts by Bowling (2005 and 2001), McDowell and Newell (1996), and Wade (1992) not only provide structure but also examine in depth many of the health and health-related quality of life measures have all been helpful. However, Bowling’s texts have been particularly invaluable and to these I now turn as a way of emerging out of the chaos and organising a complex set of data on measures and measurement. The currency and consistency of her work as well as her penchant for quality of life research with older people is also most helpful and compelling.

Bowling (2005) groups health-related quality of life measures into generic or broader health status, disease specific, domain specific, broader quality of life, utility and individual categories. She points out that while health-related quality of life measures have not specifically been developed for the older population and therefore must be considered in terms of lack of sensitivity to the values and needs of older people, some are considered appropriate for use with this population group. These will now be discussed taking advantage of Bowling’s previously mentioned groupings.
3.4.1 Generic/Broader Health Status Measures

Generic measures of health-related quality of life usually refer to broader measures of health status and encompass dimensions of physical, mental and social health. As a rule these measures centre on individuals’ subjective perceptions of their health. Investigators use generic health-related measures when trying to make comparisons between conditions or population groups. There are a number of generic instruments. However, according to Bowling (2005 and 1996) leading the field in terms of best-tested and popularity for use with older people are: the Short Form-36 Health Survey Questionnaire (SF-36), the Nottingham Health Profile, the Sickness Impact Profile, the McMaster Health Index Questionnaire, the EUROQOL Quality of Life Scale (EuroQol) and Dartmouth COOP Function Charts. These six generic health-related quality of life measures along with the instrument’s designer and what they purport to measure are represented in Table 1 below:

Table 1: Generic Health-Related Quality of Life Measures

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Designer</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36</td>
<td>Rand Corporation and Ware, J.(1990)</td>
<td>Subjective health status</td>
</tr>
<tr>
<td>Nottingham Health Profile</td>
<td>Hunt, S. (1981)</td>
<td>Lay perceptions of health and relates to how people feel when they are experiencing different states of ill-health</td>
</tr>
<tr>
<td>Sickness Impact Profile</td>
<td>Bergner, M. (1976) Revised in 1981</td>
<td>Sickness-related dysfunction and copes with minor morbidity</td>
</tr>
<tr>
<td>McMaster Health Index Questionnaire</td>
<td>Chambers, L. (1976) Revised 1984</td>
<td>Physical, emotional and social function</td>
</tr>
<tr>
<td>EuroQol</td>
<td>EuroQuol Group (1990) Revised 1993</td>
<td>Each health state and generates a single index value</td>
</tr>
</tbody>
</table>
While this table gives the appearance of a hierarchy of order that is not the intention even though I have commenced with the SF-36 on the basis that it is the most frequently used measure of broader health status and a much favoured instrument by social gerontologists (Bowling 2005). It is also favoured for its capacity to be used with any population group (Albrecht, 2006) and its reliability and validity is regarded as “exemplary” (Michalos 2001, McDowell and Newell 1996, pg. 454). Responsiveness was also identified in a systematic literature review of generic instruments in older people by Haywood, Garratt and Fitzpatrick (2005) along with the recommendation that the SF-36 is fit for use with older people, in particular community dwelling older adults with lower morbidity.

The Nottingham Health Profile also gets the thumbs up for its reliability, validity and responsiveness with older people (Haywood et al 2005). While a favoured clinical measuring instrument particularly prior to the construction of the SF-36 (McDowell and Newell 1996) it is criticised for its focus on negative rather than positive experiences (Bowling 2005).

The Sickness Impact Profile though identified as appropriate for use with older people was found to be less convincing than other instrument’s such as the SF-36, Nottingham Health Profile and the EuroQol (Haywood et al 2005). However, the instruments careful and meticulous construction ensures it continues to hold a place of esteem for use with all population groups (McDowell and Newell 1996).

While identified by Bowling (1996) as a broader health status measure of relevance for use with older people, the McMaster Health Index Questionnaire holds less favour in the current measurement environment for reasons of questionable use with frailer older people (Bowling 2005). There are also issues of reliability and validity due to the instruments very long construction phase of 22 years that make it less popular on the popular list (McDowell and Newell 1996).
The EuroQol scale comes recommended for its validity, reliability and responsiveness to substantive health changes in older people (Haywood et al 2005). A particular strength is that it can be used across a wide range of health interventions (Brooks 1996) and be sensitive to multiple morbidity (McDowell and Newell 1996). As the newest instrument amongst the suite of broader health measures there is limited literature as to its full effectiveness (Bowling 2005).

While described as “imaginative” and “innovative” (McDowell and Newell 1996, pg 415) the Dartmouth COOP Function Charts are criticised for not being sensitive to older people in certain places within the instrument (Bowling 2005).

3.4.2 Disease Specific Measures

Disease specific measures are as the name suggests, measures that have been constructed specific to a disease or condition. They are usually designed for clinical application and are responsive to change after treatment (McDowell and Newell 1996). Bowling’s (2001) text on Measuring Disease overwhelmingly reveals the vastness of disease and disease specific measures. At a quick count I identified over 200 measures that Bowling has named as being of importance. Within the scope of this literature review, this number of measures is way beyond naming let alone reviewing capacity. However, what can be said about these measures is this: cardiovascular disease, cancers, cerebrovascular disease, some mental health illnesses, neurological conditions, rheumatological conditions and diabetes are the common diseases of old age and in amongst this extensive range of disease specific measures there are various measures covering all these disease groups. This is not to say they have been designed with older people in mind. A few have, but mostly these measures have been developed for use with adults across the age spectrum.

While in the main, disease specific measures are considered to be appropriate for use with older people, there are some unique issues that investigators must carefully engage with. Of note, is the issue of multiple morbidity that is often found in this age group and which has the potential to confound findings (Campbell 1993). To safeguard against this problem Bowling
(2001) makes the suggestion that when using disease specific measures in the older population it is important they are supplemented with measures that take into account co-morbidity.

While not covering all of the common disease groups just previously outlined for older people Table 2 illustrates some disease specific measures that may be regarded as being reliable and valid for use with older people.

**Table 2: Disease Specific Measures**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Designer</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barthel Index</td>
<td>Barthel, D. (1955)</td>
<td>Activities of daily living in people undergoing (particularly post stroke) rehabilitation</td>
</tr>
<tr>
<td>Mini Mental State Examination</td>
<td>Folstein, M. (1975)</td>
<td>A person’s orientation to time and place, recall ability, short-term memory and arithmetic ability</td>
</tr>
<tr>
<td>Guyatt's McMaster Chronic Respiratory Questionnaire</td>
<td>Guyatt (1987)</td>
<td>Frequency and importance of all areas of chronic obstructive airways disease</td>
</tr>
<tr>
<td>European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire</td>
<td>European Organisation for Research and Treatment of Cancer (1993)</td>
<td>Quality of life in people with cancer</td>
</tr>
<tr>
<td>Social Dysfunction Rating Scale</td>
<td>Linn (1969)</td>
<td>Maladaptation in relation to interpersonal dysfunction in elderly people and in psychiatric outpatients</td>
</tr>
</tbody>
</table>
Again these measures have not been arranged in order of importance or priority but I have intentionally placed the Barthel Index and the Mini Mental State Examination (MMSE) to the front as not only have these instruments been designed with the older population in mind, they are both extremely well known and popular within both the clinical and research fields of gerontology. This is in spite of the Barthel Index being old, not well tested and undesirable for use in the community and for less frail or disabled persons (Bowling 2005 and 2001) and the MMSE demonstrating limitations around accuracy for older people with low education and its inability to distinguish between levels of dementia i.e. mild, moderate and severe (McDowell and Newell 1996).

As with the Barthel Index and the MMSE, the other instruments tabled, like the broader health status measures have their strengths and weaknesses. For example the EORTC has been very carefully designed collaboratively but as yet remains not fully tested for sensitivity for older people with multiple morbidity (Bowling 2001). The Social Dysfunction Rating Scale has been designed with older people specifically in mind but has both reliability and validity issues (Bowling, 2001). The Guyatt’s McMaster Chronic Respiratory Questionnaire, the Arthritis Impact Measurement Scale and the Guyatt’s Chronic Heart Failure Questionnaire all seem to have both validity and reliability strengths though are more research orientated (Bowling 2001, McDowell and Newell 1996).

### 3.4.3 Domain Specific Measures

Domain specific measures refer to instruments that are used to measure life areas that are of importance and relevance to a study, clinical or evaluative situation that is not necessarily tapped into as part of disease specific or generic measures. Domain specific measures are often used in conjunction with other health-related quality of life measures. They hold a
measurement place of some critical importance when measuring the health-related quality of life of older people. The main reason being is the previously mentioned issue of co-morbidity that may be a later life travelling companion for some older people.

Domains that are of particular importance to older people are: mental health, functional ability, well-being and self-esteem (including autonomy) and social support (Bowling 2001 and 1996). It may be that one or more domains need to be considered. For example take the situation of an older person who is being assessed post stroke or the research study investigating quality of life after stroke or the health service that is evaluating the stroke rehabilitation service. They all may need to consider domain specific measures relevant to neurological conditions such as anxiety and depression, cognitive impairment, self-esteem and self concept, life satisfaction, social support as part of measuring quality of life.

An example of a domain specific measure covering each domain is represented in Table 3.

**Table 3: Domain Specific Measures**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Designer</th>
<th>Domain</th>
<th>Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Philadelphia Geriatric Centre Morale Scale</td>
<td>Lawton (1972) Revised (1975)</td>
<td>Subjective well-being</td>
<td>Life satisfaction and self-esteem in older person’s aged 70-90 years</td>
</tr>
<tr>
<td>The OARS Multi-Dimensional Functional Assessment Questionnaire</td>
<td>Older Americans’ Resources and Services (1975) Revised (1988)</td>
<td>Functional ability</td>
<td>Functional ability</td>
</tr>
<tr>
<td>Geriatric Depression Scale</td>
<td>Brink and Yesavage (1982)</td>
<td>Psychological well-being</td>
<td>Depression in older people</td>
</tr>
<tr>
<td>Rand Social Support Scale</td>
<td>Sherbourne and Hays (1990)</td>
<td>Social Support</td>
<td>Functional support, affectionate support,</td>
</tr>
<tr>
<td>Positive social interaction and emotional/informational support</td>
<td></td>
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(Adapted from Bowling 2005 & 2001)

These four examples of domain specific measures like the measures already discussed have their strengths and limitations. Of relevance to mention here in relation to these specific examples is that the Philadelphia Geriatric Centre Morale Scale is held in high regard for its excellence over other life-satisfaction and morale testing instruments along with proven levels of reliability and validity (Bowling 2005).

The Older Americans' Resources and Services (OARS) Multi-Dimensional Functional Assessment Questionnaire is also viewed as being superior to other instruments such as the Barthel Index (Bowling 2005 and 2001 and 1996, McDowell and Newell 1996) and the Geriatric Depression Scale rates highly for reliability, validity and sensitivity in older people in community, residential or clinical settings though this may not extend to older people with cognitive issues or the very old (McDowell and Newell 1996). Technically the Rand Social Support Scale belongs to measures of broader health status. However, it is viewed as an instrument of relevance for measuring supportive relationships in older populations at a time where work continues to develop appropriate measurement methods for measuring social support and for that matter social networks (Bowling 1996).

### 3.4.4 Broader Quality of Life Measures

Bowling (2005) refers to broader measures of quality of life as a way of making the distinction between measures of health status and health-related quality of life. Broader quality of life measures for health have been developed outside of disease specific measures and are a reflection of quality of life and health defined in its broadest sense. A good example is the WHOQOL definition for health outlined in the definition section of this chapter. The WHOQOL Group has developed two instruments with which to measure quality of life and
health that directly tap into their broad definition. They are the WHOQOL-100 and the WHOQOL-BREF which is a shorter version of the WHOQOL-100 (WHOQOL Group 1998a, 1998b). Both instruments rate well on reliability and validity, and its capacity to be used inter-culturally is viewed very positively (Bowling 2005).

Another example of a broader quality of life measure that is of particular interest is the LEIPAD Questionnaire which measures multi-dimensional quality of life in older people. A further product of the World Health Organisation, this late 1990s designed instrument has been constructed in response to what is perceived by some as an appropriate alternative to the narrow and limited clinical outcomes focus as a measure of health related quality in the older age group. Due to its relative newness it has not been well tested for reliability and validity, and while designed as a multi-dimensional instrument it is found wanting with the exclusion of autonomy, control and independence domains (Bowling 2005). This is not the case in the very recently developed CASP-19 instrument.

The CASP-19 is another broader health measure which again has been designed for use with older people but specifically intended for measuring quality of life in early old age (Higgs et al 2003). The instrument’s title represents the measurement domains of: control, autonomy, pleasure and self realization. While conceivably not broad enough to technically fit as a broader health measure the CASP-19 does capture domains other instruments rarely do and its domains are closely associated with the notion of “successful ageing” (Bowling 2005, pg. 155).

3.4.5 Utility Assessments

Utility assessments are measures designed to evaluate healthcare in economic terms. The economical measure of health-related quality of life is the act of assigning a numerical value to a health state in an attempt to determine the benefits of a healthcare intervention in terms of both length of life gained and the quality of that life (Albrecht 2006, Bowling 2005 and 2001). Two of the most well-known utility assessments are the Quality-Adjusted Life Years (QALYS) and EuroQol 5D (EQ-5D) (Bowling 2005, Brooks 1996). As measures that are
widely used for the purposes of cost utility analyses and the subsequent allocation of scarce healthcare resources, they perhaps more than any other type of health-related measure attract quite significant criticism and raise serious ethical concerns. As well as issues of measurement validity, reliability, poor sensitivity and low response rates (Bowling 2001) utility assessments also draw attention to what is called the “disability paradox”.

The term “disability paradox” represents the life situation where many people with serious and enduring disabilities declare that they experience a good life in spite of what others may view as lives so dire they are not worth living (Albrecht and Devlieger 1999). Koch (2000) thoughtfully challenges the “disability paradox” as a notion and suggests the term exists because of the misguided human need to place people into a different class i.e. disabled, based on something that is considered to be less than normal. As such, an assumption is made that physical, intellectual or sensory difference results in an inferior quality of life and a possible conclusion reached that a life may not be worth living. As Aksoy (2000) perceptively points out in the discussion on quality of life and the value of life, where is the quality of life in non-existence?

The idea that the quality of somebody’s life could be judged worse than being dead with the implication that being dead is better also concerns others. In particular, Wolfensberger cited by Massarelli (2005) has coined the term “death making” and the phrases that accompany it, “being made dead” and “making people dead” to starkly illustrate this very negative side of quality of life ideology. Massarelli (2005) explains that the act of measuring a human life dependant on quality with such quantifying factors as for example: “the degree of autonomy the person enjoys, the freedom from suffering, the level of competence or consciousness, the real or perceived burdensomeness to others”, leads to a death-making mind set. More bluntly, what maybe in people’s minds is that some people’s lives are worth less than others.

That the measurement of quality of life is associated with negative outcomes is further illustrated in a study by Ravenscroft and Bell (2000) who found that in over half of the intensive care units they surveyed, decisions to terminate people’s life support were based on “arbitrary quality of life judgments”. That the professionals’ view on expected quality of life is
a key factor in determining whether effective treatment is given or withdrawn illustrate only too clearly the pitfalls in measuring the worth of a human being solely based on a quantitative scale or clinical calculation. They also make plain that these issues and others like them will ensure that quality of life measurement and utility assessments will remain a contentious moral and ethical issue in the future. Perhaps in the human services, it is not a question of judging the value of a human life, but more one of how to enhance the quality of each person's life which after all is the fundamental goal of medicine, nursing and allied health fields.

3.4.6 Individual Measures

As with the defining of quality of life where there have been recent attempts to seek the views and individual perspectives of older people themselves, this too as an idea has gained some recent traction with quality of life and measurement. This progression in development of quality of life measures is found in individual measures of quality of life where there are genuine attempts to capture individuals' views and values (Bowling 2005). Joyce et al (1999) explains that individual measures of quality of life approach health-related quality of life from a more biopsychosocial perspective rather than the more traditional biomedical model of disease. In other words it places the person instead of the condition or disease as the centre of attention. By comparison to other measures, individual measures have the capacity for people to nominate, weigh and assess the domains most relevant to their quality of life which is quite a shift from the traditional predetermined medicalised and standardised measures (Carr and Higginson 2001).

One particular individualised measure of note is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL). The architects behind this approach, Hickey, O'Boyle, McGee and Joyce (1999) have based the SEIQoL completely on the value system of the person being assessed which is underpinned by an understanding of their definition of quality of life, namely that "quality of life is what the individual determines it to be". Through a standardised semi-structured interview format people are asked to specify the five areas of their life that are most important to them and then rate their current status using a visual analogue.
The quality of life of healthy older persons has been assessed using SEIQoL. In a study by Browne, O’Boyle, McGee, Joyce, Mcdonald, O’Malley and Hiltbrunner (1994) that assessed the individual quality of life of 56 healthy community residents aged 65 years plus at baseline and 12 months later found that quality of life was higher at baseline compared to healthy adults aged just below 65 years and that for the aged 65 years plus adults their quality of life did not alter significantly over the 12 month period. The weight placed on health did not increase over the 12 month period even though there was a significant decrease in health status. The SEIQoL has also been used to assess the quality of life of older people with dementia and it was found to be both valid and reliable for use with older people with mild cognitive impairment.

3.4.7 What have the Measures Revealed?

With so many measures, and so much measurement interest from the many and differing disciplinary perspectives, it is understandable that a great deal has been written about quality of life from a quantitative perspective. The written material far exceeds the scope of this thesis study, so my intention is to focus on some key results from studies measuring the quality of life of older people.

Some health-related quality of life measurement studies utilising measures considered appropriate for use with older people have resulted in contradictory findings. For example, Livingston, Watkin, Manela, Rosser and Katona (1998) measured the quality of life of 700 older people living at home in inner London using the Index of Health-Related Quality of Life (IHQL) along with the short-CARE and an anxiety disorder instrument. They found that the (IHQL) did not demonstrate concurrent validity in older people in the community and as such should not be used to inform, especially, decisions about resource allocation in this population group. They also recommend the development and use of health-related quality of life measures that are appropriate to older people.

The use of the SF-36 amongst older people has also been criticised on the grounds of appropriateness with older people for reasons that the social and physical sub scale items were
not appropriate, specifically to long-term care (Murray, Lefort and Ribeiro 1998). The development of new and relevant measures was also a finding of a review of the current health-related quality of life instruments with regards to older people living with dementia. Selai and Trimble (1999) found that the preliminary research indicates measuring of quality of life is feasible with this group, although thorough testing and validation of existing measures needs to continue along with the development of new and appropriate measures.

Thus, the concept of quality of life is not age specific and the elements or dimensions of quality of life are the same for all human beings. This recognition underlies the development and implementation of Raphael’s (1996) instrument. Using a health promotion model as the conceptual basis for defining quality of life in terms of “being”, “belonging” and “becoming”, Raphael surveyed 250 older North Americans to assess the levels of importance and satisfaction with various quality of life issues. Respondents rated the “being” domain more important than “belonging” and “becoming”. In particular they rated “physical being” and “psychological being” as the most important. The ability to physically be able to get around the home/neighbourhood, to see and hear, to maintain own personal hygiene and overall physical health were the important quality of life items associated with “physical being”. Important quality of life items associated with “psychological being” were being free of mental illness and being able to have clear thoughts. When rating their satisfaction, these seniors rated “belonging” higher than “being” and “becoming” with “physical belonging” rating highest. To continue to make their own household decisions, living in a safe place, having a space for privacy, enough room, own personal things and living in a comfortable place were the “physical belonging” quality of life items that gave the most satisfaction.

From these importance and satisfaction ratings Raphael (1996) then calculated quality of life scores that reflected higher and lower quality of life. Scoring very highly were the “physical being” and “physical belonging” domains. Items that lowered quality of life were worry, stress, sadness, not being able to remember things, not having enough energy and bad feet.

Another study that was interested in the relative importance of quality of life domains was a large population survey of 2033 randomly sampled adults, of whom some were older,
undertaken in Britain by Bowling and Windsor (2001). These researchers found the six most important quality of life areas mentioned were: relationships with families, friends and other people, finances/standard of living/housing, own health, other people’s health, ability to work/satisfaction with work and social life.

Measuring quality of life in early old age Higgs et al (2003) using their own designed, broader quality of life measure, known as CASP-19, found quality of life to be influenced by social support and participation, the quality and quantity of social contact, feelings of trust and reciprocity about the local neighbourhood, health and financial security. In contrast, another British study by Grundy and Bowling (1999) investigated quality of life in very old age. Undertaking a structured survey interview with 620 subjects aged 85 years and over these two researchers defined quality of life in terms of physical, psychological, social and environmental wellbeing. Nine quality of life indicators were then used to represent these multi-dimensions and were categorized under three major quality of life domains: “wellbeing and autonomy”, “health and wellbeing” and “environment”. The researchers found close to half of these very old people achieve good quality of life scores on at least five of the nine indicators. This involved factors such as control, health, health problems, liking the area they lived in and warmth. Poor scores were reflected in life satisfaction, activities of daily living, activity and security. However, there were two small groups that achieved good or poor scores in all nine quality of life items. Those 21 very old people with good scores all reported high levels of emotional support from family and friends, had someone who cared about them and they could turn to, made little to no use of formal services, were involved in regular activities, outings and hobbies and felt young. In contrast, the 13 people who achieved poor scores reported more adverse life events i.e. deaths of close relatives, attack or robbery, smaller social networks, feeling lonely most of the time and feeling old. To Grundy and Bowling (1999), these findings again challenged the often held homogenous view of ageing and being old. In order to respond to the great diversity that exists within this population group a multidimensional approach on quality of life in old age must be accepted.

As well as Raphael (1996), other researchers have been interested in measuring what contributes to higher and lower quality of life states. The following three Scandinavian studies
have a particular interest in the quality of life of older people accessing both formal and informal help to live at home. Hellstrom and Hallberg (2001) sought the perspectives of 445 elderly people receiving home help on their quality of life and found that the multiple linear regression analysis showed that the number of health diagnoses or complaints, the restricted ability to be alone, living alone and age each have a significant relationship with low quality of life.

In a more recent study again by Hellstrom, Andersson and Hallberg (2004) to measure the quality of life among 4337 older people receiving help from informal and/or formal helpers at home or in special accommodation found that being a greater age, being a woman, being a widow/widower, a higher number of complaints and needing more help with personal care corresponded to a lower quality of life for those in special accommodation compared to those receiving help from informal/formal helpers at home. Higher age and having a social network of three or more people determined a higher quality of life in those receiving help at home. The type of helper did not influence quality of life but the extent of help required affected quality of life negatively.

In yet another study published in the same year by Hellstrom, Persson and Hallberg (2004) which measured the quality of life and symptoms of 1248 older people living at home with or without help found that receiving help with daily living appears to be related to a lower quality of life. So it seems irrespective of location being older and needing help with day to day living is associated with reduced life quality. In contrast, Lawton (1995) investigating the quality of daily life of older people receiving home care concluded respondents had less quality of life because they engage in passive activities such as rest, watching television and listening to the radio.

Measuring which chronic conditions are associated with better or poorer quality of life using the SF-36 and/or SF-24, Sprangers et al (2000) found patients who were older, female, had a low level of education, were not living with a partner, and had at least more than one condition, in general, reported the poorest quality of life. Urogenital conditions, hearing impairments, psychiatric disorders and dermatological conditions were found to result in
favourable functioning whereas gastrointestinal conditions, cerebrovascular/neurological conditions, renal diseases, and musculoskeletal conditions were related to poorest functioning.

To conclude this section on measures it must be said that the effort to measure quality of life has been nothing short of impressive. However, the quantitative paradigm steeped in objective and verifiable data can only tell part of the story on quality of life. Even with the development of individual measures of quality of life they remain within a rigid framework that has no real capacity to authentically tap into the subjective experience of quality of life. This state of affairs has troubled even the most committed quantitative, quality of life and health-related quality of life researchers take for example Hunt (1999) and to this end efforts have been made to look beyond the walls of positivism and understand quality of life from individuals’ meanings.

3.5 MEANINGS

As has been outlined in the previous sections on the defining and measuring of quality of life there has been an overwhelming preference to quantify the meaning of quality of life with the use of scores, scales, surveys and the like. Such approaches essentially eradicate any room for people’s individual values and what is known and understood about quality of life is more about the quantification of meanings rather than individual understandings. However, people’s individual values and judgments are critical to understanding their perception of their quality of life (Bond and Corner 2004).

While there has been a growing acceptance within quality of life research that the evaluation of quality of life is highly dependent on the person who experiences it (Bowling, 1999, pg.14) the published research on such qualitative matters has been relatively minor compared to the quantitative effort. The health research, policy and practice environment has been fully immersed in western empiricism. This has left little room for qualitative enquiry on quality of life at all levels. In particular, according to Gabriel and Bowling (2004) older people’s views and priorities and how they construct their quality of life remains a neglected area of research.
at a time of international significance, given the projected increase in the older population worldwide.

This neglect explains why my dedicated search effort for published material on individual understandings and expressed meanings that older people may have attached to their quality of life has yielded only a few studies of this nature. Most of this qualitative material has already been spoken of as part of the lay defining of quality of life. Though small, there is no intention to repeat this information here except to reiterate that these lay definitions are in effect individual understandings of quality of life. This leaves me with only a couple more studies to elaborate on. One of these is a study again drawn from the seam of qualitative literature from the already mentioned ESRC Growing Older Programme (1999-2004).

Maltby, Warren and Cook (2001) using a life story approach demonstrated the diversity of meanings quality of life had for older women. Often linking their responses to important life stages or events, the women participating in this study identified various issues that were central to their lives. These include: attitudes to ageing and being older, spiritual and political beliefs, discrimination and oppression based on age, gender, race, income, transport, family relations, health, disability, leisure, activities, use of services and nature of service provision, social rights and having a say and being listened to.

Another is an unpublished New Zealand study that similarly demonstrated the diversity of meanings quality of life had for older women. Munro (2002) explored the quality of life of 175 older women of whom 16 participated in a semi-structured interview (all the other women completed a postal questionnaire) and found these women to understand their quality of life in terms of: positive ageing, ageing in place, attitude, maintaining good health, previous life experiences, learning, grandmothersing, independence and control, living alone and the loneliness of widowhood.

There are other qualitative studies that provide valuable insights directly into the social worlds of older people and indirectly to their quality of life. This contingent lens on quality of life often has in its focus those individual dimensions or factors that are thought to determine,
influence or constitute quality of life itself. As such, these studies can shed further light onto the individual understandings and meanings of quality of life for older people. In the absence of other studies specifically exploring older people’s individual meanings on quality of life I turn to one such study that could be considered in the way I have just explained. Keeling (1999) in an ethnographic study titled *Ageing and independence in a New Zealand community: A three-dimensional view*, which explored the meaning of independence for a small group of New Zealanders experiencing advanced old age. From the extended open interviews with twenty participants Keeling (1998) found independence to be a complex notion. Taking participants understanding of independence Keeling crafts a “three dimensional view” of independence. The first dimension is what Keeling (1998) describes as “independence in a personal sense” which captured the many personal, individual understandings of independence. For example, participants expressed independence in terms of the life that has been lived and continues to be lived, day to day decision-making, planning for the future, death and loss, age, time, personal control, the meaning of their home and community. The second dimension is “independence in a social context” which reflected individual understandings of independence as expressed by participants in terms of relationships with family, friends and other relationships of significant meaning. The third dimension described as “resources for independence” represented the resources needed to sustain independence which was in the main expressed by participants in terms of health and wealth.

The meanings derived from Keeling’s study on independence and ageing are certainly not out of step with the other individual understandings on quality of life and ageing that have been discussed in this chapter. I am sure congruence would be found in other similar qualitative studies. However, what cannot be ignored is the great imbalance between the quantitative and the qualitative perspectives on quality of life and especially as it relates to the lives of older people. If its to be believed that older people’s values and judgments are vital to the understanding of quality of life in older age then continued and increased attention needs to be paid to listening to the views of older people on these matters themselves. This will require a dedicated shift in research methodology.
3.6 METHODOLOGY

The purpose of this section is to define and justify the methodology applied in this research study. This will be undertaken by discussing the development of the research design and rationale for qualitative research and the philosophical framework informing this research. The actual methods undertaken in this study will follow in Chapter 4.

3.6.1 Research Design and Rationale for Qualitative Methodology.

There are worthy arguments for both the quantitative and qualitative paradigms through which to conduct research. Qualitative, quantitative and theoretical approaches are all needed toward conceptualising and assessing quality of life. The trick for any researcher is to be able to gaze through the methodological maze and discern what is most fitting to use as scaffolding in a bid to build the best design with which to answer the research question or questions (Crotty 1998).

As evidenced in the literature review, quality of life, which is the centrepiece of this research study, has been predominantly a counted phenomenon and as such, quantitative inquiry with its emphasis on consistency and regularity has virtually reigned supreme. This is an interesting predicament as the term itself is so evocative of all things qualitative and strongly suggests a more humanistic rather than a scientific approach. The phrase alone draws me towards a qualitative approach which I appreciate is not a solid basis for making such a methodological decision but my intuition is supported by Bowling and Windsor who argue that:

Quality of life reflects both macro societal and socio-demographic influences and micro concerns, such as individuals’ experiences, values, perceptions and psychology. This poses inevitable challenges for measurement. While the division of quality of life into pre-defined individual components may be helpful for measurement purposes, this may not tap the most pertinent domains of people’s perceptions of quality of life, and this approach does not capture the subjectivity of people (Bowling and Windsor, 2001).

The purpose of this research is to tap into older people’s individual experiences and perceptions of quality of life. The choice of qualitative methodology based in the phenomenological research tradition has the capacity to do just this with its characteristic
feature of the search for meanings and understandings of the human experience. It also has the capacity to obtain insights into complex issues.

The literature review on quality of life provides substantial and compelling evidence as to the term’s complexity as well as issues of conceptual elusiveness and ambiguity. To seek answers from a quantitative perspective that relies on the issue to be “defined, relatively simple and unambiguous” (Bowling 1999) and where the emphasis is on quantity, amount, frequency or intensity (Denzin and Lincoln 2003) does not follow from or fit with the research questions in this study. The choice of qualitative inquiry as an appropriate research design for a study of this kind is also well supported by other social, nursing and gerontological researchers (Polit and Beck 2004, Merriam and Associates 2002, Netten cited in Jamieson and Victor 2002, Holloway and Wheeler 1996, Boulding 1985 cited in Patton 2002).

3.6.2 Philosophical Framework

Central to my research design and requiring articulation so as not to create any methodological confusion, are the study’s theoretical perspective and epistemology (Caelli 2001, Crotty 1998, Holloway and Wheeler, 1996). Exposing these fundamentals creates transparency around the order of philosophical assumptions underpinning this study.

An epistemology is a way of understanding and explaining how we know what we know (Davidson and Tolich 2003, Crotty 1998). The epistemological viewpoint for this study is the perspective of constructionism. This perspective is a potent and relevant choice given that constructionism underlies a basic interpretive qualitative study into which phenomenology technically fits (Merriam and Associates 2002). As a constructionist thinker I believe meaning-making is a process of construction by people as they participate with their human world (Crotty 1998) and as such I am interested in the meaning a phenomenon has for those involved. In this instance, the meaning of quality of life for a small group of older people who access low levels of home support.
The theoretical perspective informing this study is the philosophical stance of phenomenology. Simple enough, however there are differing phenomenological views but holding sway for this study are both traditional European and contemporary American phenomenology. According to Crotty (1998, pg 79) the European idea of phenomenology guided by Husserl (1931), Heidegger (1927/1962) and Merleau-Ponty (1945/1962) requires me as a researcher to “engage with phenomena in our world and make sense of them directly and immediately”. The phenomenon central to this study is quality of life. Crotty also elaborates on the important point that fundamental to the understanding of phenomenology is the notion of intentionality which acts as a kind of meaningful glue between subjectivity and objectivity and enables the objective examination of subjective experience. Also critical to European phenomenological thinking is the suspension of all currently held cultural understandings. Culture and tradition are seen as barriers to a true examination of phenomena and these must be set aside so that the phenomena in question can be revealed in their “stark immediacy”. European phenomenology is also recognised for its reflective, thus critiquing ability (Larrabee 1990 cited in Crotty 1998).

American phenomenology which has grown out of traditional European phenomenology holds dear much of what is said above but stands apart on two major points. Caelli (2000), who advocates that American phenomenology is especially relevant to the health sciences, explains these points as:

1. American phenomenological questions do not generally seek the prereflective experience but include thoughts and interpretations of the experience in the data collection and analysis.
2. American phenomenological analysis focuses on describing participants’ lived experience within the context of culture rather than searching for the universal or unchanging meaning of it.

The assumptions just outlined for both these approaches hold value for this study aimed at exploring, obtaining insights and describing the quality of life of a small group of older people accessing low level home support in a selected locale in New Zealand. But on the basis of the extreme difficulty if not near impossibility of setting aside culture and tradition, bearing in
mind my novice researcher status, I am for this study embracing Caelli’s (2000) version of phenomenology.

Also of importance is that for me as a nurse who chooses to be engaged in social research, the theoretical perspective of phenomenology makes sense as it embraces why nursing exists, which is to understand the life worlds of often very vulnerable people in order to care. At the heart of nursing is care and caring. To care is to be highly attentive to the uniqueness of the person and their life experiences or as Brooke and Kendig (2004, pg. 105) describe, to be focused on the “preferences”, “resources” and “situation” of each person. The phenomenon of caring is the nurse-person relationship with its inherent qualities of responsiveness, relationality and interdependence (Benner 1984, Leininger 1984). These acts of nursing also belong to the nurse researcher. They are acts deeply connected to the understanding of individuals’ perspectives and in turn people’s identities and sense of self.

3.7 SUMMARY OF THIS CHAPTER

This chapter has covered a great deal of literary ground on the topic of quality life. Led by a brief historical overview, the review has predominantly focused on a careful examination and discussion on quality of life as it relates to the lives of older people. The literature confirms there is a vast body of work on quality of life representing the deep interest the concept has to a myriad of disciplines. The literature also bears witness to the fact that for all their quantitative effort the academics and professionals are not much wiser as to the meaning of quality of life. I have attempted to create some sense of order out of the definitional chaos and confusion along with illuminating the great imbalance that exists between quantitative and qualitative perspectives on quality of life and especially as it relates to the lives of older people. I have argued strongly that the philosophical stance of phenomenology is the most relevant and potent pathway to take in this research project. Finally as Hunt (1999, pg.231) puts it “if the term quality of life has any meaning it must be rooted in existentialism, the values of the individual and the fluid dynamics of human attempts to cope with the exigencies of life”
CHAPTER 4: METHODS

4.1 INTRODUCTION

The primary objective of this methods chapter is to present the techniques and procedures that I adopted in this phenomenological study that explores the quality of life experience of nine older people who age in place being supported at home. This will be undertaken by describing and discussing the study’s design, the data collection and analysis, ethical considerations and concluding with the strengths and limitations of this study.

4.2 DESIGNING THE STUDY

4.2.1 Choosing the Participants

People aged over seventy five years who received between one and three hours of domestic assistance and/or personal care per week for a period of six months or more from one home support agency in a selected locale were sought to participate in this study. I based this criterion for inclusion on a number of considerations.

Firstly, as phenomenological studies typically rely on small samples of participants (Polit and Beck 2004) I decided initially that ten older people would be an appropriate number of participants from whom to gather sufficient data. Secondly, as outlined in Chapter Two it is from the age seventy five years that older people are more likely to need this type of support, it made infinite sense to set seventy five years plus as part of the inclusion criteria. Thirdly, the hours of support study participants received needed to closely align with the category of low level home support as this held particular interest to me for reasons of service vulnerability. This too has been discussed in the background chapter. The fourth consideration related to the length of time people had been receiving the service. This was important in that participants needed to actually have some sense of experience of home support in order to be able speak about it. Finally, having participants selected from one home support agency in a selected locale was a pragmatic management decision and it controlled for service variation, to a certain extent.

4.2.2 Choosing the Agency

In keeping with qualitative research the sampling strategy for the agency and participant selection was purposive sampling. Purposive sampling is a technique that seeks
information-rich cases, an essential feature of qualitative research (Polit and Beck 2004, Davidson and Tolich 2003, Merriam and Associates 2002). The home support agency was purposively selected from the six voluntary/private home support agencies within the selected locale who hold a current DHB service contract for the provision of home support services. This contract has also been spoken of in Chapter Two.

I chose the agency for its history and size. The agency was one of the first home support agencies to operate in the study's selected locale and it is one of the largest providers. I personally approached the agency to explain the proposed study and followed this visit up with a written invitation to participate once all ethical approval for the study had been finalised. The agency was most interested and supportive of the research study and willing to be part of the project.

4.2.3 Background Community Context of Agency

As it happens the agency and potential participants were located in an area where both community epidemiological and qualitative research work has been conducted in the past. These are namely the Mosgiel Longitudinal Study of Ageing (MLSA) which commenced in 1998 to investigate the cardiovascular risk factors, nutrition, disability and social support networks in the total population of the area 70 years and over (Campbell 1997) and Keeling's (1998) study which has already been mentioned in Chapter Three.

4.2.4 Participant Recruitment

It was from the agency that the participant sample was then drawn. I anticipated that the home support agency would be serving many more people who met the inclusion criteria than was sought for this study, so again, as a pragmatic way of managing this situation I decided to send letters of invitation out in 'waves' to potential participants. Potential participants were purposively selected with the assistance of the Home Support Coordinator from the selected agency who knew the clients well and as such was able to identify people who would be information rich from three electronically generated client lists that met the inclusion criteria for this study (ten older people, aged over seventy five years who receive between one and three hours of domestic assistance and/or personal care per week for a period of six months or more from the agency).
The first ‘wave’ of twenty two letters of invitation was then posted by the agency to potential participants. Accompanying the letter of invitation (see Appendix One) was an information sheet (see Appendix Two) outlining all the necessary details of the research and of myself as the researcher as well as a covering letter from the agency. Potential participants were invited to contact me directly to offer participation and find out more about the study and myself.

The first ‘wave’ of invitations to participate yielded eight women and one man into the study and at this first point of contact an interview date and time that was suitable to the participant was set with eight of the participants. One female participant was about to have surgery in the next few days but wanted me to ring her post surgery and if she was well enough she would like to be interviewed. Unfortunately this woman did not get well enough to participate in the study. This initial participant response and recruitment occurred within ten days of letters of invitation being forwarded to potential participants with seven participants selected within the first five days and a further two participants in the next five day period. I considered this to be a very successful initial response indeed.

At the end of four weeks with eight participants of whom seven were women, and no further response from the remaining fourteen invitations, I decided to send a second small ‘wave’ of letters of invitation to just three men in an effort to extend the sample. I received no response so after another ten days again a third small ‘wave’ of letters of invitation was forwarded to another three men and this yielded one more man into the study.

With nine participants selected into the study and no further responses from those who had received letters of invitation I decided at the completion of the ninth interview where data saturation (Polit and Beck 2004, pg. 308) was evident not to seek any further people into the study.

4.3 DATA COLLECTION

Data were collected from face to face interviews of the nine study participants in their own homes. In accordance with the Lower South Regional Ethics Committee approval informed consent was gathered immediately before each interview. Eight interviews were conducted over a two week period and the ninth interview four weeks later. Without
exception all of the participants wanted their interview to take place sooner rather than later with one participant declaring "seems like a long way of" as I tried to balance the interview schedule to meet individual participants’ needs.

The interviews were tape recorded and were semi-structured in format guided by five open ended questions (see Appendix Three) and a thermometer image (see Appendix Four). The questions asked were:

1. “I’m interested in how you respond when I mention the words quality of life to you”
2. “What brings quality into your life?”
3. “Of those things that bring quality into your life, what matters most?”
4. “What reduces or has a negative impact on your life quality?”
5. “How much does your home support contribute to your experience of quality of life?”

Using the thermometer image “how good or bad you rate your quality of life today?” There were no set follow up questions instead further questioning was prompted by what participants responded. However, after the second interview and in keeping with iterative process of the qualitative research cycle a phrase had emerged that I found useful as a way of summary in the subsequent interviews. The phrase was: “quality of life is all about you”

Each interview lasted for about an hour, excluding the time taken on arrival to ‘chat’ as part of helping to put the participants at ease and develop some sense of trust, to go over the consent form and research process, set up the tape recorder and further ‘chat’ after the post interview as part of disengaging. This time of disengagement also provided the opportunity to ascertain ‘code names’ as part of ensuring participants privacy and give some indication of when I was going to return with transcripts for verification. All the nine participants warmly welcomed and farewelled me in and out of their homes which I took as a sign that they that felt comfortable with what they had put themselves forward for and in the end participated in.

The interviews were verbatim transcribed by myself and then returned to eight of the nine participants for them to check and comment on as they saw fit. One man did not want his transcript returned asking “why do I have to see it? I don’t need to, I didn’t give away any family secrets, and no I’m just fine with what we did”. His wishes were respected and the
transcript was not returned. Upon returning the other transcripts to participants I was careful to explain how the transcript was a record of our spoken conversation, very much raw material and as such would not be like reading an edited book or newspaper. The transcripts were left with participants and I returned to collect them at an agreed upon date and time a couple of days later.

There were only a few alterations made. These included the correction of two people’s names and one woman personally crossed out three portions of her conversation. Two of these were viewed by her as being irrelevant and one portion she said she felt uncomfortable with it appearing because it referred to the care worker helping with an element of fairly basic housekeeping that the woman knew was not allowed by the agency and may thus impact on the care workers job.

I kept a field journal with observations and notes on the interviews and all other contact times I had with participants. This proved to be most helpful with contextual analysis.

4.4 DATA ANALYSIS

Data analysis in phenomenological study involves the “description of the meaning of an experience through the identification of essential themes” (Polit and Beck 2003, pg 584). This description commenced with the transcribing of the nine participants’ tape-recorded interviews and the keeping of an ‘initial impressions list’ as I listened again to their individual stories. The ‘initial impressions list’ was a beginning record of those things that stood out to me as significant statements as I immersed myself into the initial transcribing and transcription of the tape recordings.

Once all the transcribing had been completed by myself and the narratives verified by the participants I began to re-immersse myself with the individual transcripts by first just re-reading each transcript in order to gain some overall feeling for them. Then I read each one again, this time in the company of my ‘initial impressions list’ and transferred my first level codes from the list into the margins of the transcripts at the appropriate places. Other initial codes were added to the individual transcripts as they revealed themselves as part of this re-read. At the completion of this initial phase of analysis I created individual code cards for each identified code. On this code card I also recorded a specific example and
reference where this applied for each transcript and a brief commentary of my thoughts on what I was thinking this code and example was telling me or, in phenomenological terminology I began to formulate meanings. Through this process I ended up with fifty-four code cards. These cards were then very carefully scrutinised for similarities and differences and from this analytical task organised into fourteen clusters of themes. I then returned to the original narratives to validate the themes. This was undertaken initially by working sequentially through the key questions that were asked in the interviews in each transcript and formulating a detailed description of participants’ quality of life experience. I also developed a chart for each question on which I recorded the appropriate identified theme as well as indicating which participant the themes were relevant and important to. The charts and text were then analysed again and again for commonalities and also variations and patterns. This resulted in the final formation of six themes and the refining of my explanations and participant examples and illustrations.

The analysis of qualitative data is an iterative process and as such is a never ending process in a study of this kind. Throughout the analytical process my two Supervisors read the transcripts, ‘initial impressions’ list, codes, themes and descriptive text as part of the validation of my analysis. A step by step outline of the study’s analysis is provided in Appendix Seven. The themes and my thematic analysis are presented in the next Chapter (Five) as findings and these in turn will be discussed in Chapter Six.

4.5 ETHICAL CONSIDERATIONS

Approval for this study was sought and granted through the Lower South Regional Ethics Committee (see Appendix Five) and the Board of Graduate Studies in Health Sciences, Otago University. Recommendations and suggestions made by these two groups were incorporated into the study.

The ethical principles of autonomy, non-maleficence, beneficence and justice are considered the minimum requirements for ethically accepted research (Polit and Beck 2004 pg.143-153, Merriam and Associates 2002) and were adopted for this study. The process of informed consent was strictly adhered to, to uphold these four main ethical principles of research. Obtaining fully informed consent was undertaken just prior to the
interview using a specifically developed written consent form that had been ethically approved by the Lower South Regional Ethics Committee (see Appendix Six).

Confidentiality and privacy were maintained for the participants. This involved six of the participants choosing their own pseudonym which all held particular meaning for them and the researcher allocated code names for the remaining three participants at their request to choose for them. Participant’s pseudonyms have been used in this final written thesis and will be used in any future reports on this study including the brief research report that will be made available to all nine participants. All tapes and transcripts were kept in a locked filing cabinet and as part of the informed consent process participants were aware that only the researcher and her two Supervisors had access to the interview information.

To protect participants’ autonomy, I used an information sheet (see Appendix Two) to fully describe to each potential participant the nature of the study, their right to refuse participation, my responsibilities as the researcher and the likely risks and benefits. There was a definite sense of doing good exhibited by the level of warmth extended by the nine participants to me and the enthusiasm and interest they expressed at the first telephone contact. It was clear that these older people very much relished this opportunity to discuss their life quality and home support experience. Some even expressed a sense of satisfaction from the fact that the information shared may help others.

4.6 THE STUDY’S LIMITATIONS

All research studies have their strengths and limitations. Qualitative researchers in general have to deal with issues of data credibility, dependability, confirmability and transferability (Polit and Beck 2004). This qualitative study has been no exception. Issues of dependability, confirmability and transferability have been successfully managed by my adhering to the qualitative research practice of thick description to describe the study’s setting and findings. However, the research design decision not to provide feedback to the nine participants regarding my emerging themes and interpretations could cast doubt on my study’s data credibility. I have mediated this somewhat by ensuring that as the researcher I have been involved in all parts of the research process which has achieved a quality data analysis. Also the interview process itself allowed for the checking of
interpretations and understandings. As well I sent the nine transcripts, my ‘initial impressions’ list, codes, themes and descriptive text to my two Supervisor’s throughout the data analysis process.

The gender, ethnic and type of low level home support imbalance in the study of having mostly Caucasian women predominantly receiving household help could act to limit the findings. However, they are an accurate reflection of the demographic and service consumption reality where more women than men aged over 75 years of European descent are assessed as needing domestic assistance in New Zealand (Chal et al 2002).

A key strength of this study lies in the clear articulation of my theoretical stance and epistemological position which ensures soundness to this study and works to make its outcomes compelling.

4.7 SUMMARY OF THIS CHAPTER

The detailed presentation of my study’s design, data collection, data analysis, ethical considerations and acknowledgement of the study’s limitations has made explicit in this chapter my research pathway for this study. It is a sound research design that has enabled me to explore well the quality of life experience of nine older people ageing in place which will be evidenced in following chapters.
CHAPTER 5: FINDINGS

5.1 INTRODUCTION

This fifth chapter is significant in that it contains the heart of this research project, the presentation of the research findings. I asked five open ended questions and used a thermometer image to guide the individual participants' conversation on matters of quality of life. These questions were: “I’m interested in how you respond when I mention the words quality of life to you”, “what brings quality into your life?”, “of those things that bring quality into your life, what matters most?”, “what reduces or has a negative impact on your life quality?”, “how much does your home support contribute to your experience of quality of life?” (see Appendix Three) and using the thermometer image “how good or bad you rate your quality of life today?” (see Appendix 4).

These questions elicited many varied and similar responses and from my data analysis (outlined in the previous chapter) emerged six major themes. I have identified these as follows:

1. **Good People** - The good people in older people’s lives, that is their family, friends, neighbours and home helpers, feature significantly in the quality of life experience of elders.

2. **Day to Day Life** - The ability to take care of the day to day things of life in a personal sense for oneself and one’s home and the ability to get out and about in their community are important elements of continued independence for an older person that plays a vital part in their quality of life experience.

3. **Keeping Healthy** – Health both in terms of keeping healthy and managing ill health are notable dimensions of older people’s quality of life experience.

4. **Living with Loss** - Living with a sense of loss: that comes from the death or divorce of a long-term partner or other significant family member and the changes in their physiological functioning influence older people’s quality of life.

5. **The Future** - Thinking about the future with a primary emphasis on health and possible future support needs colours older people’s quality of life.

6. **At My Age** - A sense of surprise and expectation at being old people
Each of these themes will very shortly be used as the infrastructure for presenting my findings. Each theme will be reported in detail by weaving my thematic analysis together with examples and illustrations extracted from the participants’ interviews. These extracts are taken directly from the participants’ narratives, therefore expressing their point of view and are reported using the participants’ exact words. This approach not only communicates the vividness of the material but also acts in ways to safeguard the authenticity of the study; as Polit and Beck (2004) technically describe the trustworthiness of study data especially as it relates to dependability and confirmability. The participants’ exact words are denoted by the italic quotes.

But first something of the participants themselves. The people who participated in this study are Emma, Brownie, Susie, Jack, Jo, Maggie, Doreen, Mary-Lee and Peter. Their chronological ages range from 79-91 years. With the exception of Doreen who is married and Maggie who is divorced all the others are widows and widowers. They all have children and apart from Peter all of the participants have grandchildren. Emma, Brownie and Jack have great grandchildren. Emma, Doreen, Peter and Jack all live in their own homes and have done so for the last 56, 32, 19 and 4 years respectively. Susie lives in an ownership flat that she shares with her adult son who has an intellectual disability. They have been there for the last 10 years. Brownie, Jo, Mary-Lee and Maggie all live in their own units located within two retirement village complexes. Each of the participants receives between 1 ½ and 3 hours of home support a week and apart from Mary-Lee who has 1 ½ of personal care per week the support is domestic assistance. All the home support arrangements have been in place for 6-8 years.

5.2 GOOD PEOPLE

The people in participants’ lives are the quality of life experience that participants talk about most in this study. They are an immediate feature in the conversations and consistent reference is maintained throughout the interview. It is a prominent dimension of quality of life and family, friends, neighbours and home helpers are often quite simply referred to by the participants as “good people”. Having good
people around you is fundamental to their quality of life experience and as Jack explains about such people “you couldn’t do without them” (Int. 4, pg. 1).

5.2.1 Family

Within the theme of “good people” family is very prominent. As described earlier all of the participants have family. Spouse, daughters, sons, daughter-in-laws, son-in-laws, grandchildren and great-grandchildren are members of the participants’ family networks. Family dominates the conversation. I clearly matters and very early on I got a real sense of the importance of belonging to an intimate group known as family. A sense of identity, belonging and personal security seemed to radiate out of the conversations when family is spoken of but so too did a sense of loss as we will later see. All of the participants enjoyed a range of close and active ties with their family-based networks. Geographic distance did not appear to inhibit these feelings or connections in any way.

Spouse

Doreen is the only participant to be living with her spouse and having her husband in her life continues to be a source of great joy and happiness to her. He is her first and immediate response as she explains to me what brings quality into her life: “My husband” (Int. 7, pg.6). However, for this previously very independent and active woman who is now severely restricted in what she is able to do due to chronic post operative and osteoarthritic pain her spouse Charlie’s presence in her life now means other things. Doreen has become very reliant on this long-standing relationship (nearly fifty eight years) and this level of dependency now works in ways to detract from her overall quality of life. About her quality of life and need for Charlie she says: “Well I haven’t got any (laughter) I haven’t. I just wish every day that I could get better, feel better and I could do things instead of having to rely on my husband all the time” (Int. 7, pg. 1).

Even without their spouses, married life is important to the other participants. This is reflected in the memories shared by all of the other participants. These memories appear to be vibrant reminders of the life that has been lived and in which husbands and wives played a major role. They give quality to their lives both in terms of
looking back, and by continuing to influence their day to day lives. For example Brownie slips into the conversation:

"Every night at five o'clock I have, sit down myself as Harry and I used to every night and have a drink, just the one. Perhaps a whisky and soda or a brandy and soda or just a glass of wine and I have got quite used to having it by myself (laughter) which seems strange but no I quite enjoy it. Look forward to it now (laughter)" (Int 2, pg. 4-5).

**Daughters/sons/daughters-in-law and sons-in-law**

All of the participants have parent roles. Participants spoke freely about these relationships and they clearly hold a place of importance in their life quality. Being with, being there for, helping out and feeling included all characterise these parent and adult child relationships. This emotional, practical and social support is often reciprocal in nature. Daughter, son and in-laws contact is frequent either by physically being in each other’s presence or by speaking on the telephone. Emma, Doreen, Maggie, Susie and Jack all have family who live within “cooee” of one another and much is done together.

Emma’s adult children drop in on a very regular basis for a cuppa and a chat but also do any odd jobs that she may like done. The “boys” are all successful tradesmen in the family business her late husband established. This makes Emma feel very proud. Plus, they are “handy to boot” so she never needs to worry about any maintenance. They quickly installed her ramp at the back door after she took a tumble down the back stairs, and her daughter seldom visits without bringing an extra meal that she has plated up for Emma. Her daughter also helps out with Emma’s weekly shopping and hair do. It is a time of routine, getting the necessities and being social. Emma explains:

"Friday, yes, I go to get my hair done, always get my hair done on a Friday and I do my shopping and my daughter ah she picks me up and we have lunch at New World and then she brings me home with my groceries and then takes me to the hairdresser at one o’clock” (Int. 1 pg. 2).

A way that Emma returns these and other kindnesses is with her family-famous home-baking that she sends them home with.
Jack’s son also helps him out with the weekly shopping. Jack’s failing eyesight now means he finds things shopping a very frustrating and worrying task. He can no longer read the brands of things in the shop and know just where to find things. His son now plays a critical role in this essential task of Jack’s and this very ordinary act of day to day living is organised flexibly around their combined love for the footy, his son’s work and their shared practical weekly need for groceries. Jack tells me:

My son lives not too far away and he comes at least once a week and we go up to the supermarket and ah I just hand him my list, I push the trolley and he does the shopping, I do the paying at the finish (laughter) yeah. He does his shopping at the same time, yes. He works during the week so it works out we can either do it at night or in the weekend. We mainly do it on the Saturday or Sunday when we’re not watching football” (Int. 4 pg. 3).

Being there for and helping each other out is a daily occurrence for Susie and her adult son who has an intellectual disability. They live together in Susie’s ownership flat. This mother-son relationship is very reciprocal in nature as Susie poignantly explains:

“He’s 53 and um... he gets up here in the morning, it might be half past six in the morning and ah he gets himself ready and such like and he goes out and gets the paper and he makes the tea and toast and he gives me my tea and toast in bed and the paper. Then when I get up, anytime, the breakfast cups and plates, the dishes are done. He does those before he goes away. He goes out the door at five to eight in the morning and he is not home till ten past five. I cook the tea and he does all the dishes at night time. We help one another and I’ve always had ah, for years I had ulcers on my legs and I haven’t had them for a quite a while but I have got sort of a touch of arthritis in my knees and they get tired so he’s my other pair of legs. He puts the rubbish bag out and puts the rubbish out in the bag in the shed, puts the milk bottles out and brings the milk in, all these, and if there is washing on the line and he knows it’s dry he’ll bring it in. All these and on Saturday he will get the lux out and he luxes through. You know, so we help one another” (Int. 3, pg.2).

Family have become critical to Doreen and her husband’s social inclusion. Doreen’s personal world has moved from being out most days of the week with choir, golf, bowls and Women’s clubs to one that is now largely played out at home featuring pain and contending with disability. She tells me:

“They’re all friendly, it’s great. They have lots of meals together you know and things like that. No family occasion goes by without we’re all together. So
it’s really lovely. If we don’t go out for dinner we go to Annie’s or Barbara’s or somewhere so it’s good. They come to me now and again but they have to bring it all cos (laughter) but there’s too many when Jake and Bindy are here, because this room doesn’t hold that many people. But oh no they’re great, really, really great. Bill and Annie just lives up the hill, we’ve got them all here. So we are so lucky. If I didn’t have them I don’t know what I’d do, I really don’t and my husband’s the same” (Int.7 pg.2).

After her divorce ten years ago at aged seventy two Maggie moved to be closer to her daughter. Maggie’s daughter is in daily contact, either by visiting or calling on the telephone. They go on clothes buying trips into the city together and Maggie will often have a meal at her daughter’s on the weekend. All of this contributes to Maggie’s quality of life. However Maggie worries about her daughter. She too is divorced, raising two young boys on her own, working full time and running a home. This concern for her daughter takes away from Maggie’s quality of life but she tries to maintain a balance by helping and being there as much as she can for the daughter. She tells me:

“Well, I help where I can. I can’t help any more financially although I mean we’ll go out for a meal together and things like that. In little ways I can help and the children’s birthdays but ah apart from that I can’t go and help her mow the lawn which I’d like to do and do her garden and things like that. But I feel I can be some help to her in just contacting her you know and she rings me and I ring her and then she calls. I have the two children on a Tuesday and a Wednesday, she’s working later and I can help her in those little ways and as long as I’m here for her” (Int. 6 pg.12).

Brownie, Jo, Mary-Lee and Peter all live at a distance from their immediate family. Regular phone calls are the main form of staying in contact but sons and daughters come to stay as well. Peter’s daughter spends nearly every second weekend with him since his wife died almost three years ago. Mary-Lee’s daughter who is an unmarried teacher comes each school holidays to stay with her. Brownie’s son and daughter come from time to time. Brownie, Mary-Lee and Peter no longer travel to stay with their family as they used to but Jo at ninety one continues to fly across the Tasman for her annual visit to her two daughters who are permanent residents of Australia. Jo has no intention of moving to be with her only daughters though this has been suggested. Jo is very established at her Retirement Village and in the absence of her daughters and in the constant presence of Village staff Jo has developed strong relationships that for her are familial in character. She tells me:
“I consider the staff, the girls, the hostesses, I get on very well with them and I would, they would do anything for me and I look upon them as my family here and they bring me over my dinner if I’m not feeling any good and I do odd things for them. I’ve folded eight hundred serviettes (laughter) last winter when the football was on, it was good, you know just little things but it makes things very happy” (Int. 5 pg. 2).

Grand and great grandchildren

With the exception of Peter who has no grandchildren, all of the other participants have grand and/or great grandchildren. Similar to parenting, grandparenting is another extremely important family relationship that matters and brings quality into their lives. Photographs of grandchildren and great grandchildren are displayed proudly and without exception those participants who are grandparents showed me these before I left their homes after the interview. Grandchildren and great grandchildren give much pleasure with their own acts of individual love. Brownie’s recent birthday card from one of her little great granddaughters is a good example. She tells me:

“I got a card which my little eight year old, seven year old sorry had drawn herself and painted it all in and the thing that I thought was absolutely beautiful, across the centre there was ‘Nana is awesome’ (laughter). I thought that was quite the most beautiful card I’ve ever had (laughter). So I was thrilled with that you know” (Int. 2, pg 8).

Grand and great grandchildren also provide occasions and events to look forward to such as births, engagements, and weddings, and they play a pivotal role in acknowledging a reason for being, purpose and identity. Doreen explains: “And I keep saying to Charlie without us they wouldn’t be here” (Int. 7, pg. 16).

Grandparents are also needed for their wisdom, knowledge and experience. Doreen’s new granddaughter-in-law seeks her out to teach her how to bake and Emma’s granddaughter rings her for some advice about being in the school musical production.

5.2.2 Friends

While not as dominant as family, the place of friends is a prominent feature in the quality of life experience of eight of the nine participants and as Brownie explains
"quality of life depends on one's friends" (Int. 1, pg. 4). Similarly to family relationships the dimensions of close and active ties along with giving and receiving support are evident in these friend relationships. Friends are viewed as close friends, romantic friends and club friends. In contrast Peter conducts his life in almost a state of being friend-less.

**Close friends**

Close friends are spoken of as best friends and old friends. Doreen, Emma, Jo, Susie and Mary-Lee all talk of these types of friends. Contact is maintained by visits both scheduled and unscheduled and telephone calls. Susie explains:

"I've always got friends that ring me up on the phone to see how I am and I can ring people any old time and they're sort of all scattered all round. So yeah sort of scattered all round. And here, I mean the harbour ones I never know, there might be just a knock on the door an 'oooh whooo are you at home' and in they come. So there is ah, they don't ring up and say 'well are you going to be at home today' cos they know more than likely I will be and it's just bad luck if I'm not home when they come (laughter). They ring up afterwards and say 'oh we missed out on that cup of tea' (laughter), you know" (Int. 3, pg. 5)

**Romantic friends**

For Maggie the joy of having a new man friend close by is an important dimension to her quality of life. She referred to Walter before, during and after the interview and Walter dropped by to meet me. Walter is also present on both my return visits to Maggie. Maggie and Walter spend much of each day together enjoying food, each other's company, planning holidays together, intellectual challenges, shopping and just going out together. Maggie who doesn't drive tells me:

"One man lives not far from me. He's a wonderful friend to me. He takes me shopping um and he's very good company. He's recently bought a computer and we're trying to learn the computer (laughter) plus we are able to go out. Although he has bad health he can still drive his car and we are able to go out sometimes, mostly shopping which is good to have mmm, yes" (Int. 6, pg. 3).

Jack also has a new woman friend as part of his life as a widower. Like Maggie he speaks about her before, during and after the interview. Jack tells me that his woman friend is the person that he bought his house from and as well as her continuing to
advise him on the garden they dine out quite a bit. She is also very important to him because she reminds him of his late wife and the institution of marriage. Such close, personal and intimate relationships were of importance to Jack and his wife with concern held for each other when one or other was no longer around. Jack tells me this after the taped interview but he is happy for me to include these thoughts as part of the study. Jack explains:

"My wife was a good talker, we talked, we schemed, and we laughed, that's why the lady I see is important, she's like my wife. It makes a terrible difference. I asked my youngest daughter what Mum would have thought about my lady friend. She said 'Oh Mum, she would have been jealous but she wouldn't mind'. My wife and I used to discuss this, what would one do if the other dies. I would say 'who would you have as a man after I am gone'. Then she would ask me and I said 'I have only had one wife but I can't guarantee that I would live like a monk'.

Club Friends

Belonging to clubs or groups is a great source of friends and friendship networks. Apart from Jack and Jo all the other participants are involved with organised clubs. The nature of these groups vary enormously from choir, women's, league of mothers, craft, church, returned services to health and fitness groups such as arthritis, diabetes and balance and exercise. For some, club involvement had been longstanding and in some instances even when the club association ends, friendship connections have been maintained. Emma explains:

"there are about ten to twelve of our ladies meet on the day, we always meet in the Supermarket Café, you know in the restaurant there, um, at half past ten on the first Wednesday of the month, and that's another thing that I go to, I never miss, and that's wonderful because we do, we have a, you know, we've known each other for a long, long time and it's just lovely, yes" (Int. 1, pg. 3).

While not a club as such, the three retirement village settings did provide for maintaining of old friends and the establishment of new friendships. As a musician and music teacher Brownie admits to lots of acquaintances but few close friends. Her three closest friends now live in the Village with her and closeness takes on a physical context as well as being emotional. It also represents being social. She explains:

"Then I have three close friends here and that's fine, we have a chat every morning
on the phone and do things together. Go out to lunches and things like that, you know” (Int. 2, pg. 4).

The good friends that she has been able to establish since relocating into a Village complex have contributed to Maggie’s quality of life. However, Maggie acknowledged that living in a same age, segregated environment did not guarantee friends though “most people were nice” (Int. 6, pg. 1). Being friendly is seen as an important aspect of Village living but friendliness isn’t always available and it could be a bit of a hit and miss affair. Jo refers to this with the rather philosophical telling of the following encounter:

“I normally say hello to everybody that’s new here but I got a horrid knock back the other day. I was going over for my dinner and this other woman, she wasn’t old and she wasn’t young, and I was going along the corridor, it was one of those very bad cold days, and I said ‘hello oh isn’t the day awful’ and she said ‘well it’s winter, what are you complaining about’. Oh and I thought, well you’d better not talk like that again. You see we meet all kinds here. Sometimes it’s funny (laughter) what happens, very funny and other times it’s sad, but that’s life (Int. 5, pg. 3).

Friend-less

Compared to the other participants, Peter’s experience of and with friends has been quite different and he virtually lives in a friend-less state. The making and keeping of friends in old age can be a tricky affair anyway, as death may step in and rob people of these relationships and relationship opportunities. For Peter not only is this a factor but also his making and keeping of friends has been very much influenced by earlier life experiences. Experiences as a young Air Force pilot then navigator in World War 2 who was transferred very frequently from one assignment to another and with little expectation of a safe return appear to have set Peter into more of a pattern of disconnection with people rather than one of connecting and sustaining friendships. Even in places of expected friendship and mateship, the development of nourishing and fruitful peer friendships did not eventuate for Peter. He tells me:

“Ah I’ve been a wee bit disappointed with RSA. The ah, not so much the RSA itself but some of the people that I’ve met in there. When I first came out ah there was a chap that my wife worked with on the Railway and he was in charge of them on the Railway and I was working on the Railway. That’s where I met my wife and ah when I came here I used to go down with him
occasionally to the RSA and that was okay. Then the poor fellow died and ah...well I went down once or twice and you know, started conversation with a little group and as soon as, they were all Army blokes and cos I was in the Air Force and not the Army and as soon as they found out I was in the Air Force they sort of almost clammed up and ah, and I got the feeling well they didn’t think too much of Air Force blokes. Not everybody but you know you only need to strike a few and that happened two or three times. So I don’t really go down for any social life. I go down for ah to pick up frozen meals or go down for ah meal. They have midday meal down there and ah, they have things on there which, but I think you sort of need a companion or two to sort of go to those. Some people it’s no trouble at all but ah (Int. 9, pg. 13).

5.2.3 Neighbours

All the participants have neighbours. As ‘village’ dwellers, Brownie, Jo, Mary-Lee and Maggie are very physically close to their neighbours with adjoining single garages being the only physical separation between individual households. This close proximity of neighbours or as Mary-Lee put it “just having the people about me here” (Int. 8, pg. 3) typically describes how neighbours feature in the quality of life experience of these participants living in retirement complexes.

Susie in her older style ownership flat is even more physically close to her neighbours with just a wall dividing her from her immediate neighbours. In contrast to the ‘village’ dwellers, Susie has a lot to do with one of her neighbours at the ownership flats. This neighbour regularly visits throughout the day every day. She ‘popped’ in twice during the interview, and now that Susie doesn’t drive to the city anymore “because it’s always hard to get a park” she helps Susie by taking her to town when she needs to go.

Jack, Peter, Emma and Doreen continue to live on their quarter acre sections and are surrounded by homes and sections similar to their own with some units and flats scattered here and there. Neighbours hold a life-long importance for Jack who as a farmer in a remote part of New Zealand relied on the support of his rural neighbours. Life is a little different now he is urbanised but nonetheless neighbourliness remains a significant and important part of his life. Jack tells me:

“Our neighbours mean a terrible lot when you’re situated like that but ah I think you find the people that live in the country know that neighbours are very important you know. And here I don’t see a great deal of the neighbours,
in the houses over the back, they have high fences, you’d have to knock on the door to talk to them but ah the four flats out the front and we’re all like me fairly elderly people and grand people to get along with. We help each other. I grow a lot of vegetables and I’ve got to get rid of them so I distribute them among the neighbours” (Int. 4, pg. 9).

Emma, Doreen and Peter have lived in their respective neighbourhoods for 56, 32 and 19 years respectively. Over this time much has changed. While they age in place, others round them have come and gone. Doreen talks of the lovely young family on one side of them who they had a lot to do with ard who have now moved and how she and Charlie don’t really know the new people. Though they do have the “fun of cork” watching the youngsters on the other side who have recently moved in. Emma’s neighbour is also her home helper. While she was anxious about this initially it is working well. Of all the participants it is Peter who speaks at length about his neighbours. He only has occasional contact with some of his neighbours. However, in spite of this situation Peter knew a lot about his neighbours. He tells me:

“That place used to be let ah what was her name? Milly somebody but she owned that place and those units down there and that place was let and we had various tenants in. Some quite nice and some, well most of them were all right you know but anyhow ah, Bridie was the last one there, in there, when the chap that’s there now bought it. Oh he’s a bit of a goer really. He’s in this business, he’s one of the principals’ in it and he’s added a room on the back, he hasn’t quite finished it and he put that big garage in the front there. I don’t see him really. I’ve only spoken to him once or twice but I see his wife occasionally. They’ve got two wee girls and they come round and visit me sometimes (laughs)” (Int. 9, pg. 7).

This great level of ‘knowingness’ that Peter possessed of those living around him combined with the occasional visit seems to be socially satisfying for him and Peter can not imagine living elsewhere. He tells me: “I mean I’m quite happy here even with just a casual meeting of kids next door and somebody else from here, you know” (Int. 9, pg. 10).

5.2.4 Home Helpers
The people who provide formal help to participants are definitely viewed by participants as good people in their lives. Participants especially speak about them in response to the question “How much does your Home Support contribute to your experience of quality of life?” However, Maggie thought of her home support worker
at the very mention of the words quality of life: "Well I have my home helper once a week". Others like Emma, Jack, Doreen and Mary-Lee identify the home support worker as a part of what brings quality into their lives.

Within the home based care industry the people who are employed to undertake the work in people’s homes are predominantly called care workers or support workers. These titles are not used by participants. If and when a title was used by participants it was home help but more often than not they were just called the “girls” or by their Christian name. In line with the language of the participants it is fitting for the purposes of this thesis to use the title home help/.helpers.

Apart from Mary-Lee who receives 1 ½ hours of personal care as well as domestic assistance, all of the home help is domestic in nature. To have regular help with the household things that are no longer able to be physically managed by themselves is a source of great relief for these older women who have predominantly held traditional homemaking roles. Similarly for the men who no longer have wives in these roles the home help contributes greatly to their quality of life. Jack tells me:

“Oh it contributes greatly, yes, ah there are so many things about housekeeping that I, I’ll put it this way I had a very good wife for sixty years and didn’t have to worry about a house. I was a farmer and I can handle gardens and I’ve never had to handle housework and um I’m not terribly good at it. I give it a rough do over; things get a bit dusty and so on. But no that makes a great difference” (Int. 4, pg. 12).

As well as the relief that comes with knowing these things have been done and the difference it makes, there is also a sense of relief that all their energy has not been used to just attend to the basic but regular housekeeping that comes with a home. As Emma explains: “Well it does relieve me, you know, I wouldn’t be able to do what I do if I, I would be just too exhausted” (Int. 1, pg.18)

What Emma is making reference here to is that without her home helper she would not have the energy reserves to keep doing other things she values greatly or, which as she puts it “gives me a life”, such as; leading the choir, taking her health classes, going to her clubs and luncheons, doing her shopping. Jo also just doesn’t have the energy anymore and knows that by the time she gets up, showered, gets her breakfast,
washes her dishes, makes her bed and tidies up her bathroom she is beginning to get 
exhausted. To have to manage all the cleaning of her home would be totally time 
consuming and not very life fulfilling. Jo says: ‘Well by the time I’ve done that I’m 
tired, I’ve got to sit down, and I’ve kind of had it. If I had to do all the housework I 
would be all day and I’d be getting miserable (Int. 5, pg.16)

Home helpers are not only seen as ‘good people’ for the physical help they give but 
they are also valued and appreciated for the emotional and social support they 
provide. This seems to be the case both when the relationship is established and 
longstanding, and where it is more changing in nature. Doreen looks forward to every 
Thursday morning when her home help arrives. She played an active part in her home 
helper selection by specifically asking the agency for this home helper because she 
came recommended to her from a friend. Doreen feels it is a perfect match. Doreen 
tells me “she suits us and we suit her”. Amongst other things that the home help 
assists her with, it is when she does the weekly ironing that Doreen likes best. This is 
when they talk.

“She does my ironing and while she’s doing my ironing I’m sitting here and 
she’s talking to me and it’s just lovely. And we just talk about general things. I 
help her with problems she’s having with her family and like I don’t help her 
but I can give her an opinion and we exchange (Int. 7, pg. 8).

As Peter adjusts to living his life without his wife and taking on new roles in the 
house he too finds that to be able to just talk to his home help who has been coming 
into his home since before his wife died 2 ½ years ago of great benefit. He tells me:

“My home help lady we talk ah about odd things (laughs) you know and I get 
a few clues from her, cooking, oh yes and the price of things down at the 
market. I suppose we spend a bit too much time talking rather than, well, well 
you feel that the house is at least luxed. Ah, and she does a bit of dusting, 
she’ll do a bit of ironing ah you know it’s as much her being here I suppose as 
ah, sort of helps you know having somebody else for a wee while to talk to, 
you know” (Int. 9, pg. 17).

To be able to just sit and talk is also prized by Jack. He and his home help always sit 
down and have a cup of tea and talk when she finishes her weekly two hour clean. It’s 
a ritual that Jack likes and has maintained with the three home helps he has had in the
last six years. This social practice combined with the regular practical household help gives some insight into the nature of the relationships that develop and are sustained. Jack describes to me what his home help means to him and what it is like when they change: “Except you become friends you know from week to week, you have different talks on things. It's never the same starting with a new one but ah you soon get to know each other” (Int. 4, pg.13).

Emma too has had her fair share of changes of home helps. She has her own ideas on why this is so and thinks it is because the home helps don’t get paid enough, “they’re stressed, stretched for people to do it and I think you know, the pay is not very brilliant”. She tells me this with an air of resignation and understanding. But like Jack, Emma also wants me to understand what it personally means to have the home helps in your home. Unlike Jack she speaks of a relationship that is much closer to family in nature:

“You get close....I don’t know that....they, they are pretty rigid at the ah, place where they are sent from about this sort of thing. But it is all very well you, you know when you do, it’s, when there’s so much personal things that they do, you can’t help but becoming part of the household” (Int. 1, pg.18).

To illustrate further the nature of the relationships that are established both Jack and Emma speak of how some of their former home helps still drop in just for a cuppa and a chat. Susie also has had a number of home helps over the three years that she has been receiving formal home support and she finds it interesting to be meeting up with different people. In contrast, Brownie finds even the temporary changes of home helps over the holiday season difficult to bear. Brownie describes her regular home help as “joy” and adds “I mean she’s been here with me for quite a while”. Their routine is well established and Brownie particularly likes the fact that she quietly goes about her work not missing a thing. This level of thoroughness is important to Brownie:

“I don’t like it in the Christmas holidays when there’s one after the other sort of comes and tries to fill in. By the time I show them where everything is or tell what I would like, I would sooner do it myself, you know (laughter). No, ah the help that I get is absolutely indispensable...I'm very happy and very grateful for the support I get” (Int. 2, pg. 13).
Brownie’s comment on being very grateful for the support she gets even when the situation was not ideal is typical of how all the participants felt about their home help. Maggie in particular was experiencing difficulty with her current home help. She is young and isn’t a particularly good time keeper or housekeeper. Maggie finds this awkward and frustrating. It interferes with her plans for the day. She is a busy woman and the poor time keeping of the home help casts some aspersions that Maggie has little else to do with her day but hang around for the home help. After eight years of receiving help Maggie is clear on what makes a good home help and like Emma, also has her own thoughts on why you don’t get exactly what you want.

“I think the fact of being cheery, coming in and being cheery. I don’t mean to sit and talk for ages or that but just to have a cheery word and not be too negative and pass on all their sad parts of their life. I’ve had several girls that have told me all of their experiences but most important of all I think it’s important to do a good job when you come and that does vary I find. But I think that’s because they get very low wages. I think if they know were able to have a little higher wage that you’d get more quality people. Um I'm not complaining or that sort of thing but um I do think they would get girls that would stay longer. I have had three in three weeks this last year” (Int. 6, pg 13).

Mary-Lee also has been receiving home help for the last eight years delivered by a number of home helps over this time. Her gratitude for having somebody to do what she can no longer physically mange around the house overshadows her long held personal standards on the way the work should be performed. She told me:

“I’ve always been a bit meticulous about my home and um even though it’s not done exactly as I would have done it I’m grateful there is somebody else to do it for me because I can’t do it anymore. I think that’s the only way to look at it. ..I know that I couldn’t. I got out the Electrolux was it yesterday or the day before to pick up something I dropped and I thought oh I couldn’t use this Electrolux anymore so lets be grateful for what’s offered to me” (Int. 8, pg.16).

As for the Home Support Agency little mention is made of this service structure by participants except to say they could make contact if there were problems. Doreen says:
“I don’t have anything to do with the home support people, they send me letters every now and again to just make sure everything is alright but I don’t have to reply to them and if I did have a problem I know they’re as near as the telephone but I’ve never had to ring” (Int. 7, pg. 18).

Mary-Lee is troubled by the fact the home helps do not wear a uniform smock or name badges and they lack gloves for the dirty cleaning such as the toilet as well as they just do not seem to get paid enough. She knows that she could contact the agency about these things but feels that it’s not her responsibility.

“I could ring up and say that but that’s sort of not me. I always think an agency should see these things themselves really” (Int. 8, pg. 18).

5.3 DAY TO DAY LIFE

Woven through the participants’ individual stories on quality of life is much about the ‘dailiness’ of their lives. About quality of life Brownie simply tells me: “It’s just day to day living isn’t it” (Int. 2, pg. 1).

Looking after oneself, one’s home and getting out and about in their community keeps participants meaningfully busy and active for a big part of each day. All of the participants speak freely about the minutiae of their day to day life and they did so with an unmistakeable pride in their voices of the daily things accomplished. This proud voice on taking care of the day to day things speaks directly to the issue of continued independence. Independence with matters of daily living is clearly an important aspect of their being and their quality of life experience.

5.3.1 Oneself and home

The ordinary things, that are part of all of our lives, like getting up, showering, dressing, making food, reading newspapers, making beds, cleaning and tidying and such, are part of participants lives. For the participants they are well oiled routines that flow from one day to the next. Though for these older women and men these basic matters of daily living take up more of their time. They seem in no way fazed by these developments and in fact they seemed to relish the ‘dailiness’ of their own lives.
Susie very early into the interview captures the general mood and situation of participants with her version of taking care of the day to day things. She says: “I enjoy you know so much of life. I can’t get out the same, I don’t go out the same but I can still get up the street and do my shopping and carry on here and cook meals and do a bit of baking. It takes me longer but I get there (laughter).” (Int. 3, pg. 1)

Peter offers an insight into the issue of time and changing roles. Since his wife’s death 2 ½ years ago Peter is fully responsible for both the inside and outside of his home. For Peter there just isn’t enough time.

“Ah...well there are some things like mowing the lawn. I can do them but ah I’ve found that ah, with other jobs, you know, preparing meals, washing and ah well the old saying ‘a woman’s work is never done’. You just don’t always have the time and you’ve got to get down to the shops and that to get stores” (Int. 9, pg. 12).

Taking care of the day to day things could be a source of worry. This is the case for Doreen who of all the participants is the most physically restricted. While able to attend to some things for herself personally and around her home she depends heavily on her husband for both personal support and domestic help on a daily basis. Since her surgery two years past it is no longer possible for Doreen to fully bathe or dress on her own, housework is limited to dusting a small collection of very precious ornaments and the daily cooking is a bit of a spasmodic affair with her attempting to accomplish culinary tasks but often having to give up because of back and neck pain. Doreen’s house is immaculate. She is a proud housewife who likes things ship shape every day and is from a generation where spring cleaning is a ‘must do’ event. Taking drapes down and washing them and thorough window cleaning and the likes matter very much to Doreen. Doreen’s husband steps in constantly to help her take care of these big and little things of daily living. This dependency on Charlie worries Doreen greatly as his health while not as vulnerable as hers is not great. This does not stop her from taking charge of the situation and she proudly tells me:

“I’m going to pay to get a person to come and clean the windows inside and out and take the curtains down, we don’t mind washing them and hanging them on the line but get someone to come and put them up for us because that sort of thing we can’t do” (Int. 7, pg. 3).
5.3.2 Getting Out and About

Taking care of the day to day things took participants out of their homes and into their gardens and the community. Particularly the weekly grocery shop and the ‘popping out’ to get one or two things over the week take all of the participants into the community on a very regular basis. So does visiting the doctor and the hairdresser. As well as this practical involvement in the community participants are also very socially and creatively engaged. Many continued to actively participate in life long pleasures and pursuits. Emma is a good example.

Emma as a musician had for all her adult life got out and about doing shows, singing duets, singing solos, singing in the Choir. She was also an active club member of a local Country Women’s Institute and League of Mothers and still meets socially on a regular basis with some of the other women from their League of Mothers days. The Institute is now replaced with another Women’s Club that she regularly attends. As an older woman her voice has dropped and she is unable to hit the top notes but she continues with her long singing career by leading a local choir which meets weekly and on invitation they perform at local Rest Homes. Emma’s life long passion for music extends to going out to concerts with her daughter and she would go to more if she could afford it and had the transport. Emma also continues to go to the family crib when she gets taken. She has just recently started participating in two Health Groups, one for muscle strengthening and balance and the other for weight control. Emma speaks clearly on what these things mean to her and at the same time provides an insight into the importance of family. She says: “it’s good because it keeps, gives me a life and especially now that Tom has gone, you know, it gives me something to live for but then I have got my lovely family, yes, so I think, I think I have a pretty good quality of life really” (Int. 1 pg.1).

Brownie, Jo and Mary-Lee live in very well resourced Retirement Villages and all three of them speak at some length on what is available to get out to within the confines of the Village. They are spoilt for choice; the library, heated swimming pool, sauna, spa, bowling green, exercise rooms, tennis courts, chip and putt golf course, petanque, films, entertainment, luncheons, happy hours, bus trips, walking groups, craft groups, Village Choir and even a daily bus service that does the local shopping circuit. As Brownie says “there is so much to do, if you want it” (Int. 1, pg.2). But it
is not from this repertoire of choice that Brownie speaks of getting out and about. Instead she tells me of getting together with her three very close Village friends in each other’s houses at five o’clock for a couple of hours every few weeks, getting out on her daily walks around parts of the Village assisted by her late husband’s walker that she had taken over, getting into her car and doing her shopping, getting her hair done and visiting the doctor. This ability to be able to get out was described by Brownie as “wondeiful” (Int. 2, pg. 7).

Like Brownie, Mary-Lee too gets out and about in her car to get to the shops, get her hair done and visit the doctor. But continuous activities and regular events taking place in the Village hold importance for Mary-Lee and contribute to her quality of life experience. She explains: “The things that go on here in the Village, they do help to make our quality of life and well I could be out every day of the week really to the functions that go on but I don’t” (Int. 8, pg. 2).

When Jo moved into the Village ten years ago she used to get out to everything, played indoor bowls and even tried to learn to swim. Now at 91 she likes getting out to some entertainment in the evening and getting out every day for her walks and taking her midday meal over in the communal dining room. This is an important time of company for Jo. She tells me: “I have my hot meal over here at the kitchen and there is six of us at our table and I hate missing that meal because we have lots of fun” (Int. 5, pg. 1).

Though no longer driving like Brownie and Mary-Lee, Jo does venture out of the Village with the help of her home help to do her shopping and on her own steam to visit the doctor and her hairdresser. Getting out also extends to an annual holiday to Australia which she loves saving and planning for.

Taking care of her shopping with Walter who drives, going over to her daughter’s and being involved in several hobbies gets Maggie out and about on a regular basis. She hosts her Women’s Institute fortnightly and her interest in painting and artwork brings two of her friends and her together in each other’s houses to compare notes and learn from each other. Maggie’s craft class in the company of twenty three other
“wonderful” people also got her out to the local Adult Education Centre for a whole
day monthly. Maggie loved this day of creative work, socialising and pleasure.

“We take a plate and we have morning tea and lunch, we start at ten o’clock,
we have morning tea, we have lunch and we have afternoon tea, we do much
talking and quite a lot of work (laughter) talking in between (laughter) and
that’s a lovely outing for me” (Int. 6, pg. 4).

Susie is still driving and gets out and about to the shops, to her weekly Group, to see
her friends and her family and just goes out for wee drives when she feels like it. But
it is getting out to her vegetable garden that brought a lot of quality into her life. Susie
grows parsnips, leeks, strawberries, potatoes, lettuces, celery, silver beet, parsley and
the garden’s harvest also keeps her busy and happy in the kitchen.

“Oh my little vegetable garden out there that’s a great part of my life. It’s not
very big but the neighbours say ‘the things that you grow in that vegetable
patch’. They reckon I’ve got green fingers (laughter). So that’s one thing when
I came here I said ‘I’ve got to have a bit of ground so as I can have a
vegetable garden’. So that’s a pastime of my life and I can go out there and
you know sit in the sunshine there and pull a few weeds out, just to be able to
go out to go out and get two or three leaves of silver beet or get a bit of
parsley or stuff like that. You can’t anything fresher than straight out of the
garden and inside and in the pot. I’d be lost if I didn’t have my little vegetable
patch (laughter)” (Int.3, pg. 6-7).

Like Susie, getting out into the vegetable garden is a great source of pleasure to Jack.
With great pride he takes me to show his large and productive vegetable garden. I’m
not surprised by its dimensions. It is a reflection of the farmer who knows how to get
the best use of his land and of the man who knew how to provide well for a large
family on very little cash. He gets out and spends much time in his garden place. Jack
does not belong to any organised community groups. He never has. Unable to drive
anymore because of his failing eyesight Jack gets out with family to shop and go
places. He does get out to the local dairy as he wants and to regularly dine with his
lady friend. Jack says: “We dine out, go out together quite a bit. That helps, breaks
the monotony, it’s great to get out with other people” (Int. 4, pg.5).

In spite of her physical restrictions, getting out and about remains an important
dimension of quality to Doreen’s life. Getting out to hospital appointments is almost
the only reason she and her husband go to the city nowadays but these health visits
have taken on a sense of occasion. Doreen and her husband make these outings social and they always end up with a fish meal at a favourite wharf-side pub before returning home. Doreen also manages to still get out to one group and that is her Women’s Club once a month. The supreme effort involved signals the importance getting out has for Doreen.

“I go to the Women’s Club. I still go to that but it takes me all my time to sit and they’ve got me a nice chair because I’ve passed out twice there before I got the operation but anyway I’m right at the back of the room and one of the Committee put a chair with arms on because I’ve either got to hold my arm or you know and ah every Thursday once a month the chair is waiting for me and if I’m not going to be able to go for any reason I ring and tell her and she doesn’t put it up. But they look after me and then I have different people sitting at the table every time because if you want to leave early or something they put you at this table. So it’s great and it’s right at the door and if I have to go I can easy go. I always go before it’s all finished because I’ve had enough but I don’t want to give it up” (Int. 7, pg. 8).

Peter gets out and about by going to town on his scooter to get to the supermarket, pick up his frozen meal order from the RSA and very occasionally he will call upon a friend at the other end of town from where he lives. He also gets out with his daughter who comes to stay almost every second weekend since his wife had died. They mainly head into the city to the Shopping Mall and while Peter found it to be somewhat tiring this keeping in touch with city is important. He tells me: “You see different things you know. It keeps you up to date on the city a wee bit” (Int. 9, pg 13).

5.4 KEEPING HEALTHY

Participants speak about their health-related experiences and they do so both in terms of keeping healthy and managing ill-health. Just like the experiences that have already been presented the experience of keeping healthy and ill-health are told as part of whole and bigger lives. Similarly its importance is evident in the way it is woven consistently in some way into each participant’s story. Keeping healthy and managing ill health matters. It both brings quality of life and takes away from quality of life. Quite often participants own health is compared to the state of other older people’s lives. This seems to help determine and shape each individual participant’s perspective of their own health.
5.4.1 Being Healthy

Being and keeping healthy is important to all of the participants and they all take a serious interest in their own health. Some mention good food, some talk of the pills they take and most talk of participating in some form of regular exercise. Apart from Emma who is the only participant to attend a formal exercise class and a separate weight control session weekly, the others all took care of their own exercise routines. Walking is a popular form of exercise either as part of getting out and about to do other things as Jack and Peter did with their regular trips to the local dairy or as a dedicated activity. Jo dedicates time each day for walking and her health feels better for it. She finds that walking a certain distance each day with the aid of her walking frame reduces the aches and pains in her arthritic knees and she sleeps much better at night. To keep up her walking over the winter months Jo has designed an internal walking circuit for herself winding through the internal corridors of the retirement village complex.

“It's all heated over there and there's long corridors and I come out of the dining room there and I come across to this side here and I walk. The apartments just over there go right down to almost the end of the avenue here and I walk down there cos it's inside and it's nice and heated and warm and it's quite a long walk and I can sit on my frame and have a wee sit at the end. I didn't actually choose that corridor but I thought it was on my way home so I will do that one and then I walk back. That's quite a long walk” (Int. 5, pg. 7).

Brownie also is a dedicated daily walker and walks outside most days with the aid of her walker. But her commitment to regular exercise doesn't end there. She has equipment specifically for exercise in her villa. She says: “I do have a stepper exerciser here myself at home and I do that every day (laughter) and perhaps a bit more, up to a 100 you know. Pop into the bedroom, mmmm, yes, it feels good (Int. 2, pg. 5).

While not in the same league as Brownies 'stepper' Doreen and Maggie have leg exercisers by their lounge chairs. Maggie used to walk into town several times a week until she injured her back at the regular exercise group that she attended. Now much shorter walks and the leg exerciser which was a present from Walter are her exercise programme. Exercise has always been important to Doreen and while a far cry from
her golf that she played for 25 years and bowls, the leg exerciser allows her to keep up in some way with a life long passion for keeping fit and healthy.

A dramatic weight loss over the last few years for Susie means she is a lot healthier in many respects than she was in her younger years. Now able to wear size twelve clothing from size twenty two and no longer troubled with leg thrombosis and chronic ulcers have helped her quality of life considerably. Apart from mentioning that she is on many tablets and is a diabetic, Susie does not identify any other medical conditions that she has though tells me how she quickly gets short of breath and her feet feel as though they are just dragging. She just has to stop and sit down. This inhibits her going for walks outside though this doesn’t stop her thinking about how this could happen in light of her limitations.

"But you know if they had a, well I’ll put it like this, to walk one block up there, I’d get up to the other end and I’d think, now how am I going to get back. If there was a seat there and I could sit down for just a few minutes I’d be alright and I’d get back up and come back alright" (Int. 3, pg. 12).

5.4.2 Managing Ill-Health

From the outset a reference is made to participants’ ill-health. Mary-Lee mentions “my disposition” (Int. 8, pg. 1), Susie, “a touch of arthritis” (Int. 3, pg. 2), Brownie, “a lot of silly little things wrong” (Int. 2, pg. 5), Jack, “my eyesight” (Int. 4, pg. 1), Peter, “trouble with a leg” (Int. 9, pg 1), Emma, “the problem with my heart” (Int. 1, pg. 1) and Jo, “my stupid legs” (Int. 5, pg. 4). But ill-health develops a very specific focus for most of the participants when they consider the question on what takes away from or has a negative impact on their quality of life. Ill-health is the most cited reason for what reduces participants’ quality of life or having the potential to do so. It is even considered in terms of whether life is worth living. Brownie tells me: “I think health is the main thing to pray for and to be independent and self sufficient. If I lose that, I wouldn’t want to live, you know” (Int. 2, pg 12).

But health is also weighed up carefully with other important and valued dimensions of life.
"The health part of life is very important because if you're not reasonably healthy then you're better off dead I think and ah so that must be the most important thing, to keep reasonably healthy if you want to live a long life. If you can get around without too much pain, if you can sleep reasonably well, can eat reasonably well which I've always been able to do, enjoy going out to dine but ah I wouldn't put that ahead of your friends, relations and neighbours because you'd be wasting your time having a good life" (Int. 4, pg. 8).

Doreen is the one participant for whom ill health and permanent disability is a strong theme throughout her interview. Her opening statement in response to just the mention of the words quality of life is: "well I haven't got any (quality of life), I haven't" (Int. 7, pg. 1). She comes back to her ill-health time and time again. It colours significantly all aspects of her life, often in a negative light but it is also balanced by other things she values and cherishes and bring much quality into her life. Doreen ends her interview by telling me:

"I should not be like this. It's not fair but when I think about what the doctor said to me, that I'd be in a wheelchair or die I wouldn't have wished that on Charlie. He reckons he couldn't live without me and he would be absolutely lost if anything happened to me. So whether I'm in pain and no quality of life I'm better to be here for him because he's often told me 'I don't know what I'd do'. I know when I was in the hospital two years ago he said 'I look over at your chair and I can see you sitting there but you're not in it' and he doesn't say much, he doesn't but when he does it's something straight from the heart. So that's how I know he would hate it if I wasn't here. So that's why I put up with the pain because I'm still here" (Int. 7, pg.24).

At other times when participants speak of or make reference to ill-health it is done in a comparative way to other older people they know or see. Generally they judge themselves as better off. Emma talking about her friend is typical of how participants talk: "Marie she had a stroke and she's in a home now, you see this is what happens you see and I deem myself very fortunate to be able to do what I do, you know, cos that heart attack it could have been a lot worse, yes" (Int. 1, pg. 6).

Jo speaks about her neighbour. Her neighbour's plight becomes a measure to her of poor quality of life but Jo couches her subjective observations with a thoughtful and qualifying notion.
“You take a person who is paralysed or can’t get about. My lady next door she has all the muscles gone here and she’s just like this and she has home helps come, she doesn’t want to go into a rest home and I go in and see her. Now that’s poor quality of life um she’s pretty good, well she’s alright mentally but her body is just a shell. She has to be put to bed, she has to be undressed and dressed. Now that is terrible, that’s terrible. Um well different kinds of sickness that you can’t cope with, that’s poor but ah I know we’ve all got to pop off at some time. But um to a certain extent you make your own quality of life” (Int. 5, pg 5).

Ill-health is also spoken about in ways that suggest acceptance and adaptation. Mary-Lee admits the diagnosis of osteoporosis ten years ago impacted negatively on her quality of life but at the same time she has learnt to live with it and plans for the future.

“Well I knew I’d have to slow down a lot where other times I could get around very quickly I’ve got to think or I might lose my balance and that sort of thing. And that deteriorates you very much the way you feel. But I’ve learnt to override that and I know the day is coming when I will have to walk with a walking stick but so do thousands of other people so who cares. So yes it would be about ten years ago when I was diagnosed and of course now I live on” (Int. 8, pg. 8).

5.5 LIVING WITH LOSS

When speaking about quality of life participants made immediate and continuing reference to the losses in their lives. However, along with ill health it is the only other major topic that participants recount specifically in response to the question “what reduces or has a negative impact on your life quality”. Losses experienced included spouse, family, friends and varying degrees of physiological functioning.

5.5.1 People

With the exception of Doreen all of the participants mention the loss of a long-term partner either by death or in the case of Susie, divorce. Apart from Peter who has relatively recently lost his wife, I learn of the loss of husbands and a wife through death as they speak to me of other quality of life experiences. Susie is telling me of her bus trips around New Zealand and beyond when she links into the conversation the death of her husband.
“Yes, we went on Newton’s. I belonged to a Newton’s Group, the Sunshine Club and that’s where we did all our tripping around, all parts of New Zealand, it was an older friend that was in it and I think it was the year that I lost my husband and they were going to Fiji and I said ‘oh I would love to go’ (Int. 3, pg. 4).

Brownie also links into her husband’s death and other experiences when telling me of a new friend she has made in the Village.

“There is one lady that is most interesting because she’d lived overseas in South Africa and all kinds of places, she’s a widow. Her husband died just not long before Philip and ah so, and she has lost really most of her sight and so she doesn’t drive, of course she can’t drive now, then my other friend doesn’t drive at all, so I take them, you know, so I’m sort of the chauffeur and take them in my car. I suppose I’ll keep on doing it, I don’t know I didn’t have trouble getting my licence last time (Int. 2, pg. 9).

These descriptions from Brownie and Susie are quite typical of how participants speak of the loss of their spouses. Peter’s situation however is a little different. His wife died two and a half years ago and this experience remains quite profound for Peter. Peter’s conversation throughout the interview is very connected to this event. Peter talks of his wife’s cancer and her dying and how he cared mainly for his wife at home with the help of District Nursing, the Hospital Linen Service and the Hospice. He tells me about her last days in a Rest Home not far from where they both lived and how she only lived for a year after her surgery. I also hear how she was the car driver. Peter goes on to describe life without his wife two and a half years down the track:

“Oh well it’s not the best. I wouldn’t say (laughs)but you know as I’ve said that’s the way it is and you’ve got to, there’s no use sort of, you’re inclined to I suppose after tea at night if there’s nothing on TV you start thinking a bit but oh no it’s, I wouldn’t recommend on your own but ah” (Int. 9, pg. 5).

Maggie too speaks more directly about the loss of her husband who divorced her ten years ago when she was seventy. Ten years on she still feels not only the loss of her long-term partner but also the loss of her family home of thirty seven years. She tells me: “I think that the ideal thing would be to still have your husband and have your home” (Int. 6, pg. 2).
The loss of her baby girl at twenty nine weeks gestation remains deeply embedded in Emma’s quality of life experience. Emma tells me that she was forty two and she and Tom already had six children. Emma wondered how she was going to manage but had accepted things and thought they would get by. Her baby daughter’s still birth was made even more difficult by her never seeing her daughter. Emma says: “I never saw her and that is another thing that I think affected me so much that I wasn’t allowed to see the baby, but I mean it is so different now, that took a long time to get over” (Int. 1, pg. 3).

5.5.2 Physiological

All of the participants speak of the impact of changing health and the physical effect of growing older and being old. Things such as changes in energy, feelings of pain and weakness, diminished sensory acuity and physical strength are described as part of participants’ day to day lives. There is a sense of loss conveyed as part of these descriptions which can be seen as taking away from their quality of life but there are also positive aspects that clearly contribute to quality of life as participants accepted and adapted to the life being lived now.

Emma is no longer able to walk as far as she used to and the diuretics she needs to take daily means that she is no longer able to attend church. But she doesn’t discount it as a possibility for the future and in the meantime she uses her television to make up for the loss of going to church.

*I don’t go to church now because it’s the walking and because of my water pill it’s not easy. If, when they get this new complex up and round and they have got toilets then I might manage to go, this is the only thing that in the morning, I’ve at times, once it gets started it’s every quarter of hour, yes but I can’t not take it. So on Sunday I must have my shower by half past seven because telly, the Hour of Power at eight o’clock and then it’s Praise Be at nine and then Attitude after that which is a very good programme, it’s about varying disabled people* (Int. 1, pg. 2).

Brownie too uses the television and reading to occupy a mind that was once very devoted to music through singing, playing the piano, performing and teaching.
"I find that music doesn’t take hold of my mind. I find television can take hold of one whereas um tape recordings or records can just wash over, the mind is still busy and if it is empty well it’s much better to be interested in something. I read a lot of course imm. It doesn’t seem I suppose very interesting now but I’m quite satisfied with it" (Int. 2, pg. 3-4).

Susie talks about how she can’t get out the same and how she no longer went on holiday bus trips because she can’t get on and off the bus anymore. She feels pleased that she took the bus trips when she was physically able to do so and now feels fortunate that she can still get around enough to do certain things.

“No I’ve always said I’ve enjoyed my life, there is nothing that I’ve said that I wish I’d done. I’m not one to sit here and feel sorry for myself. I just think how lucky I am. I can still get around and my memory is alright and look at the younger people that have had no life, you know the things that young people seem to get these days and that. So I mean I just, I suppose I take each day as it comes now. (Int. 3, pg. 4).

Jack’s failing eyesight brought with it many losses to his life. Jack speaks of not being able to see the letters he gets in the mail or read the newspaper, the great difficulty he has writing out cheques, the trickiness of seed planting in his beloved vegetable garden, not being able to grocery shop, being unable to find the things that he had dropped around the house, not able to drive anymore and most frustrating of all, as a retired farmer with an enduring love of the land, is the loss of being able to see the different types of farming and buildings when going for a trip anywhere. In spite of this Jack is philosophical and works around his limitations developing new skills.

“Well you’ve just got to take it as something that happens. Ah no use getting worked up about it, you’ve just got to work your way through it. I try to go slow. Think about what you’re going to do, where you want to go and you daren’t rush into anything. I sometimes, I want to go and do this in a hurry but you can’t do that, you’ve got to think about it a bit. Patience has never been my long suit but I’ve learnt a bit about making it work. (Int. 4, pg. 2).

Peter chooses to accept the changes in his physiological function as all part of later life.

“Well it’s, you can’t do things that you used to do before and some things you can’t ah, you haven’t got the energy to do things for any length of time sometimes, you know. You get tired quicker ah but you just, I think you’ve to accept a lot of that, you know, it’s really just old age I suppose” (Int. 9, pg. 2).
The sense of physiological loss for Doreen is profound and she struggles to accept her current situation. Since her surgery she has lived with chronic pain in her upper back, neck, shoulders and down her left arm. Her right arm and hand has to do all the positioning and moving of her left arm otherwise it hangs loosely and uselessly by her side. Her balance is also affected and it is nothing for her to suddenly topple. All of this means she can no longer play golf or bowls which as a very sporty person for all her life is a real blow to Doreen. She also can no longer participate in the choir.

“I think on Monday morning, I think oh golly I’d be away to choir practice now and then they tell me on a Thursday where they’ve sung you know. ‘I think oh sugar I used to love going to Rose House. And now today I’m thinking all the time, oh wouldn’t it be lovely to be at bowls, I’d love to be there. I never missed golf rain, hail or shine” (Int. 7, pg. 14).

5.6 THE FUTURE

As part of their quality of life experience participants are thinking about their future. While Brownie is hoping to live to see her great grandchild born at the end of the year and Jo continues to save for her annual trips to Australia, most of the conversation on the future is in the context of personal health and possible future support needs.

Retirement Village living with the ability to cater for higher levels of support need is almost like a futures map for Brownie. Everything she could perhaps need is in her Village and there is almost an expectation of moving through the continuum.

“I’m in a villa or a town house whatever one calls it and then of course the next step is the apartment and they’re lovely apartments and they have care provided if one needs it you see and then of course when you can’t cope with that you go into a rest home and perhaps when one’s marbles become disturbed it’s the Alzheimer’s home (laughter) and ah then the hospital and that’s it. So the whole cycle is here” (Int. 2, pg. 6).

Things are similar for Mary-Lee at the Village where she lives. She has already made use of the rest home at the Village when her back was causing her great pain and much reduced mobility. It is a comfort to Mary-Lee knowing that if she needed that kind of help it is there and she also views it as just another step in the process. She says: “When the time comes I’ll go because in a certain way again we can turn to
quality of life, I don’t know if I would lose it all if I had somewhere to go like that. I would be very grateful. Just another step isn’t it? (Int. 8, pg. 11).

Jack, Peter and Doreen who all live in their own suburban homes and Maggie who lives in a less well resourced Retirement Village express some fear about their future. This is connected to the prospect of having to move to residential care, a thought that they do not relish but one that stands before them in terms of future. It is interesting that these participants who all receive very low levels of home support per week consider this as the next step in support options available to them. Jack thinks that maybe with a bit more help in the garden this may stave off entry to residential care.

“I am considering, asking if they can give me a bit of help in the garden. Instead of going into a home, I’ve no ambition to go into a home or a very small flat but I’d like to keep my garden going as long as I can. I’d have to be very desperate before I went into a home because I’ve been through them to see other people and I wouldn’t be very keen on the lifestyle. But I could go into a smaller place, into a flat perhaps but it does worry me a bit because I’m not used to, I’ve been, you could say I’ve been a free person all my life and the thought of sitting around in a home and having nowhere to go, no people, no rellies it’s not very inviting. But then again I suppose I’m being selfish, hell of a lot of people can’t have a choice” (Int. 4, pg. 12).

Maggie has had the experience of Rest Home care. She spent eleven days in a local rest home after injuring her back. Even with Walter visiting her three times a day she found the days long and not filled with much. The time dragged and the capabilities of others around her were not equal to her own.

“Well just being in one room and then seeing others perhaps more incapacitated than I was although I enjoyed their company. I used to, their were four of us that sat at a table and ah I enjoyed talking to them but at first I would talk and they would just look at me and wouldn’t answer. But later they got used to me and they would nod or you know some are better than others” (Int. 6, pg. 9).

The thought of being without her husband places Doreen in a very vulnerable position. She knows that if anything happened to Charlie that she could not live on her own. She makes no mention of whether she can have more home support. She and Charlie have looked at a Rest Home not far from where they live. She does not like the thought at all but as a place of last resort it is considered. Doreen says: “I don’t
want to go there for goodness sakes, I don't, but if the last resort I would” (Int. 7, pg 10).

Peter expresses that at eighty two he no longer thinks about the future. He speaks of how at this age there’s not the same future as when you are twenty or thirty years of age. But a couple of things do have him gazing with a partial eye to the future. One is his daughter who has bought some property in another part of New Zealand in preparation for her own early retirement and he wonders whether she would want him to go with her. He is uncertain about this prospect. The other thing is he occasionally visits three relatives living in Rest Homes and this makes him think about his place in a future of this kind.

“Well I've got a sister-in-law in a resi home and I go down and see her occasionally and ah you see all these old people sitting around and ah...Well I’d accept it if you have to, if you get what I mean. I wouldn’t jib at it but ah I wouldn’t say I exactly look forward to it you know. I mean I’m quite happy here even just a casual meeting of kids next door and somebody else from here you know but down there it’s ah...you know, I don't know it’s a, they do things I suppose that you don’t see when you go there” (Int. 9, pg. 10).

5.7 AT MY AGE

Quality of life is also considered by many of the participants within the context of age. There is surprise at having reached this particular age, there is a sense of expectation that certain things happen as a result of being this age and there are feelings that they are good for their age and lucky. These descriptions from Brownie at aged 87, Susie aged 84, Jack aged 89 and Mary-Lee aged 80 express these age-related elements.

“Quality of life, I’m quite happy with it, at my age, you know it’s just day to day living isn’t it? And at my age I mean, you know (laughter), that’s ah” (Int.2, pg. 1). “I mean you know, at my age I’ve got an awful lot of silly things wrong with me but really I’m very good you know (Int. 2, pg. 5). “I didn’t expect to live as long as this anyway, quite frankly. My mother was eighty one when she died, my father was only fifty two when he died of a heart attack and ah I didn’t expect to (laughter), I thought when I got to eighty one, well that’s it and I’m still here” (Int. 2, pg. 13). “But I always think for my age, I think that I do very well, I’m eighty four past you know” (Int. 3, pg. 16). “But at my age I feel very lucky at having what I’ve got” (Int. 4, pg. 1).
Mary-Lee also compared her quality of life with different decades of her life

“Quality of life would be different to when I was say forty to what it is now and I suppose at the time I am satisfied with today as I was yesterday and the day before but perhaps not a few years back. But in the meantime my quality of life is quite good for my age” (Int. 8, pg. 1).

5.8 THERMOMETER IMAGE

Using a thermometer image (see Appendix Four) based on points ranging from zero (worst) to one thousand (best) participants' reported on how good or bad their quality of life was on the day of their interview. Responses ranged from 500-1000 points with six elders reporting at 750 points or above. This brief exercise confirmed a sense of harmony between the individual narratives reflecting a life time of experience to how they felt on the day I was interviewing them. While pleased to be talking with me these findings suggest that I had a limited influence on their quality of life experience.

5.9 SUMMARY OF THIS CHAPTER

This chapter in accordance with the analysis of qualitative material has presented the findings of this study in a narrative fashion. Narrative is a powerful means of learning and gaining understanding by giving meaning to experience (Garro and Mattingly 2000) and the elders' narratives in this study have brought meaning and understanding to their experience of quality of life as recipients of low level home support. Quality of life is viewed by these elders as good people, day to day life, keeping healthy, living with loss, the future and being the age they are. These meanings will now be discussed further in the next chapter.
CHAPTER 6: DISCUSSION

6.1 INTRODUCTION

This study sought to explore and understand through narratives the quality of life experience of nine older people who received low level home support services. The primary objective in this chapter is to summarise and discuss my interpretations and meanings of this studied experience based on the findings that have been presented in the previous chapter. It is my intention also to link the findings back to both the Literature Review Chapter (Three) and my research questions. The questions being asked in this study were:

- How do older people conceptualise and express quality of life?
- What part does low-level home support play in the maintenance of quality of life for these older people?
- What is understood as low level home support and what are the policy development implications?

Before proceeding onto my discussion which will be presented by using the three interlinked key concepts that form my conceptual model for the quality of life of elders who are the recipients of low level home support I wish to outline my model’s conceptual development.

As I looked at the results and worked faithfully step by step through the analysis I began to sense and visualise in my own mind’s eye an interpretive image of quality of life and ageing in place. As an ardent fan of roses I imagined the emergent quality of life themes, the service of home support and the policy of ageing in place as a rose. I saw the phenomenon of quality of life for older people who receive low level home support set in the bloom of the rose. The rose bloom with its collection of seemingly delicate entwined petals sympathetically conveyed to me not only the participants’ expressed dimensions of quality of life but also captured their very overlapping nature that was otherwise so
difficult to impart in the writing of my thematic analysis. I pictured the solid stem with its leaves that hang in small but strategic clusters supporting the elegant but abundant rose bloom as the valued contribution that low level home support makes and which in part mediated these elders quality of life experience. On the ground embedded in the rich and fertile soil are the roots of the rose that provide the food and fuel so necessary for the rose to flourish and bloom and which represented to me the significance of ageing in place policy for older people.

Also making an impression were the variations that are commonly found in this ancient and glorious plant such as its diverse fragrances, extraordinary colour range and its different ways of growing. Notwithstanding these uniquely distinguishing features of the rose, the most striking characteristic of the rose is through all the variants it remains totally and absolutely recognizable as a rose. Little wonder that it caught my imagination as a most perfect metaphor for which to understand the meaning and variety of the quality of life experience I was exploring and its relationship to low level home support and the policy directive of ageing in place.

My conceptual model for the quality of life of older people receiving low level home support is the rose bloom representing the six expressed overlapping features of quality of life with the rose stem and the leaves portraying the valued contribution of low level home support and the root system of the rose embodied the significance of ageing in place policy for elders. Quality of life, low level home support and ageing in place form the three key interlinking concepts of my model. This model is illustrated in Figure Two.
Due to the small and subjective nature of qualitative research caution must always be exercised when drawing conclusions in research of this nature (Polit and Beck 2004, pg 17). Nonetheless this study has produced some findings which accord with other studies of this kind and answer my research questions that I just reiterated.

6.2 QUALITY OF LIFE

Central to this study was understanding how these older people conceptualised and expressed quality of life. This was a key research question. From the immediate recruitment of most of the participants into the study through to the end of the interviews
where questions were answered spontaneously it was clear that these elders did think
about and were willing to talk about quality of life. Farquhar (1995) and Hendry and
McVettie (2004) also came to the same conclusion in their own quality of life research
with older people. As well as this preparedness to talk, the participants’ narratives on
quality of life clearly demonstrated that the concept of quality of life was well understood
by the elders in this study. Unlike the conceptual elusiveness that has come to plague and
haunt the academics and professionals (described in the literature review by Albrecht et
life in no way seemed to be a ‘tricky’ or ‘slippery’ notion to these older people
themselves. Wilhelmson et al (2005) likewise found in their qualitative study that older
people had no difficulty in understanding the term quality of life.

I found that giving meaning to quality of life for the participants were ‘good people, day
to day life, keeping healthy, living with loss, the future and being the age they are. These
views were not expressed in an isolated or compartmentalized manner. Instead they were
closely interlinked just as the petals of a rose bloom are. Other researchers have also
argued for the interconnectedness of quality of life dimensions (Gabriel and Bowling
quality of life is not a fragmented experience and that “when offered the opportunity to
give a more general picture, people do not segment their lives into component parts”.

The views expressed by the elders in this study reflected that quality of life was
considered from many angles. It is not just a health-related experience as might have
been assumed, as all the participants were the recipients of a health service. I had also
wondered prior to the interviews whether participants (knowing both what I wanted to
talk about and that I was a nurse) might have engaged with me in a more clinical fashion
about their quality of life experience. This proved far from the reality. Their shared
perspectives on having ‘good people’ in your life, being able to take care of the day to
day things, keeping healthy, living with a sense of loss and contemplating the future went
well beyond what might have been talked about in a narrow clinical focus. These
identified elements were in varying degrees akin to quality of life dimensions that have

However, while kindred in character they in no way fully represent a replication of findings from previous studies on quality of life and ageing. For example, Wilhelmson et al (2005) found social relations, health, activities, functional ability, well-being, personal beliefs and attitudes, home and personal finances to be what older people considered important for their quality of life. These similar yet different perspectives demonstrate more the uniqueness of the experience and confirm the multidimensional nature of the phenomenon (Haas 1999, Hagerty et al 2001, Keeling 1998, Rapely 2004, Smith et al 2004).

While quality of life was considered from numerous angles, dominating the quality of life experience for these elders are the ‘good people’ in their lives. Having family, friends, neighbours and their home helpers around them is fundamental to their quality of life experience by giving meaning to their lives. Most prominent among these relationships is family. This finding too is in accordance with other studies (see for example Bowling 1995, Farquhar 1995, Gabriel and Bowling 2004, McKevitt et al 2002, Smith et al 2004, Wilhelmson et al 2005). Even for participants who lived far away from their immediate family the importance of family is no less prized. The practical, emotional and social support provided by family is essential to these elders’ sense of identity, belonging and personal security. Similarly the active and close connections that most participants had with friends (especially) and neighbours were equally meaningful. Perceptible in all these relationships was the ability to both give and receive support.

Being able to take care of the “day to day things” in their lives was an important and valued element of quality of life. That it mattered was reflected in the way participants spoke from the outset of being able to look after them self, home and being able to get out and about in their community. This dialogue on these ordinary acts of daily living was maintained throughout the interviews. To be busy, active and meaningfully engaged
in attending to the dailiness of life both inside and outside of their homes and in their communities gave meaning to these elders' lives and contributed greatly to their sense of independence, autonomy and identity and in turn their quality of life. Wilhelmson et al (2005) too found that having the functional ability to manage things for oneself personally and about the home along with being able to participate in community activities were important factors in the quality of life for older people.

What is striking to me in this part of the study about being able to take care of the daily things of life and having 'good people' in your life is its very ordinariness. Quality of life was about ordinary, everyday life. Things such as being able to attend to the most basic of life activities such as self and household maintenance as well as participating in the wider community, participating in leisure and pleasure activities and engaging in meaningful relationships contributed immensely to these elders quality of life. As Emma put it about doing these things "it gives me life". The life-giving nature of being able to take care of the day to day things and all that entails along with the inclusion of 'good people' in the lives of older people has been described by others as key markers to "successful ageing" (McCracken and Phillips 2005). It has also prompted others to propose that quality of life or the getting of a "good life" is inextricably linked to the meeting of basic human needs. Higgs et al (2003) have suggested that quality of life is connected to "needs satisfaction" which led these researchers to adopt a theory of human need to underpin the instrument development and implementation of the CASP 19 to measure quality of life in early old age.

Farquhar (1995) has already introduced the idea that quality of life is both a positive and negative experience for older people. Similarly this was a central finding in this study. Participants' narratives detailed the good and not so good aspects that formed their quality of life experience. What was regarded as being negative was most evident in their response to the specific question asking "what reduces or has a negative impact on your life quality"? This elicited two major responses: ill-health and loss. The experience of ill-health was spoken about both in the context of their health now and the possible effect of future health changes. Their ill-health was also considered in terms of decreased
functional ability which was often associated with a sense of loss. It was this change to functional ability that was more likely to be found woven through their entire narrative. However, the negative impact of either present or anticipated ill-health was mitigated to some degree by the other positive quality of life experiences or riches in their lives of which two dimensions have been discussed already. Lawton (1999) has suggested that the non-health related areas of older people’s lives may well override the negative aspects of chronic illness and poor health. Also participants were highly motivated to keep healthy, and they all in some way or other actively worked upon doing this. This positive attitude to their own ageing and changing circumstances demonstrated a great capacity to be able to adapt and accept the life being lived now. It also reflected the dynamism of quality of life and what has been argued by Carr and Higginson (2001) as the concept’s capacity to respond with great fluidity as people’s values and priorities change in response to life circumstances.

Having health has been identified by other researchers as being a key constituent of quality of life for older people (Bowling and Gabriel 2004, Grundy and Bowling 1999, Smith et al 2004).

All the participants but one also recounted the loss of important people in their lives, namely a spouse either by death or divorce. For the participant who had most recently lost his wife this experience remained profound for him. This man’s negative experience outweighed the positive. For the others, the way in which people recalled these events suggested, as with the other losses in old age, that this negative experience was tempered by having other positive experiences and resources to draw upon. Also what cannot be ignored is the length of time the experience of widowhood may have contributed to the acceptance of this aspect of their lives. For one elder this extended back thirty two years and another twenty six years.

These elders’ stories also demonstrated that quality of life in old age was very much influenced by events over the life course of each individual and again in both a positive and negative manner. From a positive perspective many of the participants continued to
be involved in lifelong interests and activities, continued to engage in lifetime rituals and routines, and to hold valued roles as parent, grandparent, great grandparent, friend and neighbour. On the other hand the early adult experiences of one man demonstrated that unsatisfactory situations and relationships earlier in life if not resolved continued to have agency in later life. Likewise, unresolved grief from the loss of her pre-term baby whom she never saw or held forty years ago remained a current part of another elder’s negative aspect of quality of life experience.

The narratives supported the understanding that quality of life, as well as being influenced by events that span the life course, is most definitely considered in terms of the age the person was right now. There was an element of surprise expressed at being the age they were, an air of expectation that certain things could happen as a result of their age and feelings that they are good for their age and lucky. Quality of life was also viewed relative to other older people’s lives particularly with regard to age and health which seemed to act as a barometer to help determine the quality of their own lives. This has been described by Hendry and McVettie (2004) as “relativity to others”. These phenomenological researchers found in their study on understanding the quality of life experiences of older people, that quality of life was often viewed as relative to the experiences of others.

It was apparent that given the occasion to express their views elders did have definite opinions on what they thought constituted quality of life, what mattered most and what both brought quality into their lives and took it away. This suggested that these elders were in fact the experts on their own quality of life and ageing and not the professionals as has been noted in the past (Farquhar 1995).

6.3 HOME SUPPORT

As well as seeking to understand how older people who receive low-level home support conceptualise and express quality of life, this study sought to understand what role home support plays at the lower end of government health resource allocation in the maintenance of quality of life for these elders. This was another key research question in
this study. All of the participants were seasoned recipients of home support and had longstanding arrangements of six years or more. They received on average one and a half hours’ support per week, in which domestic assistance dominated extensively over personal care. This was in line with industry patterns as was the dominance of women in the study (Chal et al 2002, Martin 2005, personal conversation).

Home Support to the elders in this study was largely thought of as the ‘good people’ that come to help them in their homes and not the agency that was responsible for the service provision. The agency was a kind of background landscape that was not really familiar to the participants though they understood that this was where their home helper came from and that they could make contact if there were problems.

It was an unequivocal finding in this study that home support or more precisely the home helpers made a vital contribution to participants’ quality of life experience. Just as the stem of the rose acts as a support and nutritional portal to the bloom, the home helpers gave essential assistance and sustenance to these elders that allowed the quality of their lives to continue to flourish. This contrasts greatly to the findings of a Swedish study that found receiving help with daily living was related to lower quality of life (Hellstrom et al 2004b). Perhaps such a vast disparity in findings could be explained by Hellstrom et al (2004b) choosing quantitative over qualitative methodology, with its limited capacity to shed light on the subjective experience of individuals and thus provide other insights of value.

Home helpers featured in more than half of the narratives before participants were posed with the specific question “How much does your home support contribute to your experience of quality of life”? Considering this question came easily and participants were unanimous in their response that having their home helpers made a great positive difference to their lives. This was the case even in situations where it was thought that the home help arrangement was less than desirable. Such situations recounted by some included the high changeover of their regular home helpers, coping with temporary home helpers and home helpers not performing to the older person’s standards in terms of
housekeeping, time keeping and dress. These problems have also been highlighted in other studies (Chal et al 2004, Henwood et al 1998, Kane cited in Kane and Kane 2001). Most elders did not complain to the agency with some preferring to accept this was the way of it, due to the very low wages home helpers were paid and the others just feeling grateful for having someone to do what they could no longer manage for themselves. Either way it did not matter, as participants continued to value and appreciate the support that was provided each week. Again this raised the positive/negative feature of quality of life and may well have reflected that these elders were well enough resourced with positive quality of life experiences to mediate the effect of experience that was more negative. Or alternatively, they are perhaps like the rose of hardy and resilient stock that continues to live on in most conditions.

Home support by its very design is a physical construct based on meeting the most basic of human needs (MOH and DHBNZ 2002) but what this study has demonstrated is that participants used it in a very socially constructed way as well. Not only did they receive benefit from the physical support, these elders found ways to engage socially and emotionally with their home helpers which quite conceivably enhanced their quality of life experience as a service recipient. There was a feeling that home helpers became part of the household but that the nature of the home helper and service recipient relationship was not appreciated or understood by the agency. Some home help relationships had become enduring friendships that continued long after the formal arrangement had finished. As a result these ‘good people’ remained and added to the ‘good life’ of these elders.

It was because of ill-health and the physical effect of growing older that participants needed home support. There was never any sense that these elders did not want to be managing the full domestic responsibility of home. After all, homemaking had been a key role in all the women participant’s lives and the men had wives who had held this role. My ongoing observation as a guest researcher in their homes was that these older people remained house proud and it was important to them and their quality of life to have somebody who could efficiently take care of aspects of the housekeeping that were now
out of their physical reach. More importantly, sharing these roles allows them to devote their precious energy to other enriching experiences. In this way low level home support was an enabling experience that contributed greatly to people's sense of continued autonomy, independence and self.

For the elders in this study, it was while they were thinking and talking about their current home support arrangement and the contribution this made to their lives that they also considered their future. Looking forwards was contemplated almost entirely in terms of personal health and what support may be required in the future. Participants expressed two differing opinions but all held the same view on what this might look like for them. This was the prospect of having to move to residential care. For those living in the better resourced retirement village complexes this held no fear for them. Perhaps having this type of care available within their complexes, a sense of familiarity of place and the fact there had been occasions in the past to be positively associated with the residential care service allayed any negative perceptions they might otherwise have had of this type of care. By comparison those elders still living in their own suburban homes and a less well resourced retirement village expressed concern at the thought of having to move to residential care. The idea of institutional living was resisted by these older people for reasons of not being life fulfilling, incompatibility with individual lifestyle and being seen as a place of last resort.

Apart from these contrasting perspectives what was striking in these narratives on institutional care was the service chasm between low level home support and residential care. These elders were the recipients of the most minimal amount of weekly support that was predominantly domestic in nature and they clearly held the view that the next step from low level home support would be institutional care. There was no thought or knowledge of being able to access more home support into their homes if and when more support was needed. This seems an extraordinary and contradictory situation at a time of unconditional policy support for ageing in place. Why this situation exists could be explained by a care model for older people in New Zealand that has been dominated by institutional placement when things are no longer able to be managed at home. Such is its
history, this is all that is known and understood by elders with regard to other support options and quite conceivably it may even colour the judgment of those charged with the responsibility of needs assessment. Also it could perhaps reflect a calculated silence on the part of those responsible for the assessment of need and allocation of support that is directly connected to the rationing of services in these times of health financial hardship (Wiles 2005).

6.4 AGEING IN PLACE POLICY

The final key research question sought to understand what low level home support is and what the policy development implications are. Both of these issues are closely aligned to ageing in place. Nourishing and shaping service provision to older New Zealanders is strategic national policy that advocates for ageing in place. The government, political parties, the Health Ministry and service providers, health professionals and allied personnel working and studying in the field of gerontology may be well versed in the policy of ageing in place but to the older people in this study it was an invisible concept. Much as the roots of the rose are fixed firmly into the ground and out of sight so to is the notion of ageing in place as a policy directive to these elders. They did not think let alone speak in terms of the current health, social and political rhetoric that graces the policy documents on older person’s health and is the language of politicians, government health officials and planning and funding executives around the country. In fact it could be said from the way these elders looked forward and pondered futures that included institutional care that they were quite ‘in the dark’ about the ability and right to age in place. While they appreciated and were grateful for the current help they got in their home this in no way translated into being able to think in terms of continuing to age in place should their health needs change and they required more support.

As mentioned earlier this seems an unusual predicament given the policy thrust towards ageing in place. The already discussed rationale of a historical care model for older people in New Zealand and the perhaps service information holding practices of NASC as a way of explaining and understanding the situation equally applies here. However, in
addition it needs acknowledgement that if the very people for whom the ageing in place policy was intended are unenlightened as to its principles, goals and actions then such a situation works outside the spirit of New Zealand’s much heralded policy documents on ageing, The Positive Ageing Strategy (2001) and the Health of Older Person’s Strategy (2002). This surely must be regarded as untenable.

Also, a lack of knowledge and understanding on the part of older people themselves on the very things that matter to them, points strongly to the fact that the economic discourse on ageing in place is the actual policy driver. Victor (2005, pg.305) has already warned that the financial implications of population ageing have placed economic concerns before the “humanitarian dimensions” found in the social discourse on ageing in place. Most certainly a lack of knowledge about services on the part of users leads to lack of use. This definitely creates budgetary economic advantage but at the same time it would seem the financial discourse is failing itself if the perception of service users is one that starts at very low level home support and moves straight to residential care. The most expensive service option and the one that is most difficult to reconcile with the concept of ageing in place.

Ageing in place demands that the support and care of older people takes place in their home and community (Health of Older People Strategy 2002). However, the meaning of home as a place of care is not well understood (Hale 2003, Wiles 2005) and this study sheds little light on this subject. Except to say there was nothing in these elders’ narratives that conveyed a sense that they felt their homes had become care environments. Instead, their preferred language of home helpers and their support being primarily domestic suggested they were being helped in their homes rather than being cared for.

The reluctance with which most of the participants spoke about the prospect of moving to institutional care indicated on the part of these elders a desire to keep living and growing older in their familiar surrounds. To be able to continue to live out their lives in their own homes, neighbourhoods and communities is after all the social backbone of ageing in
place policy (Dwyer et al 2000, Gallagher et al 2004, Keeling 1998, Marek and Rantz 2000, Reed et al 2003, Rosel 2003). It was apparent by the way each older person in this study took the time to show and talk me around their home at the end of their interviews that home was a place of significant and unique meaning that was also very much part of their quality of life experience.

6.5 SUMMARY OF THIS CHAPTER

The narratives of the nine elders in this study have brought meaning and understanding to their quality of life experience as recipients of low level home support and given answers to my set research questions. They also led to the formation of my conceptual model for quality of life, low level home support and ageing in place. This model has been used to facilitate the discussion on my study’s findings. In conclusion of this discussion chapter it is important to mention that no claims are made on the generalisability for the selected locale and this group of people. However, I have no reason to believe why this conceptual model for quality of life, low level home support and ageing in place could not be explored as to its grounding in other New Zealand communities that are comparable. A way forward might be as use for further research with other groups of older people receiving low level home support in other communities.
CHAPTER 7: CONCLUSION

"Rose is a rose is a rose is a rose" (Gertrude Stein 1913)

Stein’s quotation succinctly captures my concluding thoughts to this study about the phenomenon of quality of life for these older people who receive low level home support. Phenomenology allows analogous thinking and I have fully exercised this literary freedom to define what has been indefinable by using the analogy of the rose. This comparison with the rose has enabled me to explore the ways in which tautologist thinking can actually illuminate the very thing in question. That is the meaning of quality of life which to this group of elders quality of life is just that, quality of life is quality of life is quality of life. Just as a rose could not possibly be mistaken for any other botanical species, quality of life is completely recognizable to these elders. Researchers from many disciplines, though mainly quantitative in their research orientation, have grappled for decades now to dissect the concept of quality of life. For all their precise effort they are no closer to being able to reach consensus as to its definition. Instead the act of scientific dissection leaves the rose of quality of life colourless, scentless, and sterilized. This is a far cry from the phenomenological truth of this study. Given the opportunity to talk about their quality of life each elder participating in this study knows exactly what it looks and smells like, and how and where it grows well. Undeniably they demonstrate that they themselves are the most appropriate people to define and make meaning of quality of life as elders receiving low level home support.

Quality of life to these elders means the ‘good people’ in their lives, taking care of day to day life, keeping healthy, living with loss, thinking of the future and being the age that they are. They confirm that quality of life is a dynamic concept considered from many angles. It is made up of multiple realities that don’t stand apart from one another but can be regarded extraordinary for their ordinariness. It is an interconnected experience that is both positive and negative in nature where the whole is greater than the sum of its parts. Quality of life is influenced by events over the life course and viewed relative to other older people’s lives.
It is home helpers in person rather than home support as a service that form a fundamental feature in the quality of life experience for these elders receiving low level home support. This formal relationship is highly valued and meaningful and extends beyond the physical boundaries to include emotional and social support as well. This remains the case even in situations where the home help arrangement is thought to be less than desirable. Home help at this lower end of the allocation scale never at any point was seen as encroaching on these elders’ independence, identity, autonomy and control. If anything it worked only as an enhancement and contribution to their overall quality of life. Given this and the longstanding nature of the support it is abundantly clear that this type of service provision is very potent in enabling these older people to remain active, interested and positive in their ageing. They are not in need of a rehabilitative model of home support. With the little help they receive right now this is sufficient for them to look after their own rehabilitation in ways that are normal to them. All this considered it would seem that low level home support plays an important and effective role in both quality of life and ageing in place for older people in New Zealand. For these reasons it must maintain its rightful place on the continuum of care for older New Zealanders and for low level home support be acknowledged and valued as a critical ageing in place strategy.

Population ageing acts as the catalyst for ageing in place policy development and implementation. It is social and economic policy of importance but for those who it is written for ageing place extends no further than the low level home support they all currently receive. To be a successful policy initiative, ageing in place is not only highly reliant on the capacity and capability of community services to be able to authentically respond to the long-term needs of older people in their homes and communities but elders themselves need to be empowered in the knowledge that they can do so. Older people need to be informed at low level home support service entry of the options to access to more support of this kind as well as the other ageing in place support initiatives that are available if ever needed. This would be an important step in allaying the current fears held by older recipients of low level home support on a direct move to institutional care
should their health needs change and may well work to contribute to what is already a richly meaningful ageing in place for this group of elders.

To conclude, this phenomenological study on the quality of life experience of older people in New Zealand who access low level home support clearly breaks the overwhelming silence on this lived experience at a time of both national and international importance. As such this piece of work makes a significant contribution to a growing body of gerontological literature here in New Zealand and specifically provides a new knowledge base on an otherwise unexplored phenomenon for recipients of home based services. Internationally it also adds to the conceptual framework and body of knowledge of quality of life in old age with particular regard to the views of elders who access low level home support.

Finally in bringing this thesis to a close are the implications that can be drawn from the findings of this study. These are:

- That older people who access low level home support will do better when health professionals and others who are part of the formal support systems appreciate the meaning of quality of life as it is experienced and defined by elders themselves.
- That low level home support services are a vital service component for ageing in place which contributes to the quality of life experience elderly recipients.
- That elders receiving low level home support are not in need of a rehabilitative model of support.
- That older people be informed at the point of low level home support service entry or at any other point of the options available to remain ageing in place.
BIBLIOGRAPHY


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Bowling, A., & Gabriel, Z. (2004). An Intergrational Model of Quality of Life in Older Age, Results from the ESRC/MRC HSRC Quality of Life Survey in Britain. Social Indicators Researched), 1-36.


Hellstrom, Y., Andersson, M., & Hallberg, I. R. (2004). Quality of life among older people in Sweden receiving help from informal and/or formal helpers at home or in special accommodation. Health and Social Care in the Community, 12 (6), 504-516


ODHB (2004). Elder Services Otago: A Proposal for a Continuum of Care for Older People in Otago, A Consultation Document, Dunedin NZ: Otago District Health Board


Participants Letter

12 July 2005

Dear Potential Participant,

I am writing to invite you to participate in a research study about home support services and maintaining quality of life for older people. All the information about this study and the researcher are in the attached information sheet. Please take the time to read this sheet carefully and if you would like to be part of this study please phone me at the number given in the information sheet.

Thank you.

Yours sincerely,

Penny Hambleton
(Researcher)
Information Sheet

Ageing in Place and Quality of Life Project

About the Study
I am inviting you to show interest and take part in a study that explores the meaning of quality of life for older people who receive home support. Older people’s perspectives and experiences on these matters are essential to this study.

My name is Penny Hambleton. Currently I am a full time graduate student undertaking a Master of Health Sciences degree at the Otago University. This degree will be endorsed in gerontology, which is the study of ageing. Also, I am a registered nurse with 29 years experience in the healthcare of older people. This study has developed from my particular interest and experience in supporting the lives of older people who require long-term support.

I would like to talk with you about what quality of life means to you in your life today including the experience of getting home based services.

Participation

If you agree to take part in my study it will involve me visiting your home to interview you. This interview will take between one to two hours and will include time where you can also discuss the research process with me. I will make a return visit at a time suitable to you so that you may check what has been said in the interview. I estimate that your total participation time will be approximately four hours and will be spread over two visits.

The interview will be tape-recorded and you may stop the interview at any time. You are also free to refuse to answer any questions. The taped interview will be typed up by myself into a transcript. This transcript will be available for you to read and verify that it is a correct record of the interview. The University requires that the tapes and the transcripts are kept securely for a number of years, and then they will be destroyed.
Your participation is entirely voluntary; that is, it is your choice whether you take part or not. If you choose not to there will be no repercussions to yourself or the health and support services you access.

**Risks**
There are no physical risks associated with this study. In fact I hope you may enjoy discussing your quality of life thoughts and experience with me.

**Confidentiality**
Throughout this study your anonymity is assured. Your real name will not be used anywhere. Instead you will be asked to choose a pseudonym or code name and this will be used in the final written thesis and any reports on this study. The interview information will be kept private and will be used for this study project only, and will be seen only by my two Supervisors and myself. All the research materials for this study will be stored in a locked filing cabinet.

**Results**
The results of this study will be written up as part of my thesis and a research report is also planned for a professional health journal. There may be presentations at appropriate health and gerontology conferences. I will make available a copy of a brief research report to all ten people participating in this study. However, there will be a delay between you taking part in the study and receiving the final report.

**Consent**
If after reading this information sheet you decide not to participate in this study then you are absolutely free not to proceed. You do not have to give any reason. Choosing not to take part or withdrawing from the study at any point will in no way affect the quality of your current home support service or any other health care or support service you may be receiving now or in the future.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact a Health and Disability Advocate, free phone 0800 377 766.
If you agree to participate in this study please let me know by ringing me on 489 8139. I will then arrange to bring a consent form for you to sign and we will arrange suitable times to meet and talk.

Approval

This study has received ethical approval from the Lower South Regional Ethics Committee

Contact Details
I want people to contact me and I can be contacted:
Penny Hambleton
37 McFadden Drive
Mosgiel
Telephone: 489 8139
Email: penny.hambleton@xtra.co.nz

My Supervisors are:
Margaret McKenzie,
Senior Lecturer,
Family and Community Studies,
Otago University,
PO Box 56,
Dunedin.
Telephone: 479 7652
Email: margaret.mckenzie@stonebow.otago.ac.nz

Dr. Sally Keeling,
Lecturer,
Health Care of the Elderly,
Christchurch School of Medicine and Health Sciences,
PO Box 800,
Christchurch.
Telephone: (03) 337 7932
Email: sally.keeling@chmeds.ac.nz

31st May 2005
Interview Guidelines

Ageing in Place and Quality of Life Project

1. I am interested in how you respond when I mention the words quality of life to you

2. Could you tell me what brings quality into your life?

3. Of these things that bring quality into your life, could you tell me what matters most?

4. Could you tell me what reduces or has a negative impact on your life quality?

5. We have talked about what you think about when I mention the words quality of life, what brings quality into your life and of those things what matters most and what reduces or has a negative impact on your life quality. Could you now please tell me how much does your home support contribute to your experience of quality of life?

6. Finally, using the thermometer image I have just given you, could you indicate on this image how good or bad you rate your quality of life today?
Ageing in Place and Quality of Life
Project
Thermometer Image

Using this thermometer image can you indicate on this image how good or bad you rate your quality of life today?

While you are being interviewed today I would like you to indicate on this image how good or bad your quality of life is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the image indicates this.

Your quality of life today

Adapted from Brooks 1996
Reference; Brooks R. 1996, EuroQol; the current state of play, Health Policy 37, 53-72
08 July 2005

Penny Hambleton
37 McFadden Drive
Mosgiel

Dear Penny

Project Key: LRS/05/04/004
Full Title: Ageing In Place And Quality Of Life: The Views Of Older People Receiving Low Levels Of Home Support In A Selected Locale In New Zealand.
Investigators: Penny Hambleton, Dr Sally Keeling, Ms Margaret McKenzie
Localities: Participants Homes

The above study has been given ethical approval by the Lower South Regional Ethics Committee.

Approved Documents
Information sheet and consent form version no 2 date 31 May 2005

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Final Report (for studies less than 1 year)
The study is approved until 28/02/2006. A final report is required at the end of the study and a form to assist with this is available from the Administrator. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date. Report forms are available from the administrator.

Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is
Appendix Five

to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Riria Tautau-Grant
Lower South Ethics Committee Administrator
Email: riria_tautau-grant@moh.govt.nz
Consent Form

Ageing in Place and Quality of Life

1. I have read and I understand the information sheet dated 31st May 2005 for potential participants taking part in this study about the quality of life of older people who access low levels of home support.

2. I confirm that the researcher has contacted me following my expression of interest in this study.

3. I have had a chance to talk about this study with the researcher and I am satisfied with the answers I have been given.

4. I understand that taking part in this study is voluntary (my own choice) and that I may withdraw from the study at any time without giving a reason and this will in no way affect the quality of my current home support service or any future health services.

5. I understand that my participation in this study is confidential.

6. I understand that the results of this study will be published and that no material, which could identify me, will be used in any reports on this study.

7. I have had enough time to decide whether or not to take part in this study.

8. I understand that my participation in this study will involve me being interviewed by the researcher about my quality of life and that the interview will be tape-recorded.

9. I understand that I can ask to have the tape recorder turned off at any time during the interview.

10. I understand that the discussions the researcher and I will have during the interview will be used as information for the study.
11. I know the researcher will also take notes during the interview.

12. I know that I will be given the opportunity to check what I have said during the interview, and that I can make changes at this time.

13. I would like to receive a copy of a brief report on the study, expected by May 31, 2006. YES/NO

14. I know that if I have any questions or worries about my rights as a participant in this study, that I can contact a Health and Disability Advocate. The telephone number is 0800 377 766.

15. I know I can contact Penny Hambleton, the researcher, telephone 489 8139 if I have any questions about the study and that I can ask questions at any time during the study.

I ______________________ (full name) hereby consent to take part in this study

Date:

Signature:

Researcher:

Contact Number:

Project Explained By:

Project Role:

Signature:

Date:
### THE STUDY’S DATA ANALYSIS

<table>
<thead>
<tr>
<th>STEPS</th>
<th>METHOD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Transcribe nine interviews and develop an ‘initial impression list’</td>
</tr>
<tr>
<td>Step 2</td>
<td>Re-read all transcripts to get overall feel for them</td>
</tr>
<tr>
<td>Step 3</td>
<td>Re-read each transcript in company of ‘initial impression list’. Place these first level codes in the margins of each transcript where relevant and appropriate. Add other codes into the margins of each transcript as they reveal themselves.</td>
</tr>
<tr>
<td>Step 4</td>
<td>Create individual code cards for each identified code. Also record on the code card for each transcript a reference of a specific example as well as a brief commentary of my thoughts. End up with 54 code cards: busy, day to day things, independence, learning new things, newspaper, positive, radio, television, responsibility, telephone, music, in charge, freedom of choice, active, driving, successful, home help, home helpers, neighbours/neighbourhood, friends, good people, family, giving, memories, needed, personal possessions, rituals, sense of purpose, age, loss, boxing on, future, fear, health, changes to health, frustration, comparative, dependence, acceptance, adaptation, food, fortunate, gratitude, medication, lucky, pain, loneliness, physical aids, safety, security, stress/worry, financial, environment</td>
</tr>
<tr>
<td>Step 5</td>
<td>Code cards carefully scrutinised for similarities and differences. From this analytical task emerged fourteen clusters of themes: Family, friends, neighbours, home helpers, taking care of the day to day things, taking care of oneself and one’s home, taking care of the community activities, people loss, physiological loss, at my age, getting out and about, keeping healthy, managing ill-health, the future</td>
</tr>
<tr>
<td>Step 6</td>
<td>Return to the original narratives to validate the fourteen clusters of themes. Initially undertake this analysis by working sequentially through the key questions in each transcript and formulate a detailed description of participants’ quality of life experience. Also develop a chart for each question; record the appropriate identified theme as well as indicating which participant the themes were relevant and important to.</td>
</tr>
<tr>
<td>Step 7</td>
<td>Charts and text are analysed again and again for commonalities and also variations and patterns. This results in the final formation of six themes: good people, taking care of the day to day things, keeping healthy, living with a sense of loss, the future, at my age and the refining of my explanations and participant examples and illustrations</td>
</tr>
<tr>
<td>Steps 1-7</td>
<td>Transcripts, ‘initial impressions list, codes, themes and descriptive text were read by my two Supervisors throughout the data analysis process</td>
</tr>
</tbody>
</table>